THE THIRLWALL INQUIRY

WRITTEN OPENING ON BEHALF OF THE PARENTS OF: CHILD C, CHILD D, CHILD E, CHILD F, CHILD G, CHILD H, CHILD J, CHILD K, CHILD O, CHILD P, CHILD R

Introduction

1. These written submissions will collectively refer to the families listed above as "the Families".

2. On 21st August 2023, following a trial at Manchester Crown Court, Lucy Letby was sentenced to life imprisonment with a whole life order on each of seven counts of murder and seven counts of attempted murder. In 2024, she was convicted of a further count of attempted murder and sentenced to a further term of life imprisonment. The terms of this Inquiry rightly do not permit any analysis of the strength of those convictions however, it is important to set out a few remarks about those convictions in opening on behalf of the Families:

2.1. This case has been the subject of considerable media attention in the UK and abroad and at the time of writing these submissions views are being expressed by various groups and individuals that Letby did not commit the crimes that she was charged with and that she was wrongly convicted. I have said before on behalf of families that speculation about the strength of Lucy Letby's conviction in the press and the proliferation of conspiracy theories amongst quasi journalists and true crime dilettantes is profoundly damaging to the Families whose lives have been affected by Lucy Letby's crimes. Collectively, the Families attended every day of the criminal trial and heard all of the evidence put before the jury; they have no doubt about her guilt; two juries who heard complex evidence over two scrupulously fair trials had no doubt about her guilt; the safety of her convictions has been confirmed by the Court of Appeal, whose judgment carefully and comprehensively analyses and rejects many of the points that are repeated in the press and in other media. The Families hope that the evidence presented during this Inquiry will remind those, whose minds remain open, that Lucy Letby committed these crimes, that she murdered and deliberately harmed the babies listed above. The Families would like me to say again in public, that although their names and identities are hidden from the public, they are real people who were living ordinary lives up until the point that Lucy Letby harmed their children and their families. They will have to live with the consequences of those crimes for the remainder of their lives. All have been terribly affected by what happened to them or their children. All are entitled to dignity and respect and the proliferation of ill-informed speculation about Lucy Letby's guilt perpetuates their suffering.

2.2. The list of convictions and list of charges on the indictment provide an insight into the events that occurred at the COCH between June 2015 and July 2016, but care should be taken not to

assume that they tell the full story insofar as the Families are concerned. Lucy Letby was originally charged with the murder as well as attempted murder of Child K but by the time of trial only the charge of attempted murder remained. Child K's family believe that Child K's death resulted from the harm caused to her by Lucy Letby and whilst they accept that this causal connection could not be proven to the criminal standard, they have and will reach their own conclusions on the issue, as they are entitled to. Likewise, whilst the jury were unable to reach conclusions in relation to other charges, including allegations relating to Child H and Child J, those families also remain of the view that their children were harmed by the actions of Lucy Letby. The Families are grateful that their inclusion within this Inquiry is permitted by reference to the indictment, rather than by reference to the convictions and understand that the purpose of this Inquiry does not include an analysis of whether Lucy Letby committed the crimes that she was charged with. They would however ask that all participants to the Inquiry exercise sensitivity when describing the nature of the crimes and their victims.

2.3. The Cheshire Police, through Operation Hummingbird, continue to investigate the actions of Lucy Letby at the COCH and at Liverpool Women's Hospital (LWH) and have engaged in a broader review of other possible crimes. Oher potential victims have contacted the Inquiry and the Police. The Families understand that the Terms of Reference for the Inquiry do not allow for any attempt to define the scope of Lucy Letby's crimes, if indeed they are ever capable of being defined. They are acutely aware however that, as was the case with Harold Shipman, the offences charged on the indictment may represent only a small proportion of the crimes that were actually committed. They sincerely hope that others have not experienced the same harm that they have.

3. The Families would therefore want me to begin by reminding the Chair that whilst any Inquiry surrounding the crimes of Lucy Letby must proceed against a background of some uncertainty: about the number of her crimes, the nature of her crimes and ultimately about her motive for committing those crimes; there should be no doubt that extraordinarily deplorable crimes were committed, affecting ordinary families. The Chair will hear accounts from the Families over the coming weeks of their experiences and their aspirations for change. This written opening will not attempt to set out their experiences in detail or refer to all of the issues that they have raised individually or collectively. It will instead signpost some of the key issues that will arise from their evidence and their relevance to the terms of the Inquiry. The opening will weave aspects of the Families' evidence through those key issues by way of example but will not be exhaustive in referencing each experience to each theme. Those themes raise issues that have broader relevance to the NHS than measures to prevent a future serial killer, although that is an imperative goal in and of itself. They relate to the methods by which doctors, nurses and managers are empowered to implement safeguarding procedures when they perceive that vulnerable patients are put at risk. They ask why a culture exists whereby a Trust put its own reputation above patient safety; why managers considered it acceptable or even desirable to lie to the parents of dead or injured children or why others were uncomfortable in speaking up or

raising concerns. The Inquiry will inevitably examine the culture that existed within the COCH in 2015/2016 but it should exercise care not to fall into the trap of assuming that this culture is historical, or that the COCH is a 'bad apple' whose failings are not representative of broader cultural themes within the NHS.

4. Finally, a number of things are important to the Families, but common to all of them is a desire to ensure that their experiences are not repeated in the future. This is far from the first public inquiry to be opened in the presence of those who have suffered harm who attend with an expectation that their anguish should become the imperative for change. The evidence will show however, that, sadly, this change is often not achieved, that recommendations are ignored, and that pernicious and unhealthy cultures persist to cause harm again in the future. For the Families the best way to memorialise those who suffered harm at the hands of Lucy Letby is to ensure that the events that will be explored in this Inquiry are never repeated.

Background

5. At the relevant time, the Neonatal Unit at COCH ('the Unit') was a level two unit, subsidiary to the larger level three/tertiary units at Arrowe Park and at LWH and the Children's Hospital at Alder Hey. The Unit operated within parameters that defined the circumstances in which it could accept and treat patients, generally babies born from 27 weeks gestation, albeit in some cases those parameters were not strictly adhered to. In any case, it was common, and still is common, for the COCH to care for very young and vulnerable babies, some who were born at the hospital and others who were transferred there from other locations. In some cases, patients who were considered to be sufficiently stable were transferred to COCH, and others who required higher levels of specialist care were transferred to one or other of the level three units. The babies in the Unit were cared for by doctors, referred to here as neonatologists[1], and generally by specialist paediatric/neonatal nurses or nursing assistants . Although the Unit cared for vulnerable and sometimes sick babies, death was less common than has been implied by some sources, with between two and three deaths occurring at the Unit each year.

6. From June 2015 until July 2016, something extraordinary happened at the Unit. The number of deaths within the Unit increased rapidly. In June 2015 alone, three babies died (Child A, C and D), as many has had died in the whole of 2014 (see chart at INQ0003054_0010]). Whilst this might have been a statistical anomaly, the deaths of Child A, C and D, and the collapse of Child B on 10 June 2015, were unusual. They were entirely unexpected, some were associated with unusual discolouration to the skin, and, in the three cases that resulted in deaths, did not respond to resuscitation in the expected way. This pattern of unexpected collapses and deaths continued. Additional features became apparent that increased the index of suspicion, or should have done had they been adequately appreciated: Lucy Letby was found behaving suspiciously around

[1] Neonatologist is used as shorthand in this context to refer to doctors working in the Neonatology Unit. The Consultants working in the Unit were usually Paediatricians who had many years of experience caring for neonates.

babies at or about the time of their collapses: for example by Mother EF in August 2015, and by Dr Jayaram at the point when Child K collapsed. Exogenous Insulin was detected in Child F, only explicable by a deliberate attempt to poison him. Child O was found to have unexplained injuries to his liver, not minor injuries caused in the context of legitimate medical procedures but of the sort that might be caused by a high velocity impact, such as a road traffic collision.

7. The only common denominator through all the unexpected collapses was Lucy Letby. It would be wrong however to say that the evidence accumulated against her relied upon any statistical probability, it did not. It relied upon the manner of the deaths, the injuries found and the presence of drugs that must have been administered deliberately to poison babies. It was a remarkably similar pattern as had been seen in the Grantham and Kesteven Hospital, where Beverly Allitt murdered and attempted to murder babies and children over a four-month period in 1990. Sadly, whilst the similarities were remarked upon by a number of individuals involved at various points with the COCH, the type of action that brought Beverly Allitt's crimes to an end after four months were not taken within the same time frame and Lucy Letby was allowed to continue murdering and deliberately harming patients over the course of a year.

