Northern Ireland
Public Services
Ombudsman

Investigation Report

Investigation of a complaint against the Western Health and Social Care Trust

NIPSO Reference: 20903

The Northern Ireland Public Services Ombudsman
33 Wellington Place
BELFAST
BT1 6HN
Tel: 028 9023 3821
Email: nipso@nipso.org.uk
Web: www.nipso.org.uk
@NIPSO_Comms

The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

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Case Reference: 20903

Listed Authority: Western Health and Social Care Trust

SUMMARY

I received a complaint about the care and treatment provided to the complainant's daughter during six admissions at the South West Acute Hospital in May to July 2016. The complainant believed that her daughter's hair should have been washed during each admission; basic nursing and personal care was not provided to the patient, appropriate investigations were not performed and the patient was not assessed and treated by appropriate specialists or in a specialist ward. The complainant also said that a Do Not Attempt Cardiopulmonary Resuscitation Order (DNACPR) was discussed with the patient's father, but ought to have been discussed with her as she was the patient's Next of Kin. The Western Health and Social Care Trust (the Trust) manage this hospital. The patient was a vulnerable adult and was diagnosed with Cerebral Palsy[1], Hydrocephalus[2], Kyphoscoliosis[3], and Quadriplegia[4]. Unfortunately the patient passed away on 18 July 2016 whilst in hospital. The complainant also said that the Trust took too long to provide a response to her complaint.

In order to assist with my consideration of the complaint I obtained advice from an emergency medicine consultant, consultant physician and a nurse. Having considered the advice of the independent advisors and the medical records the investigation did not find a failing in terms of the overall nursing care provided to the patient, the pain management provided to the patient at ED and the medical investigations and referrals conducted. However the investigation did find that the Trust failed to; provide adequate oral care to the patient including the ongoing assessment and evaluation of mouthcare treatment; refer the patient to the learning disability nurse; adequately communicate with the patient's family; manage the patient's pain appropriately on the ward during all five admissions and to have an

[1] Is a group of permanent movement disorders that appear in early childhood.Signs and symptoms vary among people and over time.Often, symptoms include poor coordination, stiff muscles, weak muscles, and tremors.
[2] The build-up of fluid in the cavities (ventricles) deep within the brain. The excess fluid increases the size of the ventricles and puts pressure on the brain.
[3] is an abnormal curve of the spine
[4] is paralysis caused by illness or injury that results in the partial or total loss of use of all four limbs and torso

appropriate DNACPR conversation with the patient's Next of Kin. My investigation also established maladministration in relation to the Trust's handling of the complaint. I note the Trust previously identified and apologised for care and treatment and maladministration failures during their original investigation of the complaint.

I consider the failures identified as a result of the investigation caused the patient to suffer the injustice of loss of opportunity to receive care that was tailored to meet her needs as a vulnerable adult and distress. I consider the failings caused the complainant to suffer the injustice of upset and frustration. I recommended that the Trust apologise to the complainant for the failures identified. I also recommended that the Trust engage the help of the newly appointed Learning Disability Acute Liaison Nurse to ensure that appropriate training is provided to staff who as part of their role provide care for patients with disabilities. I also recommended the Trust develop an online resource for staff to access information on caring for vulnerable patients and patients with learning disabilities.

The Trust have advised that on receipt of the final report, an action plan will be developed to take forward the necessary actions.

THE COMPLAINT

1. I received a complaint about the actions of the Western Health and Social Care Trust in relation to the care of the complainant's daughter (the patient) over a period of six admissions to the South West Acute Hospital (SWAH) from May to July 2016.The patient was a vulnerable adult and was diagnosed with Cerebral Palsy, Hydrocephalus, Kyphoscoliosis and Quadriplegia. Unfortunately the patient passed away on 18 July 2016 whilst in hospital. The complaint believed that; her daughter's hair should have been washed during each admission; basic nursing and personal care was not provided to the patient, appropriate investigations were not performed, the patient was not assessed and treated by appropriate specialists or in a specialist ward. The complainant also said that a DNACPR Order was discussed with the patient's father, but ought to have been discussed with her as she was the patient's Next of Kin. She also complained that it took the Trust three years to provide an answer to her complaint

Issues of complaint

2. The issues of complaint accepted for investigation were:

   Issue 1: Whether the patient received appropriate care and treatment at South West Acute Hospital between 29 May 2016 and 18 July 2016?

   As part of this issue this of complaint the investigation considered the following;

   - Whether the patient received appropriate nursing care;
   - Whether the patient received appropriate pain relief;
   - Whether medical staff conducted appropriate investigations and made appropriate referrals to relevant specialisms;
   - Communication regarding DNACPR order.

   Issue 2: Whether the Trust's handling of the complaint was appropriate and reasonable?

INVESTIGATION METHODOLOGY

3. In order to investigate this complaint, the Investigating Officer obtained from the Trust all relevant documentation together with its comments on the issues

raised by the complainant. This documentation included information relating to the Trust's handling the complaint.

Independent Professional Advice Sought

4. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisor(s) (IPA):

- **General Nurse (N IPA)**: who has been managing an acute assessment unit for the past ten years which is a 54 bedded medical admissions unit.
- **Consultant Emergency Medicine (ED IPA)**, FRCEM, FRCSEd (A&E), MBBS, LLM (Medical Law), RCPathME: who has worked as a Consultant in Emergency Medicine since 2007 in a District General hospital. Clinical duties include attending acutely unwell or injured patients, in addition to providing supervision for doctors in training.
- **Consultant Physician and Gastroenterologist (FRCP) (C IPA):** a Medical Gastroenterologist and a senior consultant in the NHS who has knowledge and experience about the above complaint.

The clinical advice received is enclosed at Appendix Three to this report.

5. The information and advice which informed the findings and conclusions are included within the body of this report. The IPAs provided 'advice'; however how this advice was weighed, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards and Guidance

6. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case. I also make reference to relevant regulatory, professional and statutory guidance.

The general standards are the Ombudsman's Principles[5]:

- The Principles of Good Administration
- The Principles of Good Complaints Handling
- The Public Services Ombudsmen Principles for Remedy

7. The specific standards and guidance referred to are those which applied at the time the events occurred. These governed the exercise of the administrative functions and professional judgement those individuals whose actions are the subject of this complaint.

The specific standards and guidance relevant to this complaint are:

- The General Medical Council's (GMC) Good Medical Practice, as updated April 2014 (the GMC Guidance);
- The Nursing and Midwifery Council's (NMC) Code: Professional standards of practice and behaviour for nurses and midwives, March 2015 (the NMC Code);
- The Resuscitation Council (UK) and the Royal College of Nursing, 2016 '*Decisions relating to Cardiopulmonary resuscitation'* Guidance from the British Medical Association, (DNACPR guidance);
- Western Health and Social Services Trust '*Do not attempt Cardiopulmonary resuscitation adult* policy',, December 2012 (DNACPR policy);
- Public Health Agency '*Hospital Passport Guidance notes',* , Undated
- The Department of Health, Social Services and Public Safety's (DHSSPS) Improving the Patient and Client Experience Standards, January 2012, (the DHSSPS Standards);
- Western Health and Social Care Trust '*Policy on the Identification & Recording of Next Of Kin/Nearest Relative/ Carer'* July 2010, (Next of Kin policy);
- Western Health and Social Care Trust '*Policy for Management of Complaints'* March 2015

[5] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

- Guidelines and Audit Implementation Network '*Guidelines on Caring for People with a Learning Disability in General Hospital Settings',* , June 2010 (GAIN Guidance);
- Mencap '*Getting it right charter',* , 2008 (Mencap Charter);
- Department of Health Social Services and Public Safety: Complaints in Health and Social Care: Standards and Guidelines for Resolution and Learning (April 2009) (DHSSPS Guidelines); and
- Email provided by Trust from Acting Head of Service & Professional Nurse Lead Adult Learning Disability Services:

8. I did not include all of the information obtained in the course of the investigation in this report but I am satisfied that I took into account everything I consider to be relevant and important in reaching my findings.

9. A draft copy of this report was shared with the complainant and the Trust for comment on factual accuracy and the reasonableness of the findings and recommendations.

THE INVESTIGATION

Issue 1: Whether the patient received appropriate care and treatment at South West Acute Hospital between 29 May 2016 and 18 July 2016?

Detail of Complaint

10. I received a complaint about the actions of the Trust in relation to the care of the (the patient over a period of six admissions in May to July 2016) at the SWAH;
    - 29 May (Emergency Department)
    - 30 May 2016 to 8 June 2016 (Ward 9) (Admission One)
    - 9 June 2016 to 16 June 2016 (Ward 1, Ward 3) (Admission Two)
    - 17 June 2016 to 19 June 2016 (Ward 1, Ward 2) (Admission Three)
    - 20 June 2016 to 24 June 2016 (Ward 1, Ward 2) (Admission Four)
    - 27 June 2016 to 18 July (Deceased). (Ward 2) (Admission Five)

The patient was a vulnerable adult and was diagnosed with Cerebral Palsy, Hydrocephalus, Kyphoscoliosis and Quadriplegia. Unfortunately the patient passed away on 18 July 2016 whilst in hospital. The complaint believed that her daughter's hair should have been washed during each admission; basic nursing and personal care was not provided to the patient; appropriate investigations were not performed, the patient was not assessed and treated by appropriate specialists or in a specialist ward. The complainant also said that a Do Not Attempt Cardiopulmonary Resuscitation Order (DNACPR) was discussed with the patient's father, but ought to have been discussed with her as she was her Next of Kin.

11. Based on the concerns raised by the complainant, I decided that the investigation would look at the following four elements during each of the hospital admissions:
    - Whether the patient received appropriate nursing and personal care;
    - Whether the patient received appropriate pain relief;
    - Whether medical staff conducted appropriate investigations and made appropriate referrals to the relevant specialisms; and
    - Communication regarding the DNACPR Order.

Evidence Considered

Legislation/Policies/Guidance

12. I considered the Mencap Charter which details the following guidance for healthcare professionals;
    - *'make sure that hospital passports are available and used*
    - *make sure that all our staff understand and apply the principles of mental capacity laws appoint a learning disability liaison nurse in our hospital(s)*
    - *make sure every eligible person with a learning disability can have an annual health check*
    - *provide ongoing learning disability awareness training for all staff*
    - *listen to, respect and involve families and carers*
    - *provide practical support and information to families and carers*
    - *provide information that is accessible for people with a learning disability*

- *display the 'Getting it right' principles for everyone to see.'*

13. I considered the GAIN guidance;

'The subsequent care plan should highlight the way(s) in which the person communicates specific needs/problems such as: hunger, thirst, toileting needs etc, or pain or distress.

