

Norfolk Safeguarding Adults Board

Safeguarding Adult Review: Miss C

FINAL

DATE 15 May 2018

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Executive Summary: Safeguarding Adults Review Miss C

1. Rationale for carrying out a Safeguarding Adults Review

1.1. This review consists of the following documents:

- This Executive Summary
- Gill Poole's report April 2018
- Report by Clinical Commissioning Groups (NNCCG, SNCCG and Norwich CCG) on implementation of actions.
- Gill Poole's report dated November 2017

The reports are presented and it is recommended they are read in this order, in order to provide a comprehensive understanding of this review. It should be noted that the report April 2018 revises the report November 2017 which is included in its original form, but this should only be read in light of revised findings of the April 2018 report.

1.2. The Norfolk Safeguarding Adults Board (NSAB) received a letter from Mr C on the 15 June 2015 requesting NSAB conducted a Safeguarding Adults Review (SAR) into the death of his daughter, Miss C.

1.3. In support of his request Mr C provided the following reports:

- Addenbrookes Hospital Cambridge University Hospitals NHS Foundation Trust Serious Incident Report (10 May 2013)
- Cambridgeshire and Peterborough NHS Foundation Trust Serious Incident Report (17 May 2013)
- Professor Ciclitira's report to Addenbrookes on 21 November 2014
- Independent Professional Opinion, Dr Christine Vize (13 July 2014)
- Professor Paul J Ciclitira report to NHS North Norfolk Clinical Commissioning Group (13 October 2014)

1.4. The Safeguarding Adults Review subgroup (SARG) of NSAB met on Tuesday 7 July 2015 to consider whether the criteria was met for undertaking a SAR. At this stage more information was required and sought.

1.5. The SARG recommended to the independent chair to open a summary review which would review the existing reports and give further comment on how services had been changed since Miss C's death.

- 1.6. At this point it was understood that the Parliamentary and Health Service Ombudsman investigation report was due to be published at the end of January 2016. In light of this, and to avoid missing relevant documentation for this review, the group decide to await the publication of the Ombudsman's report before progressing the SAR. In the interim period a search was made for a report writer suitable for the complex range of issues this review would involve and Gill Poole was commissioned on the 6 April 2016. Gill Poole is an independent writer, a chair of a different Safeguarding Adults Board, with extensive and relevant experience in the NHS and voluntary sectors. The terms of reference for the review are at Appendix A.
- 1.7. However, a decision was made not to commence this work at this time as the Parliamentary and Health Service Ombudsman investigation report had not been published and it was agreed that to start a review of the existing reports could lead to potential duplication of work at a later date.
- 1.8. Gill Poole presented her outline summary findings to SARG in June 2016 and her subsequent first report was presented to SARG in May 2017. In the intervening period, the ombudsman's report was delayed and investigations and documents and information were sought from local services to enable Gill Poole to complete her report.
- 1.9. In November 2017 Gill Poole presented a report including commentary against the original Terms of Reference and possible focus for actions to be undertaken as stage 2 of the SAR including whether the recommendations made in the various reports had been actioned. At this stage the reviewer found that most of the actions remained unfinished (although this view was subsequently revised in the report dated April 2018 against evidence provided by partner agencies).
- 1.10. It was recommended to NSAB by Gill Poole that it gains assurance from the CCG's and the North East London Commissioning Support Unit that all recommendations (in the expert report itemised above) have been actioned and outcomes are evidenced.
- 1.11. Also in November 2017 the NSAB received a verbal presentation from senior NHS Officers on the provision of services for adults with eating disorders in Norfolk, and whether they are fit for purpose.
- 1.12. Following the report in November 2017, partner organisations gathered evidence as to the actions that had already been undertaken to implement the recommendations of the earlier reports and this lead to Gill Poole subsequently revising her report and findings in April 2018.

2. Case Summary: Miss C

- 2.1. Miss C was 19-year-old woman who died from anorexia nervosa on 15 December 2012.
- 2.2. Miss C had been diagnosed as suffering from anorexia nervosa. She was first seen by a voluntary organisation August 2011. Following referral to the local eating disorders service, Miss C was admitted informally to a specialist eating disorder unit at Addenbrooke's Hospital in mid-September 2011. Miss C was discharged at the beginning of August 2012, following a 10-month in-patient stay.
- 2.3. In late September 2012 she started her undergraduate course at the University of East Anglia (UEA) living in halls of residence. Her weight dropped dramatically between September and December 2012
- 2.4. On the 7 December 2012 Miss C was found collapsed at her student accommodation and was admitted via A&E to the Norfolk & Norwich University Hospital (NNUH) with low blood sugar levels. Miss C's physical health deteriorated and she was transferred to Addenbrookes hospital on 11 December 2012.
- 2.5. On 12 December 2012 Miss C's condition further deteriorated and following discussion with Miss C's parents on 13 December 2012 the decision was taken to stop active treatment.
- 2.6. Miss C died in Addenbrookes hospital on 15 December 2012, with her family by her side.

3. Methodology and Summary

- 1.1. The type of review reflected the existence of extensive expert reviews and the then on-going ombudsman's investigation. In particular the review sought to complement rather than duplicate existing work. To that end, the author was asked to carry out a summary review. The outcomes of this review have been considered by NSAB. The Board are assured of the progress of the implementation of outcomes and are monitoring the progress that is continuing to be made.

END

Appendix A

Safeguarding Adults Review for Miss C Terms of Reference:

Miss C is a young woman who tragically died in Addenbrookes Hospital in December 2012. The cause of her death was attributed to her lengthy struggle with anorexia nervosa. A range of reports have been commissioned and completed following complaints by her father against the organisations involved in her care and support prior to her death.

Norfolk Safeguarding Adults Board (NSAB) seeks to commission an independent literature review of the reports available to it in order to obtain and determine the following:

1. To produce a simple and accessible chronology of pertinent events from August 2012 until Miss C's death.
2. Are there further lessons to be learned for the organisations involved that have not been identified in the reports already completed?
3. Do the reports adequately cover lessons for all those organisations?
4. Are there considerations for NSAB about the lessons to be learned to improve the care and support of people living with eating disorders with particular reference to the education sector that are not already covered by the reports?

