

# An investigation into the death of Baby J at University Hospitals Bristol and Weston NHS Foundation Trust

## Our decision

1. Mr N complains about the care and treatment provided to his son, J, by University Hospitals Bristol and Weston NHS Foundation Trust (the Trust). J was admitted to the Trust's hospital with a respiratory tract infection on 11 April 2015. He died on 17 April.
2. After lengthy complaint correspondence and the start of a legal claim by Mr N and his wife, the Trust publicly acknowledged in October 2017 that it had missed an opportunity to provide J with timely antibiotics and that this failure had made a material contribution to his death. Because of this admission by the Trust, we have not looked at the prescription and administration of antibiotics during this investigation. However, we have included antibiotics in our story of J's care and treatment, and taken account of this issue, where we needed to, in our thinking about the question of injustice.
3. In this investigation we have looked at Mr N's complaints about other aspects of J's care and treatment.
4. We find that there was a catalogue of failings in J's care and treatment:
  - J's temperature was often lower than it should have been and not enough was done to respond to this
  - doctors and nurses did not respond appropriately to Mr and Mrs N's concerns about J's low temperature
  - when J developed Acute Respiratory Distress Syndrome (ARDS) doctors did not adhere to the relevant Trust protocol in their management of J's ventilation in terms of leaks and the use of a higher positive end expiratory pressure (PEEP, the pressure applied by the ventilator at the end of each breath) and high frequency oscillatory ventilation (HFOV, an alternative form of ventilator that delivers smaller breath volumes very rapidly to try and protect the lungs from injury)
  - doctors and nurses did not provide Mr and Mrs N with the information they needed about the ventilation leaks and the action being taken to reduce these
  - doctors did not do tests for a bacterial infection as frequently as they should have done
  - doctors were aware of J's deterioration on 17 April but did not provide him with the treatment he needed as promptly as they should have done
  - doctors did not review their decision to give J surfactant and did not examine J as thoroughly as they should have done before a third dose of surfactant (a substance given to premature babies to keep their lungs from collapsing and making breathing easier) was given on 17 April

- doctors and nurses did not ask Mr and Mrs N if they would like to stay with J when he was being treated on 17 April and did not answer questions they had about his treatment at this time
- doctors did not tell Mr and Mrs N about a pseudomonas infection J had or that they had given J antibiotics on 17 April until seven weeks after J died
- doctors and nurses did not give Mr and Mrs N the clear information they needed about the severity of J's illness and the risk he might die
- doctors and nurses did not communicate with Mr and Mrs N often enough, at the right times, and clearly and completely enough.

5. There were other areas of J's care and treatment that were in line with the standards, guidance and what would have been considered good clinical care and treatment at the time (please see paragraph 116).

6. Many babies with J's illness die despite having the best supportive care and not all patients respond in the same way to the same interventions. However, the standards and guidance that constitute good clinical care and treatment exist for a reason. They exist to ensure the best possible outcomes for patients. They are based on research which suggests they will make a positive difference. Not adhering to the standards and guidance - unless for a justifiable reason - leads to a loss of opportunity to obtain the best possible outcome. For J, the best possible outcome was that he would have lived - the prognosis of J's illness was that he had more than a 50% chance of doing so.

7. The failings we found are part of a sequence of events that tell the story of J's illness. This sequence of events includes the Trust's accepted failure to give J antibiotics sooner than it did. The Trust has accepted that the failure to give timely antibiotics made a material contribution to J's death and it has acknowledged the view that J would on the balance of probabilities have survived, if antibiotics had been given sooner than they were.

8. We find that J and his family suffered serious injustice in consequence of the failings we found in his care and treatment. This is because the failings we found - which are in addition to the accepted failure to give J antibiotics - were all lost opportunities to intervene and give J the best possible chance of recovering from his illness. Each one of the failings would have reduced the chances of the best possible outcome for J.

9. We recognise that Mr and Mrs N already have to live with the Trust's acceptance that the failure to give timely antibiotics made a material contribution to J's death and that there is a view that J would on the balance of probabilities have survived, if antibiotics had been given sooner than they were. Added to this, they now have to live with the knowledge that other aspects of J's care were not as they should have been. The injustice to Mr and Mrs N of never knowing whether things might have been different, however small that chance may have been, is something that is likely to affect them forever.

10. Added to this, we find there were significant repeated failings in doctors and nurses communication with Mr N and his wife, which left them feeling unsupported, not listened to and unprepared for J's death. They have been left not knowing whether things could have been different and whether J might have survived his illness. These are further significant injustices to Mr and Mrs N.

11. We have set out in paragraphs 250 to 279 and 364 to 368, the specific injustices we found arising from the failings we identified in this report.

12. Mr N also complains about events after J died. He complains about how the Trust responded to the questions he and Mrs N asked about J's care and treatment and the reasons for his death. We found:

- there were reasons why doctors should have considered a hospital post-mortem, but they did not do this and did not talk to Mr and Mrs N about a post-mortem
- the Trust's staff were not open and honest with Mr and Mrs N about the events surrounding J's death as they should have been:
  - immediately after J's death doctors failed to give Mr and Mrs N important information they needed and wanted to know about J's illness, and compounded this by failing to send them a copy of J's discharge summary
  - doctors did not tell Mr and Mrs N about J's pseudomonas infection until a meeting seven weeks after J died, and then told them they had done tests which were negative, when those tests had not been done. They also gave them inaccurate information about when this infection had been identified
  - doctors failed to correct these inaccuracies at the next meeting with Mr and Mrs N
- the Trust did not properly equip and empower its staff to acknowledge when things had gone wrong and to meet its duty of candour:
  - on the contrary, staff talked about deleting a recording made during one meeting while Mr and Mrs N were out of the room, because it might get the Trust into difficulty
- the Trusts' investigations into the information Mr and Mrs N had been given were not good enough and failed to address what they were asking
- the Trust should have given Mr and Mrs N more information about its Maintaining High Professional Standards investigation and because it did not, it did not comply with the recommendation Verita had made about this
- the Trust failed to recognise that the events surrounding J's death and

- Mr and Mrs N's complaints warranted consideration of a serious incident investigation
- the Trust did not properly investigate why staff failed to be open and honest with Mr and Mrs N and meet the duty of candour
  - the Trust failed to provide a single cohesive response, but instead Mr and Mrs N received a series of individual doctors' opinions which added to their concerns, particularly about the possible causes of J's death
  - the Trust failed to provide a clear explanation for its admission in October 2017 that it had missed an opportunity to provide J with timely antibiotics and that this failure had made a material contribution to his death.

13. We find Mr N and his wife suffered serious injustice in consequence of the failings we found in the way the Trust responded to their questions after J died and in its handling of their complaints. The failure to consider and talk to Mr and Mrs N about a post-mortem means they will never have answers to some of their questions about how and why J died. The Trust's failure to provide open and honest explanations, and answers to their questions over such an extended period of time, created understandable distrust and led the family to question everything they were told. This is likely to have exacerbated their bereavement and made it more difficult for them to move on from what happened to J. Having to pursue the Trust for answers is likely to have caused significant additional distress for Mr and Mrs N, as well as inconvenience.

14. We therefore uphold Mr N's complaint.

15. We make the following recommendations for the Trust:

- it should write to Mr N to acknowledge and accept the failings identified in our report
- it should provide Mr N and us with details of the patient care and safety and complaint handling initiatives that have taken place since J's admission relating to the failings we have found, explaining to Mr N and to us what has been done and the outcomes of that work and providing an action plan for any issues that have still to be addressed.

## **The complaint**

### Care and treatment

16. Mr N complains about aspects of the care and treatment provided to his son, J, by the Trust between 11 and 17 April 2015. Mr N complains that the Trust's staff:

- failed to manage his son's body temperature appropriately, with his son's body temperature below normal levels for over 12 hours at times

- failed to manage his son's ventilation appropriately, accepting ventilation leaks above the relevant protocol
- failed to act when he and his wife raised concerns about the ventilation leaks or when alarms sounded because of the ventilation leaks
- failed to carry out appropriate tests to monitor and diagnose his son's condition
- failed to respond adequately and with sufficient urgency when faced with the seriousness of his son's condition
- failed to listen to his family's concerns about his son's deteriorating condition on 17 April 2015 and did not arrange for a consultant to review his son for more than six hours
- inappropriately paralysed his son with rocuronium (a muscle relaxant) on 17 April 2015
- gave his son a third dose of surfactant on 17 April 2015 that was not in line with the relevant protocol
- asked his family to leave the room when his son was receiving urgent treatment on 17 April 2015, but then failed to tell his family what treatment had been provided and answer concerns his family had at that time
- did not tell his family until seven weeks after his son's death that a pseudomonas infection (a bacterial infection that can cause respiratory and chest infections) had been identified on the day of his son's death and that antibiotics had been given.

17. Mr N also complains that the Trust's staff failed:

- to keep his family regularly and meaningfully informed about his son's condition during the period of care
- to record accurate details in his son's medical records (including the medical certificate of cause of death).

18. Mr N believes that the Trust's failings in care contributed to his son's death. He believes his son may not have died had these failings not occurred.

#### After his son died

19. Mr N complains the Trust has failed to adequately and transparently respond to his concerns and failed to provide open and accountable answers to his questions. Mr N complains that the Trust's staff:

- took the decision that a post-mortem was not necessary without discussing this with his family
- carried out a test after his son had died and been placed in the Chapel of Rest, and later tried to hide this information from his family
- failed to complete a Root Cause Analysis (RCA)

- failed to carry out a serious incident investigation in line with NHS serious incident management principles
- provided incorrect information to the family during local resolution meetings that tests were carried out during his son's admission and were negative for pseudomonas, as well as inaccurate information about when doctors became aware of a pseudomonas infection
- failed to disclose all the relevant information about his son's care to his family in a timely manner, which led to his family not finding out crucial aspects of his son's care until much later down the line
- did not provide accurate or truthful accounts of the care and treatment his son received, and the reasons for his death, in their complaint responses - that is, about:
  - the tests done and when a pseudomonas infection was identified, as well as the role this infection played in his son's death
  - the administration of surfactant on 17 April 2015 and the role it played in his son's subsequent deterioration and death and
  - the development of pneumopericardium (air within the membrane sac surrounding the heart)/pneumomediastinum (air within the centre of the chest) on 17 April 2015 and the role it played in his son's death
- provided information to the Coroner about the reasons for his son's death that was not consistent with what his family had been told and with the Child Death Review
- failed to provide his family with a copy of the death (discharge) summary until they requested it three months after J's death
- talked during a break in a meeting with his family in July 2015 (when his family had left the room) about failings in his son's care and then discussed deleting this conversation from the recordings being made of the meeting
- failed to provide an open and honest response to recommendation 1 in the independent report completed by Verita in June 2016
- failed to comply with recommendation 3 in the Verita report
- failed to adequately address his outstanding questions in line with recommendation 9 in the Verita report
- continuously disputed that there were failings in his son's care throughout the complaints process until making a public admission of liability in October 2017 and
- did not release its apology in October 2017 to Mr N's legal team until after the media had been informed, meaning his family first learnt of the apology through the media.

20. Mr N complains that the Trust's failure to provide open and accountable responses over an extended period of time has caused him and his family significant distress and inconvenience. Mr N also complains that the Trust has not demonstrated that it has learnt lessons from what happened to his son.

21. Mr N wants the Trust to learn from his complaint. He is seeking improvements in the care and treatment the Trust provides and more openness and accountability in the way it handles serious concerns about patient safety. Mr N does not seek any financial remedy as an outcome.

## **Background**

22. J was born prematurely at 29 weeks and 2 days on 17 February 2015 at another trust's hospital. He remained in hospital for the next seven weeks. A few days after being discharged home, J became unwell and after being taken by his parents to a local hospital, he was transferred to the Trust's paediatric intensive care unit (PICU), where he arrived on 11 April.

23. J was having frequent apnoeas (episodes where he temporarily stopped breathing) so doctors put him on a ventilator (a machine to help him breathe). Later, J tested positive for human metapneumovirus (hMPV), a virus that can cause severe respiratory tract infections in the very young. J continued to be unwell and he developed acute respiratory distress syndrome (ARDS), a life-threatening condition where the lungs cannot provide the body's vital organs with enough oxygen.

24. When a baby has hMPV and develops ARDS they are supported while their bodies try to clear the viral infection. In J's case he did not improve and in the afternoon of 17 April, while doctors were treating him, he suffered a cardiac arrest. J was resuscitated and a chest X-ray showed air had leaked out of his lungs into his chest, putting pressure on his heart (a pneumopericardium). A drain was put in to release the air, but J continued to deteriorate. That afternoon, doctors also received the results of a sample taken from J's lungs the day before, which was positive for pseudomonas (*pseudomonas aeruginosa*), a bacterium commonly found in soil and water that can cause respiratory and chest infections.

25. Sadly, at approximately 9pm on 17 April J had another cardiac arrest. He could not be resuscitated and died.

26. Following J's death Mr N and his wife had a number of questions they wanted to ask the Trust about J's care and treatment. Several meetings took place with the Trust's staff both before, and after, a Child Death Review (a review overseen by a local safeguarding children board designed to learn lessons from any child deaths and where possible prevent future child deaths). Mr and Mrs N did not feel the information they were given at these meetings and subsequently, particularly about the pseudomonas infection and starting antibiotics, was truthful, accurate and transparent.

27. Mr and Mrs N went on to have a long and difficult correspondence with the Trust. Given Mr and Mrs N's ongoing concerns the Trust commissioned an investigation by Verita, an



independent consultancy, into its handling of the complaint. This was completed in June 2016. Verita made a series of recommendations to the Trust.

28. Around the same time, J's inquest took place. Mr and Mrs N were unhappy about evidence the Trust's staff gave to the Coroner at the inquest, particularly about the cause of J's death.

29. In October 2017, after Mr and Mrs N had sent the Trust a Letter of Claim (a letter putting the Trust on notice that court proceedings might be brought against it) the Trust publicly acknowledged that it had 'missed an opportunity to provide J with timely antibiotics and that this failure made a material contribution to his death'.

## Evidence

30. We use related or relevant law, policy, guidance and standards to inform our thinking. This allows us to consider what should have happened. The standards we have used in this investigation are:

- [The Ombudsman's Principles of Good Administration](#)
- Royal College of Nursing '[Standards for assessing, measuring and monitoring vital signs in infants, children and young people](#)' 2017
- NHS '[Hypothermia](#)'
- Nursing and Midwifery Council '[The Code](#)'
- General Medical Council '[Good Medical Practice](#)'
- NICE '[Clinical Guideline 149 Neonatal infection \(early onset\): antibiotics for prevention and treatment](#)' August 2012
- University Hospitals Bristol NHS Trust ARDS protocol
- [Respiratory Care 'Pediatric ARDS' Cheifetz, 62 \(6\) 718-731 June 2017](#)
- [The Paediatric Intensive Care Society 'Standards for the Care of Critically Ill Children', 2010](#)
- Office of National Statistics '[Guidance for doctors completing Medical Certificates of Cause of Death](#)', 2010
- Department of Health, '[Maintaining High Professional Standards Framework](#)', 2003
- NHS England, '[Serious Incident Framework](#)', 2015
- [The NHS Constitution](#)
- GMC '[The professional duty of candour](#)'

31. We also looked at evidence including J's clinical records, documents and statements we obtained from Mr N, papers related to the Coroner's inquest, the Trust's complaint papers, and statements of Trust's staff who cared for J or were involved in the events Mr N has complained about.

32. Additionally, we obtained advice from:

- an experienced children's nurse with extensive experience in paediatric intensive care, lead nurse for education at a leading UK children's hospital and senior practitioner lecturer at a university (the Nurse Adviser)
- an experienced paediatric and retrieval service consultant working in the paediatric intensive care unit at one of the UK's leading children's hospitals, and also an honorary senior lecturer at a university (the First Consultant Adviser) and
- an experienced consultant paediatric and neonatal intensivist working in the paediatric and neonatal intensive care units in one of the UK's leading children's hospitals and also an honorary associate professor at a university institute of child health (the Second Consultant Adviser).

33. When providing advice for us, the advisers are independent of the NHS. Where written standards do not exist, our advisers have confirmed whether the actions of the clinicians were in line with good practice.

## Findings

### Complaint 1: Mr N complains about aspects of the care and treatment provided to J

34. We look at each of Mr and Mrs N's individual points about J's care in turn. Where several points are related, we have considered them together to avoid repetition.

35. Often during Mr and Mrs N's complaint to the Trust, the consequences or injustice following from J's care became conflated with the quality of that care. This has confused some issues. Mr N also rightly points out that taking issues in isolation does not necessarily reveal the whole injustice. We look at the consequences and injustice of what we found in paragraphs 250 to 279.

### The management of J's temperature

36. Mr N says J's temperature should have been maintained at above 36.5°C. Instead, he says J's temperature was normally below this and even below 35°C for prolonged periods. Mr N says when he raised this issue with nursing staff he was told not to worry about it. He does not recall any interventions, such as the overhead heaters or blankets, being used to warm J, other than when he requested it on 14 April and again on 15 April when J was wrapped in blankets.

37. The Trust has accepted that J was 'too cold too often' and that it did not do enough to maintain J's temperature.

38. The Trust had no guidance for maintaining temperature on PICU at the time of these events. The Ombudsman's Principles say that organisations should act in accordance with recognised quality standards or established good practice.

39. A temperature of 35°C or below is considered by the NHS to be hypothermic.

40. The Royal College of Nursing standards for assessing, measuring and monitoring vital signs - which only became available after these events, but our adviser said is likely to have represented good practice at the time - says observations should be recorded dependent on the condition of the patient.

41. Our advisers agreed with Mr N that keeping J's temperature in an appropriate range was important. The body functions best in normal conditions. They also agreed a low temperature can be an indication of infection.