Communication

3. Communication should always take place with the patient in the first instance, but staff should discuss (following consent/best interest decision) with family/ carers their role in facilitating communication with the patient. Staff should listen to and respect the advice/information given by the main carer, as they will have a detailed knowledge of the person with a learning disability. '

Learning Disability Training

'2. Learning Disability Awareness Training should be mandatory for all hospital staff who have direct patient contact in order to enhance their knowledge and skills in providing safe and effective care to patients with learning disabilities.

3. All new staff within Health and Social Care (HSC) services should receive appropriate training in learning disabilities, to include disability equality training as part of their Corporate Induction Programme.'

5. Individuals with a learning disability should first and foremost be presumed to have capacity to make healthcare related decisions unless proven otherwise. Where there is doubt about capacity, this must be assessed by the professional responsible for the intervention. Family/carers should be involved in this process.

6. Where an individual is deemed not to have capacity, a best interests meeting should be convened to discuss specific decisions that need to be taken. However, in emergency/life threatening situations, health care staff can apply the doctrine of necessity which allows for immediate decision making that is deemed to be in the person's best interest.

14. I considered the Next of Kin Policy;
'Next of Kin should be engaged appropriately… and should be given an opportunity to express and/or discuss any concerns they may have'
'Next of Kin should be involved in the decision-making process and care planning for their family members'
'Parents/carers have a right to respect and should be consulted with and involved in matters concerning their families.'

15. I considered an email provided from the Trust and written by the Acting Head of Service & Professional Nurse Lead, Adult Learning Disability Services. I included this at Appendix Four.

16. I considered the DNACPR policy section 6.1
'For situations outside the above conditions e.g. the incapacitated adult, special attention should be paid to 5.0 Roles and Responsibilities. When considering the appropriateness of CPR in those people who lack the mental capacity to make such a decision, a DNACPR order should be made in accordance with the common law that is in the person's best interests (Bamford, 2009). As there is no statutory provision in Northern Ireland "for decision-making for patients who lack capacity, it is nonetheless good practice to discuss decision-making with those close to the patient in order to determine what would be in the best interests of the patient" (BMA et al, p17, 2007).'

17. I considered the DNACPR guidance including the following advice for patients who lack capacity:
    - '*6.4 Communication and discussion with those close to patients who lack capacity. If a person lacks capacity, any previously expressed wishes should be considered when making a CPR decision, bearing in mind that in some cases those wishes may relate to circumstances that differ substantially from the present situation, or from the circumstances of a future cardiorespiratory arrest (see section 10). Whether the benefit would outweigh the harms and burdens for a particular patient must be the subject of discussion and agreement between the healthcare team and whenever possible those close to or representing the patient.*

Relevant information should be shared with those close to patients unless, when they were previously competent to do so, a patient has expressed a wish that information be withheld. Consulting with those close to patients in these circumstances is not only good practice but is also a requirement of the Human Rights Act (Articles 8 – right to private and family life and 10 – right to impart and receive information)

- *Section 10.1*

  '*…it is important that a decision about CPR is not delayed inappropriately (and the quality of care for the patient compromised thereby) if it is not practical and appropriate to contact the patient's family members, or other carers, immediately to discuss a best-interests decision or to have a DNACPR decision explained to them where CPR would not be successful. In that situation the senior healthcare professional responsible for the patient's care should: • record fully their reasons for not explaining the decision to those close to the patient at that time • ensure that there is on-going active review of the decision and • ensure that those close to the patient are informed at the earliest practicable and appropriate opportunity.*

The Trust's response to investigation enquiries

General Care

18. The Trust stated in a letter to the complainant dated 27 February 2019 (after an independent review was conducted by a nurse and doctor not involved in the patient's care) that ' *We acknowledge that* [the patient's] *individual care needs were not fully achieved and that communication with you, as her next of kin, should have been consistent and clear in relation the reality of* [the patient's] *journey, the complexity of* [the patient's] *care and the delivery of this care is difficult to summarise in a letter, the main aspect* [independent reviewer] *wishes to convey to you and your family is one of a sincere apology for the experiences you had and the give you an assurance that we have changed practice and will continue to do so in* [the patient's] *name'.* The Trust further stated '*I wish to convey my own personal apology to you and your family for the fact* [the patient's] *individual needs were not fully achieved and for the obvious upset this caused. I do hope you will be reassured that* [the independent

reviewer] *has taken your complaint very seriously and the lessons learned from* [the patient's] *case will help to change practice.'*

19. In relation to pain relief, the Trust stated to the complainant on 27 February 2019 that '*Making reference to the use of the Patient Passport,* [the independent reviewer] *has noted that staff did not have information which would have informed them about how [the patient] expressed that she was in pain, uncomfortable, thirsty etc. In your account you have said you clearly advised that* [the patient's] *behaviour was outside her norm. As* [the patient's] *family you were her primary carers therefore we accept you would have better insight into* [the patient's] *response to pain and stress. Please accept my sincere apologies for this lack of attention to understanding in relation to* [the patient's] "*normal behaviour". The Ward Sister has engaged the help and support of the Learning Disability Nurse and together they are focusing on improving individualised patient care on Ward 2.'*

20. The Trust stated to the complainant on 27 February 2019 that '*Essentially in* [the patient's] *case everything that could have been done at ward level was being undertaken. Sadly* [the patient's] *condition did not respond to the high dose of antibiotic therapy.* [The patient] *underwent significant investigation in an attempt to diagnose the cause of her temperatures yet we were unable to find a source.'* The Trust also stated '*The Neurology team at RVH were contacted re: possible shunt infection, they advised highly unlikely.* [The patient] *did have temperatures of unknown origin, in that no site of infection was indicated after multiple investigations.'*

Hair washing

21. The Trust stated in response to the complainant on 27 February 2019 that due to the patient's '*condition (whilst in hospital) it was felt she was not fit enough to have her hair washed.'* The Trust stated to this office that '*On the morning of 19/06/2016* [the patient's] *hair was washed.* [The patient's father] *acknowledged that* [the patient] *had had her hair washed and how well she looked. This was the morning of* [the patient's] *discharge.'*

DNACPR Order

22. The Trust stated to the complainant on 27 February 2019 that '*From the* [consultant physician's] *account and the recorded communications in the case file it appears that* [the patient's father] *had been spoken to about her care and the processes to be undertaken for example placement of central line. Given that you were* [the patient's] *Next of Kin these discussions should have taken place with you. In addition* [the consultant physician] *has recorded that he spoke with yourself and* [the patient's] *father on 1 July 2016 explaining what was planned, updating on* (the patient's) *condition and he discussed resuscitation in case of Cardiac Arrest.* [The Consultant Physician] *recorded that he informed you that the team would continue treating infection with antibiotic and if* [the patient] *develops cardiac arrest they would keep her comfortable. DNR without discussion with and opinion of* [the patient's] *family is completely inappropriate and not the standard of care we expect for patients and their family. When seeking to explain to relatives this significant stage in a patient's journey the complete and clear understanding of what has been said what this means should be established before the DNAR status is recorded on the patient's notes. The professional governance issue will be shared with the Responsible Officer of* {the consultant physician's} *Locum Agency.'*

23. The Trust stated in response to enquiries from this Office that '*The DNR discussion took place on 27/06/2016 with admitting Consultant and discussions with* [the patient's] *father on the 29/06/2016. It is recorded by* (the consultant physician) *that he spoke with mother regards the plan of care. No reference to DNR in* [the consultant physician's] *account at that time.* [The consultant physician] *records communication with mum and dad, to explain current management at this point reference made to "treating infection with antibiotics if she develops cardiac arrest we will keep her comfortable" she agreed with that (mum).'*

Communication

24. In response to investigation enquiries the Trust acknowledged that the patient's '*individual needs were not fully achieved and that communication with* [the patient's mother], *as her next of kin, should have been consistent and clear in relation to* [the patient's] *journey.'* The Trust stated that changes have been

implemented '*which include dedicated times for communication on patient's progress and concerns. The Ward Sister has also ensured that staff have been informed regarding the 'Patient Passport'. This is a standard question in the nursing assessment process on initial admission and the information from the patient's passport is communication to all staff undertaking direct care of the patient'.*

25. The Trust explained *'the Trust and staff of SWAH fully acknowledge the distress that* [the patient's] *family have witnessed throughout the time* [the patient] *spent in Hospital and wish to convey their sincere apologies if any omission or actions by staff have added to this burden. There has been significant learning and appreciation of patients and family's needs and the importance of clear open communication acknowledged.'* The Trust stated that '*Patient Passports are asked for when patients are admitted in the absence of Passport nurses on admission ward will commence the passport. The Trust has recently appointed a new Learning Disability Clinical Nurse Specialist with whom the Patient Passport will be discussed i.e. assurance that this is widely implemented and highlighted as good practice.'*

Relevant Trust records

26. I considered the DNACPR Order which is dated 27 June 2016 and signed by the Consultant. It states the decision has been '*communicated with father'.*

27. I considered the clinical records which record a conversation with the patient's mother and father and the Consultant Physician on 1 July 2016 at 16.00. ***'…****In case of cardiac arrest we will keep her comfortable & agreed about that.'*

28. I considered the patient's records and have included some instances where the management of the patient's pain and pain relief is highlighted:
1 June 2016, entry states at 02.30
*[*The patient] *crying out and repositioned but no help ? pain 500mg perfalgan given…..'*
03.15: '[the patient] *continues to scream out, oramorph 10mg given…*
04.00: '*Patient settled and off to sleep,,,'*

6 June 2016: '*Pt calling and shouting ++ oramorph 10mg given…'*

11 June 2016: '*Patient's family feel she was in pain 500mg perfalgan given for same…'*

13 June: '*…PEG feed stopped as pt. very unsettled and lamenting ++ discomfort?*

21 June 2016, the reason for admission states '*distress/agitation, multiple admissions in June.'*

22 June 2016: '*Pt shouting out +++, sho contacted…'*

The Nursing notes document on 8 July '*patient shouting out, reassurance given.'*

Relevant Independent Professional Advice

ED IPA

29. In relation to the patient's attendance at SWAH ED on 29 May 2016, the ED IPA advised the patient had *'…blood investigations including full blood count, CRP[6], lactate[7], Urea[8] and electrolytes and liver function tests. A chest x-ray and abdominal x-ray were taken, and urinalysis requested. The tests area appropriate investigations for someone presenting with abdominal pain….The records noted by the surgical doctor, report the test results were within normal limits. Chest x-ray was appropriate if there was concern about abnormal breath sounds/ reduced air entry on examination to look for infection or lung pathology."*

30. The ED IPA advised that '*both the paramedic team and the emergency department staff have recorded '?' against the pain score assessment'.* The ED IPA advised that the patient was prescribed *'…Morphine 2mg intravenously and also diclofenac[9] 50mg suppository. A further 2 doses of morphine were administered during the time* [the patient] *was in the emergency department (the last dose at 15:00). It does appear that staff recognised that* [the patient] *was in pain and administered medication to her in order to alleviate her*

