Chairman's Statement – 31st January 2018

I welcome everyone here today for the launch of the report of the Inquiry into hyponatremia related deaths. Thank you for coming this afternoon. I realise that it has already been a long day for those of you who have been reading the report since early this morning. It will have made difficult and emotional reading for many of you. The report is very long, extending to three volumes. Nobody will have had time to read it in full this morning. I encourage you to do so when you have more time and feel able to complete your reading.

It is usual for reports such as this to have an executive summary of some sort. However the range of issues which we covered and the complexity of those issues made it impossible to draw up a summary. We experimented with the idea but in order to be accurate and fair the summary became longer and longer, thereby defeating the point of a summary in the first place. That being the position I want to take this opportunity to draw out some of the main findings of the report:

- The death of Adam Strain was avoidable.
- The death of Claire Roberts was avoidable.
- The death of Raychel Ferguson was avoidable.
- The evidence given in Banbridge showed conclusively that all three of these children received medical care which fell far below acceptable standards.
- The death of each child was the direct result of that negligent care.

If that was the total learning from the Inquiry it would be important in its own right. But what we learned is much greater and unfortunately much worse than the fact of Adam's, Claire's and Raychel's deaths. In the next part of this statement I will deal with each child in turn.

Adam Strain

Adam was four years old when he died in the Royal Belfast Hospital for Sick Children in 1995. In Adam's case we learned that it was recognised almost immediately that he had died from hyponatremia. We also learned that Adam's mother wasn't told that fact. We further learned that there was a failure to confront that issue within the Children's Hospital and with the paediatric anaesthetist whose

mistakes were so obvious. And we learned that there was a failure to assist the Coroner because those involved in Adam's treatment did not fully disclose to him what they knew and what they believed.
A major element of the Coroner's role, in addition to identifying the cause of death is to consider if action might be taken to prevent further deaths. As the report makes clear, the Coroner was led to believe that in future all anaesthetic staff would be made aware of the complications of hyponatremia and advised to act appropriately. That did not happen, even in the Children's Hospital never mind beyond. Instead the lessons which could have been learned and shared from Adam's death were neither learned nor shared.

Let me make one final point about Adam if I may – even after all the written and oral evidence I do not know the full story of what happened in the operating theatre. My belief is that evidence was withheld about what happened there. That is shocking.

Claire Roberts

Claire was nine years old when she died in the Royal Belfast Hospital for Sick Children in 1996. The Inquiry scrutiny of Claire's death came about despite the efforts of some doctors in the Children's Hospital, not because of them.

My conclusions about Claire's death are clear. Mr and Mrs Roberts were deliberately misled when they were told she had received good care. The fact that her death was not referred immediately to the Coroner for an inquest is indefensible. And it is not just indefensible with hindsight – it was indefensible at the time. The reason for not referring Claire's death to the Coroner was to avoid scrutiny of the negligent care which he had received – in effect a cover up by the two consultants who Mr and Mrs Roberts spoke to on 23 October 1996 when she died.

Even after they saw the UTV documentary in 2004 and contacted the Children's Hospital, efforts to avoid the truth continued. Some of the information given to them was inaccurate, evasive and unreliable. At the inquest in May 2006, nearly ten years after her death, efforts to minimise or deny failings in Claire's care continued. And the effort to protect the Trust's interests and reputation rather than learning lessons was apparent again. That was the position even after this Inquiry had been established.

Lucy Crawford

Lucy was 1½ years old when she died in April 2000. While she died in the Children's Hospital the critical treatment which she received was in the Erne Hospital.
As most of you know Lucy's parents withdrew from the Inquiry in 2008. This changed the scope of the investigation which focused on what happened after her

death because that was potentially relevant to the treatment which Raychel Ferguson received in Altnagelvin in June 2001.

