REVISED LIST OF ISSUES

The Revised Terms of Reference and the Chairman's exercise of his discretion require an investigation into:

- (a) The care and treatment of Adam Strain, Claire Roberts¹ and Raychel Ferguson, especially in relation to the management of fluid balance and the choice and administration of intravenous fluids
- (b) The circumstances of the death of Conor Mitchell² in the context of the guidelines on fluid management in children
- (c) The actions of the statutory authorities, other organisations and responsible individuals concerned in the procedures, investigations and events which followed the deaths of:
 - (i) Adam Strain
 - (ii) Claire Roberts
 - (iii) Lucy Crawford³ (especially in relation to the failure to identify the correct cause of death and the alleged Sperrin Lakeland cover up)
 - (iv) Raychel Ferguson
 - (v) Conor Mitchell⁴ (especially in relation to the guidelines on fluid management in children)
- (d) The communications with and explanations given to the respective families and others by the relevant authorities
- (e) Recommendations to the Northern Ireland Department of Health, Social Services and Public Safety

Chairman's announcement at the Public Hearing on 30th May 2008, p.4

² Chairman's announcement at the Public Hearing on 30th May 2008, pgs.4-5

³ Chairman's announcement by letter dated 4th February 2010

⁴ Chairman's announcement at the Public Hearing on 30th May 2008, p.5

DEATHS OF ADAM, CLAIRE, RAYCHEL & CONOR

1. ADAM STRAIN

- 1.1. Investigation into the relevance of the care and treatment that Adam Strain received at the Royal Belfast Hospital for Sick Children (RBHSC) prior to 26th November 1995 for his transplant surgery: including:
 - (1) Extent to which the information in Adam's medical notes and records relating to his prior surgical procedures should have informed the preparation for and the execution of his transplant surgery
 - (2) The course of action that should have been taken following consideration of that information and the significance of it in terms of:
 - (a) Plans for Adam's intraoperative fluid management
 - (b) How and where the transplant surgery would be carried out
- 1.2. Investigation into the care and treatment that Adam received on 26th, 27th and 28th November 1995, especially in relation to the management of his fluid and electrolyte balance, including:
 - (1) Identifying the persons responsible for the monitoring and maintenance of Adam's fluid and electrolyte balance:
 - (a) Before his transplant surgery
 - (b) During his transplant surgery
 - (2) The knowledge and understanding of the transplant team of Adam's polyuric renal failure and the extent to which this ought to have been and was actually taken into account in Adam's fluid management.
 - (3) The underlying principles, the calculations, and the assumptions made, in relation to the prescription of intravenous fluids, before, during and after the transplant surgery, in terms of the:
 - (a) Content of the fluids
 - (b) Infusion rate of the fluids administered
 - (4) Monitoring, recording and the management of the actual intravenous and enteral (via gastrostomy) fluids administered to Adam preoperatively, in terms of the content, infusion rate and total amount given.

- (5) Monitoring, recording and the management of the actual fluids administered to Adam while he was anaesthetised in terms of the content, infusion rate and total amount given
- (6) Monitoring, recording and the management of Adam's serum sodium concentration before and during his transplant surgery, including:
 - (a) the availability, accuracy and/or use of equipment and facilities to measure serum sodium concentration
 - (b) the staff and time required to arrange and carry out that measurement
 - (c) the availability, accuracy and/or use of:
 - (i) Out of hours pre-operative electrolyte checks
 - (ii) Near-patient electrolyte checks in theatre
 - (iii) Blood gas analyser electrolyte tests
 - (iv) Laboratory tests of electrolytes during surgery
 - (d) Significance of those tests (or of the absence of them) for the conduct of Adam's preoperative and/or intraoperative fluid management
- (7) Procedures, protocols and/or practices governing paediatric renal transplant surgery at the RBHSC, their adequacy and whether they were followed
- (8) The decision to accept the donor kidney for Adam and to confirm the surgery is proceeding, including factors such as:
 - (a) Size of the kidney
 - (b) Quality of the match
 - (c) Damage to the kidney
 - (d) Ischaemic time of the kidney
 - (e) Any other characteristics
- (9) The characteristics and condition of the donor kidney at the time of the transplant and its significance, if any, to the calculation, monitoring and management of Adam's fluid balance during and after surgery and to the success of the transplant
- (10) The pre-operative examination, tests, checks and assessment of Adam and the donor kidney including those that:

- (a) Were required to be done
- (b) It would have been prudent to carry out
- (c) Were actually done
- (11) The surgical technique used in Adam's surgery, its execution and the appropriateness of its use given:
 - (a) Adam's age and size
 - (b) Adam's past surgical history
 - (c) The condition and size of the donor kidney
- (12) Monitoring, recording and the management of Adam's central venous pressure during the transplant operation and:
 - (a) The reason(s) for the initial value of 17 mmHg and the subsequent higher values
 - (b) The response of the clinicians to the readings displayed on the monitor(s)
 - (c) The course of action that should have been taken in response to those values and the significance of it for the future conduct of Adam's intraoperative fluid management.
 - (d) The significance of the observations made and reported of the 'cardiac and respiratory waveforms.'
- (13) Ascertaining whether Adam's left internal jugular vein was 'tied off' and if so the significance of that, if any, for the accurate monitoring of his central venous pressure and the management of his fluid balance
- (14) The extent to which the serum sodium value of 123 mmol/L measured during surgery at 0932 by the IL Blood Gas Analyser, model 1400, serial no. 89070125 was accurate and could be used to manage Adam's fluid regime during surgery:
 - (a) The course of action it should have prompted, including the options open to the anaesthetist(s) at that time
 - (b) The likely effect of that course of action if different to that which was actually taken
- (15) Investigating when the anaesthetists in the RBHSC should have diagnosed Adam's hyponatraemia, together with:
 - (a) The course of action that they should have taken at that time