[6] A high level of **CRP** in the blood is a marker of inflammation.
[7] Measuring of blood lactate levels are minerals in your body that have an electric charge. They are in your blood, urine, tissues, and other body fluids. **Electrolytes** are important because they help. Balance the amount of water in your body.
[8] is a waste product of many living organisms
[9] Medicine that reduces inflammation.

symptoms. It is noted on the observation chart that at 16:30 [the patient] *was sleeping- this would suggest pain was controlled and she was comfortable at that time.'*

31. The ED was asked whether the patient was medically fit to be discharged on 29 May 2016. The ED IPA advised '*Medically fit for discharge' is a subjective term. Following surgical assessment in the emergency department it was decided that the cause for* [the patient's] *symptoms on the 29 May was constipation. This required ongoing treatment, but the treatment could be administered in her own home rather than a hospital setting. Thus, discharge from hospital would be a reasonable course of action.'*

32. The ED IPA was asked to comment on whether the patient's disabilities were adequately taken into consideration by staff in relation to care and treatment on 29 May 2016. The ED IPA advised that '*There were some challenges in assessing* (the patient) *due to communication difficulties and most importantly pain assessment was clearly an issue. However, staffs ensured* ([he patient] *received regular pain relief during her time in the department, so despite being unable to fully obtain a pain assessment staff considered she was experiencing pain so ensured medication was prescribed - this was appropriate. Following surgical team review* [the patient] w*as discharged from hospital and transport arranged to take her home with prescribed discharge medications. It does appear that* [the patient] *was treated in line with good practice standards for timely assessment and investigations were appropriate and also that her underlying medical conditions were supported and personal care administered whilst in the emergency department.'* The ED IPA further advised *'…whilst it was clearly known that* [the patient] *had special needs due to her long-term medical conditions there is no reference to additional support being offered due to her learning needs whilst she was in the department. I could not find any documentation in relation to mental capacity assessment. I note that 29 May 2016 was a Sunday so it is unlikely that the trust had specialist staff available to support patients with learning disabilities but there is no reference to this in the records and it is noted that* [the patient] *was unaccompanied when she arrived at hospital by ambulance and it is not clear when her mother arrived.'*

33. The ED IPA was asked to comment on the communication with the patient's family. The ED IPA advised '*On 29 May 2016,* [the patient] *was brought, unaccompanied to the hospital by ambulance. At some point* [the patient's] *mother was in attendance in the department as there is reference to her going home (in) the department in the nursing notes.'* The ED IPA advised the noted detail ''*mum states history of renal stones'' and ''mum gone home & to be phoned when* [the patient] *leaves dept''. In addition, personal care needs were documented in the nursing notes.'* However the ED IPA advised that '*neither of the attending doctors made reference to any discussions with the patient's mother- this would have been useful to record what was discussed with her and to ensure that she knew the plan for ongoing care or what to do in event of a deterioration in her condition.'*

34. The ED IPA concluded '*She had an initial assessment and subsequent medical review promptly and in keeping with good practice standards. The baseline investigations undertaken were reasonable. And the onward referral to the surgical team was appropriate as the attending doctor was concerned about an intraabdominal condition. On review by the surgical team, and in conjunction with the available test results it was concluded that* [the patient] *symptoms on the 29 May 2016 were a result of constipation plus a possible urine infection. She was therefore discharge on medication.* [The patient] *was well known to the surgical team and the emergency department team were aware of her background medical conditions.'*

35. However, the ED IPA advised '*Whilst it is appropriate for hospital teams not to admit patients for whom treatments can be given effectively at home it should be considered that when pain is difficult to manage, admission for effective symptom control may be appropriate. Patients with learning difficulties have additional needs when attending hospital and these cannot always be supported by specialist practitioners, particularly at weekends, but staff should ensure actions taken to support individual needs are accurately recorded in the medical records. Medical teams should be reminded that records must be legible, and it is clear that the hospital medical records in general are somewhat disorganised when submitted for review, this makes evaluation difficult and risk*

loss of important information. In addition, the documentation of information or conversations with carers/ next of kin are important to record to ensure all appropriate information is given about a patient's condition to those caring for them.'

N IPA

Admission One (30 May to 8 June)

36. The N IPA was asked whether the patient received appropriate nursing care on each admission, taking into account her needs as a vulnerable adult. The N IPA advised that '*Yes, appropriate nursing care was provided to the patient.'* The N IPA advised that on admission, '*a nursing assessment and plan of care was documented. This provided details of* [the patient's] *reason for admission, general demographics, past medical history and an assessment of the patient's needs. Nursing assessments were carried out including Braden skin assessment,[10] moving and handling, bed rails, and nutritional score were completed.'* The N IPA advised that '... *the nutritional score was completed poorly, however it was acknowledged that the patient was at risk of malnutrition and interventions were carried out appropriately.'* The N IPA further advised that from the nursing assessment, it was identified that the patient's plans of care '…*were based on her having cerebral palsy and requiring full care and with all activities of daily living, pain, infection and pressure areas'.* However the N IPA advised that there was '*no care plan for communication.'*

37. The N IPA advised that '*Monitoring using general observations was carried out appropriately using the NEWS [11]score. On occasion the frequency of observations were below the guidelines on the NEWS score, however I do not feel that this has had any reflection on the patient's wellbeing. The action chart was completed where nursing staff identified a change or deviation in the NEWS score. The pain score which should be taken with every set of observations was documented as "?". The patient was non communicative so asking for a verbal pain score was not achievable. Another pain tool could have been utilised perhaps using behaviour or agitation as a score. Advice from the*

[10] The Braden Scale for Predicting Pressure Ulcer Risk
[11] National Early Warning Score (NEWS). Determines the degree of illness of a patient and prompts critical care intervention.

learning disability nurse could have been helpful. Documentation from The patient's family regarding how the patient communicated, or changes in behaviour that would indicate pain would also have improved this aspect of her care.'

38. The N IPA advised that fluid balance charts were completed from '*admission to discharge…In general the input was completed satisfactorily with the urine output not being able to be measured due to incontinence. ….. A blood glucose monitoring chart had been completed on admission which indicated a low blood glucose level which was acted upon and rectified with an infusion. Ongoing care records including a cannula chart and a repositioning chart were completed.'*

39. In terms of communication from the nursing staff, the N IPA advised that '*notes were completed frequently and appropriately…. There was consistent reference and acknowledgement of* [the patient's] *overall level of comfort. This was measured by* [the patient's] *shouting and calling out or her ability to sleep and appear restful. Measures were taken to address discomfort and pain by repositioning, reassurance and the use of analgesia. There is evidence of evaluation of interventions and escalation to the medical team when measures were not successful or there was a change in the physical status of* [the patient].'

40. The N IPA was asked whether there was sufficient knowledge of the patient's understanding from the nursing staff. The N IPA advised '*On admission it was documented that* [the patient] *had cerebral palsy and also there was a patient profile from the nursing home. There is documentation acknowledging that* [the patient] *is fully dependent on nursing staff for all her care needs. A care plan related to communication would have been beneficial. Information from the family regarding how* [the patient's] *behaviour changes when uncomfortable would have assisted nursing staff to assess pain and comfort. An alternative pain score could possibly have been used to also assess pain.'* The N IPA was asked whether nursing staff escalated any issues to the appropriate professionals, the N IPA advised '*Yes, there is documentation in the nursing*

ongoing communication notes that concerns had been escalated to the medical team regarding pain and abdominal distension. There is no evidence that a referral had been made to the learning disability nurse or team'.

41. The N IPA was asked whether there was appropriate communication with the patient's family during this admission. The N IPA advised '*From the 31st May to the 3rd June there is a single documentation which states that nursing staff were intending to call* [the patient's] *mother later. There is no evidence that this occurred. Documentation states that* [the patient's] *Mother was present on the 4th, 6th and 7th June. There is no documentation to indicate what information was provided or discussions took place. From this information I am unable to concur that communication with the family was appropriate.'*

Admission Two (9 June to 16 June)

42. The N IPA advised that the patient received appropriate nursing care on this admission, and '*…nursing care plans were devised based on* [the patient's] *individual needs. These included pain, infection risk, nutrition, elimination, pressure sore risk and communication. Ongoing monitoring of skin and positioning and cannula care were also evident.'* The N IPA advised that NEWS scores were documented '*accurately'* apart from '*two occasions which both had an 8 hourly interval instead of 6 hour'.* However the N IPA advised that '*this did not appear to have any consequence'* to the patient's wellbeing.

43. In terms of pain relief, the N IPA advised that the patient's score was documented as '*0/10, whereas it is evident from the nursing communication notes that the patient has several episodes of pain. An alternative pain score could have been sought from other professionals as the standard verbal pain score used was not appropriate for the patient. Measures to assess pain were however evident in the nursing communication notes.'*

44. The N IPA advised that nursing staff did have sufficient understanding of the patient's condition and that the '*nursing assessment and plan of care completed on admission clearly documented an awareness of* [the patient] *having cerebral palsy, being non communicative and quadriplegic.* The N IPA

further advised that there was evidence of '*escalation actions documentation'* and that this demonstrated '*escalation to the medical team and the nurse in charge when the NEWS score was elevated.'* The N IPA advised that there was evidence of escalation on 12 June when the patient was unsettled and when she '*appeared to be in pain when the PEG feed*[12] *was commenced. This was communicated to the medical team during their review.'* On 14 June, the patient's PEG tube was dislodged and this was '*escalated and actioned'.* The N IPA further advised that prior to discharge '*there was communication from the learning disability nurse for review in the community related to recurring admissions'*

45. The N IPA advised that there was appropriate communication with the patient's family during this admission. The N IPA advised that the nursing staff told the nursing home that they would inform next of kin of the admission and plan of care, '*the nursing staff had documented that due to it being 23:00 they would wait until morning to contact* [the patient's] *parents. There is no documentation to confirm whether this call was made in the morning.'* The N IPA advised that there was documented communication with the patient's mother on 10, 11 12 and 14 June.

