Northern Ireland
Public Services
Ombudsman

Investigation Report

Investigation of a complaint against Belfast Health and Social Care Trust

NIPSO Reference: 21347

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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.

TABLE OF CONTENTS

Page

Case Ref: 21347

SUMMARY

The complaint is about the care and treatment provided to the complainant's mother (the patient) by the Belfast Health and Social Care Trust (the Trust).

The patient was diagnosed with lung cancer on 11 November 2014 and was successfully treated for her condition with chemotherapy and radiotherapy. The patient's treatment finished in January 2015 and she continued to attend the Oncology service as an outpatient for review appointments. The patient attended the outpatient Oncology service in the Belfast City Hospital (BCH) on 19 July 2018 complaining of new symptoms of nausea, vomiting and weight loss. The patient was diagnosed with secondary lung cancer on 30 October 2018. The patient also suffered a stroke on 12 November 2018 and was admitted to the Royal Victoria Hospital (RVH) on 14 November 2018. The patient was discharged from the RVH on 26 November 2018. However, the patient sadly passed away at her home on 29 November 2018. The complainant was concerned about particular aspects of the care and treatment provided by the outpatient Oncology service. She considered the outpatient Oncology service dismissed the patient's symptoms and failed to assess and treat her condition properly. The complainant was also concerned about aspects of the patients care during her admission to the RVH. The complainant expressed particular concern that the Trust failed to provide the patient with appropriate palliative care in the last few weeks of her life. The complaint also raised concern about to the Out of Hours (OOH) service provided on 29 November 2018. The complainant believed the OOH service was inadequate.

In order to assist with the consideration of the issues raised by the complainant advice was obtained from four independent professional advisors. Advice was obtained from a GP, a Nurse, a Consultant Neurologist and a Consultant Oncologist.

The investigation established that the care and treatment provided by the outpatient Oncology service was appropriate and reasonable and in accordance

with good medical practice.

However, the investigation established there was a delay by the Trust in admitting the patient to the stroke ward on 14 November 2018. The Trust as part of its internal investigation accepted there was a delay and introduced service improvements due to the patient's experience. These improvements were noted by the Consultant Neurologist (CN) IPA to have resulted in the Trust rating having improved from a B to an A. The investigation also found there were record keeping failures in relation to the inadequate completion of the patient's nursing assessment, completing a medications incident form and commencing a medication chart.

The investigation also established there was a delay in the patient receiving specialist support palliative care. In particular, there was a delay in the patient being reviewed by the Hospital Specialist Support Palliative Care Team (HSSPCT), a delay in the patient receiving support for managing her pain and a delay in her nausea medication being changed.

In addition, the patient's HSSPCT ought to have been more involved in her discharge planning ensuring she had the appropriate anticipatory medications upon discharge and the patient's end of life wishes documented. The advisors indicated that the failures identified in the patient's palliative care meant the patient's end of life symptoms were uncontrolled, an opportunity for advanced care planning was missed, her end of life wishes were not taken into account and her family were not supported. These failures had a very significant impact on both the patient and the complainant at an already very difficult time.

The investigation also established that a District Nurse (DN) did not escalate changes in the patient's medical condition to her GP which was not in accordance with recommended guidance. The investigation established the OOH GP did not prioritise the referral to the OOH DN service on 29 November 2019, as urgent. In addition, the investigation established the OOH DN ought to have visited the patient during the early hours of the 29 November 2018 when there had been a significant deterioration in the patient's condition. This delay meant the patient

and complainant were unsupported until the OOH GP visited later when she realised that the OOH DN had not visited to administer palliative medication to make the patient's condition more comfortable.

I made a number of recommendations to the Trust including an apology to the complainant. I also made a recommendation aimed at improving the practice of the OOH DN involved in the patient's nursing care.

I am pleased to note the Trust accepted my findings and recommendations.

THE COMPLAINT

1. The complaint is about the actions of the Belfast Health and Social Care Trust (the Trust). The complainant said her mother (the patient) was diagnosed with with non-small cell lung cancer[1] (NSCLC) on 11 November 2014. The patient's treatment finished in January 2015 and she continued to attend the Oncology service as an outpatient for review appointments. The patient was successfully treated with chemotherapy[2] and radiotherapy[3] for her condition in the Royal Victoria Hospital (RVH). The patient became unwell and was experiencing nausea, vomiting and weight loss between January 2018 and November 2018. The patient attended the outpatient Oncology service in the Belfast City Hospital (BCH) on 19 July 2018 and 27 September 2018 where she informed the Consultant Clinical Oncologist[4] of concerns regarding her symptoms. The patient was diagnosed with secondary lung cancer on 30 October 2018. The complaint relates to the care and treatment the patient received from the outpatient Oncology service. The complainant believed the Oncology service dismissed the patient's symptoms and it failed to assess and treat her condition properly.