8. The pattern of unexpected deaths and collapses continued throughout 2015 and the first half of 2016 but subtly altered as different methods were deployed. Having previously occurred during the period between midnight and 04.00 hours, the unexpected deaths and collapses began to occur during the day shifts. The change occurred following a decision to move Lucy Letby from working night shifts to day shifts for a period of three months beginning in April 2016. The unexpected deaths and collapses paused whilst Lucy Letby left the Unit for a holiday in June 2016 and stopped when Lucy Letby was removed from nursing duties in July 2016. The evidence will suggest that clinicians working in the Unit began to suspect Lucy Letby's involvement in the deaths in October 2015. Managers at the COCH did not report concerns to the Police until May 2017.

9. The outline history for each child named at the start of this written opening will be discussed below. That history is however only an outline. The families will give evidence about their experiences after which the Inquiry will hear detailed evidence about the medical care provided to each child and the reactions within the COCH to the events.

10. A common bond between each of the babies listed below is that they had each survived in the face of adversity up until the point when they were attacked by Lucy Letby. In some cases, these attacks robbed them of their lives and of their chances of continuing to grow and to thrive; in other cases they survived the attempts to murder them and were moved to places of safety. Some of those who survived sustained permanent and life-altering injuries whereas some of the babies escaped physically unscathed. The parents of all of them carry permanent psychological scars, some deep and profound.

11. The babies were in most cases the first child or children of their parents. In several cases their parents had struggled to conceive and saw the mother's pregnancy as a miracle. They were all babies who were dearly loved and treasured by their parents. Although all of the babies attacked by Lucy Letby were vulnerable, it is entirely incorrect to describe them as having been critically unwell, unstable, or on the brink of death prior to the point when they were attacked. The common experience of the families in this group is that their babies were not following some inexorable downward trajectory; they were improving. Sometimes taking small but nonetheless unmistakable steps towards normality and in other cases were seemingly well and just in need of a short period of observation or support. This point is important in that it demonstrates the inaccuracy of some reporting of the case but also emphasises the unusual nature of these events, a factor that the Families say should have been explored and examined sooner.

The Babies

Child C

12. Child C was born in June 2015. He was his mother and father's first child. His mother's pregnancy was complicated by intrauterine growth restriction and Child C was delivered at 30 weeks gestation. Despite this, he was born in a good condition and although he required the type of support that would be expected for a baby of his size and gestation, the doctors and nurses who cared for him at the COCH saw nothing that caused them to be particularly concerned about him or his progress. His parents were told that although he was small, he was breathing for himself and doing as well as he possibly could. By two days of age, his mother was able to have skin-to-skin contact with him, which continued through to the following day. The last day before the attack began as 'good day' and Child C's parents and maternal grandparents were able to visit him for the first time: "as he was doing so well." His parents were able to leave the Unit during that evening; they believed that he was safe and would continue to improve and grow.

13. Lucy Letby murdered Child C. She attacked him after his parents had left the Unit. When he died, he was slightly less than **PD** days old.

Child D

14. Child D was delivered by caesarean section at the COCH in June 2015, slightly less than a week after Child C died. She was her parents' first child and was born at 37 weeks and one day gestation. Although she appeared to be in a reasonable condition at the time of her birth, in the hours that followed there were concerns about her breathing and, taken alongside the fact that there was an extended interval between her mother experiencing rupture of membranes and Child D's birth, it was suspected that she might have an infection. She was admitted to the Unit for treatment and observation. Although unwell in the hours following her birth and requiring intubation, she appeared to respond well to treatment and during the early hours of the day following her birth the clinical signs were good, and she was being weaned off the ventilator. She

was well enough to be extubated at 09.00 hours that morning. Although her condition remained vulnerable, the general impression was that she was getting better, and she did not appear to have any obvious signs of sepsis. Father's Day came shortly after her birth and Child D's father was given a card with pictures of Child D on it. Later that day, her parents were told that "she was doing fine" and were told that her colour was better and that they "could hopefully have a cuddle the next day." Her mother was told that she could begin feeding Child D the following day.

15. Lucy Letby murdered Child D, who collapsed three times during the nightshift after air was injected into her bloodstream. When she died, she was less than **PD** days old.

Child E

16. Child E was born in July 2015. He is the twin brother of Child F. The twins were their parents' first children. They had struggled to conceive **I&S** **I&S** February 2015, **I&S** they discovered that they were pregnant, later on finding out that it was a naturally conceived twin pregnancy. Unsurprisingly, they considered this pregnancy to be 'a miracle'.

17. Child E's mother had been cared for throughout her pregnancy at the Liverpool Women's Hospital (LWH). Her pregnancy appeared to progress normally at first but when she reached 27 weeks gestation, she was told that the twins had a condition known as twin-to-twin transfusion syndrome and that Child E had intrauterine growth restriction[2]. She was admitted to the LWH for observation and advised that the condition of her twins would be monitored closely with the hope that the pregnancy could continue to, or at least as close as possible to, 30 weeks gestation or beyond. At 29 weeks and five days, Child E's mother was told that the twins would need to be delivered as soon as possible but there were no free beds in Liverpool. She was transferred to the COCH and the twins were born there before being transferred to the Unit.

18. Child E was born first and was slightly smaller than his brother, nonetheless he was born in a good condition, not a growth-restricted baby, but premature and vulnerable. Child E's mother was able to visit him in the Unit and cuddle him. He did not require ventilation or CPAP and seemed to be progressing well. His mother was advised that he was doing well and did not gain the impression from those treating him that they had any concerns or that there was anything seriously wrong with him. She recalls that the whole team at the COCH were "thrilled with their progress". There were discussions around the prospect that the twins might be transferred to a hospital closer to their parent's home, to be closer to their family. Their parents were advised that the only reason why this transfer had not occurred was because there was no transport available, as far as they were concerned the twins were well and ready to move home. When he was a few

[2] Child E did not, as a matter of fact, have intrauterine growth restriction. He was a normal size when born.

days old, Child E seemed to be “truly thriving”. He had skin-to-skin contact with his mother and father and had been washed and changed when his parents left the Unit.

19. During a night shift in early August 2015, Lucy Letby attacked and murdered Child E by injecting air into his bloodstream and by causing him abdominal injuries. His mother arrived back on the Unit, presumably shortly after he had been attacked to find him bleeding and distressed with Lucy Letby standing close by. Letby lied to Mother EF by telling her that the bleeding was the result of irritation from Child E’s nasogastric tube and by implying that the Registrar was on his way and she would draw it to the attention of a doctor. The bleeding was the consequence of harm that Lucy Letby had caused. She did not immediately report to a doctor as she had implied. Child E died when he was only **PD** days old.

Child F

20. Child F was slightly larger than his brother but was nonetheless born in a good condition. He required greater support in his early days and was on CPAP (continuous positive airway pressure) and receiving total parenteral nutrition (TPN) through his bloodstream to supplement his milk feeds. After a few days his parents believed that he was “thriving”. He was taken off CPAP at around the time that Child E died and his parents were able to see his face properly for the first time. This became particularly poignant for them, as he looked very much like Child E. His condition seemed to be stable and, if anything, improving.

21. Lucy Letby attempted to murder Child F by adding insulin to his TPN bag/s during the night shift in early August. Child F suffered an unexpected drop in his blood sugar with tachycardia on 5 August 2015. Blood samples revealed an unexplained hypoglycaemia, which persisted, despite Child F being given boluses of dextrose until his TPN bag was stopped and replaced with a dextrose infusion. He nonetheless suffered a protracted period of hypoglycaemia, leaving him with permanent learning disabilities.

Child G

22. The parents of Child G struggled to conceive **I&S** She is their first and only child. Her mother’s pregnancy was complicated by antenatal bleeding at nine weeks and 22 weeks, although scans revealed a non-sinister cause for these bleeds and Child G’s parents were reassured that the pregnancy was proceeding normally. When Child G’s mother was 23 weeks into her pregnancy, she experienced another bleed accompanied by a leak of amniotic fluid. She was assessed at the COCH but was advised that they were not equipped to deal with babies born before 28 weeks. Mother G was therefore transferred to Arrowe Park Hospital, where she gave birth in May 2015, at 23 weeks and six days gestation. Given her extreme prematurity Child G was extremely vulnerable and required maximal support but seemed to do well and her parents were told that she was making good progress. After a few

weeks she was able to breathe on her own, she grew and brain scans were interpreted as showing positive signs.