Admission Three (17 June to 19 June)

46. The N IPA advised that the nursing staff completed a '*nursing assessment and plan of care'* for the patient and this provided details on '*reason for admission, general demographics, past medical history and an assessment of* (patient's) *needs.'* The N IPA further advised that *'…from this information, nursing care plans were identified and implemented. These included all aspects of* [the patient's] *care including communication. Nursing assessments on Moving and handling, pressure ulcer risk including a skin assessment body map were completed. There were ongoing care charts regarding cannula and a repositioning chart. Observations were carried out accurately and to the correct frequency according to the NEWS score apart from on 1 occasion. This would not have had any impact on the patient's wellbeing. The pain score was*

[12] A percutaneous endoscopic gastrostomy (PEG) is a procedure to place a feeding tube through your skin and into your stomach to give you the nutrients and fluids

recorded inconsistently but pain needs were addressed as documented in the nursing communication needs. An alternative pain score would have been useful or information from [the patient's] *family on how* [the patient's] *portrays pain.'*

47. The N IPA advised that there was sufficient understanding of the patient's condition, '…t*he initial nursing assessment indicates the awareness of profound learning difficulties, being non communicative and being doubly incontinent. Assessments indicated* [the patient] *fell into the high risk category for nutritional needs and the risk of skin breakdown. There were a wide range of care plans identified which demonstrated a good understanding of the care needs of* [the patient]*.'* The N IPA advised that nursing staff escalated any issues with the patient's care and advised '*There is an occasion whereby* [the patient] *was restless therefore this was escalated to the medical team.* [The patient's] *arm also appeared red and inflamed. Nursing staff recognised this, removed the source of the inflammation and subsequent actions from the medical team were carried out. The nursing home was also asked to monitor* [the patient's] *red swollen arm on discharge.'*

Admission Four (20 June to 24 June)

48. The N IPA advised that the patient did receive appropriate nursing care on this admission. The N IPA advised that '*On admission to the ward on 20th June 2016 nursing assessment and plan of care was documented. This provided a clear understanding of the need for admission, demographics, past medical history and an assessment of* [the patient's] *nursing needs. It was recognised that* [the patient] *had learning disabilities, had a diagnosis of cerebral palsy and was non communicative. Nursing assessments on moving and handling, Braden, nutrition, beds rails and falls were completed. Using this information and the admission assessment, care plans formed to meet* [the patient's] *nursing needs. These included hygiene, communication and pain. Observations were carried using the NEWS score….There were appropriate ongoing monitoring records of cannula care, repositioning, a stool chart, hourly night time checks and a pressure ulcer wound chart. Ongoing nursing communication notes were completed appropriately and consistently*

throughout this admission. However the N IPA advised that '…*An alternative pain assessment tool could have been sourced from either the pain team or the learning disabilities nurse to facilitate pain assessment.'*

49. The N IPA advised that there was sufficient understanding of the patient's condition, as the initial assessment '*indicates an awareness'* of the patient's severe learning disabilities and cerebral palsy. The N IPA further advised that nursing staff '…*acknowledged that [*the patient] *is non communicative, takes nil orally and has a PEG feed. They have also shown awareness that there seems to be an association with being PEG fed and pain. Appropriate care plans have been devised using the nursing assessments.'* The N IPA advised that the appropriate escalations were made when the NEWS score was elevated and to the dietician. The N IPA further advised that there was appropriate communication and there were '*3 entries in the nursing communication notes stating conversations with the family. On the 21st June, it is documented that the family expressed to the nursing staff that they were unhappy with the readmissions. This was escalated to the medical team.'*

Admission Five (27 June to 18 July)

50. The N IPA advised that the patient received appropriate nursing care on this admission. The N IPA advised that '*On admission to ward 2 on the 27th June a nursing assessment and plan of care was documented. This provided details of the reason for admission, general demographics, past medical history and an assessment of* [the patient's] *needs. From this information, nursing care plans were implemented. This included communication, pain, anxiety, nutrition and elimination. There was no care plan for hygiene needs but this care was evident in the ongoing nursing communication notes and had also been identified as a need during initial assessment. The nursing assessments also included Braden score, which indicated a high risk for skin breakdown, moving and handling, falls risk, nutrition and a bed rail assessment. The observations were carried out using the NEWS score and these were accurate and appropriate. There were on occasion some observations that should have been repeated within a shorter time frame however this does not impact on the patient's wellbeing.'* The N IPA further advised that '*Fluid charts were*

completed to record PEG feed, intravenous fluids and intravenous antibiotics. Episodes of urinary continuous and bowel activity were also documented.

51. The N IPA stated that '*Ongoing nursing communication notes were completed appropriately and consistently throughout this admission. They provided detailed information on the care provided each shift, actions taken when situations needed to be escalated and particular attention to pain. The documented pain score did not reflect the level of pain as documented in the nursing communication notes. An alternative pain score could have been sought to provide a consistent mode of pain assessment.'*

52. The N IPA advised that there was sufficient understanding of the patient's condition, and it is documented on admission that the patient had cerebral palsy and quadriplegia. Furthermore, the N IPA advised that *'The reason for admission was documented and there was an awareness of multiple previous admissions. There is evidence that nursing staff had acknowledged barriers to communication due to* [the patient] *being non-verbal and the care that* [the patient] *required is evident from the care plans and ongoing communication notes. Pain was highlighted as an ongoing problem to which non-verbal indicators were recognised to identify pain.'*

53. The N IPA was asked whether the nursing staff escalated any issues with the patient to the appropriate professionals. The N IPA advised that '*Yes. There are multiple entries in the nursing communication notes to demonstrate this. Escalation action notes demonstrated that the raised NEWS scores were actioned on and referred to the medical team. On the 15th July there was an episode where the NEWS score was 7. The repeated observations were carried out and nursing actions appropriate. There is documentation on the escalation actions on the observations chart to imply that this was escalated but it is not clear who to, however appropriate interventions were carried out. The protocol states that a score of 7 or more would need the medical team to be contacted within 5 minutes.*

54. Furthermore, the N IPA advised that '*There is evidence that the learning disability team had been contacted to discuss* [the patient's] *care and treatment. There are multiple entries stating that the patient had been reviewed by the* [Consultant Physician]…*Nurses escalated a pyrexia* [13]*and requested blood cultures from the medical team. Advice was sought from the pharmacy regarding application of a Butrans opiate patch. There is evidence of discussions with the H@N team to escalate concerns. Voiced concerns from* [the patient's] *mother were actioned by nursing staff by relaying concerns to the medical team. Also concerns regarding the PEG feed and insertion site were escalated to the medical team. There is also evidence of appropriate escalation to the medical team and the H@N team during the final stages of* [the patient's] *life.'*

55. The N IPA was asked whether there was appropriate communication with the patient's family during this period. The N IPA advised that '*On admission on the 27th June, it is documented that the family were present and discussed* (the patient's) *pain with nursing staff. The following day the family discussed the PEG feed and its relationship with the onset of pain with nursing staff. From the 29th June until the 4th July there were regular visits documented by nursing staff and a conversation with the medical team to which the nursing staff appeared to be present. On the 7th July* [the patient's] *mother was informed of the PEG being dislodged and of reinsertion. On the 9th July documentation shows a discussion with the family and the consultant. It is not evident that the nursing staff were involved, it demonstrates awareness of ongoing discussions with the family. On the 12th July there is documented evidence of a conversation with nursing staff and* [the patient's] *mother regarding the appearance of dried blood in* [the patient's] *mouth. Ongoing mouth care and monitoring was explained and* [the patient's] *mother appeared content with this. On the 15th July it is documented that* [the patient's] *mother spoke with nursing staff and disclosed that she had concerns regarding the medical care. The nursing staff acted on this information. On the 17th & 18th July there are several entries in the nursing communication notes regarding communication*

[13] Raised body temperature.

from nursing staff to [the patient's] *family and vice versa. These included* [the patient's] *deterioration, concerns about the PEG site,* [the patient's] *mother wishes for all to be done for her daughter. Regular interactions with the family were documented leading up to the last hours of* [the patient's] *life.'*

General comments on all admissions

56. The complainant said that her daughter's hair should have been washed on each admission. The N IPA advised that '[The patient] *had multiple admissions of differing length of stay. Although* [the patient] *did not have her hair washed on any of the admissions, I don't feel that this is a failure in nursing care. Hygiene needs were met on every admission and hair washing is not considered a priority in providing nursing care. There was no documentation to suggest the family had specifically requested a hair wash. And it was not suggested that by not facilitating this, it would have added to* [the patient's] *distress. If there was a request by* [the patient's] *family to have her hair washed then there should have been documentation to explain the rationale for not carrying this out.* [The patient] *experienced a significant amount of observed agitation perceived to be pain. Therefore, carrying out a hair wash, considering the physicality of this procedure and the possible lack of specialized equipment to perform this, seems not appropriate or in the best interests of the patient at this time.*

57. The N IPA concluded that '*care plans to meet* [the patient's] *needs were documented on all admissions. There was slight deviation to this on each admission, however the ongoing nursing communication notes evidenced that all care needs had been addressed.'* The N IPA advised that '*a significant need for* [the patient] *throughout all admissions was pain management. The pain score on the observation chart was not an appropriate tool to use for* [the patient] *as it relied on verbal scoring and* [the patient] *was non communicative. Pain was assessed, monitored and addressed appropriately by the nursing staff but seeking an alternative pain score tool would have provided a more consistent approach to this. As* [the patient] *was non communicative it would have been useful if a discussion with* [the patient's] *family or the nursing home had been documented to inform nursing staff as to how* [the patient's]

behaviour may change as a result of pain. A behavioural chart could then have been used to also assess levels of pain.'

58. The N IPA further advised that '*The learning disability team or nurse should have been made aware of each admission so they could have provided ongoing support to [*the patient's] *family, nursing and medical staff and ultimately to facilitate the best care provisions. A learning disability document/passport could have been implemented which would accompany the patient on any hospital admission to provide consistent information regarding care needs.'* The N IPA further advised that '*There is documented evidence of communication between the nursing staff and the family. The nursing team also relayed medical concerns from the family to the appropriate team. Involvement of the learning disability team or nurse may have facilitated smoother channels of communication between the family and the nursing and medical teams.'*

C IPA

Admission One (30 May to 8 June)

59. The C IPA advised that the medication provided to the patient was '*appropriate'* during this admission. The C IPA advised that the patient underwent '*chest xray, bloods including cultures…. All investigations undertaken as per documents are appropriate for the clinical situation.'* The C IPA advised that the patient was referred to '*dieticians, chest physician, microbiologist, surgical team. Referrals to these teams were appropriate, but given the clinical background and ongoing pain referral to pain management would also have been appropriate… pain was treated with above mentioned drugs which are appropriate, but good pain control was not achieved, further referral to pain team would be appropriate.'* In relation to communication with the patient's family, the C IPA advised that '*communication has been documented but from the complaint it appears that communication was not satisfactory, given the special requirements of severe disability and vulnerability.'*

Admission Two (9 June to 16 June)

60. The C IPA advised that the medication provided to the patient was '*appropriate'* during this admission. The C IPA advised that the patient underwent '*CXR*[14]*, AXR*[15]*, Bloods, Urine'.* He also advised that referrals were made to '*surgical, medical, dietician, microbiologist'* which were appropriate. However he advised that the patient should have been referred to a pain management team as she was experiencing '*ongoing pain'.* The C IPA advised there were '*no documentations of detailed communication'* with the family during this admission.