- (b) The likely effect of that course of action if different to that which was actually taken
- (16) Relationship between the roles of medical staff and nurses on the ward and in surgery and the communication of information between medical staff and/or nurses, and the record thereof.
- 1.3. Investigation into the quality of the information on Adam provided to and received from Adam's next of kin from when the possibility of placing of Adam on the renal transplant list arose in 1994 until the announcement of the Inquiry in 2004
 - (1) How the medical personnel gathered information from Adam's mother in relation to his health, treatment and her concerns prior to the transplant and how they used that information in the planning of Adam's treatment.
 - (2) Information provided to the next of kin about Adam's condition, the transplant procedure and the prognosis for his recovery:
 - (a) At the time of placing Adam on the renal transplant list
 - (b) Prior to accepting the offer of the donor kidney
 - (c) Prior to gaining written consent from Adam's mother
 - (d) Prior to confirming that his transplant surgery was to proceed
 - (e) During his surgery
 - (f) Immediately after his surgery
 - (g) Prior to and following the carrying out of brain stem death tests

How the information provided to Adam's next of kin contributed to the consent process.

- (3) Those who should have and those who did:
 - (a) Provide information to Adam's next of kin for the purposes of consent
 - (b) Take the consent for Adam's transplant surgery.
- (4) Applicable guidelines and RBHSC procedures on the process of gaining consent and the extent to which they were adhered to
- (5) Existence of guidelines and RBHSC procedures or practices on the provision of information to the next of kin of paediatric patients:

- (a) Generally
- (b) When they become critically ill
- (c) When an unexpected death occurs
- (6) Extent to which the information actually provided to Adam's next of kin followed the guidelines, procedures or practices
- (7) Information provided after Adam's death on the cause of his death and the lessons learned from it
- 1.4. Investigation into the experience of the transplant team including surgeons, anaesthetists and nurses.
 - (1) Information relating to the relative experience of the transplant team in:
 - (a) Adult renal transplant surgery
 - (b) Paediatric renal transplant surgery
 - (2) Information relating to the experience of RBHSC as a paediatric renal transplant centre relative to other UK centres
- 1.5. Investigation into the extent to which the care and treatment provided to Adam and his family was consistent with guidance provided by the Department of Health and other professional bodies at the time.
- 1.6. Investigation into the teaching / training in Northern Ireland on fluid management (in particular hyponatraemia) and record keeping that was provided in the 20 years immediately prior to Adam's death (i.e. 1975 1995) to medical students and student nurses as part of their qualification and to doctors and nurses as part of their induction, training and continuous professional development
 - (1) Extent to which fluid management (in particular hyponatraemia) and record keeping were covered in their teaching/training
 - (2) Extent to which the care and treatment that Adam received was consistent with the then teaching/training on fluid management (in particular hyponatraemia) and record keeping
 - (3) Extent to which any deficiencies in teaching/training played a role in Adam's death
 - (4) How the teaching/training in Northern Ireland at that time compared with the rest of the UK
 - (5) If there were any changes in the teaching / training on fluid management (and in particular hyponatraemia) and record

keeping in Northern Ireland between Adam's death and 23rd October 1996, when did those changes occur and for what reason.

- 1.7. Investigation into the procedures and practices that existed in Northern Ireland at the time of Adam's death for the reporting and dissemination of information to the Department of Health, Social Services and Public Safety of Northern Ireland (DHSSPS) and the medical community in general, of unexpected deaths in Hospital and outcomes of Coroners' Inquests
 - (1) Respective roles in reporting, analysing and disseminating information on unexpected deaths and ensuring that any lessons learned feed into teaching/training and patient care of the:
 - (a) Hospital in which an unexpected death occurs
 - (b) Treating clinicians (both doctors and nurses)
 - (c) Trust
 - (d) Area Board
 - (e) DHSSPS including the Chief Medical Officer
 - (2) Respective roles in reporting, analysing and disseminating information from a Coroner's Inquest on an unexpected death in a Hospital and ensuring that any lessons learned feed into teaching/training and patient care of the
 - (a) Hospital in which an unexpected death occurs
 - (b) Treating clinicians (both doctors and nurses)
 - (c) Trust
 - (d) Area Board
 - (e) DHSSPS including the Chief Medical Officer
 - (3) Existence of procedures, protocols and/or practices to ensure the fulfilling of the roles relating to reporting, analysing, disseminating information on unexpected deaths and the outcomes of Coroners' Inquests, and to ensure that any lessons learned are fed into teaching/training and patient care
 - (a) The extent to which these procedures, protocols and/or practices were consistent with guidance in both Northern Ireland and the UK at the time.
- 1.8. Investigation into the information that was actually provided to the DHSSPS and the medical community in general on Adam's death in