42. Our advisers explained it would be appropriate to maintain a temperature of 36°C or above in a small baby. The Trust's current guidance (written since these events) agrees with this.

43. Mr N says J was a neonate and provided guidance from the World Health Organisation. This says normal temperature of a neonate is 36.5 to 37.5°C. But our advisers said at seven weeks old and 37 weeks corrected gestational age, which would be considered term, J was no longer strictly a neonate at the time he was admitted. They explained that maintaining temperature in a small baby rather than a neonate is less strict. This is because babies usually become better at regulating their own temperature as they grow.

44. Nevertheless, Mr N believes 36.5°C would have been a more appropriate temperature for J to maintain, given how small he was. Mr N also recalls being told by the nurse first caring for J that he was aiming to maintain a temperature of 36.5°C. The record of the first meeting Mr N had with the Trust, shows the doctors referenced a normal temperature being 36.5 to 37.5°C. We therefore accept Mr N's account that 36.5°C was likely to be the temperature nursing staff were hoping to maintain. However, we acknowledge, as one of our advisers has said, that the precise temperature being maintained was not as important as what was being done about any low temperature readings or falls in temperature.

45. Our advisers explained core temperature (temperature on the inside of the body) is normally used to define whether a patient is hypothermic. J's temperature was not taken as a core temperature. It was an axillary reading (under the armpit). Our advisers said an axillary reading can result in a reading that is 0.5 or 1°C lower than core temperature.

46. However, in meetings with Mr and Mrs N, the doctors who cared for J were not clear about how J's temperature was taken. The Trust's current guidance also does not advise making adjustments dependent on where temperature is taken, although all the evidence would suggest that clinical staff do this. There are a number of ways PICU staff take temperature (core, axillary and other exposed skin sites such as the sole of the foot). Given this, we cannot assume any, or what, adjustment was made at the time by the doctors and nurses caring for J.

47. Two of our advisers indicated that four hourly observations would be appropriate if there were no concerns. They said observations should be increased if there were concerns. The Trust's current guidance recommends temperature readings should be taken hourly until a normal temperature is reached.

48. The chart at the end of annex D shows the temperature recordings for J. These were taken every four hours, and often more regularly with some exceptions. Importantly those exceptions were that it took five hours or more for readings to be repeated in the early mornings of 12, 14 and 15 April, and in the middle of the day on 16 April. A significant number of the readings are below 36.5°C. Our Nursing Adviser said J's temperature was low for long periods on 12 and 14 April.

49. J was nursed on a Babytherm (heated mattress) which had overhead heaters and nurses could also use blankets. Our Nursing Adviser said that in accordance with the NMC's 'The Code' nurses should record the actions they had taken to warm J up when his temperature dropped. The only interventions that have been recorded in J's notes were when an overhead heater was switched on at 10am on 14 April and when a blanket was used from 8am on 15 April. This accords with Mr N's evidence that, generally, no action was taken to warm J up other than on those days. The evidence suggests Mr N's recollection is correct.

50. Further, our advisers said that following lower temperature readings, J's temperature should have been, and generally was, taken more frequently until it increased to near 36.5°C. However, the chart shows that this was not always the case on 12 and 14 April. The chart shows there were two or three occasions on those dates when J's temperature was not taken more frequently following a low result. This was not in accordance with the advice we have received about what should have happened, or the current national or Trust guidance.

51. For the reasons set out in paragraphs 48 to 50, we find that J's temperature was often lower than it should have been, specifically on 12 and 14 April. We also find there is no evidence action was always taken to respond to that (by repeating readings) or to maintain J's temperature close to 36 or 36.5°C at all times. This was not in accordance with providing care without undue delay, as required by 'The Code'.

52. In his evidence to us Mr N said there was a failure by the doctors treating J to recognise that he was cold. He says the low temperature could have been a sign of infection.

He explained it should be taken in context with other issues. For example, on 14 April, that J was having desaturations, and had poor saturations and blood gas results. On 15 April, Mr N says J was only warm because he was wrapped in blankets (suggesting his true temperature was still low).

53. Our advisers explained that the majority of the low readings coincide with nursing or medical interventions and therefore would have been to some extent expected by nursing and medical staff. This can be seen on the chart at the end of annex D. However, this is not the case for every reading - particularly those on 14 April.

54. Our advisers said there was also no reason to suspect J's low temperature was a sign of a bacterial infection on top of the viral infection J already had (which could equally cause a low temperature). J's lowest temperatures were often explained and were returned to near normal in hours. We understand Mr N's point that if blankets were needed to maintain J's temperature, then J could not do it. However, we understand that bacterial infection would usually cause the temperature to be persistently low despite intervention. This has also been the Trust's view.

55. There is a high level of agreement between a number of clinicians on this point. We recognise J was very poorly in other ways at this time, but we have not seen sufficient evidence to show that doctors should have recognised J's low temperature to be a key indicator that J had an additional bacterial infection (rather than his diagnosed viral infection). This does not detract from our finding in paragraph 51. It also does not detract from other findings in this report about what the doctors caring for J should have done about a possible secondary bacterial infection.

56. Mr N also told us when he pointed out to the nurses that J was cold, they told him 'not to worry'. We do not have any evidence from J's medical records about the anxieties Mr and Mrs N expressed about this or what they were told. It seems that staff were not concerned about J's low temperature being clinically significant at the time, and this is confirmed in the Trust complaint responses. As we have seen above, there are only a few records of staff taking actions to warm him up using the overhead heater or blankets, or to repeat temperature recordings. We therefore accept, on balance, that Mr and Mrs N were told not to worry. There is no evidence staff gave them a fuller explanation.

57. The explanation given to Mr and Mrs N not to worry does not recognise the extent to which Mr and Mrs N wanted to be involved in J's care. It does not recognise that they needed a more complete explanation. This was a failure to communicate to the standard set out in the NMC's 'The Code'.

The management of J's ventilation and Mr and Mrs N's concerns about this

58. Mr N's concern with J's ventilation is largely about the leaks from J's endotracheal tube. Mr N rightly points out that the observation charts show the leaks were variable from 0 to 92%.

59. There is no Trust or national guidance about the management of leaks for children ventilated with bronchiolitis. Our advisers looked at guidance from other centres, but this does not specify an acceptable percentage leak.

60. Our advisers all agreed that the management of leaks should be focused on whether appropriate ventilation can be maintained. A leak may cause lower pressures of air being delivered into the lung, meaning less of the lungs are kept open (less surface area available) and therefore poor gas exchange (the transfer of oxygen into the blood from inhaled air and the transfer of carbon dioxide out of the blood stream and into exhaled air).

61. Our advisers explained that the problems arising from a leak should be offset against the risks of changing the endotracheal tube. Those risks include damage to the windpipe and being unable to settle the patient back on to the ventilator (when a patient is taken off a ventilator the spaces in the lungs may collapse and be difficult to 'open up/recruit' again when ventilation is re-started). Drugs to paralyse and sedate the patient are also required before changing an endotracheal tube which can cause a period of instability.

62. Our advisers explained that leaks can be variable dependent on a patient's position. They explained managing a patient's position, and keeping the endotracheal tube clear of secretions, can be a way of managing leaks. We therefore accept that management of a leak in this way would be in accordance with accepted good practice, and in line with the Ombudsman's Principles and the GMC's 'Good Medical Practice', domain 1, providing a good standard of care and promptly providing suitable treatment.

63. The Trust had an ARDS protocol at the time of these events (annex A). Our advisers said this protocol represented the best practice at the time and should have been followed. The Trust said J was diagnosed with severe ARDS on 15 April. At the time of J's admission, one way of diagnosing ARDS was using the PaO<sub>2</sub>/FiO<sub>2</sub> ratio, a calculation based on arterial oxygen levels. But in J's case his arterial oxygen levels only started to be measured from 15 April, so it is not possible to calculate the PaO<sub>2</sub>/FiO<sub>2</sub> ratio prior to this date. The other way to make a diagnosis of ARDS at the time was by looking for changes on a chest X-ray and considering the timing and cause of those changes. The evidence - from our advisers and information available from the inquest - would suggest that it is likely J had mild to moderate ARDS before 15 April. However, our advisers explained the changes on J's X-ray from 14 April were not definitive of ARDS and could be interpreted as changes due to hMPV.

64. The Trust's ARDS protocol includes the following guidance about managing ventilation:

- use an appropriately fitting endotracheal tube with less than 20% air leak

- optimum PEEP 8-12cm H<sub>2</sub>O (positive end-expiratory pressure - the pressure left in the airways at the end of each breath - maintaining this above atmospheric pressure means the lungs do not passively empty of air - allowing more oxygen to be absorbed)
- use of appropriate tidal volume of 6ml/kg (the amount of air going into the lungs with each 'breath')
- aim for oxygen saturations of 88 to 92%
- try to achieve an inspired oxygen level (the proportion of oxygen in the air being used for ventilation) of 60% to prevent oxygen toxicity (damage to the tissue of the lungs from breathing in too high concentrations of oxygen).

65. The protocol also suggests trying high frequency oscillation ventilation (HFOV) in patients with severe ARDS if the above measures fail.

66. During its correspondence with Mr and Mrs N the Trust explained that it managed the endotracheal leak by changing J's position. This strategy is evidenced in J's medical record where it is written he had a positional leak and by the nursing records, which record the actions taken in response to leaks and desaturations.

67. Our advisers explained that good ventilation is more important than the percentage leak. Endotracheal leaks can be managed by changing position. J's medical notes generally show this was done successfully. By changing J's position, the leaks were most commonly recorded as under 20%. J's oxygen saturations were also generally good.

68. We recognise that J's medical records show relatively frequent desaturations (not enough oxygen is getting into the blood). We can understand Mr N would be concerned about these and that they were associated with the leak.

69. Our advisers explained that when J's desaturations coincided with leaks, the observation charts and nursing records show the desaturations to be short-lived. The nursing records show interventions such as changing J's position and suctioning his endotracheal tube were used at these times. The evidence in the nursing notes show these interventions led to J's saturations going back up to normal levels.

70. Mr N was concerned the leaks were causing a problem with J's CO<sub>2</sub> clearance, particularly on 14 April. Our advisers explained J's CO<sub>2</sub> clearance could not be accurately measured before 15 April (our advisers said an arterial line that would be used to measure arterial gases would not normally be inserted until there was a suspicion of ARDS). A leak stops end tidal measurements (measurements taken from the air breathed out) from being accurate because the volumes of air from which the concentrates are determined are not accurate.

71. On balance, for the reasons in paragraphs 66 to 70, we have seen sufficient evidence to show the Trust was taking appropriate steps before J was diagnosed with ARDS in response to

the leak in J's endotracheal tube. These steps were in accordance with good practice and guidance described in paragraphs 59 to 62.

72. After J was diagnosed with ARDS, our advisers agree with Mr N that J's endotracheal tube had, at times, significant leaks of more than 20%. This is not in accordance with that aspect of the Trust's protocol and is a failure to adhere to it.

73. Our advisers explained a leak can prevent the maintenance of pressure in the lungs. This is a particular problem when the lungs become less compliant and stiffer because air escapes more easily around the endotracheal tube rather than going into the lungs to promote gas exchange.

74. With the onset of ARDS J's lungs would be less compliant and stiffer.

75. Our advisers explained J's PEEP (the pressure remaining in the airways at the end of a breath) was lower than the Trust protocol and other national guidance recommends. The Trust's ARDS protocol recommends using a PEEP of between 8 and 12cmH<sub>2</sub>O, or sometimes higher.

76. A ventilator can cause damage to the lungs if there is too much oxygen, or too much stretching (where the alveoli in the lungs are going from close to open). The recommended PEEP increases with the need for an increased percentage of inspired oxygen. Increasing the PEEP allows the oxygen level to be decreased. Increasing the PEEP would have been a way of protecting J's lungs from further damage.

77. At the inquest into J's death, the doctors caring for J explained that they changed his endotracheal tube on 16 April because they changed ventilation strategy to aim for a higher PEEP, which could not be achieved with a leak. This would appear to reflect the reasoning in J's medical notes.

78. J's PEEP was 5 to 6cmH<sub>2</sub>O up until the 15 April. 15 April was the first time J clearly met the criteria for severe ARDS and our First Consultant Adviser explained they would have increased J's PEEP to 8-10cmH<sub>2</sub>O at this point. However, the doctors caring for J only increased the PEEP slightly. It was only in the afternoon of 16 April it was increased to 8cmH<sub>2</sub>O when J's endotracheal tube was changed and after that it wasn't increased further. There is no reasoning in J's clinical notes as to why a higher PEEP was not used on 15 April - in accordance with the ARDS protocol - and we have to assume it was not considered.

79. HFOV also prevents damage to the lungs by maintaining pressure in the lungs. The Trust's protocol says HFOV should be considered in cases of severe ARDS which are not responding to the actions listed in paragraph 64. The protocol does not say exactly when after diagnosis HFOV should be considered. However, the doctors caring for J used surfactant, which is also suggested in this section of the ARDS protocol, on 15 April. The Trust has told us



that the additional options in the protocol should be considered in turn. HFOV appears on the protocol before surfactant. It would seem reasonable to expect the doctors caring for J would have considered HFOV at least at the same time they gave J surfactant.

80. Our advisers disagreed on whether HFOV was indicated in J's case. The evidence the advisers quoted suggests the research on the use of HFOV is mixed.

81. Nevertheless, our advisers said they would have changed aspects of J's ventilation strategy sooner.

82. Our advisers have not been critical of the specific timing of when J's endotracheal tube was changed. However, to achieve the other goals in his ventilation (higher PEEP, using HFOV), J's endotracheal tube would have needed to have been changed. It would also have to be changed to take a BAL (bronchoalveolar lavage - where samples of secretions are taken from deep within the lung to test for infection), which was done on 16 April, but should have been done sooner (see paragraphs 103 and 104).

83. There is no rationale in J's medical record as to why the doctors treating him did not consider using a higher PEEP, or HFOV sooner than 16/17 April. Certainly, our advisers have said there is mixed opinion on the use of HFOV. Our Second Consultant Adviser also said there may have been good reason not to use a higher PEEP. However, both our advisers explained these interventions are used as important parts of a lung protection strategy and to maintain the recruitment of the lungs. There is no evidence the doctors caring for J gave any consideration to either intervention at the time.

84. The Trust ARDS protocol is clear that a higher PEEP should have been used once ARDS was diagnosed to 'optimise ventilation' and HFOV should have been considered as part of the measures to take if the patient is not improving. The evidence shows the doctors caring for J did not do either of these things. There is no evidence that they had good reasons for deciding these interventions were not appropriate for J.

85. For the reasons in paragraphs 72 to 84 we find that from at least 15 April the Trust failed to adhere to its ARDS protocol when managing J's ventilation. This was specifically in respect of the leak, PEEP, and use of HFOV. We have used the date of 15 April here, because it is the date the Trust says J was recognised as having ARDS. We have not seen sufficient evidence to show that the doctors caring for J should have known or suspected he had ARDS before that (see paragraphs 63 and 207 to 209).

86. Mr N said they talked to staff about the issue of leaks and about the alarms going off but were simply told not to worry.

87. Our Nursing Adviser said it could be appropriate to have told Mr and Mrs N not to worry about the alarms if the leak was a known problem and action was being taken to manage it.

In paragraph 71 we have explained the actions being taken before J was diagnosed with ARDS were reasonable. J's clinical record also shows staff were aware the leak was positional. However, there is no evidence a full explanation about this was given to Mr and Mrs N at the time.

88. In response to our provisional views, the Trust said its clinicians recalled assuring Mr and Mrs N that they were monitoring J to ensure good chest expansion and that the gas exchange was acceptable. This is not Mr and Mrs N's recollection. It is also not recorded in the medical record. It also does not provide an explanation of why the leaks were not a problem. On balance, therefore, we think it is likely that Mr and Mrs N were not given a full explanation about why the leaks were acceptable.

89. Mr and Mrs N were asking questions because they wanted to understand what was happening. By telling them not to worry, staff were dismissive of their concerns. If staff did give fuller explanations, it is, on balance, unlikely they checked Mr and Mrs N's understanding or communicated with them in a way that ensured they understood the situation. This was a failure to act in accordance with the guidance in the NMC's 'The Code', paragraph 2 and the GMC's 'Good Medical Practice', Domain 3, paragraph 32.

90. We have also explained in paragraph 85 that more should have been done to optimise J's ventilation from 15 April. This is regardless of whether Mr and Mrs N were raising concerns. The fact Mr and Mrs N were raising concerns reinforces this finding.

#### The tests done to monitor and diagnose J's illness

91. Mr N said appropriate tests were not done. Mr N is particularly concerned blood cultures that would have diagnosed J's bacterial infection were not done sooner.

92. The Trust's ARDS protocol says doctors should do 'frequent' infection surveillance and doctors should consider doing BAL to exclude lung infections. It says to do this as part of the general strategy for the management of ARDS and before escalation to other therapies such as surfactant.

93. Our advisers explained there is no national guidance about when blood tests should be done for monitoring.

94. 'Good Medical Practice' domain 1 paragraph 15 says doctors should 'adequately' assess patients and 'promptly' arrange investigations where necessary.

95. NICE Clinical Guideline 149 'Neonatal infection' paragraph 1.5.11 says blood cultures should be taken before giving antibiotics (this is because if blood cultures are taken after antibiotics have been started, the presence of the antibiotics in the blood will often mask the infecting organism).

96. Our First Consultant Adviser said there is a high incidence of bacterial co-infection in children admitted to PICU with bronchiolitis (30% to 70%). Our advisers explained secondary bacterial infection should be excluded with blood and lung cultures if a patient is deteriorating. Our advisers recognised that doing blood cultures and blood tests needed to be offset against the pain the procedure might cause and also the low circulating blood volume in a small baby. However, our advisers explained an arterial line would help offset those issues.