2. In addition, the patient suffered a stroke[5] on 12 November 2018 and was admitted to the RVH on 14 November 2018. The patient was discharged home on 26 November 2018. The complainant said her mother was admitted through the ED and believed this was inappropriate for someone who had experienced a stroke and was "dying". The complainant believed the patient

[1] About 80% to 85% of lung cancers are NSCLC. The main subtypes of NSCLC are adenocarcinoma, squamous cell carcinoma, and large cell carcinoma. These subtypes, which start from different types of lung cells are grouped together as NSCLC because their treatment and prognoses (outlook) are often similar.
[2] Chemotherapy is a type of cancer treatment that uses one or more anti-cancer drugs as part of a standardized chemotherapy regimen. Chemotherapy may be given with a curative intent, or it may aim to prolong life or to reduce symptoms
[3] Radiation therapy or radiotherapy, often abbreviated RT, RTx, or XRT, is a therapy using ionizing radiation, generally as part of cancer treatment to control or kill malignant cells and normally delivered by a linear accelerator
[4] Clinical oncologists are doctors who use radiotherapy and chemotherapy to treat and manage patients with cancer. They also use a range of other treatments to treat cancers, without using surgery.
[5] **stroke** is a serious life-threatening medical condition that happens when the blood supply to part of the brain is cut off. **Strokes** are a medical emergency and urgent treatment is essential. The sooner a person receives treatment for a **stroke**, the less damage is likely to happen.

did not receive appropriate palliative care and treatment. In addition, on 29 November 2018 the complainant contacted the Out of Hours (OOH) District Nurse (DN) and OOH GP for help and support. The complainant said the OOH service provided on 29 November 2018 was inadequate.

Issues of complaint

3. The issues of the complaint which I accepted for investigation were:

Issue 1: Whether the care and treatment from January 2015 to November 2018 was managed appropriately, reasonably and in line with relevant guidance? In particular,

- Outpatient appointments
- The patient's stroke symptoms
- The patient's admission to the ED

Issue 2: Whether the Palliative/End of Life care was managed appropriately, reasonably and in line with relevant guidance in November 2018?

Issue 3: Whether the care and treatment from the Out of Hours service was appropriate, reasonable and in line with relevant practice?

INVESTIGATION METHODOLOGY

4. In order to investigate the 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 of the complaint and the patient's medical records. The Investigating Officer also obtained the patient's GP records.

Independent Professional Advice Sought

5. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisors (IPA):

- Consultant Clinical Oncologist (CO IPA) MD, FRCP, FRCR, MB, ChB, with 26 years' experience as an Oncologist treating patients with cancer with chemotherapy and radiotherapy;
- Consultant Neurorologist (CN IPA) BSC (Hons), MBBS MD FRCP, with over 23 years' experience working and specialising in Neurology;
- General Practitioner (GP IPA), MA MSc MB MCh MRCGP, with over 20 years' experience as a GP; and
- Nursing (N IPA), RGN, Diploma in AN, BSC (Hons) MA Health Service Management, a senior nurse with over 18 years' nursing and managerial experience across primary and secondary care, including palliative and end of life care.

The clinical advice I received is enclosed in Appendix five to this report.

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

Relevant Standards

7. 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.

The general standards are the Ombudsman's Principles[6]:

- The Principles of Good Administration
- The Principles of Good Complaints Handling
- The Public Services Ombudsman's Principles for Remedy

8. The specific standards are those which applied at the time the events occurred and which governed the exercise of the administrative functions and

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

professional judgement of the Trust staff whose actions are the subject of this complaint.

The specific standards relevant to this complaint are:

- National Institute for Health and Care Excellence (NICE) Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer - The Manual (2004) (Guidance on Adults with Cancer);
- National Institute for Health and Care Excellence (NICE) Stroke and Transient Ischaemic attack in over 16s: Diagnosis and Initial Management (2008) (STI Diagnosis and Initial Management Guidance);
- Department of Health (DOH) Living Matters, Dying Matters Palliative and End of Life Care Strategy (2010) (DOH Palliative and End of Life Care Strategy);
- Department of Health (DOH) Ready to Go, Planning for Discharge of Patients from Hospitals and Intermediate Care (2010) (DOH Discharge Guidelines);
- National Institute for Health and Care Excellence (NICE) Guideline Lung Cancer: Diagnosis and Management (2011) (Lung Cancer Diagnosis and Management Guidance);
- Guidelines and Audit Implementation Network (GAIN) General Palliative Care Guidelines for the Management of Pain at the End of Life in Adult Patients (February 2011) (Palliative Care Guidelines);
- General Medical Council (GMC) Good Medical Practice (The GMC Guidance);
- Nursing and Midwifery Council (NMC) The Code Professional Standards of Practice and Behaviour for Nurses, Midwifes and Nursing Associates (2015) (The NMC Code);
- Belfast Health and Social Care Trust (BHSCT) District Nursing Service Information Leaflet (2016) (DNS Information Leaflet)
- Royal Pharmaceutical Society, Palliative Care Formulary[7] (2017) (The PCF Guide);
- Belfast Health and Social Care Trust (BHSCT) Hospital Medicines Code (2017) (Hospital Medicines Code)