1995 and the lessons that emerged from the Coroners' Inquest into it in 1996

- (1) Content and quality of the information on Adam's death and the Inquest into his death that was disseminated within the Hospital in which he was treated and to the other parts of the Northern Ireland Health and Social Services
- (2) Existence of any procedures or policies within the hospital, other parts of the Northern Ireland Health and Social Services and the coronial system for the dissemination of information on deaths in hospital to ensure that lessons learned were implemented.
- (3) Process by which (including when, by whom and to whom) the information on Adam's death and the Inquest into his death was disseminated within the Hospital in which he was treated and to the other parts of the Northern Ireland Health and Social Services
- (4) Extent to which any dissemination of information on Adam's death and the Inquest into his death followed the procedures or practices that were in place at the time
- (5) Extent to which any inadequacies in the dissemination of information on Adam's death and the Inquest into his death constituted a systems or a human error
- (6) Extent to which the Coroner made any recommendation to HPSS organisations in NI following the Inquest and the extent to which the Coroner followed up what action had been taken and what lessons were learned.
- 1.9. Investigation into what action was taken by the hospital or DHSSPS following the clinical negligence action which commenced on 25the April 1996 and which was settled on 29th April 1997.
 - (1) The extent to which this litigation contributed to the difficulty of a clear explanation being given to next-of-kin concerning the reasons for Adam's death.
 - (2) The extent to which professional staff, involved in Adam's care, were appraised following the outcome of the clinical negligence case.
 - (3) The reason for the confidentiality clause in the settlement of the civil claim brought by Adam's mother and the impact, if any, which this had on lessons learned.

2. CLAIRE ROBERTS

- 2.1. Investigation into relevance of the medical notes and records from the Ulster Hospital and the RBHSC on Claire Roberts prior to her presentation to the RBHSC on 21st October 1996:
 - (1) Extent to which the information in Claire's medical notes and records relating to her epilepsy, 'fits', 'seizures', concerns relating to her behaviour and attention, and the medication prescribed was relevant to her diagnosis and treatment at the RBHSC from 21st October 1996
 - (2) Extent to which that information influenced her diagnosis and treatment at the RBHSC from 21st October 1996
- 2.2. Investigation into the care and treatment that Claire received upon her presentation to the RBHSC on 21st October 1996 until her death on 23rd October 1996 and in particular in relation to the management and monitoring of fluid and sodium intake and output
 - (1) Identifying the persons responsible for the monitoring and maintenance of Claire's fluid and electrolyte balance
 - (2) The underlying principles, the calculations, and the assumptions made, in regard to the prescription of intravenous fluids, in terms of the:
 - (a) Content of fluids
 - (b) Infusion rate and volume of fluids administered
 - (3) Monitoring and management of the actual intravenous fluids administered, in terms of the content, infusion rate and total amount given.
 - (4) Monitoring, recording and the management of her fluid balance, fluid input and output.
 - (5) Prescription and administration of anticonvulsant drugs, calculation of dosages, together with the quality of their recording and monitoring to ensure accuracy
 - (6) Quality, accuracy, signing, dating and alterations of records and reporting of changes in Claire's condition and the extent to which these were consistent with professional guidance of the time.
 - (7) Choice, quality and timing of observations (and the recording thereof) and the level of nursing care
 - (8) Investigation into the adequacy and frequency of the tests undertaken during Claire's admission and the tests which could have been carried out on Claire between 21st and 23rd October 1996

including blood and urine tests, a CT scan, an electroencephalogram (EEG) and a MRI scan, the authorisation required for same, the location and availability of the equipment and technicians to carry out those tests during that period and the time required to arrange for those tests to be carried out.

- (9) Consideration of when Claire could and should have been admitted to PICU
- (10) Quality of the assessment, monitoring and diagnosis of Claire's condition and neurological state, and reviewing the plan for her care in light of that diagnosis
- (11) When the treating clinicians in the RBHSC should have diagnosed Claire's hyponatraemia. What course of action they should have taken at that time. What would have been the likely effect of that course of action if different to that actually taken

2.3. Investigation into the continuity, co-ordination and communication of care provided to Claire during her admission

- (1) Identifying the consultant with primary responsibility for the care and management of Claire on 22 and 23 October 1996, whether there had been a transfer of her care and if so how that had been carried out, how that was recorded, and the facts disseminated to the medical and nursing teams caring for her
- (2) Arrangements for identifying and communicating consultant responsibility for Claire and ensuring clarity regarding accountability and responsibility of consultants and junior medical staff
- (3) Management of handover arrangements between medical teams, between medical and nursing teams and between nurses
- (4) Relationship between medical staff and nurses' roles on the ward and the communication of information between medical staff and/or nurses, and the record thereof.
- (5) Responsibility for the co-ordination and quality of nursing care for Claire and the accuracy and quality of the nursing notes, care plan and records
- (6) Correlation between the medical notes and nursing notes

2.4. Investigation into the quality of the information provided to and received from Claire's next of kin from when she was in hospital in 1996 until the period of her Inquest in 2006

(1) How the medical and nursing staff gathered information from Claire's next of kin in relation to her health, symptoms and

10

concerns when taking an initial history on presentation to A&E, on admission to the RBHSC and subsequently during her care and treatment. How the medical and nursing staff recorded and used that information in the planning of Claire's treatment.