The reports involved are:

- Initial Response to questions from Mr C, drawn from correspondence prior to Christmas 2013, about the care and treatment of Miss C, from Cambridge and Peterborough NHS Foundation Trust (Dated 15 January 2013)
- Cambridge and Peterborough NHS Foundation Trust Serious Incident Investigation Report (Dated 13 May 2013)
- Cambridge and Peterborough NHS Foundation Trust Serious Incident Learning Action Plan (Dated 17 May 2013)
- Letter from Aidan Thomas to Mr C attached to initial response to questions raised by Mr C with Mark Taylor's office prior to Christmas 2013, about the care and treatment of Miss C, which pertain to services run by CPFT (Dated 17 January 2014)
- Independent Professional Opinion by Dr Christine Vize (Dated 13 July 2014)
- Complaint Concerning Care Received by Miss C Background Information for the Parliamentary & Health Service Ombudsman (Dated 18 August 2014)
- Report for Norfolk and Norwich University Hospital by Dr Paul Robinson (Dated 23 August 2014)

- Medical Report by Professor Paul J Ciclitira (Dated 13 October 2014)
- Letter from Mr C to the General Medical Council Complaint about the care provided by Dr Jane Shapleske

END.

**Report to Norfolk Safeguarding Adults Board reviewing the final report from
the Clinical Commissioning Groups for North Norfolk,
South Norfolk and Norwich, dated 10.04.2018.**

1. I have been asked by the Norfolk Safeguarding Board to review additional evidence alongside my report from November 2017 report and make further comments.
2. The Clinical Commissioning Groups for North Norfolk, South Norfolk and Norwich wrote a report of the work undertaken relating to the recommendations, I made in the November 2017 review into the services provided to Miss C. I produced a chronology of events and reviewed previous investigations by Dr Christine Vize and Dr Paul Robinson in 2014, to assess lessons learned, further opportunities for lessons to be learned, and what actions have been taken to mitigate or address issues.
3. The Clinical Commissioning Groups have detailed significant additional information and evidence of actions in a report dated 10.04.2018.
4. I have read and reviewed this report and have commented within the report at the end of each section.
5. Overall, there is evidence of substantial actions to address the recommendations of the expert reports written in 2014.
6. Given the interest in this sad case and the considerable number of reviews written from a range of perspectives; it might be prudent for the Norfolk Safeguarding Adults Board to ask for updates and assurances of continuing improvements from the Clinical Commissioning Groups in 6 and again in 12 months' time.

Gill Poole

RN, RHV, MA (Leeds)




**Report to Norfolk Safeguarding Adults Board, in response to Gill Poole review of Eating Disorders Services Investigation into the case of Miss C
FINAL – 10.04.2018**



This report has been written in response to the review and recommendations, by Gill Poole, to the Norfolk Safeguarding Adults Board into the services provided to Miss C. Gill Poole produced a chronology of events^{1 2} into the incident to assess the previous lessons learned, if there are further opportunities for lessons to be learned, and what actions have been taken to mitigate or address issues as a result. The CCG's are committed to improving the safety and quality of eating disorders services and welcome the opportunity to respond to this review in conjunction to responding to the Parliamentary & health Service Ombudsman report: *'Ignoring the alarms: How NHS eating disorder services are failing patients'*, and both CCG documents should be read in conjunction in order to obtain a full picture of CCG's response.


Recommendations from report of the Independent Professional Opinion of Dr Christine Vize, to North Norfolk CCG – 13/07/2014		
Recommendation to North Norfolk CCG	NCEDS response	CCG Comment, action points and evidence – in response to recommendation and review - 2018
1. Clinical requests e.g. for blood tests should be specific (what and when and action to be taken if abnormal)	NCEDS provides specific and individualised written communication regarding medical monitoring recommendations. General information about how to respond to common complications in patients with eating disorders will also be given. Medical monitoring recommendations will be reviewed throughout a patient's treatment and GPs updated accordingly. Discharged patients will be given a plan for continued medical monitoring within 1 week of discharge. Since 2011, 91 GPs and 57 other primary care staff have attended the eating disorder training programmes. Feedback has been overwhelmingly positive. All surgeries signed up to	CCG Comment and evidence: 1. Copy of NCEDS GP medical monitoring request form, which details tests required and frequency. This is sent with: a) written guidance on the physical health monitoring of patients with eating disorders; b) contact telephone number for advice on interpretation or management of any results; c) and direction to the King's College <i>'Guide to the medical risk assessment for eating</i>



¹ Report of the Independent Professional Opinion of Dr Christine Vize to the North Norfolk Clinical Commissioning Group, 13th July 2014.




² Report of the expert reviewer Dr Paul Robinson, commissioned by CEO of Norfolk & Norwich University Hospitals NHS Foundation Trust, 23rd August 2014

	<p>medical monitoring are expected to have at least one GP attend this training.</p> <p><u>Non-registered LCS surgeries:</u></p> <p>In the event a non-registered GP surgery has a concern about medical monitoring, a senior NCEDS clinician will contact that surgery/GP. In our experience, these instances are often related to either a misunderstanding regarding the resourcing of NCEDS or concerns about a lack of experience or knowledge.</p> <p>Attendance at the NCEDS primary care training programme and / or triage helpline usually resolves most of these concerns. In these instances, NCEDS will arrange medical monitoring with the GP as per recommendation, with clear roles and responsibilities of primary care/NCEDS.</p> <p>In the rare event a GP or surgery is not willing to perform medical monitoring, NCEDS will alert Commissioners. NCEDS have contributed to a contingency plan that has to date, proved effective. Alternate solutions include changing GP practice or using district nurses.</p>	<p><i>disorders'</i>, providing additional information and guidance on medical monitoring for patients with eating disorders.</p> <p> Medical Monitoring Update_GP form.docx</p> <p>2. Appendix E of the Service Specification for Medical Monitoring Local Enhanced Service (LES) 2017/19 for Norfolk Primary Care provides full guidance for GP's on both 'brief essential examination' and 'special investigations' which will be requested by NCEDS. This document also provides guidance to GP's over who to contact for advice on medical monitoring, both during and outside of normal working hours.</p> <p> SNCCG LES Contract 201719 CVI</p> <p>3. The above LES for medical monitoring was established in response to this LMC letter advising primary care against providing this service:</p> <p> LMC letter re Eating Disorder Medical M</p> <p>4. GP's in primary care are offered training in order to equip them with skills/knowledge to undertake this medical monitoring. This training is provided by BEAT and numbers of attendees / training details as follows:</p>
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		  Copy of GP Report 2015.xlsx GP workshop updated dec17.pptx 5. Issues which arise around medical monitoring are raised and addressed in/through the CCG/NCEDS monthly Quality Forum – see meeting minutes as inserted for point 6.
Comment from Gill Poole review 2017: Not sure the response answers the recommendation		CCG actions to take forward: 6. The CCG continues to have regular formal contact with NCEDS via monthly quality forum, to discuss and address quality issues in a more contemporaneous manner, including those around medical monitoring, GP correspondence and individual case issues. This sits alongside quarterly performance and quality meetings. 7. Where CCG's do not have universal coverage for medical monitoring from GP's, there is clear and open dialogue between primary care, NCEDS and CCG staff to address issues as they may arise. CCG's and NCEDS are currently reviewing options for triangulating data on medical monitoring, to provide assurance. 8. The CCG's are currently working to address issues which have arisen as a result of LMC issuing recommendation to members (all Norfolk & Waveney GP's) to withdraw from all LES arrangements.
Gill Poole April 2018		The completed and continuing actions address the recommendation
2. Two specifically named doctors should be given	Dr JS had an honorary contract (expired), requested honorary contracts for both Dr JS and Dr IV	CCG Comment and evidence:





<p>honorary contracts with NNUH to enable them to share information about joint patients as a matter of course</p>		<ul style="list-style-type: none"> The Norfolk & Norwich Hospital are unable to trace back a copy of an honorary contract for NCEDS staff, though JS has been able to demonstrate application for EBDS for working at Norfolk & Norwich Hospital  <p>JS_CPFT_Enhanced DBS.pdf</p> <ul style="list-style-type: none"> Service Level Agreement (SLA) with NNUH, in place of honorary contracts, to facilitate joint management of and shared information about patients have been established for all clinical NCEDS staff. There is a clear process for additions/amendments to be made going forwards.
<p>Comment from Gill Poole review 2017: This recommendation is still outstanding</p>		<p>CCG actions to take forward: Establishment of honorary contracts, SLA or other appropriate arrangement, for relevant community eating disorders services staff with other acute Trusts, as a matter of urgency. To be addressed through the MARSIPAN groups and direct contact between commissioner and provider.</p>
<p>Gill Poole April 2018</p>		<p>The review in 2014 recommended honorary contracts; although there are 'urgent' plans; the contracts are not in place. The important thing is that this does not hinder the ability to share information for joint patients of Norfolk & Norwich Hospital and NCEDS</p>
<p>3. NCEDS staff should be provided with direct access to the NNUH Pathology results system</p>	<p>Both Dr JS and Dr IV have access to web ICE.</p>	<p>CCG Comment and evidence:</p> <ul style="list-style-type: none"> NNUH IT training department have provided confirmation of (1) pathology system access for staff within NCEDS -


<p>to enable them to check blood results directly and to see the frequency of monitoring by the GP</p>		 <p>Norfolk Norwich Hospital - NCEDS IC (2) staff trained to access this system –</p>  <p>Copy of NCEDS Users.xlsx</p> <p>This access enables NCEDS staff to view pathology results for the Eastern Pathology Alliance which covers the GP surgeries to which it provides services and all 3 acute hospital trusts in Norfolk. The NNUH IT training department are unable to provide information on what dates these members of staff have been able to access this system from, due to system administration methods.</p> <ul style="list-style-type: none"> • There is an established route for NCEDS to request NNUH pathology access for new staff, as appropriate.
<p>Comment from Gill Poole review 2017: Recommendation appears to be addressed</p>		<p>CCG actions to take forward: No actions identified as an established route of training and access is in place.</p>
<p>Gill Poole April 2018</p>		<p>Recommendation has been addressed</p>
<p>4. NCEDS and Gastroenterology and Dietetics at NNUH should agree a refeeding protocol to be used at NNUH whenever a patient with anorexia nervosa</p>	<p>This policy has been set up and reviewed in the MARSIPAN group. The clinical lead for MARSIPAN at the time, Dr Papadia, had agreed to publish the policy. It is unclear whether the policy remains in place following her departure from the department. NCEDS have raised their concerns about the provision of MARSIPAN recommended care in NNUH to the commissioners</p>	<p>CCG Comment and evidence:</p> <ul style="list-style-type: none"> • The CCG's and ED system stakeholders are finalising the reviewed MARSIPAN policy at NNUH and other acute hospitals as part of the MARSIPAN task & finish groups. These discussions are documented within the group minutes:


<p>requiring refeeding is admitted. Treatment according to the protocol needs to commence as soon as the patient is assessed, before they are allocated to a ward, whatever the time of day or week they come in, and alongside whatever other treatment is required. Training should be delivered to staff in A&E, MAU and the relevant wards at NNUH in implementing the protocol, which must include advice on what to do if the patient does not consent to refeeding.</p>	<p>who have set up a meeting with all stakeholders on the 5th of April 2017.</p> <p><u>Additional comment from NNUH:</u> NNUH have a fully staffed nutrition support team (NST) which includes 3 Consultant staff, who provide medical treatment to Eating Disorders Patients in accordance with MARSIPAN guidelines. NNUH have provided teaching to SPR's in line with the Trust Guidelines, medical links via Gastro team and Acute Medical Unit (AMU), with clear guideline for highlighting Eating Disorder Patients to the NST if they are admitted to AMU's.</p>	<div style="display: flex; justify-content: space-around; align-items: flex-start;"> <div style="text-align: center;">  Eating Disorders MARSIPAN Meeting </div> <div style="text-align: center;">  Marsipan Group Meeting Notes of Di </div> </div> <ul style="list-style-type: none"> • The MARSIPAN policies includes reference to Royal College of Psychiatrists MARSIPAN: Management of Really Sick Patients with anorexia nervosa (CR189) for further clinical guidance • There are MARSIPAN policies in place at other acute NHS trusts within Norfolk & Waveney <div style="text-align: center; margin-top: 10px;">  QEJ Clinical Guidelines on the M </div> <ul style="list-style-type: none"> • Specialist knowledge &/or consultation is available from Cambridge & Peterborough Foundation Trust staff, via NCEDS and ward S3 (intensive inpatient eating disorders unit) at Addenbrookes Hospital. Collectively offering 24/7 specialist advice. • There has been a continuous programme of training provided by NCEDS and BEAT (subcontracted by NCEDS) to the acute hospitals (including NNUH) and primary care staff, with an additional date planned in April 2018 due to current demand – please see training documents inserted as for point 1 '<i>copy of GP report</i>' & '<i>GP workshop updated dec17</i>'. This training requires the involvement of the NCEDS consultant psychiatrist, so may have a significant impact on the capacity within the NCEDS service. The consultant psychiatrist in post currently provides clinical care within NCEDS 2
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		days per week and NCEDS are holding a clinical psychiatrist vacancy. The impact of providing training requires scoping around the numbers requiring training, the level of training required – dependant on clinical role and settings, and to include refresh training - and the potential impact of providing this training on NCEDS capacity to provide clinical services.
<p>Comment from Gill Poole review 2017: Need to get feedback from meeting on 5th April 2017. Actions seem to have dependent on the actions of 1 clinician, now she has left it is unclear if the actions are sustained.</p>		<p>CCG actions to take forward:</p> <ul style="list-style-type: none"> • MARSIPAN across the age groups remains high on the agenda for CCGs, acute trusts and specialist ED providers, with review of current pathways being underway as a matter of urgency in order to provide clarity over the care of patients of all ages. • Scoping of training requirements and impact on clinical capacity.
Gill Poole April 2018		Recommendation addressed
<p>5. There should be an arrangement for NNUH staff to obtain advice on the management of eating disorder behaviours from ward S3 at Addenbrooke's out of hours and from NCEDS at other times</p>	<p>This is in place and staff are able to contact the team. This is included in the MARSIPAN policy.</p> <p><u>Additional comment from NNUH:</u> NNUH have a fully staffed nutrition support team (NST) which includes 3 Consultant staff, who provide medical treatment to Eating Disorders Patients in accordance with MARSIPAN guidelines.</p>	<p>CCG Comment and evidence:</p> <ul style="list-style-type: none"> • Relevant NNUH staff have been invited to specialist training on eating disorders management, provided by NCEDS – as identified in the MARSIPAN group minutes, as inserted for point 4 – to support internal training programme at NNUH. • The local current MARSIPAN policy provides NNUH staff with details of services to be contacted within and outside of 'working' hours, to obtain specialist advice 24 hours per day. This information to be highlighted within the revised policy moving forward – expected to be finalised in Q4 2017/18.

		<ul style="list-style-type: none"> The following to be included within NNUH Contract schedule 6A  <p>MARSIPAN Wording addition to</p>
<p>Comment from Gill Poole review 2017: This recommendation appears to have been addressed</p>		<p>CCG actions to take forward:</p> <ul style="list-style-type: none"> To ensure that routes for obtaining specialist advice are clear within the MARSIPAN policies. To ensure that advice over clinical care, including reference to the national guidance CR189, is made clear in local MARSIPAN policies CCG's are working with NCEDS and the liaison psychiatry team at NNUH to confirm arrangements for the newly expanded liaison psychiatry team to provide immediate psychiatry advice and support to staff and patients at NNUH, as part of the 'Core24' psychiatry liaison service – this includes a 1hour response time to referrals in A&E, and a 24hour response time for referrals made from any inpatient ward.
<p>Gill Poole April 2018</p>		<p>Recommendation addressed</p>
<p>6. Patients designated as high risk (BMI <15) who are deteriorating and requiring weekly weighing by NCEDS, need to be seen by another member of the NCEDS team for review if their therapist is away.</p>	<p>This risk is assessed on an individual basis during the weekly High Risk Register meeting / clinical supervision and if assessed as necessary, an appointment with another member of the team is arranged. In the event that the MDT team feel it is not required, an interim plan is agreed with the patient.</p>	<ul style="list-style-type: none"> The following three documents demonstrate the weekly clinical discussions which take place regarding the 'high-risk' ED patients being managed within the community: <p>Anon copy of high risk register:</p>  <p>High Risk Register annonymous.docx</p>

		<p>Screen shot of weekly reports:</p>  <p>High Risk Register files screen shot Dec</p> <p>Screen shot of yearly files:</p>  <p>High Risk Register screen shot 2013_17</p> <ul style="list-style-type: none"> • NCEDS have clinical flexibility within the service in order to cover the needs of high risk individuals in the case of staff absence. CCG's are addressing this action as part of the response to the Parliamentary & Health Service Ombudsman review, through point 2a which states: <i>“Risk should be assessed internally by provider whenever there is staffing shortage or reduced capacity in service, for any reason, which may affect patient care. Any risk level which would affect patient care should be communicated to:</i> <ol style="list-style-type: none"> <i>commissioners for further review, within agreed timeframes;</i> <i>partner agencies”</i> • The CCG's monitor quality and maintain open dialogue with service providers to provide oversight, demonstrated through monthly quality forum <div style="display: flex; justify-content: space-around; align-items: center;"> <div data-bbox="1532 1187 1608 1270" style="text-align: center;">  <p>NCEDS Quality Forum Action Log V</p> </div> <div data-bbox="1794 1230 1870 1294" style="text-align: center;">  <p>NCEDS Quality Forum Action Log 2f</p> </div> </div>
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<p>Comment from Gill Poole review 2017: This response seems to address the recommendation; it may be prudent to ask for evidence of interim plans and the appropriate support of high risk patients</p>		<p>CCG actions to take forward: NCEDS Risk of admission register to feed into the CCG risk register, identifying where high clinical risk is being 'held' by provider(s) in the community.</p>
<p>Gill Poole April 2018</p>		<p>Recommendation addressed</p>
<p>7. Patients receiving active treatment from another service, who are then transferred to the care of NCEDS need to carry on in treatment without interruption. Transfers therefore require a different care pathway to that used for new referrals.</p>	<p>The provider works together, following an agreed protocol, including monthly meetings between identified NCEDS, CEN-CAEDS and CAMHS link workers and quarterly strategic/operational meetings with senior staff.</p> <ul style="list-style-type: none"> • CEN-CAEDS will refer patients 6 months before transition using NCEDS referral form. 6-8 weeks prior to CEN-CAEDS discharge, CED-CAEDS will send NCEDS a progress report including clinical symptoms, living circumstances etc. and recent medical monitoring results. CEN-CAEDS and NCEDS will arrange a joint meeting with the patient and their family prior to their NCEDS assessment. Forthcoming changes in confidentiality will be discussed and information about adult services (e.g. NCEDS Carer and families CEN-CAEDS will refer patients 6 months before transition using NCEDS referral form. • 6-8 weeks prior to CEN-CAEDS discharge, CED-CAEDS will send NCEDS a progress report including clinical symptoms, living circumstances etc. and recent medical monitoring results. • CEN-CAEDS and NCEDS will arrange a joint meeting with the patient and their family prior to their NCEDS assessment. Forthcoming changes in confidentiality will be discussed and information about adult services (e.g. NCEDS Carer and families session 6, end of treatment and end of follow up. For low intensity interventions, measures may be administered weekly. These include Eating disorder psychopathology: 	<p>CCG Comment and evidence:</p> <ul style="list-style-type: none"> • NCEDS lead for transitions and clinician from CEN-CEADS meet every three months to discuss upcoming transitions. Where operationally needed, e.g. upcoming increase in transition, these meetings occur more regularly. There have been operational challenges to meeting at times, but these transitions have been addressed. <p style="text-align: center;"> Dietician and CEN-CEADS email.m</p> <ul style="list-style-type: none"> • The NCEDS service remain on track with their transition CQUIN, determined as part of the national CQUIN programme. <hr/> <p>This item is also being investigated as part of the CCG's response to recommendation 3 in the Parliamentary & health Service Ombudsman report: <i>'Ignoring the alarms: How NHS eating disorder services are failing patients'</i>. The CCGs and ED service stakeholders & providers all recognise that transitions, of all kinds, are times of increased risk for people with eating disorders. For this reason, all parties are keen to review and make improvements wherever possible, in aspects of service delivery which involve transitions.</p>