23. Child G remained at Arrowe Park Hospital until she was transferred to COCH on 13 August 2015. Her parents would have preferred for her to remain at Arrowe Park but were initially happy with her progress following the transfer. By September 2015, her parents were pleased to see that she was smiling, grabbing her dummy with her hand, drinking from a bottle and recognising and responding to their voices. This impression was shared by those who were caring for Child G at the COCH and in the period leading up to her first collapse she was described as stable and improving.

24. In September 2015, Child G was approaching her 100th day of life and her parents were preparing to celebrate the milestone with staff on the Unit, who had prepared balloons, a banner and cake. When her parents left her in the Unit during the night of 6th September 2015, they were optimistic about her future, as far as they understood she was doing well. She just had to grow and would then be able to go home.

25. During the course of the early hours of 7th September 2015, Lucy Letby attacked and attempted to murder Child G by administering an excessive volume of feed and air through her nasogastric tube. She suffered repeated collapses during the early hours on 7th September 2015 before being transferred to Arrowe Park Hospital on 8th September, where she remained until 16th September 2015. Whilst she was at Arrowe Park Hospital, the parents of Child G were advised that cranial ultrasound scans had revealed abnormalities that hadn't been present before. They were subsequently advised, when Child G was back on the Unit at COCH, that she may be clumsy when she grew up, but it was not suggested that she would have any severe disabilities.

26. Lucy Letby attacked and attempted to murder Child G again at around 10.20 hours on 21st September 2015 by again administering excessive volumes of feed and air into her nasogastric tube. The indictment alleged that she attacked Child G a third time at around 15.30 hours on 21 September 2015, although she was acquitted of that offence.

27. Child G was discharged from the COCH on 2nd November 2015. She has severe cerebral palsy and requires high levels of care and support. She will never live independently.

Child H

28. Child H is her parents' first child and was born at the COCH in September 2015. Her mother has diabetes and concerns about that condition, difficulties in controlling her mother's blood sugar levels, and the potential impact on Child H, led to her undergoing a caesarean section at 34 weeks and four days. Despite these concerns, Child H was born in a good condition and her birth was uneventful. In the period following her birth, Child H's condition was unstable in the days

following her birth and over the course of a few days she suffered a number of pneumothoraces of the left lung with episodes of desaturation and bradycardia. These necessitated treatment with needle thoracocentesis and chest drains. Her treatment during this period was complicated by what has been described as 'sub-optimal' but may even be regarded as negligent care.

29. Within that context, it was alleged that Lucy Letby attacked and attempted to murder Child H on two occasions: on 26th September and on 27th September 2015. She was acquitted of the first attack but the Jury were unable to reach a conclusion in relation to the second attack. The episodes on 26th September and 27th September 2015 were particularly unusual, even within the context of the complicated and at times turbulent progress that Child H had made up to that point. They involved a cardiac arrest without an obvious precipitating cause, such as a pneumothorax, hypoglycaemia, tamponade, or sepsis and a profound desaturation and bradycardia, again without a clear explanation. On behalf of Child H, it is suggested that these episodes occurred because Lucy Letby attempted to murder Child H.

30. Child H was transferred to Arrowe Park Hospital on 27 September 2015. Thereafter she made good progress and, on the face of things, has thankfully not suffered any long-term harm. Her family have not escaped unharmed, though, and continue to suffer the effects of their experiences.

Child J

31. Child J was born in October 2015, she was the first child together of Mother J and Father J. They had desperately wanted children together but their decision to start a family was complicated by a family history of a rare genetic disorder and they required extensive tests before they were content that it was safe to proceed with a pregnancy. Their attempts to conceive were complicated I&S. When they discovered that they were pregnant with twins they were delighted and felt 'truly blessed'. Sadly, the pregnancy was complicated by twin-to-twin transfusion syndrome and in July 2015 they were advised that this condition was progressing rapidly, and that surgery would be needed to prevent the loss of both twins. They were filled with grief when that surgery led to the death of one of the twins and filled with apprehension that Child J would not survive.

32. Child J did survive and was born at COCH at 32 weeks gestation. She was transferred to Alder Hey Hospital on 1st November 2015 for treatment for a suspected perforated bowel and underwent surgery to create two stomas. She recovered well from this and was transferred back to the COCH on 10th November. She progressed well from that point and had no respiratory problems or other complications and by the time that she was two and a half weeks old she was receiving her feeds by bottle. Although her care could at times be challenging, as one would expect for a baby with a stoma, her condition did not cause concern to those who were treating

her. By the time of the night shift of 26th through to 27th November 2015 she seemed stable, there were no desaturations or problems with her stoma,

33. On 27th November 2015, Child J suffered two sudden and unexpected desaturations which required her to be resuscitated. The second desaturation caused her to suffer seizures. This was entirely at odds with her condition up until that point. Until that point she was perceived to be a lively, alert, engaging baby, ready to go home. The collapse was unexpected and had no obvious cause. The collapses occurred because Lucy Letby attempted to murder Child J. Although the jury trying the case could not reach a verdict on this issue, Child J's parents have no doubt that this is what occurred.

34. Child J survived Lucy Letby's attempts to kill her. Her family have not escaped unharmed, and continue to suffer the effects of their experiences.

Child K

35. Child K was born in February 2016 at the COCH, she was her parents' first child together after struggling for several years to conceive. The couple were 'thrilled' to discover that Child K's mother was pregnant in August 2015.

36. Mother K experienced the onset of premature labour in February 2016 at 24 weeks and six days and was admitted to the COCH. Her labour could not be deferred, and she delivered Child K at 25 weeks gestation. Although the COCH was not a Unit that would be expected to care for babies born before 28 weeks gestation, at the time of Mother K's premature labour the nearest tertiary bed available was in Preston and it was felt that the prospect of her delivering her baby in an ambulance whilst being transferred there left staff at the COCH with no alternative but to deliver and admit her to the COCH.

37. Although Child K was extremely premature, her clinical condition following birth was essentially normal, in fact good. She received surfactant, a drug to protect and improve lung function in premature babies and was commenced on an intravenous dextrose infusion. After she was transferred to the Unit she was noted to be settled and stable and a morphine infusion was commenced. Mother and Father K were able to visit their daughter, they were aware that she was small, Father K recalls that her whole hand could sit on his thumb, but they were told that she was doing "ok".

38. Lucy Letby attempted to murder Child K on 17th February 2016 by dislodging her breathing tube. She was discovered by Dr Jayaram standing by Child K's ventilator whilst Child K's oxygen saturations dropped. The alarm on the ventilator was not sounding, having been turned off by Lucy Letby. The endotracheal tube was found to be pushed down by more than 20%, over 1cm, a substantial distance given the size and fragility of Child K. Lucy Letby interfered with Child K's

endotracheal tube on two further occasions on 17th February 2016, at 06.15 hours and at 07.25 hours. Child K was shortly afterwards transferred to Arrowe Park Hospital.

39. Child K died in February 2016 when she was a little over PD days old. Although Lucy Letby was originally charged with the murder of Child K there was insufficient evidence to establish that her attempts to murder Child K resulted in her death. Child K's parents will however always believe that Lucy Letby murdered their daughter and took away any chance that she had of surviving. As with other families, their lives have been devastated by the events and their subsequent appreciation of what had happened to their daughter but also by the events that followed and the COCH's lack of candour.

Child O

40. Child O was born in June 2016; he is one of triplets and his brothers are Child P and Child R. Before becoming pregnant with Child O, Child P and Child R, Mother OPR and Father OPR had one other child together. When Mother OPR was 12 weeks pregnant she discovered that she was expecting monochorionic triplets. This was entirely unexpected news as neither family had any history of multiple births, and the pregnancy had been naturally conceived. Significant risks attached to a monochorionic triplet pregnancy and Mother OPR was subject to close monitoring in pregnancy and received prophylactic steroids at 23 weeks against the risk of premature delivery. She was cared for under the COCH and advised that the plan should be to allow the pregnancy to get as close to 34 weeks as possible to provide the triplets with the best chance of survival.