What we learned from this part of the Inquiry is depressingly familiar:

- The cause of Lucy's death was discernible with very little effort.
- Her death was avoidable.
- Her parents were not told the truth about her death.
- An investigation was at least initiated by the then Sperrin Lakeland Trust but it failed to report what was and should have been obvious.
- There was a lack of professionalism and more importantly a lack of candour on the part of many of those who should have assisted the investigation and help it reach the only conclusion possible.
- The Crawfords were excluded from playing any role in any of the investigations which considered Lucy's death.
- The cause of Lucy's death was not just identifiable in the Erne Hospital but also in the Children's Hospital.
- There was a failure to be honest with the Crawfords in the Children's Hospital as well as at the Erne.
- There was a failure to report Lucy's death to the Coroner in the way in which it should have been reported. Such report as was made was hopelessly incomplete.
- The death certificate issued in 2000 was wrong, illogical and simply made no sense – it was in effect medical gibberish.
- Lucy's death only went to the Coroner after Raychel's death and inquest because of the alertness of the late Mr Stanley Millar.
- No lessons were learnt from Lucy's death.
- Lessons could have been learned which may have affected Raychel's care.
- The inter-play between Sperrin Lakeland Trust and the Western Health and Social Services Board was inadequate. It might have led to lessons being learned but so far as we know at the moment it was allowed to fade away.

Raychel Ferguson

Raychel was nine years old when she died in June 2001. Although she died in the Children's Hospital in Belfast the critical treatment she received was in Altnagelvin Hospital.

By the time Raychel was admitted to Altnagelvin in June 2001 no lessons had been learned from the deaths of Adam, Claire or Lucy.

What happened after Raychel's death was different from the others and to a degree better. A critical incident review was conducted within Altnagelvin which led to

failings being identified and steps being taken to improve the level of care. In addition Raychel's death was reported to the Coroner. More significantly as it turned out it was reported to the Department of Health. This led to the establishment of a Departmental Working Party and to the introduction of very good guidance on hyponatremia and how to avoid it.

But, and it is a huge but, none of this information was shared with the Fergusons. Even when Mrs Ferguson and her sister met the Chief Executive and others on 3 September 2001 at the hospital the meeting was handled appallingly. No sincere effort was made to answer Mrs Ferguson's questions. The hospital representatives knew much more than they were prepared to share.

Remember – Raychel's death had already been reported to the Coroner and to the Department and failings in her care had been identified. Yet even then at a face to face meeting the truth was denied to the Fergusons.

How much anguish, anger and frustration would the Fergusons and the other families have been saved if they had just been told the truth from the start?

The truth is not very difficult. It involves four points:

- We made mistakes in the care we gave to your child.
- We are very sorry.
- We are determined that will not happen again.
- This is what we are going to do better in future.

Raychel's inquest then featured some of the same features as I have already referred to. There was an unwarranted and factually wrong challenge to the expert evidence of the Coroner's expert Dr Sumner. There was an intention to resist criticism on the basis that standard practices and procedures were followed when they were not. There was the withholding of expert medical evidence obtained by Altnagelvin which confirmed that the care given to her was inadequate. Accordingly an effort was made to mislead the Coroner.

The length of the chapters in the report shows how much more I have to say about the circumstances of each child. Again I urge you to read those chapters – they gave a much fuller picture than I can possibly can in speaking to you today.

Let me move on - I have already referred to the Hyponatremia Guidance issued by the Department in March 2002. That guidance was prompted by the report of Raychel's death. It is an example of the system working well – of a terrible case of a

child's death leading to meaningful central action. I credit everyone involved for making that happen.

But isn't that what should have happened much earlier? The frustration here is that the authorities showed that they can respond, and respond well. That is what we all want and need but we need it to happen earlier and more effectively so as to protect more children.

At this point I turn to Conor Mitchell. Conor Mitchel was 15 when he was treated in Craigavon Area Hospital in May 2003. He did not die from hyponatremia but he died after the guidance was issued by the Department. There were some concerns about the fluid management in Conor's case so the care which he received was added to the work of the Inquiry to test the way in which the guidance was followed just over a year after it had been issued.

This segment of the hearing was shortened because the Trust conceded that the guidance was not followed. Inevitably I criticise the Trust for that. However the Trust's admission to the Inquiry was welcomed by the Mitchell family and led to some better and positive exchanges which are reflected in Chapter 6 of the report. In addition there is evidence that in Craigavon sincere efforts have been made and steps taken to improve procedures and standards.