	<ul style="list-style-type: none"> Physical indicators: Body Mass Index, frequency of eating disorder behaviours (i.e. binge eating, self-induced vomiting, laxative use), amenorrhea Eating Disorder Examination Questionnaire (EDE-Q) ED-15 <p>Psychosocial functioning:</p> <ul style="list-style-type: none"> Clinical Impairment Assessment (CIA) <p>General psychiatric symptomatology</p> <ul style="list-style-type: none"> Rosenberg Self-esteem rating scale Personality Belief Questionnaire Depression, Anxiety, Stress Scales (DASS) <p>Therapeutic alliance</p> <ul style="list-style-type: none"> Working Alliance Inventory (WAI) 	
<p>Comment from Gill Poole review 2017: This recommendation appears to have been addressed</p>		<p>CCG actions to take forward:</p> <ul style="list-style-type: none"> As per the response to the Ombudsman report, the CCG's will consider, ahead of receiving further guidance from NICE, inclusion of coordination around transfer of care as an element of the Quality Standard for eating disorders services.
<p>Gill Poole April 2018</p>		<p>Recommendation addressed</p>
<p>8. NCEDS should have a specialist dietician as part of the team, working alongside therapists to review the nutritional content of meal plans where necessary, as well as providing advice directly to the patient.</p>	<p>There is a designated dietician that attends the NCEDS Clinic and also provides telephone contact to both clinicians and patients</p>	<p>CCG Comment and evidence:</p> <ul style="list-style-type: none"> NCEDS do have a dietician contracted to attend clinic periodically and who is available for telephone consultation / support outside of this time. <div data-bbox="1518 1137 1572 1203" style="text-align: center;">  </div> <p style="text-align: center;">Dietician and CEN-CEADS email.m</p> <p>No issues have been raised with CCG's as regards to dietician capacity within the NCEDS service.</p>

		This could be raised through formal processes or through the monthly quality forum meeting.
Comment from Gill Poole review 2017: This recommendation appears to have been addressed.		CCG actions to take forward: CCG's to review specification of dietician services within the wider eating disorder services
Gill Poole April 2018		Recommendation addressed
<p>General / wider CCG response:</p> <p>9. Within the contractual arrangements going forward, the CCG will seek to include, within the quality schedule for providers, that all serious incident reviews are conducted as a joint activity involving all stakeholders concerned.</p> <p>10. The CCG's have attempted to establish, with NHSE leads, the wider picture of eating disorders services provision across England. A clear picture has not been obtainable to date, however the East of England Strategic Clinical Network for Eating Disorders is currently commissioning a piece of work from the Anna Freud Centre to provide an overview of eating disorder services within the network.</p> <p>11. The CCG's and providers are all working with the East of England Strategic Clinical Network to develop a coordinated and robust approach to improving eating disorders services locally and regionally.</p> <p>12. Commissioning and provider organisations across Norfolk are reviewing and developing more robust MARSIPAN policies at present, with the target of agreeing these policies by the 31/01/2018 for implementation in acute hospital trusts.</p>		

CCG Summary

The response and actions taken forwards from this report will inform, along with other reports and their responses – such as that of the Parliamentary and Health Service Ombudsman's report: *'Ignoring the alarms: How NHS eating disorder services are failing patients'* – a wider briefing on the state of eating disorders services across Norfolk & Waveney, related risks and recommendations for the future of eating disorders services in Norfolk & Waveney.

Recommendations from expert reviewer Dr Paul Robinson, commissioned by Norfolk & Norwich University Hospital NHS Foundation Trust - 23/08/2014. Update on action plan which was initially completed by NNUH in September 2014.		
Recommendation	Norfolk & Norwich University Hospital response 2018	CCG's Response
1. The Trust should make information in the up to date MARSIPAN and Junior MARSIPAN which guides the treatment of severe anorexia nervosa readily available to	Both the guidance for the management of adults and the guidance for the management of children with eating disorders is still openly available on the NNUH intranet for all staff to access and use. These are formed in two separate guidelines agreed and authored in partnership with the community eating disorders providers, NCEDS for adults (dated January 2017) and NSFT for children (dated November 2015).	See response to point 4 of Dr Vize report above re: guidance for clinical care in MARSIPAN policies; contact details for internal (NNUH) and external (NCEDS including ward S3 at Addenbrookes) experts.

