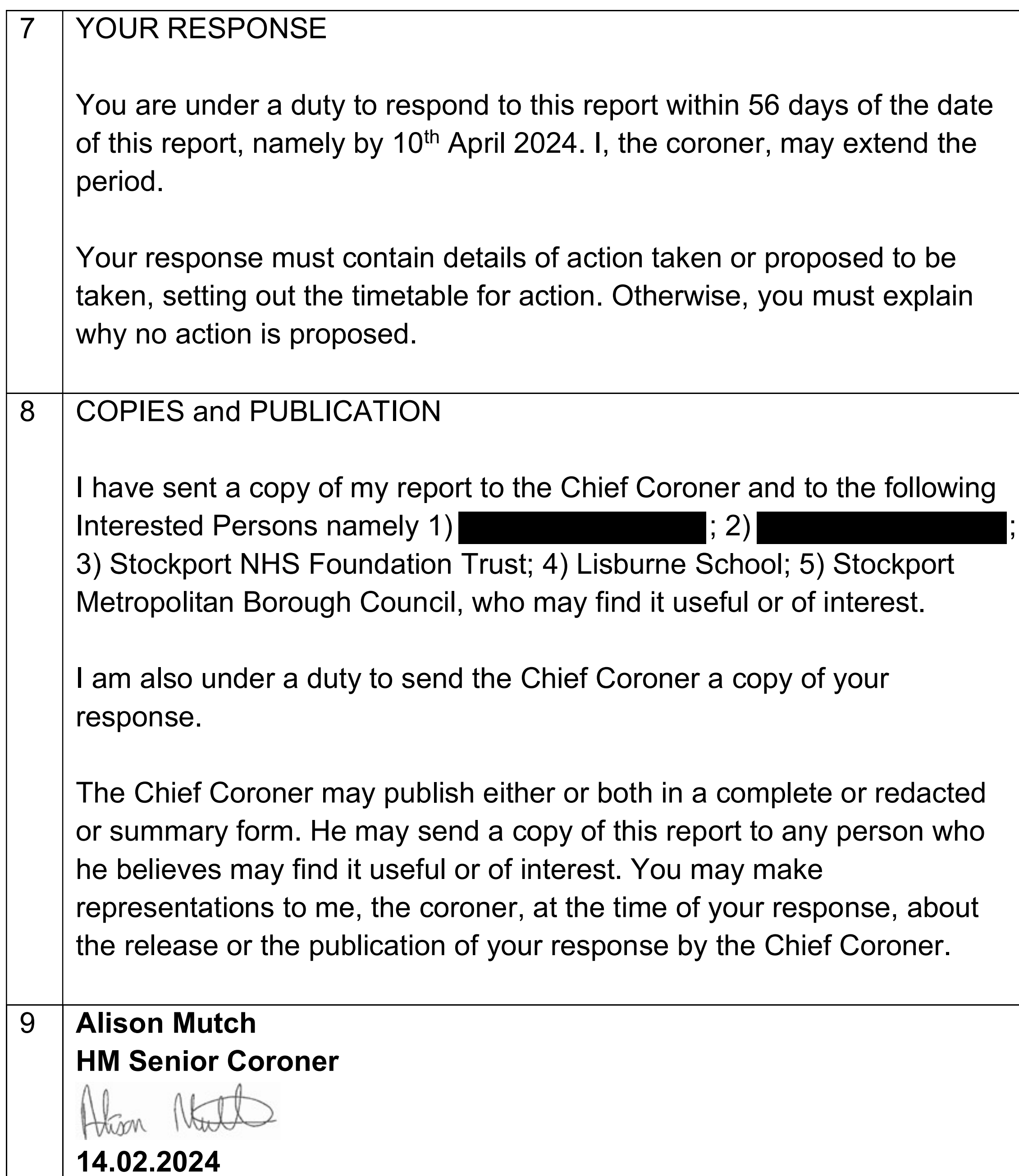
REGULATION 28: REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS THIS REPORT IS BEING SENT TO: 1) Department of Health and Social Care 2) Department of Education 3) The National Institute for Health and Care Excellence (NICE) 4) Greater Manchester Integrated Care
1	CORONER I am Alison Mutch, HM Senior Coroner, for the coroner area of South Manchester
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 20th December 2021, I commenced an investigation into the death of Alfie Anthony Kevin Nicholls. The investigation concluded on the 12th January 2024 and the conclusion was one of **Narrative: Died suddenly where his death was contributed to by malnutrition which was caused by a severely restricted diet and where the level of malnutrition and the consequential risk it posed was not recognised by professionals until after his death.** The medical cause of death was **1a) Sudden death in child with features of malnutrition on a background of developmental delay and an autistic spectrum disorder**
4	CIRCUMSTANCES OF THE DEATH Alfie Anthony Kevin Nicholls was a child with autism who was in full time education at a special school and was under the care of the child development unit. He was also known to children's services, and there was an allocated social worker to support him and his family. As a consequence of his autism and sensory issues, Alfie had a difficult

	relationship with food and a restricted diet from a young age. Following him starting school, his diet became increasingly more restricted. Health, Education and Social Services professionals involved in his care did not communicate effectively between themselves or with his family about his diet and so did not have a clear understanding of how severely restricted his diet had become and how extremely limited it was in nutritional value. The risk that his nutritionally poor diet could present to his physical health was not understood or recognised by professionals involved in his care. On 17th December 2021, he collapsed at his home address and was taken to Stepping Hill Hospital. Attempts to resuscitate him were unsuccessful and he died at Stepping Hill Hospital on 17th December 2021. A post-mortem examination found evidence of significant malnutrition caused, on the balance of probabilities, by his severely restricted diet, that on the balance of probabilities, contributed to his collapse and death on 17th December 2021
5	<u>CORONER'S CONCERNS</u> During the course of the Inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths 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. The inquest heard evidence that Avoidant Restrictive Food Intake Disorder (ARFID) was not widely understood by those involved with children and adults who may be impacted by it. That included a lack of awareness of what it was and how to approach it amongst Health, Education and Social Work professionals. The inquest was told that until awareness of it improved then similar situations to that of Alfie could go unrecognised with similar consequences. 