- (2) Information provided to the next of kin about Claire's condition:
 - (a) On presentation to A&E
 - (b) On admission to the Royal Belfast Hospital for Sick Children
 - (c) During 22nd October 1996 and prior to the departure of Mr. and Mrs. Roberts from Allen Ward at approximately 9.30pm
 - (d) When the sodium result was found to be low at 11.30 pm on 22nd October
 - (e) Following her respiratory arrest at approximately 3am on 23rd October 1996
 - (f) Prior to and following the carrying out of brain stem tests

In addition, information provided (i) after Claire's death, and (ii) from November 2004 onwards, particularly on:

- the cause of her death
- her hyponatraemia and its contribution to her death
- the lessons learned from Claire's death.
- (3) The quality of the records of the information provided to Claire's next of kin and whether these were consistent with professional guidance of the time.
- (4) Those responsible for providing the information to the next of kin and those who actually provided them with information on her condition, prognosis, and the treatment administered and a critical analysis on how this information was provided to the next of kin
- (5) Existence of guidelines and RBHSC procedures or practices governing the provision of information to the next of kin of paediatric patients:
 - (a) Generally
 - (b) When they become critically ill
 - (c) When an unexpected death occurs
- (6) Extent to which the information actually provided to Claire's next of kin followed the guidelines, procedures or practices.

11

- 2.5. Investigation into teaching and training in Northern Ireland on fluid management (in particular with regard to hyponatraemia), record keeping and drug prescribing/administration to medical students and student nurses as part of their qualification and to doctors and nurses as part of their induction, training and continuous professional development
 - (1) Extent to which the care and treatment that Claire received was consistent with the then teaching/training on fluid management (in particular with regard to hyponatraemia) and record keeping
 - (2) Extent to which any deficiencies in teaching/training played a role in Claire's death
 - (3) How the teaching/training in Northern Ireland at that time compared with the rest of the UK
 - (4) If there were any changes in the teaching/training on fluid management (and in particular hyponatraemia) and record keeping in Northern Ireland between Claire's death and 10th June 2001, when did those changes occur and for what reason
- 2.6. Investigation into changes made in patient care, particularly in regard to fluid management, between Adam's death and Claire's admission
 - (1) Extent to which any changes resulted from lessons learnt from Adam's death in 1995 and the inquest into his death in 1996
 - (2) Extent to which any changes that had occurred had any effect and if so, what that effect was
 - (3) Whether any changes made were adequate in the light of Adam's death and his Inquest
- 2.7. Investigation into the extent of any local investigation procedures to examine adverse incidents / unexpected deaths at the time of Claire's death <u>and</u> following her parents' concerns expressed in 2004 and how lessons learned were communicated.
 - (1) Whether there was a hospital system to report adverse incidents and communicate serious incidents to the Trust management.
 - (2) Whether there was any investigation (formal or informal) with local clinicians regarding Claire's clinical management and whether there was any learning arising from this.
 - (3) Whether there were any recorded discussions following Claire's death and the later inquest, in case conferences, "grand rounds", post-graduate clinical meetings, clinical specialty meetings clinical audit meetings and nurse education meetings.

(4) How parental concerns were managed in the context of the Trust's established procedures on handling complaints and concerns and how these procedures related to Departmental and professional guidance

2.8. Investigation into the accuracy and quality of information provided by the treating clinicians to the hospital pathologist for post-mortem

- (1) How the treating clinicians prepared and obtained the information for the autopsy summary that was provided to the pathologist. The extent to which those treating clinicians were trained on how to prepare and provide such information to the pathologist
- (2) Existence of guidelines, procedures or practices governing the information provided by the treating clinicians to the hospital pathologist so as to establish an accurate cause of death
- (3) The nature of signs of infection (if any) found at post-mortem and the extent to which the post-mortem findings were consistent with cell and tissue damage due to the presence of a virus infection
- (4) How the cause of death was established and agreed, including how and when the clinicians responsible for Claire's treatment discussed and agreed with the pathologist on a cause of death
- (5) Extent to which the communications between Claire's treating clinicians and the pathologist:
 - (a) Were appropriate for establishing an independent view as to the cause of her death
 - (b) Complied with any guidelines, procedures or practices governing the information provided by the treating clinicians to the hospital pathologist so as to establish an accurate cause of death

2.9. Investigation into whether it was necessary to have a full post-mortem examination and to report Claire's death to the Coroner

- (1) How a decision was reached that Claire's death did not warrant a full post-mortem and how this decision was documented
- (2) What guidelines were in place, and should be in place, to decide under what circumstances a limited, as distinct from a full, postmortem should be carried out
- (3) How a decision was reached that Claire's death did not warrant a referral to the Coroner and how this decision was documented.

- 2.10. Investigation into the extent to which, at the time of Claire's Inquest in 2006, the RBHSC revised its statistical database in the light of new information about the cause of death
- 2.11. Investigation into the extent to which procedures and practices in Northern Ireland for the reporting and dissemination of information to the DHSSPS and the medical and nursing community in general of unexpected deaths in Hospital and the outcome of Coroners' Inquests, had changed following the death of Adam, but prior to Claire's death in October 1996
 - (1) Whether there were any changes and if so:
 - (a) Their content,
 - (b) What prompted them, and
 - (c) The extent to which they were influenced by the lessons learned from Adam's death and the Inquest into his death in 1996
 - (2) Whether any such changes had any effect on medical and nursing practice, and if so, what that effect was
 - (3) Extent to which any deficiencies in the dissemination of information in respect of Adam's death in 1995 and the lessons learned from the Inquest into his death in 1996 could have played a role in the death of Claire
 - (4) How the procedures and practices in Northern Ireland at that time compared with procedures and practices in operation in the rest of the UK
- 2.12. Investigation into the information that was actually provided to the DHSSPS and the medical and nursing community in general on the death of Claire in 1996 and following the inquest in 2006.
 - (1) Content of the information on Claire's death and the Inquest into her death that was disseminated within the RBHSC where she was treated and to the other parts of the Northern Ireland Health and Social Services
 - (2) Process by which (including when, by whom and to whom) any information on Claire's death and the Inquest into her death was disseminated within the RBHSC and to the other parts of the Northern Ireland Health and Social Services
 - (3) Extent to which any dissemination of information on Claire's death and the Inquest into her death followed the procedures or practices in place at the time