41. Mother OPR went into labour at 33 weeks and 2 days gestation and her triplets were born by caesarean section at the COCH. Child O was born in good condition. He cried at birth, did not require resuscitation and his Apgar scores were noted to be reassuring. His birthweight was described by Dr S as "good" and he was considerably larger than his Mother had been led to expect. Child O was transferred to the Neonatal Unit on the day of his birth. Throughout the remainder of that day and the following day there was nothing remarkable about his condition. He seemed 'fine and stable' and was able to stop antibiotics and start on some enteral feeds, which he appeared to tolerate well. He remained perfectly well, giving concern to no-one who interacted with him. His parents enjoyed time with him in the Unit and as far as they were concerned everything was well.

42. Lucy Letby murdered Child O when he was PD days old by injecting air into his bloodstream and into his stomach via his nasogastric tube. She also caused him to sustain an injury to his liver, described by Dr Marnerides, a forensic pathologist who gave evidence at her trial, as the sort of injury that he would associate with a serious accident, such as a road traffic collision, or fall from height, or an assault. The perception of Mother OPR and Father OPR and those treating Child O was that his collapse came 'out of the blue'. Following his death Mother OPR and Father OPR

were concerned that perhaps Child O had contracted a disease that he could pass on to his brothers, so they took his body away from the Unit. Because of this they only have one photograph of their three sons together.

Child P

43. Child P was also born in very good health, active and crying spontaneously when delivered and maintaining his oxygen needs on room air within a few minutes after his birth. He was treated initially with prophylactic antibiotics, but these were stopped after a short time and on the day after his birth he was able to begin to feed on expressed breast milk provided through a nasogastric tube. Everything about his condition appeared reassuring and positive and his parents were advised that, like his brothers, he was doing well. Following Child O's death, Child P was reviewed by Dr Gibbs and Dr Cooke, who concluded that he appeared very well. Throughout that night, although he experienced one brief oxygen desaturation and episode of bradycardia the overall picture was not thought to be of any significant concern. Mother OPR and Father OPR remained concerned that Child P had an undiagnosed illness and Mother OPR visited the Unit at about 06.00 hours the following morning. She was reassured by a nurse there that her boys were 'little angels' and that she had no concerns about them. She was told to go back to the maternity ward and eat breakfast, which she did. As she was showering, she was called back to the Unit because Child P had collapsed.

44. Lucy Letby murdered Child P by administering air into his stomach via a nasogastric tube. He died when he was **PD** days old. As attempts were being made to resuscitate Child P, staff at the COCH called an extraction team to take him to the Liverpool Women's Hospital. They were led by Dr Rackham who took over the resuscitation when he arrived. Dr Brearey and Dr Rackham told Mother OPR and Father OPR that they did not know why Child P had collapsed and could not believe it. Father OPR "begged" Dr Rackham to take Child R to LWH. He eventually agreed to this, although it was necessary for Mother OPR to discharge herself from the COCH in order to follow him. Mother OPR and Father OPR believe, justifiably so, that this decision saved the life of Child R.

45. Like many parents of murdered or harmed babies, Mother OPR felt a sense that she was responsible for Child O and Child P's deaths, that: "maybe I had passed something onto the boys." This sense of guilt was left unresolved until she was able to attend the criminal trial. That parents were permitted to live with this guilt for so long is a source of justifiable resentment.

Terms of Reference

46. The Inquiry's Terms of Reference provide a broad and comprehensive scope to this Inquiry to explore issues relating to Lucy Letby's crimes and their broader implication within the National Health Service. The Families will set out two key themes below, which fall within the scope of those Terms of Reference. That list should not be seen as exhaustive at this stage and further

issues are likely to be introduced as the evidence is presented and expanded upon. It should be emphasised at this stage however that whilst the subject of this Inquiry is a serial killer working within the NHS, the purpose of the Inquiry should not be solely limited to preventing the next Lucy Letby. The Inquiry's Terms of Reference provide an opportunity to make recommendations that have broader implications, to save lives and to improve the experiences of those who work within and interact with the NHS.

47. These submissions will adopt a thematic approach to common issues raised by the Families at this stage. These themes can be summarised as follows:

    a) Why was this allowed to happen?
    b) Why was the Trust not candid or honest with the Families?

Why was this allowed to happen?

48. This is an issue common to all of the Families and can be developed in a number of ways throughout the relevant chronology.

49. The notion that a medical professional might malevolently harm their patients was not a novel or remote concept in June 2015 and parallels will no doubt be drawn within this Inquiry between the case of Lucy Letby and other murderers in recent history: Beverly Allitt (1991); Harold Shipman (2000); Colin Norris (2008). Whilst the statement within the Clothier report, published in 1994, into the crimes of Beverly Allitt, (INQ0017497 at p.131) that: "Civilised society has very little defence against the aimless malice of a deranged mind" remains true, the Families will say that it does not follow that the risk that a member of staff would deliberately harm patients was so remote or unpredictable that the COCH was entitled to ignore it altogether when it was advertised to them. Nor does it follow that proper or rigorous standards would not have protected babies from Lucy Letby's actions, either by detecting and preventing her crimes sooner, or by creating an environment where it was more difficult for her to develop the confidence to commit those crimes in the first place. These concepts are not new and indeed are clear when the quote from the Clothier Report is put into its proper context (page 131):

    "We were struck throughout our Inquiry by the way in which fragments of medical evidence which, if assembled, would have pointed to Allitt as the malevolent cause of the unexpected collapses of children, lay neglected or were missed altogether. Taken in isolation these fragments of medical evidence were not all very significant nor was the failure to recognise some of them very culpable. But collectively they would have amounted to an unmistakable portrait of malevolence. The principal failure of those concerned lay in not collecting together those pieces of evidence. The initiative and the energy needed to do this were not forthcoming at GKGH. That is the true and ultimate criticism.

Civilised society has very little defence against the aimless malice of a deranged mind. Wherever we have found the slightest possibility of prevention, we have pointed to it. The tightening of standards which we have sometimes urged must be a good in itself and such small improvements may reduce the opportunities open to another Beverly Allitt."

50. The Families will say that these comments resound through this case. There was, in the view of the Families: a lack of proper curiosity into or investigation of unexpected and unusual collapses and deaths. This lack of proper investigation prevented earlier detection of the crimes and provided the environment in which Lucy Letby could commit crimes with confidence that she would not be detected. There was a failure to act promptly and decisively once suspicions were actually raised, even when those suspicions were vocalised loudly and clearly to the highest level of management. The resonance between this case and the Allitt case does not begin and end with the conclusions of the Clothier Report. An analysis of the facts surrounding her crimes, as set out within the report [INQ0017497 pp.29 – 41] and the hospitals response to them [pp.42 – 77] reveal that, as with this case, there was an unexpected and unusual cluster of collapses and deaths within a paediatric ward where vulnerable children were cared for. The collapses often occurred in children who had otherwise appeared well. They were felt to be unexpected. In the cases of those children who died, resuscitation was noted to be unusually difficult and ineffective. Commonly, no cause could be found for the collapses or deaths, and causes of death were offered about which the treating doctors felt unsure or confused. The catalyst that revealed the crimes of Beverly Allitt was the discovery of high insulin levels with low C-peptide levels in a blood sample taken from one of the children and reported by centralised laboratory based in Cardiff. As the Inquiry will hear, a finding of high insulin and low C-peptide is pathognomonic for exogenous insulin, i.e. insulin that has been introduced into the body rather than insulin occurring naturally within the body (endogenous insulin). The laboratory identified this finding as abnormal and contacted the Hospital (see pp64 – 66) speaking with a doctor on the Unit. The Clothier Report was particularly critical of the Hospital's response having received this information and the delay of two weeks before the police were called, describing it as "feeble and indecisive" (see para 4.11.5 on p.65 and para 4.11.9 on p.66). Two weeks were allowed to elapse before the Police were contacted, in which further crimes were committed, including a further murder. The Families will say that in its reaction to these events the Grantham and Kesteven Hospital did considerably better that the COCH did, 25-years later and with the benefit of the accumulated knowledge that had been acquired in the intervening period.

51. In light of this the Families would ask:

    (a) Why were the deaths and collapses not better investigated and why were suspicions not identified or voiced sooner?

    (b) Why did the Trust fail to act when suspicions were actually raised?

Why were deaths and collapses not better investigated and why were suspicions not identified or voiced sooner?