97. J's medical record shows a full blood count and CRP (C-reactive protein, a blood test marker for inflammation in the body) were done on 11, 12, 13, 15 and 17 April. Respiratory secretions taken from a BAL were sent off on 16 April. Blood cultures were done on 11 and 17 April.

98. Mr N explained as early as 14 April the doctor in charge of J's care told him that she suspected J had a bacterial infection. J's medical record shows he deteriorated at 10am on 14 April. It also says there would be a need for antibiotics if J became 'clinically unwell'. It is not clear from the record what was meant by 'clinically unwell'. The Trust has since told Mr and Mrs N 'clinically unwell' could describe J's condition when he was diagnosed with ARDS. The doctor who was on the ward round and on whose behalf the record was written, said at J's inquest she would not have written 'clinically unwell'. She said she had been talking about being alert to signs of secondary bacterial infection and the need for antibiotics if those developed.

99. We have looked at the evidence we have from the meetings the doctors had with Mr and Mrs N, their evidence at J's inquest, and the wording in the medical record. There is evidence in the records that doctors treating J noted a deterioration in his condition on the morning of 14 April and the fact they wrote 'antibiotics if clinically unwell', indicates they must have thought there was a risk a bacterial infection could be a cause of J's deteriorating condition. This accords with Mr N's evidence that he remembers the doctor telling him a bacterial infection was a possibility on 14 April.

100. Similarly, doctors must have thought it possible that J had a bacterial infection when they did the BAL on 16 April. This is also what the evidence suggests the doctors told Mr and Mrs N. They showed us a text message they sent to a family member at 2.57pm on 16 April which said that doctors had told them J 'could also now have picked up a bacterial infection on lungs too so [doctors were] just checking ...'.

101. Despite the doctors telling Mr and Mrs N J could have a bacterial infection on 14 and 16 April, the evidence shows they did not do tests that might have led them to diagnose a bacterial infection sooner.

102. Our First Consultant Adviser said they would expect blood screening tests (CRP, white blood cell count) to have been done on 14 April given J's deterioration. But no tests were

done until 15 April. Our Second Consultant Adviser also noted it would be usual to do daily screening tests on PICU and noted the lack of any reason for the gap in those tests on 14 April.

103. The Trust has already accepted that blood cultures should have been done when J's arterial line was put in on 15 April. Our First Consultant Adviser agreed. They said J's CRP and white blood cell count on 15 April would have been reassuring and did not indicate bacterial infection. However, they said given the high incidence of secondary infection, J's further deterioration later on 15 April should have led the doctors to do a blood culture and BAL. Similarly, we note that the ARDS protocol suggests frequent surveillance for untreated infection, and doing BAL to look for this. However, again, testing was delayed until the following day (16 April) and then only a BAL was done - the blood culture was not done until 17 April.

104. All this was not in accordance with the guidance in 'Good Medical Practice'. Doctors did not carry out an 'adequate assessment' of J on 14, 15 or 16 April or arrange the investigations that were needed 'promptly'. They did not use BAL for surveillance in accordance with the ARDS protocol.

105. Mr N thinks the doctors suspected J had a bacterial infection and therefore should have treated it from 14 April when the doctors noted the possibility of a bacterial infection in J's medical record, or from 15 April when our advisers say a blood culture should have been taken, or at the very least 16 April when the BAL was done. Our First Consultant Adviser agreed with Mr N that if the doctors caring for J suspected he had an infection, they should have started treatment for it.

106. We are not considering whether antibiotics should have been started earlier as explained in paragraph 2. We have, though, looked at whether there is evidence the doctors caring for J thought he had a bacterial infection from 14 April. This is an important point for Mr and Mrs N. The doctors caring for J said at his inquest they did not think J had an infection on 14, 15 or 16 April (albeit the BAL subsequently confirmed he did). The same doctors told Mr and Mrs N in a meeting after J's death (see paragraph 311) that blood cultures showed J did not have an infection on 16 April. This statement turned out to be untrue. Mr and Mrs N have evidence the doctors told them J could have an infection on 14 and 16 April (see paragraphs 99 and 100). Given all this apparently conflicting evidence, Mr and Mrs N and are understandably concerned to know what the doctors thought at the time.

107. There is some evidence doctors knew it was a possibility J's presentation could be explained, at least in part, by a bacterial infection. The doctors caring for J told Mr and Mrs N on 14 April that a bacterial infection was a possibility. When they did the BAL on 16 April the doctors again told Mr and Mrs N J 'could' have an infection. In a meeting after J's death the doctors caring for J told Mr and Mrs N that they did the BAL because J was not behaving as he should and may have 'something else on top'.

108. However, J's medical records also show a number of entries - on 14, 15 and 16 April which mention antibiotics, but do not prescribe them. That suggests doctors were considering whether J needed antibiotics but decided he did not. At the same time as doing the BAL the doctors changed J's ventilation strategy suggesting they were also looking at the progression of his respiratory condition as the cause of his presentation. As above, at the inquest the doctors explained that they did not think J had an infection but were doing the BAL to exclude it.

109. On balance, we do not think the evidence (in paragraphs 107 and 108) we have about what doctors told Mr and Mrs N on 14 and 16 April, allows us to conclude that on 14 or 16 April the doctors actually thought J had a bacterial infection (rather than the doctors acknowledging the possibility - as explained in paragraph 107). We recognise Mr N firmly and understandably believes doctors did think J had an infection from at least 16 April, but the evidence is not sufficient to confirm this was what they thought. The evidence is only sufficient to show the doctors wanted to rule out the possibility of infection. It is important to note that our finding here does not diminish what we have found in paragraph 104, which is that whatever they thought at the time, the doctors caring for J should have had a high degree of suspicion of bacterial infection and tested for this more frequently.

#### Whether doctors and nurses responded adequately and with sufficient urgency to J's condition

110. Mr N believes there was a culture of complacency on PICU. There are a number of reasons for this:

- he recalls the matron telling him and Mrs N J 'was not a concern'
- he recalls nursing staff telling them J just had a 'cold' and would get over it
- he recalls nursing staff telling them 'not to worry' about the numbers and alarms on the machines (for temperature and ventilation leaks)
- he says they were not told when J was found to have developed ARDS, and were not told how serious that could be
- he says the medical record does not specifically mention ARDS as a diagnosis until 17 April, and only refers to giving surfactant in accordance with 'the ARDS protocol' on 15 April
- he says there were delays in doing tests to look for a secondary infection and failure to administer antibiotics
- he says there were failures to manage J's temperature appropriately
- he says there were failures to manage J's ventilation in accordance with the Trust ARDS protocol
- he says there were failures on 17 April to recognise J had deteriorated and delays in J being seen by a consultant

- he says there were delays on 17 April in administering agreed treatment (the surfactant and antibiotics)
- he says ECMO was not considered until J was extremely ill and should have been thought about earlier.

111. Mr N understandably thinks the number of mistakes and instances of poor practice and communication he has highlighted must have an underlying cause. He believes they demonstrate complacency throughout the Trust's PICU.

112. The GMC's 'Good Medical Practice' domain 1 paragraphs 11 and 16b say doctors should be familiar with guidelines and developments that affect their work. They say doctors should provide effective treatments based on the best available evidence.

113. Our advisers told us when a patient develops ARDS, doctors need to provide the best supportive care. There are very few options when a patient deteriorates. The advice we received shows research on the most appropriate interventions for paediatric ARDS are mixed or not well evidenced (as can be seen from their advice in respect of interventions such as HFOV, using a higher PEEP, and surfactant). Therefore, the care of babies with ARDS does not follow a clear pathway set out in definitive guidance. Treatment is given in response to changes in the patient's condition.

114. We can wholly understand how Mr N reached the view that multiple shortcomings in J's care must indicate an underlying issue of complacency in the PICU. It also appeared to Mr and Mrs N that staff were doing very little for J in response to changes in his condition. The advice we have received shows that sometimes the only response would have been to change J's ventilator settings or give him more sedation.

115. In addition, as we have seen already (for example, in paragraphs 57 and 87) and go on to explain later in the report (paragraphs 185 and 186, 197 and 217) the communication staff had with Mr and Mrs N was not adequate. Mr N has, again understandably, interpreted that as complacency towards J and his family.

116. We have and go on to find failings to adhere to the guidance and standards in a number of areas of J's care. There are other instances where his care met with the relevant guidance and what would have been considered good clinical care and treatment. The things the Trust got right do not cancel out the things it did not get right, but include:

- managing J's ventilation to ensure adequate oxygen saturations and CO<sub>2</sub>
- maintaining ventilator pressures at a level that would not cause damage to J's lungs
- reducing the oxygen requirement whenever possible to prevent damage to J's lungs
- responding to the leaks in the endotracheal tube and drops in saturation using positioning and suctioning

- monitoring J's cardiovascular status
- generally ensuring J was appropriately sedated and muscle relaxed (with the exception of 17 April as set out in this report)
- using lung fluid restriction and diuretics to prevent fluid overload
- managing J's skin integrity and pressure care
- ensuring J had appropriate nutritional intake
- generally conducting appropriate tests - X-rays, biochemistry, blood counts - to monitor J's condition (with the exceptions set out in this report).

117. Nonetheless, we do have some evidence that the staff caring for J appear not to have fully appreciated the risks to J, and his likely poorer prognosis, for example:

- in meetings with Mr and Mrs N after J's death the doctors caring for J told them they were not expecting J to die and were 'gobsmacked' when he did
- the doctors caring for J failed to impress on Mr and Mrs N how serious the situation was when they knew J to have developed ARDS (paragraph 213).

118. The actions of the doctors caring for J in these two instances are not consistent with research showing outcomes in premature babies with hMPV were significantly worse, or an appreciation of a mortality rate of ARDS of up to 45%. The Trust appears to have recognised this. In its report dated January 2017, the Trust told Mr N the doctors caring for J 'inadequately recognised' the additional risks associated with hMPV in a small premature baby.

119. It is not clear why the doctors caring for J 'inadequately recognised' the risks to J. However, information given to Mr N during local resolution of the complaint and statements given at J's inquest would suggest the PICU team did not see that many very small premature babies with hMPV and progressing to ARDS.

120. 'Good Medical Practice' requires doctors to keep up to date with developments and guidelines that affect their work. We would expect this to include an understanding of the risks of hMPV to smaller premature babies.

121. The doctors' failure to fully understand the risks associated with hMPV in small, premature babies like J may have contributed in some way to the failings we have and go on to identify in this report. However, we cannot say this was the only reason the failings we found occurred.

122. What we can say is that this report has shown that a number of different staff involved in J's care did not listen to Mr and Mrs N, did not communicate with them often enough, at the right time, clearly enough or completely enough (for example, paragraphs 57, 87, 185 and

186, 197 and 217). We have not seen sufficient evidence to show that this was the result of complacency towards J. We think these failings happened largely because the Trust's staff did not understand the seriousness of and the risks associated with J's condition, not because they were uncaring or unconcerned, although we recognise this is not how Mr and Mrs N saw it. The repetition of this failing across medical and nursing staff suggests an organisational failing on the part of the Trust to adhere to the Ombudsman's Principles - to provide effective services - to J and to Mr and Mrs N.

123. Mr N specifically complained about a conversation he and Mrs N had with the PICU matron. Mr N told us the attitude of the matron was indicative of the complacent attitude of all the staff. He explained the matron had not made any effort to speak to him or Mrs N early in J's admission. He said the only conversation they had with the matron was a conversation after they had emailed the matron about overnight accommodation at the hospital. He said during this conversation the matron said Mr and Mrs N were not a priority for staying at the hospital. He recalled that the matron said, 'J was not a concern' for the doctors 'as there were children on the ward who could possibly die unlike J'. He said this demonstrated the complacency surrounding J's illness. After the conversation the matron sent the ward sister to speak to them.

124. During local resolution of Mr and Mrs N's complaint the Trust gave Mr N a number of different and inconsistent explanations about the matron's communication with them. The Trust first said the matron could not recall the events, then said the matron was not on the ward for a number of days during J's admission. Finally, it said the matron was insistent that they would never have used the words Mr N attributes to them. The matron said they may have said J had caused no concern overnight. Understandably, this has made it impossible for Mr N to believe any of these explanations.

125. The NMC's 'The Code' sections 1 and 7 say nurses should treat people with kindness, respect and compassion. It says nurses should communicate effectively. It says nurses should check people's understanding from time to time.

126. The Matron's Handbook (2020) says the role of the matron has evolved since it was re-introduced in 2001. However, the NHS has always described the role as being one that is partly based on improving patient experience.

127. We spoke to the matron as part of this investigation. However, it was clear they could not remember the conversation. The only consistency between our interview and the Trust investigation is that the matron denied they would have used the words Mr N attributed to them.



128. We have two pieces of evidence. Mr N's account, and that of the matron. Without any further evidence it is impossible to conclude what the matron's exact words were, but Mr and Mrs N's perception was that it was said without compassion or kindness.

129. Regardless of the exact words, if the matron did say they had 'no concerns' about J, it is not surprising Mr and Mrs N did not feel staff were treating them with compassion or kindness, given J's situation. Equally, being told they were not a priority for accommodation at a time when they were so worried about J would not have been perceived as compassionate or kind.

130. Mr N said he and Mrs N felt they were not being given good enough information by the staff looking after J at the time they spoke to the matron. Mr N said he was being told by nurses 'not to worry' and senior staff were not engaging with them. There is some evidence the matron might have become aware of this during their conversation with Mr and Mrs N because they asked the ward sister to speak to Mr and Mrs N. At the very least, Mr N's email to the matron, which prompted the meeting, would have showed the matron they were not happy with what staff had told them about accommodation.

131. Part of the matron's role is patient experience. We have no reason to doubt what Mr N told us, so it seems likely the matron was made aware during the conversation that Mr and Mrs N had concerns (both about the lack of overnight accommodation for them and about their son's illness more generally). This would clearly have been a very difficult and upsetting time for Mr and Mrs N. The matron should have recognised Mr and Mrs N were anxious and distressed and listened carefully and responded clearly and compassionately to their concerns. That would have been in accordance with paragraph 2.6 of 'The Code'. The fact that instead Mr and Mrs N recall being told J was of no concern (whether that was exactly the words the matron used or not) means the matron's communication was not effective in achieving this standard. On balance, it is unlikely the matron adhered to other parts of 'The Code'. In particular checking Mr and Mrs N's understanding of what they had told them and using a range of verbal and non-verbal communication.

132. We cannot make a finding about whether the matron used the words Mr N attributed to them. However, we find that their communication did not meet the requirements of the relevant standards, as described in paragraph 125.

133. Mr N also believes doctors did not respond adequately and with sufficient urgency and were complacent (paragraph 110) because ECMO (extracorporeal membrane oxygenation, a machine that pumps blood from the patient's body to an artificial lung machine that adds oxygen and removes carbon dioxide) was not considered earlier in J's admission. ECMO was only considered in J's final hours.

134. The Trust's ARDS protocol said if all other therapies had failed, it was still in the first seven to ten days ventilation (as it was in J's case) and the lung disease was still felt to be potentially reversible, doctors should discuss the situation with one of the UK's ECMO centres. This is what J's doctors did on 17 April after other therapies in the protocol had been tried - HFOV, steroids, inhaled nitric oxide. The doctors looking after J considered ECMO at a time that was in line with the Trust's ARDS protocol.

135. However, our First Consultant Adviser said ECMO could have been considered sooner. They said J had severe ARDS from 15 April and it would have been appropriate to refer him for an opinion at that stage. Added to this, other findings elsewhere in this report show that other interventions recommended by the Trust's ARDS protocol should have been tried sooner, which would have affected the point at which ECMO could also have been considered. What is more, the Trust should have updated the ARDS protocol in 2014, but did not do this until 2016. This was a failing by the Trust. The new version of the ARDS protocol recommends early discussions with an ECMO centre. Had the ARDS protocol been updated in 2014 then it is likely this guidance would have been in place at the time of J's admission.

136. We therefore agree with Mr N J should have been considered for ECMO earlier than he was. There is no evidence of any consideration of ECMO before 17 April. This was a failing to meet the standards set out in GMC Good Medical Practice. Specifically, it was a failing to consult with colleagues where necessary.

#### The events of 17 April 2015

137. In this section, we consider Mr N's complaints that on 17 April the Trust's staff:

- failed to listen to his family's concerns about J's deteriorating condition
- did not arrange for a consultant to review J for more than six hours
- inappropriately paralysed J with rocuronium
- gave J a third dose of surfactant that was not in line with the relevant protocol.

138. Mr N said when he went to see J at 5.30am on 17 April, J looked very unwell. He said he was blue grey in colour and did not look right. He said J had become less swollen. He said he asked for J to be reviewed by a consultant. He also told us the nurse looking after J through the night said J's CRP had increased to 44mg/L and J would be prescribed antibiotics.

139. Mr N said he went home but returned to J's bedside at 7.30am and then stayed with J all morning. He said he kept asking for a senior review, but no one came. He said the nurse caring for J was worried about J. They had to keep 'bagging' him (manual ventilation) because J was desaturating so often. Mr N said a junior doctor saw J, but only changed the ventilator settings. Mr N said the junior doctor told him they were not even sure that was

right. He said a consultant only came to see J at around 2pm to give him rocuronium and surfactant.

140. When we spoke to the nurse in charge of J's care that morning they told us that when they came on shift at 7.30am, they thought J did not look right. The nurse said it was not an emergency situation at this point. They said J had been desaturating overnight and he continued to do that throughout the morning. The nurse said they had raised their concerns with a junior doctor and their senior nurse because they thought someone should review J. The nurse could not remember who attended J's bedside at the ward round. They said the junior doctor was back and forth to see J. The nurse said J looked pale on 17 April but was well perfused (where the skin looks as if the blood is flowing to the skin appropriately).

