

# The Life and Death of **Elizabeth Dixon:** A Catalyst for Change

Report of the Independent Investigation

Dr Bill Kirkup CBE

November 2020



Return to an Address of the Honourable  
the House of Commons dated  
26 November 2020 for

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Report of the Independent Investigation

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# FOREWORD

This investigation was commissioned by the Rt Hon Jeremy Hunt MP, as Secretary of State for Health, at a time when there was significant reluctance to look again at the events it covers. Although years have passed since the death of Elizabeth Dixon, the attitudes, behaviours and systemic problems that have been exposed have not disappeared. It was right that the investigation was commissioned, and it has been a privilege to carry it out.

The nature and extent of the problems identified make the findings more significant than might be assumed from consideration of a single individual. Elizabeth's profound disability and death could have been avoided had basic clinical principles been followed. There were failures of care by every organisation that looked after her, none of which was admitted at the time, nor properly investigated then or later. Instead, a cover up began on the day that she died, propped up by denial and deception, which has proved extremely hard to dislodge over the years. The fabrication became so embedded that it has taken a sustained effort, correlating documents from many sources and interviewing key participants, to demolish it.

The most troubling aspect of compiling this report has been the clear evidence that some individuals have been persistently dishonest, both by omission and by commission, and that this extended to formal statements to police and regulatory bodies. Had police examined the events after Elizabeth's death this must have become evident, but they closed their investigation without doing so. This represents a clear failing in the police investigation which should now be the subject of a statutory referral to the Independent Office of Police Conduct.

Elizabeth's parents, Anne and Graeme Dixon, have been denied confirmation for too long of the truths that they increasingly came to recognise about the loss of their daughter. The obvious but unimaginable distress that has been caused them is profoundly regrettable.

Thanks are due to all of those who helped the investigation, including assisting with access to documents and answering the panel's questions at interview. I am grateful to panel members and secretariat, without whom the investigation could not have been completed, and above all to Elizabeth's parents, without whose persistence and courage it would never have been started nor concluded.

It is, however, greatly regrettable that some of those who were contacted refused to take part in interviews. Cooperating with an investigation into a public service is not optional for those involved, and professionally registered doctors and nurses are under a duty to do so. Dereliction of this duty, without even the offer of an excuse, is seriously detrimental to the conduct of investigations, and contrary to the requirement for candour and transparency. The professional regulatory bodies must consider whether those who elected to withhold cooperation were in breach of their professional responsibilities.

I submit this report in the knowledge that its findings are distressing, and in the expectation that significant action and change will follow.

**Bill Kirkup**  
Investigation Chair



# 1 – ELIZABETH DIXON: WHAT HAPPENED

**1.1** Elizabeth Dixon was born on 14 December 2000 and died less than a year later, on 4 December 2001. From before she was born until the last night of her life, she was let down by every organisation that should have cared for her, and at every stage of her short life there were failures to avert its sad course. Following her death, her parents were met with indifference, rejection and outright deception instead of openness and honesty. As a result, not only did they lose a much-loved daughter, their lives were blighted by the search for truths that should have been evident from the outset, and that should have prompted local and national improvements. It is vital that what happened acts as a catalyst for the significant changes that are necessary to ensure that this does not happen again.

## Pregnancy and Birth

**1.2** The first sign of a problem arose before Elizabeth was born. A routine ultrasound scan showed unexplained areas of echo in her abdomen. Although such areas may occur as transient findings of no significance, in Elizabeth's case they persisted in subsequent ultrasound scans. This should have indicated the need for further, specialist investigation. At the very least, the ultrasound scan abnormalities should have been communicated clearly to paediatricians who would be caring for Elizabeth after she was born so they could be investigated, but they were not.

**1.3** The scan appearances were caused by a neuroblastoma, a tumour mainly of the adrenal glands.<sup>1</sup> Although some types of neuroblastoma carry a high mortality, Elizabeth had a different type. The variant of neuroblastoma she had typically arises before birth and, although the tumour may be large, it regresses spontaneously. There was no reason to suppose that the tumour itself would shorten her life, but it was important that it was recognised from the outset. Neuroblastomas often produce excess amounts of hormones that may have significant and dangerous effects, mainly on the blood circulatory system, as Elizabeth's tumour did.

**1.4** Just before 32 weeks of pregnancy, a continuous recording was made of the baby's heart rate (a cardiotocograph, CTG) at Frimley Park Hospital. This showed a significantly abnormal pattern with cyclical rises and falls in the baby's baseline heart rate, which was repeated in a second CTG. This pattern is associated with imminent risk to the baby, and an emergency caesarean section was recommended to deliver Elizabeth immediately. This recommendation was appropriate in light of the CTG.

**1.5** Communication of the recommendation for emergency caesarean section was not well handled, particularly since Elizabeth's parents were already trying to deal with a concurrent family bereavement. Obstetric staff argued with anaesthetic staff in front of Elizabeth's parents about the safety of the recommended mode of anaesthesia.

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<sup>1</sup> Paired glands located above the kidneys which produce both steroid hormones and catecholamines, hormones which have significant effects particularly on the circulatory system.



**1.6** Elizabeth was born in apparently good condition although she was eight weeks preterm, but the failure to flag the persistently abnormal scan results meant that her initial underlying condition went unrecognised for the first two weeks of her life.

## Early Care at Frimley Park Hospital

**1.7** The focus of neonatal care from the outset was on the likely problems of Elizabeth's preterm birth, including in particular lung function and risk of infection. The abnormal antenatal scan results were not followed up, and her abdominal tumour was not detected on clinical examination, although it is clear from subsequent events that it could have been. What was detected on the first day was a blood pressure above the normal range for the stage of Elizabeth's development, almost certainly the result of hormone secretion by the neuroblastoma.

**1.8** An instruction was recorded in Elizabeth's medical notes to check her blood pressure four-hourly, but the instruction was ignored, and her blood pressure was not measured again until the fourth day. Although it was at that point extremely high for a baby of her age, this failed to raise any alarm and the raised blood pressure was neither investigated nor treated. When measured again after another ten days, it was again at a dangerously high level, as it almost certainly had been throughout.

**1.9** This was a serious oversight, with profound implications for Elizabeth's future. Although relatively uncommon in small babies, high blood pressure is a problem with significant consequences. The circulatory system is poorly adapted at such young ages to protect the brain from the effects, and permanent damage is caused at relatively lower levels of blood pressure than in adults. The failure to monitor Elizabeth's blood pressure effectively, and to act on the high level detected, exposed her to a very significant and avoidable problem.

**1.10** When Elizabeth was around four days old, her parents noticed a distinct change in her condition. Where previously she had shown normal movements and reactions for a baby of her age, she quickly became floppy and unresponsive. It subsequently became clear that these were the first signs of brain damage that would become profound. The appearance and course of this brain damage was consistent with untreated high blood pressure, the cause of what had become her most significant problem.

## Admission to Great Ormond Street Hospital

**1.11** Elizabeth's abdominal tumour was finally detected after two weeks at Frimley Park Hospital, and a transfer to Great Ormond Street Hospital was arranged as a matter of urgency. Although the type of tumour was not yet known, the clinical summary which accompanied her made passing reference to high blood pressure, but incorrectly suggested that it had been only of four days duration.

**1.12** On arrival at Great Ormond Street Hospital, the significantly raised level of blood pressure was recognised but managed incorrectly in the neonatal intensive care unit. When a baby has raised blood pressure, it is important to reduce the level gradually, because of the nature of the blood vessels in the brain at this age. Any sudden reduction in blood pressure reduces blood flow to the brain, because the blood vessels cannot yet respond quickly enough to the change. The effect is ischaemic damage,<sup>2</sup> adding further to the brain damage already caused by high blood pressure. For that reason, blood pressure must be reduced to normal levels slowly, over the course of at least three days.<sup>3</sup>

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<sup>2</sup> Damage to an organ (the brain in this case) caused by insufficient blood circulation.

<sup>3</sup> British National Formulary for Children: Controlled reduction in blood pressure over 72–96 hours is essential

**1.13** Yet when Elizabeth arrived at Great Ormond Street Hospital, her blood pressure was reduced precipitately during the first afternoon, including the use of an irreversible oral medication. Her blood pressure was later allowed to rise somewhat before being reduced gradually again over the next three days, as it should have been from the start. However, the sudden initial reduction in blood pressure was sufficient to cause additional brain damage. Elizabeth's parents noted a further deterioration in her condition immediately after admission to Great Ormond Street Hospital, and her neurological condition was clinically very poor.

**1.14** MRI<sup>4</sup> findings did not conclusively confirm hypertensive damage, although some were missing, but the incorrect management of blood pressure on arrival was clearly sufficient to worsen Elizabeth's neurological damage.

## Care at Great Ormond Street Hospital

**1.15** Elizabeth had been ventilated through an endotracheal tube<sup>5</sup> for her transfer to Great Ormond Street Hospital. Over the next few weeks in the neonatal intensive care unit, it became apparent that her brain function was severely limited, which it is now clear resulted from the neurological damage she had suffered. It does not seem, however, that her neurological condition was yet seen as the principal problem by her clinicians, and attention was predominantly directed to her breathing and tumour. The delay in recognising the degree of Elizabeth's neurological damage meant that care was not best suited initially to her long-term prospects, as it was assumed that her condition was reversible.

**1.16** Several attempts were made to wean her off the ventilator and endotracheal tube, but these all failed, and Elizabeth was given a tracheostomy,<sup>6</sup> intended as a temporary measure. She was subsequently able to breathe spontaneously through the tracheostomy but not without it, apparently due to a degree of softening of the cartilage around her trachea. However, she also had a reduced drive to breathe from her brain as a result of the neurological damage that had occurred, and which now also caused intermittent periods when she would stop breathing temporarily.

**1.17** Following admission to Great Ormond Street Hospital, investigation of Elizabeth's tumour had shown that it was a neuroblastoma, unusual in arising from both adrenals but in all respects of the type that would shrink and ultimately disappear, leaving her with a normal life expectancy. To encourage this regression, and to reduce abdominal swelling that may have hindered breathing, she was given chemotherapy. Following reduction in size, surgery was discussed to remove residual tumour, although this would have been made more complex and riskier by the tumour's origin in both adrenal glands.

**1.18** By now, however, it had belatedly become clear that Elizabeth had brain damage that was both severe and irreversible. Although she had periods of movement and reaction to external stimuli, she would remain unresponsive and unreactive for long periods. She remained unable to breathe without a tracheostomy. She had suffered a single, brief episode of very low cardiac output in February 2001,<sup>7</sup> related to a change in medication. It subsequently became clear that because of her brain damage she would continue to live a severely restricted existence until at some indeterminate point, perhaps years in the future, she would succumb to a complication, most probably a respiratory infection. Faced with this tragic situation, Elizabeth's parents decided

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<sup>4</sup> Magnetic Resonance Imaging: scanning technique to visualise internal structures including the brain

<sup>5</sup> Endotracheal tube: an airway placed through the mouth into the trachea, the airway to the lungs.

<sup>6</sup> Tracheostomy: an external opening into the trachea to bypass the upper airway, through which a tracheostomy tube is inserted to keep the passage open.

<sup>7</sup> Described as 'low output cardiac arrest' although not the same as the more usual cardiac arrest due to disordered electrical activity in the heart muscle.

in conjunction with Great Ormond Street clinicians that further active treatment should not be given to Elizabeth. Discussions began about how she might be looked after closer to home, to improve the quality of life for the whole family.

**1.19** At around six months of age, Elizabeth moved to a neurology ward at Great Ormond Street, to receive maintenance care<sup>8</sup> in accordance with her parents' wishes. The clinicians who took over responsibility for her care did not recognise that her neurological damage had been caused by uncontrolled high blood pressure and its initially incorrect treatment, largely because they believed wrongly that signs of brain damage had been present from birth. Instead, they sought other causes, including a novel genetic condition linked to her neuroblastoma. Her parents, however, came to find the prospects of further invasive tests on Elizabeth distressing.

## Discharge from Great Ormond Street Hospital

**1.20** Once Elizabeth's condition remained relatively stable with the tracheostomy, and no further active treatment was to be considered, parents and clinicians alike were of the view that care nearer home would be preferable. Elizabeth was expected to survive for some time, perhaps for years, although with profound disability and at a degree of risk from infection associated with her tracheostomy. Her neuroblastoma had begun to regress and was expected to continue to shrink.

**1.21** The initial supposition was that Elizabeth would return to Frimley Park Hospital, where she had been born and from where she had been referred to Great Ormond Street. Frimley Park Hospital, however, said that it was unable to accept Elizabeth back, because there were not sufficient nurses with the requisite skills to provide round the clock care for her tracheostomy. Any patient with a tracheostomy requires frequent care, not least to ensure that the tube does not block, particularly in children who have narrower tubes, and in children with impaired neurological function. Elizabeth's brain damage caused a reduced drive to breathe, resulting in a greater build-up of secretions in her lungs and in the tracheostomy tube.

**1.22** A Great Ormond Street Hospital ward sister suggested that Elizabeth's nursing care might be provided at home by an organisation called Nestor Primecare. She knew of a previous patient whose nursing care at home had been provided by the company. As soon as they were contacted, Nestor Primecare said they would be able to set up an arrangement that would meet Elizabeth's needs.

**1.23** Nestor Primecare was part of a group of companies under an umbrella organisation, the Nestor Healthcare Group. The Nestor Primecare managing director, Angela Single, said that the organisation was keen to expand its business, and took pride in being able to deliver care that the NHS could not.<sup>9</sup> They had provided home paediatric nursing care in another part of the country, and their access to nurses working across the country for agencies that were also part of the Nestor Healthcare Group would, they said, assist recruitment of sufficient nurses with appropriate skills.

**1.24** Yet there was ample reason to be cautious about the safety of care at home. The provision of 24 hour one to one care is demanding, and the nurses involved need support. Frimley Park Hospital had already said it could not provide specialist nurses for cover round the clock. Dr Michael Tettenborn, the consultant community paediatrician who was the principal source of clinical paediatric advice to the North and Mid-Hampshire Health Authority, was clear that the local NHS community service could not hope to recruit sufficient specialist nurses either, and

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<sup>8</sup> The term 'maintenance care' is used here for treatment to reduce symptoms that is not directed at altering the course of illness. It may also be called 'palliative care', but both must be distinguished from 'end of life care', which is only applicable when death is expected in the near future. This was never the case for Elizabeth at any stage.

<sup>9</sup> Angela Single interview 26 July 2018; she remained oblivious to the inherent irony

wrote to express his reservations about home care. Despite these obvious warning signs, the Health Authority undertook minimal diligence, accepting Nestor Primecare's assurances on staffing unchallenged and failing to seek references from commissioners elsewhere who had used the company.

**1.25** One reason for the Health Authority's complacency was that it was thought that Great Ormond Street Hospital had recommended Nestor Primecare, and was therefore in a position to endorse their services. In fact, mention of the company came from an individual member of staff, and Great Ormond Street Hospital had no role in assuring the competence of Nestor Primecare. The result was insufficient scrutiny of a service whose robustness was unknown to all of the NHS organisations concerned. The 'contract' that was put in place was nothing more than a letter outlining an invoicing mechanism, and included no service specification or safety requirements, entirely inadequate in any circumstances.

## Care at Naomi House Children's Hospice

**1.26** The plan was for Elizabeth to move initially to Naomi House, a children's hospice that was nearer the family home, but only as a stepping stone to home care. This would enable the family to become accustomed to a setting less like an acute hospital, and the Nestor Primecare nurses could be introduced to the family. It was thought that Elizabeth would remain at Naomi House for a few weeks before spending gradually more time at home. When she was fully home-based, Naomi House would remain available for respite care in case of any short-term difficulty.

**1.27** In the event, there was significant deviation from this plan almost from the outset. There is evidence of a change in the assumptions made about Elizabeth's clinical condition and outlook following her transfer to Naomi House on 29 October 2001. The Great Ormond Street Hospital clinician treating her neuroblastoma was clear that it was regressing and would not affect her expected lifespan.<sup>10</sup> Clinicians at Naomi House, however, assumed that the neuroblastoma was the most serious clinical problem, perhaps partly as a result of a less than explicit handover letter from Great Ormond Street Hospital, and partly the familiarity of Naomi House with providing true end of life care, which this was not. There was, however, no clinical evidence to suggest any change in the neuroblastoma's regression.

**1.28** The immediate consequence was that a much more active approach was taken to pain relief, and various perceived changes in Elizabeth's condition prompted escalation. Elizabeth had been prescribed morphine in response to signs of abdominal pain that was probably related to disordered bowel function as a result of hormone secretion by the neuroblastoma, but over the four weeks she remained in Naomi House, the daily dose of morphine was increased over fivefold. While this may be an appropriate pattern in a child with progressive and painful malignant disease nearing the end of life, there was no evidence that this was the case for Elizabeth. The repeated increases in morphine administration are likely to have contributed further to the tendency for secretions to accumulate in the tracheostomy tube and require frequent suctioning.

**1.29** Two nurses from Nestor Primecare attended Naomi House for a visit, and raised explicit concerns over their capability to provide care at home unsupported. They were reassured by the Nestor Primecare senior nurse manager, Paul Collins, but it is not clear on what basis, as their documented experience indicated that their concerns were valid. Elizabeth's transfer home was delayed for a few days, and a specialist nurse from Great Ormond Street Hospital provided a session on tracheostomy care at Naomi House, but this was a theoretical refresher, unsuitable for those with no previous practical experience. Mr Collins had been brought in to ensure professional

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<sup>10</sup> Dr Peppy Brock interview 3 December 2018

nursing leadership of all of Nestor Primecare's nurses, which should have meant a rigorous focus on ensuring that care was safe and effective.

**1.30** Most of the nurses took the opportunity to meet Elizabeth and her mother and to experience her care at first hand. One who was noticeable to Mrs Dixon by her absence was a nurse, Joyce Aburime, whom Elizabeth's mother had also thought to be visibly uninterested in the tracheostomy refresher teaching. She raised her concern directly with Mr Collins, who reassured her that Ms Aburime was sufficiently able and experienced. Ms Aburime may have had some experience of observing the care of an adult relative with a stable and large tracheostomy, but she had no experience in the more difficult area of tracheostomy care in a very small infant. She had qualified as an adult nurse less than a year before, and was not qualified as a children's nurse. All of this was known to Nestor Primecare, and should have signalled that she was completely unsuited to infant tracheostomy care at the outset.

**1.31** Despite these concerns, and a last-minute difficulty in obtaining the necessary medications and supplies, Elizabeth was judged ready to go home on 27 November 2001. The plan for care to be split initially between home and Naomi House had been dropped. It is not clear when this decision was made or why, but the abrupt transition to home care meant that Nestor Primecare was the sole provider of nursing care from the outset, further increasing the risks that were already apparent.

## Elizabeth's Care at Home

**1.32** For the first few days, it seemed that Elizabeth's nursing care was carried out reasonably. There were, though, signs already evident that all was not well.

**1.33** There was no clarity about the provision of medical care while Elizabeth was at home. Nestor Primecare supplied nurses, but not medical care. The family GP believed that her role was restricted to writing prescriptions for medication requested by others. The consultant community paediatrician, Dr Tettenborn, was described in the records as the "Responsible Medical Officer", but it appears that the term caused confusion, and he believed that his role did not include day to day responsibility. Medical responsibility remained unresolved, and Elizabeth was never seen by the family GP or Dr Tettenborn after leaving Naomi House.

**1.34** Although Nestor Primecare had given assurances that they would provide a group of nurses who would function as a team, this was not realised in practice. Nurses were brought in to do shifts in Elizabeth's home, and there was a handover at each shift change, but no evidence of an approach based on teamwork. More than once, a nurse was brought in who had not expected to be caring for Elizabeth, and one admitted to concerns about her capability to carry out the care required. Within a few days, it was obvious that Nestor Primecare had failed to deliver their undertaking to provide a group of nurses appropriately qualified and experienced in tracheostomy care in children who would work together as a team dedicated to Elizabeth's care. This must have been apparent to the Nestor Primecare nurse managers involved, Mr Collins and Ms Ward, but no action was taken in response.

## Elizabeth's Final Night

**1.35** Nestor Primecare had difficulty identifying a nurse to cover the night shift of Monday 3 December 2001, and on the Friday a nurse not on the initial rota, Ms Aburime, was allocated. Ms Ward's previous suggestion to cover the shift herself was overruled by Mr Collins. Both Mr Collins and Ms Ward knew that Ms Aburime had no experience of tracheostomy care in a small child, and was not qualified in children's nursing. She had been recruited originally by Nestor Primecare to work on less specialised contracts nearer to home; it was her first day, and she had not yet had an



induction or been given a means to contact senior staff. Yet despite all of these obvious warning signs, she was placed in sole charge of Elizabeth's nursing care overnight.

**1.36** Ms Aburime's other employment was at University Hospital Coventry, as a 'bank nurse'<sup>11</sup>; it is not possible to tell from the information provided to the investigation whether she may have done a shift there within the previous 24 hours; it was common practice for nurses to work consecutive NHS shifts and shifts for an agency such as Nestor Primecare. In light of her lack of suitable qualifications and experience, she had a clear professional duty to refuse to continue, but she accepted the handover on the evening of 3 December.

**1.37** During the initial part of the shift, Elizabeth's parents assisted Ms Aburime and prompted her to administer medication and carry out appropriate tracheostomy care. They left Elizabeth asleep and in no apparent distress around midnight. At 2am, Ms Aburime was supposed to give Elizabeth her regular dose of 25mg sustained release morphine sulphate, but became confused as a result of the irregular drug records and her own lack of familiarity with Elizabeth's care. In consequence, she gave approximately 13mls of a different, rapid-acting oral morphine preparation. This was intended to be given in a dose of 12.5mg, but 13ml of solution was equivalent to a dose of 26mg morphine, more than twice the dose prescribed in that form. This would have sedated Elizabeth more than she was used to, although it is unlikely to have represented a fatal overdose. It is likely, however, that through its sedative effect and reduction of respiratory drive, the overdose hindered further Elizabeth's ability to prevent secretions building up in her tracheostomy tube.

**1.38** During the night, secretions did continue to accumulate in Elizabeth's tracheostomy tube, eventually to the point that it became blocked. It is not possible to say exactly when this occurred, but it is likely to have been well before 7am. The progressive obstruction would have caused an obvious difference to Elizabeth's breathing pattern, despite the additional sedation and her neurological damage, but there was no sign that Ms Aburime had recognised what was happening. Crucially, she did not attempt either to clear or to change the tracheostomy tube when Elizabeth's breathing became obstructed. As a result of the complete blockage of her tracheostomy tube, Elizabeth died in the early hours of Tuesday 4 December 2001.

**1.39** It is very difficult to understand how Ms Aburime could have failed to realise overnight that something was seriously wrong, regardless of her lack of experience of tracheostomy care in young children. Although it is impossible to be sure, the most likely explanation is that she had fallen asleep after a long journey and perhaps a preceding shift in Coventry. Whether or not this is what happened, her lack of action represents a clear failure of nursing care.

**1.40** What Ms Aburime did do, around 7am, was pick up Elizabeth's apparently lifeless body and run upstairs to cry outside the bedroom door, a response that also fell far short of the expected behaviour of a nurse. Despite her own obvious shock and distress, Mrs Dixon showed far more presence of mind by taking Elizabeth back to the cot, where she immediately did the right thing by changing the tracheostomy tube. The blockage in the removed tube was obvious, but it was too late for breathing to return. Elizabeth's parents had explicitly said that they did not want her to die by suffocation, and they called an ambulance. A paramedic recorded that she was 'lifeless'<sup>12</sup> but Elizabeth was taken by ambulance to Frimley Park Hospital, where after further brief resuscitation she was declared dead.

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<sup>11</sup> A 'bank nurse' is assigned to cover temporary staffing needs without a regular ward assignment

<sup>12</sup> Statement by paramedic, Surrey Ambulance Service 15 September 2003

## Events Immediately Following Elizabeth's Death

**1.41** The consultant paediatrician on duty at Frimley Park Hospital had been called, as expected when an ambulance was bringing in a child apparently with a life-threatening emergency; it was Dr Tettenborn, and he recognised Elizabeth's name on his arrival. The resuscitation team had by now obtained the Frimley Park Hospital notes, which included the discharge summary from Great Ormond Street Hospital. This would have indicated that Elizabeth's clinical problems were complex, but not that her death was imminent or expected. Mrs Dixon was understandably distressed, and critical of Ms Aburime's role in what had happened.

**1.42** Dr Tettenborn, however, reassured the paediatric registrar present in the Emergency Department, Dr Clarnette, that Elizabeth's death had been expected. He added a note to the clinical record:

*"Child well known to me. 1 Severe neurological disorder 2 Progressive neuroblastoma. Already discussed not for resuscitation. Discussion with nurse in attendance at home indicates sudden cardiac arrest ... previously had these but with spontaneous recovery. Death consistent with natural causes."*<sup>13</sup>

**1.43** This note was wrong in almost every significant respect. Elizabeth's neuroblastoma was not progressive. She had had one low-output cardiac episode while in Great Ormond Street Hospital ten months previously that was medication-related and never repeated. There was nothing that indicated a sudden cardiac arrest. If Dr Tettenborn had asked Elizabeth's parents, he would have known that the blocked tracheostomy tube was not consistent with natural causes; if he had not, it was premature to draw conclusions about how she died. It is also notable that Dr Tettenborn had lead responsibility for child protection at the time, and subsequently.

**1.44** As it was, this note in the clinical record could hardly have been better designed to reassure all concerned that there was nothing untoward about the death, and there is no reason to suppose that it did not reflect what he said to others in the Emergency Department. Dr Tettenborn then directed Dr Clarnette to complete a medical certificate of cause of death, and guided her on what to give as the cause of death<sup>14</sup>. As a result, the certificate incorrectly recorded neuroblastoma stage 4 as the cause of Elizabeth's death, in line with Dr Tettenborn's note in the clinical record. Dr Clarnette had already notified the coroner's office that the death had been expected.

**1.45** Dr Tettenborn then drove Mr and Mrs Dixon home with Elizabeth's body, accompanied by Ms Aburime and Sarah Trimble, the Nestor Primecare nurse who had been due to take over the day shift. This unusual and irregular procedure was apparently in response to Mrs Dixon's distressed state and the potential two hour wait for an ambulance, and the journey must have been very emotionally charged for the passengers. Although it helped resolve a difficult situation at Frimley Park Hospital, it cannot escape notice that it also ended the possibility of Elizabeth's parents saying something at Frimley Park Hospital that would have challenged Dr Tettenborn's account of an expected death following terminal care for a progressive neuroblastoma. When they arrived at the house Dr Tettenborn simply let all of the passengers out on the drive, Mrs Dixon carrying Elizabeth, and left them there.

**1.46** Sue Watson, a Health Visitor attached to the Dixons' GP surgery, had been called by Mr Dixon. She completed the controlled drug handover with Ms Trimble, as Ms Aburime had left abruptly. They discovered the morphine medication error, and confirmed that the tracheostomy tube that Mrs Dixon had replaced when trying to revive Elizabeth was completely blocked with thick secretions. It appeared that no suction tubes had been used prior to Mrs Dixon's intervention

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<sup>13</sup> Frimley Park Hospital clinical records: Elizabeth Dixon

<sup>14</sup> Dr Ruth Helen Clarnette witness statement to Hampshire Constabulary 6 June 2006

that morning. After contacting other health authority staff, Ms Watson spoke to Dr Tettenborn to report the unmistakable signs that something had gone very wrong with Elizabeth's care.

**1.47** Dr Tettenborn first called Linda Wollam, a specialist commissioning manager at North and Mid Hampshire Health Authority, who recorded at the time that he told her that the tracheostomy tube in place when Elizabeth had 'turned blue' was blocked, and that there were discrepancies in the drugs administered. Dr Tettenborn then called the Coroner's officer who dealt with Frimley Park Hospital, Sue Masters. He told her of a blocked tracheostomy tube and a medication error, but it seems that he did so in terms that questioned the relevance of either to the apparently expected death of someone receiving terminal care. He suggested in subsequent accounts that the blocked tracheostomy tube may not have been the one in place when Elizabeth stopped breathing, and that he did not believe that the medication error had contributed to Elizabeth's death; it seems likely that these views were also reflected to Ms Masters during the telephone call.

**1.48** It is clear that Ms Masters formed the view from the outset that no further action would be required, because when Dr Tettenborn spoke again to Mrs Wollam later that evening he reported that Ms Masters "was content to leave cause of death as natural causes".<sup>15</sup> Nevertheless, Dr Tettenborn has consistently maintained since that he had notified Ms Masters of very serious concerns that he expected to result in a thorough investigation on her part, and that he could say nothing to Elizabeth's parents pending that investigation. Ms Masters did speak to Mr and Mrs Dixon, but the subject of the call was predominantly whether they would wish a post mortem examination of Elizabeth's body.

**1.49** Elizabeth's parents were very opposed to the idea of a post mortem examination, because they believed with some justification that Great Ormond Street Hospital were keen to get all or part of the brain for further tests,<sup>16</sup> and the idea horrified them. They conveyed this reluctance to Ms Masters, who used it as evidence that they had no concerns about the mode of Elizabeth's death. This was both wrong and unfair: Elizabeth's parents thought that it was obvious that she had died as a result of the blocked tracheostomy tube, and could not understand why a post mortem might be needed to confirm it. In any case, should a Coroner decide that a post mortem examination is required, neither parents nor other relatives have the option to refuse: it is a legal requirement.

**1.50** The sham of a thorough investigation by the Coroner's officer continued for the rest of the week. Dr Tettenborn was not officially notified of the outcome until Sunday 9 December 2001, when he received a telephone call from Ms Masters. Despite his apparent concern over the nature of the death, he did not ask for any further details or explanation of why no further action was required.

**1.51** Two days previously, on Friday 7 December 2001, Dr Tettenborn had received a telephone call from Dr Elizabeth Williams at Naomi House, because she had been asked to be the second medical signatory to a cremation form for Elizabeth. Dr Clarnette had signed the first part on the morning that Elizabeth died, as she had been told that a cremation would be requested. Following the telephone call, Dr Williams signed the form, including the legal declaration that she knew of no reasonable cause to suspect that an inquest may be required, and confirmed that she had spoken to Dr Tettenborn. As a coroner's investigation was in progress at that time which might very well have resulted in an inquest, this was a serious breach of statutory process. Dr Tettenborn had a duty to tell Dr Williams of the investigation, but he did not. This omission is inexplicable, and fundamentally incompatible with Dr Tettenborn's subsequent claims that he had had significant concerns over the death.

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<sup>15</sup> North and Mid-Hampshire Health Authority papers: Linda Wollam file note 4 December 2001

<sup>16</sup> The Redfern report on organ retention had been published in 2001 with extensive news coverage



**1.52** In fact, no inquest or post mortem examination was required by the Coroner, a remarkable outcome given the obvious and serious breaches in her care on the night that she died. Elizabeth's body was cremated on 11 December 2001, three days before her first birthday. Ms Masters was subject to a disciplinary hearing in 2007 for having failed to communicate relevant information about the blocked tracheostomy tube and the morphine medication error to the Coroner, although it seems that she was misled as to the significance of both by Dr Tettenborn.

**1.53** Regardless of this regrettable decision, it must have been abundantly clear to all concerned that these events represented, in the NHS term of the time, a serious untoward incident that should have resulted in an investigation of what had occurred and why, across all of the organisations concerned. This was necessary to establish the truth for Mr and Mrs Dixon, to identify where systems and individuals had failed, and to ensure that corrective measures were taken to ensure that the serious errors that would have been evident were not repeated.

**1.54** Yet nothing happened. Dr Tettenborn was clearly the lead clinician at this point, and he did not trigger a serious untoward incident investigation. This was an extraordinary failure of clinical governance, not least given that he maintained that he had serious concerns about Elizabeth's death, and he had had no information to allay those concerns. Further, he did not even visit Mr and Mrs Dixon again and would not return their calls to the Health Authority.

## Subsequent Events

**1.55** In the absence of the independent – or at least health authority commissioned – investigation that was necessary, Mr and Mrs Dixon turned to the follow up investigation that they had been promised from Nestor Primecare. A report was produced in April 2002 by Dr Bill Holmes, medical director for the Nestor Healthcare Group, and Jenny Hilton, by then lead nurse for Nestor Primecare. Mr Collins, it turned out, was not on extended honeymoon as Elizabeth's parents had wrongly been told, but had left Nestor Primecare the week after Elizabeth's death. While it appears that Mr Collins's management style had not found favour within the organisation, it cannot escape notice that his rapid departure helped Nestor Primecare to deflect some of the obvious questions.

**1.56** The Nestor Primecare report was grossly inadequate and manifestly self-serving. It invented a typed note from Great Ormond Street Hospital to Naomi House, which supposedly said that Elizabeth "possibly will live for a week, maybe a month".<sup>17</sup> No such note existed and it would have been contrary to everything else Great Ormond Street Hospital said; less than two months before she died, Dr Tettenborn had been discussing Elizabeth's educational needs when aged two at a planning meeting attended by Great Ormond Street Hospital and Nestor Primecare.<sup>18</sup> The report fudged the issue of the morphine medication error, and wrongly suggested that the net effect was an underdosage, which cruelly raised the thought to her parents that Elizabeth may have had too little pain relief in her last hours. Incredibly, the report contained not a single mention of the blocked tracheostomy tube. The events of that night, it concluded, were entirely due to Ms Aburime's lack of familiarity with death in childhood. It is hardly surprising that Dr Holmes subsequently denied responsibility for authorship of the report, although it carries his name, or that Ms Hilton claimed to have little memory of it,<sup>19</sup> as did Ms Single.<sup>20</sup> It is a travesty, which Mr and Mrs Dixon justifiably found insulting.

**1.57** In a further attempt to get some answers, her parents complained to the North and Mid-Hampshire Health Authority, and a report was produced by Pat Christmas, a former director of

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<sup>17</sup> Report of the investigation into the care provided for Elizabeth Dixon by the Primecare Nursing Team 19 April 2002

<sup>18</sup> Health authority minutes of planning meeting 24 October 2001

<sup>19</sup> Dr William Holmes interview 26 July 2018; Ms Jennifer Hilton interview 17 July 2018

<sup>20</sup> Angela Single interview 26 July 2018

public health elsewhere in Hampshire, and Mike Smith, a non-executive director. This report is limited in scope, and lacks all consideration of the events on the night that Elizabeth died. The authors did not interview Dr Tettenborn. The report did identify shortcomings in the way that Nestor Primecare had been commissioned by the health authority, as well as the poor response to her parents' calls and questions after the death. It did not, however, provide any of the answers that Mr and Mrs Dixon sought about what had happened and why, stating only that "It will never be clear how Elizabeth died and if her death was natural, but the Health Authority need to acknowledge that certain things could be done better".<sup>21</sup>

**1.58** Mr and Mrs Dixon's next avenue was a complaint to the Nursing and Midwifery Council (NMC), the body responsible for the professional registration of nurses. Elizabeth's father wrote to the NMC on 1 July 2002 about Ms Aburime's lack of care; it was to be more than five years until the NMC completed its processes, and when it did many of the questions remained unanswered.

**1.59** The NMC was concerned enough about Mr Collins's contribution to placing Ms Aburime on the rota for Elizabeth's last night that they invited Elizabeth's parents to extend their complaint to him as well. The NMC investigation surprisingly decided that there was insufficient contemporary evidence to conclude that the blocked tracheostomy tube had contributed to Elizabeth's death. Although they did not see fit to obtain an expert view on the significance of the blocked tube, the NMC did commission an expert view about the morphine medication error. Unfortunately, the expert either misinterpreted the information provided or it was incorrect, because he gave an opinion based on a dose of 12.5mg of rapidly-acting morphine, whereas in reality a dose of 26mg had been given.<sup>22</sup>

**1.60** Nevertheless, the NMC Professional Conduct Committee determined in January 2005 that Ms Aburime did not possess the relevant experience, training or expertise to manage the complex care needs of Elizabeth, failed in some key procedures, and did not appropriately administer or record opiates; she was removed from the nursing register for an indeterminate period.

**1.61** Although initially it was intended that the case against Mr Collins would be considered at the same time, since the charge was that he had been responsible for putting Ms Aburime in the position of providing Elizabeth's care that night, his lawyer had successfully argued that the cases should be separate. Considerable delay ensued, initially due to difficulty in arranging hearings, and then as a result of challenge from Mr Collins's lawyer over failures to disclose evidence by the NMC lawyers. This related in part to the repeated failure of Nestor Primecare to provide documentation about what management responsibilities Mr Collins had within the organisation; many records were said by Nestor Primecare to have gone missing, presumed lost in a fire in December 2005, but some remarkably turned up subsequently when police threatened contempt of court proceedings.

**1.62** The second legal challenge concerned the initiation of a police investigation into Elizabeth's death. Having heard the evidence given to the NMC hearing, her parents had rekindled their efforts to seek an inquest. They approached the Home Office, who directed them to the Surrey Coroner's office. They were advised that there were insufficient grounds for an inquest, given the lack of a post mortem examination in December 2001, unless there were a police investigation. Mr and Mrs Dixon therefore reported Elizabeth's death to the police force in whose jurisdiction they resided, Hampshire Constabulary, who commenced an investigation.

**1.63** The NMC believed that this investigation involved only Ms Aburime. Mr Collins's lawyers were not informed, and argued that the failure to disclose the police investigation and the documents withheld by Nestor Primecare constituted abuse of process. The NMC Professional

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<sup>21</sup> North and Mid Hampshire Health Authority complaint report 2002

<sup>22</sup> Professor Imti Choonara: Medical Report on Elizabeth Dixon 22 January 2004

Conduct Committee agreed, and proceedings were stayed formally on 13 December 2007, effectively bringing the NMC process to an end with no determination regarding Mr Collins's fitness to practise.

## The Police Investigation and Inquest

**1.64** The police investigation initially progressed as planned, despite some difficulty in obtaining records from Nestor Primecare until they were threatened with legal action, and in August 2005 the Crown Prosecution service (CPS) considered there was potentially a case to answer that might have led to prosecutions for gross negligence manslaughter. However, further evidence was required, including a medical expert report, which was obtained from Dr Colin Wallis. Dr Wallis was a consultant paediatrician, not a pathologist as had been requested by CPS. Further, he was a Great Ormond Street Hospital consultant, and although he had not previously been involved with Elizabeth's care, it was not appropriate to ask a Great Ormond Street Hospital consultant to provide an expert opinion that should demonstrably have been entirely independent.

**1.65** Dr Wallis's report concluded that airway obstruction "almost certainly played a pivotal role"<sup>23</sup> in Elizabeth's death. However, he also said that he could not state with full certainty that death would not have been a possible outcome anyway on the morning of 4 December 2001, because he wrongly believed that Elizabeth was receiving end of life care for a known terminal illness.

**1.66** In addition, police sought to interview Mr Collins, as the Nestor Primecare nurse manager who had placed Ms Aburime on the rota for the night of Elizabeth's death, but he was then resident in the Republic of Ireland and medically unfit to be interviewed.

**1.67** After almost two years of police investigation, the CPS concluded on 21 June 2007 that there was insufficient evidence to prosecute Ms Aburime and Mr Collins. It is evident from the records that there were three reasons underlying this decision. First, Dr Wallis's reservation about the cause of death and his likely responses on cross-examination would undermine the case, and the lack of a post mortem would make it harder to eliminate uncertainty. Second, the view was clearly expressed that 'no jury would convict Ms Aburime without Mr Collins', and Mr Collins was in the Republic of Ireland, in poor health and very unlikely to be extraditable. Third, the role of Nestor Primecare in concealing papers and facts about the death raised the prospect that neither Ms Aburime's actions nor those of Mr Collins could be separated clearly enough from the major shortcomings of the organisation for which they worked.

