	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** 1. **County Durham and Darlington NHS Trust, Darlington Memorial Hospital, Hollyhurst Road, Darlington, DL3 6HX** 2. **National Institute for Health and Care Excellence, 10 Spring Gardens, London SW1A 2BU** 3. **Department of Health, Ministerial Correspondence, Richmond House, 79 Whitehall, London SW1A 2NS**
1	**CORONER** I am Andrew Tweddle, senior coroner, for the coroner area of County Durham and Darlington
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. (see attached sheet)
3	**INVESTIGATION and INQUEST** On 23rd December 2010 I commenced an investigation into the death of **Nathan Douthwaite** aged 17 years. The investigation concluded at the end of the inquest on 25 February 2014.. The conclusion of the inquest was natural causes, the cause of death was 1a. Abdominal compartment syndrome, perforated caecum 1b. Hirschsprung's disease.
4	**CIRCUMSTANCES OF THE DEATH** Nathan was born in November 1993 at full term and passed meconium on the first day of life and continued to open his bowels regularly over several days in hospital after birth. In 1995 when Nathan was 21 months old there is mention in his medical records of him suffering from constipation (with blood in the stool). In 1999 Nathan was admitted to hospital for his first clear out of faeces. In 2000 was 6 ½ years old he began treatment with a consultant paediatrician who had particular interest in paediatric constipation and who was involved in his care until his death in December 2010. During this 10 year period Nathan was frequently seen at hospital suffering from severe bouts of constipation and by 2010 had been admitted to hospital on 13 occasions for clear out of faeces. His treating consultant in 2007 on his 10th admission for faeces described his abdomen as "grossly distended" and with "the most enormous faecal mass the size and shape of a rugby ball extending from pelvis to diaphragm with gross distention of the colon". The clear out took the "best part of 3 weeks, with medication". In 2007 Nathan was referred to a regional paediatric surgeon in Newcastle with a view to consider an antegrade enema continence procedure (ACE). This specialist considered a diagnosis of Hirschsprung's Disease exceptionally unlikely. The specialist nurse did not believe that Nathan was likely to comply with post ACE procedures and he was not seen again by the surgical team. In 2010 it was noted that he lost 11.8 kilograms (over 17%) of his body weight. Nathan's treating consultant had made a diagnosis of functional constipation. She had not thought that he was suffering from Hirschsprung's disease. Nathan was admitted to hospital at 04.20 hours on the 21st of December 2010 as an emergency and died at 07.15 hours. At autopsy there was presence found of a massive megacolon with compression of the abdominal and thoracic organs consistent with abdominal compartment syndrome, together with a perforation of the caecum which was considered to be a very late event. The cause of death given was 1a. Abdominal compartment syndrome, perforated caecum. 1b. Hirschsprung's disease. NICE guidelines with regard to Hirschsprung's disease were introduced in 2010. No rectal biopsy was performed on Nathan as it was felt at the time (prior to the NICE guidelines being published) that he did not meet the criteria for Hirschsprung's disease.

	Even after the publication of NICE guidelines Nathan's condition would not have met the criteria for a rectal biopsy. An independent consultant paediatric surgeon gave evidence that there was a possibility that there were more cases of undiagnosed Hirschsprung's disease in older children than it was generally believed, that there was a nationwide survey being undertaken and that the NICE guidelines with regard to Indications for rectal biopsy and investigations that should be performed before undergoing an ACE procedure should be reviewed, when dealing with children with severe constipation.
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. – It is likely that if Nathan had undergone a rectal biopsy, Hirschsprung's disease would have been diagnosed with the opportunity then being available for the appropriate treatment and thus I consider (1) That NICE undertake a review of its guidelines in this regard (2) That Count Durham and Darlington NHS Trust does review its own practices and procedures in advance of a NICE review and (3) The Department of Health be aware of the circumstances of this case so that it can consider whether guidance should be issued in this regard pending the NICE review.
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 25th April 2014. 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 [redacted] of MSP Legal Services, Hartlepool, [redacted] Ward Hadaway, Care Quality Commission and to the LOCAL SAFEGUARDING BOARD (where the deceased was under 18)]. 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	**Dated - 28/2/14** **Signed**..... **A TWEDDLE LLB** **H M SENIOR CORONER** **COUNTY DURHAM AND DARLINGTON**