141. We also took a statement from the junior doctor looking after J that morning. They said one of the consultants saw J at the handover ward round. They also said that they discussed J several times with that consultant during the morning. The junior doctor said J was a concern because of his desaturations and increased need for oxygen. They said when looking up the ARDS protocol before giving surfactant, they saw that it advised to monitor for secondary infection. On that basis the junior doctor agreed with the consultant to prescribe antibiotics for J. This was after the X-ray meeting at 11am.

142. The junior doctor told us J's deterioration in the morning was respiratory (they said there were no cardiovascular problems - J's blood pressure and heart rate were fine). He was desaturating more and became more difficult to settle on the ventilator. The junior doctor told us that in the afternoon, while they were preparing to give him a dose of surfactant, he became more unstable from a respiratory perspective, more difficult to stabilise on the ventilator and needing more 'bagging'. The junior doctor told us J subsequently became cardiovascularly unstable, with low blood pressure and increased heart rate. They said this coincided with J being given a dose of muscle relaxant. They said J was treated with fluid replacement and given further sedation at this time.

143. The junior doctor told us following this treatment another consultant made the decision to continue with the surfactant administration. They said afterwards it proved impossible to mechanically ventilate J and his blood pressure was unstable. The junior doctor told us the consultants made the decision to try a different type of ventilator, but while this was being set up J's heart stopped beating and he had to be resuscitated.

144. Looking at J's medical record it shows that one of the consultants looking after J saw him at 5am on 17 April. They recorded a plan to chase the BAL results and consider a further dose of surfactant after J had a chest X-ray. A later entry (of the handover ward round) recorded the plan as, 'consider surfactant...'. Later still in the medical record the junior doctor recorded the reasoning for giving surfactant as J's worsening chest X-ray, frequent

desaturations and increased oxygen needs (up to 70 to 80% - in the night his oxygen had already been increased to 50%).

145. During the course of his meetings with, and complaints to the Trust, the Trust told Mr N consultants reviewed J on three occasions on the morning of 17 April. These three occasions were: the documented review at 5am, the handover ward round (between 9am and 10am), and the X-ray meeting - at around 11am.

146. The Trust said one of the consultants physically saw J during the handover ward round. In a written statement for J's inquest that consultant said they did not see a significant clinical change in J. However, they recognised J had deteriorated and had increased ventilator requirements. The consultant also said 'during the morning' of 17 April they had advised giving a further sedative when they had been told by nursing staff that J was not settling on the ventilator. This is not recorded in J's medical record. The Trust told Mr N this was chloral hydrate (a sedative). The prescription chart shows this was given to J on 17 April. It shows staff did not give it until the afternoon as part of the sedation required to give J surfactant.

147. The child death review concluded that J's deterioration in the last '8 to 12 hours' of his life was likely to be due to the pseudomonas infection. It also said there were no clear indications of sepsis syndrome until after 2.40pm on 17 April. Later, in meetings with Mr N, the Trust explained that J's observations (such as blood pressure and heart rate) and test results (such as white blood count, pH values - which measure acidity in the blood) did not demonstrate J had sepsis on the morning of 17 April. However, two different doctors accepted that J's blue grey colour may have been caused by the pseudomonas infection. The Trust accepted that the rise in J's CRP to 44mg/L would have been an indication to start antibiotics.

148. Our advisers said J's care was being reviewed by consultants on the morning of 17 April. They said J's medical record showed the consultants were appropriately aware of J's deterioration in respect of his X-ray and ventilator requirements and they were guiding his treatment.

149. The statements of Trust staff show the consultants looking after J were aware of his deterioration. The junior doctor and a consultant said the consultant saw J on the morning of 17 April. We note it would be usual practice for a consultant to attend a handover ward round. On balance, we accept this happened.

150. However, we can wholly understand Mr N's concern that even if a consultant saw J, the consultant reviews were not thorough enough to notice that J looked so poorly. Mr N is concerned the consultants did not do enough to spot J's deterioration might have another cause (Mr N is particularly concerned about sepsis).

151. It is very clear that Mr N was worried about J's appearance at the time. J's medical records do not provide any evidence about what was discussed with him. Certainly, there is no evidence that he was able to raise his concerns with any of the consultants.

152. Good Medical Practice Domain 3 paragraphs 31 and 34 say doctors must listen to patients and take account of their views. Parents can offer useful insights into their children's health. The lack of opportunity for Mr N to raise his concerns with the consultants making the decisions about J's care was a failure to act in accordance with the guidance on communication in 'Good Medical Practice'.

153. 'Good Medical Practice' domain 1 paragraph 15 says doctors must adequately assess patients and examine them when necessary. In this case, although we recognise that up to the morning of 17 April there was limited clinical evidence to support a bacterial infection, this was in part because the consultants had failed to arrange the appropriate tests in the preceding days, as we outline earlier (in paragraphs 101 to 109). Our First Consultant Adviser said irrespective J's doctors should have been aware of the high incidence of bacterial co-infection in children admitted to PICU with bronchiolitis (30 to 70%, paragraph 96) and a bacterial infection should have been suspected as a potential cause for J's deterioration. Indeed, the Trust has since acknowledged that antibiotics to treat J's bacterial infection should have been started sooner as we outline earlier (paragraph 2).

154. However, the evidence we have seen so far suggests the consultants only considered a secondary bacterial infection and the prescribing of antibiotics after the junior doctor read the Trust's ARDS protocol and talked to a consultant about this (paragraph 141). So although we accept that the consultants had seen J and were aware of his deterioration, we find that they did not adequately assess J as 'Good Medical Practice' says they should have done, because they failed to consider that a secondary bacterial infection could be a likely cause for J's deterioration.

155. In the event, the consultants looking after J decided to give him antibiotics and surfactant. The consultants decided to give another dose of surfactant, a dose of rocuronium and antibiotics at or around 11am. One of the consultants had advised giving J chloral hydrate 'during the morning'.

156. J's medical record shows the rocuronium and chloral hydrate were not given until around 2.30pm. Surfactant was not given until nearly 3pm. J's antibiotics were not given to him until 8pm. There are no reasons recorded for these apparent delays in the medical notes.

157. Our advisers said once the decision has been taken to prescribe antibiotics they should be given. 'Good Medical Practice', domain 1 paragraph 15 says doctors must promptly provide treatment where necessary.

158. The Trust wrote to Mr N telling him that the reason for the delay in prescribing antibiotics and giving the surfactant was because the junior doctor was called away to another patient who had pulled out their breathing tube. In a meeting Mr N had with the Trust on 22 July 2015, he was told that staff probably 'just forgot' to give them. The evidence the doctors caring for J gave at J's inquest was that antibiotics were not a priority at the time when they were providing a very high intensity of care and were therefore delayed.

159. It is understandable patients with the most urgent needs will be attended to first. It is also understandable the team attending to J were very busy treating him from around 3pm. Nevertheless, our advisers said J was 'clearly unwell' and had clinically deteriorated. The evidence of the nurse and the junior doctor looking after J shows they were concerned about him. J had to wait four hours for a sedative, a muscle relaxant and surfactant and nine hours for antibiotics. This could not be considered treating him 'promptly' in accordance with the guidance in 'Good Medical Practice'.

160. We have evidence the consultants reviewed J on the morning of 17 April and were aware of his deterioration. However, for the reasons in paragraphs 155 to 159, we do not have evidence to show that J received the prompt care he should have had. Added to this, we have seen no evidence that the consultants spoke to Mr N giving him the opportunity to tell them, and for them to listen to, his concerns (paragraph 152). It is not surprising that Mr N experienced this as nothing being done for J.

161. The Trust ARDS protocol advises trying surfactant if the measures in paragraph 64 do not work. The Trust ARDS protocol says doctors should avoid using prolonged muscle relaxants. The protocol also says surfactant should be given between days two and five of ventilation.

162. Mr N says the doctors caring for J failed to act in accordance with the protocol which clearly says surfactant should be used between days two to five of mechanical ventilation. J had been ventilated from 11 April, but had only been diagnosed with ARDS on 15 April. The ARDS protocol is written for patients who have ARDS and our advisers are of the opinion the guidance meant surfactant should be given between days two and five of mechanical ventilation after ARDS had been diagnosed. The Trust confirmed this was what the protocol meant. Mr N disagrees with this view. Mr N drew our attention to a hand-written note made by the Chair of the child death review (who was also the author of the ARDS protocol) which he believes says the third dose of surfactant was given outside the ARDS protocol. However, we do not think the notes are that clear. They say (as they are laid out):

'Add ...evidence for surfactant in ARDS good 1<sup>st</sup> dose, possible 2<sup>nd</sup> dose, no data for third dose'

and

‘Add evidence for use of surfactant in ARDS  
[Rocuronium] given to give surfactant then 3<sup>rd</sup> dose given [slightly] outside [clinical practice]  
lung injury protocol.  
Update acute lung injury protocol’

163. These notes are handwritten notes of the child death review meeting made on the edge of a proforma. Because of the way the notes are laid out and because they are not written in full sentences they do not clearly state a failing to adhere to the ARDS protocol. We can say the note suggests the third dose of surfactant was given outside ‘clinical practice’. This also accords with clinical advice we received.

164. At the time these notes were made, the ARDS protocol only specified the dosage of surfactant and the time when surfactant should be used (when ARDS was of a specific severity and between days two and five of mechanical ventilation). This would mean that the only way the surfactant could be given outside the ARDS protocol was either in respect of dosage or timing. The final record of the child death review identified the ARDS protocol needed updating because there was no evidence for the efficacy of a third dose of surfactant. That is also clear from the notes above. However, there is nothing in the notes, or anywhere else in the child death review, to suggest the doctors present at the child death review were concerned about the number of days J had been ventilated before he was given surfactant.

165. On balance, we do not think the notes meant J was given surfactant outside of the ARDS protocol. The ARDS protocol in place at the time of J’s care was ambiguous but, on balance, we do not think it was understood by the doctors caring for J as recommending surfactant be given within days two to five of mechanical ventilation, regardless of when the diagnosis of ARDS was made.

166. Nevertheless, the child death review clearly acknowledged that there was little evidence for giving three doses of surfactant. We note the ARDS protocol was not reviewed in 2014 as it should have been. When it was updated after the child death review it was clear only two doses of surfactant should be given. Had the protocol been updated sooner that guidance would have been in place at the time of J’s admission.

167. Like the child death review, our consultant advisers highlighted issues with giving a third dose of surfactant to J. Both said the third dose of surfactant was probably not indicated on 17 April, even if the clinical decision to give it in the absence of any other treatment was understandable. They noted that J had tolerated surfactant before but explained J’s response to the previous doses had been only very transitory. He had required higher levels of oxygen soon after.

168. Our First Consultant Adviser said they would expect the doctors looking after J (or the physiotherapist) to have done a full examination before and after giving surfactant. This was particularly given his deterioration at around 2pm. They said at around 2pm J was having even more frequent desaturations. They said this further deterioration could have been caused by a pneumothorax or pneumopericardium. Giving surfactant can cause or exacerbate these and they should have been excluded before the surfactant was given. Likewise, our Second Consultant Adviser said there were risks associated in giving surfactant. It involves instilling a large volume of fluid into the lungs and manual ventilation. They said given J had deteriorated at 2pm (shortly before the surfactant was given), and there was a risk he would further deteriorate after having it. Because of the risks of giving surfactant to an unstable child, our Second Consultant Adviser also said the decision to give surfactant should have been reconsidered when J deteriorated in the afternoon of 17 April.

169. There is no evidence from the medical record that an appropriate assessment - a full examination - was done before the doctors gave J surfactant or that they reconsidered the use of surfactant when J deteriorated. The lack of an examination or review was not in accordance with the guidance in 'Good Medical Practice'.

170. Mr N has questioned whether J should have been given surfactant at all when he was so poorly. The advice we received is mixed. Our consultant advisers explained that the doctors looking after J decided to give surfactant in response to the deterioration in his respiratory condition. One adviser said that in the absence of any other treatment, giving surfactant was an understandable decision. The other adviser said that in their view the risks of giving surfactant outweighed its potential benefit. The advice we have received also suggests the situation was different after 2pm to when the surfactant was prescribed (at 11am). By 2pm J had deteriorated further and the risks of giving surfactant had potentially changed.

171. There is no objective guidance or standard we can rely on to say whether J should or should not have been prescribed surfactant. It was a matter of clinical judgement. Our advisers have different opinions about the right clinical judgement at the time. We cannot say, even on balance, that the decision to give surfactant was a service failure.

172. What is a clear service failure, however, is that J should not have been given the surfactant when he was without a full examination or reconsideration of its suitability (paragraph 169). We also note the change made to the ARDS protocol in 2016 to only give two doses (paragraph 160) was clearly in line with the evidence that was available at the time of J's care. That change to the protocol could have been made when it was due for review in 2014. Had this happened, the revised guidance would have been in place at the time of J's admission. These points are significant. If J had been examined, the risks of giving him surfactant would have been clearer and could have been properly taken into account. A decision may have been made not to give surfactant. Had an examination happened, or had a third dose not been given at all - either following an examination, or in line with updated



guidance - it would have avoided the ongoing uncertainty about when and why J developed a pneumopericardium and the course of his deterioration following the surfactant.

173. Mr N was also concerned about whether J should have been given rocuronium. Our consultant advisers explained that rocuronium is a short-acting muscle relaxant. It was within the Trust's ARDS protocol to give it. Our consultant advisers explained that it is appropriate to give muscle relaxant when babies are becoming more unwell and are not synchronising with their ventilator.

174. Our consultant advisers explained that in this case it was necessary to give J a muscle relaxant before giving him the surfactant. They explained that it should also have been considered at other times to help J settle on the ventilator. In fact, J had tolerated rocuronium on other occasions.

175. Our First Consultant Adviser said rocuronium can cause or aggravate hypotension, which it did with J, but this is usually mild and easily managed.

176. Given the advice we have received, we have seen sufficient evidence to show that giving J rocuronium was in keeping with accepted good practice and in accordance with the Ombudsman's Principles.

#### Mr and Mrs N were asked to leave the room while J was receiving treatment

177. Mr N says he and Mrs N were asked to leave J's room at around 2pm on 17 April. He said he knew staff were going to give J another dose of surfactant. Once they left the room staff gave J a dose of rocuronium, which caused his blood pressure to drop. Mr N said they later found out from J's medical record that he had been given a 50ml blood transfusion at 2.35pm.

178. During local resolution the Trust acknowledged Mr and Mrs N were asked to leave the room when J was given surfactant on 17 April. The Trust said it was usual practice in PICU to do this. We spoke to the nurse and junior doctor looking after J that day. They said they did not recall asking Mr and Mrs N to leave the room but said it was common practice. The nurse said parents could stay if they did not want to leave, but a nurse would be assigned to sit with them and explain what was happening.

179. Also, during local resolution, the Trust told Mr N that the blood transfusion had been given at about 4.35pm, not 2.35pm. The Trust said the time on the blood transfusion record was a mistake. The Trust acknowledged the mistake had been overlooked by two other members of nursing staff who were responsible for checking the red blood cells and signed the blood transfusion record. The Trust said J had been given a bolus of fluid (plasmalyte) at 2.30pm after his blood pressure dropped.

180. J's medical record includes the blood transfusion record, which gives the time of 2.35pm for the blood transfusion. The medical record also includes an entry by a junior doctor which is a timed chronological list of the events following J's cardiac arrest. This times the blood transfusion at 4.35pm. The medical record also includes an undated/untimed record by the junior doctor who helped give J rocuronium and surfactant. That says a bolus of plasmalyte was given to J when his blood pressure dropped after the rocuronium was given.

181. On balance, we do not think there is enough evidence to show that J was given a blood transfusion at 2.35pm without Mr and Mrs N knowing.

182. J's medical record regularly says Mr and Mrs N were 'updated' but it rarely provides more detail than this. Only a record very late on 17 April (6.30pm) describes how Mr and Mrs N were told about J's pneumopericardium and that he had become critically unwell.

183. There is no evidence in the medical record about what information staff gave Mr and Mrs N in the early afternoon of 17 April, or what questions they had or how they were answered. In its response to our provisional views the Trust said that despite its best efforts what parents were told was not always recorded in detail. It is understandable that records of the information given to parents might be brief. However, the PICS standards say that parents should be able to participate fully in decisions about the care of their child and in giving this care. The GMC's Good Medical Practice and the NMC's 'The Code' say that accurate records should be made, including of the information given to patients.

184. Our Nursing Adviser said there are no clear guidelines about whether parents should be present for interventions, other than for the situation of cardiac arrest. That guideline says parents should be present if possible, with appropriate support. Our Nursing Adviser said, generally, it is appropriate for parents to stay in the room if they want to, provided they have a member of nursing staff with them to explain what is happening.

185. There is no evidence Mr and Mrs N were given the option of remaining with J when he was given surfactant. J's medical record provides no evidence that this was discussed with them. It provides no evidence nursing or medical staff made any attempt to understand how involved or present Mr and Mrs N wanted to be in J's care. It is clear the practice on PICU was that parents could stay in the room for their child's interventions if they wanted to do that. This is in accordance with the advice we have received. However, there is no evidence Mr and Mrs N were given an opportunity to express their wishes.

186. Similarly, there is no evidence in the medical record about what Mr and Mrs N were told about what happened after the rocuronium and surfactant were given, or what questions they had. In the absence of any other evidence, we have decided, on balance, to accept Mr

N's account that staff failed to tell them what treatment had been given or answer their questions.

187. On balance, we have found the Trust failed to act in accordance with the GMC's 'Good Medical Practice' domain 3, paragraphs 32 and 33 which says doctors should give patients the information they want and need. It says they should be sensitive to, and support, the needs of patient's relatives. It also says (domain 1, paragraph 21) clinical records should include the information given to patients.

