REGULATION 28: REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. The Right Honourable Matt Hancock, Secretary of State for Health and Social Care** [redacted] **2.** [redacted]**, Chief Executive of the NHS;** [redacted] **3.** [redacted]**, Medical Director and Director of Education Standards, General Medical Council;** [redacted] **4.** [redacted]**, Chief Executive of the Academy of Medical Royal Colleges;** [redacted] **5.** [redacted] **Chief Executive of Health Education England** [redacted]
1	**CORONER** I am Sean Horstead, Assistant Coroner, for the Coroner area of Cambridgeshire & Peterborough
2	**CORONER'S LEGAL POWERS** I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.
3	**INVESTIGATION and INQUEST** On 23rd January 2018 I commenced an investigation into the death of Averil Miranda Hart, aged 19 years. The investigation concluded at the end of the inquest on 6th November 2020. The medical cause of death was confirmed as 1a Anorexia Nervosa; I recorded a narrative conclusion that the death was avoidable and that it was contributed to by neglect. I identified the following systemic and individual failings: (1) The lack of a formally commissioned service for the provision of medical monitoring of an Anorexia Nervosa (AN) patient at high risk of relapse and, in this lacunae, the absence of a written service level agreement between primary and secondary care, led to confusion as to precisely how the two services were to work together. This systemic failure contributed significantly to the lack of clear two-way communication between the GP practice at the UEA Medical Centre and the Norfolk Community Eating Disorder Service (NCEDS), which in turn impacted upon the assessment and management of, and response to, Averil's risk of relapse. (2) In the context of a severe staffing crisis, the inappropriate allocation by NCEDS of an AN patient at a high risk of relapse to the case load of an inexperienced trainee psychologist designated the dual roles of therapist and Care Coordinator, but for whom inadequate training and insufficient supervision for the latter role was provided, in turn compounded by a lack of proactive support from the wider NCEDS team leading to significant shortcomings in the coordination of Averil's case. (3) The failure of the NCEDS team to speak directly with Averil's father following his raising of grave concerns regarding his daughter's serious deterioration (over a week prior to her collapse) to obtain

	details of his concerns, leading to a missed opportunity to arrange an urgent medical review of Averil and, on balance, avoid the subsequent collapse and emergency admission to hospital; (4) The failure to adequately plan for or provide any nutritional support to Averil over the course of four days at North Norfolk University Hospital (NNUH), in the context of her severely malnourished condition (recognised on admission), directly contributed to Averil's death and was a gross failure amounting to neglect. (5) Inadequacies in the commissioned structure at NNUH resulted in the absence ofweekend support from both a consultant psychiatrist fully conversant with eating disorders and a dietician trained to provide AN dietetic support as required by theMARSIPAN Guidance. In the context of the lack of any nutritional support, the failure by staff to recognise and manage Averil's Anorexic behaviours whilst on the Acute Medical Unit contributed to her continued deterioration which in turn led to her emergency transfer to Addenbrookes Hospital (AH). (6) An unexplained four-hour delay before the consultant gastroenterologist was informed following her arrival at AH was compounded by the eight hour delay in Averil being clerked by a junior doctor and her bloods being taken. This led to a missed opportunities to (a) start nasogastric feeding on the afternoon of her arrival; and (b) rapidly identify and treat her hypoglycaemia which was left untreated overnight (7) These missed opportunities were compounded by miscommunication over the telephone in the early hours of the following morning between the junior doctor on the ward and the responsible consultant with respect to the recognition of Averil's (continuing) hypoglycaemia and treatment thereof. However, given the already greatly diminished chances of survival Averil faced following her period at NNUH prior to her arrival at AH, it could only be safely concluded that the identified failings in care at AH *possibly* contributed to her death.
4	**CIRCUMSTANCES OF THE DEATH** On 15th December 2012 Averil died from Anorexia Nervosa at Addenbrookes Hospital, Cambridgeshire 6 days short of her twentieth birthday. On 3rd August, Averil had been discharged from Ward S3, the Specialist Eating Disorder Unit, run by Cambridgeshire & Peterborough NHS Foundation Trust (CPFT), based at Addenbrookes Hospital. She had received 11 months' treatment for the AN from which she had been suffering for some three years prior to her admission. At discharge her weight had increased from 30.4 kg (with a BMI of 11.2) on admission to 45.2 kg (a BMI of 16.6). Averil had accepted an offer of a place to study at the University of East Anglia and moved in to University halls of residence in September 2012. GPs at the UEA Medical Centre, where she registered on 29th September, agreed to provide Averil with medical monitoring on a weekly basis. From mid-October Averil also received therapeutic counselling (Cognitive Behavioural Therapy) froma trainee clinical psychologist at the Norfolk Community Eating Disorder Service (NCEDS – also run by CPFT) during the course of which it was decided that Averil was to be weighed by the therapist (rather than theUEAMC GPs) on a weekly basis. Averil was last weighed at NCEDs on 23rd November, after which her therapist was on leave for a fortnight. Her weight was recorded on that occasion as 38.2 kgs, with a BMI of 14. On the 28th November, having met up with his daughter earlier that day for the first time in a month, Averil's father had contacted Ward S3 to raise his grave concerns regarding Averil's apparent physical and mental presentation which he considered had dramatically deteriorated. He told the recipient of the call that, in his opinion, her BMI appeared to be lower than when she had been admitted to hospital the previous year. [redacted] was later informed that the NCEDS team had been made aware of his concerns. Averil's scheduled therapy session for the 30th November, where her weight would have been taken, did not take place as her therapist was on leave. Alternative