**1.68** Following this decision and the consequent ending of the police investigation, an inquest into Elizabeth's death was begun in December 2008. The Coroner concluded that the quality of evidence given by witnesses from Nestor Primecare was exceptionally poor. He found that the cause of death was the blocked tracheostomy tube, but that there was insufficient evidence to support a verdict of unlawful killing by gross negligence manslaughter. He also considered that any failure of care that had occurred was restricted to a moment on 4 December 2001, the day of Elizabeth's death, with insufficient evidence to conclude that neglect was a contributory factor to her death.

## Flawed Investigations

**1.69** The police investigation, the CPS decision and the inquest were all seriously flawed by two very significant errors. First, the consistent view that Elizabeth's care had previously been exemplary underpinned the idea that all had been well up to the point of a single tragic incident on the night she died. As the rest of this report has shown, her previous care was very far

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<sup>23</sup> Dr Colin Wallis: Medico-Legal Report on Elizabeth Dixon 2 July 2006

from exemplary, and there were failures at every stage, but in this context the most significant shortcomings are those that led to Elizabeth being placed in the hands of Nestor Primecare, an organisation that patently could not provide her with safe care.

**1.70** Second, the pervasive misconception that Elizabeth was terminally ill with a progressive form of cancer led to the widespread view that she would inevitably have died anyway within a short time, perhaps a matter of days. This was far from the case: Elizabeth's tumour was regressing as expected, and prior to her death plans were clearly being made for her long-term care. Both the police expert medical opinion on the cause of Elizabeth's death<sup>24</sup> and the Coroner's findings<sup>25</sup> were fundamentally damaged by this misconception.

**1.71** Although undoubtedly there were other errors that have been set out in this report, these two substantially undermined the basis of both the police investigation and the inquest. The origin of these mistakes clearly lay in the initial cover up of what had happened, but it is difficult to understand how they could still remain uncorrected so many years later, and contribute to the failure to acknowledge publicly the truth of what had happened.

**1.72** The police investigation and the inquest were the culmination of Mr and Mrs Dixon's attempts to gain recognition of what had happened to Elizabeth, and when they ended there were few further avenues open. Understandably, Elizabeth's parents remained deeply dissatisfied, and tried ceaselessly to raise her case with individuals and organisations, sometimes to their own detriment and that of others. There was a subsequent GMC investigation but, based on the same flawed premises, it added nothing.

**1.73** Following any death, particularly under such harrowing and worrying circumstances as Elizabeth's, the very least that a bereaved family deserves is a truthful and complete account of what happened and why. This was denied to the Dixon family from the outset, a situation that unforgivably has been allowed to fester for almost twenty years. With full knowledge of events that none of the later investigations managed to uncover, it is manifestly obvious that concealment of what happened began on the day of Elizabeth's death, and has continued ever since. That a cover up so rapidly and simply instigated could be so influential and persistent has significant implications for all of us, and for how public services react when things go wrong.

**1.74** Further, with knowledge of all of these events, it is inescapably clear that some individuals have consistently concealed the truth and fabricated alternatives. This was fundamental to the cover up in the first few months, but it has been sustained since, including in written statements and in evidence. This raises very significant concerns over the conduct and veracity of individuals, some of whom have occupied senior positions, which would have emerged if police had examined the events after Elizabeth's death, but they closed their investigation without doing so. These concerns now require investigation by the relevant authorities.<sup>26</sup>

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<sup>24</sup> Dr Colin Wallis second interview 19 February 2020: he remained under the impression that Elizabeth was terminally ill with progressive neuroblastoma

<sup>25</sup> Inquest recordings 16 January 2009: "her neuroblastoma tumours were incompatible with life"

<sup>26</sup> The investigation's papers will be passed immediately to the proper authorities; a detailed account of the police investigation and inquest is therefore not published here.



## 2 – COMMENTARY

**2.1** It is vitally important that we do not lose sight of the problems raised by the life and death of Elizabeth Dixon, and its aftermath. Elizabeth was one child, but the failures that affected her care at every stage are not unique. Had she lived, she would be almost twenty years old, but the same attitudes and behaviours as were evident then may still be found in places today. As a result of the concealment of key facts about her death from the outset, her parents have been left for far too long without a complete, true account of what happened. This was a needless and cruel burden for a mother and father already grieving the loss of their child. It must not happen again.

**2.2** There were opportunities from the outset to prevent Elizabeth's decline into irreversible illness and death. Her first problem, a type of tumour known as a neuroblastoma, was not detected at first, and the high blood pressure that it caused went undetected for ten days because checks were not done regularly. On the few occasions that her blood pressure was measured, the very high levels found were ignored. When Elizabeth's high blood pressure was finally recognised, it was mismanaged: inappropriate medication was used to cause a rapid drop, instead of a gradual reduction over days to protect the circulation to her brain. Both the sustained very high levels of blood pressure and the subsequent rapid reduction were sufficient to cause the serious, irreversible brain damage that became Elizabeth's most significant problem.

**2.3** High blood pressure is not a common condition in babies, but its effects can be devastating, as they were for Elizabeth. It is not well or easily recognised by clinicians, who are often more concerned with the commoner problem of low blood pressure in new born babies. Monitoring of blood pressure in small babies may be sporadic or non-existent, and the normal range of blood pressure depends on both the age of the baby and the extent to which they may have been born preterm, so complicating any assessment. Heightened awareness of the significance of hypertension in babies and children, effective monitoring of blood pressure against standardised charts, and a proper emphasis on the absolute requirement to reduce blood pressure gradually would have almost certainly led to a very different outcome for Elizabeth, and for other babies and children to this day.

**2.4** When it belatedly became clear that Elizabeth's brain damage was permanent – by which time she had acquired a tracheostomy in the expectation that it was a temporary measure until her condition improved – it was appropriate to seek care either closer to home or at home. The limiting factor was her tracheostomy, which required constant care to prevent it blocking, administered by nurses qualified and experienced in managing the care required for such a small baby. It may be supposed that this would require careful planning, particularly given that the necessary specialist nursing skills were in short supply, but the reality was very different. A private healthcare provider was identified through an informal personal communication, and the company's assertion that they would be able to provide qualified and experienced nurses around the clock was barely challenged. The health authority 'contract' was a brief letter specifying an invoicing mechanism, entirely inadequate to commission care from any provider, let alone one previously unknown to the health authority. It is difficult to avoid the thought that had Elizabeth not been disabled, more consideration would have been given to assuring the safety and effectiveness of her care, a double standard that should be intolerable.

**2.5** During the course of Elizabeth's transfer home there was an unwarranted change in perceptions of her outlook. Her respiratory difficulties were severe, and would probably have



shortened her life at some point when an overwhelming infection occurred, but by its nature there could be no estimated timespan for that to occur. She was receiving maintenance care that was intended to relieve symptoms and give her as comfortable a life as possible, but she had no progressive condition that would inexorably limit her lifespan over a defined period, and plans were already in place for an assessment when she was two years old.

**2.6** Her care could reasonably be described as palliative, but only with a clear understanding that this did not imply that she was receiving end of life care, previously described as terminal care. This distinction was not properly made at repeated points, most notably when Elizabeth's daily morphine dose was increased over fivefold in a four-week period without written evidence for this need. The same error was used later to suggest wrongly that her death had been expected at any moment, when it was not. It is essential that terms such as palliative care, terminal care and end of life care are clearly understood by key stakeholders and not wrongly conflated, and that the intended care is explicit to all.

**2.7** Elizabeth died in the early hours of Tuesday 4 December 2001 as a result of a blockage of her tracheostomy tube that could and should have been cleared, either by suctioning or changing the tube. The sole clinician present was a nurse who has to date had to shoulder the entire burden of responsibility for the death. There is no question that she should have recognised her own inability to provide safe care, but there is also no doubt that she was placed in that position through a series of failures that involved people who knew that she was not qualified as a children's nurse and had no experience of infant tracheostomy care, as well as by those who commissioned the care from an organisation incapable of providing it safely. It is fundamentally unjust that the only person held formally responsible has been the most junior involved, who also happened to be both female and of an ethnic minority. This is a sad indictment of an investigatory system that can be deflected so easily, and its convenience for others cannot escape notice.

**2.8** Elizabeth's death should have been treated as unexplained. Instead, it was treated as expected, attributed to 'progressive neuroblastoma' even though it was known that she had no progressive cancer and had not been expected to die imminently. Once the existence of the blocked tracheostomy tube and morphine overdose emerged, it was no longer just an unexpected death, it was very clear that something had gone badly amiss with Elizabeth's care. It is profoundly unsatisfactory that this remained unexplored and inadequately investigated from the outset, by the coronial service, the health authority, and the private healthcare provider. This may have appeared at first to be simply a startling lack of curiosity, but it clearly progressed to the point that facts were wilfully ignored and alternatives fabricated. That this resulted in a cover up of significant facts that stood for so long is greatly disturbing.

**2.9** The opportunity for a health authority safety investigation was squandered at the outset, and the grossly inadequate private provider's report went unchallenged, leaving the family's questions unanswered. Elizabeth's parents pursued what avenues were open to them in search of the truth, beginning with a complaint to the health authority. The response was an investigation limited to a narrow interpretation of the health authority's role, and another opportunity was missed to carry out a more searching review of what had happened, and why. This is a recurring feature of health services complaints: instead of serving as a valuable warning of problems, they are seen as something to be fended off with limited, closed and defensive responses, which is deeply unsatisfactory for all concerned.

**2.10** When the health services involved failed to provide the answers that should have been there from the start, there were limited options for Elizabeth's parents to pursue in search of the truth. As other families do in such circumstances, they sought to invoke the professional regulatory and criminal systems. These systems are based on the assumption of discrete, single events involving individual practice, and are very unsuited to examining complex multiple failures spanning different

organisations. It must surely have become obvious during the professional regulatory and criminal processes considered here that the failures involved significantly more than isolated individual actions; however, there is no obvious mechanism to halt a professional regulatory process or criminal investigation while the necessary informed and expert review is carried out into the underlying failures. In its absence, the outcome in such cases is unlikely to result in the answers that families deserve.

**2.11** The detail of the criminal investigation has not been considered here for reasons explained elsewhere, but one problem stands out. Investigations of this nature necessarily deal with matters of a technical, clinical nature that are outside the expert knowledge of lawyers and police. When expert clinical advice was required in Elizabeth's case, the problems with how this is provided were amply illustrated.

**2.12** First the requirement for expert advice was initially stated correctly as for a pathologist, but this was misinterpreted as referring to a children's specialist. There is no defined system to generate an expert opinion in such cases: police services are dependent on informal approaches and word of mouth, and lack the specialist knowledge to ensure that an appropriate clinician is commissioned. Great Ormond Street Hospital was approached simply because it seemed an obvious source of expertise in paediatrics, but the hospital had no system to identify a suitable candidate, and a respiratory paediatrician responded to a general email request. Not only was he not a pathologist, it was in any case inappropriate to seek someone from a hospital that had been closely involved in Elizabeth's previous care. The opinion he gave was based on incomplete information and significantly flawed, but there was no mechanism within the Crown Prosecution Service to challenge it. In effect, having obtained their first advice in this way, they were stuck with it as their sole expert opinion, because to seek another would inevitably have been portrayed as fishing for a view that suited their case. This haphazard approach to clinical expert witnesses is a deeply unsatisfactory system on which to base decisions of such importance to all concerned.

**2.13** When patients and families are not met with openness and transparency when something has gone wrong, they face a complex landscape of possible actions. Their priorities are most often to discover the truth and to prevent the same thing happening to others, but they may also understandably seek accountability for individual or corporate actions, or compensation. The landscape they have to navigate includes internal and external safety investigations, inquests, the Patient Advice and Liaison Services, Healthwatch, complaints, civil litigation, professional regulators such as the Nursing and Midwifery Council and General Medical Council, the Care Quality Commission, the Parliamentary and Health Services Ombudsman, and criminal investigation by police services. It is hardly surprising that families may feel bewildered about the approach best fitted to give them the answers and actions they seek. At the least, this landscape requires clear signposting.

**2.14** The initial spark which kindled what became a twenty year cover up was the deep and widespread reluctance of clinicians to admit that something had gone very badly wrong with Elizabeth's care. Sadly, this is a common reaction, although the extent of cover up that was to become manifest in this case is thankfully less frequent. If we are to address the problems of a service that does not effectively investigate and learn from error and is not always honest and open with those harmed, it is essential that we understand how to change this. The reasons have been understood for some time: there is a deeply ingrained personal and professional culture in clinicians that is intolerant of any deviation from an impossible standard of perfection; and there is an equally deeply ingrained fear of being blamed, by patients and relatives, by the media and public, by professional regulators, and by the justice system. Clinical error, openly disclosed, investigated and learned from, should not result in blame or censure; equally, conscious choices to cover up or to be dishonest should not be tolerated.



**2.15** This investigation depended in significant measure on interviewees who shared their experience and knowledge, and we are grateful to those who did so fully and candidly. It must not be forgotten, however, that all health services staff are required to take part in any such investigation to set out the truth and to improve health services. It is reprehensible that some individuals refused to take part without providing any reason, and those professionally registered appear to be in breach of their professional duties.

**2.16** The issues raised by the history of Elizabeth Dixon and its aftermath are serious and far-reaching, and go to the heart of a national health service founded on principles of humanity, equality and honesty. A full response will require some deep-seated changes in organisational and professional culture as well as better recognition of clinical problems and response to safety incidents. The recommendations that follow are intended to indicate the areas most in need of improvement; they should be regarded as a starting point and by no means a complete solution, which will require collaborative efforts from a wide range of stakeholders.

# 3 – RECOMMENDATIONS

1. Hypertension (high blood pressure) in infants is a problem that is under-recognised and inconsistently managed, leading to significant complications. Its profile should be raised with clinicians; there should be a single standard set of charts showing the acceptable range at different ages and gestations; and a single protocol to reduce blood pressure safely. Blood pressure should be incorporated into a single early warning score to alert clinicians to deterioration in children in hospital. (NICE, CQC, RCPCH, DHSC)
2. Community care for patients with complex conditions or conditions requiring complex care must be properly planned, taking into account and specifying safety, effectiveness and patient experience. The presence of mental or physical disability must not be used to justify or excuse different standards of care. (NHSE, CQC, DHSC)
3. Commissioning of NHS services from private providers should not take for granted the existence of the same systems of clinical governance as are mandated for NHS providers. These must be specified explicitly. (NHSE)
4. Communication between clinicians, particularly when care is handed over from one team or unit to another, must be clear, include all relevant facts and use unambiguous terms. Terms such as palliative care and terminal care may be misleading and should be avoided or clarified. (Royal Colleges, HEE)
5. Training in clinical error, reactions to error and responding with honesty, investigation and learning should become part of the core curriculum for clinicians. Although it is true that curricula are already crowded with essential technical and scientific knowledge, it cannot be the case that no room can be found for training in the third leading cause of death in western health systems.<sup>27</sup> (GMC, NMC)
6. Clinical error, openly disclosed, investigated and learned from, must not be subject to blame. Conversely, there should be zero tolerance of cover up, deception and fabrication in any health care setting, not least in the aftermath of error. (NHSE, GMC, NMC, MoJ)
7. There should be a clear mechanism to hold individuals to account for giving false information or concealing information relating to public services, and for failing to assist investigations. The Public Authority (Accountability) Bill drawn up in the aftermath of the Hillsborough Independent Panel and Inquests sets out a commendable framework to put this in legislation.<sup>28</sup> It should be re-examined. (MoJ)
8. The existing haphazard system of generating clinical expert witnesses is not fit for purpose. It should be reviewed, taking into account the clear need for transparent, formalised systems and clinical governance. (DHSC, MoJ)
9. Professional regulatory and criminal justice systems should contain an inbuilt ‘stop’ mechanism to be activated when an investigation reveals evidence of systematic or

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<sup>27</sup> Makary MA and Daniel M. Medical error – the third leading cause of death in the US. *BMJ* 2016; 353: i2139.

<sup>28</sup> (11) The preamble to the Bill reads as follows: “Set a requirement on public institutions, public servants and officials and on those carrying out functions on their behalf to act in the public interest and with candour and frankness; to define the public law duty on them to assist courts, official inquiries and investigations; to enable victims to enforce such duties; to create offences for the breach of certain duties; to provide funding for victims and their relatives on certain proceedings before the courts and at official inquiries and investigations; and for connected purposes.”

organisational failures and which will trigger an appropriate investigation into those wider systemic failures. (HO, MoJ, DHSC, GMC, NMC)

10. Scrutiny of deaths should be robust enough to pick up instances of untoward death being passed off as expected. Despite changes to systems for child and adult deaths, concern remains that without independent review such cases may continue to occur. The introduction of medical examiners should be reviewed with a view to making them properly independent. (DHSC)
11. Local health service complaints systems are currently subject to change as part of wider reform of public sector complaints.<sup>29</sup> Implementation of a better system of responding to complaints must be done in such a way as to ensure the integration of complaints into NHS clinical governance as a valuable source of information on safety, effectiveness and patient experience. (NHSE, CQC)
12. The approaches available to patients and families who have not been treated with openness and transparency are multiple and complex, and it is easy to embark inadvertently on a path that is ill-suited to deliver the answers that are being sought. There should be clear signposting to help families and the many organisations concerned. (NHSE, DHSC)

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<sup>29</sup> Making Complaints Count: Supporting complaints handling in the NHS and UK Government Departments. Parliamentary and Health Services Ombudsman 15 July 2020.

# APPENDIX 1: MRS DIXON'S PREGNANCY AND ELIZABETH'S BIRTH<sup>1</sup>

## Pregnancy

**A1.1** Elizabeth's parents married in their late thirties, and knew they wanted children from their marriage. They also knew there were some risks: Graeme Dixon, an engineer, suffered from an eye condition that may have hereditary elements; Anne Dixon, a bank administrator, was trying for children relatively late. They were advised that these risks should not deter them and they moved to a new house near the Hampshire/ Surrey border that would be suitable for a family.

**A1.2** Mrs Dixon had a history of anxiety and knew this was an area of vulnerability for her during her pregnancy. In the first year of marriage she had had what she thought was an early miscarriage. When she became pregnant again in 2000, she asked for regular monitoring. She was candid about her history of anxiety to her doctors, and her notes record patterns of speech and behavior that were consistent with marked anxiety. Sometimes she could get locked into repetitive thought processes, and her speech delivery sometimes seemed pressured. She might ask the same questions repeatedly from a variety of angles until she felt she understood the answers. This meant that conversations on important issues could become lengthy and repetitive. But she was also intelligent and perceptive, and could retain a great deal of detail.

**A1.3** Mrs Dixon was first booked for antenatal monitoring at St Peter's Chertsey, with an expected date of delivery of 11 February 2001. At 6 weeks of pregnancy she asked to be scanned after having had abdominal pains; the scan was reported as showing a normal viable pregnancy. At 12 weeks the routine nuchal translucency and dating ultrasound scan showed a low risk for trisomy 21 (Down syndrome) and confirmed an expected date of delivery of 11 February 2001. A doppler ultrasound scan the same week identified 'notched' uterine artery blood flow. This pattern sometimes results from abnormal placentation, which can be associated with preeclampsia in the mother and reduced fetal growth: it is a warning sign that prompts more careful monitoring.

**A1.4** Otherwise, the pregnancy seemed uneventful for the most part. Both parents took care to avoid situations that might be stressful. At the beginning of September 2000 (around 17 weeks gestation) Mrs Dixon had transferred her antenatal care to Frimley Park Hospital (FPH), because the clinic was closer to her new home. She was offered regular monitoring by FPH to help reduce her anxiety about the pregnancy. Frimley Park Hospital had recently merged with the military hospital services in Aldershot, so her ultrasound scans and antenatal appointments took place in both Aldershot and Frimley. She took the monitoring seriously and took care to attend her appointments.

**A1.5** Mrs Dixon was assigned to the care of Dr Jayne Cockburn, a consultant obstetrician, who later commented 'she transferred her care to FPH because she felt she wasn't getting the

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<sup>1</sup> Unless otherwise specified, information in this appendix is derived from Frimley Park Hospital clinical records.

right attention'. It appears that the baby was not considered to be at high risk, and no additional monitoring was suggested despite the maternal age and notched uterine artery blood flow.

**A1.6** By the second trimester the pregnancy was considered to be progressing normally, although it was noted that the fundal height was slightly less than expected; fetal movements were satisfactorily frequent. Every clinic appointment record, however, noted Mrs Dixon's own obvious and continuing anxiety. Her worries had some foundation: her blood pressure was sometimes high when tested, and the 'notching' of uterine artery blood flow was a risk factor for both her and the fetus.

**A1.7** An ultrasound scan was carried out at 20 weeks and 5 days gestation at Aldershot, following which an entry was made in the FPH notes recording that fetal growth was assessed as on the 5th centile, which would suggest significant growth restriction. This ultrasound also showed 'echogenic bowel' which meant that something in the fetal abdomen was reflecting ultrasound waves more than expected: this may prove of no significance but it may also be associated with an increased risk of abnormality in the fetus. A note in the clinical record from FPH says the ultrasound results were brought to the attention of the maternity care clinicians.

**A1.8** Taken together, these findings of a fetus with possible growth restriction at 20 weeks, echogenic areas on abdominal ultrasound and a notched uterine artery blood flow signal a higher risk to the pregnancy that required to be followed up. We consider that the most appropriate course would have been referral to a specialist centre for fetal medicine for further specialist tests and closer monitoring. This did not happen: instead, the notes record that Mrs Dixon should be seen at Dr Cockburn's clinic in the Delivery Assessment Unit (DAU) at Frimley Park Hospital, which monitored higher risk pregnancies and that she should have a repeat scan at 24 weeks gestation.

**A1.9** In the DAU clinic on 10 October 2000, Mrs Dixon advised Dr Cockburn that the scan in Aldershot had found fetal growth restriction, as she had been advised to do. Dr Cockburn recorded Mrs Dixon's concerns at 6 weeks pregnant and the (low) risk estimate she had been given for Down syndrome at 12 weeks. She noted that Mrs Dixon had not wanted 'invasive tests' at the time she was given the Down syndrome estimate. Her note of discussion recorded 'seems a lot of anxiety, also needs to know a lot but fair enough. Husband said 'so you can stop worrying now' at end of consultation'. There is no record against this date of any discussion about the size of the fetus or the echogenic bowel, although there is a note of '5th centile'.

**A1.10** On 24 October 2000, at a gestational age of 24 weeks + 2 days, the baby was again measured by ultrasound at Aldershot as being on the 5th centile, this time with what seemed to be a 'normal' bowel. However, the chart has been marked at the 25 weeks gestation line, and had it been correctly entered just above the 24 week gestation line, growth would have been assessed as above the 5th centile, although still less than the 50th centile.

**A1.11** The date of the medical record from the next DAU clinic is difficult to read but may be 27 October. It is not written by Dr Cockburn. It gives the fetal age as 25 weeks, records the finding of 5th centile for fetal growth and notes that a further scan and Doppler should be ordered within 4 weeks.

**A1.12** At this stage, if the growth of the fetus was not noted to be normal and there was a finding of echogenic bowel on record, a reasonable expectation would be referral to a fetal medicine unit, a screen for conditions associated with fetal growth restriction<sup>2</sup> and a cystic fibrosis screen. Again, this did not happen. No extra measures were taken that recognised increased risk to the fetus apart from repeat scans.

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<sup>2</sup> Sometimes referred to as a TORCH (toxoplasmosis, rubella, cytomegalovirus, herpes simplex and HIV) screen, but other conditions may be included.

**A1.13** On delivery Elizabeth was more than 25% smaller than she had been predicted to be in the most recent antenatal records. We therefore examined the records from FPH closely to see if we could work out the reason. One possibility considered (given the later diagnosis of neuroblastoma) was that Elizabeth had an intermittently distended abdomen in utero which threw out the scan measurements at Frimley. Abdominal girth is regularly used as a predictor of size, although not the only one. Detailed inspection of the ultrasound growth charts suggests that measurements of the head size, particularly the biparietal diameter, gave lower growth estimates than abdominal girth, but also lower than femoral length.

**A1.14** Having had her baby's growth recorded twice in October as being only at 5th centile Mrs Dixon was scanned again on 30 October, this time at the DAU. The baby's measurements were not taken; but a note on the ultrasound report recorded that the 24 October scan six days before had shown normal growth. This was not an accurate reflection of the contemporaneous record from 24 October. Looking at the FPH growth charts, it is clear that they have been completed at the appropriate gestation for the date of the scan, and show growth on or around the 50% centile apart from biparietal diameter, which is below the 50th centile but not as low as the 5th centile. The apparent change from the Aldershot scans may be no more than the correct gestational age being plotted, assuming an expected date of delivery of 11 February 2001.

**A1.15** The next assessment was again at the DAU, 3 weeks later on 20 November. The fetal age was recorded as 28 weeks. On this basis, the fetal size was recorded as being on the 50th centile. Again, the fetal bowel was found to be 'mildly echogenic'. Maternal blood pressure was recorded as 130/85 mm HG, which is distinctly high for 28 weeks, when blood pressure is normally still at the low levels typical of the second trimester of pregnancy. Given that echogenic bowel had now been noted in repeated scans, a notched uterine artery blood flow pattern was again confirmed, and maternal blood pressure was now raised, there should have been a more considered and definitive attempt to reassess both fetal growth and fetal and maternal wellbeing. No such attempt was made, but Mrs Dixon's antenatal surveillance was increased with weekly clinic visits and twice weekly visits to the day assessment unit to check her blood pressure and for the baby to be monitored.

**A1.16** In her clinic appointment with Dr Cockburn on 20 November, Mrs Dixon asked for an explanation of why the growth estimates for her baby had changed so markedly. She was told that the baby was simply bigger than previously thought. The note of the discussion recorded that her repetition of concerns that she might lose the baby (described as speaking 'over and over again at speed') were met with reassurance. Dr Cockburn recorded that she told Mrs Dixon that centiles were not absolute, and that Dr Cockburn could not talk to her husband about physiology in a 10 minute appointment but was willing to arrange another time to talk about it if that was wanted.

**A1.17** Between 20 November and 11 December, Mrs Dixon attended the DAU twice a week for monitoring. During this period the baby's baseline heart rate was noted to be around 150 bpm on the 27th and 30th November 2000. Cardiotocograms (CTGs)<sup>3</sup> on the 4th, 6th and 11th December 2000 recorded baseline fetal heart rates between 145 and 160 beats per minute, towards the upper end of the range but not unduly so, particularly at 32 weeks gestation. The CTG on 6 December was a self-referral – Mrs Dixon had worried that the baby had reduced movements. She was reassured that the baby was fine.

**A1.18** In hindsight, it may be that a baseline fetal heart rate consistently towards the upper end of the normal range may have been related to hormone secretion by the neuroblastoma that

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<sup>3</sup> Recordings of the fetal heart and uterine activity: changes in the baseline rate, variability and temporary accelerations or decelerations can all indicate concern over the baby's condition in the uterus.

subsequently became evident. This was not by itself sufficient reason to prompt further concern, but the repeated finding on ultrasound scan of echogenic bowel should not have been overlooked.

**A1.19** Our conclusion is that on paper, Mrs Dixon was monitored closely in her pregnancy from 20 weeks until Elizabeth was delivered, partly at least because she requested it. In practice, however, several features of concern did not prompt further action, although they should have. Discrepancies in fetal growth were removed when the correct gestation was plotted, although the biparietal diameter measurements remained discordant, and repeated findings of echogenic bowel should have been clearly flagged for attention once Elizabeth was born. The failure to flag and fully investigate scan abnormalities were missed opportunities by the DAU to ensure early interventions for the problems with which Elizabeth was later diagnosed. Although it would be unlikely to diagnose the neuroblastoma on this basis, the abnormal findings were sufficient to warrant referral to a tertiary centre where this might have been picked up, or at the least to flag clearly that something required investigation when Elizabeth was born.

**A1.20** Elizabeth's mother has never tried to hide her difficulties with anxiety. But whatever the reason for commissioning extra tests during pregnancy, it is reasonable to expect the results to be looked at carefully. On reviewing the written medical records, it is clear that those recording the discussion of test results with Mrs Dixon during her pregnancy did not understand much about clinical presentations of anxiety. Dr Cockburn certainly expressed confusion about Mrs Dixon's behaviour in her notes and referral letters. Dr Cockburn and her colleagues also seem to have discounted what Mrs Dixon told them because of the way Mrs Dixon expressed herself. After Elizabeth's birth they made no effort to ensure that antenatal test results were investigated, although Dr Cockburn referred Mrs Dixon to be assessed for psychiatric support.

## Final Day Pre-Delivery

**A1.21** On 11 December 2000, Mrs Dixon went for a scan and was again told that the baby was average size for a gestation of 30 weeks; her expected date of 11 February 2001 would give a gestation of 30 weeks plus 1 day, but this is not a material difference. A finding of mildly echogenic bowel was recorded again. A CTG was taken and was considered unremarkable, although the fetal heart rate was once more at the upper end of the normal range.

**A1.22** Three days later, on Friday 14 December Mrs Dixon went to antenatal class in the morning and then to FPH in the afternoon for a checkup. She was having a busy day – her father in law had just died and she was intending to drive her husband to Hertfordshire that evening so that he could pay his respects and they could both attend the funeral. She was trying to fit some essential shopping in between her antenatal appointments. This was undoubtedly stressful, and Mrs Dixon considered cancelling her afternoon appointment, but decided against it.

**A1.23** At FPH, she had a routine CTG, starting at 15.31pm. The CTG showed a sinusoidal pattern – cyclical variation in the baseline fetal heart rate. This is pattern is associated with significant fetal problems: it indicates a high probability that the fetus is severely compromised and requires urgent delivery. There were no periods of normal variability of the fetal heart rate.

**A1.24** We have seen this CTG. It runs from 15.31 to 16.10, and is clearly abnormal. Fetal movements were described as “+++”. There was lots of loss of contact. The trace was not linked by clinicians with the echogenic USS findings and abnormal blood flow findings, but the standard clinical assumption is such a trace suggests deteriorating placental blood flow and severe fetal hypoxia or, more rarely fetal blood loss or anaemia.

**A1.25** Perhaps because of the scale of loss of contact, no immediate action was taken. According to Mrs Dixon's recollection they repeated the trace and the baby's heart rate had



returned to normal. We have not seen any record of such a CTG. The medical record from the unit is timed 17.15pm. It records a sinusoidal tracing, and that the plan was to repeat the CTG after 1 hour. Mrs Dixon was given some food and was asked to wait. She was advised to phone her husband but did not think there was any particular urgency about the concerns being investigated.

**A1.26** We have seen a second CTG trace, which was shown to us by Mr Beynon, the on-call surgeon who delivered Elizabeth later that evening. This CTG does not have a time on it but it was the one on which the decision was taken that emergency delivery was needed. It is most likely in our view to have been recorded between 18.30 and 19.30 that day. A single dose of dexamethasone is shown as being administered at 19:15; this was a precaution to prepare the baby's lungs for an emergency caesarean section.

**A1.27** There is no record that the on-call obstetric consultant was consulted about the CTGs. At 19.45, Dr Cockburn, who was not on-call, was phoned at home about the trace. There is no evidence that she was sent a copy of the trace itself. She later recorded that she told the registrar that "if he felt the trace was sinusoidal it meant a hypoxic baby and that it needed delivery stat".

**A1.28** She suggested an emergency caesarean section, and that the paediatricians should be advised that there might be an immediate delivery of a premature baby. She also told the registrar that it was not a suitable case for transfer elsewhere (presumably to a tertiary centre).

**A1.29** Mr Beynon was called at 8pm. He did not know the history of the pregnancy and had not previously met the Dixons, but he agreed that an emergency caesarean section was indicated on the basis of Dr Cockburn's opinion. Mr and Mrs Dixon were then told by the obstetric registrar that emergency delivery was recommended.

**A1.30** Mrs Dixon was surprised and concerned, and asked to see the surgeon before giving consent. She was not in labour; the baby was not due for another eight weeks and she was worried about the risks to it of such a premature delivery. She had not spoken to Dr Cockburn. Mrs Dixon was also concerned that she and Graeme were in the middle of a family crisis, and that if she was not discharged she could not drive her husband to be with his family. He would not see his father's body and might miss his father's funeral. It is not surprising that she wanted to be sure.

**A1.31** When Mr Beynon arrived at the hospital an hour later he asked to see the CTG. He immediately thought the risk to the fetus was high and an emergency section was needed. He recorded his decision, then went to speak to the Dixons. Mrs Dixon was not convinced by what he told her. She did not understand why she was suddenly being told it was an emergency when earlier in the afternoon a decision had not seemed so urgent. Because she thought that the baby's heartbeat had stabilized earlier, she wondered whether it could be encouraged to do so again without the need for a caesarean section.

**A1.32** It seems clear from the clinical records that communications between Mrs Dixon and Dr Cockburn were never ideal, and it seems that the conversation between Mr Beynon and Mrs Dixon was also difficult. Mrs Dixon wanted to be convinced; and the clinicians wanted their opinions to be trusted.

**A1.33** The management plan and decision making around the CTG and delivery plan seem to us to have been illogical. If a midwife or junior doctor considers a CTG to show a sinusoidal rhythm, they should regard it as a serious clinical concern that needs a quick decision, especially on a Friday. If a senior clinician then concludes that the trace is pathological, then delivery needs to be expedited as soon as possible. In practice, it took Frimley clinicians seven hours after starting the CTG to deliver Elizabeth.



**A1.34** It would not be usual practice to discontinue a CTG showing such a significantly abnormal pattern and restart it at a later time. Such traces can be the precursor to fetal death. In addition, Mrs Dixon was not asked to remain nil by mouth in anticipation of an emergency delivery.

**A1.35** We have considered whether the emergency caesarean section would have been delayed and AD referred for further investigation, if the trace had been considered in light of all available evidence from previous scans and tests.

**A1.36** Given the evidence of echogenic areas in the abdomen and the subsequent diagnosis of neuroblastoma, there may have been causes of fetal distress other than problems with placental blood flow and oxygenation, but decisions on urgent delivery can only be based on the evidence available to clinicians at the time. The trace was clearly indicative of severe fetal distress and we consider that the decision to recommend urgent delivery by caesarean section was not only reasonable, it was urgently required.

**A1.37** The delay in confirming the case for the urgent delivery is inexplicable, and potentially placed Elizabeth in further jeopardy. There was significant delay at every stage: between the interpretation of the first CTG at 16.15 and the decision at 19:15 that there was serious cause for concern and dexamethasone should be given; between that concern being communicated to a consultant obstetrician at about 19.30 and senior review of the trace at 21.15; and between then and Elizabeth's delivery at 22:25.

**A1.38** Much of the last was due to Elizabeth's parents' reluctance to give consent, but this should have been anticipated and tackled earlier. It may be that her consent had been taken for granted. Having carefully reviewed the clinical records and interview evidence, it does also seem to us that, perhaps in trying to overcome the impact of the earlier lack of urgent decision-making, communication of the recommendation that an emergency caesarean section was needed was not well handled by the clinicians concerned.

**A1.39** Elizabeth's parents were already trying to deal with the ramifications of a family bereavement, and needed convincing that the caesarean section – which Mrs Dixon knew would deliver a very preterm baby and make her husband miss his own father's funeral – was necessary. Mr Beynon therefore found himself dealing with an understandably sceptical mother, who was shocked to be told – when she didn't feel any symptoms – that there was suddenly an emergency and that refusal to give consent would endanger her child. Mr Beynon's view on coming in on-call to conduct the surgery, and on seeing the CTG trace, was that the baby needed to be delivered as soon as possible. It seems that he expressed this view in forthright terms, to Mrs Dixon's distress.

**A1.40** Faced with the prospect of serious risk to Elizabeth's life that had been spelled out to her if she were to leave the hospital, both parents then consented to the emergency caesarean section, but Mrs Dixon remained extremely anxious about the course of action. The anaesthetist thought her so anxious that he decided that a general anesthetic was necessary, but there a further disagreement in front of Mrs Dixon between the anaesthetist and the obstetric surgeon about the case for this. It is clear from the accounts we heard that this disagreement was bad tempered.

**A1.41** Eventually, however, Elizabeth was delivered by an uncomplicated lower segment caesarean section under general anaesthesia, and was initially considered to be in good condition given her preterm delivery. Mrs Dixon recovered consciousness at midnight, an hour later, and was told that her baby was fine and had been taken to the special care baby unit. She saw Elizabeth the next morning.

**A1.42** Elizabeth's parents have had awful experiences since her birth, and undoubtedly suffered traumatic stress as a result. The first in a series of precipitating factors was the handling of her emergency delivery: whilst it might have become forgettable had all else gone well, in light of what

happened subsequently it did not. Mrs Dixon had previously been told she was making a fuss for no real reason; she was now being told there was something wrong when her fetus was active and she felt well. The impact of this would surely have been made worse by the argument between the surgeon and the anaesthetist that took place in front of her.

**A1.43** Handling complex conversations in urgent situations is never easy for patients or for clinicians. More attention has been paid in recent years to promoting the necessary skills in clinicians, but there is no doubt room for further improvement.

## Post Delivery

**A1.44** Elizabeth was in good condition at birth, and her Apgar scores<sup>4</sup> were satisfactory. There was no obvious cause of the previously abnormal CTG, but she did show some respiratory distress, as expected from her preterm delivery. FPH staff recorded that she was 'moving hands and legs, opening eyes', and had no fits, all of which strongly suggested that she had suffered no neurological damage as a result of antenatal problems or preterm delivery. She was taken to be looked after in the special care baby unit in view of her respiratory distress.

**A1.45** Like many babies she had some jaundice, but it was not of the type or severity which results in kernicterus (the accumulation of bilirubin in the grey matter of the brain with associated neurotoxicity and brain lesions, which impact on the central nervous system). Although she was born at 31 weeks and four days, when her liver and kidneys had not yet finished developing, her kidney and liver functions were good.

**A1.46** Elizabeth weighed significantly less than had been estimated in the antenatal ultrasound scans, but consultant paediatrician Abdus Mallik saw her and recorded her satisfactory condition. He remained apparently unaware of Mrs Dixon's antenatal history and abnormal scan results: although the antenatal records were available these had not been highlighted to the paediatricians, and Dr Mallik seemingly assumed that Mrs Dixon had gone into preterm labour spontaneously.

**A1.47** The findings of echogenic bowel were documented in the transfer notes to the special care baby unit but not the abnormal CTGs before Elizabeth's birth, or the history that she had been considerably undersized earlier in the pregnancy and at birth, when compared to her prenatal estimates. There was no follow up of the echogenic evidence findings beyond routine checks. The day after her birth Elizabeth was given an ultrasound brain scan and an X-ray of her abdomen, which are standard for preterm neonates. Elizabeth's parents asked for an abdominal ultrasound because of the record of echogenic traces, but were told this was not necessary. Her parents were reassured that she was doing well following her preterm delivery despite their concerns that she looked unwell.

**A1.48** Elizabeth's first full medical review, on 14 December 2000, noted echogenic bowel and notched uterine artery blood flow under 'maternal history'; by her second assessment on 15 Dec (day 1 afternoon) this had dropped off the record (although noted again on 17 Dec alongside a note saying 'Dopplers normal').

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<sup>4</sup> A composite assessment of the condition of a neonate conventionally recorded one and five minutes after birth. Introduced Dr Virginia Apgar, the scores correlate very well with subsequent outcome.



# APPENDIX 2: ELIZABETH'S NEONATAL CARE AT FRIMLEY PARK HOSPITAL<sup>1</sup>

## Elizabeth's condition at birth

**A2.1** We now know that Elizabeth had some fundamental health problems when she was born, but at the time of her delivery at 22.25 on Friday 14 December 2000 the neonatal team were fairly satisfied with her condition. The primary focus of the attendant neonatal team at birth is to support the breathing and associated systems – particularly to ensure that the circulation and blood pressure is adequate. From this perspective the care provided to Elizabeth, in the immediate period at her birth and in the first few hours of her life, was to a good standard. She received appropriate immediate resuscitation, respiratory support, fluids, intravenous antibiotics, surfactant and monitoring. Her general support requirements were appropriately met.