188. It also failed to act in accordance with the NMC's 'The Code' sections 2 and 7 which say nurses should listen to people and respect the level people want to be involved in decisions about their care. It says nurses should listen and communicate effectively.

#### When J's family were told about the pseudomonas infection and the antibiotics he had been given

189. When we spoke to the junior doctor caring for J on 17 April, they told us they had agreed with one of the consultants that J should have antibiotics. They said this decision was taken at around 11am.

190. The decision to give J antibiotics on 17 April is not recorded in his medical record, other than on the prescription. The antibiotics were prescribed at 3pm. (The Trust has accepted, as we outline earlier (paragraph 2), that they should have been given earlier). J's death summary did not include information about the decision to give antibiotics or the prescription either.

191. The Trust initially told Mr and Mrs N during local resolution of their complaint that the BAL taken on 16 April was reported as positive for pseudomonas after J's death. Later, it said the report was received in the afternoon of 17 April, but not looked at by a registrar until an hour before J died. It said the registrar did not tell the consultants about the result because J was already having antibiotics. A blood culture taken on 17 April was also reported as positive for pseudomonas on 19 April.

192. There is no evidence in J's medical record that the doctors caring for J on 17 April told Mr and Mrs N about the prescription of antibiotics or the result of the BAL. The Trust has provided no evidence that it did this.

193. The transcript of the meeting between Mr and Mrs N and the Trust on 4 June shows this was the first time they were told about the pseudomonas infection. It was only after the

meeting on 16 October 2015 when they found out about when antibiotics were given and why (paragraph 189). It was only a year later, after Mr and Mrs N had pressed the Trust, that it acknowledged the BAL result was available on the afternoon of 17 April.

194. The Trust accepted during the complaint process that it had not told Mr and Mrs N about J's pseudomonas infection until approximately seven weeks after his death. The Trust apologised for this.

195. The PICS standards say parents should be kept informed about their child's condition and the care plan and be updated regularly.

196. The GMC's 'Good Medical Practice' domain 3, paragraphs 32 and 33 says doctors should give patients the information they want and need. It says they should be sensitive to, and support, the needs of patient's relatives. It also says (domain 1, paragraph 21) clinical records should include the information given to patients.

197. Not telling Mr and Mrs N about the BAL result and the prescription of antibiotics was not in accordance with the PICS guidance, or GMC guidance.

198. This part of Mr N's complaint, and the fact that it took the Trust seven weeks to tell Mr and Mrs N about the result is closely linked to other parts of his complaint. We explore this issue further in the section of the report starting at paragraph 301.

#### His family were not kept regularly and meaningfully informed about J's condition

199. Mr N told us that he and Mrs N were not given accurate or correct information about J's illness or likely prognosis. He said they were led to believe J 'just had a cold' and would 'get over it'. He said when J was getting worse on 14 or 15 April, they were told J would get worse before he got better, or that 'day five is the worst'. They were not told J had developed ARDS, or the significance of that.

200. Mr N said during the inquest one of the studies quoted by the Coroner's expert found that out of 11 babies who developed ARDS from hMPV (who had a complicating factor - which can include prematurity) eight died, a mortality of 72%. He said this meant J had a very high chance of dying. He said they were not told about this.

201. The GMC's 'Good Medical Practice' domain 3, paragraphs 32 and 33 says doctors should give patients the information they want and need. It says they should be sensitive to, and support, the needs of patient's relatives. It also says (domain 1, paragraph 21) clinical records should include the information given to patients.

202. The PICS standards say parents should be kept informed of their child's condition and care plan and be updated regularly.
203. Our clinical advisers said the normal course for bronchiolitis is that it takes around seven to ten days to fully recover. Often it gets worse before it improves.
204. Our First Consultant Adviser also said that the prognosis for very young babies who had been born prematurely is worse.
205. Our Second Consultant Adviser said the mortality rate quoted in the study referred to at the inquest (and by Mr N) was 9% for children who had severe respiratory infection (not just those who also had ARDS) caused by hMPV.
206. Our clinical advisers said the mortality rate for paediatric ARDS is accepted to be between 22% and 45%.
207. J's medical records do not make a specific diagnosis of ARDS. The Trust said ARDS was diagnosed on 15 April.
208. On 15 April, J's medical record says J was given surfactant 'in accordance' with the Trust ARDS protocol. The protocol recommends giving surfactant to patients who are not responding to other measures set out earlier in the ARDS protocol. This implies those other measures would be tried first. The medical record does not specifically state the diagnosis or severity of J's ARDS, but the reference to the ARDS protocol and surfactant implies the doctors caring for him suspected he had ARDS at this point. The doctors caring for J also started to take arterial blood gases on 15 April, which are necessary for categorising the severity of ARDS.
209. Our advisers and the medical expert at J's inquest said J may have had a milder form of ARDS before 15 April. This is demonstrated by changes in J's X-rays between 12 and 14 April, and his increased oxygen requirements. However, our advisers said J's X-rays could equally be indicative of the respiratory infection he was known to have. There is no definitive evidence to show that the doctors caring for J were aware that he had a milder form of ARDS before 15 April, although this is implied by the reference to the ARDS protocol and the use of surfactant - which is advised only after other measures have not been successful. On balance, we can say the doctors knew J had developed ARDS by 15 April at the latest and may have suspected he had developed ARDS before this. Given the equivocal X-ray results however, we have not concluded that the doctors caring for J should have suspected ARDS sooner than 15 April.
210. As we noted in paragraph 182, J's medical record often refers to Mr and

Mrs N being 'updated', but rarely provides any information about what they were told. The Trust has said that despite best efforts staff might not be able to record every aspect of what had been discussed. However, in line with the NMC's 'The Code' and the GMC's 'Good Medical Practice', paragraph 21, we would expect staff to keep records that are accurate and record information that is given to patients. It is not possible to know from J's medical record anything about what information staff gave Mr and Mrs N when they were 'updated' or 'up to date'.

211. Mr N says they were aware J's bronchiolitis might get worse before it got better. He said nurses told them J just had a 'cold'. There is no information in J's medical record about when or how Mr and Mrs N were told this.

212. hMPV is a virus that most commonly causes a cold. At the inquest, one of the consultants looking after J described hMPV as a cold-like virus. We find it likely that this description was also used in explanations given to Mr and Mrs N. Most people would consider a cold a mild illness. Explaining that hMPV is a cold-like virus would not be a clear, accurate or complete explanation of the situation facing J.

213. There is no evidence the doctors looking after J told Mr and Mrs N about the expected duration of J's bronchiolitis. There is no evidence the doctors caring for J told Mr and Mrs N J's likely prognosis, or that J's young age and prematurity were additional risk factors in his chance of developing ARDS and of dying. Indeed, Mr N points out he and his wife were not even made aware of these facts when the doctors gave J surfactant on 15 April. J's medical record says they left to go home before it was given. It is clear they did not know the gravity of the situation.

214. Our advisers make clear that with the onset of ARDS, the prognosis for J changed significantly.

215. The figure Mr N saw in the study used at J's inquest suggests a much worse prognosis for J than that quoted by our advisers, but whether one uses Mr N's figure or the figure quoted by our advisers, it is clear J's development of ARDS from hMPV gave him a much worse prognosis. We can see J had a number of complicating factors - articulated by Mr N and our advisers - which would potentially put him at a higher risk than other children with hMPV and ARDS.

216. By 15 April at the latest, it should have been clear to the doctors that (with a mortality rate of up to 45%) it was almost as likely J would die as live, regardless of the medical care he received. Mr and Mrs N should have been given clear, accurate, complete and relevant information at that time.

217. Mr and Mrs N needed information to equip themselves for the course of J's illness and the possibility he might die. The guidance is clear that people should be given the information they need at the appropriate time. The evidence we have seen suggests J's doctors did not do this, either at the time of J's admission or when he developed ARDS. We also think that it is unlikely that Mr and Mrs N would simply forget they had been told this. They even went home shortly before the doctors gave J surfactant on 15 April. It seems very unlikely they would have done that had they known J was so seriously unwell. On balance, we find this was a very significant failure to adhere to the guidance and communicate clearly with Mr and Mrs N.

The accuracy and completeness of J's medical records (including the medical certificate of cause of death)

218. Mr N told us the BAL culture result which showed J had a pseudomonas infection was not recorded in J's medical record. He said it was seen by a junior doctor on the afternoon of 17 April and he also thought it was seen by a consultant before J died. Mr N said despite the result of the BAL being available at the time, one of the doctors looking after J signed the medical certificate of cause of death without pseudomonas being listed on it.

219. During local resolution of Mr and Mrs N's complaint and at the inquest, Mr N said he thought the lack of information on the medical certificate of cause of death was a deliberate attempt to cover up the fact that J had a pseudomonas infection and died from pseudomonas sepsis.

220. The GMC's 'Good Medical Practice' domain 1, paragraph 19 says doctors should record events at the same time as they are happening or as soon as possible afterwards.

221. The guidance for doctors completing medical certificates of cause of death says the family should get a copy of the certificate. It says it provides the family with an explanation of how and why their relative died, and should include clear, accurate and complete information about the diseases or conditions that caused the death. It also says that the certifying doctor should have access to relevant medical records and the results of investigations. However, it says the results of investigations do not have to be known before completing the certificate if the doctor knows 'in broad terms' the disease that caused death. Finally, the guidance says doctors are 'expected to state the cause of death to the best of their knowledge and belief'; they are not expected to be infallible'.

222. There is a section on the back of the certificate that can be ticked to show that further information about the cause of death might become available.

223. During local resolution the Trust accepted it was an omission that the BAL result was not recorded in J's medical record.

224. We agree the BAL result should have been recorded in J's medical record. Not to have done that was not in accordance with GMC guidance.

225. As we outline above (paragraph 191), the Trust initially told Mr and Mrs N that the result of the BAL was reported after J's death. It took the Trust a year to admit that the positive result was reported at 4.11pm on 17 April. It said the only person to see the result was a junior doctor who failed to record it in the medical record. The Trust said the junior doctor did not bring the result to the attention of the other doctors looking after J.

226. Mr N does not accept this explanation. He believes the other doctors did know about it. He says they have denied knowledge of it to assist in covering up errors in J's care. This is an understandable view given the delay in the Trust's acknowledgement of when it was reported.

227. Mr N says information in the death summary and information provided to the child death review shows one of the doctors knew J may have had a secondary infection when he talked to the ECMO centres during the evening of 17 April.

228. J's medical record also shows the doctors looking after J should have suspected he had a secondary infection from at least 6.10pm on 17 April. This is when J's blood results were found to be indicative of an infection and a blood culture was later taken. (In saying this, we recognise Mr N thinks the doctors suspected J had an infection days before this. We have looked at that issue in paragraphs 98 to 109). This does not tell us anything more about who knew about the BAL result, or when, though.

229. Second, Mr N refers to what one of the doctors told him in a meeting on 4 June:

'It can be more common when a child with [hMPV] then gets a pseudomonal infection, then we're talking about a patient which immediately brings the consultant to the bedside and say, "We've got a different situation here, and it requires a different direction of travel". And I think that intelligence happened in the latter part of J's stay on the intensive care unit. And we need to tease out exactly when that was'.

230. This statement was made in response to Mr and Mrs N asking when death from hMPV would be 'common' enough to tell parents death was a possibility. There had already been a conversation about when the BAL result was known and by whom. During that part of the conversation, the doctors told Mr N they only found out about the positive BAL result after J died. However, neither of them were there on the afternoon of 17 April.

231. The statement is evidence the doctors caring for J did have intelligence about a secondary bacterial infection at some point before J died, but it does not give a time for



that. Saying that there was 'intelligence' concurs with J's medical record. There were a number of clinical indicators recorded in J's medical record and in his discharge (death) summary that suggest he had a secondary infection on the afternoon of 17 April. So regardless of when doctors became aware of the BAL result, there would have been clear indications by this stage that J had a secondary infection.

232. Finally, Mr N refers to a comment one of the doctors (who had been at the meeting on 4 June and told him the BAL result was not available until after J died) made at the inquest. This was, 'we were only aware that J had a bacterial infection when the BAL came back on the evening of that ... up until that time ...'. The date was not apparently specified by the doctor at the inquest, but it is reasonable to assume from the subsequent sentence this meant 17 April.

233. The comment at the inquest was made by a doctor who was not looking after J on 17 April. At the meeting on 4 June the same doctor said the BAL was not known about on 17 April. This is an inconsistency and misleading in the context of our findings (paragraph 228) that there were other indicators by this stage that would have pointed to a possible secondary infection. We have found elsewhere in this report that the doctors who met with Mr and Mrs N on 4 June gave them incorrect information about the tests done and the results of those. It is therefore reasonable to think the comment at the inquest might carry more weight about what actually happened - that is, the BAL result was known about on the evening of 17 April.

234. Our advisers told us that a BAL result would not normally be available for 48 hours. They told us a provisional result may be available sooner that could show colonisation of bacteria. However, it is normally only the later result that would give specificity about the best antibiotic to use. They told us doctors would not generally check for a result sooner than 48 hours for this reason. In J's case, the situation was different, doctors had not done the BAL to confirm the type of bacteria and its specificity. The BAL was done to check if J had an infection. The initial result would have therefore been useful in making a decision to start antibiotics. This makes it more likely that the doctors caring for J would have checked for this result, as Mr N believes. Certainly, there is a note in J's medical record at 5am to chase the BAL, so this was something that the doctors had considered. However, we have no evidence they actually did check the result.

235. Mr N believes the Trust lied about whether the BAL result was checked and who saw it, to cover up the fact that doctors knew about J's bacterial infection before he died and still failed to treat it. He says by denying the BAL result was available on 17 April, the doctors could leave out secondary infection when completing the medical certificate of cause of death.

236. However, it is clear from J's medical records and his death summary that the doctors caring for J suspected he had a bacterial infection and sepsis before he died, even if they did not know the type of bacteria that was causing it. The doctors would be required to record a bacterial infection or sepsis on the medical certificate of cause of death if they thought that it was contributory to J's death. They did not need to have confirmation of that from the BAL (which by itself would not indicate sepsis or even an infection if there was a low concentration of bacteria). Denying knowledge of the BAL result could not cover up the facts in J's medical record or have enabled anything different to be written on the medical certificate of cause of death. It is therefore unlikely the motivation for this was to cover up.

237. Nevertheless, we agree with Mr N that given all of the evidence in paragraphs 223 to 233 there remains uncertainty about who knew about the BAL result and when. We are unable to say, even on the balance of probability, that any of J's doctors, other than the junior doctor the Trust has accepted knew, were aware the BAL had been reported as positive for pseudomonas at 4.11pm on 17 April. We do not have evidence to conclude the doctors are lying.

238. The guidance on completing the medical certificate of cause of death shows doctors should complete it to the best of their knowledge and belief. The guidance does not say doctors must check the results of investigations or wait until the results are known. If the doctor signing the certificate 'knew in broad terms' the cause of death and thought the investigations would only supplement that, then the guidance says it is appropriate to complete the medical certificate of cause of death.

239. It would appear the doctors looking after J already suspected J had secondary sepsis. J's death summary and the record of the child death review both said the presence of a possible secondary sepsis was one of the reasons J was declined for ECMO on the evening of 17 April. Blood tests taken at 6.30pm on 17 April were also suggestive of sepsis.

240. The doctor who signed J's medical certificate of cause of death would also have been aware that there were outstanding laboratory investigations - the BAL taken on 16 April and a blood culture taken earlier on 17 April. Had they thought the results of those investigations would make the cause of death uncertain they should not have signed the medical certificate of cause of death and waited until they had checked the results.

241. However, the Trust said the doctors felt they knew the cause of J's death. Despite having a suspicion that J had a bacterial infection, it does not appear they thought it was the primary causal factor in his death, or contributory to his death. The doctors seem to have thought the progression of J's ARDS was the cause of his death and largely due to hMPV. However, that view clearly changed later, with the doctors at the child death review for example, accepting that the pseudomonas infection had been a more significant factor in J's death.

242. After Mr N commented on our provisional views, we asked one of our consultant advisers about this issue. Our adviser said that doctors should complete the medical certificate of cause of death with the information available at the time if they know the cause of death. They told us that hMPV alone could cause ARDS and death. They said an additional diagnosis of sepsis was not needed to explain J's deterioration on 17 April. That is, J's presentation could have been symptoms of ARDS or sepsis or both. However, our adviser said the results that later became available - with pseudomonas present in both the BAL and the blood culture - showed pseudomonas was likely to have been present from 16 April and contributory to the poor outcome for J. They said, therefore, that once those results were known, the cause of death could reasonably have been written to include pseudomonas as a contributory factor. Because the results were not available when the medical certificate of cause of death was signed, our adviser said it was acceptable for the doctors to complete the medical certificate of cause of death form, but it should have been ticked to show that there were test results still outstanding at the time it was completed. In saying this, we recognise that Mr N thinks the doctors should have checked for test results before completing the medical certificate of cause of death. However, those would not have been more helpful in completing the medical certificate of cause of death until much later when both results were available.

243. Mr N thinks the doctors looking after J should have known the pseudomonas infection was a contributory factor in his death. The advice we have received shows Mr N is probably right that pseudomonas made some contribution to J's illness and deterioration (although our advisers are clear they agree the primary cause of death was ARDS caused by hMPV). At the time though, the evidence only shows the doctors were aware J may have developed a secondary bacterial sepsis later in the evening on 17 April. There is no evidence they thought it was a cause of his death, or contributory to it, when they signed the medical certificate of cause of death.