Admission Three (17 June to 19 June)

61. The C IPA advised that the medication provided to the patient was '*appropriate'* during this admission. He advised that the patient underwent '*CXR, AXR, Bloods, Urine'* which were '*appropriate'.* He advised all referrals made were '*appropriate';* however the patient should have been referred to a pain management team. The C IPA advised that there '*are no documentations of any detailed communication with* [the patient's] *family during this admission. Nursing notes on admission mention that family and nursing home aware of this admission.*

Admission Four (20 June to 24 June)

62. The C IPA advised that the medication provided to the patient was '*appropriate'* during this admission. The C IPA advised that the patient underwent '*CXR, AXR, Bloods, Urine'* and these were '*appropriate'.* He advised that referral to '*surgical, gastroenterology, cardiology'* was *'appropriate.'* The C IPA advised that there is documentation to evidence that the patient was '*experiencing pain'* and advised that the patient was given drugs but the patient was '*not referred to pain management team. It is documented that patient is comfortable on 2 occasions suggesting pain had been treated.'*

Admission Five (27 June to 18 July)

63. The C IPA advised that the medication provided to the patient was '*appropriate'* during this admission. The C IPA advised that the patient underwent '*Bloods,*

[14] Chest x-ray
[15] Abdominal x-ray

urine, CXR, CT head, CT CAP, Echocardiogram. This admission documentation reveals extensive investigation to identify source of agitation, pain and sepsis, All of these were appropriate'. The C IPA advised that '*Despite all treatment given for pain it appears that pain control was not fully achieved.'*

General comments on all admissions

64. The C IPA was asked to comment on whether the patient's disabilities were given adequate consideration by staff in relation to care and treatment. The C IPA advised that '*Documentation reveal that notes were repeatedly made of her vulnerability and her past medical history. However there is no record of MDT and referral to specialist care for vulnerable adult. Furthermore despite the above and recorded documentation, there appears to be a lack of detailed communication between the family and the senior doctors and nurses involved in* [the patient's] *care.'*

65. The C IPA was asked to comment on the patient's referral to the neurosurgery department at Royal Victoria Hospital (RVH) and whether this was adequate or whether the patient should have been referred earlier. The C IPA advised '*The two recorded contact with RBH Neurosurgical department as per their information is 29/06/16 & 15/07/16, however there is clinical documentation suggest that telephone conversation had taken place on another occasion in July 16. As no Neurosurgical concern was clinically suspected by tertiary Neurosurgical unit after full discussion and review of CT, earlier referral or discussion would not have altered clinical outcome.'*

66. In terms of pain management, the C IPA advised '*Review of records show that agitation, behavioural change and screaming as a part of pain response in this complex cerebral palsy patient was recorded on multiple occasions, however it appears that though appropriate pain treatment was given on multiple occasions, it appears that pain control was not satisfactorily achieved as per the family's complaints. It may have been appropriate in this situation to have involved specialist pain control team as well as specialist adult vulnerable psychiatrist service to achieve a multi team approach to this complex case.'*

DNACPR Order

67. The C IPA advised that '*a DNR is a clinical decision not to attempt CPR in the event of severe clinical cardiopulmonary collapse, also known as DO NOT ATTEMPT CARDIOPULMONARYRESUSCITATION (DNACPR) The overall clinical responsibility for a DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) order lies with the most senior clinician in charge of the patients care as defined by local policy.'* The C IPA advised that a DNACPR conversation with family should entail '*A detailed discussion with family with full explanation why this decision is required given the extremely poor outcome in a clinical situation should be undertaken by senior medical practitioner treating the patient.'* The C IPA advised that the DNACPR form was completed on 27 June 2016, and '*this decision was further reiterated by* (Consultant Physician) *to both* [the patient's] *mother and father during her last admission'.* The C IPA advised that the DNACPR conversation was '*appropriate'.*

68. The C IPA concluded that '*there appears to be reasonable and good standard of medical care provided. However there appears to be some lack of regular & good communication between the family, especially with* [the patient's mother] *and the senior medical and nursing staff who were involved in the clinical care of this complex case, during the multiple admissions. It may be appropriate for the trust to undertake some special educational training sessions focusing mainly on the importance of good communication in vulnerable adults with complex medical issues and disabilities. Both medical and nursing staff should be encouraged to attend these courses as a part of their regular mandatory training programmes.'*

The Complainant's response to a draft copy of the report

69. The complainant raised concerns that specific issues in relation to the nursing care of the patient had not been addressed appropriately ie. hair not brushed, face/body not washed, oral care not carried out, soiled clothing and bed linen, position in bed and submitted photographs as evidence to these issues. In relation to issue of the DNACPR the complainant highlighted that she had

spoken with a consultant 6 June 2016 and had strongly disagreed with a DNACPR at that time.

70. The complainant hoped that by bringing this complaint that children, vulnerable adults and anyone without a voice would be safe guarded, protected and their rights respected.

Further Independent Professional Advice received.

71. Following receipt of the complainant's response to the draft report, I sought additional N IPA advice. The additional clinical advice I received is enclosed at Appendix Three to this report.

Oral Care

72. The N IPA advised that *'Ideally the patient's teeth should have been brushed twice daily but this depends on patient compliance. Once daily would be acceptable. Two hourly mouthcare would have been necessary…This would have been necessary to moisten the mouth, gums and tongue and to prevent debris build up which could lead to infection….An oral care assessment should have been carried out and a plan of care documented and evaluated.'* The N IPA also advised that for the patient's first four admissions the *'…frequency of the mouthcare as documented did not meet the requirements of the patient. There are no supporting photographs for this period of the patient's mouth but dry cracked lips, and a dry coated mouth would have possibly caused discomfort. Patient could be more susceptible to infection.'* For the patient's third admission 17 June 2016 to 19 June 2016 the N IPA advised *'The nursing assessment and plan of care had identified that the patient's mouth was dry, coated with lips that were cracked and sore…..'* and '…*Identified dry, cracked and coated lips would have resulted in discomfort. Patient could be more susceptible to infection.'*

73. For the patient's admission over the period 27 June 2018 to 18 July 2016 the N IPA advised *'…Lip lubricant, chlorhexidine and nystatin were used which would indicate an infection had developed. There is one entry to indicate that the patient's teeth had been cleaned. Although there are multiple entries indicating*

mouthcare had been delivered, it was not consistent throughout the admission and lacked detail on what interventions had been carried out. There is evidence of some elements of mouthcare daily throughout this admission and use of appropriate mouthcare products. However the photographs supplied by the family, showing the patients mouth and lips indicates that interventions were not meeting the needs of the patient. There was no evidence of ongoing assessment and evaluation of current mouthcare treatment. Lips, tongue and teeth are all dry and coated which would have resulted in discomfort for the patient.' The N IPA concluded that *'Mouthcare needed improvement. There was evidence of mouthcare throughout the admissions but documentation lacked detail. Interventions did not appear to be optimal as the patient's mouth and lips appeared to be in a very poor state. (verified by the family pictures). Interventions did not appear to be evaluated and therefore changes in care to improve mouthcare were not evident.'*

Positioning

74. The N IPA advised that *'…a combination of pillows, wedges or bumpers would have been appropriate to use…' for the patient*. For admissions one to four the N IPA advised that there is evidence from the nursing communication notes, repositioning charts and photographs that care in relation to re-positioning was appropriate. In relation to the patient's fifth admission from 27 June to 18 July 2016 the N IPA advised '*There are frequent entries in the nursing communication notes that demonstrated that regular repositioning occurred. It is also documented that wedges were used to aid positioning and a diagram was used to guide them in the use of wedges. There is a night check form which monitors comfort and this was completed throughout the stay. There are three photographs that demonstrate that at this particular time that the photograph was taken the wedges and pillows were not in the appropriate place and the patient did not appear to be in an optimum position. There is no evidence to state how long the patient had been in this position so I am not able to say that this care was inappropriate.'* The N IPA concluded by advising that *'There was regular documentation regarding positioning of the patient and acknowledgement of the the [sic] patients contractures and how her position in bed was variable. There was some evidence of the use of wedges and pillows*

to facilitate positioning and prevent harm. There was no evidence that the patient suffered harm from not having the wedges at all times, however, this was a significant risk to her and documented evidence to reduce this risk should have been consistent.'

Personal Hygiene (including face/body washing, hair brushing, changing of soiled clothing and linen)

75. The N IPA advised *'Soiled clothing or sheets should be changed as soon as possible after they are found to be soiled.*' *'It would not be expected of nursing staff to document each time a soiled bed sheet or item of clothing was changed for a caseload of patients. Picture number 700 shows a small amount of blood to the sheet. I am not able to comment as to whether reasonable practice had been carried out regarding this soiled sheet as there is no indication of how long the sheet had been soiled for. This blood stained sheet would not have had any impact on the patient.'*

76. In relation to her previous advice about personal hygiene needs being met daily during the patient's first two admissions the N IPA confirmed that '*Daily hygiene would include a full body wash, including the face, and a change of bed clothing and sheets where appropriate. Hair brushing should be offered during this time. Mouthcare and teeth brushing are usually undertaken also…'* The N IPA went onto to advise that *'appropriate care'* was given between 17 and 19 June 2016. For the patient's admission from 20 June 2016 to 24 June 2016 the N IPA advised that *'…There is documentation in the nursing communication notes that a bed bath was given on the 21st June, 23rd June and the 24th June. It was not documented that a wash was given on the 22nd June. There is evidence of continence care only. This omission would not have had any impact on the patients physical wellbeing. ' During the patient's admission form 27 June 2016 to 18 July the N IPA advised that '…There is documented evidence that daily hygiene needs were carried out throughout this admission but these entries are not consistent...During this stay there are seven days where documentation does not state that personal hygiene needs were met. However, on each of these days, there is documentation that some aspects of*

personal care had been undertaken as repositioning and mouthcare entries are evident.'

Trust response to a draft copy of the report

77. In relation to the oral care and the use of the positioning wedges the Trust commented that both these elements of care would have been known about in greater detail had the patient's Hospital Passport accompanied her on her admissions.

Analysis and Findings

78. I will examine the issue of complaint under the following five elements:
    - Nursing care;
    - Hair washing;
    - Investigations and referrals;
    - Pain relief; and
    - DNACPR order.