	arrangements for another member of the team to review Averil and her weight had not been made. On Friday 30th November the Lead Consultant Psychiatrist for NCEDS, having been alerted to [redacted] concerns about his daughter's weight loss, reviewed the NCEDS records relating to Averil and concluded that a medical review should be undertaken by a fellow consultant psychiatrist. He emailed his colleague to this effect the same day and a medical review was subsequently arranged for Friday 7th December, some nine days after the concern raised by [redacted]. On the evening of the 6th December Averil cancelled the appointment. The following morning she was found in a collapsed state in her University accommodation and was taken to Norfolk and Norwich University Hospital (NNUH) by ambulance. On admission her weight was recorded as 30.7 kg with a BMI of 11.3: her over-all weight loss in four months since discharge from Ward S3 was therefore some 14.5 kg, a third of her body weight. Although Averil was assessed by clinicians at NNUH, including a Consultant Gastroenterologist (who was also the Lead in Nutrition) and recognised to be severely malnourished, over the course of her four-day admission she received no monitored oral nutrition and nor did she receive feeding via a nasogastric tube; in addition, her continuing Anorexia driven, energy-expending behaviours were not addressed. Averil's condition continued to deteriorate and by the morning of Tuesday 11th December she was struggling to swallow; an emergency transfer by ambulance with blue lights and siren for specialist care at Addenbrookes Hospital was arranged. Despite the urgency of the transfer, Averil was not reviewed by the specialist medical team at AH, led by a Consultant Gastroenterologist, until around 19.00 hours, approaching five hours after her arrival; Averil was only formally clerked in by a junior doctor (and her bloods taken for analysis) sometime after 22.30 hours that evening. Overnight her finger prick blood sugar level was *"unrecordable"* and once the results of her blood test were received in the early hours of the morning, these confirmed that her laboratory serum glucose was 1.9 mmols/l. Notwithstanding the written instructions of the Consultant that Averil's blood sugar levels should be carefully monitored overnight and that she should receive oral glucose should her BM fall below 3 mmols/l (and following a miscommunication during a telephone call between the consultant and the junior doctor on the ward) Averil's hypoglycaemia remained entirely untreated. On the morning of the 12th December the Consultant visited Averil and found her in a state of collapse. She was treated with intravenous dextrose, oxygen and nasogastric feeding but she further deteriorated, did not regain consciousness and passed away on the 15th December.
5	**CORONER'S CONCERNS** During the course of the inquest the evidence revealed matters giving rise to concern. A number of the concerns raised by the evidence at Averil's inquest, were also reflected in the evidence I received at the separate inquests of four further women in the year preceding Averil's inquest, namely the inquests of [redacted](found deceased 07/09/2017); [redacted] died (09/01/2018); [redacted] (died 20/08/2018) and [redacted] (died 22/08/2018). For all of these women Anorexia Nervosa was identified as the medical cause of death; to a significant degree, the five inquests shared common themes of concern. In my opinion there is a risk that future deaths could occur unless action is taken. In the circumstances it is my statutory duty to report to you. The **MATTERS OF CONCERN** are as follows. – Evidence at both Averil's inquest, and those of the women referred to above, established that a number of the serious matters raised by the Parliamentary Health Service Ombudsman (PHSO) Report *'Ignoring the alarms: How NHS eating disorder services are failing patients'* published on 8th December 2017 and then reiterated in the *'Follow-up Report'* to the latter, published by the House of Commons Public Administration and Constitutional Affairs Committee (PACAC) on 18th June 2019, had not been adequately addressed. The Government provided a Response to the recommendations of the PACAC *'Follow-up Report'* dated 13th August 2019.