244. To Mr N, it seems only logical that sepsis - an illness that can cause death - must have contributed to how poorly J was on 17 April. He says it must have been contributory to his death and should have been included on the medical certificate of cause of death. He rightly says the doctors caring for J clearly suspected J had secondary sepsis from at least around 6.20pm on 17 April when blood tests became available, they took a blood culture and gave J antibiotics. He points out that shortly before J died, J also developed a bleed from his lungs which can be a complication of both sepsis and ARDS. He says the doctors therefore must have known that sepsis contributed to J's collapse and death. The clinical advice we received agrees with Mr N's view insofar as our advisers explained, in their view, pseudomonas could have contributed to the progression and severity of J's ARDS as well as to his instability on 17 April. Our First Consultant Adviser explained that they may have written the medical certificate of cause of death differently, particularly with knowledge of the BAL and the blood culture results that later became available.

245. However, the guidance on signing the medical certificate of cause of death does not expect doctors to be infallible. The evidence the doctors who cared for J gave at his inquest suggests they did not think a bacterial infection or sepsis were significant in J's deterioration and death on 17 April such that it needed to be included on the medical certificate of cause of death. This is a tenable view for the doctors to have held at the time they signed J's medical certificate of cause of death: our clinical adviser told us that ARDS caused by hMPV could explain the types of symptoms J was experiencing on the 17 April, even though they concluded J's medical certificate of cause of death could reasonably have been completed to include pseudomonas.

246. Even if the doctors looking after J did not suspect the possible secondary sepsis was a cause or contributory factor to his death, the test results would still appear to have been a relevant consideration in his death. This is shown by the inclusion in the discharge (death) summary one of J's doctors completed a few days later, which said secondary sepsis may have contributed to J's instability on 17 April. Not ticking the back of the medical certificate of cause of death form in accordance with the guidance on completing the certificate was therefore an error.

247. For these reasons we find that the medical certificate of cause of death was not completed in accordance with the relevant guidance. This was service failure.

248. We have not seen evidence that the lack of information about the pseudomonas infection on the medical certificate of cause of death shows the doctors looking after J were trying to 'cover up' the fact of the pseudomonas infection. One of the doctors caring for J wrote in the medical record later that day that J may have had a bacterial infection. The positive result was then included in J's death summary, which would normally be copied to the family. Those actions are not compatible with trying to hide the existence of the pseudomonas infection.

249. We acknowledge the death summary was not sent to Mr and Mrs N. We look at this part of their complaint later from paragraph 301.

#### The impact (injustice) of the failings we have found in respect of Mr N's complaints about J's care

250. Mr N, in his comments on our clinical advice, said any failings we find in J's care would have inevitably contributed to the course of J's illness and death.

251. Mr N is making a perfectly reasonable point. In J's case, where the treatment options were so few, and the situation so serious, we can wholly understand his view that no failing is acceptable and any failing could have a material effect on the outcome for J.

252. The standards and guidance that constitute good clinical care and treatment exist for a reason. They exist to ensure the best possible outcomes for patients. Not adhering to the standards and guidance - unless for a justifiable reason - causes a loss of opportunity for a patient to obtain the best possible outcome.

253. We therefore agree with Mr N that the failings we have found were lost opportunities to help secure the best possible outcome for J. We agree that those lost opportunities had the potential to make a difference to J and perhaps change the course of his illness.

254. However, it is important to remember that the purpose of care in J's situation was to support his body while he tried to recover from his illness. While we can say J was denied the best possible chance of recovering from his illness because of the failings we have identified, we cannot say, even on the balance of probabilities, J would not have died but for these failings. Sadly, our advisers point out that a very high number of babies die from ARDS even with the very best supportive care.

255. This does not, however, undermine the Trust's acceptance that J should have been prescribed antibiotics sooner than he was and that this made a material contribution to his death. Indeed, in its letter to the Secretary of State for Health, the Trust acknowledged the view that J would on the balance of probabilities have survived if antibiotics had been given sooner than they were.

256. As explained in the paragraphs above we have found the following failings by Trust staff caring for J to adhere to relevant standards, guidance and good practice in respect of:

- responding to his low temperatures, particularly on 12 and 14 April (paragraph 51)
- a delay in changing J's ETT (paragraph 85)
- failing to use higher PEEP or HFOV at least one day sooner (paragraph 85)
- a delay in carrying out blood cultures between 15 and 17 April (paragraph 103)
- a failure to examine J before giving him a third dose of surfactant and reconsider its use (paragraph 169)
- a delay in giving J prescribed treatments on 17 April (paragraph 160)
- poor communication (paragraphs 57, 87, 122, 185 and 186, 197 and 217).

257. We will look at the advice we received about the consequences of these failings in J's care in turn:

### Temperature

258. Our Nursing Adviser said the body works best at normal temperature. They said as babies get bigger having a variation in temperature is not as concerning as in newborn babies.

Our consultant advisers explained that J's low temperatures were not indicative of a bacterial infection or indicative he needed treatment for that. They said J's low temperature would not have caused J's secondary infection. A number of J's low temperatures returned to normal. None of our advisers thought J's low temperatures would have been a significant detriment to him.

259. We accept J's low temperature was not a direct contributory factor in his development of ARDS or his development of a pseudomonas infection. However, as outlined above, our Nursing Adviser pointed out that the body works best at a normal temperature. The longer periods when J's temperature was low may have meant that his body was not working at its best during these times. Mr N rightly points out patients are kept at a normal temperature for a reason; our advisers said the body functions best at a normal temperature. Temperature is maintained to help support recovery.

260. We are of the view that the failings we found in maintaining J's temperature are likely to have been a lost opportunity to support J's recovery as well as it could have been.

#### Delay in changing J's ETT

261. Our advisers explained that while J's ETT could have been changed sooner, the right steps were being taken to minimise the leaks coming from it. The leaks do not appear to have been continuous. Our advisers all said J's gas exchange was good and did not change for the better when the ETT was changed from an uncuffed to a cuffed tube. As such, we do not find that there was an injustice to J as a result of the leaks from his ETT. However, we find that there was an injustice to J as a result of not increasing his PEEP or trying HFOV sooner.

#### Failing to use a higher PEEP or HFOV sooner

262. Our consultant advisers explained that there is some evidence using a higher PEEP and HFOV are associated with better outcomes in ARDS. The literature is though mixed. It is also not specifically targeted at paediatric ARDS. However, the fact that the Trust's ARDS protocol specifically suggests trying these measures would suggest to us the Trust recognised these measures could be associated with better outcomes.

263. Our Nursing Adviser explained there may be risks in changing the ETT and using a different type of ventilation. However, we have seen no evidence so far that the doctors looking after J made their decisions about J's ventilation on this basis.

264. The failure to use a higher PEEP or HFOV sooner was a lost opportunity to provide the best possible support for J while he tried to recover from his illness.

265. Our advisers say J's ventilation was generally good. The purpose of ventilation is to support the body in its recovery. It cannot generate recovery.

266. Nevertheless, no matter how small the chance these measures might have made a difference, any parent would have wanted their child to have had that chance. Knowing that J did not have this chance is a significant injustice to J and his family.

#### Delay in taking blood tests and cultures

267. As outlined earlier, we have not considered when J should have been given antibiotics. This is because the Trust has already accepted that antibiotics should have been started sooner. The Trust accepted that the failure to give timely antibiotics made a material contribution to J's death and acknowledged the view that J would on the balance of probabilities have survived, if antibiotics had been given sooner than they were (paragraph 255). We have found testing for a bacterial infection should have been done more frequently and sooner.

268. We do not know what the blood cultures would have shown had they been done sooner. However, had the Trust done those tests it is possible it would have known about J's pseudomonas infection earlier or had more information about when the infection developed and been able to treat it sooner.

269. Mr and Mrs N told us they suspect J had a bacterial infection from 14 April and this may have been the cause of his ARDS. We cannot say when J contracted the pseudomonas infection. Had the doctors done more frequent testing, we would have had more evidence about this. However, the clinical views we have seen throughout the evidence, all concur that J's ARDS developed as a result of hMPV. Both our consultant advisers say that a pseudomonas infection may have worsened the progression of J's ARDS, but identify bronchiolitis caused by hMPV as the trigger for ARDS.

270. However, as a result of the failings we identified, Mr and Mrs N will never know the actual cause of J's pseudomonas infection, or its contribution to his illness, and will always have doubts about what could have been done and when. This is a significant injustice to them.

#### The giving of surfactant and delays on 17 April

271. We find that although doctors saw J in the morning of 17 April, they did not assess him adequately. They did not recognise that a secondary infection was a likely cause for his deterioration. Again, as we outline earlier (paragraph 255), the Trust has acknowledged that antibiotics should have been started sooner and that the failure to give timely antibiotics made a material contribution to J's death.

272. Despite one of the doctors apparently advising J should be given a sedative during the morning of 17 April, there is no evidence this was done at least until the afternoon of 17 April.

273. Our Second Consultant Adviser explained chloral hydrate would not necessarily have been the first choice of sedative to help J settle on the ventilator (they explained an intravenous sedative or a muscle relaxant would have been a more appropriate choice). Our Second Consultant Adviser also explained the doctors caring for J appeared to have thought that J's desaturations were due to his deteriorating respiratory condition, rather than him being out of synch with the ventilator. The doctors prescribed surfactant to manage this.

274. However, we recognise a different sedative may have been appropriate. We also recognise a doctor said J should be given a sedative. There was presumably a reason for that, and this is likely to have been that he was 'fighting' the ventilator. In not giving the sedative, or by delaying doing so, the Trust missed another opportunity to secure the best possible outcome for J.

275. There was also a delay giving J surfactant. Prior to giving it, J was not examined and the appropriateness of giving it was not reconsidered in light of his deterioration. We also noted the Trust ARDS protocol was not updated at the time J was given surfactant.

276. These points are significant. Our advisers explained that giving surfactant to a patient with a pneumopericardium would exacerbate it. Our advisers explained that it was possible J already had a small air leak causing a pneumopericardium before he was given surfactant. His ongoing deterioration and frequent desaturations could have been evidence of this. If J had been examined, the risks of giving him surfactant would have been clearer and could have been properly taken into account. Had the ARDS protocol been updated to include the advice to only give two doses of surfactant, any decision to give a third dose outside of the ARDS protocol (which our advisers explained might be an understandable decision in these circumstances) would have been properly considered and justified by his clinical condition. Had either of these things happened it would have avoided the ongoing uncertainty about when and why J developed a pneumopericardium and the course of his deterioration following the surfactant.

277. The doctors caring for J recognised that he was deteriorating and it is clear they thought that surfactant might improve his situation. Clearly, if a full examination of J had been done as we outline above (and there were no reasons not to give J surfactant), then the delay we have identified in giving him surfactant was also a loss of opportunity to secure the best possible outcome for him. However, in saying this, we recognise that there was only a small likelihood the surfactant would have improved J's situation. The advice we have received is that the previous doses of surfactant made only a transitory difference.



## Communication

278. We have found a number of failings in respect of J's care and treatment. At the time each of those failings occurred an opportunity was lost. This finding is, in itself, a significant injustice to Mr and Mrs N. It leaves space for doubt that things could have been different. This can only add to Mr and Mrs N's grief and bereavement.

279. So far in this report we have also seen that Mr and Mrs N were not given the information they needed. They give an account of feeling unsupported and of not being listened to while their baby son was dying. They do not feel their concerns were heard or acted upon. They were not given time to prepare for his death. It is unimaginable how Mr and Mrs N must feel. The failure to communicate effectively with Mr and Mrs N has left a space where they are likely to think things could have been different in more ways than we have identified in this report. This is a significant injustice at any time, and more so after the death of a child.

## Complaint 2: Mr N complains about events after J died

280. The way in which the Trust engaged with Mr and Mrs N after J's death was undeniably poor, as we will see in the rest of this report. Mr N is of the view that the reason for this is the Trust has conspired to hide from him the true reasons for J's death and the Trust's liability in that. It is entirely understandable from the evidence we have seen how he has reached that view.

281. We have looked at Mr N's concerns under the bullet points listed in his complaint. However, a number of these are very similar and we have considered those together.

## What doctors told Mr and Mrs N about a post-mortem

282. Mr N says before J's death the doctors caring for J told him that J would recover. He says the doctors therefore must have thought J's death was unexpected. He thinks the doctors should have arranged for a post-mortem.

283. The NHS website explains a coroner can ask for a post-mortem to be carried out once a death has been referred to them. Deaths are referred to the coroner if the cause of death is unknown, or the death was unexpected.

284. If a coroner's post-mortem is not needed, hospital doctors can ask for a hospital post-mortem to provide more information about a patient's illness or cause of death. This can only be done with the consent of the next of kin. Family members can also ask for a hospital post-mortem.

285. The Ombudsman's Principles say people should be given complete, clear, relevant and timely information. They say organisations should provide effective services with competent and appropriately trained staff.

286. During local resolution of the complaint the Trust acknowledged that a hospital post-mortem should have been discussed with Mr and Mrs N. However, Mr N remains of the view that the doctors themselves should have thought a post-mortem was necessary.

287. Mr N is right to say that in a sense the doctors caring for J were not expecting J to die and therefore his death was unexpected. We think, as we outline elsewhere in this report, that the doctors caring for J had not grasped the potential course his illness might take and that there was a risk J might die. However, the doctors would have known that some children do die from hMPV and ARDS. They knew that J had ARDS and they thought that was the principal cause of J's death (paragraph 241). J's death was not one that fits with the definition of a death to be referred to the coroner.

288. Nevertheless, the doctors caring for J were surprised when he died. Mr N told us they asked a doctor whether there would be a post-mortem but were told that was not necessary. When they asked a nurse whether a post-mortem would be done she asked them, 'what for?'. We accept this was what happened. It also fits with the Trust's comments that the doctors caring for J thought they knew the cause of death and therefore a referral to the coroner was not necessary. However, despite the doctors being confident of a cause of death, this would have been an opportunity for the doctors caring for J to have recognised that a hospital post-mortem might be appropriate.

289. By around 11pm on 17 April there was even more reason for the doctors to have considered a hospital post-mortem might be helpful. At this time one of the doctors caring for J reviewed J's medical record and specifically wrote a bacterial infection/sepsis might have been contributory to J's collapse. The entry in J's medical records at around 11pm was significant because while doctors had suspected J may have an infection before this time, this appears to have been the first time the doctors acknowledged that the secondary sepsis may have contributed to J's collapse. That would have made the course of J's last hours less clear due to the difficulty in separating out the relative contributions of ARDS and sepsis.

290. These are circumstances where a doctor should consider a hospital post-mortem on the grounds that more information might be needed about J's death - either for their own knowledge or that of J's family.

291. During local resolution of the complaint, the doctor who signed the medical certificate of cause of death gave a statement to say he had not felt it appropriate to speak with Mr and Mrs N after J's death. This does not explain why a hospital post-mortem was not considered

appropriate by any of the doctors caring for J. It does not explain why Mr and Mrs N were specifically told that a post-mortem was not necessary and were not informed about the possibility of a hospital post-mortem despite asking about it.

292. The Trust has not explained the failure to consider a hospital post-mortem for J. It has not explained why no one spoke to Mr and Mrs N about this. Mr N suspected, from a note he had seen on J's medical record, that staff may have routinely been neglecting to offer post-mortems. We agreed, and therefore asked the Trust whether it had any data on post-mortems offered in 2015. Without a detailed audit of all the relevant patients' medical records, the Trust could not tell us. We have not asked the Trust to do that. The Trust could tell us that 44% of children who died on PICU in 2015 had a post-mortem. This compares roughly to the figures in subsequent years up to now. This includes the years after the Trust introduced a check list item to ensure staff did offer post-mortems. This suggests to us that it is unlikely that staff were routinely neglecting to offer post-mortems.

293. As such, we consider that this was a specific instance of the doctors caring for J failing to offer Mr and Mrs N a post-mortem when they should have. We find this was a failure to act in accordance with the criteria for hospital post-mortems and with the Ombudsman's Principles to provide effective services.

#### The test done after J died and whether the Trust tried to hide this from his family

294. Mr N said in the information he received when he asked for a copy of the Trust's records was a wound swab apparently taken from J on 19 April and sent to the laboratory. He pointed out this was two days after J had died and while J was in the hospital's Chapel of Rest. Mr N was concerned that this test might have been done without his family's knowledge or that a mistake might have been made that resulted in another child's test being logged against J's name.

295. The evidence we have seen shows that in July 2015, when this wound swab first came to light, the Trust's staff thought it might have been recorded against J's name in error. It shows they had concerns about confidentiality and did not want to share information with Mr and Mrs N that might relate to another patient. So, at this point they took a decision to withhold the information about the wound swab from J's parents. The evidence shows the Trust's head of service for cellular pathology was asked to investigate, with the intention that information would be shared with J's parents in the meeting scheduled for 22 July 2015. But this did not happen.

296. Instead, Mr N was only given an explanation for the wound swab after he raised the issue with the Trust in March 2016. At first Mr N said he was told the test was not carried out on J and had been 'mixed up' with another patient. But later the Trust said it thought the charcoal swab that appeared on the system as being requested, collected and received on 19

April was a re-request of an earlier sample, although it said it could not be certain of this. It said the swab had been taken from the site of J's peritoneal dialysis catheter (a soft plastic tube that had been inserted into J's abdomen so that doctors could remove waste products from his blood because his kidneys were not able to do so adequately) and in the laboratory the sample had not grown any organisms that might cause disease.

297. When pressed by Mr N the Trust investigated further. It acknowledged that 'confusingly' both the test request and subsequent result said the sample was collected at 8.24pm on 19 April 2015, but the Trust said it did not and would not have taken a sample from J in the Chapel of Rest after he died.

298. The Trust explained that a junior doctor had been contacted and they recalled that a charcoal swab was taken from J's catheter site and labelled before he died, but not sent to the laboratory. The sample was placed in J's medical notes. It said a nurse later asked the junior doctor what should be done with the sample. It said the medical team decided to send the sample for testing, as it might help to explain J's deterioration and subsequent cardiac arrest. The Trust said the request was processed at 8.24pm on 19 April and results reported by the laboratory at 10.10am on 22 April.