Nursing care

79. The complainant said that basic nursing care was not provided to the patient. I further note the complainant's comments that this included issues such as personal hygiene not being addressed, oral care not carried, soiled clothing and bed linen not changed as well as the patient's positioning in bed. I also note the photographs provided by the complainant. The N IPA provided a detailed analysis of the nursing care provided to the patient including oral care, positioning and personal hygiene. The N IPA advised for each admission that in general appropriate nursing care was provided to the patient. However, there were areas where the nursing care was not in line with appropriate standards. I note and accept the N IPA'S advice that oral care '…*interventions were not meeting the needs of the patient. There was no evidence of ongoing assessment and evaluation of current mouthcare treatment.'*

80. I further note the N IPA's evidence in relation to personal hygiene care and it is my opinion that overall the patient's personal hygiene needs were met during her hospital admissions. I also note that the N IPA advised that repositioning

charts were completed for the patient throughout her admissions and '…*There was some evidence of the use of wedges and pillows to facilitate positioning and prevent harm. There was no evidence that the patient suffered harm from not having the wedges at all times..'* However I note the N IPA considered that this issue *'…was a significant risk to [the patient] and documented evidence to reduce this risk should have been consistent.'* I also note the Trust's comments that the oral care and the use of the positioning wedges are elements of care that would have been known about in greater detail had the patient's Hospital Passport accompanied her on her admissions. I will consider the Hospital Passport further at paragraph 97.

81. Although I accept the N IPA's advice that there is no evidence that the patient suffered harm from not having wedges at all times I remain concerned that this area of significant risk was not appropriately managed by the Trust particularly as the photographs provided by complainant point to the patient wedges and pillows not being appropriately positioned. I would ask the Trust to reflect on how to address this issue and consider whether additional training of staff is required.

82. The N IPA advised that for each admission '*a nursing assessment and plan of care was documented. This provided details of* [the patient's] *reason for admission, general demographics, past medical history and an assessment of* [the patient's] *needs. Nursing assessments were carried out including Braden skin assessment, moving and handling, bed rails, and nutritional score were completed.'* The N IPA advised that during each admission the nursing staff's assessments indicated '*an awareness of profound learning difficulties'* and advised that the care plans '*demonstrated a good understanding of the care needs of the patient.'* The N IPA advised that '*care plans to meet* [the patient's] *needs were documented on all admissions. There was slight deviation to this on each admission, however the ongoing communication notes evidenced that all care needs had been addressed.'* I also note that the N IPA advised that the patient's NEWS score and fluid charts were completed for each admission.

83. However she advised that during Admission five '*there were on occasion some observations that should have been repeated within a shorter time frame however this does not impact on the patient's wellbeing.'* Furthermore, the N IPA advised that for all five admissions, there was documentation to indicate that '*concerns had been escalated to the medical team'.* This was evident during Admission two on 12 June and 14 June when the patient had issues with her PEG tube. These issues were communicated to the medical team. This was also evident during Admission four, when the nursing team escalated the patient's red and swollen arm to the medical team.

84. I note the N IPA advised that in terms of the patient's pain management it would have been beneficial to employ another pain tool in order to assess the patient's pain. I will discuss this further under the pain management section at Paragraph 83. Furthermore, the N IPA advised that '*The learning disability team or nurse should have been made aware of each admission so they could have provided ongoing support to* [the patient's] *family, nursing and medical staff and ultimately to facilitate the best care provisions.'* For each admission a nursing plan of care was formulated which demonstrated a '*good understanding'* and '*evidenced that all caring needs had been addressed.'* I accept this the advice from the N IPA.

85. Therefore I partially uphold this element of the complaint and although I accept that overall the nursing care was appropriate I consider there was a failure to provide adequate oral care to the patient including the '…*ongoing assessment and evaluation of mouthcare treatment'.* I am satisfied this failure caused the patient to experience the injustice of distress and the complainant to experience upset. I also note the nursing team were in contact with learning disability nursing during Admission two, I will consider this further at Paragraph 96.

86. I note the complainant's specific issues in relation to nursing care were addressed by the Trust in its response to the complainant dated 27 February 2019. I note learning was identified and apologises were previously provided in relation to some of the issues.

Hair washing

87. The complainant said that her daughter's hair should have been washed during each admission. I note the Trust stated that the complainant's hair was washed on 19 June 2016, however the Trust also stated that due to the patient's '*condition whilst in hospital, it was felt she was not fit enough to have her hair washed.'* The N IPA also advised that '*Nursing focus was on patient's pain and discomfort. Personal hygiene needs were met every day. Hair washing is not considered an essential part of daily hygiene nursing care. However if the patient's family had specifically asked for this to be carried out then it should have been considered. I cannot find any documentation which indicates that hair washing was requested by the family.*

88. In relation to Admission five, the N IPA advised that '*this was a 20 day admission so consideration should have been made to* [the patient's] *hair being washed. However,* (the patient's) *medical condition was fragile during this time and she appeared to experience significant distress during this admission and therefore care was focused on alleviating this. It would have been perhaps not in the best interests of the patient at this time to attempt to wash her hair during the intervals where she appeared settled and rested. To interrupt these periods to attempt to wash hair, whereby the facilities to conduct this were possibly very limited, seems not the most appropriate course of action.'* I understand the complainants concerns in relation to this issue and the impact this can have on a patient's dignity. I consider in cases where a patient would not have the capability to undertake tasks for themselves there is an onus on health care staff to seek to understand their views and where this is not possible to speak to the patient's family.

89. I note the advice from the N IPA that hair washing is not an essential element of daily hygiene for a patient. The IPA acknowledged that during longer admissions hair washing should be considered however this needs to be balanced against the condition of the patient at the time. During admission 5 the patient was very ill and I accept the N IPA's advice that it was not in her best interests for her hair to be washed during her periods of rest. While acknowledging the clear concern of the complainant in this regard and her

desire to ensure the best possible care for her daughter on balance given the rationale set out above I do not uphold this element of the complaint. I do however consider the situation could have been improved if there had been clear communication with the patient's family on issues such as this. This would have assisted staff to have balanced the clinical needs of the patient with the family's views in deciding whether to wash the patient's hair.

Investigations and referrals

90. The complainant said that the patient did not receive the appropriate investigations and referrals to different specialisms during her admission. I will examine the patient's attendance at ED primarily, followed by her five admissions in SWAH. I note the ED IPA's advice that the patient underwent '*…blood investigations including full blood count, CRP, lactate, Urea and electrolytes and liver function tests. A chest x-ray and abdominal x-ray were taken, and urinalysis requested. The tests area appropriate investigations for someone presenting with abdominal pain…..'* I also note the ED IPA advised that '*It does appear that* [the patient] *was treated in line with good practice standards for timely assessment and investigations were appropriate and also that her underlying medical conditions were supported and personal care administered whilst in the emergency department.'* I accept the advice from the ED IPA and consider that the patient received the appropriate investigations and referrals during her time in ED on 27 May 2016.

91. Regarding the patient's further five admissions, I note the C IPA advised that for each admission the investigations and referrals were '*appropriate.'* The C IPA advised that the patient was referred to the RVH Neurosurgical department and that '*as no neurosurgical concern was clinically suspected by tertiary neurosurgical unit after full discussion and review of CT, earlier referral or discussions would not have altered clinical outcome.'* The C IPA advised that '*there appears to be reasonable and good standard of medical care provided.'* Therefore I do not consider that the patient should have been transferred to another ward or to RVH. I also consider that the patient received the appropriate medical investigations for her presenting symptoms.

92. However, both the C IPA and ED IPA advised that communication with the patient's family was not sufficient. The ED IPA advised that '*neither of the attending doctors made reference to any discussions with the patient's mother- this would have been useful to record what was discussed with her and to ensure that she knew the plan for ongoing care or what to do in event of a deterioration in her condition.'* The N IPA did highlight that the nursing staff spoke with the patient's mother. However she advised that although '*There is documented evidence of communication between the nursing staff and the family. The nursing team also relayed medical concerns from the family to the appropriate team. Involvement of the learning disability team or nurse may have facilitated smoother channels of communication between the family and the nursing and medical teams.'* I note the N IPA advised that during the patient's second admission '*Prior to discharge there was communication with the learning disability nurse for review in the community related to recurring admissions.'* However this was the only referral to a specialist disability service throughout all of the patient's admissions to SWAH.

93. Communication with a patient and a patient's family is extremely important for all individuals, but especially when the patient is a vulnerable adult. I reviewed the Mencap Charter which states that medical professionals should '*listen to, respect and involve families and carers'.* I also reviewed the GAIN guidance which states *'When a person with a learning disability is required to use the general hospital setting, carers should be engaged as healthcare partners throughout the pathway of care alongside, not instead of, healthcare staff.'*

94. I accept the advice from the N IPA that communication would have been enhanced by the referral to the disability learning team or nurse on all five admissions. I also note the advice from the ED IPA *'…whilst it was clearly known that* [the patient] *had special needs due to her long-term medical conditions there is no reference to additional support being offered due to her learning needs whilst she was in the department. I could not find any documentation in relation to mental capacity assessment. I note that 29 May 2016 was a Sunday so it is unlikely that the trust had specialist staff available to support patients with learning disabilities but there is no reference to this in the*

records and it is noted that [the patient] *was unaccompanied when she arrived hospital by ambulance and it is not clear when her mother arrived.'*

95. Furthermore, the C IPA advised that '*Documentation reveal that notes were repeatedly made of her vulnerability and her past medical history. However there is no record of MDT and referral to specialist care for vulnerable adult. Furthermore despite the above and recorded documentation, there appears to be a lack of detailed communication between the family and the senior doctors and nurses involved in* [the patient's] *care.'* I note the GAIN guidance from 2010 which states that '*When a person with a learning disability needs to be admitted to hospital, steps should be taken to prepare them, the hospital staff and the ward to ensure that they receive safe and effective care during their hospital stay.'* The same guidance also states that '*Each hospital ward should gather resources that can help when a person with a learning disability is admitted and ensure that this is accessible to all staff. For example, information regarding the contact points of local learning disability services'* and *'…the hospital should identify staff to take on a link or champion role specific to the care of the person with a learning disability.'*

96. I therefore consider that the Trust failed to adequately communicate with the patient's family. I acknowledge that there was one referral to the learning disability nurse for review in the community prior to discharge during the patient's second admission. However I consider that the patient should have been referred to a learning disability team to support the patient and her family during her admissions. Therefore I consider the Trust failed to refer the patient to the learning disability nurse during the patient's attendance at ED and during all five subsequent admissions to hospital. As a result of these failings, I consider the patient suffered the injustice of the loss of opportunity to receive care to meet her needs as a vulnerable adult. This care would have been enhanced by regular care and communication with the learning disability nurse. I also consider the complainant suffered the injustice of frustration as referral to the learning disability nurse would have also improved communication between the staff and the patient's family.