The Department

What then of the Department itself? The answer emerged quickly and was conceded by the Department at the hearing – the Department simply had no system in place for knowing what was going on in its hospitals.

How did this come about? The answer is that when the Health Service was reorganised in the early 1990s and Trusts were established, no requirement was imposed on those new Trusts to report deaths or other serious incidents to the Department. That was a huge mistake. Senior departmental witnesses said that they would have expected to be told about all of these deaths. They weren't but they should have realised that they were not being kept informed because our Health Service could not possibly have been operating so well.

As Chapter 7 shows I credit the Department for its work on the guidance, the first such guidance in the United Kingdom. However, I go on to criticise the then Chief Medical Officer Dr Campbell for her responses to the media and particularly to Ulster Television when its programmes exposed the hyponatremia issue. She was inaccurate, defensive, evasive and complacent.

Final remarks

Is there any reason to be more optimistic today? In November 2013 I heard evidence about current practices in the Health Service. The point of that evidence was to test the line which I had heard repeatedly that things were by then much better than they had been between 1995 and 2001. That evidence showed some signs of improvement but such improvement as there was was inconsistent and patchy.

Chapter 8 of the report sets out further steps which have been taken since 2013. If those measures are followed and enforced they will bring important positive change but the Department, the Health and Social Care Board and the other statutory bodies must be vigilant. The unfortunate lesson from this Inquiry is that not all doctors and managers can be trusted or relied on to do the right thing at the right time.

I do not believe that all doctors and managers behave so inadequately, evasively, dishonestly and ineptly as some of those who featured in this Inquiry. We all know that is not the case. There will be many people working in the Health Service who will be dismayed and angered by what came out in the course of the Inquiry. They will feel let down and they will be right to feel let down.

The Health Service has to improve so that when mistakes are made they are faced up to and the families are told. That already happens with good doctors and good managers. It must happen in all cases. That is why in Chapter 9 of the report my first recommendation is that as a matter of urgency a statutory duty of candour should be introduced. This would impose an obligation to tell patients or their families about major failings and to give a full and honest explanation of what has happened. There are 96 recommendations but that is the key one.

I want to finish this statement by making four final points:

(1) This Inquiry was established as a health inquiry under health legislation. My remit does not extend to coroners, but I welcomed and was grateful for the input and experience of Mr John Leckey who was the Senior Coroner for Northern Ireland until his retirement. He took the time and trouble to come to Banbridge and gave significant evidence.

I am sending this report to Mrs Justice Keegan who is now the Head of the Coronial Service because there are lessons to be learned by coroners. My fundamental concern is this – the evidence we gathered shows that on some occasions, the ones we looked at, some doctors and managers worked against the principles behind inquests rather than with them. It is time the medical profession and health service managers stopped putting their own reputations and interests first and put the public interest first instead.

(2) The same applies to litigation. No parent benefits significantly from suing a Trust over the death of a child. Financial compensation is limited. The cases brought against the Trusts in the deaths which I have examined were open and shut. But instead of accepting that, the Trust aggravated the parents' grief with denials of liability and efforts to impose confidentiality clauses. In these cases those responses were unwarranted and inappropriate.

(3) I urge doctors, nurses and managers to do three things:

(i) Listen to parents
(ii) Talk to parents
(iii) Tell them the truth

(4) In Banbridge on 30 August 2013 Altnagelvin fully and publicly accepted its responsibility for Raychel's death. In October 2013 the Belfast Trust followed by accepting fully responsibility for the deaths of Adam and Claire. And in a more limited context the Southern Trust apologised for the failings revealed in Conor's case.

I cannot imagine how the families felt in hearing those apologies. I understand they were welcomed but they would have been more valuable and more meaningful if they had not been extracted by a long inquiry after extensive questioning of witnesses who in some cases had to have the truth dragged out of them.

Inquiries do not and cannot happen all the time. Often they take too long and cost too much. And they demand of families the resolution and dignity in pursuit of the truth which the families in this Inquiry have shown. None of that should be necessary. If patients and families are told the truth inquiries will be largely unnecessary. The ordeals which these families endured must be avoided in future. The responsibility for that lies with everyone in the Health Service from the top to the bottom.