**A2.2** The notes suggest no suspicion that there were grounds to be alarmed about her health other than her prematurity and the stress of delivery. No grounds were noted either that would explain the symptoms of distress which prompted her delivery: there was no placental abruption, the placental tissue was healthy, uterine liquor showed no haemorrhage and no meconium, Elizabeth had no signs of hypoxia and no abnormalities of the umbilical cord. She had no myopathy – the staff at FPH recorded that she was 'moving hands and legs, opening eyes' – and no fits, which can be a risk for preterm babies. Her mother did not have an infection, and a post-natal blood test excluded the possibility of a significant fetal haemorrhage.

**A2.3** The description of Elizabeth at birth and in the first few days of life, her head growth being generally proportionate to her birth weight and two apparently normal cranial ultrasounds in the first 5 days of life are all supportive indicators that Elizabeth was not born with an established structural antenatal brain injury. We have reviewed the cranial ultrasound images taken on 15 and 19 December 2000. They are of poor quality, so we cannot be certain, but in general we agree with the assessment at the time that no obvious congenital or antenatal pathology can be seen. On the day of her birth Elizabeth, like most 32 weeks' gestation infants in 2000, would have been expected to survive and to do so neurologically intact in the absence of other pathology.

**A2.4** Elizabeth was given Apgar Scores of 7 at 1 minute and 9 at 5 minutes. The Apgar score describes the condition of newborn babies based upon their colour, heart and respiratory rates, responsiveness and tone. Each parameter is scored from 0 to 2, giving a maximum score of 10. The 5-minute score is the more reliable indicator of how well the baby is and how well they have transitioned to extra-uterine life; Elizabeth's score was therefore very encouraging.

**A2.5** She was suffering from a degree of respiratory distress. The degree of support she required seem to be fairly typical for a baby born at 31-32 weeks' gestation without there having been natural labour and insufficient time for antenatal steroids to optimize lung maturation.

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<sup>1</sup> Unless otherwise stated, information is from Frimley Park Hospital records.

**A2.6** In such circumstances, the commonest immediate problem that will arise is a variable degree of respiratory insufficiency caused by immature lung development and a lack of surfactant within the newborn lungs. This in turn leads to small volume, stiff lungs which have a limited area for gas exchange. Breathing with such lungs requires great effort on the part of the baby and the rib cage often shows this effort by what is called ‘recession’. The baby may need artificial respiratory support to survive, but most will recover well.

**A2.7** In Elizabeth’s case she was noted initially to be blue in colour, with some tone, a good heart rate, some respiratory effort and some responsiveness. This describes a baby in good condition at 1 minute of age. Elizabeth was given bag and mask artificial ventilation for 1 minute, and at 2 minutes of age she was described as having an increasing respiratory rate, an improving colour but with intermittent apnoea (absence of breathing). She was given oxygen by facemask to support her breathing.

**A2.8** By 5 minutes of age, when the next Apgar score was calculated, she was described as only being blue at the peripheries (a common finding), responsive, with a good heart rate, a respiratory rate of 40, and improving tone. She was transferred to the Special Care Baby Unit (SCBU) supported by facemask oxygen. She was showing signs of chest recession – a sign that she was still working hard for breath – once she arrived in SCBU, so she was placed on Nasal Continuous Positive Airway Pressure (NCPAP). This is a relatively non-invasive form of intermediate respiratory support, more than oxygen by mask alone but less than full mechanical ventilation.

**A2.9** Her blood oxygen saturations continued to fall despite the NCPAP, so she was intubated by a breathing tube placed into her trachea (first a 2.5 mm tube, then a 3.0 mm tube) and mechanically ventilated. She was also given intravenous fluids to support her circulation, morphine to settle her on the ventilator and Survanta, a bovine surfactant that helps to replace surfactant deficiency in the premature lung (surfactant is required to help maintain the air sacs open and is in low concentrations in infants born below 34 weeks’ gestation).

**A2.10** By 04.30 on 15 December, Elizabeth was noted to have a reduced oxygen requirement and required a falling level of support from mechanical ventilation as a result of good blood gases. By 09.00 there was a plan to wean Elizabeth from both morphine and the ventilator if the repeated blood gases supported it. She was duly weaned off respiratory support by a reduction to the morphine she was being given and then by receiving a dose of caffeine to stimulate breathing. It was decided that she did not need a second dose of surfactant, and she was extubated to NCPAP on the afternoon of 16 December before being weaned off NCPAP during the course of 18 December.

**A2.11** Elizabeth was not noted to have any new or recurrent respiratory problems for the next nine days apart from transient, largely self-limiting apnoeas and bradycardias (these are short-lived episodes of stopping breathing and slow heart rate, often seen in premature babies). Until 27 December her respiratory support was minimal, with occasional supplemental oxygen therapy and then no additional support at all.

**A2.12** We consider the escalation of Elizabeth’s respiratory support in the first few days of her life to have been appropriate, as was control of her blood gases. This is relevant given her later diagnoses. Babies born in a severely depressed condition at birth or those who require significant resuscitation would be considered at a higher than average risk for subsequent neurological problems. This did not apply to Elizabeth. Similarly, there is no biochemical evidence from the blood gases analyses available of any period of persistent postnatal hypoxia (an abnormally low level of oxygen in the blood) or hypocarbia (an abnormally low carbon dioxide level in the blood) in the first few hours after birth. This is relevant for Elizabeth as both hypoxia and hypocarbia – if severe, prolonged and uncorrected – can cause brain injury in the preterm infant.

**A2.13** Although she was born before her liver and kidneys had finished developing, Elizabeth's kidney and liver functions were good. The clinical records show that Elizabeth underwent regular checking and treatment for jaundice, and had serial blood testing as well as other types of routine nursing care. Levels of electrolytes were all appropriately managed. Elizabeth received phototherapy for the physiological jaundice of the newborn, and there were no sustained elevated levels of bilirubin that can be causative of specific types of brain injury. Her heart function was also healthy. Elizabeth was examined on a regular basis as recorded in the clinical notes. No apparent concerns regarding Elizabeth's cardiovascular system were explicitly expressed in the first few days with Elizabeth's heart sounds described as normal, with usually normal peripheral circulation and normal pulses. Her heart rate was typically noted as 150-170 during this period. Review of Elizabeth's blood gases did not demonstrate any persisting or increasing abnormality.

**A2.14** At 2am on 15 December, when Elizabeth was just over three hours old, the consultant paediatrician covering the neonatal unit, Dr Abdus Mallik, arrived to review her condition as he tried to do for all preterm babies transferred to the SCBU. He made a full assessment of Elizabeth and wrote a detailed management plan. Dr Mallik noted that Elizabeth was stable and pink, with an oxygen saturation of 94%, a mean arterial blood pressure of 46 mmHg, was well perfused, had good air entry, had passed urine and was "fairly synchronized" on the ventilator. The condition of her lungs was noted to show "mod[erate] RDS" (respiratory distress syndrome). Elizabeth received a chest x-ray to adjust the position of the endotracheal tube and an umbilical venous catheter (inserted after attempts had been made unsuccessfully to insert central and peripheral arterial catheterizations). He met Elizabeth's parents, who were understandably shocked and anxious – and in her mother's case recovering from general anaesthesia and an emergency caesarean section – and reassured them that there was every reason to expect Elizabeth to recover well from her preterm delivery.

**A2.15** The detailed management plan devised by Dr Mallik asked for a number of routine interventions, including target blood gas parameters, the need for antibiotics, a blood transfusion, indications for a second dose of surfactant, repeat blood gases, 4 hourly blood pressures, and repeat assessments. These were all interventions appropriate for a neonate of Elizabeth's prematurity. In addition, the mean blood pressure that had been recorded was above the normal range for a 32-week newborn, which made the regular monitoring of her blood pressure particularly important.

**A2.16** Dr Mallik also asked for Elizabeth to be given an ultrasound brain scan and an Xray of her abdomen, both standard for premature neonates, although Elizabeth had to wait two days for the ultrasound to be conducted. It is very likely that as now, there were very few staff on duty over the weekend who could provide an adequate ultrasound service.

**A2.17** The antenatal ultrasound findings of areas of echogenicity in the abdomen did not prompt any further investigation by the paediatric team for some days, and we therefore considered whether staff were adequately aware of all relevant antenatal information.

**A2.18** Elizabeth's parents were usually with her in hospital and shared their concerns and the story of her antenatal ultrasounds. Even so, the written record did not always include the antenatal problems as active risk factors. Some years later (in conducting a review of her care) Dr Mallik himself seems to have been under the impression from looking at the medical notes that Mrs Dixon had gone into premature labour. We therefore looked carefully at the records to see what prenatal information was available through the notes to the neonatal clinicians, as well as how instructions recorded in the management plans were followed up.

**A2.19** Elizabeth was born at the start of a weekend (with reduced medical rounds and poorer diagnostic cover), and in December when the hospital was at increased risk from staff discontinuity



while medical and nursing staff were taking turns with annual leave. There were always consultants on duty, but the Christmas holiday season inevitably increases churn. Elizabeth was seen by at least 5 consultants and six junior doctors in her two weeks at FPH. Keeping an accurate and complete record is always important, but there are certain times of the week and year when the management of written information becomes crucial.

**A2.20** It seems clear that Dr Mallik was told about the prenatal findings just after Elizabeth's delivery, at least in summary. His first assessment of Elizabeth on 15 December recorded that there had been an abnormal CTG (noting that this was cause to watch Elizabeth carefully for signs of sepsis), although there was no detail of the nature of the CTG abnormalities. In addition, echogenic bowel and notched uterine artery blood flow were noted under 'maternal history' and had been documented on the front page of transfer notes to the special care baby unit.

**A2.21** There was no mention in Dr Mallik's management plan of following up the repeated prenatal findings of an echogenic bowel or the abnormal antenatal sinusoidal trace that had prompted the decision to deliver Elizabeth by emergency caesarean section. Until the point it was realised Elizabeth had abdominal masses and hypertension, it seems it was not considered relevant to her care beyond being possible markers for a finding of sepsis. By the time of the second full assessment of Elizabeth's condition on the afternoon of 15 Dec (day 1 afternoon) the notching in prenatal uterine blood flow had dropped off the record and did not reappear apart from being noted one other time on 17 Dec alongside a note saying 'Dopplers normal'. Echogenic bowel was not recorded in the 'problem' list which the clinical team were most likely to go straight to in any discussions of Elizabeth's condition. This is not unusual with such prenatal information; but an information design problem in medical records that does not put relevant information on the right page carries inherent risk, because findings can thereby disappear from discussions.

**A2.22** When they first spoke to Dr Mallik, Elizabeth's parents asked for an abdominal ultrasound because of the echogenic record, but were told this was not necessary and Dr Mallik reassured them that Elizabeth was doing well for her prematurity. They also asked about whether her weight should cause alarm. Elizabeth's weight at birth was 1294g, which was not consistent with previous estimates of 1752g from the antenatal scan a week before. This inconsistency was dealt with without curiosity. Her parents, who had previously been reassured that any prenatal scans which showed their daughter was tiny were incorrect, say they were now told that the scans suggesting she would be larger must have been incorrect for the same reason – an inaccuracy in Elizabeth's due date.

**A2.23** We have considered whether the refusal of an abdominal ultrasound was reasonable considering Elizabeth's prematurity, unexpectedly low birthweight, the repeated echogenicity found in prenatal scans, and the request from her parents (which was repeated at intervals over the following week). Echogenic fetal bowel is not a rare finding and its significance is often unclear. It may, of course, not even be connected to the bowel: the term covers the abdominal area in general. But – and in particular if it persists beyond 16-20 weeks' gestation and into the third trimester – it warrants a formal consideration of first line investigations to determine possible causes, and the possibility of referral to a tertiary centre, if there are significant concerns or other associated findings. It can be associated with chromosomal anomalies, cystic fibrosis, congenital (in utero) infections, primary gastro-intestinal pathologies such as atresia or obstruction, and intra-uterine growth restriction.

**A2.24** Elizabeth subsequently turned out to have bilateral masses arising from her adrenal glands (which also wrapped around some major blood vessels such as her abdominal aorta) due to a type of tumour called a neuroblastoma. Abdominal masses were identified on examination, but not until she was two weeks old, although it is clear that they would have been detectable earlier. This finding was confirmed by the first abdominal ultrasound she had after delivery, which showed

that the masses arose from her adrenal glands. Neuroblastoma occurs when neural crest tissue in the developing fetus does not 'turn off' when it is meant to, so the tissue keeps on growing. In Elizabeth's case the neuroblastoma secreted adrenal hormones as well as compressing adjacent organs. It is highly likely that Elizabeth's extremely high blood pressure, which was belatedly recognised at the same time, resulted from the effect of adrenal hormones – catecholamines – secreted by the neuroblastoma.

**A2.25** Neuroblastoma which develops while the baby is still in the uterus is not common, and it is not possible to say with certainty that the ultrasound finding of echogenic bowel was directly related to the neuroblastoma. Nevertheless, the finding should have prompted further examination following delivery, including abdominal ultrasound. This would have identified the masses two weeks earlier, and potentially shown the importance of the high blood pressure that had been noted and then ignored. This would have been crucial in preventing the neurological damage that soon became Elizabeth's most challenging problem.

**A2.26** The failure to recognise that the antenatal ultrasound finding required follow up was very damaging to Elizabeth's condition. Paediatric staff were aware of the finding, but it was never highlighted as something that required attention. When it was pointed out by Elizabeth's parents it was wrong to ignore their concern, as well as their suggestion that an ultrasound examination should be done now she had been born. The paediatric team also failed to detect the abdominal masses on physical examination, although they were palpable on subsequent examination.

**A2.27** The neonatal team at FPH were initially confident about Elizabeth's condition – and as a result, in their own competence to care for her. The special care baby unit at FPH was assessed as level 1, although the hospital was aspiring to qualify as level 2. This meant that babies delivered and looked after at FPH were not expected to have significant problems. Infants born at 31-32 weeks' gestation will require a range of general supportive measures regardless of any specific conditions that they may have beyond prematurity. Such support will include managing jaundice of the newborn, regular laboratory monitoring of blood counts, renal and hepatic function and general nursing care, such as skin care, airway management and toilet. The clinical records show that Elizabeth had good routine nursing care.

**A2.28** But at the age she was born, Elizabeth qualified to be looked after at FPH only if she was considered low risk: if she had been considered moderate risk, she should have been moved to a level 2 unit. She clearly was not considered to be at moderate risk that first day of life; and on Saturday 16 December Elizabeth was judged by the consultant on duty, Dr Tettenborn, to be making progress (albeit slowly).

**A2.29** But by the afternoon of Sunday 17 December it was noted that Elizabeth was struggling with abdominal distension and her skin was beginning to look mottled. Although Dr Mallik (who had been off duty over the weekend) reassured her parents that he still thought Elizabeth was 'improving' when he saw the family again on Monday 18 December, it is clear from the notes that the clinical team thought Elizabeth was unwell. They suspected that Elizabeth was developing an infection in her gut. They could have increased her risk assessment to 'moderate', but there is no sign this was even considered. Sepsis was within the range of conditions the unit was competent to treat. There is some evidence that junior doctors on duty considered whether her symptoms might relate to anything more unusual – and a couple of suggestions that abdominal organs other than her intestine were enlarged. But at ward round examinations no-one could find anything conclusive, and the two tests that could have told them – abdominal ultrasound and blood pressure monitoring – were not conducted until after Christmas.

**A2.30** The infection they suspected was a type of sepsis called necrotising enterocolitis (NEC). Once she started being fed (given her prematurity she was nourished intravenously at first, then



weaned onto delivery of food by tube into the upper part of her intestine) Elizabeth had general difficulty in digesting: she often had a very distended abdomen and diarrhoea, and reacted to feed being given with temporary breathing cessation, suggesting discomfort. By 19 December the medical notes are clear that the clinical team was actively concerned about the possibility of NEC.

**A2.31** NEC is a serious infectious condition of the bowel which typically affects premature, sick babies and carries a significant morbidity and mortality. It presents with bile-stained aspirates, feed intolerance and abdominal distension. Presumptive NEC was treated with keeping Elizabeth nil by mouth, and administering broad spectrum intravenous antibiotics. Elizabeth was managed with a combination of minimal enteral feeds, intravenous fluids and total parenteral nutrition (TPN, a form of intravenous feeding). By the time of Elizabeth's transfer to Great Ormond Street Hospital (GOSH) she was still to establish full enteral feeds and remained on broad-spectrum antibiotics.

**A2.32** The clinical team were focussed on their suspicion of NEC, even though several measures taken to try and confirm the diagnosis over the following week found no evidence of infection. The laboratory markers for infection were all negative for sepsis, and the reported x-ray results (we were unable to find any images) were not definitive for NEC. Unfortunately, this is not unusual for babies with this condition. For this reason, it is considered appropriate to treat for NEC on clinical signs and symptoms even when there is no definitive evidence.

**A2.33** Given Elizabeth's prematurity and her clinical appearance with a distended abdomen and bile-stained aspirates, we consider that it was reasonable that the clinicians considered NEC as a possible diagnosis and decided to treat her for it. Elizabeth's management was appropriate to NEC and to a good standard, with one notable exception. Her blood pressure was not monitored. When NEC is suspected clinicians should provide organ support as required, such as oxygen and blood transfusions, and be vigilant for indications that suggest a surgical intervention is needed. This vigilance includes monitoring the patient's blood pressure, but this did not happen.

**A2.34** Unfortunately, the clinical pursuit of the NEC diagnosis – which subsequently proved unfounded – seems to have precluded any real consideration of alternative causes for a few days. When – over the Christmas period – it was decided that another cause should be looked for, the clinical team continued to look in the wrong direction. Elizabeth was assessed for myotonic dystrophy, then for a more localised infection. Her abdomen continued to be distended intermittently, but an abdominal ultrasound was still not undertaken. An ultrasound would have revealed Elizabeth's neuroblastoma earlier.

**A2.35** The clinical team also seemed to have been circumspect about the full extent of their own concerns about Elizabeth's condition. Elizabeth's parents became frustrated at receiving nothing but reassurance, when they thought Elizabeth's posture, silence and relative immobility was obvious. There may have been other reasons for this reticence. Elizabeth's mother was demonstrating clear signs of anxiety, and was not making a quick recovery from the caesarean section; and her father was partially sighted as well as being under stress from his own bereavement. If so we think this reticence misplaced, because it left them feeling as if no-one was listening to them: despite repeatedly expressing concerns about their daughter's progress they were met with blanket reassurance and no variation in the basic approach to her care. In the circumstances we have described, an earlier abdominal ultrasound was surely warranted.

**A2.36** It is now clear that Elizabeth did not have NEC, but was struggling with problems from high blood pressure that developed quickly after her birth. The levels that we believe she was experiencing during her first few days were sufficient to damage her brain significantly. Additionally, the vascular response in the cerebral circulation would require a careful approach to reducing her blood pressure to avoid further damage. This was not yet relevant, as the high blood pressure remained unrecognized and untreated until she was two weeks old.

**A2.37** Elizabeth's hypertension was almost certainly triggered by the action of catecholamines (particular types of hormones that increase blood pressure) secreted by her neuroblastoma. It is also possible that the neuroblastoma impeded blood flow in the arteries leading to the kidneys, which itself can raise blood pressure. The catecholamines may also have interfered with the operation of her otherwise healthy intestinal tract, causing distension and digestive delay, and contributing to the misdiagnosis of NEC.

**A2.38** Hypertension, raised blood pressure, is uncommon in newborn babies, but its effects can be devastating, as in Elizabeth's case. Although it is not straightforward to measure blood pressure in neonates, it is important to do so (as well as for the more common hypotension, low blood pressure). The failure to monitor Elizabeth's blood pressure, even after observing a reading that was raised, was a significant omission that changed Elizabeth's outlook dramatically.

**A2.39** Elizabeth did have her mean arterial blood pressure (MAP) measured soon after birth, because Dr Mallik noted the result in his first assessment. It was recorded as 46 mmHg. He made no comment in the record about it other than to leave an instruction that the blood pressure should be monitored 2-4 hourly. This level of blood pressure was only slightly raised for a newborn baby born at 32 weeks gestation, and the instruction to monitor was reasonable, but it was essential it was followed.

**A2.40** Easy access to the charts showing the normal range of blood pressure in preterm babies may not be readily available in neonatal units, but it should be. A very rough rule of thumb in use in 2000 was that a mean blood pressure in mmHg, equivalent to a preterm baby's gestational age in weeks, was acceptable in the presence of clinical evidence of adequate circulatory function. Elizabeth's mean blood pressure at 46 mmHg was distinctly above the expected level of 32 mmHg by this yardstick. It was high enough to have prompted some concern although Elizabeth had just been born, had had extensive handling and was likely to have been distressed. It was vital that the instruction to monitor the blood pressure was followed. In the event, it was not measured again for four days; although it was unmistakably high on that occasion, it was not measured again for another ten days, when it was again very high. The likelihood is that it had been high since shortly after her birth.

**A2.41** Elizabeth's pulse remained rapid throughout, initially attributed to possible infection. She was noted to have a mottled appearance from 17 December, both almost certainly due to catecholamines secreted by her neuroblastoma. Although this had not yet been detected, the rapid pulse and mottling should have prompted a thorough assessment of her cardiovascular system, including blood pressure.

**A2.42** By Monday 18 December Elizabeth's blood pressure had risen significantly. Dr Mallik told us at interview that he thought at his ward round on Monday 18 December he was told that Elizabeth's blood pressure was "normal", that is within the expected range for her gestation; and that this may have been why he did not think to ask after it again. He also suggested that the main focus would have been on ensuring that her blood pressure was not low, the more usual problem in preterm babies, and that he may have been reassured that it was not. In reality, however, Elizabeth's blood pressure had not been recorded since her first day, four days previously, so it is not clear on what any reassurance could have been based. What is clear is that a single blood pressure was recorded later that day, and the mean blood pressure of 73 mmHg was extremely high for a baby of that age.

**A2.43** Such a level of blood pressure should have prompted significant concern and urgent follow up. The level was high enough that damage would inevitably result sooner or later, and in the absence of any measurements there was no way to know that it had not been present since the first day. Instead, the observation was not repeated, and does not seem to have been reported

to anyone who recognized it as significant. This was a dangerous missed opportunity to detect Elizabeth's hypertension; and after this point there is no evidence in the medical or nursing notes that Elizabeth's blood pressure was checked again until 27 December. It seems everyone simply forgot about the need to keep her blood pressure under review.

**A2.44** The absence of regular blood pressure monitoring, from the day after Elizabeth was admitted to SCBU, was a clear departure from the standard of care that was expected in 2000 and that had been asked for by Dr Mallik. Although Elizabeth recovered quickly from the respiratory distress associated with preterm delivery, it would have been reasonable to expect her blood pressure to be monitored for the first few days of life. Certainly, it should have been monitored during the period of ventilation and oxygen support, and also during the following few days when she was being treated for presumed abdominal sepsis.

**A2.45** Monitoring blood pressure in neonates is difficult and uncomfortable for the baby, and in Elizabeth's case one factor that may have drawn attention away from circulatory disturbance and hypertension was the abandoned attempt to install an arterial catheter. Had this been successfully inserted as planned, it is likely that continuous blood pressure readings would have been available and noted. The decision on 15 December not to persevere with the effort to insert an arterial catheter is understandable, given that Elizabeth's respiratory status was not extreme. Many neonatologists would avoid an indwelling arterial catheter in such circumstances, given their associated risks.

**A2.46** But there are other ways to monitor blood pressure, especially when the lead consultant has given a clear instruction to do so. There is no evidence that blood pressure readings were considered, asked for, reviewed or discussed by consultants and junior doctors between 18 – 26 December. Had Elizabeth's hypertension been diagnosed within a few days of her birth as it should have been, it would have been treated promptly, avoiding the serious damage to her brain which subsequently blighted her life.

**A2.47** Elizabeth's digestive problems were never fully understood during her lifetime, and it was understandable that there remained a focus on possible NEC. In hindsight, it was most likely that the catecholamines secreted by the neuroblastoma were affecting her bowel motility, but her neuroblastoma had not yet been diagnosed.

**A2.48** From 19 December Elizabeth was consistently noted to be generally hypotonic, a finding often associated with cerebral problems. She had seemed to her parents to become increasingly distressed and mottled over her first weekend, and she suffered some kind of event in the afternoon of Monday 18 December when she vomited blood. By that evening her limbs were mottled and it was noted that at one point she became hypertonic, but she later became floppy overall. By 19 December she was described as having "generalized hypotonia<sup>2</sup> and very abducted hips".

**A2.49** Elizabeth's subsequent progress makes it clear that these were the first signs of what became a profound neurological impairment. It was not present at birth, and repeated cranial ultrasounds at FPH found no sign of a tumour, clot or bleed, but subsequent neurological examinations intermittently continued to confirm abnormalities of tone and posture, irritability on handling, head lag, variable but persisting temporary cessation of breathing, some responding to stimulation. The neurological findings were not consistent: for example, Elizabeth was described as 'responsive' on 24 December, which appears an optimistic assessment.

**A2.50** Given the levels of blood pressure that were apparent on those few occasions it was measured, which were very high relative to the normal range at that gestation, and the timing

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<sup>2</sup> Hypotonia refers to reduced muscle tone, or floppiness: hypertonia to increased muscle tone or rigidity.

of its onset, the most obvious cause of Elizabeth's neurological deterioration was hypertensive encephalopathy.<sup>3</sup> It is not clear at what point recognition of the diagnosis could have reversed these changes, but it is clear that recognition and management of the very high blood pressure before it had led to hypertensive encephalopathy could have prevented neurological impairment from this cause.

**A2.51** Elizabeth's breathing cessations increased over time. Many preterm babies have irregularities in breathing, until their respiratory regulatory systems mature. Generally, these show steady improvement unless there is other respiratory disease. This was not the case for Elizabeth and suggests that the neurological impairment was affecting her respiratory drive. By the time of her transfer to GOSH on 29 December the transfer note records she was having 8-10 pauses in breathing or episodes of slow breathing each day and even more regular reductions in her blood oxygen – to the point that she was reventilated on 29 December even before the decision was made to transfer her to GOSH (babies are often ventilated to support them during a transfer by ambulance).

**A2.52** Overnight on 26 to 27 December, Elizabeth finally had another blood pressure reading taken. The clinical team was made aware it was very high, and her blood pressure started being taken fairly regularly, but there is no evidence of alarm in the clinical records and it was not mentioned as an issue in the record of the ward round discussion on 28 December, despite Elizabeth being described as having 'no spontaneous activity.'

**A2.53** In the early afternoon of 28 December Elizabeth was reviewed by Dr Tettenborn, who was covering the neonatal unit that day. He noted that her liver and spleen seemed slightly enlarged, and considered her blood pressure readings. He checked whether her blood pressures were symmetrical in her limbs and clearly started to consider potential causes. He speculated in the notes that she might have a chromosomal disorder, fungal infection, or a disorder of immunity; and ordered an abdominal ultrasound to examine her spleen. This revealed that Elizabeth had bilateral abdominal masses in the region of the adrenal glands. Dr Tettenborn explained to Elizabeth's father that the finding of enlarged adrenals might explain Elizabeth's presentation of hypertension and temperature instability.

**A2.54** He had also decided to seek advice from the paediatric endocrinologists at GOSH. This would have been a perfectly appropriate alternative to consulting a paediatric nephrologist (who was most likely to understand the implications of her sustained hypertension) as long as an indication was given that one of Elizabeth's main problems was one of unexplained hypertension. Unfortunately, little emphasis was placed on the hypertension. GOSH clinicians advised that a few more tests be conducted, but at this stage her parents were advised that a transfer to GOSH was not considered to be likely. Nothing was done to try to reduce Elizabeth's hypertension, and there is no record of any concern raised about it by GOSH clinicians.

**A2.55** At the point where an abdominal ultrasound demonstrated bilateral adrenal masses, no consideration was given to the possibility of adrenal tumours such as neuroblastoma; although other rare causes of adrenal enlargement such as congenital adrenal hyperplasia were considered. Neuroblastoma does not appear to have been a possible diagnosis suggested by GOSH. The tests suggested by the endocrinologists were complicated and the results were not available for three weeks, but they found a steroid profile in the normal range with 'no biochemical indication of CAH or a tumour' (this would have been a tumour that produced steroid hormones, which she did not have).

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<sup>3</sup> Hypertensive encephalopathy: brain damage resulting from high blood pressure (hypertension).

**A2.56** By the next day, on 29 December, it was agreed that Elizabeth could not wait for test results to come in and that she should be transferred to GOSH for further investigations and treatment. At this stage she was experiencing sufficient episodes of cessation of breathing to cause concern. She was put on a ventilator at 4pm, well in advance of her transfer to GOSH.

**A2.57** A seven page referral letter was sent with Elizabeth to GOSH but – as was and remains common practice with paper records – her full medical record did not transfer. GOSH clinicians were therefore reliant on the contents of the referral letter which was written by one of the junior doctors. Clinical practice is to list problems in order of descending severity. Elizabeth’s letter mentioned seven problems: prematurity, mild respiratory distress syndrome, jaundice, bilateral adrenal masses, frequent apnoeas and bradycardias, hypotonia, and presumed sepsis. There is no mention of hypertension in the problem list, and the only reference in the letter is that Elizabeth has been “running high BPs...last 4 days” and a “tachycardia (fast heart rate) of 190-220/min”.<sup>4</sup> This ignored the two previous blood pressure readings that suggested that she had been hypertensive for at least ten days and probably more.

**A2.58** The main thrust of the briefing was that after prenatal scans showing areas of echogenicity (which were not explored) and suspicions of organomegaly in her abdomen, by 28 December masses were identified above the adrenal glands, which were expected to be some kind of tumour. It was noted that before a relatively uneventful emergency delivery on 14 December she had not been treated with dexamethasone for any extended time (which can be associated with cerebral palsy). Elizabeth was described as having had a fast recovery from RDS and jaundice, but had failed to thrive. She found it particularly difficult to tolerate feeds although there was no sign of NEC. She had started to lose muscle tone from about the third day and had developed bilateral hernias.

**A2.59** The referral letter also suggested ‘?? is this a picture of hyperadrenalism rather than sepsis. Could this be bilateral neonatal phaeochromocytoma’. There was no speculation about neuroblastoma, but although at this stage of Elizabeth’s course hypertension was already established, the discussion on the possible causes of the abdominal masses may have made the diagnosis of neuroblastoma the more prominent problem. This in turn may have affected how the blood pressure was subsequently managed at GOSH.

**A2.60** There was one last omission in the clinical records shared with us by Frimley Park Hospital. They do not record any reflection or response prompted by the eventual diagnosis of neuroblastoma. Certainly, there does not appear to have been any exploration or discussion of the postnatal abdominal ultrasound findings with the radiology service at Frimley. The value of joint clinical and radiological discussion is well illustrated in Elizabeth’s case and points to one of the potential limitations of not ensuring that opportunities are found for joint discussion.

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<sup>4</sup> Elizabeth Dixon clinical notes, Great Ormond Street Hospital.



# APPENDIX 3: ELIZABETH'S CARE AT GREAT ORMOND STREET HOSPITAL<sup>1</sup>

**A3.1** When Elizabeth arrived at Great Ormond Street Hospital (GOSH) on 29 January 2001 there was a clear understanding that she had masses in her abdomen, near to or arising from the adrenal glands and also potentially impinging on her abdominal aorta and at least one of her renal arteries. This was initially thought to be the result of congenital adrenal hyperplasia, a genetic metabolic disorder that causes overgrowth of the adrenal glands, and she was first seen by an endocrine specialist team. However, it was also recognised that this could be a tumour.

**A3.2** Elizabeth was moving her arms and legs, and opening and shutting her eyes, in a way that was considered to be normal for her age. She also did not show any evidence of fits or seizures. But she was hypotonic, mottled, was finding it hard to process feeds, and was also suffering occasional 'desaturations' – episodes where the oxygen level in her arterial blood fell – and episodes of either rapid heartbeat (tachycardia) or slow heartbeat (bradycardia). She was breathing without assistance again, following being ventilated for transfer from Frimley Park Hospital (FPH).

**A3.3** It is now clear that Elizabeth had begun to demonstrate signs of brain damage. This had first been seen by hospital staff and her parents and hospital staff around four days after her birth. Although unrecognised at the time, Elizabeth's blood pressure was extremely high, due to the secretion of catecholamines by her adrenal tumour. This was the cause of her brain damage, as was clear from the timing of its onset and the severity of the raised blood pressure.

**A3.4** On Elizabeth's arrival at GOSH, the medical records indicate that the clinical team's priorities were to reach a definitive diagnosis of the masses detected above her adrenal glands at FPH, to stabilise her intake of nutrients since she seemed very intolerant of feeds, and to address her hypertension – which had now at least been recognised – in a way that was safe and caused her no collateral damage. Only the first objective was met.

## Blood pressure control

**A3.5** Although it was third on the clinicians' list, the most pressing priority was to manage Elizabeth's raised blood pressure. When blood pressure is raised in a baby, the small arteries that supply blood to the brain constrict to protect against the effects, but they are less effective at doing this than in older children and adults, and the brain will suffer damage. It is clear that this process began while Elizabeth's hypertension went unrecognised in FPH. Crucially, however, when the blood pressure is reduced in a hypertensive baby, those blood vessels take longer to dilate again than in an adult. If blood pressure is reduced rapidly, blood flow will fall to levels insufficient to supply the brain adequately, and catastrophic cerebral damage may quickly occur. To prevent this scenario, established guidance then and now is to bring the blood pressure down in stages under

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<sup>1</sup> Unless otherwise stated, information is from Great Ormond Street Hospital records.

careful control over the course of several days, using intravenous treatment that can be stopped quickly if the blood pressure falls too fast at any point.

**A3.6** Records of the attempts to control Elizabeth's hypertension following transfer to GOSH show significant deficiencies. However, there is nothing in the medical records that suggest that they were regarded as problematic, and Elizabeth's parents were not aware that there was any reason to be concerned about their potential effect on Elizabeth's neurological state or potential for development. There is no record that the possibility of hypertensive encephalopathy was considered at GOSH before decisions were taken about how to control Elizabeth's blood pressure, and it seems that clinicians there thought that she had shown signs of brain damage from birth whereas her hypertension had begun only a few days before. Both of these assumptions were incorrect.

**A3.7** When Elizabeth arrived at GOSH, her blood pressure had already fallen, probably as a result of the morphine administered to sedate her while travelling, but it soon rose again. A decision was taken to bring Elizabeth's blood pressure down, but this was done rapidly, in fact over the course of a few hours rather than a few days, using nifedipine, which is a medication which was administered orally so its effects could not easily be reversed. It is not possible to ascertain from the records exactly how this clinical plan came about. It is possible that the wrong instructions were given on how to control the blood pressure, or that the instructions were ineffectively communicated and misunderstood. What is clear is that an oral agent was prescribed in contravention of the guidance, and the blood pressure was reduced precipitately, so either there was a lack of knowledge of the guidance or a conscious decision was taken to operate outside it.

**A3.8** The result was a rapid fall in blood pressure to a much lower level over Elizabeth's first afternoon in GOSH. This degree of reduction in her blood pressure over a short period was certainly sufficient to cause a significant degree of encephalopathy, and it would be surprising if it did not do so.<sup>2</sup> In fact, further deterioration in her neurological state was seen both by parents and by clinicians over the next few days that would be compatible with further damage of this origin.

**A3.9** We cannot absolutely exclude the possibility that another cause or causes might have contributed to Elizabeth's severe brain damage,<sup>3</sup> and the outcome had her blood pressure been properly managed in FPH and GOSH cannot be known with complete certainty. It is, however, entirely possible that her brain would have developed normally and that her neuroblastoma would have regressed as it was expected to do, and she would then have had a normal life.

**A3.10** Elizabeth's blood pressure was subsequently managed less aggressively, using intravenous labetalol, a beta blocker in any case better suited to managing hypertension related to excess catecholamines. However, it was never maintained consistently at an acceptable level, and she continued to suffer sporadic periods of hypertension. On one occasion another type of beta blocker, propranolol, was used, and she suffered a low-output cardiac arrest the next day, 25 February 2001, almost certainly associated with the suppressive action of propranolol on the heart.

**A3.11** The failures to manage Elizabeth's hypertension properly should have been recognised at the time and disclosed frankly to her parents, but they were not. In contrast, staff did admit promptly after her low output cardiac arrest in February that there had been a misjudgement

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<sup>2</sup> In compiling this assessment of the management of Elizabeth's hypertension, we have drawn extensively on reports prepared by Dr Malcolm Coulthard, a paediatric nephrologist and expert on hypertension in children. We are grateful for his cooperation and access to the reports.

<sup>3</sup> Confirmatory signs of either posterior reversible encephalopathy syndrome or generalised cerebral ischaemia were not found on a subsequent MRI scan, but it is notable that the type of MRI scan that would be expected to show these signs was either not done or was missing from the records.



the previous day in making a change to her medication. We found the lack of curiosity by clinicians, and openness with her parents, over the failures of hypertension management extremely disappointing, and they contributed significantly to the unnecessary distress suffered by Elizabeth's parents.

## Diagnosis of the abdominal masses

**A3.12** The masses in Elizabeth's abdomen were initially thought most likely to be enlarged adrenal glands as a result of congenital adrenal hyperplasia. This was reasonable in view of their location and involvement of both adrenal glands. Abdominal scans after admission, however, showed appearances more suggestive of tumour, and tissue samples taken from the masses under general anaesthetic confirmed the presence of neuroblastoma. Elizabeth's genetic constitution made her more vulnerable to the development of this condition, an uncommon but well-recognised tumour arising from neural crest tissue (embryonic cells which give rise to parts of the nervous system and adrenal glands).

**A3.13** Elizabeth's neuroblastoma was unusual in involving both adrenal glands, but in every respect – stage, onset before birth, genetic constitution and the cellular characteristics of the tumour – it was of a type that carried a very favourable outlook. It was unlikely to become progressive, but on the contrary would regress either spontaneously or with the help of chemotherapy and perhaps surgery to reduce tumour bulk. The oncologist caring for Elizabeth considered that provided the complications of her neuroblastoma could be successfully managed her life would be unaffected in the longer term, and remains of that view<sup>4</sup>.

**A3.14** There were two principal complications of the tumour that required to be successfully managed. First, neuroblastoma may commonly cause raised blood pressure, because the tumour secretes catecholamines, hormones that affect the cardiovascular system. Second, the masses occupy space in the abdomen, which can carry significant consequences for respiration and feeding, particularly in a small baby such as Elizabeth.

**A3.15** Clinical assessment by the GOSH team suggested that the most significant problems for Elizabeth were due to pressure on other organs by the tumour masses, causing feeding and breathing difficulties. Whilst this is a reasonable supposition, it is clear that insufficient attention was given initially to the vascular effects of catecholamine secretion by the tumour, evident in the persistent high blood pressure, rapid heart rate and skin mottling. In addition, both catecholamines and gastro-intestinal hormones often produced by neuroblastoma may affect intestinal function.

**A3.16** As a result of concern over the effects of tumour bulk within Elizabeth's abdomen, it was decided that 'watch and wait' was not appropriate in Elizabeth's case. Instead her parents were advised that despite her size and age (she had still not reached full term in terms of age corrected for prematurity), some courses of mild chemotherapy should be administered. This was intended to reduce both tumour bulk and hormone secretion, and accelerate the expected regression of the neuroblastoma.

**A3.17** The chemotherapy she received was not considered likely to leave her with lasting complications, although it exposed her to risk from infection and uncomfortable side effects including nausea and diarrhoea in the shorter term. With some reluctance, since they did not want Elizabeth to suffer further discomfort or harm, her parents consented to the chemotherapy.

