	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. [redacted] – Woodlands Surgery** **2. [redacted] – East Surrey Clinical Commissioning Group** **3. [redacted] Associate Director – Eating Disorder Services for Adults** **4. [redacted] President – Royal College of Physicians** **5. [redacted] President – Royal College of Pathologists** **6. [redacted] Chair – Royal College of Psychiatry, Eating Disorders**
1	**CORONER** **I am Karen HENDERSON, assistant coroner for the coroner area of Surrey**
2	**CORONER'S LEGAL POWERS** I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of the Coroners (Investigations) Regulations 2013
3	**INVESTIGATION and INQUEST** On 11th July 2014 I commenced an investigation into the death of Clare Serena Anke COOPER, 24 years of age. The investigation concluded at the end of the inquest on 11th July 2014. The medical cause of death given was: 1a. Addisonian Crisis 1b. Undiagnosed Addison's disease 2. - My narrative conclusion was: **Clare died from the consequences of Addison's disease when opportunities were lost with diagnosis and treatment which could have affected the outcome**
4	**CIRCUMSTANCES OF THE DEATH** Ms Cooper was a previously fit and well young adult who had rarely troubled her GP throughout her short life. She presented to her GP in May 2012 complaining of weight loss and excessive tiredness. Reassurance was given but little evidence was documented to confirm the symptoms were explored in depth by taking a history or undertaking simple measurements such as weight and other vital signs (HR, BP etc.) at the time or subsequently. However a blood test was ordered by the GP to assess Ms Cooper's immune status, which was found to be normal. Ms Cooper presented again to her GP surgery in September 2012 after a significant 'faint' but nothing relating to this was recorded in the notes (only treatment for a long-standing foot disorder). Ms Cooper further presented to the GP practice in October, November and December 2012 with a continuing and increasing history of lassitude, difficulty in eating resulting in further unwanted weight loss and increasing anxiety. Latterly she chose to see a different GP as she felt her symptoms were not being taken seriously by her own longstanding GP. Documentation of the latter consultations were scant and do not confirm there was an in depth history taken to assess the severity and nature of the presenting and persistent symptoms. Whilst a body weight was measured at least once in December there was no indication of any other measurement of her weight and it was therefore not possible to quantify the proportion of weight lost. Vital signs (heart rate, blood pressure etc) were also not measured and I heard evidence that it may have shown significant evidence of a postural drop, which may have prompted further investigation. Ms Cooper had a blood test organised by the GP's in November and a further three in December 2012. Whilst she had a normal blood sodium in November 2012 (136 mmol/l) two sequential tests in quick succession in December showed an isolated low blood sodium of 126 mmol/l. A further blood test two

	weeks later indicated the sodium had returned to normal levels at 136 mmol/l. No significance was attached to the low sodium levels other than a presumption it may have arisen from a reduced diet or from vomiting which was mild (2-3 times a week). I heard expert evidence that Intermittent vomiting and food restriction would not ordinarily cause a low sodium, particularly when all other electrolytes were normal. I also heard evidence that an isolated blood sodium of 126 mmol/l should have been independently investigated in its own right, particularly if there is an absence of common causes (usually in the elderly) such as prescribed medication and despite the fact it had ostensibly returned to normal. I heard evidence that there was no formal protocol in place at the GP surgery to 'flag-up' abnormal results and no system in place to assess and manage electrolyte abnormalities. Equally there was no formal system in place for a clinical pathology service to highlight abnormal results to the relevant GP practice. In any event no other investigations were undertaken at the GP surgery to explore the possible cause of the low sodium and simple measures such as the measurement of vital signs and regular weight measurements in the presence of weight loss were not undertaken. Also, no consideration was give to a referral to hospital to assess whether there was a physical/organic cause of her symptoms and/or hyponatraemia. As it was, the final 'normal' sodium was likely to have been falsely reassuring. I also heard evidence that there is a lack of clarity locally and nationally as to how low a blood sodium level should be (either consistently or intermittently) before requiring assessment and investigation (although it was agreed a level of 126 mmol/l fulfilled the criteria). Also, 'clinical practice' medical textbooks were also unhelpful with regard to the management of low blood sodium levels with little emphasis on looking for a clinic-pathological connection. Thus a young person with an intermittently low sodium level may require a higher index of suspicion rather than individuals with underlying medical conditions or on prescribed medication known to cause a low sodium level. At the same time, Ms Cooper's lassitude was such she was signed off sick from work in November 2012 and she did not work again. Again the significance of this was not explored. She was then referred to the Eating Disorder Service (EDS) in December 2012 although there was no evidence she was deliberately attempting to lose weight or worried about putting on weight. Ms Cooper was seen for triage at the EDS In January 2013 and she was found not to satisfy the criteria for an eating disorder. It was thought her poor appetite was a consequence of her anxiety although a cause of her anxiety was not examined in detail. A physical cause was not considered for her symptoms other than a thyroid function test even though Addison's disease is a rare but well recognised cause of weight loss and difficulty eating. She was discussed at a multidisciplinary meeting and it was decided to continue to care for Ms Cooper to develop strategies associated with her anxiety as a cause of her poor appetite. She was also prescribed Fortisip and on follow up her weight had increased by approximately 1kg confirming, in part, she had no fear of gaining weight. I heard evidence the proforma used for triage at the EDS was overly focussed on psychological causes rather than a possible underlying physical cause of the signs and symptoms of an eating disorder and it was without adequate prompts to obtain relevant information which may have prompted an investigation for a physical cause of her symptoms. This includes no clear policy for screening for organic/physical illness or to have the full set of notes from the GP/clinical practice available at initial assessment. I also understand that this may be an issue nationally on a survey undertaken by the family of Ms Cooper with regard to EDS proformas from various institutions. Also, the risk assessment form for all mental health services was not thought to be sufficiently reflective of the needs of the eating disorder clinic. Retrospectively her parents commented that she had developed a love of salty food (eating noodles at breakfast covered in soy sauce) and had began to tan easily for 12-18 months prior to death but the significance was not understood at the time and were therefore not highlighted to the medical doctors caring for her. Unfortunately Ms Cooper continued to deteriorate at home with increasing severe symptoms of lassitude, dizziness, nausea and difficulty eating. She sadly had a cardiorespiratory arrest at home on 1st February and despite aggressive resuscitation after emergency admission to East Surrey Hospital she died on 2nd February 2013 (not sure of the dates). I heard expert evidence that the constellation of signs and symptoms were such that it was highly likely Ms Cooper was suffering from Addison's disease, which was not recognised as such. I concluded her final admission into hospital and subsequent death was from an Addisonian crisis and that whilst it is a very rare disease, her underlying symptoms and signs in the presence of a low blood sodium level were such that they required independent investigation whether or not Addison's disease was a consideration.