<p>doctors, nurses and dieticians who may be called upon to assess and manage such patients</p>	<p>Contact details for staff with special interest at NNUH are embedded into each guideline alongside where to seek specialist support from the community provider, with contact name and number.</p> <p>The adult guidance is currently going through a review with final changes being made prior to presentation at Mental Health Board for final approval in April 2018. This guidance is based on the premise that patients with Anorexia requiring specialist inpatient treatment should be treated in a SEDU if possible. It should be used by staff if treatment in an acute hospital is required for medically unstable patients, patients requiring interventions or monitoring which not available in SEDUs. On rare occasions admission may be required if an SEDU bed is not available. In this latter scenario, it should be a priority for patients to be transferred to a recognised unit in a timely manner when required.</p>	
<p>2. This information should be placed on-line and be introduced in sessions at which new staff receive induction into different roles</p>	<p>See above re intranet availability</p> <p>Adult teams where there is more exposure to eating disorders have been targeted with SPR teaching in general medical and gastro completed and scheduled to be repeated.</p> <p>Due to the complexity of eating disorders care and treatment more junior Dr's and other staff are signposted to the guidelines and seek more specialist input.</p> <p>Paediatrics is more contained and support provided via the named consultants in the guidance, with most suspected and known cases jointly managed by NSFT and NNUH staff. All under 16 year olds will be managed on one area if an inpatient stay at NNUH is required.</p>	<p>As per NNUH response</p>
<p>3. The main clinical areas in which this educational approach is relevant include A&E, Acute Medical Units, Medical</p>	<p>See above</p>	<p>As per NNUH response</p>

<p>Wards and Paediatric Wards</p>		
<p>4. A formal arrangement should be put in place so that any clinician at NNUH who encounters a challenging problem in a patient with an eating disorder has ready access to an Eating Disorders Consultant Psychiatrist; including provision for rapid assessment</p>	<p>As per the NNUH's response in September 2014, this is fully outlined and covered in the two NNUH guidelines for the management of eating disorders.</p> <p>Specialist support for children is provided by NSFT and for Adults by NCEDS, contact details for both are embedded in the guidelines, providing specialist support 24/7.</p> <p>There is also 24/7 mental health expertise provided by mental health practitioners and Monday to Friday support from a psychiatrist and a psychologist employed by the NSFT CORE 24 mental health liaison team should general mental health support be required.</p>	<p>As noted in NNUH response, information on accessing expert advice on the management of eating disorders is detailed within the NNUH MARSIPAN guidelines. This includes expertise internal to NNUH and externally within specialist eating disorders services, and provides access to expert support covering the 24 hour period</p>
<p>5. Out of hours Consultant Psychiatrist cover should be organised</p>	<p>Should an out of hours consultant psychiatrist be required this would be via the consultant on call processes via NSFT switchboard or if detention is required, via NCC routes.</p> <p>With the expanding liaison service at NNUH provided by NSFT it is envisaged that consultant psychiatrists would be available 7 days per week during 9-5 hours</p>	<p>As per NNUH response</p>
<p>6. Information sharing policies should be reviewed to ensure they do not impede the sharing of patient information with professionals outside of the organisation.</p>	<p>SLA in progress with NCEDS to enable full working arrangements at NNUH, information Governance arrangements to be finalised by mid-march 2018.</p> <p>NSFT cover in place and working well.</p> <p>Discussed in depth at both the adult and children's eating disorders meetings (MARSIPAN), as previously outlined both guidelines readily available for staff with contact points to access as and when required.</p>	<p>As per NNUH response and CCGs response to point 2 of Dr Vize response above.</p>

<p>7. The process for the production of nursing care plans for patients with anorexia nervosa should be reviewed with reference to MARSIPAN guidelines</p>	<p>This is closely aligned to the eating disorders guidance documents for both adults and children accessible to all staff groups via the NNUH intranet.</p> <p>Any specialist care plan would be produced with input from the nutritional team.</p>	<p>As per NNUH response. CCGs are actively involved in the production/review of MARSIPAN guidelines.</p>
<p>8. Nurses completing clinical records such as the MUST should be trained in the calculation and recording of BMI</p>	<p>MUST training is part of induction and all patients have an assessment on admission. There is an initial care plan based on the score.</p> <p>Children's services use a stamp based on weight & height chart calculation with a chart displaying this laminated clearly visible on wards. Training is part of staff induction.</p>	<p>As per NNUH response.</p>
<p>9. The range of wards, number of patients and other duties expected of doctors covering at weekends and out of hours should be reviewed to ensure services can be improved</p>	<p>Covered in the two aforementioned policies which are available to all NNUH employees 24/7.</p> <p>Where to access specialist support outlined clearly.</p>	<p>As per NNUH response.</p>
<p>10. The training and supervision of doctors providing cover on call should be reviewed to improve their ability to diagnose and treat patients</p>	<p>Adult teams where there is more exposure to eating disorders have been targeted with SPR teaching in general medical and gastro completed and scheduled to be repeated.</p> <p>Due to the complexity of eating disorders care and treatment more junior Dr's and other staff are signposted to the guidelines and seek more specialist input.</p> <p>Paediatrics is more contained and support provided via the named consultants in the guidance, with most suspected and known cases jointly</p>	<p>As per NNUH response. Training provided by NCEDS staff (to primary care) has been opened to include relevant staff from acute and community services. Training provision is also being addressed nationally and regionally, through the strategic clinical network in the East of England, and through GMC & HEE as part of the recommendation from the Parliamentary & Health Service</p>

	managed by NSFT and NNUH staff. All under 16 year olds will be managed on one area if an inpatient stay at NNUH is required.	Ombudsman's report ' <i>Ignoring the Alarms</i> ' (2017)
11. Consideration should be given to the establishment of a Nutrition Support Team with a consultant physician, a senior nurse and dietician to provide advice and support to all units to which patients with serious nutritional problems might be admitted.	NNUH have a fully staffed nutrition support team (NST) which includes 3 Consultant staff, who provide medical treatment to Eating Disorders Patients in accordance with MARSIPAN guidelines. There was a period of 6-9 months where there was no lead clinician, however post September 2017 the full team are in situ and functioning well.	As per NNUH response. Support and specialist advice has remained available from specialist teams.

Gill Poole's report dated November 2017

1.1. This report gives details of the findings of the review of services provided to Miss C and makes recommendations to the Norfolk Safeguarding Adults Board.

1.2. The terms of reference for Stage 1 of the review were:

- 1) To produce a simple and accessible chronology of pertinent events from 2011 until Miss C's death.

This was produced.

- 2) Are there further lessons to be learned for the organisations involved that have not been identified in the reports already completed?