**A3.18** As documented in her clinical records, the chemotherapy was effective in reducing the size of the neuroblastoma masses, the objective of the treatment, although as expected the tumour tissue did not yet disappear entirely. Given her other continuing problems with feeding and

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<sup>4</sup> Dr Peppy Brock Interview – 3 December 2018.

respiration a surgical intervention to reduce the residual tumour was considered. This would have carried additional risk to the functioning of her adrenal glands, because both had been involved with the tumour, but was in any case abandoned in June 2001 when the full extent of Elizabeth's neurological problems was discussed with her parents.

## Toleration of feeds

**A3.19** Elizabeth had been tolerating feeds poorly since her delivery, with regular abdominal distension, flatus and diarrhoea. Her failure to tolerate feeds well had underpinned suspicions at FPH that she was suffering necrotising enterocolitis, a severe bowel infection that preterm babies are prone to but which Elizabeth did not develop. As a preterm baby her digestive tract was developed if not fully mature, but she would not have been expected to have a successful suck reflex at 31 weeks gestation. In the event she never developed a successful suck or swallow, probably related to the cerebral damage that subsequently became evident.

**A3.20** A review of Elizabeth's problems by endocrinologists on her arrival suggests that her failure to take nutrition successfully was seen as her biggest problem at that time, listing her problems as 1) low birthweight for age at 25th centile 2) failure to tolerate oral feeds 3) abdominal distension (worse after feeds) 4) hypertensive 5) bilateral adrenal masses 6) tachycardic 7) respiratory distress 8) jaundiced 9) hypotonic 10) presumed episodes of sepsis. This is an accurate, if daunting, list of problems with the exception of sepsis (although Elizabeth later developed a recurring series of hospital acquired infections).

**A3.21** There were three potential causes of Elizabeth's poor toleration of feeds. First, the mechanical effect of the tumour masses would have compressed abdominal organs including the stomach and bowel. Second, hormones secreted by the neuroblastoma, including catecholamines and gut hormones, would affect her digestive functions. Third, the neurological problems that were becoming evidently severe would lower abdominal muscle tone, reducing bowel motility.

**A3.22** But the immediate decision was to at least exclude the possibility that she had some kind of colonic obstruction. Elizabeth had a barium enema on 31 December 2000, which confirmed that she had no obstruction and that her bowel appeared generally normal although the end of her small bowel was positioned within her large right-sided inguinal hernia. She had a surgical repair of both hernias on 25 February, but her feeding difficulties persisted, as recorded by detailed records of what she was fed and her continuing poor toleration of feeds and intermittently tense or distended abdomen.

**A3.23** It seems from the clinical records that GOSH clinicians considered that the most effective response was to reduce the tumour bulk. This seems a reasonable supposition, as it would be expected to decrease both the mechanical effects of the tumour bulk and its secretion of hormones potentially affecting the digestive system (and causing hypertension). Following chemotherapy, which would probably itself cause further bowel dysfunction, her bowel problems continued to wax and wane, sometimes associated with feeding. She had an endoscopy and colonoscopy on 26 June 2001 that showed no abnormality. After those tests, she continued to have frequent episodes of feeding difficulties and abdominal distension.

**A3.24** Given the importance first ascribed to this issue, it may be surprising that there was not more concern evident in the clinical records over this aspect of her difficulties. It seems likely that this received decreasing attention relative to the growing realisation of the significance of her neurological condition. There was no evident consideration of the interrelationship between these two aspects of Elizabeth's condition. Additionally, the usual response to poor toleration of feeds was to withdraw the feeds until Elizabeth appeared more comfortable. Given that Elizabeth was

born preterm and would have little energy reserve, this could have reduced her resilience, and it is disappointing that there was no recorded discussion about why this might have been necessary.

**A3.25** This clearly had an impact on the rate at which Elizabeth grew. She continued at or around her birthweight of 1.2-1.3 kg until at least the end of January 2001, and she was slow to put on weight thereafter. Apart from a brief period of total parenteral nutrition, she was given energy-dense, milk-based feeds through a nasal tube into her stomach or upper bowel, sometimes with added breast milk that her mother worked hard to sustain for many months to improve Elizabeth's recovery.

**A3.26** In July 2001, Elizabeth was put on continuous feeds by nasal tube, despite the accompanying discomfort and reactive symptoms (feeds tended to prompt episodes of oxygen desaturation). This was successful in making her gain weight more rapidly, although she remained small for her age throughout her life.

## Elizabeth's longer term outlook

**A3.27** The evidence we have seen suggests that Elizabeth's parents were some weeks in advance of her clinicians in reaching the view that Elizabeth could not recover to an outcome which did not include significant disability, to the point that she had no quality of life. They came to the view that although they did not want her to be deprived of air, food, water, basic care and pain relief, further aggressive interventions were doing nothing but increase her discomfort and should stop. This is not surprising: they spent most time with Elizabeth, without being distracted by other patients or families, or the need to undertake other administrative tasks such as record keeping. Family members not uncommonly point out things to the clinical team that may not have been recognised otherwise, at least until later.

**A3.28** Elizabeth's general condition had deteriorated further in January 2001, and was not improved by her chemotherapy, although it reduced the tumour size. This is indicative that her principal problem was not the neuroblastoma, but the brain damage related to hypertension. She had several crises due to reduced oxygen levels, tachycardias or episodes of involuntary movement. These were presented to her parents as unexplained, until they were told about an area of brain damage. By February, Elizabeth's blood pressure was not well controlled and she was struggling with repeated respiratory crises in respiration requiring her to be ventilated, and a single episode of low-output cardiac arrest after a significant change to her medications.

**A3.29** The low-output cardiac arrest in February 2001 was the only event for which there was a clear explanation, but it was also the most serious. This is a condition in which the heart muscle is acting so ineffectively that there is no blood circulation, but distinct from the better-known cardiac arrest with very disordered electrical activity in the heart. Although the condition was reversed and a good cardiac output was recovered, it took several minutes to resuscitate Elizabeth fully and there was concern that the episode could have caused further neurological damage. The origin of this episode clearly lay in the combination of medication used to control hypertension, and once corrected she had no further recurrence of the problem.

**A3.30** Based on comments in the medical records, it seems that some clinical professionals at GOSH were disconcerted by what they saw as undue questioning by Elizabeth's parents over all aspects of her care, and there were inappropriate comments recorded in the clinical notes about their response and the interaction between Elizabeth's parents and staff members. In the years following Elizabeth's death, changes were introduced at GOSH to ensure a better focus across the hospital on the needs of parents who had to consider issues relating to end of life decisions, and on the ethical issues that might affect such decisions. More nursing and administrative staff were assigned to liaison work with parents, to ensure concerns could be raised in a neutral environment,

and a new patient safety team could become directly involved in managing conflicts, including applications to the Court of Protection where agreement could not be reached.

**A3.31** We considered whether those involved with Elizabeth would have had a different experience if those resources had been available at the time. Although it seems to us likely that some of the difficult interpersonal problems could have been avoided, it seems equally likely that there would still have been disagreement. Considerable uncertainty remained over whether Elizabeth's neurological state was permanent or whether at least some degree of resolution could be expected in view of her age. Its cause remained unclear to GOSH clinicians, and there seems to have been significant reluctance to acknowledge the role of hypertensive damage. In infants this young, when uncertainty remains over the origin of brain damage, a policy of watchful waiting seems appropriate; the question is for how long this should reasonably be maintained before accepting that damage is irreversible.

**A3.32** What might have assisted in resolving differences was an earlier recognition of the need to get a broader range of clinical opinion. More emphasis is now laid on the need for wider input, particularly when this can help put things in the perspective of the family. Families facing circumstances such as this often seek information avidly from many different sources, including parent support as well as whichever clinicians they can engage, and Elizabeth's parents were no exception. They doubted that her level of consciousness was sufficiently and consistently low to make her unaware of pain or other symptoms, and they doubted that her condition would improve spontaneously with time.

**A3.33** During this time, Elizabeth's mother was a constant presence on the ward, and it does appear from the documentary evidence that consultants felt they had lost control of their message. Dr Petros told Elizabeth's parents that they must stop asking questions of other staff. Viewed from their perspective, and given that the predictions of consultants had previously proved to be wrong, the Dixons had ample cause for concern and confusion.

**A3.34** From this perspective, their view as recorded in the clinical notes that they considered that the further interventions proposed to minimise the impact of the neuroblastoma would risk her remaining life and comfort for doubtful benefit is understandable and reasonable. They expressed the view that they did not fear having a disabled child who was well, but they thought that a child who was perpetually ill, in pain and struggling to breathe would have no quality of life and no prospect of recovery. They wanted the option of 'giving up' to be discussed; but at that stage the response was that this was a conversation that they had no grounds for, and no right to insist on.

**A3.35** Elizabeth was born sufficiently preterm that by March 2001 she had only recently passed her original due date, and there were no clear milestones against which her neurological development could be assessed. It is clear from the records that the clinical team at GOSH thought that while her lack of development was concerning, it was simply too early to tell if it was more than a temporary delay resulting from the pressure imposed by her neuroblastoma and the treatment for it, and the as yet unexplained neurological problems that beset her since her admission.

**A3.36** So instead of finding that the clinicians agreed with their significant concerns and were willing to discuss some kind of withdrawal of the aggressive interventions found necessary to keep Elizabeth alive, the family met resistance. Symptoms that troubled them were explained away, in a manner which failed to reassure them given what they saw as signs that Elizabeth was experiencing increased distress.

**A3.37** By the first week in March Elizabeth's neuroblastoma was considered to be reacting well to the chemotherapy she had received, but GOSH clinicians were pessimistic about weaning Elizabeth from ventilation. They concluded she had tracheobronchomalacia, a condition characterised by softening of the cartilage of the upper airways, allowing the affected part of the

airway to collapse partially and impede air flow, although it is unusual to see this spontaneously and progressively develop two months after delivery. They advised that a tracheostomy would solve some of her problems, and would be temporary.

**A3.38** By this time, Elizabeth was developing abnormal movements, and her episodes of apnoea and 'spontaneous' reduced blood oxygen levels were becoming more frequent. The neurology team concluded that she was suffering epileptic fits and treated her symptoms accordingly, with phenobarbitone.<sup>5</sup> Although her electroencephalogram (EEG)<sup>6</sup> tests did not show findings suggesting epilepsy, this was a reasonable approach given that EEG findings do not always match clinical findings in small babies.

**A3.39** On 11 March 2001 Elizabeth's parents had their first formally recorded conversation with clinicians about the undeniably difficult issue of her future. They were reassured on every front that Elizabeth was likely to get over her problems; and told that decisions on how actively to treat their daughter were not theirs to make. Meanwhile, Elizabeth's episodes of low blood oxygen and 'fits' increased: she was having crises or displaying abnormal symptoms in nearly every hourly observation.

**A3.40** ENT specialists were not sure a tracheostomy was in Elizabeth's best interests, and their first investigation did not confirm tracheobronchomalacia, but the paediatric intensivists recorded their belief that this could make a difference to Elizabeth's symptoms. Elizabeth's parents were persuaded to give consent to a tracheostomy on 20 March 2001, in the belief that this was a temporary measure designed to support Elizabeth for a month or so until her airways matured. For the first time, however, the clinical team agreed that in the event of another cardiac episode they should not attempt anything other than a short intervention 'because of the additional risk of neurological damage.'

**A3.41** By this time Elizabeth's parents had sat by her cot for four months, and in their opinion she had deteriorated, rather than improved. She also seemed to them less engaged with the world and more often distressed. The clinical notes confirm their questioning whether continuing aggressive interventions to deal with her problems was in her best interests.

**A3.42** By 1 March 2001, Elizabeth's mother had asked to see her admitting consultant Dr Petros, wanting to ask about the first days of Elizabeth's care in an attempt to pinpoint whether there was anything there that needed to be taken into account. He recorded she was "exhibiting strong signs of delusion, confusion and self-doubt... she might benefit from seeing a psychiatrist". Although Elizabeth's mother was recorded as anxious and, unsurprisingly, distressed, there is no evidence that she was either delusional or confused. There is no evidence that Dr Petros reviewed the medical records to see if anything had been missed or errors made; the mismanagement of Elizabeth's blood pressure on arrival at GOSH would have been evident if he had.

## Was the clinical approach reasonable?

**A3.43** We have looked carefully at the evidence to see if and when any clinical doubts were expressed about Elizabeth's potential to recover. For the first three months there were few. The approach in the intensive care unit was based on an expectation of Elizabeth's recovery, and treatment was directed towards speeding it. The neuroblastoma was expected to regress spontaneously, perhaps with some chemotherapy to accelerate it; reduction of the tumour bulk in her abdomen was expected to improve her breathing, with assistance from a temporary

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<sup>5</sup> An anticonvulsant drug now known as phenobarbital.

<sup>6</sup> Electroencephalogram: an external recording of electrical activity originating in the brain that can identify changes consistent with epilepsy, among other things.



tracheostomy when the breathing problems turned out to be more stubborn. Neither the extent of the neurological damage nor its irreversible nature was appreciated until later.

**A3.44** Faced with parents who were understandably less optimistic about Elizabeth's recovery in light of all that had happened since her birth, GOSH clinicians recorded in the clinical notes their concern and frustration at being asked repeatedly what they were doing to help or diagnose Elizabeth and why. Some clinicians were more understanding, recognising that Elizabeth's parents were facing an extremely difficult and distressing situation, but that should have been the rule and it was not always.

**A3.45** These discussions were particularly focused around the treatment of Elizabeth's tracheobronchomalacia, and the recommendation by clinicians that she would be best having a tracheostomy to assist with positive pressure ventilation. It is clear from the records that this was seen as a temporary measure, as it was likely to be had Elizabeth's neurological state improved in the future, but there was no evidence of consideration that it may prove irreversible. When it did prove irreversible, Elizabeth was left with a permanent tracheostomy and the need for continuous nursing, and these problems came to dominate her care for the remainder of her life.

**A3.46** Hindsight is problematic but having examined medical and nursing records closely, we believe it would have been reasonable for the clinicians in charge of Elizabeth's care to have considered earlier whether they were being over-optimistic. Elizabeth's condition rarely gave any ground for optimism with the exception of her neuroblastoma, which was regressing as expected, yet despite her clear signs of decline otherwise the advice for week after week was to watch and wait. The content of the medical records over this period suggests that staff were struggling to understand why Elizabeth was not improving in response to the interventions given.

## NICU after the tracheotomy

**A3.47** From May onwards, the records record a deteriorating relationship between NICU staff and Elizabeth's parents, in part due to their perception that the reactions of staff towards Elizabeth's condition were inconsistent. In turn, the records show staff seeing Elizabeth's parents as argumentative, and impatient in their unwillingness to accept reassurances without understanding the underlying evidence.

**A3.48** It is clear from the records that there were grounds for concern. Many different specialists had become involved in different aspects of Elizabeth's care, including intensivists, oncologists, neurologists, ENT surgeons, paediatric nurses and others, and as a result advice was not always consistent. They might be told that Elizabeth was showing improvement by one clinician when it was clear that from the perspective of another in a different specialty that she continued to have real challenges. This inconsistency is clear in the clinical notes.

**A3.49** A stronger approach to multidisciplinary team working than was evident would not only have reduced this inconsistency, it would have reduced the risk that decisions taken by one team without full discussion with other specialist areas would prove unhelpful in the long run. The records we have seen of the meetings between professionals record a series of reports of tests to the NICU team, rather than multidisciplinary discussions reviewing Elizabeth's overall condition and outlook in light of the several problems she had. These were distinct but interrelated, and they all played a part in determining her prospects, but they were too often considered separately, and therefore in isolation.

## Subsequent progress in GOSH

**A3.50** By June 2001, Elizabeth's neuroblastoma was regressing well, and her blood pressure, while variable, was generally within fairly safe limits. Examination of her trachea had also suggested that her presumed tracheobronchomalacia had improved.

**A3.51** Her breathing was still a problem, however, and it was thought that perhaps residual neuroblastoma in her abdomen may be interfering with the ability of her lungs to expand fully. She was still dependent on a tracheostomy, which was difficult to maintain because of her small size, despite the improvement in her tracheobronchomalacia. As a result, she remained at risk from chest infection, and from the build-up of secretions that could trigger episodes of breathing difficulty, potentially incubate pathogenic bacteria, and threaten to block the tracheostomy. The episodic cessation of breathing and shortages of oxygen continued, although they had been the original reason for the tracheostomy.

**A3.52** Elizabeth's digestive system also continued to be affected. She had regular abdominal distension and diarrhoea, during which she showed signs of discomfort. The most probable cause was the production of hormones by the neuroblastoma, which can also affect the bowel.

**A3.53** The most significant contributor to Elizabeth's condition was the neurological damage, which it was increasingly clear was the principal cause of her breathing difficulties. By May 2001 it seemed that Elizabeth's neurological development had not just stalled, but was regressing: her visual problems focusing and tracking movement were worse, her eyes were no longer coordinated, and she was jittery or twitchy in response to stimuli. Her skull size was not increasing as it should if her brain was developing normally.

**A3.54** The consultants in charge of Elizabeth's care in NICU had been very reluctant to decide that Elizabeth's developmental delay was irrecoverable. In the absence of clear evidence of a fundamental brain malformation or lesion that could explain her condition, the lead neurologist, Dr Lucinda Carr and the lead NICU consultant, Dr Petros, clearly chose a conservative approach. Dr Carr in particular maintained a strict adherence to the protocol that development cannot be assessed accurately before the infant reaches the three-month milestone.

**A3.55** Elizabeth had a brain scan in February 2001 after she suffered the low output cardiac arrest attributable to changes to her hypertension medication, but despite an increase in abnormal movements being noted after the arrest, tests were considered to show no evidence of additional damage and her parents were reassured that there should be no ill effects. Despite this, throughout April and May 2001 Elizabeth continued to experience an increased number of episodes of abnormal movements in her limbs and her eyes. There were no clear EEG changes to explain these, although it was assumed at the time that they might be epileptic in nature. In retrospect, it is probable that they were due to the severity of neurological damage and the areas of the brain affected.

**A3.56** At the time, however – and for several weeks after – GOSH consultants simply hoped that Elizabeth would outgrow problems that might relate to how unwell her preterm delivery and the neuroblastoma and its treatment had been making her. From 19 March 2001 onward, however, oncologist Dr Brock was clear that she did not regard the neuroblastoma as Elizabeth's 'key problem'.

**A3.57** The hypothesis that Elizabeth had been made ill by the cancer treatment she had received strictly qualifies as a suspicion of what is called iatrogenic damage, or damage caused by a medical intervention. While there is evidence that this possibility was considered, we believe it unfortunate that chemotherapy was the only potential cause explored, given all the interventions that Elizabeth had received. There is no evidence of any fundamental multidisciplinary review of



Elizabeth's records that should have identified the mistakes in treating her hypertension and their potential to cause her neurological damage.

**A3.58** In May 2001, there was a proposal for surgery to remove the residual neuroblastoma, which was still thought to be impeding her breathing. Because of the tumour's origin from both adrenal glands, there was a significant risk that she would be left with no adrenal cortical function as a result.<sup>7</sup> The recommendation for this surgery was presented to Elizabeth's parents as agreed by a range of clinicians to reduce her episodes of reduced oxygen and abdominal discomfort, and their consent was asked for without prior involvement in those discussions.

**A3.59** Since it is now clear that Elizabeth's overall condition was much more closely related to her neurological condition, in retrospect it is as well that the surgery was not consented to and not attempted. But at the time, the disagreement between parents and clinicians remained difficult, and jeopardised trust.

**A3.60** By the end of May 2001, Elizabeth's parents had asked for formal meetings to discuss the recommended operation, and once their concerns had been heard by oncology, neurology and NICU clinicians – although without the endocrinologists or ENT specialists being present – it was agreed that second opinions should be arranged about Elizabeth's developmental delay. By now Elizabeth had reached an age where her interactions with her environment could be judged against the expected behaviour of full-term babies at three months, which the neurological clinicians at GOSH had set as a significant milestone.

**A3.61** In early June 2001, reviews of Elizabeth's neurological condition were undertaken at the invitation of GOSH neurologist Dr Carr by two paediatric neurologists new to her case: on 4 June 2001 by Dr Carlos de Sousa of GOSH (who had previously not been involved in Elizabeth's care) and on 13 June 2001 by Professor Richard Robinson of Guy's and St Thomas' Hospitals. Both concluded independently that Elizabeth was suffering from serious neurological developmental problems that carried no realistic prospect of recovery and speculated about potential causes without considering iatrogenic damage.

**A3.62** Professor Robinson's report was detailed and specific. He commented that the longer Elizabeth's lack of development continued the more severe her learning difficulties were likely to be, and that she would probably have a 'relatively limited' life expectancy. The only comfort he could offer was the assessment that her condition was not an intrinsically deteriorating one, and that her lack of development would not cause her distress. The implication was that Elizabeth would never be aware of her condition, and Elizabeth's subsequent course confirmed this, given that she made no significant progress in developing new skills before she died.

**A3.63** The opinions given by Dr de Sousa and Professor Robinson removed any remaining optimism about anything other than the future resolution of Elizabeth's neuroblastoma. It also confirmed that Elizabeth's parents had been correct in coming to the conclusion some months previously that her neurological condition was not resolving and would be permanent.

**A3.64** Unfortunately, there was little recovery in relationships between the parents and the NICU consultants. Some of the causes are clear, at least in retrospect. Elizabeth's parents held the view that the NICU clinicians failed to ensure they conferred with specialist colleagues to the extent that there was full consideration of Elizabeth's condition in the round (and it is clear from the medical records that there was justification for this). It also seems clear that for some specialists Elizabeth's mother became regarded as a 'problem mother' when she asked questions, because

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<sup>7</sup> The adrenal cortex is distinct from the central part of the gland from which the neuroblastoma had arisen; the corticosteroid hormones it secretes are important in regulating electrolyte balance and glucose metabolism, and deficiency is a serious condition.

her questions could not be dealt with quickly. Although this is understandable, and clinicians may struggle to deal with questions they cannot answer being put to them repeatedly, it is important that they find a way to deal with it sympathetically, even when – especially when – the situation is complicated by a marked degree of parental anxiety.

## The shift to maintenance care

**A3.65** Following the clinical opinions from Dr de Sousa and Professor Robinson that Elizabeth could not be expected to develop neurologically to any significant extent, there was a marked shift in the views of all of Elizabeth's clinicians at GOSH about what support she now needed. The effect of the neurological prognosis was fundamental: planning and effort moved from interventions intended to keep Elizabeth alive long enough to give her biological development the best chance of a spontaneous recovery, to interventions designed to enable her discharge from the hospital and to continue her life elsewhere.

**A3.66** Elizabeth's neuroblastoma was still regressing, and was expected to resolve spontaneously. It was now considered, however, that her neurological problems would not recover. Dr de Sousa's long-term neurological prognosis was that she would have moderate to severe disability; Professor Robinson's forecast was that her lifespan was likely to be limited even though Elizabeth's condition was 'not an intrinsically deteriorating one'. He advised that children who made little or no progress as a new born baby and had temperature instability often had a relatively limited outlook. Because of her lack of neurological development, he thought she was not capable of being actively distressed by her condition and was not likely to become so. This judgement is reasonable: throughout the course of our investigation we found no evidence that Elizabeth ever developed more awareness than could be expected of a newborn baby.

**A3.67** Given these new parameters for planning there was sustained discussion with Elizabeth's parents about what treatments were both appropriate and ethical. It was now agreed by the clinical team that Elizabeth's comfort and quality of life should be the priority going forward, and that her circumstances no longer warranted further invasive treatments of her neuroblastoma aimed at reducing its effect pending spontaneous resolution, including the surgery that may have left her with no adrenal function. In addition, it was agreed that everyone caring for her would avoid an interventionist approach to cardiac resuscitation; Elizabeth's parents were clear, however, that they did not want any future airway obstruction to be left unrelieved, having witnessed her struggling to breathe without her tracheostomy. The aim of treatment from then on was to minimise the impact of her symptoms and the nursing interventions she required.

**A3.68** While moving to symptom control rather than cure is rightly described as palliative care,<sup>8</sup> this should not be taken as implying that Elizabeth was considered to be at the end of her life or even that it was thought she might make no further progress at all. Certainly, she was no longer considered capable of attaining 'normal' good physical health. The main problems that continued to affect her – temperature instability, breathing and feeding difficulties – were now considered permanent risks to her quality of life, although she had proved sufficiently robust to survive their effects for some time. The most significant problem appeared to be the recurrent episodes of respiratory cessation, but although alarming they continued to resolve quickly.

**A3.69** It was assumed that she would probably not live into adulthood because of the greater risks she ran of infection, her continual problems with desaturations, and the difficulty of giving her adequate nutrition. But at this time, Elizabeth's survival beyond infancy was presented to

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<sup>8</sup> The term 'palliative care' was previously used for what is now 'end of life care', that is care given over the final stages of life where death is expected at any time; we would rather avoid the potential confusion but unfortunately many of those commenting at the time and afterwards have confused the two, and taken them as synonymous. They are not.

her parents as the most likely scenario. She could not be regarded in any sense as having a terminal condition. Her considerable resilience in the face of desaturations, apnoea, poor digestion and infections suggested that with reasonable care and in the absence of any progressive life-shortening complications, her expected lifespan could be measured in years.

**A3.70** In light of decisions taken about the organisation of Elizabeth's care after she was discharged from GOSH, this was an important conclusion. On the day she was discharged, her parents were told by Dr de Sousa, the consultant then in charge of her care at GOSH, that if she did not succumb to severe respiratory illness she might live for several years. This was in some respects a concern, because in previous discussions he had confirmed that he also thought it probable that she would always be unwell, not just disabled.

**A3.71** From the point of diagnosis of her developmental delay in July 2001, all clinical plans made by GOSH for Elizabeth assumed that other health providers should now take over primary responsibility for her care. Her need for complex support had not changed, but once the focus of care shifted from curative to maintenance treatment, as the records make clear, she was no longer considered a suitable patient for GOSH. The new priorities were to identify where she could be discharged to and how transfer could be facilitated. At first, helping the family find some sort of 'normality' by looking after Elizabeth at home was not discussed. The initial assumption was that, as a very small baby with a tracheostomy, Elizabeth certainly could not go home. She continued to be at high risk of infection or suffocation if she did not receive expert care.

**A3.72** The first sign of this shift in focus was in July 2001 when NICU at GOSH were contacted by the symptom control team to discuss the practicalities of moving Elizabeth out of intensive care. This was not because her condition had improved. At that point Elizabeth was as poorly as she had ever been, and still needed a high level of care, particularly the nursing skills to manage her tracheostomy safely and effectively. But despite her fragility, once it was agreed that no further surgical procedures would be planned and that significant recovery would not take place, intensive care was not considered an appropriate environment.

**A3.73** The result of the decision was an immediate focus in NICU on efforts to 'wean' her off interventions that needed specialist care and equipment and would leave her at risk of failures in both. Elizabeth's parents also asked if she could be moved to another ward. Dr de Sousa was the consultant responsible for children with long term neurological conditions. He agreed to Elizabeth's move to his care on Churchill Ward, on condition that that her tracheostomy would be reversed and a plan for discharge would be put in place before the internal transfer was made.

**A3.74** Respiratory obstructions and infection from reliance on the tracheostomy were still the most significant problems Elizabeth potentially faced, and the most likely to shorten her life. A tracheostomy had implications for a continuing dependence on specialist nurses, who were hard to find outside the main tertiary centres. By its nature, the narrow tracheostomy tube that was required in a baby as small as Elizabeth was prone to blockage with secretions, and her underpowered infant lungs and the disordered nature of her respiration due to her brain injury meant that problems occurred particularly frequently.

**A3.75** The NICU team agreed that there should now be a sustained effort to reverse the tracheostomy, both to improve her quality of life and to make it easier to secure her discharge from GOSH. Reversing the tracheostomy would improve Elizabeth's comfort, reduce her risks of blockage or infection and make her easier to care for as she grew. It was not expected to be difficult: the original justification used to support the tracheostomy operation was that Elizabeth had a degree of tracheobronchomalacia, and this was no longer considered to be significant. The clinical team sought to reduce her reliance on her tracheostomy by reducing the use of ventilation and CPAP, and decided that they should attempt to find alternatives to the use of therapeutic oxygen when she suffered episodes of hypoxia and breathing cessation.

**A3.76** Unfortunately, this reduction in support proved not to be possible. Although Elizabeth's reliance on ventilation was successfully reduced for a short while, the attempts to further reduce her dependence on the tracheostomy failed. Although the records show no definitive diagnosis of why this was, in retrospect it seems most likely that her neurological damage and resulting reduced respiratory drive were crucial in the failure to adapt to managing the increased airway resistance without the tracheostomy. Without supplemental oxygen at regular intervals she struggled. Because of her size and a supply problem with small enough fittings the respiratory team had continually struggled to fit her tracheostomy with what is now called 'a Swedish nose' through which air can be warmed and humidified. When she did wear it her oxygen shortages seemed to increase: on the other hand not wearing a Swedish nose and receiving the regular administration of oxygen reduced air temperature and humidity.

**A3.77** The attempts in NICU to reduce her dependence on CPAP,<sup>9</sup> as a precursor for reversing the tracheostomy, coincided with – or perhaps prompted – a crisis caused by a chest infection that made Elizabeth very ill. This chest infection was the first thorough test of interpretation of Elizabeth's new 'do not attempt resuscitation' order and care plan, which had only recently been agreed. The resulting dissent and renewed discussion offer an illustration of why such plans can be problematic. Discussions were by their nature fraught, as is clear in the records, for both clinicians and parents, and tensions were never far from the surface. As of 4 July 2001, several weeks after the neurologists had confirmed the permanence of her neurological problems, references were being made to staff being 'concerned that we act in best interests of E and not her parents'.

**A3.78** Elizabeth's parents had been assured that although their daughter would always be at risk of losing her life there was a general expectation that with care, she might live a long time. Since they assumed that they would be able to ensure that she was looked after carefully, they concluded that they should plan for the long term but be clear about the circumstances in which 'nature should be allowed to take its course'. They longed to have the experience of having their daughter with them at home, and this was subsequently used by clinicians as justification for decisions about the circumstances of her discharge, but the records make clear that they did not want her home at any cost to her. Her level of vulnerability was described succinctly in the discussions that underpinned the agreement of her 'do not attempt resuscitation' order.

**A3.79** The decisions taken covered resuscitation but also maintenance care. Consensus was brokered over time between the GOSH NICU and symptom control teams and Elizabeth's parents, who had long maintained that it might be in Elizabeth's best interests to be allowed to die, as long as this was as part of a natural process. The resulting agreement was intended, as far as her parents were concerned, to allow a possibility for 'nature to take its course' without heroic interventions to prolong a life that looked intolerable, and without causing Elizabeth active discomfort. In practice, some elements had to be revisited and refined. From the clinicians' point of view, they needed to be sure that decisions were taken in Elizabeth's best interests and not for the sake of everyone else's convenience. From the parents' point of view, they wanted Elizabeth to be given the best chance of dying with comfort and dignity.

**A3.80** The GOSH medical notes clearly record the necessarily slow development of an agreed position on interventions and resuscitation. This had to balance her clinicians' concern for their ethical responsibilities, her parents' natural love and respect for the sanctity of Elizabeth's life, and the growing belief that it might be better for her to slip away peacefully.

**A3.81** As part of the care plan, Elizabeth's parents had agreed that in the event of a serious infection sufficient to endanger her life Elizabeth should not be given intravenous antibiotics. In all other respects they expected her to be given the support that the NHS would expect to give

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<sup>9</sup> Continuous positive airway pressure: a method of increasing the efficiency of respiration and blood oxygenation.

a 'normal' infant, including care of her tracheostomy site and treatments designed to support her airway.

**A3.82** The chest infection in NICU in late July 2001 prompted further discussion, because Elizabeth's parents had arrived at the hospital to find her being given intravenous antibiotics and also being ventilated, seemingly contrary to the care plan. It was explained to them that although Elizabeth had a serious and alarming-looking chest infection, it was not thought to have the potential to prompt a terminal decline. It was, however, considered that without intervention she was likely to have a more lengthy and uncomfortable recovery. At that point they agreed the interpretation of the care plan being followed by the clinical team.

**A3.83** These discussions were stressful for all concerned, as were the attempts to interpret the do not attempt resuscitation (DNAR)<sup>10</sup> order in situations like the one described. But it is clear from the records, as the DNAR order and care plan for Elizabeth developed, that when her parents understood the consequences of withholding certain types of care – such as oral antibiotics or maintenance of her airway – they always opted for the choices that would minimise discomfort or distress. If she were to die, they wanted her death to be peaceful. They remained adamant throughout Elizabeth's life that she had as much of a right to life and safe, humane care as any other child, and that this should drive the attitudes of the healthcare professionals to whom they entrusted her care: this has also driven their belief since her death that they were entitled to expect action to be taken if her rights were ignored.

**A3.84** It is worth noting that clinical teams often share these difficulties in interpretation of care plans, and these may not always be discussed with the family. In Elizabeth's case this is best shown by the references in her medical notes to antibiotics. It had been decided in principle in July 2001 to avoid the prescription of any antibiotics, and from this point on Elizabeth had not been given prophylactic antibiotics to prevent her from developing a urinary infection. But when she developed the chest infection in NICU it is clear that the nursing team had acted against the instruction that Elizabeth should be given no antibiotics and that no new intravenous access was needed. A few weeks after transfer to Churchill Ward, Elizabeth had a second major chest infection. Again, she survived: it turned out she had already started a course of oral antibiotics to try and improve her tracheostomy site and maximise the chance of a successful decannulation, and these were not discontinued.

## Churchill Ward

**A3.85** By the end of July 2001, when Elizabeth was considered to be recovering from her chest infection, it was agreed that she should move to Churchill Ward with her tracheostomy after all, and that the tracheostomy issue would be revisited by ENT specialists when Elizabeth became stronger. At the same time, consideration began of where she would best be cared for in future, as GOSH was an unsuitable environment for longer-term care once potentially curative interventions had been discounted (see Appendix 5).

**A3.86** Dr de Sousa agreed to accept Elizabeth's transfer to Churchill Ward, although neither of the original conditions he set had been met, because it was considered that she would benefit from being on a less intensive ward, and the ENT specialists thought their taking over the lead might improve her chances of being weaned from reliance on the tracheostomy. For her parents, the transfer out of NICU signified welcome movement if not actual progress.

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<sup>10</sup> A statement that cardiopulmonary resuscitation should not be attempted in the event of acute collapse, either as a result of the declared wishes of a patient who is able to decide and state their wishes, or made in accordance with a legal framework as being in their best interests if not.



**A3.87** Elizabeth was transferred from NICU to Churchill Ward on 29 July 2001, and remained there for another three months. The choice of a neurology ward was appropriate to the nature of Elizabeth's predominant problem, her lack of neurological development.

**A3.88** Elizabeth had begun to gain weight, and her physical condition started to improve as she recovered from the chest infection that had interrupted attempts to reduce her reliance on the tracheostomy. Her neuroblastoma seemed slightly larger, but her parents were reassured in early August that while it might still grow as she grew overall, it already had some parts in regression. Her notes recorded 'in the German experience where in some infants no treatment is given, growth can continue more than 1 year before spontaneous regression sets in.'

**A3.89** Elizabeth had transferred to Churchill Ward with a plan to reduce her reliance on respiratory support from CPAP and supplementary oxygen as the first stage of a determined attempt to reverse her tracheostomy, which by now she had been relying on for 5 months. It had originally been intended as a temporary intervention designed to help relieve her regular episodes of breathing cessation and reduction of blood oxygen until her physical development caught up with the demands being placed on it. Initially, it was thought that tracheobronchomalacia may have been contributing significantly to her respiratory problems, but by this time any upper airway weakness was considered to have resolved. She was, however, diagnosed with a condition of her larynx, partial arytenoid prolapse, which may have related to damage from mechanical ventilation in NICU.

**A3.90** Unfortunately, Elizabeth's episodic breathing cessation and reduction in blood oxygen had continued despite the tracheostomy. She had continued to need CPAP intermittently until she left NICU at the end of July. She also received supplementary oxygen regularly. In order to maximise the chance of a successful reversal of her tracheostomy, in July NICU clinical staff started trying to prolong the intervals before she was given either supplementary oxygen or CPAP to reverse an episode of absent breathing. They suctioned her tracheostomy tube more often, in the hope that she would adjust over time and her level of secretions would stabilise.

**A3.91** The respiratory nurse also tried again to fit her tracheostomy with a Swedish nose, the attachment designed to humidify the air the patient inhales with moisture trapped as they exhale. A Swedish nose is usually preferred to reliance on artificially humidified air, which is more complex to set up and may encourage chest secretions more than air humidified in more passive ways.

**A3.92** Unfortunately, Elizabeth's use of a Swedish nose was again intermittent. She was so small that the attachment did not really fit her and made her neck sore, and there were so few Swedish noses in stock in small sizes at GOSH that she often went without. When she was discharged, she was not wearing one, and after that it did not seem to be regarded as important by those who took over responsibility for her care. It was suggested that this may have been because the amount of secretions produced implied that her airways were damp enough without humidification, but there was no record of an active decision being taken to discontinue it.

**A3.93** If, on the other hand, Elizabeth's respiratory system was drier than it should have been, through the absence of humidification potentiated by the frequent use of added oxygen, this may have caused damage to the small airways, with consequent additional mucus secretions from the airways. In turn, this would increase her susceptibility to respiratory infection.

**A3.94** Although Elizabeth had no further CPAP or ventilation after leaving NICU, withdrawal of supplementary oxygen turned out to be problematic. Her longstanding respiratory problems were increasingly attributed to a reduced drive to breathe as result of neurological damage to the respiratory centres in her brain, and it is likely that at least part of her stimulus to breathe originated

from shortage of oxygen.<sup>11</sup> Under these circumstances, frequent use of oxygen supplementation can make reversal of a tracheostomy less likely to be successful.

**A3.95** Throughout August 2001, the nursing notes suggest that there was a fundamental difference between the objectives of the medical team and the nursing team as they applied to oxygen administration. The decisions of the medical team were dominated by the DNAR and care plan, including a continuing pressure to get Elizabeth ready for tracheostomy reversal. To support this effort, they needed supplementary oxygen to be reduced in concentration and regularity of administration. In contrast, the nursing team in Churchill Ward quickly concluded, as evidenced in the written record, that the surest way to prompt Elizabeth to recover from the regular desaturations she experienced was to give her increasing amounts and concentrations of supplementary oxygen.

**A3.96** There seems to have been a damaging failure of agreement, which is likely to have undermined the efforts to enable Elizabeth to live without the tracheostomy. By mid-August 2001 she was regularly on 40-60% oxygen, although her consultants continued to assume that she was on 28% when they were discussing her progress. The medical records show that her mother pointed out on 21 August 2001 that the clinical team were giving conflicting advice that they wanted to optimise Elizabeth's lung function in order to try to reverse the tracheostomy, while giving Elizabeth more oxygen at the same time.

**A3.97** Unfortunately, the calm environment in Churchill Ward had been shattered on 20 August 2001. Another patient had died as a result of a fabricated or induced illness terminating in a fatal salt poisoning administered during a ward visit on the ward (this patient's mother was subsequently convicted of manslaughter). Many on the ward, including Elizabeth's mother, had previously raised concerns about the behaviour of the perpetrator, but no-one expected the fatal outcome. We heard repeated accounts of the devastating effects on both staff and other families.

**A3.98** Churchill Ward was closed immediately after this incident pending a police investigation. Elizabeth's parents arrived to visit and found the entire ward barricaded off without warning. It took them some time to get news of their daughter, who was for a week the only patient on the ward, kept there in a side room as she had a healthcare acquired infection. We cannot know for sure what effect this incident and its aftermath had on the care of other patients including Elizabeth, but we heard that at the least it comprised a significant distraction for clinical staff.

**A3.99** At the end of August 2001, Elizabeth survived a crisis involving further respiratory struggle and infection. She recovered without CPAP or ventilation, despite some reservations expressed by the clinical team, but did require an emergency tracheostomy tube change and treatment with antibiotics for a pseudomonas infection.