	I also heard evidence that the diagnosis of Addison's disease is difficult to diagnose at post mortem as changes to the adrenal gland may be subtle and as such there should be a higher index of suspicion in unexplained deaths in the young population to look for Addison's disease rather than giving a cause of death as Sudden Adult Cardiac Death syndrome (which was the initial cause of death given at PM). I also received evidence that pathologists undertaking coronial post mortems can be supplied with all the hospital or GP notes rather than relying on the coroner's death report with the possibility of improving clinico-pathological correlation in cases where death is uncertain or unascertained.
5	**CORONER'S CONCERNS** During the course of the inquest the evidence revealed matters giving rise for concern. In my opinion there is a risk that future death will occur unless action is taken. In the circumstances it is my statutory duty to report to you. The MATTERS OF CONCERN are as follows: 1. Poor GP documentation 2. Lack of evidence of a robust assessment of presenting signs and symptoms with a presumption of a psychological/psychiatric problem without considering or excluding an organic cause. 3. Lack of GP routine vital sign monitoring e.g. heart rate, blood pressure and weight measurement when weight loss is a concern with a lost opportunity to assess the severity of weight loss. 4. No established system for recognition, assessment and management of electrolyte abnormalities within the GP practice and/or consideration of the chemical pathology service to 'flag-up' particularly concerning results. 5. Lack of understanding of the underlying causes of hyponatraemia (consistently or intermittently low) and the level below which will require further investigation, and the investigations that should be carried out, particularly in circumstances when there is no obvious cause of the low sodium. 6. Insufficiently detailed referral letter to EDS (mentioning 'low sodium' but not accompanied with a copy of the blood results) and an opportunity was lost for its significance to be considered 7. Insufficiently robust EDS proforma used to triage patients for an eating disorder: lack of prompts and a need to emphasise and exclude possible organic causes, however rare. The lack of a documented list of potential diagnoses to be assessed and excluded at triage, including organic causes. A need to facilitate communication from the referral agents to the eating disorder service. 8. The lack of a national protocol for assessing patients seriously ill with an eating disorder with the possibility of detecting individuals with an organic basis for the condition. 9. Lack of hospital or GP notes available for the pathologist undertaking the post mortem to facilitate a greater opportunity for clinic-pathological correlation in deaths which are unascertained and a higher level of suspicion to explore rare causes of unexpected death, especially in the young. 10. The need to highlight this case nationally to clarify published guidance with regard to the causes, investigation and treatment of low blood sodium and to reinforce the importance of excluding an organic basis of an illness before labelling the condition a psychiatric or psychological disorder.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe the GP practice (Woodlands Surgery) and other organisations; East Surrey Clinical Commissioning Group, Eating Disorder Services for Adults - Surrey and Borders NHS Trust, Royal Colleges of Physicians, Pathologists and Psychiatry, Eating Disorders, 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. I, the coroner, may extend this 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; [redacted] - Chief Medical Officer – Department of Health [redacted] – NHS Medical Director, NHS England [redacted] – Medical Director, Health Education England [redacted] – President, Royal College of General Practitioners [redacted] – President, Royal College of Psychiatrists [redacted] Chair, Joint Commissioning Panel for Mental Health [redacted] – Chair, Joint Commissioning Panel for Mental Health [redacted] Professor of Endocrinology Oxford University, OCDEM [redacted] – Consultant Psychiatrist in Eating Disorders [redacted] – GP, Woodlands Surgery [redacted] – Expert General Practitioner [redacted] – Consultant Endocrinologist, Brighton & Sussex University Hospitals Medical Defence Union Medical Protection Society Medical Defence Union of Scotland I am also under a duty to send the Chief Coroner a copy of your response. 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 useful or of interest You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner.
9	**DATE: 25th July 2014** **SIGNED: Dr Karen Henderson**