2. Evidence before the Inquest was that in addition to there being increased awareness amongst professionals there needed to be strategies within and across Health, Education and Social care to ensure effective strategies were put in place and those with ARFID or at risk of developing ARFID were identified and managed effectively. 3. A feature of the evidence before the Inquest was a normalisation

	of poor and restricted eating by children with autism. This meant that the impact on their overall health and wellbeing was not considered. Children with autism were measured against each other in relation to their eating with phrases such as “we have children with poorer diets …” being used. 4. Whilst there was an Education, Health and Care Plan (EHCP) in place for Alfie there was little evidence that EHCPs were being used as a holistic tool to understand the inter relationship between health and education. There was evidence that those writing EHCPs needed to consider a child more holistically for the EHCP to cover all the aspects that it was meant to cover and not just to focus on education. 5. The Inquest heard that the school nurse service could play a vital role in identifying health issues and supporting other professionals. This key role was significantly impacted by the high demand on the service and the very high caseloads school nurses working with complex children were being asked to carry nationally. 6. The role of a dietician in supporting children with eating disorders could be fundamental in maximising the nutritional value of what they consumed. Demands on the service and a limited understanding of how they could work to support children with disorders such as ARFID (nationally) meant that there was rarely regular input from dieticians. 7. ARFID, the Inquest was told, could lead to medical emergencies in eating disorders (MEED). The evidence given at the Inquest was that whilst this concept had been the subject of guidance amongst Psychiatrists it had been less publicised and there had been far less guidance by other Royal Colleges. In particular the Inquest was told that MEED needed to be far better understood by medical professionals in acute settings such as Emergency Departments and Paediatrics to avoid a situation where the impact of ARFID and the medical risk it posed was not understood until it was too late.
6	ACTION SHOULD BE TAKEN In my opinion action should be taken to prevent future deaths and I believe you 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 10th April 2024. 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 namely 1) ; 2) ; 3) Stockport NHS Foundation Trust; 4) Lisburne School; 5) Stockport Metropolitan Borough Council, who may find it useful or of interest. 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	**Alison Mutch** **HM Senior Coroner** **14.02.2024**