However, in my view, unless and until the following concerns are appropriately addressed there remains a risk of avoidable future deaths. The specific concerns giving rise to the risk of future deaths are as follows:

(1) Inadequate training of doctors and other medical professionals re eating disorders

Evidence from a wide range of clinicians who had engaged with Averil in 2012 echoed the evidence of clinicians attending the four inquests of the women referred to above. All five inquests revealed a common theme of wide-spread and continuing lack of training, knowledge, or experience on the part of physicians and medical staff (including GPs and nurse practitioners, as well as acute hospital doctors, nurses and dieticians) regarding eating disorders (EDs) and specifically Anorexia Nervosa (AN). Many witnesses (from both the death 2012 and those in 2017/2018) conceded that they had had only the most superficial knowledge of the often complex issues relating to recognition, monitoring, management and treatment of EDs and AN specifically. Their evidence often reflected a lack of familiarity with the King's College Guidance for the treatment of AN in the community. The evidence of hospital staff revealed, at best, inconsistent implementation of the Royal College of Psychiatrists MARSIPAN guidance for the emergency treatment of AN patients and, at worst, a failure to implement the Guidance at all.

Evidence at Averil's inquest (and at those of [redacted]) suggested that limited progress has been made in respect of the *PHSO* recommendation with regard to the training of doctors and other medical professionals, (notwithstanding the further recommendations of the *PACAC Follow-up Report* and the Government Response to the latter's Recommendations). These concerns have been reiterated by the Position Statement of the Royal College of Psychiatrists (PS04/20) of September 2020 *"Improving core skills and competence in risk assessment and management of people with eating disorders: What all doctors need to know."*

The evidence at inquest of senior practitioners in the fields of psychiatry, psychology, acute medicine, dietetics, gastroenterology and GP practice all confirmed that there remains, as there was in 2012, a continuing and serious shortage of eating disorder specialists across the country with many Trusts finding it difficult to fill vacancies; such shortages inevitably impact upon the level and quality of support available to primary care providers and other specialists and therefore, in my view, risks avoidable future deaths.

(2) Lack of formally commissioned service level agreement for the provision of robust and effective monitoring of moderate to high risk AN patients by primary or secondary care providers

Evidence confirmed that in response to the *PHSO Report* an Expert Reference Group (ERG) was convened by NHS England (NHSE) to address the specific recommendation for NHSE to review the existing quality and availability of services to achieve parity for adult ED services with children and young people's ED services. The National Collaborating Centre for Mental Health (NCCMH) was commissioned to develop new guidance published in August 2019: *"Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care – Guidance for Commissioners and Providers".*

However, the clear and unchallenged evidence received at Averil's inquest confirmed that there remains a lack of formally commissioned provision for the monitoring of AN patients in primary or secondary care across large parts of the United Kingdom. Whilst the evidence received indicated that Cambridgeshire & Peterborough NHS Foundation Trust are seeking to develop models to ensure the provision of medical monitoring for all ED sufferers, including moderate to high risk patients, there are many areas in the country – including parts of the East of England Region – which still have no such formally commissioned provision. Further, unchallenged evidence identified a number of regions as not even having consultant level psychiatric in-put to the ED services that are purportedly available.

