

REGULATION 28: REPORT TO PREVENT FUTURE DEATHS

	<p>REGULATION 28 REPORT TO PREVENT FUTURE DEATHS</p> <p>THIS REPORT IS BEING SENT TO:</p> <p>Matt Hancock, Secretary of State for Health and Social Care, House of Commons, London, SW1A 0AA</p> <p>Simon Stevens, Chief Executive Officer, NHS England, Skipton House, 80 London Road, London, SE1 6LH</p>
1	<p>CORONER</p> <p>I am Dr Shirley Radcliffe, Assistant Coroner for the area of Eastern Area of Greater London</p>
2	<p>CORONER'S LEGAL POWERS</p> <p>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. http://www.legislation.gov.uk/ukxi/2013/1629/part/7/made</p>
3	<p>INVESTIGATION and INQUEST</p> <p>On the 14th December 2017 an investigation was opened into the death of Sophie Holman. The investigation concluded at the end of the Inquest on the 14th January 2019. The conclusion of the Inquest was a narrative conclusion:</p> <p>Sophie Holman was a 10 year old girl who suffered from chronic asthma. Her long-term management by primary and secondary care was inadequate. On the 12th December 2017 she attended her General Practitioner with an acute exacerbation of her asthma. She was treated and sent home with a prescription for steroids.</p> <p>She collapsed and died from an asthma attack the following day. She was pronounced life extinct at Queens Hospital, Romford on the 13th December 2017.</p> <p>A fuller assessment, earlier steroid administration and better safety netting on the 12th December 2017 would have prevented her death.</p>
4	<p>CIRCUMSTANCES OF THE DEATH</p> <p>Sophie Holman was born on 23.7.2007 and died prematurely due to a severe asthma attack on 13.12.2017 at the age of 10 years 5 months. Her asthma first started troubling her at the age of 9 months and she was first admitted to hospital with an attack at the age of 20 months. She attended her general practice and three hospitals on innumerable occasions for asthma attacks throughout the next 10 years -48 in all – 26 times in the last four years of her life. She was cared for by a series of medical personnel in primary and secondary care; the treatment was directed to alleviate the symptoms of the immediate presenting and acute attacks. Some of these attacks had life threatening features of asthma however, there was no appreciation that these episodes were clear signs of her underlying poorly controlled possibly severe chronic asthma.</p>

She attended the Ripple Road Surgery with her mother on the morning of the 12th December 2017 with breathing difficulties that had deteriorated over the previous week and was treated for an asthma attack (the fourth in 12 months) by the practice nurse who called for assistance of one of the doctors. symptoms of an asthma attack. Following failure to respond adequately a second dose of high dose reliever medication, alleviated her symptoms, Sophie was discharged home with a prescription for cortisone tablets and advice to take a high "weaning dose" of reliever inhaled medication every 4 hours. Sophie continued to use her reliever inhaler to try and move the mucus which she couldn't cough up, and the following morning after a night's sleep her parents decided to take her to hospital because she didn't appear to have improved from the previous day. On the way, she became very short of breath, collapsed and despite resuscitation attempts by bystanders, paramedics and the hospital paediatric team, sadly she died at 22:49 that night. Following a post-mortem examination the cause of death was noted as: *1a: Sudden Death in Bronchial Asthma and ii: Lower Respiratory Tract Infection*

Sophie was admitted 4 times to the Barking, Havering and Redbridge University Hospitals NHS Trust, a trust operating a 2 site model (Queens Hospital & King Georges Hospital) for general paediatrics and A&E. Whilst acute care was adequate, this child had been seen in A&E 18 times with acute asthma, over 70% of these encounters being retrospectively characterised as severe / life threatening. Each of these events were treated appropriately as an acute event but were not viewed collectively, or in terms of severity as unusual, life threatening or as part of a long term potentially fatal condition.

Clinical notes were not readily available across the two sites and temporary hand written folders were often created and later photocopied into the clinical case notes. Subsequently temporal order was lost and vital information was missing. Documentation and the standard of note keeping fell below GMC recommendations.

A child protection review system was in place in A&E. This collated the number of A&E visits a child had made, but this system disregarded the medical condition asthma, and so the clinicians were not alerted to the frequency of attendances.

Sophie was referred to a general paediatrician by her GP, and following acute admissions referred for follow up by 2 ward based paediatricians to the same general paediatrician for follow up. The paediatrician did not have sufficient experience in asthma to identify the risks to this child, carry out pertinent investigations, or make the necessary tertiary referral. The paediatrician did not have enough knowledge to recognise the limitations of their practice.

Despite 12 general paediatricians within the department, there was no one with an interest in paediatric respiratory disease. No paediatric asthma nurse was employed by the Barking, Havering and Redbridge University Hospitals NHS Trust, and there was no facility to carry out objective measurements of peak flow or spirometry. Consequentially no personalised action plan was created, and no patient education delivered. Overall the department failed to view Sophie's asthma as a potentially life threatening or as a long-term condition requiring a long-term intervention and plan. At no time was there a communication with the family regarding the lack of adequate control severity of Sophie's condition. Sophie was not brought to 7 of 10 outpatients patients' appointments. It is likely that had the family been told the severity of Sophie's condition their attendance would have been more frequent.