52. The Families understand that some clinicians will say that they had suspicions that Lucy Letby may be involved in deliberately harming children from October 2015 onwards. Others might suggest that suspicions became acute in June 2016. The reaction to suspicions that did exist and whether those reactions were adequate is an important topic within this Inquiry and will be explored in detail. The Families would not however wish the Inquiry to allow the necessary scrutiny surrounding that issue to distract from the COCH's response to events earlier in the chronology. They believe that there was a failure to adequately investigate the spike in suspicious deaths that began with Child A in June 2015, and which was continuing at the time when suspicions were eventually aroused. The Families will say that events during this period should have raised a higher index of suspicion, or at least greater curiosity regarding the cause of unexpected deaths and collapses. The Families say this for the following reasons:

    (a) The deaths and collapses were unexpected and unexplained.
    (b) The babies involved were not critically unwell prior before they collapsed and the collapses when they occurred were unforeseen and unexpected. These were not babies who would have been predicted to be at risk of collapse and sudden death.
    (c) The babies did not respond to timely resuscitation manoeuvres in a way that would be expected, save for Child B. Child C unexpectedly showed signs of life after a prolonged and unsuccessful resuscitation in a way that was at odds with what would be expected.
    (d) The collapses and deaths involved unusual features that could not be explained by those who witnessed them, including unexplained skin changes.
    (e) The deaths occurred in a cluster that was entirely at odds with experience on the Unit throughout previous years. Three deaths occurred in June 2015 alone, the same number or more as had occurred annually in preceding years. The Families would ask why this unexpected spike in deaths did not trigger greater curiosity or investigation.

53. The evidence obtained so far suggests that whilst limited investigations were undertaken at the time of these deaths, they were incomplete and inconclusive. Despite this, the COCH repeatedly advised families and external bodies such as the Coroner, that the deaths were natural and capable of explanation. The Families are concerned that this impression of certainty did not reflect the actual beliefs of the clinicians at the Trust. This disparity, and why it was allowed to occur and persist needs to be addressed and understood.

54. The Families are aware that following an increase in deaths during this period the COCH ceased reporting deaths to MBRACE. They find this decision extremely worrying and would ask why an NHS Trust would cease to provide information to MBRACE.

55. A post-mortem examination was performed on the body of Child C. Its findings were inconclusive and it appears that Dr Gibbs queried with the pathologist whether the finding of diffuse myocardial ischaemia, which was recorded on the post-mortem report, was the precipitating cause of the collapse or a histological feature that occurred due to prolonged resuscitation. It is evident from his evidence that this was not a finding that he readily accepted or agreed with, nonetheless the COCH permitted this cause of death to be recorded on Child C's death certificate and permitted the Coroners' investigation to end without an inquest [INQ0008979 and INQ0000108 at p152 – 161]. This is particularly surprising given that: Child C's death was clearly thought to be unusual and unexplained at the time that it occurred (see Minutes of SUDI/C meeting on 2 July 2015 INQ00002047 at page A188) and given that Dr Gibbs clearly had concerns regarding the suggested cause of death. In his witness statement Dr Brearey comments that none of the recorded causes of death explained why Child C suddenly collapsed after a period of normal stability [INQ0103104 at paragraph 96]. This is not simply based upon the reconstruction of events after suspicions had been raised. When Child C was discussed at the PMM meeting on 11 February 2016 a slide of the neonatal observation charts presented by Dr Gibbs showed a completely normal stable set of observations for 12 hours leading up to the collapse (see Brearey at paragraph 141).

56. In the case of Child D a post-mortem examination, reported on 26 August 2015, recorded that the cause of death was pneumonia and acute lung injury [INQ0000762 p139-150]. This can be contrasted with the conclusions of the Child Death Review Panel at COCH on 16th July 2015, which listed the cause of death as "complications of delivery" [INQ0012220]. Neither conclusion adequately explained the sudden and unexpected nature of Child D's death or the inability to properly resuscitate her when she collapsed, but in the absence of concern on these issues being properly ventilated the enquiries into her death did not progress further and the inquest process stalled. The conclusion that Child D's death was caused by overwhelming infection, which was the conclusion promoted to the Coroner by the COCH, was not at all consistent with Child D's condition preceding her collapse. There were no prodromal symptoms, or fever, and the mottling and tracking regions across her trunk that were observed but then disappeared was unusual and not typical for overwhelming infection. In fact, it was caused by an air embolism introduced by Lucy Letby.

57. It is clear that staff at the Hospital had in mind that Child D's death was part of an unusual cluster and the Datix report into the death of Child D (INQ0002658 p.2) refers to two other recent deaths (Child A and Child C). The entry by Dean Bennett within the Datix identifies that a single member of staff had been present for all three deaths. It is not clear to the Families what the purpose behind this reference is, although it raises the question of whether suspicions had already been aroused as to a common link.

58. Child D's family had no option but to advocate many times on behalf of Child D before further investigations were eventually resumed by the Coroner. It is notable that when the Coroner finally embarked upon an investigation the report obtained by him from Dr Mecrow highlighted the extraordinary and unexpected circumstances of Child D's death [INQ0002045 at p218]. The same conclusion could readily have been reached by the COCH and contextualised alongside the other unexpected deaths. The tenacity of Mother D and Father D should be commended but it should not have been necessary.

59. When Child E died on 4th August 2015, his parents were told a post-mortem examination was not necessary and that death was caused by necrotising enterocolitis (NEC). This was not a reasonable conclusion to reach without a post-mortem and that condition did not adequately explain the sudden and unexpected nature of Child E's collapse or the complexities and unusual features surrounding his resuscitation. The decision not to undertake a post-mortem examination led to Child E's death being categorised as a death due to natural causes and caused the Coroner to close his investigations. This is at odds with the perspective on his death from those who treated him. The statement of Dr Harkness refers to Child E's episode of bleeding as "unusual" and "out of nowhere", not something that he had seen before or since [INQ0102350 at paragraph 17].

60. The Families will say that there were further suspicious features surrounding Child E's care at the Unit and about Lucy Letby's conduct, which could have been identified had Child E's mother been provided with the opportunity to share them. Child E's mother found her child screaming and with blood around his mouth. Lucy Letby, who was standing close by, reassured Mother E that she would contact a doctor and asked her to leave the Unit. Subsequent investigations demonstrated that this was a lie and that a doctor was not called immediately.

61. Child F, Child E's twin brother, collapsed and suffered a profound episode of hypoglycaemia. This episode was unexpected and unusual. Samples of Child F's blood were taken during the early evening of 5 August 2015 and sent to the laboratory for testing [INQ0000844]. The results of these tests were of particular importance in the criminal trial and remain important within the context of this Inquiry. The level of insulin in Child F's blood was 4657, many times over the normal range for a neonate. The Insulin C-Peptide results, recorded within the same test report, were less than 169 pmol/L indicating that the insulin within Child F was exogenous, i.e. administered to him rather than created by him. This feature is identified by Dr Brearey within a statement that he gave to the Cheshire Police [INQ0000887] but does not appear to have been appreciated by him at the time. The presence of exogenous insulin in a baby such as Child F, who had collapsed due to a prolonged episode of hypoglycaemia that was refractory to treatment, and who was not being treated with insulin at the time of his collapse should have raised alarm bells. It was a red-flag for deliberate harm but when reviewed by Dr ZA, assumed to be an error. She felt that the idea that insulin had been given deliberately was 'ridiculously unlikely' so

assumed that the result must be wrong and did nothing further [INQ0099097 paragraph 48]. Insulin has been implicated in previous cases of deliberate harm (Allitt and Norris). The Families are concerned that this highly unusual finding was not flagged and investigated sooner. It is surprising to read that systems for highlighting a finding of exogenous insulin were less robust in 2015 than they were in April 1990 and that learning from previous cases did not lead to a greater index of suspicion. The Families of those children who were harmed after Child F will feel a profound sense of loss that the actions that led to the apprehension of Beverley Allitt did not bring a prompt end to the crimes of Lucy Letby.

62. Child G collapsed in early September 2015 before being transferred to Arrowe Park Hospital. Her collapses resumed when she was transferred back to the COCH later in September. Her collapses were not preceded by any obvious deterioration in her health and, whilst they were attributed to sepsis at the time her inflammatory markers and negative cultures were not consistent with that diagnosis, as would have been evident with closer investigation. The Families note that Dr Gibbs, in his statement to the Police observed that: “Overall, it is not clear why Child G collapsed on 21/09/15 and none of the possible explanations discussed above provide a clear explanation for the reasons mentioned, although they still remain as possible causes” [INQ0000339].