It was difficult to answer this, as there were more questions to be answered.

- 3) Do the reports adequately cover lessons for all those organisations?

The reports contained recommendations and actions, many had not been undertaken.

- 4) Are there considerations for NSAB about the lessons to be learned to improve the care and support of people living with eating disorders with particular reference to the education sector that are not already covered by the reports?

The main concerns related to the lack of action by health services rather than education.

2. Summary of findings from Stage 1

2.1. There were failings in the care and support provided to Miss C. She was discharged from the specialist eating disorder unit in July 2012 against guidelines when her weight and BMI were low and she had not reached her target weight. The medical centre contracted to undertake weekly checks did not undertake the checks adequately. There were delays in a medical review when Miss C's deteriorating condition was picked up; and her care on admission and transfer between hospitals was not as per MARSIPAN guidelines.

2.2. The various independent reports have recommendations for action but no documentation has been seen by the reviewer relating to the implementation

or completion of these actions. It is therefore difficult to address items 2 & 3 of the terms of reference.

- 2.3. In relation to item 4 of the terms of reference it would be useful to explore whether the university have a policy relating to students suffering from anorexia nervosa and if not to facilitate the development of such a policy.

3. Possible focus for actions to be undertaken as Stage 2 of the SAR

3.1. Establish the answers to following questions:

1.

- a) Was the Coroner involved and is there a Coroner's report?

There was found to be no Coroner involvement or report.

- b) Have the recommendations made in the various reports been actioned?

After a long process, the reviewer found that most of the actions remained unfinished.

- c) What is the current position in relation to the complaints made by Mr C.

It is the understanding of the reviewer that Mr C remains unhappy with the responses to his complaints.

2.

Development of a SAB action plan relating to gaining assurance from NHS England and the NHS North Norfolk Clinical Commissioning Group that all recommendations (in the reports itemised above) have been actioned and outcomes are evidenced.

4. Findings

- 4.1. This report focusses on actions undertaken since recommendations were made in reports commissioned in 2014, on the whole there are very few of the actions completed since 2014, little seems to have changed.

- 4.2. Recommendations resulting from a report of the Independent Professional Opinion of Dr Christine Vize to the North Norfolk Clinical Commissioning Group dated July 13th 2014

Recommendation to North Norfolk CCG	NCEDS response	Comment
<p>9. Clinical requests e.g. for blood tests should be specific (what and when and action to be taken if abnormal)</p>	<p>NCEDS provides specific and individualised written communication regarding medical monitoring recommendations. General information about how to respond to common complications in patients with eating disorders will also be given. Medical monitoring recommendations will be reviewed throughout a patient's treatment and GPs updated accordingly. Discharged patients will be given a plan for continued medical monitoring within 1 week of discharge. Since 2011, 91 GPs and 57 other primary care staff have attended the eating disorder training programmes. Feedback has been overwhelmingly positive. All surgeries signed up to medical monitoring are expected to have at least one GP attend this training.</p> <p>Non-registered LCS surgeries In the event a non-registered GP surgery has a concern about medical monitoring, a senior NCEDS clinician will contact that surgery/GP. In our experience, these instances are often related to either a misunderstanding regarding the resourcing of NCEDS or concerns about</p>	<p>Not sure the response answers the recommendation</p>

Recommendation to North Norfolk CCG	NCEDS response	Comment
	<p>a lack of experience or knowledge. Attendance at the NCEDS primary care training programme and / or triage helpline usually resolves most of these concerns. In these instances, NCEDS will arrange medical monitoring with the GP as per recommendation, with clear roles and responsibilities of primary care/NCEDS.</p> <p>In the rare event a GP or surgery is not willing to perform medical monitoring, NCEDS will alert Commissioners. NCEDS have contributed to a contingency plan that has to date, proved effective. Alternate solutions include changing GP practice or using district nurses.</p>	
<p>10. Two specifically named doctors should be given honorary contracts with NNUH to enable them to share information about joint patients as a matter of course</p>	<p>Dr JS had an honorary contract (expired), requested honorary contracts for both Dr JS and Dr IV</p>	<p>This recommendation is still outstanding</p>
<p>11. NCEDS staff should be provided with direct access to the NNUH Pathology results system to enable them to check blood results directly and to see the frequency of monitoring by the GP</p>	<p>Both Dr JS and Dr IV have access to web ICE.</p>	<p>Recommendation appears to be addressed</p>

Recommendation to North Norfolk CCG	NCEDS response	Comment
<p>12. NCEDS and Gastroenterology and Dietetics at NNUH should agree a refeeding protocol to be used at NNUH whenever a patient with anorexia nervosa requiring refeeding is admitted. Treatment according to the protocol needs to commence as soon as the patient is assessed, before they are allocated to a ward, whatever the time of day or week they come in, and alongside whatever other treatment is required. Training should be delivered to staff in A&E, MAU and the relevant wards at NNUH in implementing the protocol, which must include advice on what to do if the patient does not consent to refeeding.</p>	<p>This policy has been set up and reviewed in the MARSIPAN group. The clinical lead for MARSIPAN at the time, Dr Papadia, had agreed to publish the policy. It is unclear whether the policy remains in place following her departure from the department. NCEDS have raised their concerns about the provision of MARSIPAN recommended care in NNUH to the commissioners who have set up a meeting with all stakeholders on the 5th of April 2017.</p>	<p>Need to get feedback from meeting on 5th April 2017. Actions seem to have dependent on the actions of 1 clinician, now she has left it is unclear if the actions are sustained.</p>
<p>13. There should be an arrangement for NNUH staff to obtain advice on the management of eating disorder behaviours from ward S3 at Addenbrooke's out of hours and from NCEDS at other times</p>	<p>This is in place and staff are able to contact the team. This is included in the MARSIPAN policy.</p>	<p>This recommendation appears to have been addressed</p>
<p>14. Patients designated as high risk (BMI <15) who are deteriorating and requiring weekly weighing by NCEDS, need to be seen by another member</p>	<p>This is risk assessed on an individual basis during the weekly High Risk Register meeting / clinical supervision and if assessed as necessary, an</p>	<p>This response seems to address the recommendation; it may be prudent to ask for evidence of interim plans and the appropriate support of high risk patients</p>