(4) Extent to which any inadequacies in the dissemination of information on Claire's death constituted a systems or a human error

3. RAYCHEL FERGUSON

3.1. Investigation into the steps that were taken and/or ought to have been taken following Lucy Crawford's death on 14th April 2000 in order to ascertain the causes of her death

A. In relation to the Royal Belfast Hospital for Sick Children:

- (1) Steps taken by the RBHSC to investigate the circumstances leading to Lucy's death and to ascertain its causes and the outcome
- (2) How the cause of Lucy's death was established and agreed, including how and when the clinicians responsible for Lucy's treatment discussed and agreed on a cause of her death
- (3) Extent and quality of the information conveyed to the Coroner's office about the circumstances of Lucy's death and whether it complied with any governing guidelines, procedures or practices
- (4) Reason(s) it was decided that a Coroner's post-mortem was not required for Lucy and why a hospital post-mortem was carried out
- (5) The significance of the reference to hyponatraemia within the clinical diagnosis section of the autopsy request form for Lucy and the:
 - (a) Consideration, if any, that was given to hyponatraemia when examining the cause of death
 - (b) Conclusions reached following any such consideration
- (6) The actions that the RBHSC took and should have taken to disseminate the findings of the hospital post-mortem that was carried out including whether the findings of the post mortem should have been brought to the attention of the Coroner, and:
 - (a) Why Lucy's cause of death was certified as being cerebral oedema due to or as a consequence of dehydration and gastroenteritis
 - (b) What steps the Coroner would have taken if the findings of the hospital post-mortem had been brought to his attention
 - (c) Whether the steps taken by the RBHSC to investigate the circumstances of Lucy's death, to ascertain its causes and to

15

disseminate information about the death, were adequate in all the circumstances

B. In Relation to the Erne Hospital/Sperrin Lakeland Trust

- (7) Steps taken by the Erne Hospital/Sperrin Lakeland Trust to establish an investigation into the circumstances leading to Lucy's death and to ascertain its causes, and whether its establishment and conduct complied with any applicable guidelines, protocols or practices
- (8) The adequacy of the investigation and its findings
- (9) Steps taken to disseminate the outcome of the investigation to any other hospital and in particular Altnagelvin Hospital, Craigavon Hospital, and other Trusts, Boards and the DHSSPS
- (10) Whether and when the Erne Hospital/Sperrin Lakeland Trust suspected fluid mismanagement or hyponatraemia as being relevant to the cause of Lucy's death, including consideration of how the investigations conducted by the Royal College of Paediatrics and Child Health were dealt with by the Hospital/Trust
- (11) Whether the Erne Hospital/Sperrin Lakeland Trust should have referred the death of Lucy to the Coroner's office or to any other body
- (12) Whether Lucy's parents were involved in the investigation and if not, whether Lucy's parents were provided with information about the outcome of the investigation

C. Others

- (13) What the following bodies knew about Lucy's death, when they knew it and what steps they took when they received information about her death:
 - (a) Western Health and Social Services Board
 - (b) DHSSPS
- 3.2. Investigation into the extent to which, at the time of Lucy's Inquest in 2004, the RBHSC revised its statistical database in the light of new information about the cause of death
- 3.3. Investigation into the procedures and practices that existed in Northern Ireland at the time of Lucy's death in April 2000 for the reporting and dissemination of information to the DHSSPS and the medical community in general, in relation to unexpected paediatric deaths in Hospital.

- (1) The respective roles in reporting, analysing and disseminating information in relation to unexpected deaths in Hospitals of:
 - (a) The Hospital in which an unexpected death occurs
 - (b) The treating clinicians (both doctors and nurses)
 - (c) The Trusts
 - (d) The Area Boards
 - (e) DHSSPS including the Chief Medical Officer
- (2) What procedures or practices were in place in April 2000 to ensure that any requirement to report, analyse or to disseminate information relating to an unexpected Hospital death were complied with, and what procedures or practices were in place to ensure that any lessons learned were fed into teaching/training and patient care.
- 3.4. Investigation into the care and treatment that Raychel Ferguson received especially in relation to the management of fluid balance, to include an investigation into the care that she should have received
 - (1) Prescription and administration of the intravenous fluids in terms of choice of fluid, infusion rate and total amount
 - (2) Monitoring and management of her fluid balance
 - (3) The consideration given to the appropriateness, of Raychel's IV fluid management, including the communication, if any, that took place between nursing staff and medical staff
 - (4) Whether Raychel's care plan should have been reassessed and if so, at what time and in response to what events
 - (5) Whether there was a delay on the part of the surgical team in responding to calls from the nursing team to see Raychel, and if so, why that delay occurred, and whether nursing staff should have taken any further steps to secure the prompt attendance of a member of the surgical team
 - (6) Whether the nursing and medical teams who cared for Raychel adequately monitored her condition, and whether they provided her with appropriate treatment, both before and after she suffered a tonic seizure
 - (7) If not, what steps should have been taken to adequately monitor her condition and to provide her with appropriate treatment

