	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. Sheffield Teaching Hospitals NHS Foundation Trust**
1	**CORONER** I am Abigail Combes, assistant coroner, for the coroner area of South Yorkshire (West District)
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 14 February 2018 I commenced an investigation into the death of Laura Booth born on 14 December 1994. The investigation concluded at the end of the inquest on 26 April 2021. The conclusion of the inquest was:- Laura Booth went into the Royal Hallamshire Hospital on 25 September 2016 for a routine procedure. She became unwell whilst she was a patient at the hospital and amongst other illnesses, she also developed malnutrition due to inadequate management of her nutritional needs. Her death was contributed to by neglect. She died at the Royal Hallamshire Hospital on 19 October 2016. And I amended the medical cause of death to reflect:- 1a. Respiratory Failure 1b. Bronchopneumonia 1c. Partial Trisomy13 (Patau's Syndrome) 2. Malnutrition, Immunodeficiency (treated), Crohn's Disease (treated), Insulin-dependent diabetes mellitus, juvenile arthritis (treated)
4	**CIRCUMSTANCES OF THE DEATH** Laura Booth was required to go into hospital for a routine elective eye surgery because of in growing eyelashes. She had previously been under the care of Sheffield Children's Hospital however on becoming an adult she had transitioned to the care of Sheffield Teaching Hospitals which includes both the Royal Hallamshire Hospital and the Northern General Hospital. A plan was in place for Laura that should she need an inpatient admission, this would be facilitated, wherever possible, through ward E2 at the Royal Hallamshire Hospital. This plan had been enacted successfully in April 2016 however following surgery on that occasion Laura's diabetes was not well managed by the hospital. This is acknowledged by the hospital and resulted in a decision being taken that when Laura was due to attend for her eye surgery in September 2016, she would be admitted the night before the surgery and be kept overnight to support her diabetes management. Her parents would be able to remain with her whenever she was an inpatient at the hospital. When Laura attended at the hospital on 25 September 2016 it was clear that this message had not been adequately communicated and staff were not expecting her however the hospital was able to allocate Laura a room on the ophthalmology ward which was of sufficient size to accommodate Laura and her parents.

It became clear, through the anaesthetic assessment, that Laura was not going to be able to have her operation when it became evident that she had issues with low potassium. This had been apparent on pre admission screening but had not been noted. As a result, Laura was kept in hospital to treat her low potassium and try to get her into a position where she was well enough for surgery.

It was clear that Laura required medical oversight rather than surgical oversight and from the point of her admission on 25 September 2016 to the point of her move to ward E2 on 29 September 2016 there were numerous attempts to move her care to a medical team. She did move on 29 September 2016 and was seen by a senior registrar from the gastroenterology team. On this occasion it was clear that there were concerns over Laura's nutrition and a request was made for her to be referred to the nutrition team.

A repeated request had to be made on 3 October 2016 and a referral was made.

This commenced a series of reviews by nutrition services and discussions with medical teams treating Laura although throughout Laura's admission there was no one individual identified to make decisions about Laura's nutrition and it is clear that Laura's nutritional needs were not managed or overseen by any individual. It was not until the 19 October 2016, which is the day that Laura died, that Dr [redacted] took overall control of this decision and TPN determined to be appropriate for Laura.

From 29 September 2016 until 19 October 2016, although Laura's nutrition was a significant concern and was discussed by a number of professionals involved in her care there were no attempts to engage Laura or her parents in a best interests meeting to determine the way in which Laura's nutrition should be managed in her best interests. There appears to have been an incorrect view that Laura's father had indicated that NG feeding would not be tolerated by Laura however this was not the subject of an MDT meeting and subsequently not the subject of any best interests meeting; consequently, this option was unlawfully ruled out with decisions made in contravention of the requirements of the Mental Capacity Act 2005.

I made the following findings based on the evidence which I heard at the inquest:-

1. Laura's nutritional intake was a concern from her admission on 29 September 2016 on the basis of the Trust's own records. Despite this, feeding charts were not commenced.
2. Laura's nutritional intake was not given sufficient weight or discussion from 29 September 2016 to the 19 October 2016.
3. Clinical decisions were made for Laura unlawfully
4. There was an inappropriate weight placed on Laura's clinical history and myriad of diagnosis
5. Laura should have been discussed in an MDT and a formal plan and strategy should have been developed by no later than 7 October 2016 for nutrition
6. Alternative feeding, whether via NG tube or TPN should have been tried and commenced between 29 September 2016 and no later than 14 October 2016.
7. The decision not to adequately manager Laura's nutrition was a gross failure of her care.
8. Laura's malnutrition contributed to her death and contributed in a way which was more than minimal, negligible or trivial.

I have deliberately not focussed on Laura's underlying conditions in this summary of the circumstances of her death. As can be seen from the findings above, I believe that there was an inappropriate weight placed on these conditions and that resulted in her basic human needs being overlooked. For the sake of completeness, Laura was diagnosed with partial trisomy 13 (Patau's syndrome), immunodeficiency, Crohn's disease, juvenile arthritis and insulin dependent diabetes mellitus. It is significant that her immunodeficiency, Crohn's disease and arthritis were all controlled and inactive at the time of her admission on 25 September 2016 and her diabetes was well managed by Laura with support from her mum and dad.