299. We recognise that the Trust has been unable to provide Mr N (and us) with definitive evidence to support its account and that given other things that have happened since J died, Mr N has a right to be suspicious of what the Trust has told him. Not least because the Trust's final explanation was only forthcoming after he had challenged its original explanations. However, we have seen the statement the junior doctor gave the Trust in April 2016 and we think that the Trust has provided Mr N with the most likely explanation - that is, the sample was collected before J died, not on 19 April, and the request to the laboratory was processed with the date it was sent and not the date it was taken. We accept though that we will never know precisely what happened.

300. The Trust was slow to provide Mr N with the most likely explanation for the timing of the sample. The investigations it carried out in April 2016 could have been done when Mr N first questioned the date of the sample. The Trust failed to provide complete and timely information.

The quality of the Trust's investigations and the honesty, accuracy and completeness of the information the Trust gave to Mr and Mrs N and the Coroner

301. Mr N makes a number of related complaints about what, when and how the Trust told them about J's pseudomonas infection and the events leading up to J's death. He says the Trust has continually failed to be open and honest. He suggests that the individual doctors and the Trust as a whole has conspired to cover up failings in J's care.

302. A number of the complaints Mr N put to us are, or relate to, indisputable facts about how the Trust has handled the family's concerns:

- when Mr and Mrs N were still in the hospital immediately after J's death, the staff caring for J did not take the opportunity to discuss J's care more fully with them. This included the suspicion of a secondary bacterial infection/sepsis and the outstanding test results for that (see also paragraph 194)
- J's death summary was not copied to Mr and Mrs N. The doctor writing the summary did not arrange for anyone to contact Mr and Mrs N to discuss the discovery of the pseudomonas infection
- it was 50 minutes into the meeting on 4 June 2015 (some seven weeks after J died) when the doctors who had cared for J first mentioned the pseudomonas infection
- during the meeting on 4 June 2015 the doctors said blood cultures had been taken on 16 April and had been reported as negative for bacterial infection the next day, when no cultures had been done
- at the subsequent meeting on 11 June 2015 the same doctors failed to put right this misinformation
- at a meeting on 22 July 2015, doctors spoke about J's care in a more open way during a break than when Mr and Mrs N were present. The doctors and the complaint manager then talked about deleting that section of the recording
- despite accepting J should have been given antibiotics sooner in October 2015, the Trust took until October 2017 to openly acknowledge that was material to J's death
- no root cause analysis or serious incident investigation was ever conducted into Mr and Mrs N's concerns about J's care
- the Trust's views changed over time as more evidence was presented by Mr and Mrs N. The evidence was given differing weight by the Trust and Trust staff (the Trust's report dated January 2017 describes this as development of thinking)
- the Trust did not take sufficient steps to ensure Mr and Mrs N were informed about its admission of liability before it was made public

303. For the reasons we set out below, we agree with Mr and Mrs N that the Trust has failed to be open and honest with them about the events surrounding J's death. It has done this to such a degree that it could be seen, as Mr N has, as a deliberate attempt to deceive. It is certainly a failure to meet with the values and rights set out in the NHS Constitution. We do not consider the Trust has accepted or acknowledged all the failings we have identified in this report in an open and clear way. It has failed to do that over a number of years.

304. We have set out below a brief summary of our findings in respect of the events as they happened chronologically.

305. During local resolution of the complaint, the Trust acknowledged that immediately after J's death it had failed to discuss J's care with Mr and Mrs N. The Trust said this was partly because of a change of staff on shift at the time J died, but it recognised this did not excuse the failing. Mr and Mrs N were not given the opportunity to be given the information they needed and wanted to know about J's care at this time.

306. This was a failure of Trust staff to act in accordance with the GMC's 'Good Medical Practice', Domain 3, paragraphs 32 and 33, which say patients should be given the information they need or want to know in a way they can understand. It says doctors should be sensitive and responsive in giving information and support.

307. It was also a failure to meet Mr and Mrs N's rights under the NHS Constitution. These include the right to information and support to make decisions about care and the right to an open and transparent relationship with the organisation.

308. The Trust sent a discharge summary to J's GP in which it acknowledged information had become available about J's death that Mr and Mrs N did not know about. The Trust made no effort to ensure Mr and Mrs N were specifically told about that, despite saying in the summary that they would be told about it. Again, this was a failure to act in accordance with the GMC's guidance and the NHS Constitution.

309. The Trust said its Palliative Liaison Care Nurse would normally contact bereaved parents two to three weeks after a child's death. It is unlikely Mr and Mrs N would have known the timescale for this contact. We have seen a statement from the Trust's Nurse that he tried to contact Mr and Mrs N after J's death (on 27 and 28 April, less than two weeks later) but was unsuccessful and left messages. This was after Mrs N had been to see her GP to request support on 27 April. It is not clear whether the contact was prompted by the GP, but in any event, it was within the Trust's stated timescale for contact. When the Nurse was unable to reach Mr and Mrs N, he contacted Mrs N's GP on 1 May. We note that in the meeting with the Trust on 22 July, Mrs N acknowledged she had had contact from the Nurse, but noted it was only after she had seen her GP. This accords with the Trust account.

310. However, while the Trust appear to have attempted contact in its usual way, there is no evidence any efforts were specifically made to ensure the particular information about the pseudomonas infection reached Mr and Mrs N as soon as possible even when contact was made. The Trust did not give this information to them in a 'timely' way. This was a failure to act in accordance with the Ombudsman's Principles of Good Administration. It was also a failure to engage with Mr and Mrs N in an open and transparent way as was their right under the NHS Constitution.

311. At the meeting on 4 June 2015, the doctors who had cared for J failed to give

Mr and Mrs N the information about the pseudomonas infection until 50 minutes into the meeting. The doctors then gave Mr and Mrs N incorrect information about how and when the pseudomonas infection was discovered. Specifically, the doctors said that they took a blood culture on 16 April, and it was negative. That did not happen.

312. During local resolution of the complaint, the Trust said the doctors made mistakes because they were speaking from memory. This does not excuse what happened. The doctors were aware before the meeting that they were going to have to give Mr and Mrs N new information about J's illness. The doctors were aware of Mr and Mrs N's right to openness and transparency. The GMC's guidance says doctors should give people the information they want and need. The doctors should have accessed sufficient information in order to be able to do that. The doctors failed to prepare well enough to give that information clearly, completely and accurately. They failed to give clear, evidence-based reasons for their decisions (that is, about testing for a bacterial infection). All this was a failure to act in accordance with the NHS Constitution, the GMC's guidance and the Ombudsman's Principles.

313. At the next meeting on 11 June 2015, the doctors had J's medical record, but failed to put right the incorrect information given on 4 June 2015. The reason the Trust gave during local resolution was that the doctor had not yet looked at the transcript of the meeting on 4 June and had not realised they had given incorrect information on 4 June. The doctor said Mr and Mrs N likewise had not appreciated the discrepancy until later looking at the transcripts. However, we would not expect Mr and Mrs N to have understood the significance of the incorrect information, whereas this should have been clear to the doctor.

314. We acknowledge the doctor's explanation, but it does not excuse the failing here. The reason for the second meeting was in part to discuss in more detail, and with more clarity, what had happened in respect of J's pseudomonas infection. The details of the investigations that had been done for a secondary bacterial infection and the point at which the infection was identified were clearly going to be key parts of that discussion. The doctors should have been prepared to be 'sensitive and responsive' in accordance with the GMC's guidance, and open and transparent in accordance with the NHS Constitution. That would include making sure that all information was clear and complete, given the importance of the issue. It would include being able to answer any questions about what Mr and Mrs N had been told in the meeting on 4 June. The doctor should also have been 'equipped and empowered' by the Trust to recognise that a mistake had been made earlier and put that right. The doctor's actions at this meeting were again a failure to act in accordance with the GMC's guidance, the NHS Constitution and the Ombudsman's Principles.

315. The child death review on 17 June 2015 concluded that J's pseudomonas infection was the most likely cause of J's deterioration on 17 April. However, because of a failure to properly record the BAL result in J's medical record, which was itself a failing (see paragraph 224), the child death review concluded the result (the positive pseudomonas infection) was

not known until after J's death. The child death review concluded J's death was the result of ARDS caused by hMPV and sepsis. It said it was unlikely that giving antibiotics any sooner would have made a difference because there were only clinical signs of sepsis syndrome on the afternoon of 17 April.

316. A further meeting was held with Mr and Mrs N on 22 July 2015 to discuss the child death review. By this time Mr and Mrs N were very concerned a bacterial infection could have explained some of J's symptoms as early as 14 April. At the meeting the doctor (who had chaired the child death review) failed to give Mr and Mrs N clear evidenced-based reasons for the Trust's decisions not to give antibiotics to J until 17 April (we have looked at the delay in giving antibiotics on 17 April in paragraphs 155 to 159).

317. During the Trust's subsequent investigations, the doctor said they did not feel empowered to discuss the issue because colleagues who cared for J were not at the meeting and they had not discussed it with them. The doctor should have known that Mr and Mrs N had been unhappy with the information they had been given at the previous two meetings by their colleagues and should have been fully prepared for this further meeting, but they were not. Nevertheless, their comments during a break in the meeting (Mr N has complained about this and we will look at his concerns in paragraph 320), and subsequent comments as part of the Trust's investigation of this issue show they thought antibiotics could have been given to J sooner than they were. One of the doctors at the meeting said during the break that they 'struggle[d] to see why [J] wasn't given antibiotics if on the Tuesday [14 April 2015] they've said if he gets worse give him antibiotics'.

318. The duty of candour requires organisations to be open and honest with patients as soon as possible after they realise something has gone wrong. Following the meeting of 22 July, particularly in combination with the findings of the child death review, the doctor apparently realised something may have gone wrong with J's care that had the potential to affect the outcome for him. We think at this point the Trust should have acted to provide open and transparent, clear and complete information to Mr and Mrs N about this.

319. The Trust had a responsibility to ensure its staff were properly equipped and empowered to acknowledge when things had gone wrong. It had a responsibility to ensure its staff were properly trained to deliver the duty of candour. It had a responsibility to ensure there were clear lines of authority and decision making to support staff. We have seen no evidence the Trust's staff took any action to meet its obligations to Mr and Mrs N at this time.

320. As outlined earlier, during the break in the meeting on 22 July the doctors continued to speak. They were more open and forthright in saying that J should have been given antibiotics sooner during this break than when Mr and Mrs N were present. The doctor who had chaired the child death review said they thought what they had said during the break could make things difficult and they asked a complaint manager if this part of the recording could be



deleted. The complaint manager agreed to do this. However, they then looked at Mr and Mrs N's device and discussed the fact they could not delete this section of Mr and Mrs N's recording without deleting the whole meeting. The recordings were subsequently not deleted, albeit the Trust's recording device was turned off. When Mr and Mrs N returned to the meeting, the complaints manager told them the conversation had continued during the break, but they were not told what was said. They only found that out by listening to the recording on their way home in their car.

321. The conversation staff had during the break raised a serious issue of probity and has justifiably brought the Trust into disrepute. The Trust did nothing about it until Mr and Mrs N complained. This was despite the doctor raising the matter with their managers. Even then, the Trust investigated this as a complaint under the limited scope of looking at whether the information given to Mr and Mrs N was contradictory to what was said in the break. The Trust only interviewed the doctor, not the complaint manager. It concluded the doctor had no intent to deceive. It did not consider the fundamental question of why the doctor had suggested deleting the recording and why the complaint manager had agreed to do so.

322. The Trust only investigated the matter under the maintaining high professional standards framework (The Department of Health introduced the Maintaining High Professional Standards in the NHS framework in 2003. It is used for investigating serious concerns about the conduct or capability of doctors) in December 2015 after Mr N had taken his concerns to the media. The doctor and the complaint manager were interviewed as part of that investigation (although the complaint manager would not have been subject to the MHPS procedure and had also by then retired). Mr and Mrs N were not given significantly more information after that investigation. The Trust maintained that there was no actual intent to delete the recording. The Trust did not provide a clear explanation as to why it reached this view. Mr and Mrs N clearly remained of the view the recording was not deleted only because the doctor and complaint manager did not know how to delete Mr and Mrs N's recording.

323. The Trust needed to explain its position. The doctor and complaint manager clearly did have an intent to delete the recording because they specifically discussed this and staff checked whether they could do this on Mr and Mrs N's device. There clearly was an intent to prevent Mr and Mrs N from hearing the information that was discussed, even though this was not followed through. The Trust did not explain why it thought this was acceptable. It did not explain why it accepted that the recording was not deleted because there was no real intent, rather than because the recording on Mr and Mrs N's phone could not be deleted. This is not in accordance with the Ombudsman's Principles, or the requirement to be open and transparent.

324. Following these meetings, we recognise the Trust took more actions to engage with Mr and Mrs N at a more senior level and to ensure independence and transparency in its responses. It did this by commissioning an independent investigation and using senior

clinicians not involved in J's care in other investigations and actions. In particular, the Trust commissioned an independent investigation by Verita into the Trust's handling of Mr and Mrs N's complaints about the meetings on 4, 11 June and 22 July 2015 and published it online. It subsequently engaged a senior clinician not involved in the events to help implement the action plan with Mr and Mrs N's involvement. This all shows more intent to be open and transparent. However, as we explain in paragraphs 325 to 329 we do not think all of the Trust's responses to that investigation were open and transparent enough.

325. Verita completed its investigation in June 2016. It concluded the Trust failed to grasp the severity of Mr and Mrs N's complaints. It said the Trust's investigations of their allegations were not good enough. It said the interviews with staff were not robust enough. The Trust had failed to investigate what Mr and Mrs N were asking. That included 'why' they had been given incorrect information. We agree with Verita's findings. The Trust also accepted them.

326. With regard to the meeting on 22 July Verita recommended (Recommendation 3) the Trust give Mr and Mrs N more information about its Maintaining High Professional Standards (MHPS) investigation. The Trust did not do that. The Trust said it could not release the report without the doctor's consent. This is right. However, as a result of both the investigations (the complaint investigation and the MHPS investigation) into this matter, the Trust could provide more information about what it found that led it to conclude there was no intent to deceive. The Trust could provide more information and explanation about why the doctor suggested deleting the recording, and the complaint manager agreed, if not to conceal information from Mr and Mrs N. It could explain why it accepted there was no intent when the only thing apparently preventing the recording being deleted was that Mr and Mrs N had left their recording running when they left the room and staff did not know how to delete this. Mr and Mrs N say the Trust has not complied with Verita's third recommendation. We agree. The Trust's explanations are not open and transparent, and it has not given clear explanations of its decisions.

327. During its investigations of this issue, the Trust appeared to recognise that more needed to be done to help staff be open and transparent in discussions with families. This is reflected in its subsequent updating of its policies. However, there is no evidence - certainly no information was given to Mr and Mrs N - about what analysis was done of the situation at the time. There was no consideration of how the Trust, as an organisation, had reached the point where, in three separate meetings and a child death review, members of staff had failed to act in accordance with the values in the NHS Constitution and potentially the duty of candour. This was a remarkable failing by the Trust to act in accordance with the principles of continuous improvement and learning from complaints, set out in the Ombudsman's Principles.

328. Verita's report further pointed out to the Trust that it had not determined how and why the situation had arisen whereby Mr and Mrs N had been given incorrect information in

the meetings of 4 and 11 June. It pointed out to the Trust that this situation needed to be resolved (as part of Recommendation 9). However, we have seen no evidence the Trust did this. We have seen no evidence the Trust considered from an organisational point of view how the situation had arisen. As Verita explained, the Trust simply retold the doctors' explanations.

329. Verita also recommended (Recommendation 1) the Trust tell Mr and Mrs N exactly which doctors saw the BAL result after it was available at around 4pm on 17 April. After this, the Trust did tell Mr and Mrs N it was a junior doctor who saw this and failed to record it in the notes. The Trust accepted it was a failing not to have made a record of the result. Mr and Mrs N do not accept this explanation. They say doctors should have checked the BAL result given J's deterioration on 17 April. We have looked at this issue in detail in paragraphs 223 to 237. We do not have evidence to show that anyone other than the junior doctor knew of the BAL result or that the Trust's explanation is therefore inadequate. We can say the doctors would have been able to tell Mr and Mrs N about the initial BAL result (which was available) had they spoken to them in more detail immediately after J's death and recognised that Mr and Mrs N would have wanted this information. We have already found the poor communication with Mr and Mrs N after J's death was a failing.

330. Following the meeting on 22 July 2015, the Trust was in position where there were clearly serious misgivings in some clinicians' minds about J's care and some evidence there may have been an omission in care that had contributed to his death. The doctors in that meeting were apparently of the view that antibiotics could have been given sooner (albeit their opinions may have differed as to when and whether this would have made a difference). The child death review had concluded that J's final deterioration was in keeping with sepsis. The meetings on 4 and 11 June and 22 July had also caused further complaints from Mr and Mrs N that brought the probity of the Trust into question.

331. The national Serious Incident Framework, 2015 defines a serious incident:

'in broad terms, serious incidents are events in health care where the potential for learning is so great, or the consequences to patients, families and carers, staff or organisations are so significant, that they warrant using additional resources to mount a comprehensive response. Serious incidents can extend beyond incidents which affect patients directly and include incidents which may indirectly impact patient safety or an organisation's ability to deliver ongoing healthcare'

332. The Framework says the types of incidents that may be considered as serious are ones where an omission or action caused or contributed to a death or serious harm. Serious incidents can also be incidents that have the potential to bring the organisation into disrepute - such as prolonged adverse media coverage. It says incidents can be identified from complaints. It says an initial review should be undertaken (within 72 hours) by a senior

clinician to determine if a serious incident has taken place and the level of response. An incident can be downgraded if it is later identified that the incident is not 'serious'.