**A3.100** This crisis did seem to prompt consideration of recent entries in the medical record about oxygen administration, because it was then decided to stop monitoring Elizabeth's blood oxygen levels and to try once again to reduce the concentration of oxygen administered. After this point Elizabeth proved able to cope with 28% oxygen if she received regular suctioning, but she did require frequent suctioning to remove thick mucus. She also showed more signs of distress, perhaps precipitated by the more frequent interventions to suction her tracheostomy, and was prescribed Oramorph<sup>12</sup> in response.

**A3.101** Entries in the clinical records over this period show a decline in Elizabeth's ability to sustain a consistent pattern of breathing despite the tracheostomy, just as it was becoming clear

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<sup>11</sup> Respiratory drive most often originates from increased carbon dioxide levels under normal circumstances, but if this fails due to damage or chronic disease then shortage of oxygen (hypoxia) becomes the driver.

<sup>12</sup> A short-acting oral preparation of morphine used for relief of pain.



that there was no hospital care solution in Surrey or Hampshire for an infant with a long-term tracheostomy. The pressure to resolve this situation was now bearing down on staff as well as parents. In the first week of September 2001, ENT team members had started to discuss whether they should continue the attempt to wean Elizabeth off the tracheostomy at all, or even try to downsize the size of the tracheostomy tube (a necessary precursor to full decannulation) since Elizabeth was so unstable.

**A3.102** On 10 September 2001, the clinical records set out a fundamentally more robust action plan suggested by a senior ENT surgeon, which was pursued actively over the next two weeks. Its nature illustrates the ethical complexities that were being navigated.

**A3.103** The plan overall was to physically downsize the diameter of the tracheostomy in stages before trying to remove the tracheostomy tube entirely. If the tube were eventually removed and Elizabeth could not tolerate the results, the tube would be replaced and as necessary upsized once more, on the condition that the process would not be attempted again. Downsizing the tracheostomy cannula had the effect of making Elizabeth get used to making more of an effort to get air in and out of her lungs, but would result in shortage of oxygen if she were less than fully successful. Elizabeth's parents were told that if her condition deteriorated because of further downsizing of the tracheostomy tube, the process would not be reversed; instead attention would be given to 'symptom management and palliative care'. It was thought possible that if Elizabeth was in such a situation, FPH might reconsider their refusal to offer Elizabeth a bed.

**A3.104** The tracheostomy tube was duly downsized on 10 September 2001. Elizabeth was considered to cope with the change well enough, but two days later, it was decided that it would be acceptable to help Elizabeth tolerate the extra stress of coping with a smaller sized tracheostomy by increasing her dosage of morphine and reducing the strength of her nasogastric feeds.

**A3.105** In the event Elizabeth's tracheostomy tube was not downsized further. The Trust ethics committee met on 14 September 2001 to consider her case. At that stage they gave permission for the tracheostomy tube to be simply taken out, on the grounds that this might improve Elizabeth's quality of life 'despite the risk of obstruction.' The justification was that without the tracheostomy, if Elizabeth survived decannulation, everyone could progress with plans for Elizabeth's transfer to FPH paediatric ward, home or a hospice which would improve her quality of life.

**A3.106** After considering this prospect over the weekend, Elizabeth's parents asked if the tracheostomy could simply be capped in the first instance, to make Elizabeth reliant on her own upper airway. It would let everyone judge if Elizabeth would be able to tolerate the impact of decannulation; but the capping could be easily or quickly reversed if she showed signs of great distress.

**A3.107** This procedure was tried on 18 September 2001 but unfortunately the results were equivocal. Elizabeth did not tolerate the first attempt to get her to use her upper airway very well, becoming unsettled and showing physical signs of distress, but her air entry seemed to be sufficient. After two hours of continuing signs of distress, the tracheostomy tube was unblocked and she settled. After a break another attempt was made, but this time Elizabeth became unsettled almost immediately and the attempt was abandoned after 25 minutes. Some hours later it was decided to see if Elizabeth would do better if she was given opiates beforehand to settle her, but again when the tube was blocked she seemed to be working hard for breath, and after waiting for nearly an hour to see if she settled, the tracheostomy was reopened.

**A3.108** Elizabeth was left for a week with the smaller sized tracheostomy tube, while her condition was observed for any signs of deterioration, but none were evident. During this period,

she was certainly considered to be gravely ill, but although she needed regular suctioning of the narrower tube, she was managing to cope with the assistance of morphine and regular supplementary oxygen. A full decannulation attempt was planned, then delayed over the weekend. It had been decided to remove the tube entirely: if the attempt failed the tube would be replaced if possible, and the attempt would not be repeated.

**A3.109** This trial of Elizabeth's attempt to manage without the tracheostomy was witnessed by Elizabeth's parents on 24 September 2001. Although they were keen for this to be tried, especially after hearing that Frimley Park Hospital refused to take Elizabeth if she still had the tracheostomy, in the event Elizabeth's struggles trying to rely on her normal airway were very distressing and the attempt was discontinued. From this point, Elizabeth's parents accepted that a way would have to be found to support her at home with a tracheostomy, but they also developed a dread of her suffocating, based on what they had observed happening when the tracheostomy tube was removed. They turned their attention to looking for assurances that Elizabeth could be cared for safely at home despite her small size and fragility. They were increasingly clear that they would not sanction any course of action that would risk her tracheostomy becoming blocked, and equally clear that should it inadvertently become blocked the blockage should be cleared and Elizabeth supported while normal breathing was restored.

**A3.110** No further attempt to reverse the tracheostomy was suggested, although her tube was not immediately upsized. Elizabeth struggled with a small tube for several more days, reliant on oxygen and with further signs of pseudomonas infection, but gradually stabilised with careful nursing and regular tube changes before her tube was increased in size.

**A3.111** Meanwhile, plans for Elizabeth's future care had progressed. Dr Goldman, a palliative care consultant at GOSH, had suggested that a move to a hospice as an interim measure might be a solution to the process of getting Elizabeth home. Her initial suggestion was for Helen House in Oxford, which had clinical links with GOSH. Elizabeth's parents, however, looked for a hospice closer to home. A formal offer was received on 5 October 2001 that she could move to Naomi House Children's Hospice in Hampshire as a first step towards care at home. On 8 October Elizabeth's tracheostomy tube was changed for a larger size again by Jo Cooke, and again on the next day.

**A3.112** Elizabeth left GOSH for Naomi House on 29 October 2001.

# APPENDIX 4: CARE AT NAOMI HOUSE CHILDREN'S HOSPICE<sup>1</sup>

**A4.1** Elizabeth moved from Great Ormond Street Hospital (GOSH) on 29 October 2001 to Naomi House, a children's hospice in Hampshire. This was the first step in a planned transition to care at home. It was located nearer to the family home, and would acquaint her family with care in a less hectic setting than an acute hospital. It was also intended to allow the nurses from Nestor Primecare, who would be caring for Elizabeth when she went home, to meet the family and familiarise themselves with her care. Initially, it was supposed that Elizabeth would stay for a few weeks before beginning to spend more time at home<sup>2</sup>. When she was fully established at home, the hospice would remain available for brief periods of respite care if needed.

**A4.2** Naomi House was run as a charity, as is usual for such hospices. In 2001 hospices did not receive any government funding (although this has now changed) and health authorities were discouraged from offering financial support on the grounds that they already used charitable income to support their services. The Head of Care was Maggie Fry, an experienced nurse who was responsible for the operational management of the hospice.<sup>3</sup> Naomi House had a children's cancer specialist, Dr Erica Mackie, who usually attended regularly from her main post at Southampton. Day to day medical care was the responsibility of a number of local GPs organised by a lead GP, Dr Theresa Creagh.<sup>4</sup> The hospice had nursing and other staff, one of whom, Sue Foster, acted as contact worker for Elizabeth's parents.<sup>5</sup>

**A4.3** It is clear that Elizabeth was cared for kindly and sympathetically while she was in Naomi House, and that the arrangement generally worked well. There was, however, evidence of a significant and far-reaching change in the assumptions made about her clinical condition and outlook. As we have seen, Elizabeth's neuroblastoma was non-progressive and expected to continue to regress.<sup>6</sup> The children's cancer specialist at GOSH was clear that "she was not going to die from neuroblastoma".<sup>7</sup> The Naomi House records, however, show that clinicians there assumed that the neuroblastoma was the most serious underlying clinical problem, and began to see her symptoms as related to end-stage cancer. It seems that the expectation of Naomi House clinicians that they were providing end of life care for a child with progressive cancer shaped their perceptions of the care required.<sup>8</sup> In addition the GOSH discharge summary that accompanied Elizabeth was not explicit on the nature of her neuroblastoma.

**A4.4** Unfortunately, at one point this view was reinforced by a telephone call to GOSH during which a direct question on whether her neuroblastoma might have become active again

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<sup>1</sup> Unless otherwise stated, information is from Naomi House records.

<sup>2</sup> Health Authority Files (s11) & ED GOSH Medical File pt 5 nursing and observations p26.

<sup>3</sup> Margaret Fry interview 7 December 2018.

<sup>4</sup> Dr Theresa Creagh interview 20 December 2018.

<sup>5</sup> Margaret Fry interview 7 December 2018.

<sup>6</sup> GOSH Clinical records: Elizabeth Dixon.

<sup>7</sup> Dr Peppy Brock interview 3 December 2018.

<sup>8</sup> Dr Theresa Creagh interview 20 December 2018.

was answered with “it might”. There was, however, no clinical evidence to suggest it, and no investigations were carried out.

**A4.5** There were two immediate consequences. First, at least some staff began to speak of a shorter lifespan than had been identified by the GOSH specialist oncologist and neurologist. Second, a much more active approach was taken to pain relief, and various changes in Elizabeth’s condition prompted escalation in the dose of morphine sulphate solution she was being given. There is inadequate record keeping to justify these changes or reliable note keeping of the effect of additional or “as required” enteral morphine (Oramorph); on one occasion the wrong dose was prescribed, but the error was spotted by the pharmacy.

**A4.6** As a result, the dose of morphine Elizabeth was receiving each day increased more than fivefold over the four weeks she remained in Naomi House. While this is an appropriate pattern in a child with progressive and painful malignant disease nearing the end of life, this was not the case for Elizabeth. The repeated increases in morphine administration are likely to have contributed further to the tendency for secretions to accumulate in the tracheostomy tube and require frequent suctioning. There were also documented discussions about the potential use of antibiotics but these were not commenced, most likely because of Elizabeth’s assumed prognosis.

**A4.7** Elizabeth continued to have episodes of sweating and patchy cyanosis, almost certainly related to the release of catecholamines secondary to residual neuroblastoma. This was suggested during a telephone consultation with the GOSH consultant oncologist who recommended treatment with phenoxybenzamine or propranolol or both.<sup>9</sup> This would have been an unusual change to consider commencing in the context of a children’s hospice, and in any case was not agreed by Elizabeth’s parents in view of a previous medication-related cardiac complication when she was at GOSH.

**A4.8** Following visits by some of Nestor Primecare’s nurses and a refresher session on infant tracheostomy care that are described in Appendix 6, Elizabeth left Naomi House for home on 27 November 2001.

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<sup>9</sup> Dr Peppy Brock interview 3 December 2018.

# APPENDIX 5: INVOLVEMENT OF NESTOR PRIMECARE

**A5.1** Transfer to a local acute hospital was initially considered the best choice for Elizabeth, not only because care closer to home would relieve some of the burden on her parents, but also with the intention that further work on a longer-term option could be undertaken by people with local knowledge. The difficulty proved to be in finding a local acute hospital that would accept responsibility for small baby with a tracheostomy that required round the clock care by suitably trained nurses.

**A5.2** The most obvious destination was Frimley Park Hospital (FPH), where Elizabeth was born and from where she had been referred to Great Ormond Street Hospital (GOSH). FPH had the necessary facilities to nurse babies and small children, and staff were initially receptive to a discussion with colleagues at GOSH NICU about whether the hospital could take Elizabeth back.<sup>1</sup> Ward staff at FPH suggested that in principle they could find a bed for a paediatric patient with a tracheostomy, provided it was for a time limited period. But once the consultants at FPH dealing with the negotiation (Dr Peta Maltby and Dr Michael Tettenborn) knew that Elizabeth was expected to survive for an unknown but potentially lengthy period, and that GOSH was beginning to assume that Elizabeth might have to live with a tracheostomy for the foreseeable future, resistance grew to the expectation that Elizabeth could be transferred to FPH.<sup>2</sup>

**A5.3** FPH declared in late August that its paediatric unit would not be able to care for an infant with a tracheostomy for anything other than the short term. They did not have the number of staff available with the right training and experience, and correspondence shows that they did not expect there to be additional funding from the health authority to employ more even if there had been any available for recruitment. They could manage for a strictly defined limited period by diverting nursing resources from elsewhere, but this was not a sustainable solution given the need to care for their other patients.

**A5.4** In addition, the records show another cause for reluctance on the part of FPH staff: they had had a difficult experience with a different family that had left them seriously doubtful that the level of care they could provide would match the family's expectations for their daughter. This seems to have hardened the view that FPH was a hospital suited to care of acutely ill patients, but ill-equipped and unsupported to manage small babies requiring complex continuing care<sup>3</sup>.

**A5.5** In Elizabeth's case it is clear that the FPH paediatric clinical director, Dr Tettenborn, wrote to the health authority to ask for help with additional resources if they wished her to be discharged back there. There is no record of a reply to his letter, and it seems from other correspondence that his expectation of this leading to a solution was low. Nor was there any realistic prospect of finding another local hospital with the necessary resources.<sup>4</sup>

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<sup>1</sup> GOSH clinical records: Elizabeth Dixon.

<sup>2</sup> FPH correspondence; Dr Michael Tettenborn interview 26 July 2018.

<sup>3</sup> Letter from Dr Michael Tettenborn to Dr Ann Goldman dated 29 August 2001.

<sup>4</sup> FPH correspondence.

**A5.6** Meanwhile, a suggestion had been put forward for possible home care for Elizabeth that would include managing a permanent tracheostomy. It is important to recognise that this suggestion originated with an informal observation by a ward sister at GOSH that she was aware of another small child with a tracheostomy who had been discharged to home care elsewhere in the country, and she had a business card that had been left by the private company that had provided the home nursing care. She believed that the arrangement had been satisfactory, but had no more knowledge of the details or the outcome.

**A5.7** This company, which has been referred to by different names at different times, is here designated as Nestor Primecare, a part of the Nestor Healthcare Group, a company that was looking to expand its activities into complex community care.<sup>5</sup> The North and Mid-Hampshire Health Authority responsible for Elizabeth contacted Nestor Primecare in pursuit of a potential solution to support her discharge home.

## Nestor Primecare

**A5.8** In 2001 Nestor Primecare was a relatively new company in the Nestor Healthcare Group, a group of for-profit limited companies established to provide clinical services to both NHS and private sector clients. Other Nestor Healthcare Group companies provided agency nurses and doctors to fill temporary shortfalls in staffing within NHS organisations, but Nestor Primecare provided community nursing packages, particularly for patients who required more complex care at home. Although both Nestor Primecare and the Nestor Healthcare Group have since gone into liquidation, they had profitable business models at the time. Such companies have been involved in NHS provision since before 2001, commissioned alongside services provided by NHS Trusts. In 2001 the bodies responsible for commissioning NHS services from private providers were health authorities, in this case North and Mid-Hampshire Health Authority.<sup>6</sup>

**A5.9** Clinicians working for agencies are registered medical and nursing practitioners who have often trained within the NHS but who want to work via an agency rather than – or in addition to – directly for an NHS provider. General guidance to the NHS on the employment of agency staff generally concentrates on the financial impact or the taxation status of staff, advising NHS trusts against over-use of agency staff on grounds of cost. Trusts can instead build their own staffing ‘banks’ of employees who apply to work extra hours or flexible hours, although this is not always sufficient to meet their needs. An agency is likely to charge a premium on contracts where the market will bear it, such as when the NHS is short of staff in a particular specialty or geographical area, where demand outstrips supply.

**A5.10** The staff provided by an agency may be self-employed, paying a commission to the agency (more common when the staff provided are doctors), or they may be employed by the agency on hourly rates through zero hours contracts (more common when the staff provided are nurses). National requirements for clinical supervision and governance have been slow to influence the behaviour of agencies, although the best employers will work hard to ensure that staff work as part of the local team and to similar standards as their NHS colleagues.

**A5.11** Staff working through an agency may be seeking variety, increased work/life flexibility, or simply more money. In some cases, work that does not involve a continuing relationship with the same patient or patients may be appealing. The immediate remuneration from agency work is usually higher than that received directly from the NHS. For some individuals, agency work provides an additional source of income to NHS pay rather than a substitute. There is no legal bar

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<sup>5</sup> Angela Single interview 26 July 2018.

<sup>6</sup> Health authorities commissioned most NHS services in 2001, but some specialised services were commissioned regionally or nationally; primary care trusts later became responsible for most commissioning.



to their working both substantively for the NHS and using their time off to work part time for an agency (often over night shifts), increasing their overall income and overcoming shift restrictions conferred by working time legislation. The overall workload of staff working both for an NHS provider and an agency is rarely monitored by anyone other than the clinician themselves, and this remains an issue still.

**A5.12** When an acute healthcare provider contracts with an agency to provide staff, there are two main advantages to the client: confidence in the supply of staff members, and confidence that staff members will have been vetted for appropriate skills and experience. Most agency nurses join a pre-existing team in an acute trust and will come under the operational management of whoever is already leading that team. Briefing and supervision of practice is then the same as for a nurse who is directly employed, with an established clear system of oversight and management. Nestor Primecare did not simply supply nurses to existing NHS providers, however: it supplied an entire nursing service for a patient, working autonomously in the patient's home. Under those circumstances, safe and effective practice requires good teamworking and a system of clinical governance, to ensure that clinical standards are met; there is no wider NHS nursing team into which individual practitioners can be absorbed.

**A5.13** There is little remaining internal documentary evidence of Nestor Primecare's systems and processes; however, none of their dealings with North and Mid-Hampshire Health Authority, Elizabeth's family, or other relevant organisations suggests that they gave adequate attention to clinical governance until October 2001, when the Nestor Healthcare Group appointed Dr Bill Holmes as its medical director with a specific brief to develop clinical governance across all of the companies in the Nestor Healthcare Group.<sup>7</sup> Dr Holmes had previously been a non-executive director of the Nestor Healthcare Group and a GP. In October 2001, a month before Nestor Primecare took over Elizabeth's nursing care, he found that there was little evidence of clinical standards and guidelines within the group, and clinical governance remained "a blank box".<sup>8</sup> Nestor Primecare's Managing Director, Angela Single, commented that the organisation took pride in being able to deliver the sort of care at home that the NHS could not, but was apparently unable to see the irony inherent in the claim given the outcome for Elizabeth.<sup>9</sup>

**A5.14** Nestor Primecare relied on a mix of NHS funded and privately funded contracts. The particular appeal of Nestor Primecare to NHS service commissioners was that it could find suitable nurses who were known to the nursing agencies elsewhere in the Nestor Healthcare Group to fill a roster. This would allow them to draw upon a larger pool of nurses with the necessary skills – at least that was the theory – than most NHS hospitals or community services could. When considering commissioning the home nursing care for Elizabeth, the health authority were well aware of this: "The agency [Nestor Primecare] are clearly proposing to recruit children's trained, ICU trained nurses from outside our area and 'bus them in'... this is an activity we could not undertake administratively or managerially...".<sup>10</sup> Most of the nurses who were subsequently proposed as part of the rota for Elizabeth's care at home had previously worked regularly for other Nestor Healthcare Group nursing agencies.<sup>11</sup>

**A5.15** In 2001 there were significant ambitions to expand Nestor Primecare's business,<sup>12</sup> and a ready supply of nurses from other agencies in the Nestor Healthcare Group was integral to that expansion. Simon Austin, Financial Controller for four companies in the Nestor Healthcare

<sup>7</sup> Dr William Holmes interview, 26 July 2018.

<sup>8</sup> Ibid.

<sup>9</sup> Angela Single interview 26 July 2018.

<sup>10</sup> Dr Michael Tettenborn email to Linda Wollam 5 November 2001, North and Mid-Hampshire Health Authority papers.

<sup>11</sup> Christie Watson interview 17 July 2018 ; Helen Janes interview 6 November 2019.

<sup>12</sup> Angela Single interview 26 July 2018.



Group, including Nestor Primecare, arranged a seminar in 2001 to talk to nurse managers about identifying and following up opportunities to capture new business, including access to other Nestor Healthcare Group nurses.<sup>13</sup> Some 200 nurses ended up registered with Nestor Primecare, of around 40,000 on the books of the Nestor Healthcare Group as a whole. This should have provided an adequate pool from which to deploy nurses with the requisite skills and experience.

## Nestor Primecare's Initial Approach

**A5.16** Within two days of the contact from North and Mid-Hampshire Health Authority in September 2001, two Nestor Primecare representatives came to Churchill Ward at GOSH to speak to staff there and to meet Elizabeth. They were Susanne Ward, an experienced nurse manager who worked mostly in the Warwickshire area, and Paul Collins whom Nestor Primecare had recruited in April to work as a senior nurse manager to whom Ms Ward would report.<sup>14</sup>

**A5.17** Ms Ward was experienced in laying the groundwork for new contracts for Nestor Primecare, working directly to the Managing Director, Angela Single.<sup>15</sup> She was not a specialist paediatric nurse, which was one reason why Mr Collins had been recruited in April 2001,<sup>16</sup> but she had seen other specialist contracts staffed by Nestor Primecare with relative ease, although it is unclear to what standards.

**A5.18** Elizabeth Dixon did not conform to the usual Nestor Primecare patient. She was less than a year old and had severe neurological problems and developmental delay. She was prescribed palliative care, but she was not terminally ill and none of her conditions were progressive. She required regular experienced assessment, and keeping her safe and comfortable relied on constant oversight and specialist nursing care. All of this was clear from Nestor Primecare's first contact with the clinical team at GOSH.<sup>17</sup> Although eventually there was dispute between Ms Ward and Mr Collins about who carried primary responsibility for ensuring the nurses sent to look after Elizabeth were adequately qualified and experienced, both were fully informed about her condition when they assured GOSH, the health authority and Elizabeth's parents that Nestor Primecare could care for her safely and effectively. Their involvement was clearly central to both Nestor Primecare's decision to offer their services and the health authority's acceptance of the offer.

## North and Mid-Hampshire Health Authority's role

**A5.19** As the NHS commissioner of Elizabeth's care at home, the health authority was required to satisfy itself that Nestor Primecare could provide the required service safely and effectively. They were not entitled to assume, as they would for an NHS provider, that the organisation's systems and processes were those expected of an NHS provider; with assurance given by an NHS Trust board overseen by the NHS regulatory system of 2001.

**A5.20** Yet the evidence shows a significant level of complacency on the part of the health authority. Elizabeth would require continuous nursing care, most importantly to ensure that her tracheostomy remained clear and her breathing unobstructed, as well as all of the other nursing requirements of a baby with profound disability due to cerebral damage. It was clear to the health authority that the critical point was the need for an uninterrupted rota of nurses with the necessary skills and experience: that was exactly the difficulty that stood in the way of Elizabeth going back to FPH or being cared for local NHS community services. From the outset, Nestor Primecare

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<sup>13</sup> Simon Austin interview 13 July 2018.

<sup>14</sup> Sue Ward interview 26 July 2018.

<sup>15</sup> Ibid.

<sup>16</sup> Jennifer Hilton interview 26 July 2018.

<sup>17</sup> Sue Ward interview 26 July 2018.

undertook to the health authority and to Elizabeth's parents that they would provide sufficient qualified children's nurses with experience of infant tracheostomy care to staff a continuous rota. Even given the nursing agencies in the Nestor Healthcare Group that they could draw upon, that was a bold assertion which needed to be tested.

**A5.21** In reality North and Mid-Hampshire undertook minimal diligence: there had been one informal contact with another Health Authority that had contracted for a similar package of care, but no references were requested<sup>18</sup>. Dr Tettenborn, providing paediatric clinical advice to the Health Authority, and Ms Fry from Naomi House both commented on the difficulty of obtaining sufficient specialist nurses to staff a rota round the clock; Mr Collins simply stated that Nestor Primecare nurses would all be paediatric nurses practised in using the equipment.<sup>19</sup> That was the sum total of challenge to Nestor Primecare, woefully inadequate for commissioning any service let alone one as complex as this.

**A5.22** One factor that seems to have given inappropriate comfort to the Health Authority was the incorrect assumption that Nestor Primecare was endorsed by GOSH. In reality, approaching the company was a suggestion from one member of staff who had had informal feedback from parents based on a Nestor Primecare care package elsewhere. No doubt she was trying to be helpful, but the assumption that GOSH had had some role in quality assuring Nestor Primecare was false comfort.

**A5.23** In reality GOSH clinicians had little input into the decision to award the contract for Elizabeth's care to Nestor Primecare. Although GOSH was not directly involved in the contract, they had significant expertise in tracheostomy care and were under a duty to ensure that they were discharging a patient to safe and effective care, as applies to any patient. It seems, however, that another incorrect assumption crept in at that point, that she was being discharged to Naomi House and that her discharge from there to home would be Naomi House's responsibility.<sup>20</sup> It was clear from the documentation throughout, however, that Naomi House was only ever an interim measure to smooth her route home. During her brief interim stay, Naomi House staff did raise concerns about the adequacy of the arrangement with the Health Authority, but saw no role for themselves in deciding whether the discharge arrangements were acceptable.<sup>21</sup>

## Discharge planning

**A5.24** The arrangements for Elizabeth's discharge and care at home were formally agreed at a discharge planning meeting held at Naomi House on 24 October 2001.<sup>22</sup> The meeting was chaired by Mrs Wollam from the Health Authority; present were Ms Bailes, also from the Health Authority, and Dr Tettenborn, recorded as a consultant paediatrician of Surrey and Hampshire Borders NHS Trust, although he was also employed by FPH; also Dr Ann Goldman, Jane Crooks, Rowena Ellis and Dianne Gumley (all GOSH), Judith Rogers (Social Services), Sue Watson (Health Visitor, Richmond GP Surgery), Angela Garrett (Head of Community Children's Nursing, Surrey and Hampshire Borders NHS Trust), Dr Theresa Creagh, Maggie Fry, Sue Foster and Jill Purkiss (all Naomi House), Mr Collins (Senior Nurse Manager, Nestor Primecare), and Mr and Mrs Dixon.

**A5.25** It is clear from the meeting notes that all present were working from an assumption that Nestor Primecare would be providing the package of nursing care at home for Elizabeth and that

<sup>18</sup> Report of an Independent Impartial Enquiry into a complaint made to North and Mid Hampshire Health Authority from Anne & Graeme Dixon, by Pat Christmas and Mike Smith.

<sup>19</sup> Notes of discharge planning meeting 24 October 2001, North and Mid-Hampshire Health Authority papers.

<sup>20</sup> Dr Colin Wallis interview 19 February 2020.

<sup>21</sup> Maggie Fry interview 7 December 2018.

<sup>22</sup> Notes of discharge planning meeting 24 October 2001, North and Mid-Hampshire Health Authority papers.

the meeting was to resolve uncertainties about other aspects of her care, such as the provision of equipment, medication and medical input. At that point – Elizabeth had not yet left GOSH – there was uncertainty that remained to be resolved about what equipment she would need at home. It was assumed that Elizabeth’s GP, Dr Sinclair, would prescribe necessary medication but she was not at the meeting, although she had been invited. Dr Creagh observed that this could be difficult as Dr Sinclair did not know Elizabeth, which clearly raised the question of medical input into Elizabeth’s care, but the point was not pursued. Later in the meeting, it was noted that Dr Tettenborn “agreed that he will be the responsible medical officer once Lizzie leaves GOSH. He will be available for advice and could arrange a home visit...”<sup>23</sup>

**A5.26** The term ‘responsible medical officer’ in the notes of this meeting has been the subject of dispute since. Dr Tettenborn has maintained that he had not agreed to this, and would act only as a community paediatrician,<sup>24</sup> but there is no record of his disagreement at the time, while Mrs Wollam has said that it referred only to the senior clinician responsible for assuring the Health Authority that a case met the criteria for continuing care funding.<sup>25</sup> Regardless of the dispute, two things are clear: first, there was no clarity or shared understanding, and second, this was an inadequate basis on which to plan complex care at home.

**A5.27** The meeting notes confirm that the Health Authority “had no timescale in mind for the length of time that Lizzie would need care”, and Dr Tettenborn stated that “at the age of two they would be looking at other educational needs”.<sup>26</sup> The package would be reviewed formally every three months after an initial review a few weeks after Elizabeth had gone home.

**A5.28** At this meeting and subsequently, assumptions were clearly made that Nestor Primecare could be relied upon to deliver its promises, principally to deliver a continuous rota of qualified children’s nurses experienced in infant tracheostomy care. Mrs Wollam said:

*“I had very few dealings with Mr Paul Collins of Nestor Primecare and at no stage was there a requirement for him to submit to the Health Authority a list of nurses that were booked to care for Elizabeth Dixon. However, the expectation of the Health Authority was that he as Nurse Manager, acting on behalf of Nestor Primecare, provided appropriately qualified and experienced specialist nurses throughout the daily 24 hour period to deliver the necessary and appropriate package of care to Elizabeth Dixon.”<sup>27</sup>*

## The Nestor Primecare Contract

**A5.29** The negotiation of the ‘contract’ between the health authority and Nestor Primecare was short. Details were dealt with by finance managers, who moved forward on the assumption that they needed to pay specialist rates for nurses with specialist qualifications and skills. There is no evidence they sought to confirm the Nestor Primecare declarations that only specialist staff would be deployed.

**A5.30** Dr Tettenborn confirmed to Mrs Wollam on 5 November 2001 that the care was required and that the NHS community service managed by Surrey and Hampshire Borders NHS Trust could not provide the resource or recruit sufficient nurses with the required skills;<sup>28</sup> this was necessary for the continuing care funds to be committed by North and Mid-Hampshire Health Authority.

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<sup>23</sup> Ibid.

<sup>24</sup> Dr Michael Tettenborn interview 13 December 2018.

<sup>25</sup> Linda Wollam interview 16 November 2018.

<sup>26</sup> Notes of discharge planning meeting 24 October 2001, North and Mid-Hampshire Health Authority papers.

<sup>27</sup> Linda Wollam 11 November 2003 Witness Statement for NMC.

<sup>28</sup> Dr Michael Tettenborn email to Linda Wollam 5 November 2001, North and Mid-Hampshire Health Authority papers.

**A5.31** On 13 November 2001, Eileen Spiller recorded an agreement between Dr Simon Tanner, who was the health authority director of public health, and Dr Tettenborn, who was advising the health authority: “Dr Tanner and Dr Tettenborn have discussed the clinical issues concerning the care of this baby. The HA will accept responsibility for her care at home while this is deemed appropriate by the care team. I am sure that review meetings will be required to ensure that the care provided remains safe, appropriate and achievable”.<sup>29</sup> There is no evidence that any steps had been taken previously to ensure that care would be safe or achievable.

**A5.32** On the next day, 14 November, the formal letter of understanding was presented to be signed between the health authority and the agency. At this stage Ms Bailes, who was responsible for ensuring the proper use of Continuing Healthcare funds, asked for more assurances. She emailed Mrs Wollam “if you can confirm the ... review periods, clinical involvement/responsibility – I will sign the quote”.<sup>30</sup> There is no evidence of such clinical governance arrangements being agreed, beyond monthly high level review. The contract was signed anyway: it comprised only a two-page schedule, in effect an invoicing mechanism for Nestor Primecare to charge the health authority.<sup>31</sup>

**A5.33** Overall, this would be an inadequate level of diligence for any external contract, let alone one for complex specialist care where even the most cursory request for assurance had already revealed concerns. There is no evidence that Nestor Primecare’s plans for looking after Elizabeth were described in detail or considered by health authority commissioners. The basis of the contract was the bare calculation of cost for the agreed cover of round the clock specialist nursing care, and a statement of expectation that more senior Nestor Primecare nurses would be available on call to give advice. There is no record that Nestor Primecare was asked to describe its process for identifying suitably qualified front line staff. No specified standards or monitoring of safety and effectiveness was included in the ‘contract’.

**A5.34** Nestor Primecare were clear that they could provide only nursing care, yet there is no evidence that anyone recognised that there was an obvious need for medical input. Elizabeth’s condition required complex care that should have been subject to regular multidisciplinary reviews, case conferences at which all of the professionals involved in her care could communicate and agree on any changes that might be required. There is no evidence that multidisciplinary review was ever discussed. Dr Tettenborn resisted the idea that as consultant community paediatrician he had any role beyond availability for advice.<sup>32</sup> Mrs Wollam said that “it would be unreasonable to describe Mike Tettenborn’s role as the supervisor of day to day delivery of care... The role of RMO, in ensuring that continuing care criteria were met in qualifying for funding, was quite broad...”.<sup>33</sup> Responsibility for prescribing had been raised at the planning meeting, and Dr Tettenborn was recorded as saying that he “expected her GP’s surgery to sort this out”.<sup>34</sup> Dr Sinclair, the family GP, was clear that she did not have the specialist experience to review Elizabeth’s medical care, but would prescribe medication as recommended by someone who did.<sup>35</sup> These arrangements not only lacked clarity and led to confusion amongst the clinicians involved, they fell far short of the multidisciplinary input required.

**A5.35** Nevertheless, an agreed date was set for Elizabeth’s transfer home on 20 November 2001.

<sup>29</sup> Email, Eileen Spiller to Kate Bailes, North and Mid-Hampshire Health Authority papers.

<sup>30</sup> Kate Bailes email to Linda Wollam, 14 November 2001, North and Mid-Hampshire Health Authority papers.

<sup>31</sup> North and Mid-Hampshire Health Authority papers.

<sup>32</sup> Dr Michael Tettenborn interviews, 26 July 2018 and 13 December 2018.

<sup>33</sup> Linda Wollam interview, 16 November 2018.

<sup>34</sup> Notes of Discharge Planning Meeting 24 October 2001, North and Mid-Hampshire Health Authority papers.

<sup>35</sup> Dr Michelle Sinclair interview 12 July 2018.



# APPENDIX 6: ELIZABETH'S MOVE HOME

**A6.1** Nestor Primecare secured the contract for Elizabeth's home nursing care from North and Mid-Hampshire on 15 November 2001, with an initial expectation that she would go home on 20 November 2001. The immediate task facing them was to identify the nurses who would between them cover the continuous rota that Nestor Primecare had committed themselves to. The question of whether Mr Collins or Ms Ward was primarily responsible has caused confusion since. Mr Collins's dismissal and subsequent reticence (related at least in part to his ill health) has not helped to reduce this, and nor have the missing Nestor Primecare papers initially attributed to their loss in a fire (see Appendix 8). The most probable explanation is that the position changed over time: prior to Mr Collins's arrival in April 2001, Ms Ward provided nursing managerial oversight to care packages such as Elizabeth's, including those for children, but one reason Mr Collins was brought into Nestor Primecare was specifically to provide qualified paediatric nursing leadership of children's care packages.<sup>1</sup> Ms Ward had been involved in the initial contacts because of her familiarity with Nestor Primecare's mode of operation, but by mid-November 2001 the lead role lay with Mr Collins. Sometimes in his absence, or through familiarity with her previous role, staff might approach Ms Ward, but when they did they were redirected to Mr Collins.<sup>2</sup>

**A6.2** There is no evidence of any formal mark of the transition of responsibility with Nestor Primecare, and given Mr Collins's rather sudden departure within days of Elizabeth's death it may be supposed that it was helpful to both Nestor Primecare and other staff there to talk up his role. Nevertheless, all of the contemporary accounts point both to Mr Collins assuming responsibility at some point prior to Elizabeth's discharge home and Ms Ward's diminishing part in the arrangements.

**A6.3** As is evident from the statements and interviews of all those involved at first hand, Nestor Primecare arranged Elizabeth's care as a collection of nursing shifts. Nestor Primecare's Managing Director Angela Single claimed that the package included caseload and package management<sup>3</sup> – but there is no evidence whatsoever of this type of approach being employed, either in the clinical records in the notes or from the accounts of those involved. Had there been a caseload manager, Nestor Primecare could hardly have remained unaware of valid concerns raised at the time by the nurses, the health visitor and Elizabeth's parents, and when those concerns were pursued the organisation could hardly have failed to understand their significance. Yet that is what happened.

**A6.4** In the absence of a caseload management approach by Nestor Primecare, it was left to a non-clinical coordinator to approach nurses considered suitable to attempt to fill a continuous rota. In Elizabeth's case this was Annette Robinson, a non-clinical administrator recently recruited by Nestor Primecare. Elizabeth's was the first care package that she worked on alone, after a brief period shadowing another patient coordinator. Her job was to contact the names she had been given and start the process of filling a rota of nurses who would work sequential shifts. She

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<sup>1</sup> Angela Single interview 26 July 2018.

<sup>2</sup> Annette Robinson witness statement, 22 September 2005.

<sup>3</sup> Angela Single interview 26 July 2018.



also provided basic briefing to nurses unfamiliar with the patient they would be looking after, and information on transport options, travel times and accommodation locally.<sup>4</sup>

**A6.5** Ms Robinson found that Nestor Primecare did not have sufficient suitable nurses on their books to cover the rota for Elizabeth. Her clinical supervisor was Mr Collins, who advised her to contact first one then another nursing agency within the Nestor Healthcare Group. When it became apparent that there would still be gaps in the rota he asked her to contact a nurse who had been newly appointed to Nestor Primecare, Joyce Aburime. Ms Aburime was not a qualified children's nurse and had no experience of infant tracheostomy care.<sup>5</sup> She had not formally started working for Nestor Primecare at this point, and was yet to have an induction with the company.<sup>6</sup> It is clear that Nestor Primecare was struggling to find nurses to cover the rota for Elizabeth's care, and that they had already abandoned their commitment to using only qualified children's nurses experienced in infant tracheostomy care.<sup>7</sup>

**A6.6** On 14 November 2001, Ms Ward had visited Naomi House with two of the nurses who were on the list that Nestor Primecare intended to use for Elizabeth's care, Liz Welch and Sarah Trimble. During the visit, both nurses told Elizabeth's mother that they had not previously looked after a baby with a tracheostomy, and that they needed more experience in infant tracheostomy care. Mrs Dixon immediately expressed concern to Ms Ward, and suggested that Ms Cooke, specialist respiratory nurse at GOSH, had offered to ensure that all of the nurses Nestor Primecare planned to use were properly trained.<sup>8</sup> Ms Ward phoned Mr Collins on the spot to ask him to arrange extra training with Ms Cooke. Ms Cooke has been clear, however, that a single session training was not appropriate for nurses with no previous experience of infant tracheostomy care, and saw no role for herself in assuring the competence of the nurses.<sup>9</sup>

**A6.7** It is clear that there were concerns about Nestor Primecare's preparedness at this point. Ms Fry said that she had had concerns while Elizabeth was still in Naomi House, and "if she had her time again, she would not have allowed [Elizabeth] to go home",<sup>10</sup> but it is not clear if these concerns were raised with either the health authority or Nestor Primecare.

**A6.8** On 20 November 2001, Angela Garrett of the Surrey and Hampshire Borders community nursing team emailed Dr Tettenborn:

*"We have had to take more suction catheters for Elizabeth at Naomi and at the last visit were informed that many of the Prime Care team have no paediatric tracheostomy experience and some are not Children's Nurses. This has distressed Mrs Dixon further and we have arranged a tracheostomy training for them at Naomi next week. The discharge date has been postponed to 27<sup>th</sup> Nov but Mum is still very anxious. Prime Care are unable to give any cover from 19<sup>th</sup> Dec until after Christmas and Naomi are finding it difficult with funding issues. Can some of the funding from Prime Care be directed to Naomi so that we can have some securely booked regular breaks from home as this agency doesn't appear as good as we were led to believe?"<sup>11</sup>*

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<sup>4</sup> Annette Robinson witness statement, 22 September 2005.