5 **CORONER'S CONCERNS**

During the inquest the evidence revealed matters giving rise to 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. –

(1) I heard evidence at the inquest about the changes which have been made in the Hospital to the nutrition services and I found these changes highly encouraging. I am now satisfied that there is an identified clinician with decision making responsibility in these circumstances. I am therefore not making recommendations which relate to the nutrition services within the hospital.

(2) I am satisfied and remain gravely concerned about the lack of knowledge, respect and application of the Mental Capacity Act principles amongst staff treating patients who may not have capacity to make decisions for themselves.

(3) Having heard evidence at the inquest I remain gravely concerned that Senior Clinicians have limited or no understanding of the Mental Capacity Act and apply it in a way which undermines the principles and requirements of the legislation.

(4) I have heard evidence of online training tools which have been undertaken; whilst some training is better than no training it is clear to me that this training is insufficient to embed, in practice, knowledge and understanding of the Mental Capacity Act in a way which protects the vulnerable people it is intended to serve.

(5) There appears to be a lack of understanding that decisions, when referred to in a best interests sense, are specific. This is not an overall catch all care plan. For example, the decision about whether Laura should receive an NG tube is one specific decision it is not bound up with ceilings of care decisions or any other decisions to be made with and for Laura.

(6) Laura was non verbal but she could communicate. There was no evidence of anyone seeking Laura's parents' views in a way which would be compliant with the Mental Capacity Act and even more worryingly, no evidence of clinical teams seeking Laura's views at all.

(7) There was evidence in the clinical notes of one best interests form completed for Laura's admission for her eye surgery. The completion of this form, whilst a positive that it had been completed and is evidence that best interests had been considered, remains woefully inadequate in details and upon further exploration it was apparent that no attempt had been made to engage Laura in the decision making.

(8) There appeared to be a view that although there was no formal best interests meeting for decisions about Laura's nutrition, clinical discussions were taking place with the right clinicians and therefore the decisions would not be changed by a best interests meeting. This is a fundamental misunderstanding about the requirements of the Mental Capacity Act and best interests, clinical decisions are not a substitute for the individual being supported to decide for themselves or for a decision made in their best interests to be reflective of their own views. In the same way as an individual with capacity may decline a treatment or intervention, even where it is recommended by a clinician in the highest possible terms, a treatment or intervention can be declined on Ps behalf where that decision is made in their best interests in accordance with the requirements of the Mental Capacity Act. Where necessary this may require application to the Court of Protection where there is a dispute.

	(9) I remain concerned that all staff treating Laura have expressed the view that they did not expect Laura to die in this admission and were very upset when she did. I am therefore at a loss as to why the verification of death form records her as being an expected death. I would therefore challenge the Trust to consider whether there is a need to reflect on the completion of these forms and their importance and likewise whether there is a need to reflect on presumptions made about an individual's underlying health conditions when completing verification of death forms. (10) I also remain concerned at a lack of understanding about the importance and relevance of Laura's hospital passport. This is a document which if read and understood by those treating Laura should mean that they can understand her, her communication style and her support needs so that she can be involved in decision making. It also should, if utilised properly, ensure that Laura's parents could have a level of reassurance that even if they were not there, Laura would be treated as if they were as staff would know how to communicate with Laura and understand what it was that she needed from them.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe your organisation have the power to take such action. I would ask that your responses specifically consider the following:- 1. What action the Trust shall carry out in order to address the failures and limitations in staff understanding so that the intended consequence of the Mental Capacity Act 2005 and the DOL Safeguarding provisions have meaningful practical effect on patients' care. 2. What action the Trust will take to ensure that Senior clinicians are familiar with the provisions of the Mental Capacity Act and any subsequent legislation developed with the same aims and objectives and make this business as usual for those individuals and the junior clinicians they supervise. 3. How individuals who lack capacity will be supported to influence decisions about their own care as much as possible. 4. How families are brought into these discussions where patients cannot make decisions for themselves and what measures are in/being brought into place to ensure that there is a clear audit trail of the thoughts and feelings of families and relatives. 5. What measures will be taken to ensure continuous compliance to both the practical application of the statutory regime as well as individual understanding of it. 6. What measures the Trust have in place to ensure that staff are aware of hospital passports and the contents of those and how they can seek advice and support if they do not understand or cannot locate a passport which should be available to them.
7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report, namely by 4th July 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: [redacted], the Sheffield Teaching Hospitals NHS Foundations Trust. I am also under a duty to send a copy of your response to the Chief Coroner and all interested 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. In this case I have sent a copy of this report to NHS England and to NHS Sheffield CCG and the South Yorkshire and Bassetlaw ICS as the legacy organisation for CCGs as well as the Care Quality Commission 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.
9	 **5th May 2021** Abigail Combes **Assistant Coroner**