333. The Framework says serious incidents can be investigated using the principles of root cause analysis and should aim to identify a root cause.

334. The situation that was known to the Trust after 22 July 2015 would seem to fall squarely within the definitions of an incident that requires a serious incident investigation. At the very least, the Trust should have asked a senior clinician to review the evidence. We think the Trust's failure to act at this point was a clear failing to adhere to the national Framework.

335. It took the Trust until October 2015 to acknowledge J could have been given antibiotics sooner than he was. At the time, the Trust had asked a senior doctor not previously involved in J's care to investigate Mr and Mrs N's concerns. In a meeting on 16 October 2015, the doctor nominated by the Trust to do the investigation acknowledged to Mr and Mrs N that that the time to start antibiotics would have been when the BAL was done. This is in keeping with the advice we received (paragraph 105). The doctor also acknowledged that J was probably developing an infection on the morning of 17 April (the Trust had also acknowledged this at the meeting on 22 July 2015). The doctor also said that giving J antibiotics sooner would have given him a 'better chance' (because the pseudomonas infection was sensitive to antibiotics). The doctor could not say if antibiotics would have stopped J from dying. The Trust's transcript of the October meeting says the doctor had spoken to 'many of' the staff who had treated J and they had 'changed their minds' (that is, they agreed) that they should have given J antibiotics. It says, 'Most of them have now said they would give antibiotics sooner'. However, Mr N's transcript shows that in the meeting the doctor said 'all' their colleagues had changed their minds. Mr N has told us that it was made clear to him in the meeting that all the doctors involved in J's care had been interviewed and that all had changed their minds.

336. In a follow up letter, the Trust again said it did not know if giving J antibiotics sooner would have saved his life, but it would have given J a better chance of surviving his illness. Despite this, the Trust did not identify a root cause of the failure to give antibiotics and Mr N understandably continues to believe it was complacency by the doctors caring for J as a result.

337. With regard to J's pneumopericardium, in the meeting on 16 October 2015 the doctor said the Trust 'could not say' whether the pneumopericardium caused J's cardiac arrest. The doctor said the first time it was possible to say J had a pneumopericardium was when the X-ray was done after J's first cardiac arrest. The doctor explained the pneumopericardium would have happened regardless of whether antibiotics were given and said the air leak was the 'major thing' that happened that day.

338. In its follow up letter to the October meeting, the Trust said J's pneumopericardium was a life-threatening event. This was despite telling Mr N in the meeting that J's first cardiac arrest could not be definitely linked to the pneumopericardium. Mr N understandably saw this as a change in emphasis from the meeting, as well as the child death review, which had appeared to him to largely identify sepsis in response to J's untreated infection as the cause of J's deterioration on 17 April. Mr N saw this as an attempt by the Trust to avoid liability for J's death and avoid acknowledging the significance of the delay in starting antibiotics. Below we will look at further contradictions Mr N has seen in what the Trust has said. We add here that a single serious incident investigation may have avoided these issues which in part arose from multiple investigations expressing a range of different opinions.

339. Mr N says that when giving evidence at the inquest the Trust's doctors failed to acknowledge J should have been given antibiotics sooner and focused on the pneumopericardium as the cause of his death. He says the opinions the doctors expressed were different to ones they had expressed in other meetings or correspondence. He says this is evidence of the Trust coaching staff to present a view that relieves it of its failure to give antibiotics. He says the Trust was trying to avoid saying the pseudomonas infection contributed to J's death.

340. It is clear from the quotes Mr N has provided that there are numerous places where he has been told different things. In particular, these relate to whether antibiotics should have been given sooner, whether J had sepsis and the significance and cause of J's pseudomonas infection, sepsis and pneumopericardium.

341. We have looked carefully at the evidence Mr N has referred to and the evidence given at the inquest. We can see that what Mr N has been told reflects the complexity and differing clinical opinions about the course of J's illness and sad death. This report also reflects that complexity and, in particular, identifies the following:

- blood tests should have been done more frequently to look for evidence of a secondary infection
- our advisers did not know whether antibiotics would have prevented J from dying
- the presence of pseudomonas was likely to have contributed to the progression of J's ARDS
- we do not know when J got pseudomonas, or its significance in the progression of J's ARDS because the first confirmation of pseudomonas was from the BAL taken on 16 April
- the child death review considered J's deterioration later on 17 April was probably due to sepsis (caused by pseudomonas), it considered ARDS caused by hMPV would 'rarely' cause death

- our advisers said J's prognosis was much worse once he was diagnosed with ARDS and that he had a much greater chance of dying from ARDS caused by hMPV than appears to have been recognised by the Trust or at the child death review
- our advisers said hMPV was the primary driver for J developing bronchiolitis and ARDS
- our advisers did not consider the pseudomonas infection or sepsis was necessary to understand J's cause of death and his deterioration on 17 April (which they said could be explained by the progression of ARDS caused by hMPV alone), but they commented that pseudomonas would have contributed to J's instability and the progression of ARDS. They said the blood culture results that became available later could not entirely be dismissed, and suggested pseudomonas could have been included at '1(c)' or '2' (factors contributory to, but not part of sequence of the cause of death) on the medical certificate of cause of death
- J's pneumopericardium was related to his ARDS (albeit a secondary bacterial infection may have worsened the progression of J's ARDS and affected the intensity of treatment he was receiving for it, which may contribute to a situation where a pneumopericardium is more likely)
- the pneumopericardium was only identified by X-ray after J had his first cardiac arrest soon after the administration of surfactant
- there are differing opinions as to when the pneumopericardium occurred and whether it occurred as a result of the effects of the surfactant and whether it caused his first cardiac arrest, and none can be verified because there is no evidence other than the X-ray evidence.

342. Given these findings, we can see there are a range of clinical views that could be expressed about the likely course of J's illness and death. These could be different and yet still tenable given the facts. J had a pseudomonas infection, as has been shown by test results at least from 16 April. However, as seen above, this does not exclude a clinical view that J's deterioration on 17 April was not due to sepsis syndrome. We have seen that one explanation for J's deterioration on that day was that it was caused by his ARDS, which in turn was caused by bronchiolitis caused by hMPV (albeit that the pseudomonas may have contributed to the progression of the ARDS). Similarly, the evidence and advice we have received does not preclude J's deterioration being due to sepsis, or a combination of sepsis and ARDS.

343. Looking at the evidence Mr N has provided, the range of opinions the Trust has given him (with different emphasis on sepsis and ARDS) would appear to fall within the boundaries of what we have found in this report. However, it is clear the Trust and the doctors caring for J have been inconsistent in what they said and have not clearly expressed the reasons for their opinions, any differences between them, or changes to them.

344. Mr N is particularly concerned about evidence the doctors gave at J's inquest in respect of the pseudomonas infection, antibiotics and the pneumopericardium.

345. First, Mr N says doctors at the inquest said that there were no significant indicators J had a bacterial infection. This is despite suggesting to Mr N as early as 14 April that J could have a bacterial infection, and repeating that they thought J might have a secondary bacterial infection in meetings after J's death. We have looked at this issue in detail in paragraphs 101 to 109. We do not think telling Mr and Mrs N that it was possible J could have a secondary bacterial infection meant the doctors caring for him actually thought he did.

346. Second, the Trust's doctors gave opinions that antibiotics may not have made a difference to the outcome for J (that is, prevented his death). They said this was because he developed sepsis so late on in his care, and because his pneumopericardium was more significant. Mr N points out this contradicts what he was told in the meeting on 16 October - that 'all' the doctors caring for J had concluded that they would give antibiotics if faced with a similar situation again and antibiotics 'would have given [J] a better chance'.

347. Third, doctors said at J's inquest that J's pneumopericardium happened before, and was the cause of, his first cardiac arrest. Mr N says this contradicts what he was told in the meeting on 16 October 2015, which was that it was not possible to say that J had the pneumopericardium before the X-ray, because the X-ray was the first evidence of it.

348. In the context of what the Trust said to Mr and Mrs N during meetings and what doctors said at the inquest, it is important to acknowledge the difference between fact and opinion. It is possible to form different clinical opinions on the basis of evidence, such as the X-ray that showed J had a pneumopericardium.

349. We can also see that at the inquest two doctors also reflected on what they had said previously and changed their thinking. That would have appeared contradictory to Mr N. However, the two doctors who changed their views were open about when they were changing their view and when they were expressing personal opinions. They recognised that the Trust had accepted antibiotics should have been given sooner.

350. It is clear from the evidence the doctors gave at inquest that telling Mr and Mrs N that all the doctors had changed their minds was not accurate and was misleading. This is not to say the doctors should not have changed their minds (this report has shown that our clinical advisers agreed with the view that antibiotics should have been given sooner), but there is not enough evidence they were presenting a different view at the inquest to one they had held before.

351. As such, while we acknowledge that the responses Mr N heard at the inquest contradicted what he had been told in other forums, we have not seen any evidence that this was a deliberate attempt by the Trust to mislead.

352. Had the Trust acted much sooner - as it should have - to properly investigate Mr and Mrs N's concerns and provide one comprehensive response that was in accordance with the Duty of Candour, the NHS Constitution, the Serious Incident Framework and the Ombudsman's Principles, Mr and Mrs N's experience of the inquest may well have been different.

353. In January 2017, to comply with Verita's Recommendation 9, the Trust sent Mr and Mrs N a report to address all their outstanding concerns.

354. The report acknowledged it may have appeared to Mr and Mrs N that the Trust had given them conflicting information about the cause of J's death. The report concluded that the Trust had been consistent that J's death was caused by a combination of ARDS caused by hMPV, the pneumopericardium - which was itself related to the condition of J's lungs caused by the ARDS - and the pseudomonas infection. It said the weighting given to these factors was considered differently by different clinicians.

355. To some extent, we agree with the Trust that there were a number of factors in J's death which different clinicians have weighed differently. Our own clinical advisers differ in their views of the weighting of these factors in J's death.

356. Nevertheless, the Trust should have reached a clear view on what had gone wrong and the effect of this on J's care and outcome. It did not do that - it presented a range of views from its clinicians. If it was not possible to reach a clear view because of the range of valid clinical opinions, the Trust should have clearly explained the position it had reached, and why, to Mr and Mrs N. That explanation should have included what weight it was giving to what view and why. This would have been in accordance with the Ombudsman's Principles. We have seen no evidence it did that.

357. Notably, the January 2017 report said the Trust could have been more open in response to Mr and Mrs N's concerns about J's pneumopericardium and its cause. However, it did not put this right. While the report recognised that there were always risks that had to be balanced in the giving of surfactant (which may cause an air leak) it stopped short of providing any comment on whether it considered that decision to be the right one in J's case.

358. From the evidence we have seen, it does not appear that the Trust presented a clear view on the decision to give J surfactant on 17 April 2015, or how it thought this related to J's pneumopericardium. This was a central part of Mr N's complaint, given that the Trust appeared to have placed more weight on the pneumopericardium as the cause of J's death. Again, this was a further failure to act in accordance with the guidance to give clear explanations and reasons for decisions and act with openness and transparency.

359. The Trust appears to have again failed to give clear explanations for its admission of liability, issued in October 2017. In that admission the Trust said there were a range of views



about when antibiotics should have been prescribed. But the Trust has failed to provide an explanation of, or give reasons for, this statement, despite Mr N asking for it. The Trust has cited legal privilege as the reason for not providing this information. We do not agree legal privilege prevents the Trust from giving Mr and Mrs N clear explanations and reasons for its statement.

360. The Trust also failed to ensure Mr and Mrs N had received and read its admission of liability before it was published. This was not in accordance with the value of 'compassion' set out in the NHS Constitution.

361. We recognise that Mr N believes there was an ulterior motive for these failings. He believes that the Trust was conspiring to cover up an error, or errors, in J's care.

362. We do not have sufficient evidence to show the Trust conspired to cover up errors in J's care. However, as we have explained above, at an organisational level the Trust completely failed Mr and Mrs N. Subsequently, we have seen no evidence of a robust analysis by the Trust as to how this situation has arisen.

363. The guidance on complaints, duty of candour and serious incidents is clear that being open and transparent and learning from incidents and complaints is an integral part of patient safety. We acknowledge the Trust has taken some steps to improve its investigations into incidents as well as its communication with bereaved parents. However, we have seen no evidence that it has fully grasped why these events happened as they did. There is no explanation from the Trust about why there was such a universal failure to be open and transparent with Mr and Mrs N. It is therefore impossible to know whether the steps taken by the Trust will prevent the same things from happening again.

### Injustice

364. Each one of the failings we have found in respect of how the Trust engaged with Mr and Mrs N after J's death will have had a significant impact on them.

365. The Trust's failure to consider a post-mortem for J, or talk to Mr and Mrs N about it, has meant that Mr and Mrs N will never have the answers they are looking for about J's death and the reasons for it. It is possible a post-mortem may not have given them all the answers they were looking for. However, in that situation, they would at least have the comfort of knowing all there was to know about J's illness and the cause of his death. Not to have this knowledge is clearly a significant injustice that will stay with them for the rest of their lives. The lack of this knowledge has also contributed to their need to engage and complain to the Trust to obtain answers. It has contributed to their distrust of the Trust and of what they are being told. It has therefore affected their ability to live a relatively normal life for at least the period of their complaint.

366. Similarly, the Trust's failure to engage with Mr and Mrs N immediately after J's death and to provide them with all the information it had about the course of J's illness had a significant and lasting impact on them. It meant Mr and Mrs N lost the opportunity for a post-mortem at any stage because they chose to have J cremated.

Mr N has described these two concerns as 'the most irreversible of all failings. We agree. The impact of these failings has had far reaching consequences for Mr and Mrs N. Mr N says that these failings have had the most impact on their mental health and, alone, is one of the reasons he does not think he and Mrs N will recover from J's death.

367. In its own way, each one of the other failings we have found here prevented Mr and Mrs N from understanding what happened to J and why. Mr N told us that losing their son had been the most devastating time he and Mrs N had ever experienced and the Trust's failure to provide open and accountable responses over an extended period of time has caused him and his family significant distress, as well as inconvenience. We recognise that the failings we have identified, which, as Mr N has pointed out extended over a number of years, can only have exacerbated his and Mrs N's bereavement and prevented them from being able to move forward.

368. We cannot easily estimate the psychological impact on Mr and Mrs N. But Mr N has told us that his family has not been able to move on and Mrs N, in particular, has not been able to return to a normal life. We can see that having to pursue the Trust for answers to their questions over such an extended period is likely to have caused significant additional distress for Mr and Mrs N, as well as inconvenience. These are all significant injustices to them.

## Recommendations

369. In considering our recommendations, we have referred to our Principles for Remedy. These state that where poor service or maladministration has led to injustice or hardship, the organisation responsible should take steps to put things right.

370. *Our Principles* say that public organisations should seek continuous improvement and should use the lessons learnt from complaints to ensure they do not repeat maladministration or poor service.

371. As a result of Mr N's complaint, the Trust agreed to make a number of improvements to its services. Those included:

- a new temperature policy for PICU
- new guidance for the use of surfactant

- improvements to staff checklists to ensure hospital post-mortems are routinely offered to parents
- improvements in bereavement services, and
- improvements to the way in which staff prepare and respond to complaints.

372. The Trust also said its staff were now more aware of the risks to babies, like J, with hMPV.

373. However, this report draws out multiple failings to communicate well with Mr and Mrs N about the risks to J and about his care. It highlights broad issues of the empowerment and preparedness of staff in responding to concerns and issues. It shows there were problems with openness and transparency within the Trust at this time.

374. This report also identifies failings in aspects of J's care that the Trust had not acknowledged.

375. The Trust has taken some steps to improve its services in response to Mr N's complaint.

376. However, there has been no comprehensive analysis of how Mr and Mrs N's experience with the Trust - both during the time J was a patient, and after - became so poor. Despite the actions the Trust has taken, the Trust has not demonstrated that it fully understood what went wrong or that it was able to learn from this complaint.

377. Mr N's 'is seeking improvements in the care and treatment the Trust provides and more openness and accountability in the way it handles serious concerns about patient safety'.

378. It is now six years since J was a patient at the Trust. In that time, there have been a number of national initiatives relating to patient safety and the transformation of culture within the NHS.

379. We have looked at the most recent CQC inspection report. This report is for the Bristol Royal Infirmary Main Site but includes the women's and children's division. The Children's Hospital is not inspected separately. This report is an indicator that the service is generally operating appropriately and is reassuring in respect of many of the issues Mr N raises, such as communication and the response to issues of patient safety.

380. However, we recognise that Mr N has received no assurance about what exactly the Trust has done or about the improvements it has made.

381. We therefore recommend the Trust puts the improvements it has made into context by writing to Mr N and us, within three months of this report, with:

- details of the patient care and safety, and complaint handling initiatives that have taken place since the time of J's care that specifically relate to the failings we have found.

382. The Trust should explain what has been done and the known outcomes of that work. The Trust should provide enough detail to provide reassurance that the failings we have identified in this report would be unlikely to happen now.

383. The Trust should develop an action plan if there are any issues identified through this report that have not already been addressed.

384. The Trust should also write to Mr N within one month of this report:

- to acknowledge it accepts the findings of our report.

385. The Trust should send us a copy of its letter to Mr N.

## Parliamentary and Health Service Ombudsman

Citygate  
Mosley Street  
Manchester  
M2 3HQ  
United Kingdom

Telephone: 0345 015 4033

Textphone: 0300 061 4298

Fax: 0300 061 4000

Email: [phso.enquiries@ombudsman.org.uk](mailto:phso.enquiries@ombudsman.org.uk)

[www.ombudsman.org.uk](http://www.ombudsman.org.uk)

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