63. Child H’s collapse was equally unexpected and unexplained but likewise there was no sense of curiosity as to its cause. She was rapidly transferred to Arrowe Park Hospital, where thankfully she recovered. It is tempting to assume that those who treated her felt that all was well that ended well. Her collapse was nonetheless one within a cluster of unexpected and unexplained collapses. The Families feel strongly that this pattern should have triggered a greater concern, greater curiosity, and more rigorous investigations. Closer investigation of these cases, in the opinion of the Families, would have resulted in earlier detection of Letby’s crimes. Exogenous insulin in Child F would have represented a clear smoking gun, as it did in the Allitt case.

64. Whilst it may be obvious that a failure to act in response to the actual concerns, once they had begun to coalesce and be expressed openly, would provide a clear opportunity to prevent further harm, it should not be assumed that the earlier and more rigorous investigation of unexplained deaths and collapses would not have brought about the same outcome i.e. the detection of Lucy Letby’s crimes. The Chair may conclude, having heard the evidence, that a lack of curiosity and scrutiny provided Lucy Letby with an environment where she felt free to act, confident that her crimes would not be discovered. That a killer would find greater opportunity to evade detection if working in an environment where unexpected death was not adequately investigated.

<u>The reaction to suspicions when they were raised.</u>

65. The Families would observe that there is considerable evidence and documentation to suggest that the consultants within the Unit: Dr Gibbs, Dr Brearey and Dr Jayaram, began to raise

concerns that Lucy Letby was a source of harm to babies on the ward from October 2015 onwards (see for example the evidence of Dr Elizabeth Newby INQ0101317 at paragraphs 54, 63 and 74). The evidence suggests that these concerns coalesced at the latest point following the death of Child I in October 2015 but the Inquiry will of course explore whether suspicions were aroused before that date.

66. As with the earlier incidents, the collapses and deaths of the babies who followed Child I were unexpected and unexplained and involved elements that should undoubtedly have raised suspicions, as it appears they did. If Dr Jayaram's evidence is accepted, as it was at the more recent trial, he effectively caught Lucy Letby red-handed. Again, it is surprising that this did not lead to more decisive action being taken sooner, although this issue will require further exploration.

67. The Families of Child J, Child K, and Children O and P were obviously concerned to discover that there were suspicions that Lucy Letby was deliberately harming patients before their children suffered harm. They consider that there was a failure to safeguard their children in the presence of a suspected or known threat, or at least one that had been identified by some of the senior clinicians on the Unit. They will ask why the existence of those concerns did not lead to earlier escalation and safeguarding being put in place to prevent harm occurring to their children? Insofar as concerns were raised and escalated, and it is clear as time went on that this did happen in a more persistent and vocal way, why were these concerns not acted upon sooner and more effectively? Why were structures not in place to allow a more effective framework of safeguarding to be created in response to concerns that did exist? Several of the parents who are core participants to this Inquiry work in industries where there is a positive duty to raise issues of misconduct or safeguarding and act in response to safeguarding/conduct concerns when they are raised. To all of the Families affected by Lucy Letby's crimes it is an anathema that those who provide healthcare to children would owe strict safeguarding duties, and have a clear structure to deal with safeguarding concerns where they suspected that parents or other family members were causing harm to their children, but would not appear to owe similar duties or have similar structures where that concern related to harm caused by a colleague. If those structures did exist, why were they ineffective or why were they neutralised?

68. The reasons why steps were not taken to recognise and act upon suspicions at the point that they came into existence is a key issue for this Inquiry to explore. The Families believe that attempts to 'blow the whistle' and escalate concerns were supressed by the COCH at the cost of further harm to victims. They The Families believe that seven babies were murdered or harmed in the period following October 2015 because proper steps were not taken to explore those concerns and that each successive delay allowed further harm to be caused. The Families who are represented within this group believe that proper safeguarding in response to those concerns would have avoided that harm and saved lives.

69. The Families are concerned that a culture has developed within the NHS where legitimate concerns by clinicians can be suppressed and where 'whistleblowers' are inhibited from acting because they fear that their reputation, careers and livelihoods will be at risk. The Families would ask why this has been allowed to happen, given that a culture of promoting patient safety should be seen as a key component of effective and safe healthcare?

Communications, Candour, Honesty and Transparency.

70. The failure to provide clear, complete and truthful information to families about the condition of their children and any issues that have arisen in relation to their care in hospital causes genuine and persistent harm. It causes parents to speculate as to why their children came to suffer harm. It prevents further questions being asked by the parents that might have highlighted other concerns. It causes them to blame themselves for passing on illness or disease or genetic abnormalities to their children. It erodes the trust that they have in their own judgement, and public trust in the probity of medical professionals or healthcare organisations and institutions. It affected parents' relationships with other or future children, their experience of childbirth and pregnancy. It causes them to worry about the health of their surviving children and their safety and the safety of others within the healthcare system. If they accepted the information given to them by medical professionals, they felt guilt and shame when the truth was revealed, that they had not advocated more persistently on behalf of their children. By the time the truth became known some, such as the parents of Child G, had made decisions and taken irrevocable steps based on incomplete, dishonest or faulty information. If families questioned the advice they were given they were put into conflict with the COCH, left to fight battles on their own with all of the stress and anxiety that accompanies that process. The truth, when it was revealed, did not provide them comfort, as the damage had already been done. When the truth was revealed for the Families, it was done in a hurried and unexpected way, often not through proper channels but through leaks to the media and newspapers, and some even during the course of Lucy Letby's criminal trial. All of the Families continued to discover new information during the Crown Court trial. Some will continue to discover it through this Inquiry.

71. The provision of honest, comprehensive and clear information to families is a basic right. It is not an indiscernible or nebulous concept. It does not put an unreasonable burden on hospitals or clinicians to ask them to provide honest and accurate information to parents or patients. It is not going too far to say that hospitals and clinicians should not lie to or mislead parents or patients.

72. The themes identified by the Families can be put into three categories:

    a) Families were not kept informed about the condition of their children;

b) Families were not informed about known issues with regard to the care provided to their children;

c) Some families were given information that was misleading or dishonest.

Information about their children's condition

73. This section is distinct from the duty of candour, which is discussed below. It relates to the Families' experiences of not being kept informed about their children's condition. It does not relate to failures to inform them of incidents of poor healthcare, or 'near misses', nor does it relate to failures to inform them about suspicions surrounding Lucy Letby.

74. There are multiple examples within the Families' witness statements of family members discovering information about their baby's condition years after the event. For some families, such as the Families of Child D, Child J, and Child G, they were unaware of the number of times their children had collapsed until they heard evidence given at the Crown Court. Others were not kept up to date with the condition of their children despite attending the ward regularly. The Family of Child G were informed that the deterioration in her condition leading to her collapse on 7th September 2015 was 'neonatal sepsis' when there was no evidence to support that conclusion and it remained a dubious one in the eyes of those who treated her. Her collapse was unexplained. The Family of Child K were not informed that their child's endotracheal tube had dislodged on three occasions causing her to desaturate or that she had required active resuscitation. Her parents believe that had this information been provided to them, they would have asked questions about how this could have occurred and is left with the sense that this information could have provided her with an opportunity to advocate for her daughter and question why the tube was repeatedly dislodged. The Family of Child F were not informed that he had suffered a prolonged episode of hypoglycaemia and were instead told that he had suffered an infection in his longline but was responding well to antibiotics. The first time that Mother F discovered that her son had suffered an episode of hypoglycaemia coincided with her being told that the Police s that Child F required an MRI scan to look for signs of hypoglycaemic damage to his brain. She was left to work out how this damage may have occurred by undertaking her own research.