- (8) Whether those treating Raychel should have reached the view that she was seriously ill, and if so by what time, what action should have been taken, with what effect
- (9) Whether any lessons learned from Adam's death in 1995, from the Inquest into his death in 1996, from Claire's death in 1996 and from Lucy Crawford's death in April 2000, affected how Raychel's care was managed, and if so, in what way

3.5. Investigation into the quality of the information provided to Raychel's next of kin whilst she was in hospital in 2001

- (1) What information was provided to the next of kin by the Altnagelvin Hospital and the RBHSC at the various stages of Raychel's treatment and after her death
- (2) Identifying the guidelines, procedures and practices that existed within the Altnagelvin Hospital and the RBHSC governing the provision of information to the next of kin of patients:
 - (a) Generally

Inquiry

- (b) When a patient becomes critically ill
- (c) When an unexpected death occurs
- (3) To what extent the information which was provided to Raychel's next of kin, the manner in which that information was given and the timing of that information followed the procedures and practices of the Altnagelvin Hospital and the RBHSC.
- 3.6. Investigation into the experience and state of knowledge of the medical and nursing teams at Altnagelvin, including an investigation into the teaching/training which was available to the medical and nursing teams
 - (1) What understanding those who cared for and treated Raychel had of the risks associated with her management and condition
 - (2) To what extent fluid management and record keeping was covered in the teaching/training of members of the respective teams
 - (3) To what extent the care and treatment which Raychel received was consistent with the then teaching/training on fluid management and record keeping
 - (4) How the teaching/training for nursing and medical staff in Altnagelvin at that time compared with that available in other Northern Irish and UK hospitals and included guidance provided by professional bodies

303-038-495

- (5) If there were any changes in the teaching/training on fluid management and record keeping in Northern Ireland between Raychel's death and 12th May 2003, when did those changes occur and for what reason
- 3.7. Investigation into the extent to which procedures and practices in Northern Ireland for the reporting and dissemination of information to the DHSSPS and the medical community in general in relation to unexpected deaths in Hospital and the outcome of Coroners' Inquests, had changed by the time that Raychel died in 2001
 - (1) Whether there were any changes and if so:
 - (a) Their content
 - (b) What prompted them
 - (c) The extent to which they were influenced by the lessons learned from Adam's death in 1995, the inquest into his death in 1996, Claire's death in 1996 and Lucy's death in April 2000.
 - (2) Whether any such changes had any effect, and, if so, what that effect was
 - (3) The extent to which any deficiencies in the dissemination of information in respect of Adam's death in 1995, the lessons learned from the Inquest into his death in 1996, Claire's death in 1996 and Lucy's death in April 2000 could have played a role in the death of Raychel
 - (4) How the procedures or practices in Northern Ireland at the time of Raychel's death compared with procedures in operation in the rest of the United Kingdom
- 3.8. Investigation into the steps taken by the Altnagelvin Hospitals HSST to investigate the causes of Raychel's death, disseminate information about it and address the procedures for safe fluid administration, including an investigation into the information that was actually provided to the DHSSPS and the medical community in general on the death of Raychel in 2001
 - (1) Whether steps were taken by Altnagelvin to investigate the causes of Raychel's death and what conclusions were reached
 - (2) Whether steps were taken by Altnagelvin to disseminate information about Raychel's death both internally and to other parts of the medical community, the adequacy of any steps taken and the adequacy of any information that was disseminated

Inquiry 303-038-496

- (3) Extent to which any dissemination of information relating to Raychel's death followed the procedures or practices that were in place at the time
- (4) Channels of communication that were made available by Altnagelvin to the Ferguson family so that they could learn about the causes of Raychel's death, and what were they told
- (5) Extent to which Altnagelvin provided the Ferguson family with an adequate explanation of the events which led to Raychel's death
- (6) Whether steps were taken to address the procedures for safe fluid administration in the Altnagelvin Hospital after Raychel's death, and whether the steps which were taken were adequate

4. CONOR MITCHELL

- 4.1. Investigation into the dissemination, circulation, implementation and enforcement of the DHSSPS Guidelines on the Prevention of Hyponatraemia in Children receiving intravenous fluids ("the Guidelines") issued in March 2002:
 - (1) The actions taken to circulate and disseminate the Guidelines by the DHSSPS, the Hospitals and in particular Craigavon Hospital, the Trusts and Boards.
 - (2) The actions taken to implement the Guidelines and to ensure that they were followed in the treatment of all children, whether on paediatric or adult wards, by the DHSSPS, the Hospitals and in particular Craigavon Hospital, the Trusts and Boards.
 - (3) Extent to which the guidelines had been both implemented and incorporated into clinical practice for all children, whether on paediatric or adult wards.

4.2. Investigation into the care and treatment that Conor received in 2003 in relation to the management of fluid balance

- (1) What understanding those who cared for and treated Conor had of the fluid management issues raised by his condition
- (2) To what extent fluid management and record keeping was covered in the teaching/training of members of those who treated Conor
- (3) To what extent the care and treatment which Conor received, both in Craigavon Hospital and the RBHSC, was consistent with the then teaching/training on fluid management and record keeping, in particular the Guidelines.