Recommendation to North Norfolk CCG	NCEDS response	Comment
of the NCEDS team for review if their therapist is away.	appointment with another member of the team is arranged. In the event that the MDT team feel it is not required, an interim plan is agreed with the patient.	
15. Patients receiving active treatment from another service, who are then transferred to the care of NCEDS need to carry on in treatment without interruption. Transfers therefore require a different care pathway to that used for new referrals.	<p>The provider works together, following an agreed protocol, including monthly meetings between identified NCEDS, CEN-CAEDS and CAMHS link workers and quarterly strategic/operational meetings with senior staff.</p> <ul style="list-style-type: none"> • CEN-CAEDS will refer patients 6 months before transition using NCEDS referral form. 6-8 weeks prior to CEN-CAEDS discharge, CED-CAEDS will send NCEDS a progress report including clinical symptoms, living circumstances etc. and recent medical monitoring results. CEN-CAEDS and NCEDS will arrange a joint meeting with the patient and their family prior to their NCEDS assessment. Forthcoming changes in confidentiality will be discussed and information about adult services (e.g. NCEDS Carer and families CEN-CAEDS will refer patients 6 months before transition using NCEDS referral form. • 6-8 weeks prior to CEN-CAEDS discharge, CED-CAEDS will send NCEDS a progress report including 	This recommendation appears to have been addressed

Recommendation to North Norfolk CCG	NCEDS response	Comment
	<p>clinical symptoms, living circumstances etc. and recent medical monitoring results.</p> <ul style="list-style-type: none"> • CEN-CAEDS and NCEDS will arrange a joint meeting with the patient and their family prior to their NCEDS assessment. Forthcoming changes in confidentiality will be discussed and information about adult services (e.g. NCEDS Carer and families session 6, end of treatment and end of follow up. For low intensity interventions, measures may be administered weekly. These include <p>Eating disorder psychopathology:</p> <ul style="list-style-type: none"> • Physical indicators: Body Mass Index, frequency of eating disorder behaviours (i.e. binge eating, self-induced vomiting, laxative use), amenorrhea • Eating Disorder Examination Questionnaire (EDE-Q) • ED-15 <p>Psychosocial functioning:</p> <ul style="list-style-type: none"> • Clinical Impairment Assessment (CIA) <p>General psychiatric symptomatology</p> <ul style="list-style-type: none"> • Rosenberg Self-esteem rating scale • Personality Belief Questionnaire 	

Recommendation to North Norfolk CCG	NCEDS response	Comment
	<ul style="list-style-type: none"> • Depression, Anxiety, Stress Scales (DASS) Therapeutic alliance • Working Alliance Inventory (WAI) 	
<p>16. NCEDS should have a specialist dietician as part of the team, working alongside therapists to review the nutritional content of meal plans where necessary, as well as providing advice directly to the patient.</p>	<p>There is a designated dietician that attends the NCEDS Clinic and also provides telephone contact to both clinicians and patients</p>	<p>This recommendation appears to have been addressed.</p>

Recommendations of expert reviewer Dr Paul Robinson, commissioned by CEO of Norfolk and Norwich University Hospital NHS Foundation Trust dated 23rd August 2014

12. The Trust should make information in the up to date MARSIPAN and Junior MARSIPAN which guides the treatment of severe anorexia nervosa readily available to doctors, nurses and dieticians who may be called upon to assess and manage such patients.
13. This information should be placed on-line and be introduced in sessions at which new staff receive induction into different roles.
14. The main clinical areas in which this educational approach is relevant include A&E, Acute Medical Units, Medical Wards and Paediatric Wards.
15. A formal arrangement should be put in place so that any clinician at NNUH who encounters a challenging problem in a patient with an eating disorder has ready access to an Eating Disorders Consultant Psychiatrist; including provision for rapid assessment.
16. Out of hours Consultant Psychiatrist cover should be organised.
17. Information sharing policies should be reviewed to ensure they do not impede the sharing of patient information with professionals outside of the organisation.
18. The process for the production of nursing care plans for patients with anorexia nervosa should be reviewed with reference to MARSIPAN guidelines.
19. Nurses completing clinical records such as the MUST should be trained in the calculation and recording of BMI.
20. The range of wards, number of patients and other duties expected of doctors covering at weekends and out of hours should be reviewed to ensure services can be improved.
21. The training and supervision of doctors providing cover on call should be reviewed to improve their ability to diagnose and treat patients.
22. Consideration should be given to the establishment of a Nutrition Support Team with a consultant physician, a senior nurse and dietician to provide advice and support to all units to which patients with serious nutritional problems might be admitted.

4.3. NHS North and East London Commissioning Support Unit updated that they appreciate that the response below does not deliver an individual reply to

each recommendation. There was a joint meeting across three providers (Community eating disorders, adults and children and NNUH) at the beginning of April 2017 where there was agreement regarding the ongoing MARSIPAN groups for both Adults and Children. As a result of this the Clinical Commissioning Groups are picking up on commissioning gaps which have been identified since the departure of senior NNUH staff who had a special interest and skills in this eating disorders.

- 4.4. This is the response from Norfolk and Norwich University Hospital NHS Foundation Trust regarding the recommendations resulting from the SCR:

‘As a Trust we acknowledge and are mindful of the 11 recommendations made from the report we commissioned in 2014.

We note that we are not commissioned to provide this specialist service and previous attempts to recruit a suitable individual to deliver such a service have been unsuccessful.

They trust this response addresses the initial query and apologise for the delay in providing a response.’

5. Conclusion

- 5.1. Many of the recommendations made by the specialists in 2014 have not been completed, or in some cases even commenced.
- 5.2. In the reviewer’s opinion, there is nothing to suggest that patients would experience different treatment from that received by Miss C. Therefore, if a similar situation occurred now, the young person would be no safer than Miss C.
- 5.3. The responsibility lies with the health commissioners to address these issues.

6. Recommendations

- 6.1. The Norfolk Safeguarding Adults Board should consider holding the CCGs and North East London Commissioning Support Group to account and insisting that actions are taken to address the recommendations.
- 6.2. The NICE guidelines <https://pathways.nice.org.uk/pathways/eating-disorders> should be employed. NSAB should be assured by local health commissioners that these guidelines are implemented, and if not the plans to execute, including timescales and responsibilities.

- 6.3. NICE are developing quality standards for eating disorders which will be published 26th April 2018. NSAB should require the local health commissioners to assure them that these standards are being met by local provision.

END.