There was unanimity on the part of each of the senior clinicians who gave evidence, as well as a number of independent, instructed experts in the fields of ED and AN, that the continued absence of such monitoring and treatment provision gave rise to not only the risk of avoidable future deaths, but - in the views of many - the inevitability of the same. Evidence confirmed that

	whilst AN has the highest mortality of any mental disorder affecting young people and adults this should not be simply accepted and that AN and other EDs are treatable mental disorders, with even severe complications such as malnutrition safely reversible. The evidence further established that whilst in the long term primary prevention strategies including early recognition and treatment of the disease was critical, in the short to medium term, improving access to treatment and the effective monitoring of the severely ill is to be regarded as essential to address the risk of avoidable future deaths. (3) <u>Lack of robust and reliable data regarding the prevalence of eating disorders</u> Evidence also confirmed that the lack of precise information on the prevalence of eating disorders in the United Kingdom, described by the *PHSO Report* and the *PACAC Follow-up Report* as *"shocking, given the claim that up to 1.25 million people are suffering from an eating disorder and the fact that eating disorders have the highest mortality rate of mental illnesses"* persists. The witness evidence also confirmed the view expressed in the *PACAC Report*: *"This vagueness limits the ability of NHS commissioners to gauge what services need to be provided and encourages them to devote resources to better recorded diseases."* Further, I am concerned that there may also be a significant under-reporting of the extent to which EDs have caused or contributed to deaths, leading to cases either not being referred to the coroner or, if they are, the coroner in question determining that death was one of 'natural causes' with only the terminal cause of death, and not the underlying ED cause or contribution to the death, being recorded. In such circumstances there is a concern that a number of such deaths (where, for example, lack of care may have contributed to the death) are neither investigated appropriately by the coroner nor taken to inquest with a concomitant risk of a significant under-estimation of the true mortality rate of EDs. *(I propose to explore this issue in separate correspondence with the Medical Examiner for England and Wales (copied in to this Report), the Office for National Statistics and the Coroners' Society of England and Wales).* In my view, taken together, the absence of statistically robust data on the numbers of those suffering from EDs and the potential under-estimation of those deaths to which EDs may have caused or contributed, gives rise to an objective risk that avoidable ED deaths will continue in the future. (4) <u>The impact of the COVID 19 pandemic</u> I am concerned that the matters giving rise to the risk of future deaths identified at points (1) to (3) above have been - and will continue to be - significantly exacerbated by the on-going pandemic. I therefore request that responses to the above recognise and expressly address this concern.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you and your organisation(s) have the power to take such action.
7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report, namely by Wednesday 28th April 2021. I, the coroner, may extend the period. Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise you must explain why no action is proposed.
8	**COPIES and PUBLICATION** I have sent a copy of my report to the Chief Coroner and to the following Interested Persons: • *The family of Averil Hart*; • *Cambridgeshire & Peterborough NHS Foundation Trust (CPFT);*

	• *University of East Anglia (UEA);* • *University of East Anglia Medical Centre (UEAMC);* • *Legal Representatives for [redacted];* • *Legal Representatives for [redacted];* • *North Norfolk Clinical Commissioning Group (NNCCG);* • *Cambridge University Hospitals NHS Foundation Trust;* • *Legal Representatives for [redacted];* I have also sent it to the following who may find it useful or of interest: • *The family of [redacted]; the family of [redacted]; the family of [redacted]; the family of [redacted];* • [redacted], Chair of the Royal College of Psychiatrists; • [redacted], Deputy Leader of the Liberal Democrats, House of Lords; • *The PHSO Lead* with continuing responsibility for the '*PHSO Raising the Alarms Report';* • *The Chair of the Public Administration and Constitutional Affairs Committee* now responsible for the *'Follow up Report to the PHSO Raising the Alarms Report'*; • [redacted], Chair of the Adult Eating Disorder Expert Reference Group; • [redacted], Chief executive of Cambridgeshire LMC; • [redacted], Chief Executive of Beat (beating eating disorders); • [redacted], Kings College London; • [redacted], Lead Medical Examiner for England wales I am also under a duty to send a copy of your response to the Chief Coroner and allinterested persons who in my opinion should receive it. I may also send a copy of your response to any other person who I believe may find it useful or of interest. The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it usefulor of interest. You may make representations to me, the coroner, at the time of your response, aboutthe release or the publication of your response.
9	**3rd March 2021**  **Sean Horstead** **HM Assistant Coroner, Cambridgeshire & Peterborough**