75. The evidence will suggest that the Families were not at all times supported to be actively involved in the care being provided to their children. Supporting parents to be actively involved in the care being provided to their children necessarily involves providing parents with accurate information about the condition of their child, any medical interventions that have been provided and about any issues that have arisen. Providing this information permits parents to take part in decision making, consent to treatment and provides them with the opportunity to advocate for their children. It is therefore an important element in achieving person centred care in accordance with Regulation 9 of the Health and Social Care Act 2008 (Regulated Activities)

Regulations 2014. On a more basic level, providing accurate information to parents is a bedrock of compassionate healthcare. Parents should have the opportunity to know as much or as little about the condition of their child as they choose. Discovering that a child, who you assumed to be doing well, is in fact critically unwell is shocking and traumatising. Discovering years after the event that your child's learning disabilities were caused by an episode of hypoglycaemia as a newborn deprives you of the opportunity to understand their condition, seek appropriate rehabilitation or support and advocate on their behalf through the healthcare and education systems. It may also dispel an insidious sense that their condition was in some way caused by you. The effects of removing agency from parents are obvious and stark but eloquently summed up by Mother H in her witness statement (paragraph 43):

"I felt as though [Child H] was not my baby because I didn't have much of a say, I had to hand over all care and I was limited to seeing her at visiting hours"

76. The lack of support persisted beyond the point when harm had been caused. The Families whose children survived were provided with little if any information about what had happened to them. Those who lost babies were not provided with adequate bereavement support. It is not asking much that a hospital provide bereavement support to those who have suffered loss. Mother EF was so moved by the inadequacy of the support provided to her following the death of Child E that she trained to be a bereavement counsellor following his death (see paragraphs 140 – 144 of her statement).

Candour

77. The duty of candour came into force in December 2014 with the implementation of Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 [see INQ0012634, statement of Ian Trenholm at paragraphs 34-35]. It was therefore in force throughout the relevant period.

78. The duty is closely defined and relates to a duty to act in an open and transparent way in relation to "Notifiable Safety Incidents." The term "Notifiable Safety Incident" is defined as any unintended or unexpected incident that occurred in respect of a service user during the provision of a regulated activity that, in the reasonable opinion of a health care professional, could result in, or appears to have resulted in: the death of the service user, or severe harm, moderate harm or prolonged psychological harm to the service user [INQ0012634 paragraphs 42-44].

79. There is no evidence that the duty of candour was followed in respect of any of the Families at any point. The Families would like to know why this was the case and whether the duty of candour is sufficiently robust in its present formulation. It is notable that many of the parents found out about suspicions regarding Lucy Letby for the first time through news reports or when they were first contacted by the Police. Mother H and Father J contacted the Cheshire Police in

May 2017 after reading a newspaper article which raised concerns about the Unit and referred to Police investigations. Mother H was contacted by the Police and informed about suspicions regarding Lucy Letby for the first time at 6am on the morning of Letby's arrest. Father C heard about investigations into the Unit when a friend was sent a link to an article in the Cheshire Chronicle, Mother C first became aware of the article when she received it from him. She was heavily pregnant at the time and had attended multiple appointments at the COCH. She attended the bereavement office at the COCH and refused to leave until she had been seen. It was only then that she was informed that her son was part of the police investigation. She should not have been put in a position of having to be 'difficult' in order to find out such basic information about her child.

80. Mother and Father C were only informed that there was a suspicion of deliberate harm by a member of nursing staff when they received a telephone call from Cheshire Police at between 6am and 7am on the day of Lucy Letby's arrest. Mother and Father G had the same experience. Child K's parents were unaware that there had been any issues with their daughter's care until they were contacted by the Police in May 2017. The family of Child J first became aware of issues in the Unit when they read about them in the newspapers, Mother J comments in her statement (paragraph 116):

"We went through this at the time with minimal written explanation. We then discovered about the investigation into deaths and collapses via the newspaper and read that the hospital and Police had supposedly contacted all parents involved. My husband contacted them to check if they had looked into Child J's collapse and they said the hospital had not passed on our records, despite us never getting an explanation as to the reason for the collapse. We then found ourselves part of the investigation once the police had looked at our records."

81. There are also examples of parents not being informed of suspected substandard care in relation to their children. Mother OPR was unaware that Datix reports had been created in respect of her son's care until she attended the Crown Court trial. Mother and Father C were, for a substantial time, unaware that a report by Jane Hawdon had criticised the care provided to their child or that she had concluded that suboptimal care was probably and possibly relevant to his death [INQ0003172 p.25]. When this report was belatedly provided to them by Ian Harvey it remained incomplete and so they were unaware that Jane Hawdon had concluded that their son's death may have been preventable [INQ0003172 p.44]. The Family of Child H were unaware that their daughter had been the victim of suboptimal or negligent care. Mother D was told there was no requirement for IV antibiotics earlier, during labour, despite this being contrary to guidelines and it being identified in the Datix report completed following the death of Child D [INQ0002658]. Mother D was not given any explanation as to why her daughter, who was stable when Mother D was sent away from the Unit, had suddenly and unexpectedly deteriorated and died. Within the same report at p.8 it is noted that there was the potential to provide an additional dose of

intravenous antibiotics to Child D. Her parents were never informed of this. Jane Hawdon's report in October 2016 identified the delay in providing antibiotics as "major suboptimal care" and "probably relevant" to outcome [INQ0003172 p.23] despite this, Mother and Father D were not informed of any issues with the care provided to their daughter. In February 2018, Child D's case was discussed at a meeting with Margaret Bowron QC and described as "indefensible" [INQ0003081 p.3]. There is no evidence that proper candour was shown even at this stage. The Inquest into the death of Child D was adjourned *sine die* in November 2020, when the Coroner was informed of the CPS' decision to prosecute Lucy Letby. A review of the Coroner's file [INQ0002045] reveals no correspondence from the COCH to the Coroner to inform him that major failings had been identified in the care provided to Child D, or to disabuse him of the impression that he might have reached upon reviewing the COCH statements and case reviews from 2016, which describe the care provided to Child D as in line with accepted practice and state that "antibiotics were commenced within the recommended time limit" [INQ0002045 p. 463].

82. The Families were unaware that the COCH had requested an investigation from the Royal College of Paediatrics and Child Health and the Royal College of Nursing, with many hearing about the existence of the investigation for the first time when they received a letter from Ian Harvey dated 8th February 2017 [INQ0008990]. The full report was not sent to the Families but a redacted and incomplete version was uploaded to the Hospital's website. Some Families were not able to access this for many months (for example the parents of Children E and F). The Families were not provided with Jane Hawdon's report, which was available from October 2016, and which had been provided to the Consultant Paediatricians at the Hospital along with the Royal College Report on 3 February 2017 [INQ0003117].

83. The Families were given little, if any, notice that the report would be released before they received their letter in February 2017. The telephone logs for Child O and Child P reveal two attempts to call the family on 3 February 2017 at between 18.42 and 18.52. No messages were left and no further attempts were made to contact them [INQ0005801 pp.5 and 7]. The contact with Father OPR was eventually made on 8 February 2017 but only after the report had been released to the public [INQ0005801 p.9] which caused them considerable distress and had been directly contrary to an undertaking given to the Coroners' Office [INQ0011980 at p.4. This is far from a unique story for the Families. The lack of proper communication was woeful. It compounded the harm to Families and eroded what trust if any was left.

84. The version of the RCPOH report provided to the Families was significantly and substantially different from the final version provided to the COCH by the RCPOH. The final and unredacted version of the report appears at INQ0009618 and contains references to Lucy Letby (referred to as Nurse L) and the suspicions of the consultant body regarding her involvement in the deaths [see INQ0009618 at p.8 paragraph 3.12 and the section at pp.9 – 10 entitled "The individual nurse"]. These sections have been removed from the version provided to the Families which

appears at INQ0009619 (contrast paragraph 3.12 at p.8 and p.9 with the same pages on the Final unredacted version). The Families regard the decision to redact this information as a blatant lack of transparency and candour on the part of the Trust. They regard it as dishonest. If they had known about these concerns, they would have asked why the Police had not been contacted.

85. The broader issues surrounding the COCH's interactions with the Royal College and with Jane Hawdon are complex and require careful analysis during the course of the Inquiry. The Families believe, given the suspicions that had been raised by the Consultants, that the appropriate organisation to investigate the unexpected and unexplained deaths on the Unit was the Police. Had the Families been aware of the suspicions expressed within the unredacted RCPOH report they would have contacted the Police themselves, if the COCH were unwilling to do so. They are similarly concerned that the RCPOH did not itself recognise that the suspicions raised by the Consultants warranted immediate involvement of the Police.