The Serious Incident review was initiated in December 2018, one year after the child's death. Currently the recommendations of this report, and the verbal statement of the clinicians given at the inquest fall short of national guidance. The 10 year plan for the NHS emphasises the need for a clinical network model around paediatric asthma. Four asthma deaths in childhood have occurred within the local STP since 2016. With good medical leadership in paediatrics and asthma care Barking, Havering and Redbridge University Hospitals NHS Trust could and should play an important role in local professional education, and improved clinical care.

Despite the publicised recommendations from the National Review of Asthma Deaths (NRAD) and previous Regulation 28 Statements (on preventable asthma deaths) by HM Coroners, there were many missed opportunities to optimise and co-ordinate Sophie's medical management during her 48 attendances and admissions in the practice and hospitals (at least 10 of which included life threatening features) and particularly in her final year when she had four asthma attacks treated in the practice.

There were a number of missed opportunities to refer this child to a specialist respiratory team for investigation to characterise the nature and triggers of her chronic asthma condition and to optimise her medical management. The medical records in the practice and hospitals, lacked clear information highlighting the severe ongoing risk of poor outcome including future asthma death in the case of this child; there was no cohesive long term plan for managing Sophie's asthma with the result that no one recognised the cumulative risk factors that should have led to a specialist respiratory referral which may have resulted in a very different outcome.

5 **CORONER'S CONCERNS**

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 medical management of this child's asthma attacks on the innumerable occasions she presented to her general practice and hospital was centred solely on treating the immediate presentation as an isolated acute event seeking its stabilisation and returning her to the care of her family
- 2) There was:
 - a. No coordinated record of these occasions
 - b. No analysis of the frequency or circumstances of these events
 - c. No analysis of the underlying chronic asthma condition
 - d. No appreciation of the risk factors for future attacks and death due to asthma in this child
 - e. No long-term management plan for the care of this child despite innumerable attendances for attacks and failure of the parents to bring the child on occasions for routine hospital and practice appointments
 - f. No evidence of provision of a written personal acute asthma self-management plan recommended in the UK BTS/SIGN asthma guidelines
 - g. No evidence that the family were informed of the risks of poor outcome evidence in this child's history
 - h. No evidence that anyone considered referring this child as recommended in the NRAD, to a respiratory specialist or severe asthma service for investigation, characterisation of the nature and phenotype of this child's asthma so that a long-term management and treatment plan could be formulated and implemented
 - i. No clear understanding or awareness by the health professionals caring for Sophie of the current UK asthma guidelines, the recommendations of the NRAD or of the prescribing advice in the British National Formulary for the management of asthma
- 3) As in the case of two recent child asthma deaths resulting in Regulation 28 statements (Michael Uriely and Tamara Mills), despite the presence of numerous health professionals involved no single individual or organisation took overall responsibility for assuming management of her care overall.

- 4) In and of itself this episode demonstrates a profound and woeful indication of the lack of understanding of how this condition, its recurring nature can and should be managed by someone with the proper training and understanding of this chronic respiratory disease.

In the primary care practice there was:

- a) No clear agreed practice protocol for managing asthma
- b) The medical records did not contain an up to date summary of current and past problems; in particular correspondence from hospitals following treatment for asthma attacks was not Read Coded. As a result clinicians consulted could not readily see the evidence of this girls chronic poorly controlled asthma
- c) A failure to recognise the risks of future poor outcome such as
 - a. Excess salbutamol prescriptions after the publication of the NRAD in May 2014. The child was prescribed 28, 22, 30 and 16 of these inhalers in 2014, 2015, 2016 and 2017 by her general practice
 - b. Failure to recognise the only 5 of the required preventer inhalers were collected in Sophie's final year of life
- d) No clear supervision of junior doctors and nurses delegated to provide asthma care
- e) Failure to objectively assess severity and progress when treating acute asthma attacks as per the UK BTS/SIGN asthma guidelines
- f) Failure to recognise that absence of symptoms and distress does not exclude the presence of a severe attack, as highlighted in the UK BTS/SIGN asthma guidelines
- g) Failure to follow up after attacks as detailed in the NICE Quality Statement of 25, 2013
- h) No clear evidence of detailed specific safety netting advice and over-reliance on prescription of unlicensed, non-specific based high dose salbutamol 'weaning plans' which may have masked recognition of deteriorating signs due to a requirement for excess reliever medication in Sophie's final fatal attack – which may have led the parents to seek help earlier than 24 hours after leaving the surgery
- i) Potentially dangerous advice on occasions: in particular when a nurse sent the child home and advised mother to administer reliever treatment with a nebuliser at home for an asthma attack
- j) No evidence of provision of a written Personalised Asthma Action Plan for recognition of uncontrolled asthma and attacks and any action to be taken by the family and how and when to obtain medical assistance
- k) There was only one example where one of the 16 general practitioners who treated this child arranged a post-attack follow-up review soon after attacks
- l) No attempt to increase the medication dose for three and a half years despite at least 14 recurring asthma attacks