<sup>5</sup> Nursing and Midwifery Council papers.

<sup>6</sup> Ibid.

<sup>7</sup> Angela Garrett email to Dr Michael Tettenborn 20 November 2001, North and Mid-Hampshire Health Authority papers.

<sup>8</sup> Report into the preparation and delivery of nursing care to Elizabeth Jean Dixon in the community, Graeme Dixon, 12 June 2002.

<sup>9</sup> Jo Cooke interview 29 January 2019.

<sup>10</sup> Maggie Fry interview, 7 December 2018.

<sup>11</sup> Angela Garrett email to Dr Michael Tettenborn 20 November 2001, North and Mid-Hampshire Health Authority papers.

**A6.9** Dr Tettenborn forwarded the email to Linda Wollam at the health authority, commenting “seems to be a real concern here”,<sup>12</sup> but there is no record of any further action. It is instructive that although Mrs Dixon’s distress and anxiety is referred to twice, there is no comment on the very obvious divergence from Nestor Primecare’s promise of a full team of children’s nurses experienced in paediatric tracheostomy care, nor whether this should prompt reconsideration of the plan. It is also worth noting again that tracheostomy training mentioned in the letter was a theoretical training overview described by Jo Cooke as “to ensure everyone was on the same page, but she would not have pretended it was a practical foundation course”.<sup>13</sup>

**A6.10** Nestor Primecare had already contacted the health authority. A health authority letter dated 20 November recorded a call from Ms Robinson to say that Nestor Primecare was not ready to support Elizabeth’s discharge home, and that it had been agreed that it should be delayed beyond the agreed date of Friday 23 November.<sup>14</sup> It was agreed that as an exceptional measure the health authority would fund Naomi House to extend Elizabeth’s stay and would fund Nestor Primecare to provide a nurse to cover the night shifts at Naomi House from 23 November until she went home. There is no record to indicate that the concerns of Ms Fry, Ms Garrett or Nestor Primecare themselves prompted any reconsideration of the care package itself; nor did the problems being correctly identified by Elizabeth’s parents sound any alarm. A Health Authority senior manager, Eileen Spiller, noted on 21 November 2001 that “Linda [Wollam] will pick up the detail when she returns, but meanwhile I think we need to get her home and see how they all cope. We can only do our best and I don’t think it is going to be a perfect solution”.<sup>15</sup>

**A6.11** The tracheostomy refresher session went ahead at Naomi House on 26 November 2001, attended by Nestor Primecare nurses including Ms Aburime, as well as some from Naomi House as Elizabeth had been expected to return to the hospice as a break from home care. Mr Collins and Ms Ward both attended from Nestor Primecare, but surprisingly there was no specific team discussion about Elizabeth’s care, although it was clear that there were some problems to resolve before she could go home: her clinical notes at that time included “drugs and times – if need double checking [controlled drugs] then currently impossible; ordering supplies – how do we do it?” and highlighted the absence of “list of contact numbers... documentation of policies... plans of care... legal issues regarding administration of controlled drugs by agency staff”.<sup>16</sup> This problem list required urgent resolution, but it did not prompt reconsideration of her discharge home the next day, 27 November 2001.

## Joyce Aburime’s employment

**A6.12** In many respects, Ms Aburime was an accomplished individual in 2001. She spoke several languages, had raised four children, was educated to postgraduate level, and had emigrated to a new country in middle age before starting nurse training in the NHS. She was a qualified nurse, albeit recently so, registered as a general nurse by the NMC. After Elizabeth died, she continued her nursing career for three years, mostly within the NHS, and was subject to no adverse reports during that period.<sup>17</sup>

**A6.13** Ms Aburime had arrived in the UK in 1994 as a visitor, but with an extended visa associated with the needs of a relative who was receiving long term care. Documentary evidence shows that after her arrival she was diligent in making applications to ensure the continuing

<sup>12</sup> Dr Michael Tettenborn email to Angela Garrett 20 November 2001, North and Mid-Hampshire Health Authority papers.

<sup>13</sup> Jo Cooke interview, 29 January 2019.

<sup>14</sup> North and Mid-Hampshire Health Authority papers.

<sup>15</sup> Eileen Spiller email to Dr Michael Tettenborn, 21 November 2001, North and Mid-Hampshire Health Authority papers.

<sup>16</sup> Naomi House clinical records: Elizabeth Dixon.

<sup>17</sup> Nursing and Midwifery Council papers: Joyce Aburime.

authorisation of her stay in the UK. In 1998 she was given permission to remain in the UK to train as a nurse, and this permission applied until she qualified in 2001. Up to the point of her qualification her visas had prohibited paid or voluntary work, although she subsequently admitted (in a police interview) that she had taken paid roles as an agency care assistant prior to qualification, including working for an agency that was part of the Nestor Healthcare Group. It seems that nursing agencies were less than diligent in requiring proof of work permit status at the time, perhaps because the time taken to process applications then meant that many applicants were able to claim that they were awaiting approval.

**A6.14** Ms Aburime's leave to remain in the UK as a student nurse lapsed when she qualified in 2001, but on application to the overseas labour service she was granted a visa to work for University Hospitals Coventry. The records of Ms Aburime's contractual status with University Hospitals Coventry and Warwickshire NHS Trust are incomplete, and current hospital staff felt unable to assist us with further information. What we do know is that she was given a bank contract (an internal agency arrangement common to NHS hospitals) and a temporary fixed term contract covering the first six months of her practice as a qualified nurse.

**A6.15** Ms Aburime's fixed-term contract with University Hospitals Coventry and Warwickshire NHS Trust was due to expire at the end of November 2001. The Trust subsequently wrote to Elizabeth's parents claiming that she had had a permanent contract from February 2001, but since that would mean that it was issued at the same time as the fixed-term contract and is contradicted by Ms Aburime's police statement, it is likely that this date was probably given in error for February 2002 and that there were a few months when Ms Aburime was waiting for her permanent contract to come through. It is clear, however, that she did continue to do nursing shifts in Coventry as a bank nurse.

**A6.16** In August 2001, Ms Aburime sought employment with Nestor Primecare on the basis of a full-time contract, albeit on a zero hours basis, and her work permit was extended to cover working for Nestor Primecare. She was interviewed on 11 September 2001 by Ms Ward, who was nurse lead for Nestor Primecare's nursing contracts within Warwickshire, which was the intended place of work for Ms Aburime. When interviewed, Ms Aburime had been qualified as a nurse for six months, had no specialist paediatric experience, and no specialist intensive care experience; she had some experience of tracheostomy care for her relative, but tracheostomy management in a fully-grown adult is a very different proposition to tracheostomy care in a small infant. All of this must have been clear to Ms Ward at interview. Mr Collins was not present at the interview, but accepted the recommendation that she be recruited.

**A6.17** Following the interview, Ms Aburime accepted Nestor Primecare's offer of a permanent contract. Within a month, Ms Ward was promising clinicians at GOSH on 1 October 2001 that Nestor Primecare's team would comprise nurses qualified and expert in tracheostomy care in an infant, and by the end of November, Ms Aburime was considered capable of becoming part of Nestor Primecare's home care package for Elizabeth.

**A6.18** There was no reference to tracheostomy care in the record of Ms Aburime's job interview, but it is likely that her experience of an adult relative and observing his tracheostomy care was mentioned to Nestor Primecare staff, either then or soon after. It seems probable from police statements that Nestor Primecare twice assigned her to cover overnight rota gaps in the care of teenagers with tracheostomies in Warwickshire, after her interview but prior to her permanent employment starting. It must be stressed again, however, that tracheostomy care in an adult or teenager remains a very different prospect from tracheostomy care in a small infant.

**A6.19** We have seen no evidence to suggest that Ms Aburime misrepresented her level of skill or experience to Nestor Primecare. Their staff, including nurses with children's nursing experience,

must have been aware of the particular requirements of small infants and of the non-transferability of competence gained with an adult tracheostomy. They were also clearly aware that she had been a registered nurse for only six months when appointed, and had no experience of either paediatrics or intensive care as a qualified nurse.

**A6.20** Ms Aburime was sent by Ms Robinson to attend the half day refresher training in tracheostomy at Naomi House on 26 November 2001. Whether this was with the knowledge and at the instigation of Mr Collins or Ms Ward, the session was delivered by Ms Cooke who was clear that it was only suitable for nurses with previous practical experience of infant tracheostomy.<sup>18</sup> Mr Collins attended the refresher training session himself, and when Ms Aburime appeared disengaged to Elizabeth's mother, she took this up with him. Given Ms Aburime's inexperience and unfamiliarity with tracheostomy care in a small infant, as well as the nature of the course, this should have been a very significant concern. Mr Collins reassured Mrs Dixon about her ability to care for Elizabeth, and took no further action.

**A6.21** Ms Robinson subsequently approached Ms Aburime in connection with the rota for Elizabeth's care at Mr Collins's suggestion.<sup>19</sup> This was a serious error of judgement on his part: either he was aware of her inexperience and lack of relevant skills or he deployed her without knowing whether she was capable of the job.

**A6.22** It seems likely that at the refresher training Ms Aburime considered it unlikely she would ever be called upon to look after Elizabeth. She expected to be working in Warwickshire, where her early assignments had been to shifts caring for teenage patients with tracheostomies, akin to her informal experience observing an adult relative's care and quite unlike caring for a small infant with a tracheostomy. It was nevertheless remiss of her not to realise from the content of the refresher that she had no experience relevant to Elizabeth's care.

**A6.23** Ms Aburime was not sufficiently trained, experienced or qualified to look after an extremely vulnerable infant with neurological and respiratory problems and a tracheostomy. She did not fulfil the agreed requirements of the Health Authority, which had commissioned Nestor Primecare to provide specialist nurses with the training and experience to care for Elizabeth competently and safely. Nor did she meet the legitimate expectation of Elizabeth's parents. The evidence that she should not have been assigned to a shift caring for Elizabeth was overwhelming, then and now.

**A6.24** Elizabeth was transferred home on the next day, 27 November 2001, in accordance with the revised date. The plan for care to be split initially between home and Naomi House had been dropped. It is not clear when this decision was made or why, but it represented a missed opportunity to avoid the increased risks inherent in an abrupt transition to home care. Even on the morning she was due to go home, the clinical notes record that Elizabeth's mother "had worries and concerns about going home, but the accepted plan was that her father would contact seniors at Primecare by telephone to voice concerns".<sup>20</sup>

## Elizabeth's care at home

**A6.25** Elizabeth's first night at home was marred by considerable discomfort, because no-one had thought to ensure that sufficient long acting morphine sulphate was available and dispensed for her use. The nurses were forced to rely solely on Oramorph which is an effective but short acting remedy, generally used only for break-through pain between doses of long acting morphine.

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<sup>18</sup> Jo Cooke interview 29 January 2019.

<sup>19</sup> Annette Robinson witness statement 22 September 2005.

<sup>20</sup> Naomi House records: Elizabeth Dixon.

It was a problem that would have been avoided through better coordination between Nestor Primecare and local primary care practice.

**A6.26** After that, however, the first few days at home progressed better, with Nurses Sarah Trimble, Christie Watson and Liz Welch covering day and night shifts. Elizabeth required frequent suctioning, as she had for some time, and had some episodes of temporary breathing cessation as previously. However, these seem from the records and from what we heard to have been managed well, and it is clear from contemporaneous evidence that they formed a good rapport with Elizabeth's parents.<sup>21</sup>

**A6.27** Nestor Primecare had undertaken to Elizabeth's parents and to the Health Authority that they would put together a team of nurses that were dedicated solely to Elizabeth's care.<sup>22</sup> It was, however, very clear to Elizabeth's parents by this point that the group of nurses did not comprise a clinical team.<sup>23</sup> They were disparate individuals who were only brought together once, during the 'refresher' half day training in tracheostomy care at Naomi House, and met otherwise only when one nurse handed over to another at the shift change. They did not have any case reviews together, and they did not meet with health authority, primary care or community staff other than incidentally. This was not teamworking in any meaningful sense: it was a nursing roster that was filled from day to day.

**A6.28** On 30 November 2001, a Friday, the day shift was taken by Helen Janes, a nurse working for an agency that was another part of the Nestor Healthcare Group. This was not expected by Elizabeth's parents because she had not previously been identified to them by Nestor Primecare, although she had attended the refresher training at Naomi House four days previously. Ms Janes subsequently told the NMC that "following handover by the night nurse [Liz Welch] to me I felt apprehensive as to my abilities to look after baby Elizabeth mainly because of the tracheostomy. I expressed my doubts to Elizabeth's parents and they gave me moral support and said they would assist me with Elizabeth's nursing care where necessary".<sup>24</sup> This re-emphasised the challenging nature of managing Elizabeth's tracheostomy to her parents, and also demonstrated the importance of engaging them honestly and openly. The shift passed off uneventfully.

**A6.29** Mr Collins attended the house on the morning of 30 November 2001. Subsequent accounts are consistent on one point, that Elizabeth's parents raised again their concern about Ms Aburime's competence to nurse Elizabeth. It seems that his response was to praise Ms Aburime's abilities and experience, although again it is not clear on what evidence he based this response.

**A6.30** During the same day, the skin around Elizabeth's tracheostomy site became reddened and inflamed, perhaps through minor trauma associated with tracheostomy care. The GP surgery was contacted, but it was too late in the day for a swab to be sent for bacteriological testing. The family GP, Dr Michelle Sinclair had not been involved in Elizabeth's care beyond ensuring that a Health Visitor was assigned to Elizabeth, and necessary prescriptions were signed; her experience of very complex, specialised child care was insufficient to allow anything more.<sup>25</sup> The only doctor who saw Elizabeth after she went home was a doctor from the out of hours service who attended the following day and prescribed a topical antibiotic.

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<sup>21</sup> Nestor Primecare nursing records: Elizabeth Dixon.

<sup>22</sup> Angela Single interview 26 July 2018.

<sup>23</sup> Report into the preparation and delivery of nursing care to Elizabeth Jean Dixon in the Community, Graeme Dixon 12 June 2002.

<sup>24</sup> NMC Hearing transcripts.

<sup>25</sup> Dr Michelle Sinclair interview 12 July 2018.

**A6.31** The weekend of 1 December 2001 and 2 December 2001 passed uneventfully for Elizabeth, with both day shifts covered by Ms Janes and night shifts by Ms Welch and another nurse provided through Nestor Primecare, Anne Pearse.





# APPENDIX 7: ELIZABETH'S LAST NIGHT

**A7.1** By Friday 30 November 2001, Nestor Primecare had not identified a nurse to cover the night shift for Elizabeth on the following Monday, 3 December. There were three possibilities for the Nestor Primecare senior nurse manager, Mr Collins: he could have asked if Naomi House would take her back for a night or two, in accordance with the original plan to introduce home care gradually; Ms Ward, an experienced nurse manager could have covered the shift, as she had already volunteered to do;<sup>1</sup> or he could deploy a nurse new to Nestor Primecare, Joyce Aburime. As has been seen (see Appendix 6), Ms Aburime was not a qualified children's nurse and had no experience in infant tracheostomy care; Elizabeth's parents had expressed their reservations about her capabilities again to Mr Collins that day. Yet when Ms Robinson contacted him about Monday's night shift, he advised her to telephone Ms Aburime.

**A7.2** Ms Aburime demurred, as she was due to begin her induction into the company on the same Monday.<sup>2</sup> She had no mobile phone and did not know who to contact in an emergency (although Nestor Primecare's policy merely appeared to be to call 999).<sup>3</sup> Ms Robinson made these points to Mr Collins, but he directed her to put Ms Aburime down for the shift anyway as her induction could be postponed.<sup>4</sup>

**A7.3** The evidence is clear that it was Mr Collins who made the ultimate decision to deploy Ms Aburime, and bore professional responsibility for it. Ms Robinson was in no position to question the decision as a non-clinical patient coordinator. It is also clear, however, that Ms Ward knew too, because she had volunteered to cover the shift in question and had been told by Mr Collins that the reason it would not be necessary was that Ms Aburime had been rostered instead.<sup>5</sup> Ms Ward did have a professional responsibility to challenge this, but she "felt the decision was semi taken away from her" and that she "felt a tinge of relief that she did not have to do a night shift".<sup>6</sup> Ms Ward had interviewed Ms Aburime for her appointment with Nestor Primecare and so must have been aware of her unsuitability for the role she was being rostered for, but raised no objection.

**A7.4** At this point, Ms Aburime was working as part of the University Hospitals Coventry and Warwickshire NHS Trust, and the records<sup>7</sup> indicate that she retained this role throughout her employment with Nestor Primecare.<sup>8</sup> It is not possible to tell from the records available what work she may have done in Coventry as part of the nurse bank over the weekend. This appears to have been routine practice, and nurses evidently saw no practical problems in working consecutive shifts both for the NHS and for agencies such as Nestor Primecare.<sup>9</sup> It is incumbent on the

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<sup>1</sup> Susanne Ward Witness Statement 18 December 2003.

<sup>2</sup> Police interview, Joyce Aburime 26 February 2007.

<sup>3</sup> Lucy Phillips interview 18 December 2019.

<sup>4</sup> Annette Robinson Witness Statement 22 September 2005.

<sup>5</sup> Susanne Ward Witness Statement 18 December 2003.

<sup>6</sup> Susanne Ward interview 26 July 2018.

<sup>7</sup> University Hospitals Coventry and Warwickshire NHS Trust papers.

<sup>8</sup> Nestor Primecare records: Joyce Aburime.

<sup>9</sup> Christie Watson interview 17 July 2018.

practitioner and their agency supervisor to ensure that such practice is not unsafe for the patient. Although Nestor Primecare rotas included commitments to several weeks of consecutive night shifts for nurses in full time NHS employment, there is no evidence that anyone within Nestor Primecare was monitoring their overall workload.<sup>10</sup>

**A7.5** On Monday 3 December 2001, Elizabeth passed a fairly comfortable day, seeming to require suction less often than usual and sleeping well. Ms Aburime arrived at Elizabeth's home around 5pm, in readiness to cover the night shift. She had driven from the Coventry area, a drive of some two hours, and Mrs Dixon offered to make her a meal before she took over at 8pm, but she left to eat elsewhere. She returned around 7pm for a handover from Sarah Trimble who had covered the day shift.<sup>11</sup> Ms Trimble spent the hour explaining the equipment, including the oxygen supply, suction, nasogastric tube and pump for nasogastric feeding, and the medication, including the two forms of morphine, a regular long acting preparation and a rapid acting form for pain that might become apparent between doses.<sup>12</sup> Elizabeth's parents observed that the explanation of the drug regime took most of the time, and that Mrs Dixon assisted with the equipment.<sup>13</sup> Ms Trimble then left for her lodgings, as she was due to take over again at 8am on the following morning.

**A7.6** From 8pm until 11:30pm, Ms Aburime and Mrs Dixon looked after Elizabeth together, Mrs Dixon showing Ms Aburime how to carry out some of the procedures which Ms Aburime seemed unfamiliar with, such as flushing the nasogastric tube, using the nebuliser and leaving a suction catheter primed.<sup>14</sup> After Mrs Dixon went to bed, Mr Dixon intended to stay awake until the early hours as he usually did, but understandably became tired and went upstairs around an hour later as it had been his first day back at work.

**A7.7** From then until around 7am on the morning of Tuesday 4 December, the only eye witness accounts of what happened are those of Ms Aburime. Unfortunately, she has given four different accounts, all of which are contradictory, and it is clear that none can be relied upon.

**A7.8** At some time on the morning of Elizabeth's death, she completed the shift nursing record and signed for drugs administered in the drug record;<sup>15</sup> some days or weeks later in 2002 she wrote and then amended a statement left with Nestor Primecare for use in what she had been told would be an internal inquiry;<sup>16</sup> in 2004 on hearing that she was to face proceedings by the NMC she wrote and signed a formal witness statement in defence of why her actions should not lead to her being struck off the professional register;<sup>17</sup> and in February 2007 she was interviewed under caution to the police while they were considering the case for criminal charges.<sup>18</sup> Not only are parts of these statements inconsistent with each other, they also conflict with other documented evidence for the periods before and after the night in question. The later the statement, the more exacting the pressure she was under to tell the truth; but the later the statement, the larger the risk she was facing, the more distant she was from events and the more information she had about what others had said about her actions.

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<sup>10</sup> Nestor Primecare papers: nursing rotas February 2002.

<sup>11</sup> Report into the preparation and delivery of nursing care to Elizabeth Jean Dixon in the community, Graeme Dixon, 12 June 2002.

<sup>12</sup> Sarah-Jane Trimble Witness Statement 6 September 2003.

<sup>13</sup> Report into the preparation and delivery of nursing care to Elizabeth Jean Dixon in the community, Graeme Dixon, 12 June 2002.

<sup>14</sup> Ibid.

<sup>15</sup> Nestor Primecare clinical records: Elizabeth Dixon.

<sup>16</sup> Nestor Primecare records.

<sup>17</sup> Joyce Aburime: witness statement for Nursing and Midwifery Council 22 March 2004.

<sup>18</sup> Joyce Aburime police interview record 26/27 February 2007.

**A7.9** The earliest record was written around the time of Elizabeth's death and formed the nursing notes. The timing of when it was written is problematic. It appears that the usual practice by Nestor Primecare nurses, though not elsewhere, was for the nursing notes to be written at the end of a shift. The entry by Ms Aburime is written in the same style, a continuous narrative – for example, what is recorded for 3am runs on in a single paragraph from what happened at 10pm, not as a separate timed entry. However, the account ends abruptly at 6:15am with nothing recorded by Ms Aburime about the final events.<sup>19</sup> If this account was written when Ms Aburime returned to the house later it should have included the events surrounding the death, and not ended at 6:15am. It is not clear what would have prompted it to be written between 6:15am and 7:00am, well in advance of the shift ending and contrary to usual practice by Elizabeth's nurses; nor is it clear what Elizabeth's condition would have been at the time.

**A7.10** The note also records that "Lizzie was awake and playing at 6am",<sup>20</sup> which would have been contrary to all accounts of Elizabeth's development and mental capabilities. Ms Aburime herself later told police that her statement to Nestor Primecare contained inaccuracies, and that statement was clearly based on her own shift notes as well as on the notes of the nurses from previous shifts. Taking all of this into account, it is impossible to conclude that the shift notes were accurate or can be relied upon as a description of events.

**A7.11** The nursing note recording the overnight shift makes no mention of any events or actions before 10pm. There is also no entry in the drugs chart to suggest that Elizabeth was given a saline nebuliser at 8pm, when it was due. This must be compared with Elizabeth's parents' account of the evening, that Ms Aburime had to be shown how to assemble and use the nebuliser at 8pm and Elizabeth's mother gave the first nebuliser herself.

**A7.12** Ms Aburime signed for more saline at 10 pm and recorded using the saline nebuliser at 10pm in the notes and drug record. She noted that Elizabeth had been restless and wheezy. This was also recorded in Ms Aburime's 2002 Nestor Primecare statement. The shift nursing note does not mention suctioning Elizabeth at this time. Based on the contemporaneous records and on the parents' account,<sup>21</sup> it seems that Elizabeth's mother carried out suctioning around 10pm, because she realised that it was due and that Ms Aburime was unsure of what to do, and also reminded her to keep a fresh catheter attached to the suction machine ready to use at all times. Ms Aburime's later statements on this issue are in conflict with this. In her statement to Nestor Primecare made in 2002, Ms Aburime asserted that she wanted to suction Elizabeth around 10:30pm but "mum told me not to." In her NMC statement she said she suctioned Elizabeth at 10:30pm after Elizabeth's mother told her to "go to see to the child". In her police interview, Ms Aburime said that she showed Elizabeth's mother how to suction, not the other way around, and that Elizabeth's mother was "quite happy" and told her she was good at it.

**A7.13** Prior to this suctioning at 10:30pm on 3rd December 2001, according to the records, Elizabeth had not been suctioned for over 12 hours. Each suctioning should have been recorded in the nursing notes, together with some assessment of whether it was productive. There should have been a proforma on which to record hourly and two hourly checks at the time they were done, with a record of any suctioning and its results, but this was never provided for the nurses by Nestor Primecare. As it is clear that not all were recorded, it is not possible to tell from the absence of further records whether that was the last time Elizabeth was nebulised and suctioned before she died.

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<sup>19</sup> Nestor Primecare nursing records: Elizabeth Dixon.

<sup>20</sup> Ibid.

<sup>21</sup> Report into the preparation and delivery of nursing care to Elizabeth Jean Dixon in the Community, Graeme Dixon, 12 June 2002.

**A7.14** According to her Nestor Primecare statement,<sup>22</sup> Ms Aburime had given Elizabeth two of her medicines, triclofos and Docusate. But her nursing notes do not mention Elizabeth being given two others that were due, Gaviscon and ranitidine, although the ranitidine was signed for on the drug chart. She had also given Elizabeth some liquid paracetamol, although it appears that she needed guidance from Elizabeth's parents in how to flush it through the nasogastric tube, but this again was not signed for in the drug chart. At 2am, a 25mg dose was due of MST, a long-acting morphine preparation, and was recorded as given, but the subsequent controlled drugs check revealed that the sachet had not been used. Instead 13ml of a rapid-acting morphine preparation, Oramorph, equivalent to 26mg of morphine, was missing. Ms Aburime first stated that this was an error due to confusion over the different forms of morphine,<sup>23</sup> then subsequently that she had consciously intended to give the Oramorph instead of the MST – but that she had given only the 12.5mg of this form that was prescribed, and the remaining Oramorph solution unaccounted for was as a result of there being less in the bottle than the records indicated at the start of the shift.<sup>24</sup>

**A7.15** Ms Aburime's statement to Nestor Primecare in 2002 claimed that she suctioned Elizabeth twice between midnight and 3.30am. However, there is nothing in the contemporary nursing notes to confirm this, which show no record that Elizabeth was nebulised or suctioned between 10:30pm and past 4am.<sup>25</sup> These notes say that Elizabeth settled and slept until she had a bowel movement at 3am, then became 'restless and wheezy' at 4am, was given another saline nebuliser then and that suctioning at the time 'did not produce much effects'. The nursing note continued that Elizabeth settled with cuddles but stayed restless and wheezy for 'well over' an hour, that another attempt was made at suctioning at 5.45 am with the assistance of extra 'sodium chloride' at a lower dilution, and that 'Lizzie appears to be cyanosed during the attacks.'<sup>26</sup> In her police interview, Ms Aburime suggested that she suctioned the tracheostomy "throughout the night", the last occasion being shortly before 7am when Elizabeth became cyanosed.<sup>27</sup>

**A7.16** In her Nestor Primecare statement, Ms Aburime said that after 3.30am Elizabeth was wheezing and turning blue; and that she "kept suctioning, gave nebulisers 2 hourly and at a certain stage instilled 0.2ml sodium chloride...I remarked in the nursing cardex that the suctioning was not very effective and I had a better result with the sodium chloride. I must have suctioned her at least 6 times during this time."<sup>28</sup> This statement claimed that Elizabeth then recovered spontaneously, was active, comfortable and smiling for an hour, had a sudden apnoea and did not recover. This statement is not a credible account of events, partly in light of the subsequent course of events and the demonstrably blocked tracheostomy tube, and partly because Elizabeth's neurological condition made her unable to show behaviour such as playing and smiling. This was a fact evidently lost on Ms Aburime as she was insufficiently familiar with Elizabeth's condition.

**A7.17** In her NMC statement in 2004,<sup>29</sup> Ms Aburime said that she spent the whole night suctioning Elizabeth every half hour using 2 catheters each time, and giving her saline nebulisers every 2 hours, filling in the medical records while she went; and then Elizabeth suddenly went limp at which point Ms Aburime thought she had better go for help.

**A7.18** It is clear that not only are there very significant inconsistencies in these statements, the version of events that they present becomes progressively more defensive over time. Further, they

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<sup>22</sup> Nestor Primecare records.

<sup>23</sup> Joyce Aburime: witness statement for Nursing and Midwifery Council 22 March 2004.

<sup>24</sup> Joyce Aburime police interview record 26/27 February 2007.

<sup>25</sup> Ibid.

<sup>26</sup> Ibid.

<sup>27</sup> Joyce Aburime police interview record 26/27 February 2007.

<sup>28</sup> Nestor Primecare records.

<sup>29</sup> Joyce Aburime: witness statement for Nursing and Midwifery Council 22 March 2004.

all conflict significantly with both contemporary and subsequent evidence of others. In particular, the controlled drug charts indicated that 13ml of Oramorph had been given, equivalent to a dose of 26mg,<sup>30</sup> and no suction tubes had been used overnight prior to the events that occurred around 7am.<sup>31</sup>

**A7.19** It is impossible to place significant weight on any of these accounts and the version of events that they give: they must all be regarded as unreliable. Unfortunately, all of the previous investigations of Elizabeth's case have, to a greater or lesser extent, relied on one or more of them. Taking all of the available evidence into account, and drawing on the contemporaneous and subsequent evidence given by others, the following represents the most probable sequence of events on that night.

**A7.20** At 2am, Ms Aburime administered a morphine preparation in error. She should have given a long-acting form of morphine, 25mg MST, as regular pain relief. Instead, she administered 26mg of Oramorph, a quick-acting morphine preparation that was intended to be used in a dose of 12.5mg in response to signs of breakthrough pain. Although the dose of morphine was not dissimilar to the intended dose of MST, it would have had a markedly sedative effect in view of its rapid action, and it was more than double the dose prescribed of that form of morphine.

**A7.21** As has already been established, Elizabeth was regularly troubled by mucus secretions in her airways, which required suctioning to clear. She had not received the regular suctioning that she should have had over the previous hours. The increased sedation consequent upon the morphine medication error would have reduced her breathing effort, potentiating the build-up of mucus secretions in her tracheostomy tube. At some point during the small hours of the night, the tracheostomy tube started to become blocked.

**A7.22** This would have been signalled partly by increased respiratory efforts by Elizabeth (although it is possible that these would be somewhat masked by her increased sedation) and partly by wheezing noises from the narrowing bore of the tracheostomy tube. Had Ms Aburime been paying adequate attention to Elizabeth's condition, this must have been apparent even given her inexperience with tracheostomy in a small infant. In consequence, it is very difficult to conclude that she was paying attention to Elizabeth's condition. Although it is impossible to be sure, this is more likely than not to have been because she had fallen asleep. She had driven to Hampshire from Coventry that afternoon, with less than two hours break before commencing the night shift. We cannot exclude the possibility that she had also done a 'bank' shift in Coventry during the previous 24 hours, because the records are inadequate to confirm or deny this.

**A7.23** The alternative would be that Ms Aburime stayed awake while Elizabeth began to wheeze progressively and began to turn blue, perhaps making attempts at nebulisation and suctioning (with the catheter left ready by Elizabeth's mother), but failing to recognise that Elizabeth's condition was becoming seriously and progressively compromised or that she required a tracheostomy tube change. It may be that Ms Aburime lacked the confidence to change the tracheostomy tube in a small infant, but she should have woken Elizabeth's parents or called for assistance, and it seems difficult to believe that she would have done nothing knowing that Elizabeth's airway was becoming completely blocked. It is equally hard to believe that even as a recently qualified nurse she would have failed to realise the seriousness and acute urgency of Elizabeth's condition. It seems more likely that she had fallen asleep.

**A7.24** Whatever the cause, Ms Aburime remained unaware of Elizabeth's predicament until shortly before 7am, when she clearly became aware that something was very wrong indeed. In

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<sup>30</sup> Nursing and Midwifery Council records: Joyce Aburime.

<sup>31</sup> Sue Watson interview 12 July 2018.



light of all of the supporting evidence, it seems that Elizabeth was incapable of resuscitation at that point, and had most probably been dead for some time.

**A7.25** Whatever scenario may be imagined, it can provide no comfort to Elizabeth's parents, and has understandably been the source of much torment for them. On the balance of probabilities, we believe that Elizabeth died quite quickly, due to the shortage of oxygen caused by blockage of her tracheostomy tube by a build-up of thick mucus. We believe that this most probably happened at a time when her respiratory effort was compromised by the overdose of rapid-acting morphine, which both allowed the accumulation of mucus to build up and reduced the time that Elizabeth struggled to overcome the blockage because she was more sedated. The implication is that Elizabeth died prior to 7am, most probably several hours earlier.

**A7.26** When Ms Aburime belatedly realised that something had gone very wrong, she picked Elizabeth out of her cot and carried her upstairs, crying out incoherently to Elizabeth's parents. This was a bizarre reaction if Elizabeth had just collapsed and died in front of her eyes, and suggests that at some level Ms Aburime realised that Elizabeth was already dead. Certainly, any attempts at resuscitation depended on her being in her room with suction equipment close to hand. Being unaware of the position, Elizabeth's mother naturally took her daughter back to her cot where she attempted resuscitation. She quickly realised that she could not pass a suction tube through the blocked tracheostomy tube, which she therefore changed, correctly and appropriately, but unfortunately without respiration returning.

**A7.27** Given the shock of Elizabeth's lifelessness and its inexplicable nature (at that point), Elizabeth's parents contacted the emergency services, as was both understandable and appropriate. It is clear that Ms Aburime did not take charge of the situation: she neither attempted to resuscitate Elizabeth nor contacted the emergency services prior to Elizabeth's mother taking over and asking her to. She had never dealt with an infant tracheostomy or an emergency paediatric resuscitation and she had not worked on her own with patients with complex conditions. In taking the handover from Ms Trimble the evening before, however, in circumstances she knew she was not competent to manage, Ms Aburime had accepted professional nursing responsibility for Elizabeth's care.

**A7.28** As appropriate to the highest priority ambulance call, a paramedic was sent at the same time as an ambulance was despatched, and William Porter recorded his arrival at 7:26am. He found Elizabeth with a tracheostomy tube in place, which he did not realise that Elizabeth's mother had just changed, but not breathing. He administered oxygen and suctioned the tracheostomy tube in the hope of triggering breathing. One minute later an ambulance vehicle arrived and the crew began hand ventilation and cardiac compression, as Elizabeth had no respiratory effort or pulse.<sup>32</sup>

**A7.29** The ambulance staff at the site decided that Elizabeth should be taken urgently to Frimley Park Hospital. She was put into the ambulance still being hand ventilated and given chest compressions, and the ambulance left the house at 7.36am.<sup>33</sup> They arrived at Frimley Park Hospital at 7.50am and an emergency call was made at 7.55am for a team to attend Elizabeth in the resuscitation room. Elizabeth was seen by a resuscitation team comprising the paediatric registrar on call (Dr Ruth Clarnette), two anaesthetists and junior doctors from both the Emergency Department and paediatrics.<sup>34</sup>

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<sup>32</sup> Statement by paramedic, Surrey Ambulance Service 15 September 2003.

<sup>33</sup> Ibid.

<sup>34</sup> Frimley Park Hospital clinical records: Elizabeth Dixon.

**A7.30** Meanwhile, Elizabeth's father had followed the ambulance in the rapid response vehicle. On his arrival in the Emergency Department, Elizabeth's father told the resuscitation team of the agreement in place that excluded invasive interventions for Elizabeth. The clinical staff recorded in the notes that Elizabeth was both very pale and cold, and that she had neither heart beat nor respiration, but they tried further cardiac compressions and two more minutes of ventilation with bag and mask before agreeing within a few minutes that it was time to declare her dead, at 8.05am.

**A7.31** None of the eyewitness accounts suggests that Elizabeth could have been resuscitated after 7am that morning, and she was repeatedly described as pale and cold, as well as pulseless and not breathing. It is difficult to assess the time at which a small infant died, but taking all of the evidence into account, it is most probable that she had been dead for some hours. The time of death given in the hospital notes – the time when the brief attempts at resuscitation in the Emergency Department were abandoned – was misleading and, as is set out in Appendix 8, prepared the ground for significant and far-reaching irregularities in the aftermath.



# APPENDIX 8:

## INITIAL AFTERMATH OF ELIZABETH'S DEATH

**A8.1** When Elizabeth had been declared dead in the emergency department at FPH, timed at 8:05 am on 4 December 2001, Dr Clarnette recorded the admission in the clinical notes:

*“Respiratory arrest at home. Father arrived with ambulance crew. Father informed us that ED was not for active resuscitation – she had been originally for palliative care at home but father wished to call ambulance when event came. DOES NOT want active resuscitation. Only wants cardiac compressions and bag and mask. No other intervention ie lines. On arrival: baby – tracheotomy in situ. Pale ++. Cold. No heart rate/no respiratory rate. Cardiac compressions & bag & mask. Ventilation commenced for further 2-3 minutes (had received 10 mins in ambulance). No change in clinical state – agreement with team (2 anaesthetists, 1 A&E SHO, 1 Paed SHO). Baby handed to father.”<sup>1</sup>*

**A8.2** It is clear that Dr Clarnette had no previous notes or correspondence on which to base her diagnosis and management, as would be expected when the admission was unexpected and an emergency; she rightly obtained as much information as she could from Elizabeth's father. Her mother had not yet arrived at the hospital. It is notable that Dr Clarnette described Elizabeth's care at home as 'palliative'; this is correct, as care was directed towards symptom control rather than cure, but it must be carefully distinguished from terminal or end of life care, with which it is not synonymous.

**A8.3** The consultant paediatrician on call for FPH that morning was, as it happened, Dr Tettenborn. As would be expected, he had been called to attend the emergency department urgently, and arrived by car. He was informed by Dr Dhillon, a more junior member of the paediatric team on call, that resuscitation had already been discontinued in the absence of any response. His subsequent accounts say that Dr Dhillon also told him that the resuscitation team had “acquired the information that Elizabeth was known to have a terminal disease and was not for resuscitation”. This was incorrect: Elizabeth did not have a “terminal disease”. In a subsequent statement, Dr Clarnette added “in other words, she was terminally ill” in parentheses after “palliative care”, which suggests that she erred in conflating the two terms, and it may be that Dr Dhillon did the same in speaking to Dr Tettenborn. Dr Tettenborn, however, was familiar with Elizabeth's condition, and knew that she was not terminally ill. Less than two months previously, he had told a planning meeting for Elizabeth's discharge that her educational needs would be reviewed at the age of two.<sup>2</sup>

**A8.4** By now, Elizabeth's mother had arrived at the hospital, and Dr Clarnette went to speak to her. Mrs Dixon was naturally shocked and upset, but Dr Clarnette subsequently reported that she had also been hostile towards Joyce Aburime, saying words to the effect that Ms Aburime had

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<sup>1</sup> FPH Hospital records.

<sup>2</sup> Health Authority minutes of planning meeting 24 October 2001.

killed her child.<sup>3</sup> Ms Aburime later confirmed that Elizabeth's mother said this to her at FPH. This was, Dr Clarnette said, outwith her previous experience of bereaved relatives, but there is no evidence that Dr Clarnette enquired further of Elizabeth's parents as to what may have prompted the reaction.

**A8.5** Dr Tettenborn also then spoke to Elizabeth's parents with Dr Clarnette, but Elizabeth's mother apparently did not repeat what she had said about Ms Aburime's role in Elizabeth's death, and Dr Tettenborn told us that he was unaware of it at the time. It is, however, difficult to believe that Dr Clarnette made no mention of it to Dr Tettenborn, especially given that Dr Tettenborn then discussed with her how to complete the medical certificate of cause of death (MCCD).