20

- (4) Whether the fact that Conor was admitted to an adult ward at Craigavon Hospital rather than a children's ward was relevant to whether the Guidelines were adhered to.
- 4.3. Investigation into the education, training and professional development of doctors and nursing staff in Northern Ireland in fluid management and record keeping by the time that Conor was admitted to hospital in 2003
 - (1) Extent to which any changes that had occurred had any effect, and if so, what that effect was
 - (2) Extent to which any changes resulted from lessons learned from Adam's death in 1995 and the Inquest into his death in 1996, Claire's death in 1996, Lucy Crawford's death in April 2000 and Raychel's death in June 2001 and Inquest into Raychel's death in February 2003
 - (3) Extent to which the care and treatment that Conor received was consistent with the then teaching/training on fluid management (in particular hyponatraemia) and record keeping
 - (4) How the teaching/training in Northern Ireland at that time compared with the rest of the UK
- 4.4. Investigation into the extent to which procedures and practices in Northern Ireland for the reporting and dissemination of information to the DHSSPS and the medical community in general of unexpected deaths in Hospital and the outcome of Coroners' Inquests, had changed by the time that Conor died in 2003
 - (1) Whether there were any changes and if so:
 - (a) Their content
 - (b) What prompted them
 - (c) Extent to which they were influenced by the lessons learned from Adam's death and the Inquest into his death in 1996, Claire's death in 1996, Lucy Crawford's death in April 2000 and the death of Raychel and the Inquest into her death in February 2003
 - (2) Whether any such changes had any effect, and if so, what that effect was
 - (3) Extent to which any deficiencies in the dissemination of information in respect of Adam's death in 1995 and the lessons learned from the Inquest into his death in 1996, Claire's death in 1996, Lucy Crawford's death in April 2000 and the death of

- Raychel and the Inquest into her death in February 2003, could have played a role in the death of Conor
- (4) How the procedures and practices in Northern Ireland at that time compared with procedures and practices in operation in the rest of the UK

ACTION TO MINIMISE THE LIKELIHOOD OF SUCH DEATHS HAPPENING AGAIN

5. ISSUES RELATING TO THE PERIOD 2002 - TO DATE

- 5.1. Investigation into the education, training and professional development of doctors and nursing staff in Northern Ireland in fluid management and record keeping since the introduction in March 2002 of guidelines on 'Prevention of Hyponatraemia in Children'
 - (1) Nature and date of any changes made to the teaching/training provided to medical students and student nurses as part of their qualification and to doctors and nurses as part of their induction, training and continuous professional development since Conor's death.
 - (2) Extent to which guidelines issued, in March 2002 by DHSSPS, on the prevention of hyponatraemia in children receiving prescribed fluids, had been both implemented and incorporated into clinical teaching/training, induction and continuous professional development in Northern Ireland.
 - (3) Extent to which any changes made to the teaching/training provided to medical students and student nurses as part of their qualification and to doctors and nurses as part of their induction, training and continuous professional development resulted from lessons learned from: the death of Claire and the Inquest into her death in 2006, the death of Lucy Crawford and the Inquest into her death in February 2004, the death of Raychel and the Inquest into her death in 2003 and from the death of Conor and Inquest into his death in 2004.
 - (4) The mechanisms that currently exist for ensuring that the teaching/training of student doctors and student nurses and the induction and continuous professional development of doctors and nurses are informed by lessons learned from unexpected deaths in Hospital and from Coroners' Inquests
 - (5) How the present teaching/training of student doctors and student nurses and the induction and continuous professional development of doctors and nurses compares with that in the rest of the UK

22

- 5.2. Investigation into the present procedures and practices in Northern Ireland for the reporting and dissemination of information to the DHSSPS and the medical community in general of unexpected deaths in Hospital and the outcome of Coroners' Inquests in Northern Ireland, so that lessons might be learned
 - (1) Extent to which there have been any changes since the death of Conor in 2003
 - (2) Extent to which any changes had any effect, and if so what that effect was
 - (3) Extent to which any changes resulted from lessons learned from Claire's death and the Inquest into her death in 2006, from Lucy Crawford's death and the Inquest into her death in February 2004, from Raychel's death and the Inquest into her death in 2003 and from Conor's death and the Inquest into his death in 2004.
 - (4) Respective roles of the:
 - (a) Hospital in which an unexpected death occurs,
 - (b) treating clinicians (both doctors and nurses),
 - (c) pathologists undertaking post-mortem examinations
 - (d) Trust,
 - (e) Area Board,
 - (f) DHSSPS including the Chief Medical Officer,

in reporting, analysing and disseminating information from a Coroner's Inquest on an unexpected death in a Hospital and ensuring that any lessons learned feed into teaching/training and the care of patients

- (5) Procedures or practices to ensure the fulfilling of the roles relating to reporting, analysing, disseminating information on unexpected deaths and the outcomes of Coroners' Inquests, and that any lessons learned are fed into teaching/training and the care of patients
- (6) Means by which the effectiveness of the present procedures or practices are currently being monitored and assessed
- (7) Extent to which Northern Ireland now has a set of procedures and or practices that are capable of ensuring that information on the circumstances of an unexpected death relating to fluid mismanagement, particularly hyponatraemia, will be reported, analysed, monitored and properly disseminated within the Northern Ireland Health and Social Services

(8) How those procedures and or practices compare with procedures presently in operation in the rest of the UK