Honesty and Transparency

Interactions with Families

86. The Families do not regard the lack of candour or transparency in COCH's communications with them as a product of uncertain principles, rules or policies. They believe that the Management of the COCH was dishonest, that it covered up and supressed the concerns that were being expressed about Lucy Letby's conduct on the Unit and the harm that she had caused to their children. The motives for this may be multifarious but the need to protect reputations appears to be a common refrain. If that was the motive, and the Families believe that it was, it should be condemned in the strongest possible terms. The reputation of a Trust and its managers is subordinate to the need to protect patient safety and the need to provide injured parties with truth and recompense. The Families will say that the excuses advertised in some statements, that it is better to protect the reputation of an NHS hospital because of the greater good that it serves, are feeble and self-serving. The reputation of a hospital and of the NHS as a wider organisation, is predicated upon its ability to serve its community. Dishonesty corrupts its reputation and erodes trust in both the hospital and the NHS. It creates a culture that puts reputation and image above substance and reality and creates an environment where patient safety issues, the concerns of whistleblowers and the complaints of those who are injured are disregarded, suppressed and denied. It denies the opportunity to learn from mistakes or prevent future harm.

87. The Families will say that the Trust's interactions with them, especially following June 2016, were lacking in transparency and were dishonest. There are numerous examples of this throughout the experiences described by the Families but the experiences of Mother C are particularly apposite. She was contacted by Sian Williams on 3rd February 2017 and informed that there had been a leak of information regarding investigations in the Unit and that an article would be published in the Sunday Times that weekend. Having picked up a copy of the report upon returning from holiday she wrote to Ian Harvey on 7 February 2017 [INQ0008969]. This is a long letter setting

out the poor history of communication from the Trust and includes the words: "The report does strike me as having some suspicion that there were some unusual features of the deaths of the babies on the unit and that perhaps there was something going on on the unit that caused or at least contributed to the increase in mortality…"

88. Mother C subsequently attended a meeting with Ian Harvey in February 2017, describing the meeting in the following terms in paragraph 31 of her statement:

"Ian Harvey apologised to us for the poor communication. He advised us that some small areas that could be improved upon had been noted in the review of Child C's care, but nothing of concern; and there was nothing that could have been changed about his care that would have affected the outcome and prevented his death. We were relieved to hear this. This was what we wanted to hear, and we were aware that nothing ever goes perfectly so we had expected some areas of improvement to be noted. The conclusion of the investigation would allow us to move forward and not to have this investigation and uncertainty hanging over us…"

89. If the Inquiry accepts Mother C's evidence on this issue, Ian Harvey lied to her. At the time of the meeting he was in possession of a report from Jane Hawdon that criticised the quality of the care provided to Child C and concluded that his death may have been preventable had the standard of care been better. Ian Harvey was aware at the time of this meeting that serious concerns had been expressed by Consultants in the Unit that Lucy Letby had deliberately harmed babies on the Unit, including Child C. He was aware that Mother and Father C had been provided with an incomplete version of the RCPOH report which omitted references to that issue.

90. Ian Harvey wrote to Mother and Father C, as he did to other affected Families, on 3rd March 2017 stating that the review has "indicated that a small number of areas of investigation are required and I aim to undertake this as quickly as possible" [INQ0008970]. That is despite advising some media outlets in February 2017 that the Trust had acted 'swiftly' and that the reviews had been completed. It is notable that Tony Chambers had received a letter on 1st March 2017 signed by seven consultants on the Unit expressing their concerns that "the unexpected collapses have not yet been adequately investigated", levelling legitimate criticism of the quality and independence of the investigations undertaken thus far and requesting a further "broad forensic review" [INQ0006816]. It is implausible that Mr Harvey was unaware of the strength of feeling amongst the consultants in the Unit at this stage or that he did not recognise the limits to the investigation undertaken. His letter to the parents was therefore at best a serious distortion of the truth, at worse an outright lie.

91. Mother C requested a full and unredacted copy of the RCPOH report, having appreciated that the one she had seen was incomplete, and a copy of any subsequent investigations regarding Child C. Ian Harvey wrote to her on 28th April, he did not attach a full copy of the RCPOH report but

referred to the earlier disclosure (INQ0012620). His letter is notable in two respects: firstly the version of Jane Hawdon's report attached to the letter was incomplete and omitted the supplementary conclusion categorising the standard of care received by Child C; secondly, and perhaps more importantly, it omitted to mention that he had on the previous day attended a meeting with a representative of the Cheshire Constabulary, Detective Chief Superintendent Nigel Wenham, following which he had been advised to write a formal letter to the Chief Constable of the Cheshire Constabulary requesting a forensic investigation (INQ0003337 and INQ0003340). A similarly incomplete and misleading letter was sent to Mother E and F on the same date. There is justification behind her comment at paragraph 108 of her statement:

"I felt fobbed off. When I look back now, it seems obvious that Ian Harvey was never going to speak to me, and the letters were just for show"

92. The impact on her is clearly expressed at paragraph 110 of her statement and will be the same for others:

"This situation impacted me greatly and made me feel so powerless. I felt COCH knew more information than what they were giving me. I don't understand why I was told nothing when [Child E] was my son"

93. The Families regard the approach of the Trust during this period as going beyond a lack of candour. They believe that the senior management at COCH deliberately misled them in order to hide the truth and in order to protect their own reputations and those of the Trust. Their actions represented a gross derogation of their duties as managers of a public body. The Families would like to know why a culture has developed that would allow this to happen.

94. The Families note that attempts to report senior members of the COCH management to the GMC and NMC have not resulted in disciplinary action against the individuals in question. They are concerned by this and by the lack of oversight in relation to hospital managers who do not fall under the remit of the GMC and the NMC. They are concerned that managers who engage in this type of behaviour are free to continue working within the NHS and seek promotion or well remunerated posts in other Trusts.

<u>Interactions with other bodies and organisations</u>

95. The Families believe that the lack of transparency shown towards them is evident in the COCH's interactions with other individuals and organisations. The Families note that Jane Hawdon does not appear to have been informed of the suspicions regarding Lucy Letby when she prepared her report. She considers that this information would have been relevant and should have provided to her (INQ0099063 p.10 paragraph 24). Had she been informed she would have contacted Ian Harvey and urged him to follow appropriate Trust safeguarding and governance processes

(INQ0099063 p.12 paragraph 32), more strongly recommended the involvement of a perinatal pathologist (p.12 paragraph 36) and more strongly recommended an urgent review of staffing access as part of a broader forensic investigation (paragraph 38). She was not informed that the pattern of deaths and unusual incidents had ceased with the removal of the member of staff. Had she been informed she would have contacted Ian Harvey and urged him to follow appropriate Trust safeguarding and governance processes (p.13 paragraph 46). The Families are concerned that the COCH's motivations in providing imperfect information to Jane Hawdon were motivated by a desire to whitewash the truth. The Families will say that there is no other or better explanation.

96. The Families note that accurate or full information was not provided to the Coroner (see above). They are concerned that this information was hidden from the Coroner as a means of avoiding the scrutiny that an Inquest might bring to bear.

97. The Families are concerned that the COCH's use of external bodies, such as the RPOCH and the review by Jane Hawdon were not undertaken with a genuine desire to find out the truth behind the incidents that had occurred between June 2015 and July 2016. They are concerned that the RPOCH was chosen by the COCH because it would undertake a superficially comprehensive but in reality incomplete review of the issues being complained of, since it was entirely ill-equipped to explore whether crimes were being committed by a member of staff. The report when it was obtained emphasised the positive more loudly that the negative issues, allowing censure to be drowned out by congratulation. The process by which the report was redacted and edited before being provided to Families might provide them with the impression that the RPOCH and/or the COCH were fulfilling their duties whilst hiding key facts from them.

98. The Families fully support the aims of this Inquiry. The themes discussed above are a summary of their key concerns but should not be taken as final or comprehensive. They are thankful of the opportunity to give their accounts of their experiences and in due course hear the accounts of others and their explanations for their actions. Their ultimate goal is to ensure that their experiences are not repeated. This desire is however tainted by the sadness of the events that brought the Families to this Inquiry, as eloquently summed up by the Mother of Child J:

"It is difficult to move forward when you are still looking back at the past and revisiting the sadness, anxiety and stress of the memories and images from that time. So, the biggest impact this experience has had on our future, is not being able to grow our family and regrettably we are now too old and fearful to try. I so much want to be part of doing good and assisting the Inquiry but the shadow of this remains. I hope that the recommendations of this Inquiry are far reaching and substantial enough to make real change in the NHS and protect patients going forward."

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