**A8.6** Dr Tettenborn told us that by the time he arrived in the emergency department the resuscitation team had already concluded that Elizabeth had a terminal condition and had died from natural causes. He first said that the resuscitation team had read Elizabeth's GOSH notes and concluded that she had progressive neuroblastoma, but in fact the GOSH notes had neither been sent to FPH nor copied to FPH.<sup>4</sup> He subsequently clarified that he meant that Dr Dhillon had read letters from GOSH in the FPH notes.<sup>5</sup> The only correspondence in Elizabeth's FPH notes covering her clinical condition on leaving GOSH was the discharge summary signed by Dr de Sousa dated 23 October 2001. This mentions bilateral neuroblastomas, but does not describe them as progressive or life-limiting. The section on prognosis states that:

*"It is certain that she has a condition that will cause life-long and severe neuro-developmental retardation. Because of the severity of this condition, its early onset and the association with severe respiratory illness, Elizabeth is at increased risk of sudden death. However it is not possible to predict with certainty whether she will survive and for how long."*<sup>6</sup>

**A8.7** There is no suggestion in this record that Elizabeth had a terminal condition due to progressive neuroblastoma. It may be thought that the use of the term "sudden death" meant that she could collapse and die without warning, but Dr de Sousa's preceding sentence clarifies the nature of what he meant: "If Elizabeth should have a sudden, life threatening episode then she should be made comfortable but should not be given artificial ventilation..." This was how all of the GOSH clinicians that we spoke to told us that they assumed she would die: through an unpredictable respiratory infection associated with the tracheostomy at an indeterminate point in the future. It is impossible to read the whole discharge summary and conclude that any unexplained sudden collapse was consistent with natural causes prompted by progressive neuroblastoma, and there was nothing to suggest that Elizabeth had had a preceding severe respiratory infection.

**A8.8** Following a conversation with Dr Tettenborn, Dr Clarnette completed the medical certificate of cause of death (MCCD). While she was doing so, Dr Tettenborn wrote in Elizabeth's notes, the last entry in her clinical record:

*"Child well known to me.*

*(1) Severe neurodevelopmental disorder*

*(2) Progressive neuroblastoma*

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<sup>3</sup> Police statement by Dr Ruth Clarnette, 2006.

<sup>4</sup> Dr Michael Tettenborn interview 26 July 2018.

<sup>5</sup> Dr Michael Tettenborn interview 13 December 2018.

<sup>6</sup> GOSH Discharge summary 23 October 2001.

*Already discussed and not for resuscitation. Discussion with nurse in attendance at home indicates sudden Cardiac Arrest. Has previously had these but with spontaneous recovery.*

*Death consistent with natural causes.”<sup>7</sup>*

**A8.9** This entry is incorrect in almost every significant respect. At the outset, Dr Tettenborn states that Elizabeth is well known to him, suggesting that he is able to supply information that would not be evident from the FPH notes and therefore known to the resuscitation team. He identifies the first salient condition as severe neurodevelopmental disorder, which is accurate, and it was the principal clinical problem leading indirectly to her death. He identifies the other salient condition as progressive neuroblastoma. This incorrect – her condition was not progressive – and it is the only time that ‘progressive neuroblastoma’ appears in the FPH notes.

**A8.10** After noting that Elizabeth was “not for resuscitation” – which omits the crucial rider that her parents wanted any asphyxia to be reversed – Dr Tettenborn then states that discussion with Ms Aburime leads him to suppose that she had had a cardiac arrest. It is worth noting that nothing in any of the various accounts given by Ms Aburime of Elizabeth’s death would support a sudden cardiac arrest. “Has previously had these but with spontaneous recovery” is also incorrect: Elizabeth had had a single low-output cardiac episode associated with a medication change in GOSH and it had been reversed with further medication. It is apparent that the inaccuracies in this entry in the clinical record all lead towards the final sentence that death was “consistent with natural causes”.

**A8.11** Dr Clarnette said that she completed the MCCD on the basis of a private conversation with Dr Tettenborn, during which he requested that she should complete the MCCD and guided her in how it should be completed. She accepted this guidance as Dr Tettenborn had been the “Consultant personally involved in [Elizabeth’s] care”, and she was clear that her “conclusions would have been arrived at following consultation with Dr Tettenbourn [sic]”.<sup>8</sup>

**A8.12** The MCCD was completed on the basis that Dr Clarnette had seen Elizabeth alive on admission to FPH, which was questionable to say the least in light of the accounts of Elizabeth being pulseless and cold with absent respiration when the ambulance and paramedic arrived at the house, regardless of the brief period of attempted resuscitation. In order to complete the MCCD, however, it was necessary for Dr Clarnette to be able to say that she had seen Elizabeth before death, as she had not previously been her medical attendant. The cause of death was given as bilateral neuroblastoma stage 4, with contributory factors of tracheobronchomalacia associated with extreme prematurity with recurrent apnoea and cyanosis.

**A8.13** In contrast to Dr Clarnette’s statement, Dr Tettenborn told us that he had not spoken to her about how to complete the MCCD, and he “could not say why Dr Clarnette’s statement said that [he] guided her to say it was expected and in how to complete the death certificate”; he suggested that she “might have wanted to check the death certificate process with [him]”.<sup>9</sup> However, Dr Clarnette was an experienced paediatric registrar familiar with the death certification process, and she had no reason to believe that the cause of Elizabeth’s death was progressive neuroblastoma unless Dr Tettenborn told her it was: there is no suggestion that this was the case in any documentation available to Dr Clarnette or the resuscitation team.

**A8.14** Dr Clarnette telephoned the Surrey Coroner’s office to discuss Elizabeth’s death, as she was required to do for any death in childhood by the hospital’s protocol. The timing of this

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<sup>7</sup> FPH Elizabeth Dixon clinical notes.

<sup>8</sup> Police statement by Dr Ruth Clarnette.

<sup>9</sup> Dr Michael Tettenborn interview 13 December 2018.



telephone call is not certain, but it seems probable that it followed the conversation between Dr Tettenborn and Dr Clarnette, as she had no information relevant to Elizabeth's clinical condition after discharge from GOSH until that conversation. Dr Tettenborn told us that nursing staff at FPH had contacted the Coroner's office before his arrival at the hospital to say that her death had been from natural causes.<sup>10</sup> This would be an extremely unusual task for a nurse, and it is most unlikely that the Coroner's officer would have accepted the information without speaking to a registered medical practitioner. Assuming the information conveyed in Dr Clarnette's call was essentially that in the MCCD and the final entry in the clinical notes, that Elizabeth had succumbed to a progressive and terminal illness, it is not surprising that no further action was required by the Coroner's office at that point.

**A8.15** Shortly after that call, Dr Clarnette completed the first clinical section of a Cremation form – Form B as then described – because, she said, she had been warned that a cremation would be requested. It is not clear on what basis this 'warning' was given. The cause of death was identical with that on the MCCD, but the mode of death, respiratory arrest, differed from Dr Tettenborn's clinical note which referred to cardiac arrest. It is notable that respiratory arrest of 30 minutes' duration, as recorded on Form B, would be incompatible with Elizabeth having been alive on arrival at FPH at 7:55am and dying at 8:05am, and therefore with Dr Clarnette having seen her while still alive.

**A8.16** Dr Tettenborn offered to drive Mr and Mrs Dixon home with Elizabeth's body, and the two Primecare nurses, Ms Aburime and Ms Trimble. This was a highly unusual step. Not only was transporting the recently deceased body in a private car unconventional to say the least, there must clearly have been a significant degree of interpersonal tension around Ms Aburime in the light of the views expressed by Mrs Dixon at FPH.

**A8.17** On one hand, it may be supposed that this was an altruistic offer by Dr Tettenborn. Elizabeth's parents were naturally very distressed and keen to leave the hospital environment. They wanted to take her home. The FPH emergency department staff had suggested that they would have to wait two hours for an ambulance. Dr Tettenborn said that he "reluctantly agreed" to take them home in view of the "exceptional degree of distress being shown particularly by Mrs Dixon".<sup>11</sup>

**A8.18** On the other hand, it cannot escape attention that every minute that passed while Elizabeth's parents were still in the hospital raised the chance that they would say something that would cast doubt on the version of events now recorded in the clinical notes, in the MCCD and in the Cremation Form B, that Elizabeth was terminally ill with progressive cancer. Moving them from the FPH Emergency Department and Dr Clarnette brought that possibility to an end.

**A8.19** In either case, there should have been some concern about putting the nurses in the same car as the family and the body of their daughter, for the sake of all concerned. When the car arrived at the family home, Dr Tettenborn simply allowed the passengers to disembark and left while they were still on the drive.

**A8.20** Elizabeth's parents went upstairs to be alone with the body of their daughter. Ms Aburime did not stay long, and did not speak to Elizabeth's parents before she left, although they tried to speak to her when they heard her go through the front door.

**A8.21** Around 11am, Sue Watson, the health visitor assigned to the family, arrived at the house. She had been telephoned by Elizabeth's father, who said to her after she arrived that "the tracheostomy tube was blocked and that was why she had died".<sup>12</sup> Ms Watson subsequently

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<sup>10</sup> Dr Michael Tettenborn interview 26 July 2018.

<sup>11</sup> Police statement, Dr Michael Tettenborn.

<sup>12</sup> Sue Watson interview 12 July 2018.

began to assist Ms Trimble in tidying up Elizabeth's room, but they were asked not to move anything by Elizabeth's parents. Elizabeth's mother pointed out the tracheostomy tube that had been in place until she had replaced it with a new one in an attempt to resuscitate Elizabeth, and Ms Watson helped her to bag it for safe keeping. Ms Watson told us that she held the tube up to the light and could see that it was completely blocked; additionally, the suction tubes that should have been used overnight were still in their sealed wrappers.

**A8.22** Contrary to what should have happened, Ms Aburime had left the scene without completing a contemporaneous account of what had taken place, and had not completed the handover necessary given that Elizabeth was receiving two forms of morphine, a controlled drug. Ms Trimble and Ms Watson undertook the controlled drug check, and immediately discovered a discrepancy. A 25mg dose of long-acting morphine sulphate, MST, had not been administered overnight as it should have been, but 13ml of a rapid acting morphine preparation, Oramorph, was missing, equivalent to a 26mg dose. Realising the potential significance both of the drug discrepancy and the blocked tracheostomy tube, they undertook to inform colleagues. The first one Ms Watson was able to contact was Sue Mitchell, child protection team leader at the health authority. Ms Watson told us that Ms Mitchell instructed them (Ms Watson and Ms Trimble) to record everything together; and also not to tell the parents about the drug error, so they therefore did not do so.

**A8.23** It is difficult to unpick the exact sequence of notification about the blocked tracheostomy tube and the morphine overdose, because accounts are not always consistent, contemporaneous records were not generally kept and participants were not questioned on the timing until much later. What is clearly evident, however, is that at Nestor Primecare, Paul Collins was notified; at the Health Authority, Linda Wollam; and at Naomi House, Maggie Fry.

**A8.24** We could find no evidence of any immediate response by Nestor Primecare: they appear to have waited reactively to see what transpired. Mr Collins did tell Ms Fry that there would be an internal investigation but he left the organisation within days. Dr Bill Holmes, the Nestor Healthcare Group medical director responsible for clinical governance, said that he met Ms Aburime a few days later only because he "happened to notice that she was in head office" and introduced himself "to discuss with her how she was feeling following the circumstances around the death".<sup>13</sup> She was not asked for her note of what had happened.

**A8.25** The NHS staff who were aware appear to have been of one mind, that Dr Tettenborn should lead the response to these disturbing findings concerning Elizabeth's death. He had been designated as responsible medical officer for Elizabeth's care and, although he subsequently disputed what responsibilities were encompassed in the term, there is no doubt that overall clinical responsibility rested with him on behalf of the health authority.

**A8.26** Ms Watson spoke to Dr Tettenborn that day, and informed him of both the morphine dose discrepancy and the blocked tracheostomy tube. Dr Tettenborn told her that he would contact the Coroner's officer, but he first rang Mrs Wollam at the health authority at 5:45pm, apparently after a clinical commitment that he had that afternoon. Mrs Wollam recorded in a contemporaneous note that Dr Tettenborn had told her that Elizabeth's parents "had examined the trachy tube (which they insisted must remain at their home) which was in situ when Lizzie went 'blue' and found it to be blocked" and that "there were found to be discrepancies in terms of the administration of drugs and what was written upon the chart." The drug is not named or identified as a controlled drug, and the note records that "Mike [Tettenborn] did not feel that this would have caused Lizzie to die however."<sup>14</sup>

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<sup>13</sup> NMC Hearing, Dr William Holmes evidence 11 January 2005.

<sup>14</sup> North and Mid Hants HA file.

**A8.27** Dr Tettenborn then called the Coroner's officer as agreed with Mrs Wollam. There are different versions of the dialogue that took place with Sue Masters, the Surrey Coroner's officer who covered FPH. Dr Tettenborn has said consistently ever since that – as he put it to us – he explained to Ms Masters about the wrong form of morphine, and that he had been told that a blocked tracheostomy tube had been found. Ms Masters has said consistently since that – as she put it to us – she was told that Elizabeth's death was expected, and that she had no recollection of anyone mentioning a blocked tracheostomy tube or any missing morphine. Ms Masters had also spoken to Maggie Fry at Naomi House about Elizabeth's case, and Ms Fry subsequently told a disciplinary hearing against Ms Masters that she had discussed the blocked tube; Ms Fry subsequently told us that she “could not recall for sure but thought that she probably did [mention the blocked tracheostomy tube]”.<sup>15</sup>

**A8.28** Having considered all of the evidence that we have seen and heard, it seems that both the blocked tracheostomy tube and the medication error were part of Dr Tettenborn's conversation with Ms Masters, but we believe that the context was such that she was encouraged to think that they were not material. Dr Tettenborn told us that he could “not comment further about the tube without more information, such as whether it been taken out electively and replaced” – that is, it may not even have been the tracheostomy tube in place when Elizabeth had died and that was replaced by her mother in an attempt to revive her.<sup>16</sup> Subsequently, he said that when he phoned Ms Masters he had told her that he would need more information before he could comment on the blocked tube: the nurse had told him only that they had found a blocked tracheostomy tube on site and he did not ask the nurse under what circumstances she found it, or whether the tube had been there the night before because he felt it needed a full review and for the Coroner's officer to speak to the parents and the nurse. He also said that he told Ms Masters that the total dose of morphine had been the same as intended although in a faster acting form.<sup>17</sup>

**A8.29** Given the clarity with which he conveyed the information that the blocked tracheostomy tube had been the relevant one to Mrs Wollam, his reticence with Ms Masters and subsequently is hard to comprehend; conversely it seems he may not have identified which drug was involved in the medication error to Mrs Wollam.

**A8.30** Dr Tettenborn has stressed to us and others that in his view the right person to answer any uncertainties surrounding the provenance of the blocked tracheostomy tube and the effect of the wrong form of morphine being prescribed was the Coroner's officer. However, a notifying doctor is required to provide as much information as possible to assist the Coroner, including both medical details and any other information that may be relevant, not to withhold salient facts to be discovered by an investigation by the Coroner's officer.

**A8.31** Whatever the intention of Dr Tettenborn's communication with Ms Masters, it is clear that she did not consider the death to warrant a recommendation to the Coroner to open an inquest. She spoke to Elizabeth's parents by telephone that evening (4 December 2001) at Naomi House where they had taken Elizabeth's body to stay in their rest facility. It appears that she asked them if they would be prepared to have a post mortem examination and, she told us, if they had any concerns about Elizabeth's death. They were very opposed to the idea of a post mortem examination because they believed with some justification that GOSH were very keen to obtain a sample of her brain to research the cause of her encephalopathy, and the idea horrified them. This was poor practice by Ms Masters: if there were concerns about Elizabeth's death a post mortem examination would be legally required by the Coroner, but linking the parents' wishes regarding post mortem examination put pressure on Elizabeth's parents to minimise their concerns. They

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<sup>15</sup> Maggie Fry Interview 7 December 2018.

<sup>16</sup> Dr Michael Tettenborn interview 26 July 2018.

<sup>17</sup> Dr Michael Tettenborn second interview 13 December 2018.

should not have been put in that position, and nor should it have been used as justification not to recommend an inquest.

**A8.32** At 9pm on the same day, 4 December 2001, Mrs Wollam recorded a further phone call from Dr Tettenborn:

*“MT had spoken to Coroner’s Officer and appraised her of the issues raised by parents. COfficer had spoken to parents by phone (at Naomi House). Parents very clear that they did not want a post mortem so CO was content to leave cause of death as ‘natural causes’ – CO will speak to parents again tomorrow.”<sup>18</sup>*

**A8.33** Ms Masters told us that based on what Dr Tettenborn and the Dixons had told her that day, there was nothing that she thought needed further investigation. She told us that she informed the Coroner, who decided that there should be no further action.<sup>19</sup> There is, however, significant doubt about what the Coroner was told. Ms Masters was subsequently the subject of a police disciplinary hearing (Coroners’ officers are employed by police services) at which a case was upheld that she had “failed to provide information to the Coroner as a result of which no post mortem was held.”<sup>20</sup> We believe that Ms Masters had been placed in an invidious position having been provided with partial and misleading information herself, a position which rapidly unravelled when the details of Elizabeth’s death subsequently became less ambiguous. Had she kept a written record of the telephone calls this would have been clearer, but no record was ever found.

**A8.34** Ms Masters told us that she “would have” notified Dr Tettenborn of the final decision to take no further action on the following day, Wednesday 5 December 2001, after she had spoken to Elizabeth’s parents again to give a further chance to raise concerns (they wanted to know what had happened, she said, but remained adamant they did not want a post mortem examination); however, she also said that the call back to Dr Tettenborn was at the weekend.<sup>21</sup> There are significant reasons to think that Dr Tettenborn was not told of the final decision until later. First, in his subsequent statement to the police investigation, he said that “over the weekend, I had two or three further phone calls from Sue Masters briefing me on her investigations...”<sup>22</sup> Second, he told us that he waited all week for the Coroner’s officer to call him back and heard nothing until the Sunday afternoon (9 December 2001). He expected to be asked for further details to complete an investigation, but was told only that the parents did not want a post mortem examination; he did not question whether this was sufficient investigation because he was half asleep and groggy after being up all night.<sup>23</sup>

**A8.35** Although Dr Tettenborn’s evidence to us differs from his earlier police statement in identifying clearly that there was only a single further call from Ms Masters, it does confirm that the last call was on the Sunday, as in the police statement, not the previous Wednesday. This is also in agreement with Ms Masters’ comment to us that she called back at the weekend. It therefore seems to us that the telephone call confirming that there would be no further action on the part of the Coroner’s office did not take place until Sunday 9 December 2009.

**A8.36** On Friday 7 December, the records show that Dr Tettenborn was telephoned by Dr Elizabeth Williams, a GP who also worked at Naomi House. Dr Williams had been asked to complete the second medical section of the cremation form for Elizabeth, Form C, which

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<sup>18</sup> North and Mid Hants HA file.

<sup>19</sup> Sue Masters interview 19 December 2018.

<sup>20</sup> Gross Misconduct Hearing – Sue Masters 27 February 2007.

<sup>21</sup> Sue Masters interview 19 December 2018.

<sup>22</sup> Dr Michael Tettenborn police statement 8 February 2006.

<sup>23</sup> Dr Michael Tettenborn interview 26 July 2018.

she signed on 7 December, certifying that she had “spoken by phone to consultant Dr Mike Tettenborn” and that the cause of death was bilateral neuroblastoma.<sup>24</sup> This form required Dr Williams to sign a declaration that she knew of “no reasonable cause to suspect that the deceased... died in such place or circumstances to require an inquest...”

**A8.37** Dr Williams has said subsequently that she had no recollection of the content of the telephone conversation.<sup>25</sup> Dr Tettenborn had not received formal notification of the Coroner’s decision at that point, and he was legally and professionally obliged to tell Dr Williams that an inquest might be required. If she was aware of any Coroner’s process, she was obliged to refrain from signing the cremation form: had she signed under those circumstances, she would have been making a false declaration on a statutory form. It is very hard to believe that Dr Williams would put her career and professional standing in jeopardy in this way to sign a cremation form, and the only reasonable conclusion is that Dr Tettenborn did not tell her.

**A8.38** It seems to us that to understand how this could possibly have come about, it is necessary to return to Mrs Wollam’s contemporaneous file notes of 4 December 2001, later in the day that Elizabeth died. The first, at 5.45pm, records the first telephone call from Dr Tettenborn, and under action notes “Mike [Tettenborn] to contact Coroner’s Officer”; the record of the second call from Dr Tettenborn, timed at 9.00pm, includes “C[oroner’s]O[fficer] content to leave cause of death as ‘natural causes’...”<sup>26</sup> This is entirely consistent with Ms Masters’ account that she decided on 4 December 2001 that there was nothing that she thought needed further investigation,<sup>27</sup> but it is surprising that Dr Tettenborn was able to pass this information to Mrs Wollam within four hours of agreeing to contact Ms Masters.

**A8.39** We can only conclude that Dr Tettenborn and Ms Masters agreed between them that that would be the outcome, without any further information. In that case, it was clear to all from the outset that there would be no further investigation, no questioning of the nurses who had discovered the blocked tube and medication error, and further discussion with Elizabeth’s parents could be disregarded. The expectation that Ms Masters was on 4 December 2001 commencing a thorough investigation, was a sham.

**A8.40** Nevertheless, in the absence of a formal response from the Coroner’s office on Friday 7 December 2001, Dr Tettenborn was not entitled to assume what the outcome would be; he was still bound by professional duty to inform Dr Williams that it was unsafe for her to sign a declaration that she knew of no reasonable cause to suspect that an inquest may be required.

**A8.41** Dr Williams was subsequently required by the crematorium medical referee to contact Dr Clarnette, as was mandatory for completion of the cremation form since Dr Clarnette had signed Form B. Dr Williams could have received no further information about the involvement of the Coroner’s officer on the evening of Elizabeth’s death, because Dr Tettenborn had not told Dr Clarnette about it. Her original statement as part of Form B therefore stood from the morning of 4 December, including that the Coroner had been informed with “no further action required”; this, however, was from the telephone call she had made to the Coroner’s officer before the blocked tracheostomy tube or the medication error had come to light. Dr Clarnette was clear that “neither of these issues was ever brought to my attention”.<sup>28</sup> Given that serious doubt had been raised later on 4 December about the basis for the MCCD and Part B of the cremation form, both of which had been signed earlier by Dr Clarnette, it is surprising that she had not been informed.

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<sup>24</sup> Elizabeth Dixon cremation form.

<sup>25</sup> Dr Elizabeth Williams police statement 2006.

<sup>26</sup> North and Mid-Hampshire Health Authority file.

<sup>27</sup> Sue Masters interview 19 December 2018.

<sup>28</sup> Dr Ruth Clarnette police statement 6 June 2006.



**A8.42** Elizabeth's parents remained unaware of much of this at the time, although it would become painfully clear later. During the week between Elizabeth's death on 4 December 2001 and her funeral and cremation on 11 December, they tried to find someone who would give them an explanation of what had happened, and why. They found staff generally reluctant to discuss the blocked tracheostomy tube and the medication error, perhaps understandably as they believed that there was ongoing discussion with the Coroner's office, and they were told that Dr Tettenborn would talk to them.

**A8.43** Dr Tettenborn did visit Naomi House to talk to Elizabeth's parents, probably on Friday 7 December.<sup>29</sup> He did not answer any of their questions, but said only that he had "set in motion the exploration by the Coroner's officer who might be able to give them more information" and "emphasised the importance of the investigations being conducted by the Coroner".<sup>30</sup>

**A8.44** Elizabeth's parents believed that Mr Collins, the nurse manager at Nestor Primecare, was due to visit Naomi House on Friday 7 December when they expected to be able to question him. They were told he went to visit Ms Aburime instead, which understandably angered and distressed them. We do not know what he discussed with Ms Aburime, and before Elizabeth's parents had a chance to meet him he had left Nestor Primecare on 14 December 2001. It seems from those we interviewed<sup>31,32</sup> and documents we saw<sup>33</sup> that Mr Collins' management style had caused unrest within the company for a few months, and it may be that his departure was a coincidence, but it cannot escape notice that his absence was a significant convenience for Nestor Primecare in dealing with any subsequent criticism.

**A8.45** At this point, Mr and Mrs Dixon's records confirm that they were beginning to feel great concern that they would never get the answers that they expected on how and why Elizabeth had died. They questioned whether they had done the right thing by saying so definitely that they wanted to avoid a post mortem examination, but they had been reassured by Dr Tettenborn by telephone that a post mortem was not required. Unfortunately, their interpretation of that was that a post mortem examination was not required to confirm that the blocked tracheostomy tube was instrumental in causing death – because it seemed so obvious that it was. It must have come as a considerable shock and disappointment to them to find, completely to the contrary, that their reluctance was interpreted as evidence that they had no concerns about the untoward nature of the death.

**A8.46** Elizabeth's body was cremated on 11 December 2001, ending any possibility of a post mortem examination and closing any potential involvement of the Coroner for the foreseeable future. Yet her parents still had no account of what had happened. They believed – correctly as it transpired – that their daughter had died as a result of a series of serious service failures that had led to her death as a result of asphyxiation from a blocked tracheostomy tube, but they could find nobody who would confirm for them what had happened and why.

**A8.47** The correct course of action by the health authority that had commissioned her care was manifestly obvious, in 2001 as it is today. They should have logged the unexpected death of a baby as a serious safety incident, subject to an investigation that would have identified what had gone wrong and what steps needed to be taken to prevent its recurrence. Given the multiple agencies involved in Elizabeth's care – FPH, GOSH, Naomi House, Nestor Primecare and the

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<sup>29</sup> Dr Michael Tettenborn interview 26 July 2018.

<sup>30</sup> Dr Michael Tettenborn police statement 8 February 2006 (the statement implies that the meeting took place on the evening of 4 December but this tallies with no other account).

<sup>31</sup> Angela Single interview 26 July 2018.

<sup>32</sup> Simon Austin interview 13 July 2018.

<sup>33</sup> Simon Austin police statement 27 November 2006.



primary and community services locally – this should have been independent, with the ability to look across all of the organisations. At the very least, the health authority should have carried out an investigation itself. It did neither.

**A8.48** There is no doubt that responsibility for prompting the declaration of a safety incident and investigation lay squarely with Dr Tettenborn. He was the health authority’s designated responsible medical officer and principal source of paediatric medical advice, as well as the consultant paediatrician overseeing her care at home; he had, by his own account, sufficient concern about the circumstances to report Elizabeth’s death again to the Coroner, apparently in the expectation of a thorough review; on 7 December 2001 he had told Elizabeth’s parents that they should direct all their questions to the Coroner’s officer who was conducting an important investigation.<sup>34</sup> On 9 December 2001 he was told by the Coroner’s officer that there would be no further action by the Coroner. He did not ask for any further information because (he told us) he was tired. So he knew nothing further about the death nor what the role of the blocked tracheostomy tube was, nor the morphine overdose. Yet he did nothing. He did not return to speak to Elizabeth’s parents. He did not declare a serious safety incident. He did not inform his health authority colleagues that there should be an investigation.

**A8.49** Dr Tettenborn “had trust in the Coroner’s Officer” and, he told us, “thought his own view needed to be subordinate to the Coroner’s decision”.<sup>35</sup> Yet he made no attempt to contact the Coroner’s officer again about the case, or enquire what her supposedly thorough investigation had discovered, or whether there might be lessons to be learned for the benefit of future patients.

**A8.50** It is notable that Dr Tettenborn was also the designated doctor for child protection for the area and named doctor for child protection for FPH. This must be placed in the context of child protection procedures in 2001. There were extensive reforms to procedures later in the 2000s, culminating in the establishment of Child Death Overview Panels in 2008, charged with reviewing every child death. In 2001, however, their forerunner was the Area Child Protection Committee, whose remit in relation to deaths was restricted to investigating through a ‘Part 8 review’ those where there was a suspicion of child abuse, a term which was not understood to encompass the possibility of defective or negligent care by health professionals. Without detracting from the obvious failure to follow up Elizabeth’s death, we cannot say that the child protection role as it operated in 2001/02 directly required further action by Dr Tettenborn. Nevertheless, it is difficult to reconcile his subsequent inaction with the vigilance required of health professionals over deaths in childhood.

## The Nestor Primecare report

**A8.51** Records kept by Elizabeth’s parents shortly after the events note that they were visited on 28 December 2001 by Dr Bill Holmes, recently appointed as Medical Director for the Nestor Healthcare Group, and Angela Single, Managing Director of Nestor Primecare. They said that they were unable to give any information about Elizabeth’s death, but undertook to “document the parents’ concerns, to identify answers to these concerns as best we could, and to meet again in about two weeks’ time to discuss the information”.<sup>36</sup> It seems that Elizabeth’s parents were told that Mr Collins could not be contacted as he was taking a belated honeymoon.

**A8.52** On 6 February 2002 a further meeting took place with Dr Holmes and Jenny Hilton, Lead Nurse for Nestor Primecare who had replaced Mr Collins. Dr Holmes and Ms Hilton admitted that

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<sup>34</sup> Dr Michael Tettenborn interview 13 December 2018.

<sup>35</sup> Dr Michael Tettenborn interview 26 July 2018.

<sup>36</sup> Nestor Primecare internal note, Dr William Holmes to Emma Thomas, Angela Single and Jennifer Hilton, 5 January 2002.

Mr Collins had already left Nestor Primecare (on 14 December 2001) and that they had not yet produced a report. They again undertook to do so.<sup>37</sup>

**A8.53** The Nestor Primecare report was not produced until 19 April 2002. Dr Holmes told us that although he was named as a joint author of the report it had largely been produced by the other author, Ms Hilton, and that he had taken no part in any interviews that may have taken place.<sup>38</sup> Ms Hilton herself had a very poor memory of the report when interviewed and was unable to add anything useful about its production, but she did say that Dr Holmes had interviewed nurses alongside her in producing the report and took the lead in its production.<sup>39</sup>

**A8.54** The report itself is, in our considered view, grossly inadequate. It contains a claim that “the correspondence between GOS and the Hospice also contains a typed note about the planning of Elizabeth’s care which states ‘possibly will live for a week, maybe a month’”<sup>40</sup> Despite an extensive search of the records from both GOSH and Naomi House, we have been unable to find any trace of such a note. It is also contrary to all of the other contemporaneous evidence concerning Elizabeth’s prognosis. In fact, the planning meeting on 24 October 2001 attended by Mr Collins on behalf of Nestor Primecare had been informed that there was “no timescale in mind for the length of time that Lizzie would need care” and “at the age of 2 they would be looking at other educational needs”.<sup>41</sup>

**A8.55** The report then claims that “the nursing care records outline increasing secretions from the tracheostomy and episodes of cyanosis, over a period of three days prior to Elizabeth’s death” and that she was “prescribed antibiotics to treat a suspected infection”. Having reviewed the nursing records for this period, we are unable to see how they could be interpreted as showing a change in Elizabeth’s condition. The infection for which she received a topical antibiotic was a superficial skin infection around her tracheostomy site, not a respiratory infection as was wrongly implied by the Nestor Primecare report.

**A8.56** The report notes that Ms Aburime was asked if it was possible that Oramorph suspension had been administered instead of morphine sulphate and that she said that it may have been; the report notes that “during our investigation we were not able to exclude this possibility... we cannot be sure if this was the case... as the drugs were returned to the pharmacy following Elizabeth’s death”.<sup>42</sup> As is clear from Ms Watson’s account, and as she wrote to Dr Holmes at the time, the reason that the drug discrepancy had come to light was the presence of a morphine sulphate dose that should have been given and the absence of 13ml of Oramorph suspension; the drugs had been retained for inspection at the pharmacy they had been returned to and were not destroyed until 8 November 2002.<sup>43</sup> Dr Holmes’s first report, dated 3 January 2002, was clear that the medication administered at 2am was “undoubtedly Oramorph and not MST, as prescribed”,<sup>44</sup> and the reason for his subsequent backtracking is not clear. The final report’s conclusion that it is not possible to be sure if there was a medication error is not only incorrect: by failing to mention that the Oramorph was given at twice the prescribed dose, it also cruelly and wrongly raised the prospect to Elizabeth’s parents that she had been given too small a dose of morphine in her last hours.

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<sup>37</sup> Graeme Dixon Report 12 June 2002.

<sup>38</sup> Dr William Holmes interview 26 July 2018.

<sup>39</sup> Jennifer Hilton interview 17 July 2018.

<sup>40</sup> Report of the investigation into the care provided for Elizabeth Dixon by the Primecare Nursing Team 19 April 2002.

<sup>41</sup> Health authority minutes of planning meeting 24 October 2001.

<sup>42</sup> Ibid.

<sup>43</sup> Sue Watson interview 12 July 2018.

<sup>44</sup> Problems arising in the care of Elizabeth Dixon, deceased, DOB 14.12.2000, Dr Holmes 3 January 2002.

**A8.57** After accepting uncritically that Ms Aburime had suctioned Elizabeth's tracheostomy several times overnight, contrary to other evidence, the report notes that she became concerned [at 7:05am] that this was a severe attack, and at this stage "decided to alert Elizabeth's parents... [she] was unhappy to leave Elizabeth on her own so she took her up to her parents' bedroom".<sup>45</sup> There is no comment on why Ms Aburime thought it was appropriate to remove Elizabeth from her cot, with its suction and other equipment and oxygen, or why she needed to go upstairs with her to shout to the parents.

**A8.58** Then, the report notes, "there was an attempt to change the tracheostomy tube by Elizabeth's mother...". In fact Elizabeth's mother changed the tube successfully despite the obvious pressure of the circumstances, and to describe it as an "attempt" is once more needlessly cruel. Further, no mention is made of why Ms Aburime had not already undertaken this obvious move, nor of the blockage that was subsequently evident in the tube that was removed.

**A8.59** Finally, the only critical conclusions are that "[Ms Aburime] had not experienced the death of a child before..." and "it is the professional opinion of the Head of Nursing for Nestor Primecare [Ms Hilton] that the events which occurred on the night that Elizabeth died were the result of a nurse inexperienced with death in infancy trying to cope with Elizabeth's death and the needs of her bereaved parents."<sup>46</sup> This is an astonishing conclusion: despite the abundant evidence of serious errors made in Elizabeth's care that led to her death, the report claims that somehow the events were due to Ms Aburime's unfamiliarity with death in infancy. There is not one single mention of the blockage in the tracheostomy tube.

**A8.60** Taken overall, this is a shockingly inadequate and self-serving report. It is not surprising that Elizabeth's parents found it insulting, or that Dr Holmes disclaims authorship and Ms Hilton has little memory of it.<sup>47</sup>

**A8.61** There is no record of any response by Nestor Primecare to the report. Dr Holmes said that it had led to a changed approach by Nestor Primecare, which had "pulled its horns in" afterwards;<sup>48</sup> staff "were all distressed at the time and needed to learn from it".<sup>49</sup> This must have stemmed from knowledge of what had actually transpired separate from the report, because there is nothing in its written content that would justify such a reaction: the medication error was not properly documented and the blocked tracheostomy tube was not even mentioned.

**A8.62** The role of the managing director, Angela Single, would have been crucial in how Nestor Primecare responded. In a Hampshire Constabulary witness statement in 2006, she reported having been aware at the time that "the controlled drugs chart did not correspond to the drugs found at the house after the death, and also the tracheostomy tube was reported to be blocked".<sup>50</sup> As a qualified nurse she would have understood that both issues were of central significance in Elizabeth's death. She had read the report,<sup>51</sup> and Ms Hilton said that she "reported to Angela Single after all of the interviews".<sup>52</sup> It is difficult to understand how, with this knowledge of the central events, Ms Single could possibly have regarded the report as satisfactory, or an honest account for Elizabeth's family. Ms Single subsequently claimed that she had no knowledge of the report or any implications for Nestor Primecare:

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<sup>45</sup> Report of the investigation into the care provided for Elizabeth Dixon by the Primecare Nursing Team 19 April 2002.

<sup>46</sup> Ibid.

<sup>47</sup> Dr William Holmes interview 26 July 2018.

<sup>48</sup> Ibid.

<sup>49</sup> Angela Single interview 26 July 2018.

<sup>50</sup> Angela Single Witness Statement 30 November 2006.

<sup>51</sup> Ibid.

<sup>52</sup> Jennifer Hilton interview 17 July 2018.

*“[she] did not recall ever seeing a report. If anything had needed to be changed as a result of its recommendations, [she] would have done that. [She] recused herself from that report and thought this was rightly so”.*<sup>53</sup>

**A8.63** Not only does this claim strain credulity, it stands in direct contradiction to Ms Single’s 2006 witness statement.

## The Health Authority report

**A8.64** Elizabeth’s parents had complained to the Health Authority, by telephone on 25 January 2002. Initially, this may have been focused on their failure to get any response from Health Authority staff to their questions. Mrs Wollam, the Health Authority’s commissioning lead for specialist care, had written to them on 13 December 2001 saying that the key person they should contact with questions about what happened was Dr Tettenborn, but they were unable to get either to return their telephone calls.<sup>54</sup> It seems that the Health Authority failed to log the telephone call on 25 January 2002 as a complaint, and took no further action.<sup>55</sup>

**A8.65** Following the grossly unsatisfactory report from Nestor Primecare on 19 April 2002, Elizabeth’s parents were still expecting a response from the Health Authority that would give them some of the answers they sought. When nothing had materialised by June, Mr Dixon compiled his own report on everything that had happened up to that point, including the failure to respond by the Health Authority,<sup>56</sup> and submitted it as part of a formal complaint to the North and Mid Hampshire Health Authority. The scope of this complaint encompassed both the Health Authority’s actions in commissioning the care from Nestor Primecare and its treatment of Elizabeth’s parents after her death. The Health Authority asked Patricia Christmas, a former director of public health elsewhere in Hampshire, and Mike Smith, a non-executive director, to report on the complaint.<sup>57</sup>

**A8.66** Their report was commissioned on 16 August 2002, and the undated report was produced later that year. They met Elizabeth’s parents on 9 September and Mrs Wollam on 23 September; their report does not record interviewing anyone else.<sup>58</sup> The omission of Dr Tettenborn as an interviewee at least seems to us a significant flaw in the process. They did review both Mr Dixon’s report and the report from Nestor Primecare dated 19 April 2002.

**A8.67** The report sets out a very brief summary of Elizabeth’s clinical course and the involvement of the Health Authority in commissioning the package of home nursing care from Nestor Primecare. Of the discharge planning meeting on 24 October 2001, the report notes that “LW [Linda Wollam] made it clear that there was risk in bringing a child out of hospital to be cared for at home and all shared that risk including parents”.<sup>59</sup> This slightly curious remark was also repeated to us by Mrs Wollam,<sup>60</sup> but there was no record of it in the minutes of the meeting.<sup>61</sup> If it was an attempt to suggest shared responsibility for the outcome, it was misguided: whilst there was undoubtedly some inherent increase in risk inherent in nursing away from the specialist facilities found in an acute hospital, that should under no circumstances have been suggested to include the grossly substandard nursing care evident on the night that Elizabeth died.

<sup>53</sup> Angela Single interview 26 July 2018.

<sup>54</sup> Graeme Dixon report 12 June 2002.

<sup>55</sup> North and Mid Hampshire Health Authority complaint report 2002.

<sup>56</sup> Graeme Dixon report 12 June 2002.

<sup>57</sup> North and Mid Hampshire Health Authority complaint report 2002.

<sup>58</sup> Ibid.

<sup>59</sup> Ibid.

<sup>60</sup> Linda Wollam interview 16 November 2018.

<sup>61</sup> Minutes of Discharge Planning meeting 24 October 2001.

**A8.68** In fact, the report is silent on the events of that night, noting only that “it is difficult to ascertain exactly what happened the morning Elizabeth died as a report by the nurse on duty has not been seen” and that “the parents can only surmise that Elizabeth died by suffocation compounded by a morphine overdose due to the inability of the nurse on duty at the time”; it also notes that Elizabeth’s parents “refused a post mortem”.<sup>62</sup> This is poor: there was a wealth of evidence to be discovered about what had happened had they looked further, and following a referral to the Coroner the decision about a post mortem examination should not have been unfairly given to the parents to make.

**A8.69** The report notes that there was a critical event meeting held on 14 June 2002 which had apparently been attended by Dr Tettenborn on behalf of the Health Authority as well as Elizabeth’s parents and representatives of Nestor Primecare. We have been unable to find any record, other than an agenda, or tangible output from this meeting.