5.3. Investigation into the introduction into Northern Ireland in March 2002 of guidelines on 'Prevention of Hyponatraemia in Children'

- (1) Whether information available from research, publications and practice at the time should have led to production of guidelines on fluid management and hyponatraemia, either by individual trusts or more generally throughout NI, prior to Adam's admission in 1995, prior to Claire's admission in 1996, prior to Lucy Crawford's admission in April 2000 and prior to Raychel's admission in 2001
- (2) Extent to which guidelines issued in March 2002 by DHSSPS on the prevention of hyponatraemia in children receiving prescribed fluids, had been circulated within hospitals and particularly in Craigavon Hospital, prior to Conor's death in 2003
- (3) To what extent the DHSSPS guidelines on prevention of hyponatraemia in children had been targeted to ensure that they were issued to and circulated in all clinical areas where a child might be treated
- (4) Adequacy of the process by which those guidelines were formulated and subsequently revised in September 2007
- (5) Adequacy of the current guidelines and the existence and adequacy of a process for monitoring and revising them
- (6) Had these guidelines on fluid management and hyponatraemia been in place when Adam was admitted to Hospital in 1995, when Claire was admitted to Hospital in 1996 and when Raychel was admitted to Hospital in 2001, to what extent they could have played a role in avoiding their deaths
- (7) Extent to which the revised guidelines took into account the information and lessons learned from the Inquests in 2003 into the death of Raychel, in 2004 into the deaths of Conor and Lucy Crawford and in 2006 into the death of Claire
- (8) Procedure for monitoring the circulation of the guidelines, the adherence to the guidelines and the mechanisms for assessing their effectiveness
- (9) Level of adherence to the guidelines to date in hospitals in Northern Ireland
- 5.4. Investigation into the introduction into Northern Ireland in September 2007 of 'Paediatric Parenteral Fluid Therapy (1 month 16 years): Initial Management Guideline' and what has happened since

- (1) Whether there is a procedure to revise the guidelines and if so, what it is
- (2) Whether there are procedures within Trusts or the DHSSPS to monitor compliance with the guidelines and any revisions thereto, and if so, what they are
- (3) An examination of the Department's Consultation Document published in October 2006 entitled 'Regional Multi Agency Procedure to be followed in cases of Sudden or Unexpected Child Deaths from Birth to 18 years'
 - (a) Recommendations made
 - (b) Recommendations adopted/actions taken
 - (c) Impact on hospital practices of any action taken as a result of the Consultation
- (4) The impact of the Regulation and Quality Improvement Authority's (RQIA) Independent Review; "Reducing the Risk of Hyponatraemia when Administering Intravenous Infusions to Children (June 2008)
 - (a) Nature of Review
 - (b) Recommendations made
 - (c) Extent of compliance with recommendations
 - (d) Extent of enforcement
 - (e) Impact on hospital practices of any action taken in respect of the Review

6. BASIS FOR FURTHER ACTION THAT MIGHT BE TAKEN

- 6.1. Investigation into the extent to which hospitals in Northern Ireland generally, and the RBHSC in particular, revise their statistical database in the light of new information about the cause of death
- 6.2. Investigation into the system of protocols, procedures and practices by which hospitals in Northern Ireland 'code' the causes of deaths and adverse incidents, including:
 - (1) How accurate codes are in general
 - (2) How the accuracy of coding is checked and verified
 - (3) Who has responsibility for the coding of a death/adverse incident

25

- (4) On what basis and/or using what documents the decision on coding of a death/adverse incident is made
- (5) How inaccurate coding affects statistical analysis (e.g. by the National Confidential Enquiry into Perioperative deaths) of deaths/adverse incidents in hospitals
- (6) Differences between Northern Ireland and the rest of the U.K. in the way in which coding is approached
- 6.3. Investigation into the deaths in Northern Ireland during the last 20 years in which fluid management/ hyponatraemia was: (i) the primary cause of death, (ii) the secondary cause of death
 - (1) Breakdown of those deaths by:
 - (a) Hospital,
 - (b) Age of patient, and
 - (c) Date of death
 - (2) Extent to which those figures are in keeping with equivalent figures for:
 - (a) The rest of the UK and
 - (b) Other western European Countries
 - (3) Conclusions, if any, which may be drawn about the current incidence of deaths in Northern Ireland from deaths in which fluid management/hyponatraemia in particular, was:
 - (a) The primary cause of death,
 - (b) The secondary cause of death
- 6.4. Investigation into lessons that might be learned from other jurisdictions to assist in the reduction of death from fluid mismanagement/hyponatraemia in Hospitals in Northern Ireland
 - (1) Organisation and content of teaching/training of medical students and student nurses on:
 - (a) Fluid management (in particular hyponatraemia) and
 - (b) Record keeping
 - (2) Organisation and content of the teaching/training/induction/continuous professional development of doctors and nurses on:
 - (a) Fluid management (in particular hyponatraemia) and

- (b) Record keeping
- (3) Organisation of the flow of information on unexpected deaths in Hospital and from Coroners' Inquests so that it feeds into improvements in patient treatment and care, including the persons/institutions responsible for:
 - (a) Reporting and disseminating it,
 - (b) Analysing and monitoring it, and
 - (c) Responding to it and implementing it
- 6.5. Investigation into lessons that might be learned from other jurisdictions to assist in the improvement in the quality of the information provided to the next of kin in Northern Ireland when patients become critically ill in Hospital and / or suffer an unexpected death