In the secondary care there was:

- a) Failure to recognise and act upon the underlying chronic condition punctuated by a number of severe attacks with life threatening features one of which was a near-fatal attack where Sophie was 'blue and unresponsive' with an oxygen saturation of 86% (2.7.2012)
- b) Failure to recognise the need for and initiate referral of this child to a specialist respiratory service as recommended in the NRAD recommendations
- c) Failure to take appropriate action when it was known that the family had a home nebuliser
- d) Failure to implement the recommendations in the NICE Quality Statement 25, and BTS/SIGN guideline to ensure a pre-discharge review of the child's asthma by an appropriately trained individual
- e) Failure to effectively communicate changed medication in 2013 of the child

	<p>to the general practitioner</p> <ul style="list-style-type: none"> f) Implementation of a hospital policy whereby this child was discharged from secondary care three times because of failure of the parents to bring the child to planned outpatient appointments g) No clear evidence of detailed specific safety netting advice and over-reliance on prescription of unlicensed, non-evidence based high dose salbutamol 'weaning plans' which may have masked recognition of deteriorating signs due to a requirement for excess reliever medication <p>5) The child's parents failed on occasion to bring the child to routine appointments; however there was no communication by any health professional alerting the health visitors or safeguarding team regarding this. On the other hand, the child's asthma attacks were treated in hospital and general practice 'as an acute illness', without detailed patient education or a co-ordinated long-term management plan. There was little evidence of any patient education – particularly aimed at ensuring that the child's parents were aware of the fact that she was at risk of poor outcome even asthma death according to her risk factors; perhaps explained the behaviour of her parents.</p> <p>6) The National Review of Asthma Deaths (NRAD) was published in a report entitled 'Why asthma still kills' on the 6th May 2014, 3 ½ years before Sophie's death. The process of management of Sophie's asthma demonstrates many of the same examples of poor practice providing clear evidence of why 'asthma still kills' and which led to the early death of this child:</p> <ul style="list-style-type: none"> a) Failure to recognise ongoing and future risk by general practitioner and secondary care b) Repeated attacks despite asthma treatment c) Excess salbutamol (reliever) prescriptions and the presence of a home nebuliser d) Insufficient collection of Inhaled corticosteroids in her last year of life e) Requiring 3 different asthma drugs f) Previous severe attacks g) Failure to attend appointments h) Failure to refer this child to a tertiary respiratory service – the NRAD recommended referral of anyone having 2 or more asthma attacks in a year
6	<p>ACTION SHOULD BE TAKEN</p> <p>In my opinion action should be taken to prevent future deaths and I believe you have the power to take such action.</p> <p>In the context of seeking to avoid future preventable asthma deaths, and to reduce preventable asthma attacks, the details of Sophie's inquest, the NRAD review and the Regulation 28 statements on Tamara Mills and Michael Urieli identify a need by both local and national agencies to revisit the recommendations, the formal substance of training identified as appropriate for the care and treatment of asthma, the nature of that disease and strategies for the long term management, care and prevention of uncontrolled asthma and re-occurring attacks.</p> <p>There are undoubtedly resource issues implicated in this matter but a demonstration of resolve and an effective lead given by the Department of Health and those involved in the provision of Health Service guidance and education nationally would demonstrate a universal resolve to standardise the care of chronic asthma patients and to make preventable paediatric asthma deaths and preventable asthma attacks 'never events'.</p>

	<p>A. A national consistent policy for management of asthma should be implemented based upon clear, uniform, easy to understand guidelines clarifying:</p> <ul style="list-style-type: none"> a. The chronicity of asthma b. Recognising risk and when to refer to specialist services. <p>B. The recently announced 10 year plan for the NHS offers an opportunity for implementing change, for example by ensuring that every Primary Care Network, caring for groups of 50000 patients, should have access to an expert led paediatric asthma service with provision of an expert respiratory trained nurse and the facilities to ensure patients like Sophie and others like Michael Urielly and Tamara Mills have access to a named individual responsible for overseeing their care</p>
7	<p>YOUR RESPONSE</p> <p>You are under a duty to respond to this report within 56 days of the date of this report, namely by the 26th March 2019. I, the coroner, may extend the period.</p> <p>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.</p>
8	<p>COPIES and PUBLICATION</p> <p>I have sent a copy of my report to the Chief Coroner, [REDACTED] parents of Sophie Holman, the Director of Public Health Mr Matthew Cole, [REDACTED] the experts.</p> <p>I am also under a duty to send the Chief Coroner a copy of your response.</p> <p>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.</p>
9	<p>[DATE] 29/1/19. [SIGNED BY CORONER] <i>[Signature]</i></p>