**A8.70** Under “Observations of impartial enquiries”, the report notes that:

*“No references were requested, or taken up, for Nestor Primecare*

*Primecare’s representative exaggerated their ability to provide cover and the experience of the nurses they employed*

*The contract was not shown to or given to Mr and Mrs Dixon*

*Some of the agency nurses were not trained in Elizabeth’s special needs”*

**A8.71** In addition, it was noted that the family GP did not visit Elizabeth before discharge or after she was at home, Mrs Wollam was carrying responsibilities beyond an administrative role, and there was no follow up from the Health Authority after Elizabeth’s death “giving the impression that the Health Authority did not care”.<sup>63</sup>

**A8.72** These conclusions were surely correct as far as they went, but they were far from the entirety of what could have been discovered had the report’s authors enquired more widely and in particular interviewed Dr Tettenborn. The report made some recommendations to improve the commissioning of specialist care in the future, but it entirely missed the point that there were some very serious questions that remained unanswered about Elizabeth’s death. It did say that Nestor Primecare should be “sanctioned”, but did not explain what that meant and there appears to have been no follow up action.

**A8.73** The Health Authority was uniquely placed to require the independent cross-organisation investigation that was badly needed to answer the serious unresolved questions about Elizabeth’s death, but they had not done so. The failure of the complaint report to identify that major failure and recommend that it be put right was a serious oversight. Understandably, Elizabeth’s parents remained deeply unhappy that their questions remained unanswered, and sought further ways to discover the truth.

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<sup>62</sup> North and Mid Hampshire Health Authority complaint report 2002.

<sup>63</sup> Ibid.

# APPENDIX 9: NURSING AND MIDWIFERY COUNCIL INVESTIGATIONS<sup>1</sup>

**A9.1** In June 2002, less than six months after Elizabeth's death, her father wrote a detailed report laying out her parents' concerns about what had happened, and the way the North and Mid-Hampshire Health Authority and Nestor Primecare had failed to respond appropriately. Having concluded that no credible investigation had been carried out into Elizabeth's last few hours or the preceding events, he wrote to the Nursing and Midwifery Council (NMC) to report the family's concerns about the competence and actions of Joyce Aburime. As other families do, Elizabeth's family concluded that this was a chance of finding out what had happened, because the NMC has an investigatory function when complaints are made against those it regulates. They also started civil proceedings for damages against Nestor Primecare.

**A9.2** The NMC referral led to a process that lasted for five and a half years. Under its legal framework, the NMC's investigation was limited to the role of individual registered nurses and whether they had complied with the requirements of their profession. It was not, and could not be, an investigation into the systemic failures evident at each stage. Although Elizabeth's parents welcomed their concerns apparently being taken seriously, by the nature of the process they would not get the candour they sought over the circumstances surrounding her death. It would be no substitute for the full and frank investigation that should have occurred and that had been promised by Nestor Primecare and, later, the Health Authority.

**A9.3** As a professional regulatory body, the NMC did not and does not follow the same principles that should be adopted by a safety investigation. Information disclosed during the NMC process was not automatically shared with the family, who were regarded as witnesses (although Mr Dixon was not asked to give evidence despite being the initial complainant). They had to wait for the public hearing of the case against Joyce Aburime, some 37 months later, before learning more about the circumstances in which their daughter died. Enough was revealed to them to expand their main objective from uncovering the facts to holding individuals and organisations to account for evident failures and attempts to conceal them. It is worth noting that because of the timing of the complaint their case was dealt with under a procedure that was in the process of being replaced. Although the NMC investigations uncovered new information that was greatly distressing for the family, it brought them little comfort.

**A9.4** Instead it led to new struggles. Elizabeth's parents had been seeking an inquest since 2003, but after learning at the NMC hearing of Ms Aburime's case that she was not properly qualified to provide specialised nursing support for an infant with a tracheostomy, they renewed their efforts. They wished to secure an inquest to consider whether her right to life had been breached by commissioning decisions taken by the NHS and to have the cause of death on her death certificate amended. When they approached the Home Office, they were advised to contact the Surrey Coroner; he advised that given the lack of post mortem examination they would need to report her

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<sup>1</sup> Unless otherwise stated, material in this section comes from the Nursing and Midwifery Council Papers.



death to the Hampshire police as a potential crime before he could take any further actions. This would have significant implications for the NMC process.

## The NMC investigation

**A9.5** In the first nine months after opening the case, little happened beyond the procedural steps needed to get an investigation off the ground, although Elizabeth's parents were asked to secure a statement from their Health Visitor, Sue Watson. The case was put to the Preliminary Proceedings Committee<sup>2</sup> after basic access to medical records was secured. Significantly, the NMC invited Elizabeth's parents to extend their complaint to Paul Collins given he was also a registered nurse and was – according to preliminary information – the nurse manager responsible for putting Ms Aburime on the rota to care for Elizabeth on the night of her death.

**A9.6** It was not until May 2003 that the case had been approved for investigation and was referred to the Council's solicitor Blake Laphorn Linnell (BLL). The work was led by their investigator for Hampshire, David Hammond, previously a Superintendent Divisional Commander for Staffordshire constabulary, working with solicitor Sarah Wheadon. The allegations against Nurse Aburime were that she had failed to provide a satisfactory standard of care to Elizabeth, failed to take control of the situation when Elizabeth became lifeless, failed to administer morphine sulphate as prescribed and failed to keep adequate records. The allegations against Mr Collins were that he failed to ensure that Nurse Aburime was adequately experienced to care for Elizabeth, failed to act on her parents' concerns, and falsely reassured her mother concerning Nurse Aburime's experience.

**A9.7** Mr Hammond set about efforts to collect the physical evidence of the controlled drugs in use in the house the night Elizabeth died, and the blocked tracheostomy tube still kept by her parents in a plastic bag in the drawer of her bedroom, and started contacting potential witnesses. He reassured Elizabeth's mother that his investigation would be to police standards.

**A9.8** It is clear that between July and September 2003 Mr Hammond concentrated on gathering the basics of the evidence relevant to the case, including working with Elizabeth's mother to produce a witness statement for her to sign. She left a manuscript note on the cover note to this statement recording the decision that while she was concerned about the NMC investigation prejudicing the civil case they were pursuing against Nestor Primecare (for which they got no legal aid) she thought proceedings necessary if it would make other potential patients safer.

**A9.9** Mr Hammond also ensured the collection of the blocked tracheostomy tube. A year later an independent medical expert, Dr Kevin Ives, commissioned as part of the civil case against Nestor Primecare gave his opinion that the blocked tracheostomy tube was ample evidence of Elizabeth's death by suffocation. In contrast, Mr Hammond and Ms Wheadon decided without taking expert advice that there was insufficient evidence to support the tube as the most likely cause of death. The records show that they considered the tube to have 'negligible' evidential value, because there was insufficient contemporary evidence confirming that it was the one in place when Elizabeth died. The statement they had taken from Sarah Trimble said she did not look at the tube when Anne picked it up in the bedroom, and the ambulance staff did not record the fact that Anne Dixon had fitted a fresh tube before ambulance staff arrived to make further attempts to resuscitate her. Nevertheless, it is very hard to imagine that had it been necessary to change a fully blocked tracheostomy tube in the preceding few days that would not have constituted an obvious emergency and been recorded as such. Although the Nestor Primecare nursing notes are

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<sup>2</sup> The NMC committee responsible for determining which cases should proceed to a definitive hearing and which could be rejected without further investigation.

complete and reasonably comprehensive prior to the night of 3 December 2001, there is no entry suggesting that anyone had changed a fully blocked tube in the days before Elizabeth's death.

**A9.10** The NMC investigators did commission and receive advice from an expert witness on the medication issue. They asked Professor Imti Choonara, a clinical pharmacologist with a special interest in the effect of medicines in children, for an opinion about the potential implications of the mistakes in the opiate doses given to Elizabeth on the last night of her life. At this point they clearly assumed his evidence might be material, and his report was later brought into evidence in a hearing in June 2005. Unfortunately, the content of his evidence raises concerns about weaknesses in the process of eliciting such evidence.

**A9.11** Professor Choonara's report<sup>3</sup> was clear that he had considered the implications of giving Elizabeth a dose of 12.5 mg of Oramorph instead of 25mg of MST suspension. In his opinion it would have no particularly untoward adverse clinical effect, because the amount of morphine in Elizabeth's system would not have fallen significantly at first. This was not surprising since it is clear that he had somehow reported on an amount that was not given: the error was in administering 13ml of Oramorph solution instead of 12.5mg, but 13ml of Oramorph solution would have contained 26mg of morphine sulphate, twice the prescribed dose of Oramorph. Although this was roughly equivalent to the intended dose of MST, Oramorph is a much more rapidly acting preparation, and the question was not whether Elizabeth's morphine levels may have fallen too low, as Professor Choonara supposed, but whether they may temporarily have become too high as a result of the rapid absorption of Oramorph. Having considered this latter question carefully, we agree with the conclusion of other expert commentators that the effect would be very unlikely to have been fatal to Elizabeth, but would probably have led to a period of increased sedation and respiratory depression.

**A9.12** It may be that Professor Choonara was misled by the briefing given him by the investigators, or perhaps misread the medical record, but it is inexplicable that the error in his expert report was not spotted by the NMC team, despite the clearly worded conclusion referring clearly to "the underdosing of morphine...". Nor did anyone at the subsequent NMC Professional Conduct Committee hearing pick up the error: until in a break in the hearing, Elizabeth's father told the BLL solicitor, Ms Wheadon, that the expert had made a mistake and given evidence on the wrong question. This was not reported to the hearing, apparently because Ms Wheadon judged that the case would not be damaged if the hearing panel were not told. In the event it did not alter the outcome of the hearing, but it upset Elizabeth's family greatly. They were left mystified by the decision to call and put weight on the evidence of an expert witness if the accuracy of the evidence they gave was not considered to be important. Their bewilderment and distress are understandable.

## Subsequent progress

**A9.13** By May 2004, both Ms Aburime and Mr Collins had been sent notices of proceedings, inviting them to make formal responses to the allegations against them before decisions would be taken that might lead to Fitness to Practise hearings being ordered. At this stage the cases were joined: that is, the NMC intended to consider the case against both nurses together.

**A9.14** Ms Aburime submitted a statement made with the assistance of the Royal College of Nursing. Mr Collins did not. In August 2004, the Preliminary Proceedings Committee decided to refer the case to the Council's Professional Conduct Committee, which meant a hearing would be held.

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<sup>3</sup> Professor Imti Choonara: Medical Report on Elizabeth Dixon 22 January 2004

**A9.15** At this time the intention was to hold a joint hearing in November 2004, but solicitors for Mr Collins submitted a successful application for the two cases to be held separately. The Professional Conduct Committee decided to hold the hearing for the case against Ms Aburime first; this was the logical approach since if it was found that Ms Aburime had done nothing wrong, it was unlikely that a case against Mr Collins (based on failing to ensure that she was adequately experienced) could be pursued. This sequence, however, gave Mr Collins's team the advantage of hearing the evidence against Ms Aburime before deciding how to conduct his defence. Ms Aburime's hearing was set for January 2005, Mr Collins's for March.

**A9.16** Coincidentally, the civil case by the family for corporate damages against Nestor Primecare also began formal process in January 2005. Ms Aburime and Mr Collins were probably unaware of this, but those witnesses to the NMC who were still employed by Nestor Primecare must have been conscious of it, and of the possibility that admissions in one forum might affect conclusions in the other.

## **NMC Professional Conduct Committee: Ms Aburime**

**A9.17** The hearing of the charges against Ms Aburime was held over three days, 10 – 12 January 2005. Ms Aburime did not attend, although she had originally said she would and would be represented. She gave notice on the day that this was intentional, and the Committee decided to proceed in her absence. When asked by the police in February 2007 why she had not appeared, Ms Aburime said that she could not face the ordeal of attending the hearing. She also said to the NMC Professional Conduct Committee that although she did not consider all the charges against her to be well founded, she did admit to three elements: failing to change the tracheostomy tube when she realized it was an emergency, failing to control the scene and failing to have left a suction catheter ready for use in an emergency. She further accepted that as the nurse on scene she had to be accountable for her actions and expressed herself willing to be struck off the register for what she thought would be a short time, if it would give the family comfort.

**A9.18** The solicitor presenting the case against Ms Aburime, Ms Wheadon, relied heavily on evidence from other Nestor Primecare nurses and Dr Holmes, the Nestor Healthcare Group Medical Director. This made it inevitable that some of the building blocks of the case against Mr Collins had to be set out at the hearing.

**A9.19** Sarah-Jane Trimble, who had nursed Elizabeth over four day shifts in the seven days before her death and had arrived for a further shift just after Elizabeth had been taken to FPH by ambulance, gave evidence that she thought that the management support for the nurses looking after Elizabeth was poor. She also suggested (against the evidence of her contemporaneous notes, which were not presented in evidence) that Elizabeth had looked appreciably more ill the day before her death and had needed a lot of close nursing and suctioning for thick secretions. It is possible that this was intended to convey that there was an element of increased risk to Elizabeth over her last 24 hours, but as it is unsupported by other evidence and contrary to what she recorded at the time, we conclude that it should be given no weight.

**A9.20** Dr Holmes gave evidence as Nestor Healthcare Group Medical Director. He denied any personal responsibility for ensuring clinical staff were competent to do the jobs they were assigned, saying that was the responsibility of the nurse manager in charge of the case. He also said the nurse managers were responsible for ensuring that staff employed by the agency on zero-hours contracts could juggle their shifts with the fatigue and pressure of any work for other employers. He admitted that he had not considered the adequacy of skills, experience or training of the nurses involved in Elizabeth's care in the course of the internal investigation he had conducted for Nestor Primecare into Elizabeth's death, saying he expected that to have been considered by Jenny Hilton, appointed Nestor Primecare's Nurse Lead after the death and co-author of the investigation

report. He did not draw the Committee's attention to the absence of any mention of it in the investigation report, or to the significant changes that had been made to Ms Hilton's drafting by the time the report was finalized.

**A9.21** Given that Mr Collins could not be called as a witness in view of his own impending case, Susanne Ward had been called on to give evidence about how the nurse managers at Nestor Primecare ensured that contracts were fulfilled. Ms Ward told the Committee that Elizabeth's nursing requirements were "very very challenging", but she had agreed with Mr Collins that "with time and planning" they would be able to provide the service by drawing on nurses elsewhere in the Nestor Healthcare Group. She had interviewed Ms Aburime for Nestor Primecare, recording only a basic nursing qualification, and had expected her to have an induction period on starting work, but Ms Aburime was deployed to cover the night shift of 3 December on what should have been the first day of her induction.

**A9.22** On 12 January 2005 the Committee reached its verdict. It accepted that Ms Aburime did not possess the relevant experience, training or expertise to manage the complex care needs of Elizabeth, failed in some key procedures, and did not appropriately administer or record opiates. Ms Aburime was struck off the nursing register for an indeterminate period, with the comment that "it is evident ... that her acts and omissions were fundamentally incompatible with being a registered nurse."

**A9.23** In response to an enquiry from the Committee, the NMC solicitors reported that they did not know if Ms Aburime was working, and she was not there in person to be warned that she must no longer work as a registered nurse. In fact, records show that Ms Aburime had returned to work full time for Coventry University Hospitals in 2002, some months after Elizabeth died, as a staff nurse in the ophthalmology outpatient department. She was told by letter of the Committee's decision in early February, but kept working for the hospital in Coventry for several more weeks. The letter from the NMC did not specifically tell her what to do about her employment, just that she could not "hold yourself out" to be registered and that she must return her proofs of registration to the NMC. The hospital eventually found out from a newspaper report that their employee had been struck off, and Ms Aburime's employment was terminated.

## **NMC Professional Conduct Committee: Mr Collins**

**A9.24** The charges against Mr Collins were that he had failed to ensure that Ms Aburime was adequately experienced to care for Elizabeth, failed to act on concerns raised by Elizabeth's mother during the refresher training in tracheostomy care at Naomi House, and falsely reassured Elizabeth's parents concerning Ms Aburime's experience.

**A9.25** The case did not seem initially to present any great obstacles, but in the event there never was an opportunity to put it in full before an NMC Professional Conduct Committee. At first, procedural delays interrupted attempts to get the case heard. The hearing date was first set for March 2005, a reasonable ten months after notice was served on Mr Collins that charges against him would be heard. Records show that this date had to be changed because of a difficulty in getting a quorum of committee members to hear the case. At that time the NMC was trying to catch up a large backlog of cases waiting to be heard under procedures that were about to be replaced, as well as bringing in the new procedures to replace them. A new hearing was set for June 2005, but three days proved insufficient to hear all the evidence and arguments and an additional date of August 2005 was set. It proved impossible again to find a quorum of committee members for this because of summer leave arrangements.

**A9.26** By the time another date could be set, it is clear from the documents that Mr Collins's legal defence had adopted a new strategy, based on what came to be known as 'the disclosure

issues'. The basis of these was that the NMC legal team had a duty to disclose available evidence to Mr Collins's legal team, firstly concerning his responsibility for assigning nurses to Elizabeth's care and the company's failure to disclose it, and secondly concerning the police investigation that had commenced into Elizabeth's death, and they had failed to discharge that responsibility properly. These issues were argued intermittently over the following two years, during which time Mr Collins's health deteriorated, and he did not attend any hearing after June 2005.

**A9.27** The first issue was the production of evidence by and from Nestor Primecare which, it was argued, undermined the ability to put an adequate defence.

**A9.28** It is clear from consideration of the documents relating to both the NMC case and the police investigation that the Nestor Healthcare Group, as a corporate legal personality involved in providing services in accordance with UK law, failed to discharge their basic obligations on disclosure. The company first ignored NMC requests and then claimed that the documents required could not be found, presumed destroyed in a repository fire. Given that some of these documents were subsequently produced for the police when individuals were threatened with being held in contempt of court, it is difficult to conclude that this was anything other than willful obstruction. The NMC's overriding purpose is to protect public safety, and it seems clear that the Nestor Healthcare Group was prepared to jeopardise this by putting its own self-interest first.

**A9.29** Details of the Nestor Primecare lines of management responsibility were essential to one aspect of Mr Collins's defence, that he had been scapegoated for failing to discharge responsibilities he had in fact never been given. The failure to provide employment and management records to the investigation if anything supported this line, and strengthened the argument that the NMC case was fatally flawed by the non-disclosure of significant facts.

**A9.30** We have considered carefully all of the evidence available from documentary records, witness statements, and our own panel interviews. It is clear that there was considerable advantage to Nestor Primecare in being able to point to the failures of a single individual who had left the organisation as the root cause of Elizabeth's care being placed in the hands of an insufficiently qualified and inexperienced nurse on the night that she died. Given the organisation's evident readiness to suppress documents, this is a plausible supposition and suggests that responses from individuals involved at Nestor Primecare at the time must be treated with significant scepticism.

**A9.31** Nevertheless, there is sufficient evidence from outside Nestor Primecare, both at interview and in contemporaneous records, to confirm that Mr Collins had been widely perceived at the time of Elizabeth's death as the person in charge of the Nestor Primecare arrangements for Elizabeth's care. Given the reservations over Nestor Primecare's subsequent approach and the lack of clarity over their management lines, however, it is impossible to conclude with certainty that he was the only person responsible.

**A9.32** During the three days of NMC Professional Conduct Committee hearings in June 2005, witnesses were consistently cross-examined on whether he had been responsible for assuring the competence of Ms Aburime or for the decision to assign her to the rota of nurses for Elizabeth, or whether this responsibility had been Susanne Ward's. Ms Ward had excused herself from giving any further evidence, pleading illness. Mr Collins's legal team highlighted that Ms Ward had initially been in charge of the arrangements for Elizabeth's care and that there was a remarkable absence of documentation by either Nestor Primecare or the health authority of the transfer of responsibilities to Mr Collins before Elizabeth went home.

**A9.33** The Professional Conduct Committee concluded that while there was evidence that Ms Ward had been appointed as the nurse responsible for providing Elizabeth's care, and that she approved the recruitment of Ms Aburime while noting she needed further training, there was no



documentary evidence to support the NMC's case that a transfer of responsibility from her to Mr Collins was effected before Elizabeth's death. The Committee noted that the investigators for the NMC had difficulty getting information out of the Nestor Healthcare Group and were given "probably fanciful explanations" for its non-production, but they also noted that the investigators failed to seek assistance from a higher court to force the production of the documents. The Committee regarded this as a crucial failure to act.

**A9.34** The second issue of disclosure that delayed proceedings for many months, although it was not eventually included in the grounds for the decision to stay the case, was the issue of whether information should have been shared with Mr Collins earlier that the police had started investigating a potential case for his prosecution. The first Professional Conduct Committee hearing in June 2005 was held without his legal team being aware that police inquiries were under way. Regrettably, in trying to show that the failures in disclosure were unintentional, the NMC legal team blamed Elizabeth's mother for having withheld information deliberately, even going to the extent of securing a court order to compel her attendance to give evidence on the matter at a time when she was clearly and seriously unwell.

**A9.35** The evidence clearly supports a different conclusion. In early 2005, shocked by the revelations at Ms Aburime's hearing about her lack of experience and lack of training as a specialist paediatric nurse with tracheostomy expertise, Elizabeth's mother contacted the Home Office to ask what steps could be taken to secure an inquest into Elizabeth's death. Elizabeth's parents expressed themselves very concerned about the system failure suggested by Ms Aburime's deployment and the lack of appropriate candour and investigation after Elizabeth's death; they wanted a judicial authority to tell the system to change.

**A9.36** They were redirected to the Surrey Coroner's office, and were successful in securing a meeting. They were told that there were great difficulties in holding an inquest without a post mortem examination, and such proceedings were usually triggered by a police investigation. As seemed logical in light of this advice, Elizabeth's mother contacted police hoping to secure this outcome. Formally this meant she reported Elizabeth's death as a crime, although it was made clear to her that charges were not for her to try to determine. The officers to whom she spoke passed the file as a matter of course to the Major Crime Unit of Hampshire Constabulary, who set up a preliminary investigation.

**A9.37** For the first few months, as is usual in such cases, the police investigation was covert. Officers tried to determine the basic facts without contacting any witnesses or organisations. While they did not instruct Elizabeth's parents to treat their contact with police as a secret, they would have understood that it was a covert investigation at that point, and they certainly had no instruction to inform the NMC. In the event, Elizabeth's mother did mention her initial contact with police to the investigator working for the NMC solicitors, the ex-policeman David Hammond. He later confirmed formally that he scribbled a note in his book just after talking to her by phone on 8 April that she had told him police were considering whether any crime had been committed. At that stage, he assumed that their interest was limited to Ms Aburime, and it is unlikely at this stage that Elizabeth's parents knew that the case might be extended to consider Mr Collins's role.

**A9.38** Mr Hammond also wrote that he found it hard to believe the police would bother with a case that was over 3 years old, and said later that he had assumed that the police investigation would not go anywhere. He had not read the report prepared by Elizabeth's father that described his concerns about the organisation of Elizabeth's care, and he claimed that he never considered whether a police investigation might come to include potential charges against Mr Collins as well as Ms Aburime. Given that the NMC had itself expanded its own case to include Mr Collins's involvement, this is difficult to understand.



**A9.39** By May 2005, the police were certainly considering whether there might be a case to bring against Mr Collins, as well as a potential prosecution of Nestor Primecare, but this was waiting for a comprehensive first review of evidence and advice from the Crown Prosecution Service (CPS). The CPS decision on whether there was likely to be a case to answer was expected to be difficult, given the passage of time since the death, the lack of a post mortem, and the absence of existing remains (as Elizabeth's body had been cremated). It is clear from the contemporary documentation that Elizabeth's mother was asked to be patient and await this review, and it did not occur to her that a police investigation she was being told little about (since she was a potential witness as well as family to the victim) might have implications for the NMC proceedings in June. When senior solicitors found out, however, the implications were obvious.

**A9.40** When BLL disclosed the bundle of documents to Mr Collins's legal team, it comprised 44 documentary items supplied by Elizabeth's parents, including her father's 32-page report and an additional 160 pages of evidence supplied by the NMC solicitors; but there was no mention of the police investigation. Mr Hammond had recorded the fact of the police investigation of Ms Aburime, but he had not passed on the information to his own colleagues and did not think that this might have been extended to Mr Collins. When Mr Collins's legal team became aware of the police investigation, they saw the possibility of successfully arguing for an abuse of process by the NMC, and later coupled this with the non-disclosure of relevant documents by Nestor Primecare. Although it took until 2007, the NMC Professional Conduct Committee hearing was eventually 'stayed' on these grounds.

**A9.41** This outcome was unsatisfactory in several aspects. It left the charges against Mr Collins as un-hearable by the NMC, and the NMC unable to determine whether or not Mr Collins's professional conduct represented a threat to patient safety. It left Elizabeth's parents with no resolution to their question of how an incompetent and inexperienced nurse was left in charge of their daughter on the night she died, nearly six years previously.

**A9.42** Given the scale of the failures of the NMC investigative and legal team in preparing the case, it was inevitable that the case would end in this way. Nor should the defence counsel attract any censure for using the opportunities presented by the procedural failures to argue successfully for a stay of the case: that is the nature of an adversarial legal process.<sup>4</sup> It remains, however, a sad episode that contributed further to the growing sense of injustice felt by Elizabeth's parents.

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<sup>4</sup> We note without comment that his legal firm's website describes him as having "an incredible success record and often manages to stop a case with his procedural arguments."

# APPENDIX 10: INVESTIGATION METHODOLOGY

## Commissioning the report

**A10.1** In 2017 the Secretary of State for Health and Social Care, the Rt Hon Jeremy Hunt MP, asked Dr Bill Kirkup CBE to examine Elizabeth Dixon's care and how it was organised: to also consider the family's concerns about the response to her death; and to provide government with a reasonable interpretation of what the evidence available suggested. The Secretary of State was acting in pursuance of his powers under the NHS Act 2006 rather than the Inquiries Act 2005.

**A10.2** Dr Kirkup was previously Assistant Chief Medical Officer for England and has extensive experience of independent investigations that consider concerns about medical care. The following terms of reference were agreed by Dr Kirkup with the family:

1. to investigate the care given to Elizabeth Dixon between her date of birth and her date of death, with reference to the quality of care given and its outcome, including the design and implementation of the home care package;
2. to investigate the care given to Anne Dixon during her pregnancy up to and including Elizabeth Dixon's birth and afterwards, with reference to the quality of care given and its outcome;
3. to investigate the response following Elizabeth Dixon's death by all of the agencies responsible for her care, with reference to the immediate actions taken, the reporting of her death, investigation of serious incidents, communicating with the family, learning lessons and responding to concerns and complaints;
4. to investigate the response following Elizabeth Dixon's death by the health service and other regulatory and investigative bodies, with reference to the effective discharge of their functions;
5. to investigate any other aspects of Elizabeth's Dixon's care and the response following her death that give rise to concern during the course of the investigation; and
6. to draw conclusions and make recommendations.

**A10.3** Dr Kirkup invited several experts to act as an investigation panel, contributing advice particularly on specialist aspects of his investigation:

Dr Jag Ahluwalia – acute paediatric care

Dr Pat Carragher – paediatric hospice care

Mr Gary Copson – policing

Dr Daghni Rajasingam – obstetrics

Mr David Widdas – paediatric community nursing

**A10.4** In addition, expert advice was sought from two experts specifically on raised blood pressure in infancy and its effects on the brain:

Dr Malcolm Coulthard – paediatric nephrology

Dr Robert Forsyth – paediatric neurology

**A10.5** Support was provided to the investigation through a secretariat:

Ms Mary Newman, Director of Secretariat

Ms Wendy Hempson, Secretariat Manager

Ms Niki Dakin, Secretariat Support

Ms Anna Sinfield, Communications Lead

**A10.6** Ms Newman was commissioned by NHS Improvement from the NHS Independent Management Advisory Service to lead the Secretariat, and had previously worked within government and the NHS. Ms Hempson and Ms Dakin were provided via Urban IQ Ltd. Ms Sinfield was previously a senior press officer in government.

## Earlier history of investigations

**A10.7** Elizabeth Dixon's life and death have been formally reviewed by many organisations since 2001. Her death was originally considered by the Surrey Coroner's office. Her nursing care at the time of her death was considered by Nestor Primecare, the private nursing agency commissioned to provide it. Arrangements for her care were considered by the North and Mid Hampshire Health Authority, the organisation responsible for commissioning them. Allegations about the fitness to practise of two nurses working for the nursing agency were considered by the Nursing and Midwifery Council.

**A10.8** Allegations about the nurses, their employers and other individuals involved in her care were considered by the Hampshire Constabulary and the Special Casework Team of the Crown Prosecution Service. Allegations about actions of staff at the Surrey Coroner's office were considered by the Surrey Constabulary. Allegations about the fitness to practise of medical staff involved in her death were considered by the General Medical Council, and complaints were considered by Frimley Park Hospital and Great Ormond Street Hospital. Her treatment for hypertension was considered by the Care Quality Commission. NHS England initially indicated that they would review the case, and then that they would not. A review of her care was commenced by Professor Peter Hutton, before it was suspended and then replaced by the commission to Dr Kirkup.

**A10.9** Recognition of the delays and difficulties in this case is crucial to understand the burden it has imposed on Elizabeth's family and to some extent on those individuals who cared for her with love and compassion during her short life. It also made the initial stages of this investigation more difficult, as many individuals believed that everything possible had already been done and nothing remained to be discovered. This has proved far from the case.

## Conduct of the investigation

**A10.10** Dr Kirkup chaired seven meetings in plenary with the panel and also had bilateral discussions with them individually.

**A10.11** During the course of the investigation Dr Kirkup and Ms Newman had many discussions with Mr and Mrs Dixon both face to face and by telephone conference. In November 2018 the expert advisers, Dr Kirkup and secretariat members also had extended meetings with Mr and Mrs Dixon.

**A10.12** Forty one individuals with involvement in Elizabeth’s care or with investigations into her death have been interviewed<sup>1</sup> by Dr Kirkup and panel members, supported by secretariat members. Some individuals we approached declined to be interviewed and the investigation had no legal power of compulsion. This is considered further in the recommendations and forward to the report.

**A10.13** Each interview followed an agreed Interview Protocol<sup>2</sup> and a careful note was made of discussion. Interviews were held in London, Surrey, Oxfordshire and Hampshire. Formal meetings and interviews were held at venues independent of the NHS and DHSC wherever possible, with preference given venues that supported voluntary organisations and charities such as:

National Council for Voluntary Organisations  
Society Building, 8 All Saints Street, London N1 9RL

Coram’s Fields Charity  
93 Guilford Street, London, WC1N 1DN

Living Space  
1 Coral St, Waterloo, London SE1 7BE

Coin Street Community Builders  
108 Stamford Street, South Bank, London SE1 9N

**A10.14** Dr Kirkup, panel members and members of the secretariat also met with the following organisations or visited in order to access restricted archived material;

The Nursing and Midwifery Council – January and February 2018

Frimley Park Hospital NHS Foundation Trust – May 2018

Naomi House Hospice – May 2018

The Chief Coroner’s Office (by phone) – June 2018

HM Coroner for Hampshire – July 2008 and April 2019

Hampshire Constabulary – June, October, November, December 2018 and January and April 2019

Great Ormond Street Hospital NHS Foundation Trust – July 2018

The General Medical Council – August 2018

Coventry University (by phone) – August 2018

The Crown Prosecution Service – April 2019

Department of Health and Social Care – April 2019

## Access to written evidence

**A10.15** The various previous investigations into aspects of Elizabeth’s care all produced material and much of that material was shared with her parents in subsequent years. Mr and Mrs Dixon kindly opened their entire archive of written documents to us and shared a large number of emails.

**A10.16** In addition, the Nursing and Midwifery Council, Frimley Park Hospital, Great Ormond Street Hospital, the General Medical Council, and Naomi House Hospice all provided the investigation with copies of the files and records they held on Elizabeth and, in the case of Great Ormond Street Hospital, took considerable trouble to try and restore records of diagnostic scans.

<sup>1</sup> Dixon Investigation List of Interviewees

<sup>2</sup> Dixon Investigation Interview Protocol

**A10.17** The Department of Health and Social Care, Hampshire Constabulary, the Crown Prosecution Service and the Hampshire Coroner allowed us ‘preliminary access’ to their files – that is we could study them and take notes – although they considered that the most recent data protection legislation did not allow them to formally disclose documents by our photocopying or removing copies from their secure storage.

**A10.18** Material was submitted to and retained by the investigation in a variety of electronic file formats and hard copy. Urban IQ Ltd is registered with the Information Commissioner’s Office but the investigation held all electronic copies of documents, and summaries of their content, on a secure platform. These will be passed for data control purposes to the Department for Health and Social Care after publication of the investigation report. No material will be retained after publication of the investigation report by Urban IQ Ltd or by panel or secretariat members. This has been a fundamental governance arrangement to ensure the safe release and transfer of material from interested organisations and individuals. No personal contact details of interviewees will be retained and any voice recordings from interviews will be destroyed on completion of the investigation.

## List of interviewees

### Dixon investigation list of interviewees

Name	Occupation related to investigation	Date of Interview
Dr Abdus Mallik	Consultant Paediatrician/Neonatologist, Frimley Park Hospital	31st July 2018
Andrew Bradley	HM Hampshire Coroner	1st: 27th July 2018 2nd: 24th April 2019
Angela Single	Managing Director at Primecare	26th July 2018
Dr Ann Goldman	Consultant in Paediatric Palliative Care, Great Ormond Street Hospital	9th January 2019
Dr William Holmes	Group Medical Director Nestor Healthcare Group PLC	26th July 2018
Dr Carlos De Souza	Consultant Paediatric Neurologist, Great Ormond Street Hospital	11th December 2018
Christie Watson	Agency nurse engaged by Primecare	17th July 2018
Dr Colin Wallis	Consultant Respiratory Paediatrician, Great Ormond Street Hospital	1st: 7th July 2018 2nd: 19th Feb 2020
Dr Deirdre Dunbar	Doctor at Naomi House Hospice	21st January 2019 (by phone)
Gareth Beynon	Consultant in Obstetrics & Gynaecology, Frimley Park Hospital	26th July 2018
Gareth Cruddace	Chief Executive, Hampshire and Isle of Wight Strategic Health Authority	13th December 2018
Helen Janes	Agency nurse engaged by Primecare	6th November 2019
Jenny Hilton	Lead Nurse at Primecare	26th July 2018
Jo Cooke	Tracheotomy nurse specialist, Great Ormond Street Hospital	29th January 2019
Kate Bailes	Continuing Care Manager, North and Mid-Hampshire Health Authority	29th October 2018
Lesley Vass	PA to Linda Wollam, North and Mid-Hampshire Health Authority	5th April 2019 (by phone)
Liz Delicata	Community Children's Nurse	6th November 2019
Lucy Phillips	Nurse Manager at Primecare	18th December 2019
Maggie Fry	Head of care at Naomi House	7th December 2018
Dr Melissa Lees	Consultant in Genetics, Great Ormond Street Hospital	11th December 2018
Dr Michelle Sinclair	GP at Richmond Surgery, Fleet	12th July 2018
Dr Michael Tettenborn	Consultant Community Paediatrician, Frimley Park / Responsible Medical Officer	1st: 31st July 2018 2nd: 13th Dec 2018



Name	Occupation related to investigation	Date of Interview
Nicola Hawley	Manager of Health Visitors & District Nurses	29th October 2018
Olga Senior	Director of Corporate Affairs, South Central Strategic Health Authority	22nd October 2018
Patricia Christmas	Director of Public Health at South West Hampshire Health Authority	20th May 2019 (by phone)
Dr Peppy Brock	Consultant Paediatric Oncologist, Great Ormond Street Hospital	3rd December 2018
Richard Samuel	Employed by Hampshire & Isle of Wight Strategic Health Authority	10th December 2018
Rowena Ellis	CLIC Sargent Social Worker at Great Ormond Street Hospital	11th December 2018
Dr Ruby Parmar	Naomi House Hospice doctor	22nd October 2018
Sarah Jordan	Community Children's Nurse	6th November 2019
Simon Austin	Operations Manager and Financial Controller at Primecare	13th July 2018
Dr Simon Fraser	Naomi House doctor	13th December 2018
Sue Masters	Coroner's officer for Surrey	19th December 2018
Sue Ward	Nurse Manager at Primecare	26th July 2018
Sue Watson	Health Visitor	12th July 2018
Dr Theresa Creagh	Clinical Lead Doctor at Naomi House	20th December 2018
Linda Wollam	Development Manager for Children's Services, North and Mid-Hampshire Health Authority	16th November 2018 (interviewed together)
Eileen Spiller	Director of Policy and Performance, North and Mid-Hampshire Health Authority	
Colin Matthews	Hampshire Constabulary police officers	19th May 2019 (interviewed together)
Jim Antczak		
Neil Cussen		

**A10.19** The following were invited to interview but refused to participate without attempting to provide an excuse:

- Dr Andrew Petros, Great Ormond Street Hospital intensivist
- Paul Collins, previously nurse manager, Nestor Primecare.

We were unable to make contact with Ms Joyce Aburime or Ms Sarah-Jane Trimble.

# Interview protocol

## INTERVIEW PROTOCOL Dixon Investigation

### Chaired by Dr Bill Kirkup CBE

#### 1. Background

The Dixon Investigation is an independent investigation into the case of baby Elizabeth Dixon, who died in December 2001.

The Investigation is chaired by Dr Bill Kirkup CBE and was commissioned by Jeremy Hunt, the Secretary of State for Health and Social Care.

#### 2. Who will the Investigation interview?

The Investigation Secretariat will draw up a list of interviewees who will be invited to interview and be asked to provide oral information. This list will be kept under review and updated as necessary. Additional interviews may be arranged at a later date in response to evidence seen or heard by Dr Kirkup.

Interviewees will be invited to give their own account and observations to the extent they are relevant to the Terms of Reference, as well as respond to questions. The Investigation report will not refer to “witnesses” or “giving evidence” to reflect the collaborative approach the Investigation is taking which is an investigation to establish the facts and make recommendations for improvement.

#### 3. The storage of interviewee details

Once responses are received from interviewees, their contact details will be stored by the Investigation on a database. The database will be password protected and will only be accessed for the specific purpose of liaising with the interviewee.

Contact details of individual interviewees will be retained by the Investigation for the duration of its work and until four weeks after the Report has been published.

Contact details will then be destroyed by the Investigation in accordance with Data Protection requirements.

#### 4. Invitation to interview

As the Investigation is not part of a legal process, interviewees may not be legally represented and the Investigation will not deal with anyone other than the interviewee.

Interviewees will be advised that they are welcome to bring a relative, friend or colleague with them to the interview who will be able to remain with them but not to comment on the proceedings or to ask any questions during the interview.

Appropriate refreshments will be provided for the interviewee and any relative, friend or colleague who accompanies them.

Each interviewee will be entitled to claim reimbursement from the Investigation for reasonable expenses incurred as a direct result of their attendance at the interview.

Receipts will be required for all claims and evidence will be required prior to reimbursement. A claim form will be provided on the day of interview.

## **5. Attendance at the interview**

All interviewees will be sent a brief factsheet giving them information about the practical arrangements for their interview.

Interviews will take place at The National Council for Voluntary Organisations (NCVO) Society Building, 8 All Saints Street, London N1 9RL, or at a similar venue in London.

The Chairman will give a brief welcome to each interviewee, introducing any advisers who may be present, explaining how the interview will proceed and reminding all present of the responsibility to respect confidentiality.

The investigation Secretariat will make a recording of the interviews. The recordings will be made to aid the production of the note of the interviews and will not be published. The recordings of all interviews will be destroyed when the Investigation Report is published.

It will be a matter for interviewees how they respond to the questions they are asked and it will be a matter for the Secretary of State and others what action is taken in response to the Investigation's findings and recommendations.

## **6. Following the interview**

Written records from the Investigation will be retained by the Department of Health and Social Care after the Investigation Report has been published. At that stage they will be accessible to others through applications made under the provisions of the Freedom of Information Act. Interviewees are asked to share any concerns about this with the Secretariat before they attend an interview.



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