97. The Trust stated that *individual needs were not fully achieved and that communication with* (the patient's mother), *as her next of kin, should have been consistent and clear in relation to* [the patient's] *journey.'* I note the hospital passport was launched in Stormont in 2017 and was developed in line with GAIN Guidance. I also acknowledge that the Trust have since implemented changes to ensure that this does not happen again, '*which include dedicated times for communication on patients progress and concerns. The Ward Sister has also ensured that staff have been informed regarding the 'Patient Passport'. This is a standard question in the nursing assessment process on initial admission and the information from the patient's passport is communicated to all staff undertaking direct care of the patient'.* Furthermore, I note the update from the Trust that it has 'r*ecently appointed a learning disability acute liaison nurse in the WHSCT, the first appointed in NI and she is located on the Altnagelvin Area site, however [the Trust] have now secured funding for a second LD acute liaison nurse who will be located on the SWAH site and Omagh site.'* I am pleased to record that the Trust has implemented these changes. It is disappointing to note that the GAIN guidance was formulated in 2010; however these changes did not occur until 2019.

Pain relief

98. The complainant said that her daughter was in pain and this was not managed effectively. I note the Trust stated in response to the complainants concerns that '*…staff did not have information which would have informed them about how* [the patient] *expressed that she was in pain… In your account you have said you clearly advised that* [the patient's] *behaviour was outside her norm. As* [the patient's] *family you were her primary carers therefore we accept you would have better insight into* [the patient's] *response to pain and stress. Please accept my sincere apologies for this lack of attention to understanding in relation to* [the patient's] "*normal behaviour". The Ward Sister has engaged the help and support of the Learning Disability Nurse and together they are focusing on improving individualised patient care on Ward 2.'*

99. During her time in ED the ED IPA advised that *both the paramedic team and the emergency department staff have recorded '?' against the pain score*

assessment'. The ED IPA advised that the patient was prescribed *'…Morphine 2mg intravenously and also diclofenac 50mg suppository. A further 2 doses of morphine were administered during the time.* The ED IPA further advised that *there were some challenges in assessing [the patient] due to communication difficulties and most importantly pain assessment was clearly an issue. However, staffs ensured [the patient] received regular pain relief during her time in the department, so despite being unable to fully obtain a pain assessment staff considered she was experiencing pain so ensured medication was prescribed - this was appropriate.'* Therefore I consider the patient's pain was managed effectively in ED.

100. However, I note that the C IPA advised that for all five of the patient's admissions, '*good pain control was not achieved, further referral to pain team would be appropriate'.* I also note the C IPA's advice that '*Review of the records show that agitation, behavioural change and screaming as a part of pain response in this complex cerebral palsy patient was recorded on multiple occasions, however it appears that though appropriate pain treatment was given on multiple occasions, it appears that pain control was not satisfactorily achieved as per the family's complaints. It may have been appropriate in this situation to have involved specialist pain control team as well as specialist adult vulnerable psychiatrist service to achieve a multi team approach to this complex case.'* The N IPA advised that '*The pain score which should be taken with every set of observations was documented as "?".* [The patient] *was non communicative so asking for a verbal pain score was not achievable. Another pain tool could have been utilised perhaps using behaviour or agitation as a score. Advice from the learning disability nurse could have been helpful. Documentation from The patient's family regarding how the patient communicated, or changes in behaviour that would indicate pain would also have improved this aspect of her care.'*

101. I reviewed the GAIN guidance which provides guidance on the assessment and management of pain. The guidance states that '*Staff should be aware of possible indicators and expressions of pain that may be different than those usually seen and are specific to the individual receiving care.'* The GAIN

guidance further states that '*Hospital staff should utilise the skills and expertise of specialist pain nurses if they are available'* and that '*staff must communicate with family/carers well known to the patient, paying particular attention to baseline indicators of comfort and contentment, descriptions of changes in behaviour or previous/similar episodes.'* I was unable to find any documentation within the clinical records which illustrates that staff spoke to the patient's mother to understand how the patient communicates pain or what signs to look out for.

102. I also reviewed the patient's records and it is evident that the patient experienced pain on a regular basis. The records show that staff did attempt to manage this and provide pain relief. However I accept the advice from both the N IPA and C IPA and consider that the patient's pain was not assessed using the appropriate tools, the patient was not referred to the pain management team and the staff did not adequately consult with the patient's family on their knowledge of the patient's pain indicators. I therefore consider the Trust failed to manage the patient's pain appropriately throughout all five admissions. I consider this lead to the injustice of distress as the IPA advised '…*good pain control was not achieved'* throughout the five admissions. I also consider that this caused the complainant to suffer the injustice of upset as she saw her daughter in pain. I acknowledge the response and apology from the Trust on this matter.

103. I consider that an individual's human rights can be infringed as a result of poor care. The Patient and Client Experience Standards (DHSPSS) reflect human rights principles of fairness, respect, equality, dignity and autonomy (FREDA). Central to applying human rights in practical terms is the recognition of a patient as an individual and the delivery of care appropriate to their needs. I consider these human rights values when applying the Ombudsman's Principles of Good Administration. The first Principle of good administration "Getting it right" – acting in accordance with the law and with regard for the rights of those concerned – explicitly creates expectation that public authorities will have regard to published standards such as the Patient and Client Experience standards (DHSSPS) and failure to do so will attract criticism. It is

my view that the Trust did not show regard for the patient's human rights in terms of dignity, equality and respect by failing to meet her pain management needs during her inpatient stays. I therefore conclude that the failure of the Trust to manage the patient's pain does not meet these principles, I consider this failing to constitute maladministration and a failure in the patients care and treatment. This lead to the injustice of distress to the patient.

DNACPR Order

104. The complainant said that a DNACPR Order was discussed with the patient's father and this should have been discussed with her as the patient's Next of Kin. I further note the complainant's comments that, on 6 June 2016 in a conversation with a consultant, she disagreed with a DNACPR being placed on the patient. I further recognise that this conversation is not recorded in the medical notes.

105. I note the response and apology from the Trust on this issue. The Trust stated that the DNACPR Order was discussed with the patient's father on 27 June 2016. The Trust further stated that the Consultant Physician spoke with the complainant and the patient's father on 1 July 2016 and '*recorded that he informed you that the team would continue treating infection with antibiotic and if the patient develops cardiac arrest they would keep her comfortable.'* The Trust stated that '*DNR without discussion with and opinion of* (the patient's) *family is completely inappropriate and not the standard of care we expect for patients and their family.'* I reviewed the DNACPR guidance which states that '*Consulting with those close to patients,,, is not only good practice but is also a requirement of the Human Rights Act (Articles 8- right to private and family life and 10- right to impart and receive information...)'*

106. I also note the guidance on communicating with a Next of Kin states that '*Next of Kin should be engaged appropriately... and should be given an opportunity to express and/or discuss any concerns they may have'* and '*Next of Kin should be involved in the decision-making process and care planning for their family members'.* I also note the DNACPR guidance which states that the healthcare professional should '*record fully their reasons for not explaining the decision to*

those close to the patient at that time'. I consider that the DNACPR conversation held on 27 June 2016 should have taken place with the complainant as her daughter's Next of Kin to take her views into account prior to the decision as required by the DNACPR guidance. Therefore I consider the Trust failed to hold an appropriate DNACPR conversation with the complainant. I consider this caused the complainant to suffer the injustice of frustration as she was not kept informed of the decisions being made regarding her daughter's care.

107. I was unable to find any evidence that a conversation between the complainant and a consultant took place on 6 June 2016 or that any objections, from the complainant about the DNACPR were noted. Furthermore, I was unable to find any evidence which recorded the consultant's reasons for not discussing the DNACPR, with the patient's Next of Kin. Although I note that a conversation regarding keeping the patient comfortable was held with the patient's parents on 1 July 2016, however it does not make reference to the DNACPR Order in place and occurred four days after the DNACPR Order was signed. Therefore, I consider the consultant failed to record '*reasons for not explaining the decision to those close to the patient at that time'* and thus consider the consultant failed to record decision making in terms of the DNACPR conversation. I consider this constitutes a failure in record keeping. The Principles of Good Administration state that public bodies must keep '*full and accurate records'* and provide '*honest evidence based explanations and give reasons for decisions'.* I consider that the consultant did not provide enough detail in the records to explain why the DNACPR conversation was held with the patient's father and not communicated to the patient's Next of Kin (her mother). I consider this amounts to a failure of maladministration. I consider this caused the complainant to suffer the injustice of frustration as she was not kept informed of the decisions being made regarding her daughter's care. I am pleased to note that the Trust has already recognised this as a failing and apologised to the complainant. The Trust further stated that this issue will be shared with the Responsible Officer of the Consultant Physician's Locum Agency.

Issue 2: Whether the Trust's handling of the complaint was appropriate and reasonable?

Detail of Complaint

108. The complainant expressed dissatisfaction about the Trust's handling of her complaint. In particular, the time taken by the Trust to respond to her complaint. The complainant said that the Trust took three years to investigate her complaint and communication in relation to the delay was poor. A chronology detailing the complaints process is enclosed at Appendix Five.

Evidence Considered

Legislation/Policies/Guidance

109. I referred to the following guidance which was considered as part of investigation enquiries:

    i. I considered the DHSSPS Guidelines. The following relevant extracts were identified:

    '3.32 all correspondence and evidence relating to the investigation should be retained. The Complaints Manager should ensure that a complete record is kept of the handling and consideration of each complaint'. Standard 5 criteria 8 also requires that '*all correspondence and evidence relating to the investigation will be retained in line with relevant information governance requirements'*

    '3.37 Whatever the reason, as soon as it becomes clear that it will not be possible to respond within the target timescales, the Complaints Manager should advise the complainant and provide an explanation with the anticipated timescales. While the emphasis is on a complete response and not the speed of response, the HSC organisation should, nevertheless, monitor complaints that exceed the target timescales to prevent misuse of the arrangements.

    Responding to a complaint

3.38 A full investigation of a complaint should normally be completed within 20 working days…

3.42 The response should be clear, accurate, balanced, simple and easy to understand. It should avoid technical terms, but where these must be used to describe a situation, events or condition, an explanation of the term should be provided. The letter should:
• address the concerns expressed by the complainant and show that each element has been fully and fairly investigated;
• include an apology where things have gone wrong…

STANDARD 5: INVESTIGATION OF COMPLAINTS
All investigations will be conducted promptly, thoroughly, openly, honestly and objectively…
STANDARD 6: RESPONDING TO COMPLAINTS
All complaints will be responded to as promptly as possible and all issues raised will be addressed…
Criteria

1. *The timescales for acknowledging and responding to complaints are in line with statutory requirements;*
2. *Where any delays are anticipated or further time required the HSC organisation will advise the complainant of the reasons and keep them informed of progress…'*

The Trust's records

110. I considered the Trust's written response to the complaint dated 12 September 2017. '*Firstly I apologise sincerely for the extensive delay in providing a response to your correspondence, however I understand* [the Complaints Manager] *has maintained regular contact with* [Individual from Patient Client Council] *regarding this matter.'*

111. I am critical of the records provided by the Trust to this office in terms of complaint handling. I was not provided with all internal records in relation to the communication between the Trust and the complainant, nor was I provided with

all of the internal communication amongst Trust staff which records the decision making in relation to the complaint. I was provided with a timeline by the complainant which was from the Patient Client Council (PCC). I relied on this timeline for evidence of communication between the complainant and the Trust. I included this timeline at Appendix four (PCC Timeline).

The Trust's response to investigation enquiries

112. The Trust stated that the complaints manager has '*sincerely apologised to* [the complainant)] *for the delays she experienced as part of the complaints process.* [The complaints manager] *wishes to reiterate this apology… the reason for the delays were due to a number of factors which included staff sickness within the Complaints Department and delays incurred in getting information from professional staff involved in the investigation…'*

Analysis and Findings

113. The complainant said there was a delay in the Trust responding to her complaint. I note that the Trust forwarded its initial response to the complainant 98 working days after the receipt of the typed transcript of the meeting held on 19 September 2016. I note that the DHSPPS Guidelines state that '*a full investigation of a complaint should normally be completed within 20 working days'*. I considered the records contained within the complaints file.

114. I note the complaint comprised 21 individual issues and due to the complexity, the complaints team recognised that a full investigation would not be completed within 20 working days. A meeting was held internally with staff regarding the complaint on 18 October and the complaints department received responses from medical staff involved in the complaint on 21 October and 31 October 2016. However a response was not provided to the complainant until 20 February 2017. The PCC timeline indicated the complainant requested updates on three occasions. It also indicated the Trust informed the complainant of delays in the process. I note on 8 December 2016, the Trust informed the complainant that the response would be sent to her before Christmas. On 5 January 2017, the Trust advised it would send the response within two weeks. The Trust further advised the complainant of a delay on five

occasions in January and February, the complainant received the response on 20 February 2017.

115. Furthermore, I note the complainant was unhappy with the initial response from the Trust and submitted a second letter on 22 March 2017. The Trust responded to this submission 120 days after receiving the letter on 18 September 2017. The complainant was unhappy with this response and submitted a third letter on 1 November 2017, the complainant received this response to this on 27 February 2019, 336 days after submission. The timeline provided by the PCC indicates that a number of updates were requested by the complainant and the Trust advised of delays due to a number of matters including staff sickness and awaiting responses from clinicians. Furthermore, the Trust provided me with the details of an SAI Round Table discussion which was conducted on 12 April 2017, however the Trust did not provide me with a copy of the minutes of this meeting or any decisions taken at this meeting. I also note that an independent review was conducted and was initiated on 24 January 2018 according to the PCC timeline. I note this was delayed due to sick leave according to the PCC timeline, however the Trust did not provide me with any evidence of internal communication regarding the delay or to demonstrate the decision making taken around this issue.

116. The timescales to provide a response to a complaint can present a challenge in some complaints. The DHSSPS guidance recognises that response times may not always be achieved. Ii is important that organisations invest resources in managing complaints. This ensures that complainants receive responses or updates within an appropriate time and the opportunity to learn from complaints is maximised. While recognising the complexity of some of the issues raised in this complaint it is not acceptable to take 98 days to respond to a complaint, and then to take over 120 days to respond to questions arising from the response. In addition the complainant waited for over a year for a response to her letter querying the second response. I note that the DHSSPS Guidelines states that '*as soon as it becomes clear that it will not be possible to respond within the target timescales, the Complaints Manager should advise the complainant and provide an explanation with the anticipated timescales'*.

117. I acknowledge that an independent review was conducted and that there were issues in terms of staff absence due to sickness. I recognise the complaints department did provide the complainant with updates and anticipated timescales; however I consider that the delay in responding to the complaint was significant and unacceptable. I acknowledge the Trust's reasons for this significant delay, which were outlined to the complainant in its response. However, I do not consider that those involved in the investigation demonstrated sufficient urgency to respond to the complaint. Therefore I uphold this issue of the complaint.

118. Furthermore, paragraph 3.32 of the DHSSPS Guidelines requires *'all correspondence and evidence relating to the investigation should be retained. The Complaints Manager should ensure that a complete record is kept of the handling and consideration of each complaint'.* Standard 5 criteria 8 also requires that '*all correspondence and evidence relating to the investigation will be retained in line with relevant information governance requirements'* I consider all correspondence compiling and maintaining proper records is a basic necessity. I was not provided with all evidence of internal and external communications regarding this complaint. I was provided with partial evidence of communications and partial documentation relating to the SAI, but was not provided with evidence of decisions taken at this meeting. In these circumstances I was unable to establish the nature and extent of the matters discussed. Good record keeping is a key tenet of good administrative practice and having full and contemporaneous records means that those involved are clear at the time about what took place.

119. The First Principle of Good Complaint Handling, *'getting it right'*, requires bodies to act in accordance with '*relevant guidance and with regard for the rights of those concerned*'. The Second Principle of Good Complaint Handling, *'being customer focused'*, requires bodies to deal with *'complainants promptly and sensitively, bearing in mind their individual circumstances'*. The third principle '*Being open and Accountable'* requires a public body to keep proper and appropriate records. I consider that the Trust failed to act in accordance with these Principles in its handling of the complaint. I am satisfied that this

constitutes maladministration. I therefore uphold this issue of complaint. As a consequence, I am satisfied that the maladministration identified caused the complainant to experience the injustice of frustration, uncertainty and the time and trouble of bringing the complaint to this office.

CONCLUSION

120. I received a complaint about the care and treatment provided to the patient from May to July 2016 in SWAH. The complainant also said that the Trust did not respond to her initial complaint in a timely manner.

Issue one

121. The investigation did not find failings in care and treatment in respect of the following issues

- Overall nursing care provided to the patient;
- Patient's hair not washed during admissions;
- Pain management during her attendance at ED; and
- The medical investigations and referrals conducted.

122. However the investigation found the following failings in care and treatment;

- Failure to provide adequate oral care to the patient including the ongoing assessment and evaluation of current mouthcare treatment
- Failure to refer the patient to the learning disability nurse during all admissions;
- Failure to adequately communicate with the patient's family during all admissions;
- Failure to manage the patient's pain appropriately during all five admissions to SWAH; and
- Failure to hold an appropriate DNACPR conversation with the Next of Kin.

123. The investigation found the following failings in maladministration

- Failure to record decision making in terms of the DNACPR conversation
- Failure of the Trust to show regard for the patient's human rights by failing to meet her pain management needs.

124. I consider these failings caused the patient to suffer the injustice of loss of opportunity to receive care to meet her needs as a vulnerable adult I also consider the patient suffered the injustice of distress as she experienced pain throughout all five admissions. I also consider these failings caused the complainant to suffer the injustice of frustration and upset.

Issue two

125. The investigation established maladministration in relation to the following matter:

    i. The Trust's handling of the complaint.

126. I am satisfied that the maladministration identified caused the complainant the injustice of frustration, uncertainty, and time and trouble by bringing a complaint to this office.

Recommendations

127. I am pleased to note that the Patient Passport initiative is already in use across the Trust and that the Trust has received funding for a Learning Disability Acute Liaison Nurse to be located on the SWAH site.

128. I recommend that the Trust provides the complainant with a written apology in accordance with NIPSO 'Guidance on issuing an apology' (June 2016), for the injustice caused as a result of the maladministration/failures identified (within **one month** of the date of this report)

129. I further recommend the Trust should

- Engage the help of the Learning Disability Acute Liaison Nurse to provide training for staff who care for patients with a learning disabilities. This training should include the topics of good

communication with patients and families and ensure that staff are familiar with appropriate assessment tools and guidance.

- Develop an online learning disability resource on caring for people with learning disabilities. The resource should include copies of GAIN guidelines and pain assessment tools. The Trust should ensure that this is shared with all relevant staff.
- Provide evidence to indicate that the feedback on the DNACPR conversation was provided to the consultant physician.
- Carry out a review as to how oral care is assessed and evaluated for patients with learning disabilities within SWAH.

130. I recommend that the Trust implements an action plan to incorporate these recommendations and should provide me with an update within **three months** of the date of my final report. That action plan should be supported by evidence to confirm that appropriate action has been taken (including, where appropriate, records of any relevant meetings, training records and/or self-declaration forms which indicate that staff have read and understood any related policies).

131. The Trust accepted my findings and recommendations and advised that an action plan will be developed to take forward the necessary recommendations.

MARGARET KELLY
Ombudsman **June 2021**

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Appendix 2

PRINCIPLES OF GOOD COMPLAINT HANDLING

Good complaint handling by public bodies means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Ensuring that those at the top of the public body provide leadership to support good complaint management and develop an organisational culture that values complaints.
- Having clear governance arrangements, which set out roles and responsibilities, and ensure lessons are learned from complaints.
- Including complaint management as an integral part of service design.
- Ensuring staff are equipped and empowered to act decisively to resolve complaints.
- Focusing the outcomes for the complainant and the public body.
- Signposting to the next stage of the complaints procedure in the right way and at the right time.

2. Being customer focused

- Having clear and simple procedures.
- Ensuring that complainants can easily access the service dealing with complaints, and informing them about advice and advocacy services where appropriate.
- Dealing with complainants promptly and sensitively, bearing in mind their individual circumstances.
- Listening to complainants to understand the complaint and the outcome they are seeking.
- Responding flexibly, including where appropriate co-ordinating responses with any other bodies involved in the same complaint, where appropriate.

3. Being open and accountable

- Publishing clear, accurate and complete information about how to complain, and how and when to take complaints further.

- Publishing service standards for handling complaints.

- Providing honest evidence-based explanations and giving reasons for decisions.

- Keeping full and accurate records.

4. Acting fairly and proportionately

- Treating the complainant impartially, and without unlawful discrimination or prejudice.

- Ensuring that complaints are investigated thoroughly and fairly to establish the facts of the case.

- Ensuring that decisions and actions are proportionate, appropriate and fair.

- Ensuring that complaints are reviewed by someone not involved in the events leading to the complaint.

- Acting fairly towards staff complained about as well as towards complainants

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.

- Providing prompt, appropriate and proportionate remedies.

- Considering all the relevant factors of the case when offering remedies.

- Taking account of any injustice or hardship that results from pursuing the complaint as well as from the original dispute.

6. Seeking continuous improvement

- Using all feedback and the lessons learnt from complaints to improve service design and delivery.

- Having systems in place to record, analyse and report on learning from complaints.

- Regularly reviewing the lessons to be learnt from complaints.

- Where appropriate, telling the complainant about the lessons learnt and the changes made to services, guidance or policy.