[7] **Palliative Care Formulary** (**PCF6**) is an essential resource for clinicians who prescribe for patients with progressive end-stage disease

- Belfast Health and Social Care Trust (BHSCT) Policy and Procedure for the Management of Comments, Concerns, Complaints & Compliments (2017) (The Trust Complaints Policy);
- Regional Palliative Medicine Group, Guidance for the Management of Symptoms in Adults in the Last Days of Life (2018) (Guidance for the Management of Symptoms);
- Belfast Health and Social Care Trust Referral Criteria for District Nursing Services (2018) (Referral Criteria for DN Service);
- Sentinel Stroke National Audit Programme (SSNAP) SSNAP Portfolio for April-June 2019 Admissions and Discharges, Results for Royal Victoria Hospital, Belfast (2019) (Stroke Audit Programme);
- www.belfasttrustcancerservices.hscni.net/PalliativeCare
- www.triagenet.net/classroom/mod
- https://www.rcn.org.uk/clinical-topics/end-of-life-care/fundamentals-of-end-of-life-care
- https://www.nhs.uk/conditions/end-of-life-care/changes-in-the-last-hours-and-days/

9. I did not include all of the information obtained in the course of the investigation in this report but I am satisfied that everything that I consider to be relevant and important was taken into account in reaching my findings. Where relevant, I included information in the report from the patient's GP records to provide the appropriate context. However, the investigation is solely considering the actions of the Trust.

10. In accordance with the NIPSO process, a draft copy of this report was shared with the Trust and the complainant for comment on factual accuracy and the reasonableness of the findings and recommendations.

INVESTIGATION

Issue 1 Whether the care and treatment from January 2015 to November 2018 was managed appropriately, reasonably and in line with relevant guidance.

Detail of Complaint

11. The complainant said the patient had been experiencing symptoms of nausea, vomiting and weight loss from January 2018. The patient informed her Consultant Clinical Oncologist on 19 July 2018 about her concerns. The patient was referred for further investigations with dermatology, gastroenterology and cardiology on 19 July 2018. The Consultant Oncologist reviewed the patient on 27 September 2018 and subsequently referred her for a CT brain scan, a PET scan and to a Consultant in Palliative Medicine[8] on 27 September 2018. The patient was diagnosed with secondary lung cancer on 30 October 2018. Subsequently, the patient suffered a stroke on 12 November 2018. The patient attended the ED in the RVH on 14 November 2018 where she was admitted to the stroke unit for two weeks and discharged on 26 November 2018. The complainant believed the outpatient Oncology service dismissed the patient's symptoms on 19 July 2018 and failed to investigate her ongoing nausea, vomiting and weight loss. The complainant also believed that as the patient had suffered a stroke, it was inappropriate to admit her through the ED in the RVH on 14 November 2018.

Evidence Considered

Guidance

12. I considered relevant extracts of the Lung Cancer Diagnosis and Management Guidance;

1.6.1 'Offer all people with lung cancer an initial specialist follow-up appointment within 6 weeks of completing treatment to discuss ongoing care. Offer regular appointments after this, rather than relying on the person requesting appointments when they experience symptoms.

[8] In some **care** settings, such as specialist inpatient units in hospitals or hospices, the **palliative care** physician is responsible for the medical management of the patient. ... strives to achieve the best quality of life for the patient for as long as possible. involves managing and anticipating pain and other symptoms.

1.6.2 Offer protocol-driven follow-up led by a lung cancer clinical nurse specialist as an option for people with a life expectancy of more than 3 months, and

1.6.3 Ensure that people know how to contact the lung cancer clinical nurse specialist involved in their care between their scheduled hospital visits'.

13. I considered relevant extracts of the Hospital Medicines Code which are included at Appendix four.

The Trust's response to investigation enquiries

14. In response to enquiries regarding the patient's symptoms being dismissed, the Trust stated '*the patient was diagnosed with stage three locally advanced non-small cell lung cancer in November 2014. She received concurrent chemotherapy along with 20 fractions of radiotherapy to her right lung under the care of Consultant Clinical Oncologist. The aim of this treatment was to cure her cancer. The patient's treatment finished in January 2015 and she continued to attend the Oncology service as an outpatient for regular review appointments on a 3-6 monthly basis with the oncology team. The purpose of providing follow up care was to monitor the patient for disease recurrence as well as also monitoring how any acute side effects of treatment were settling in the initial phase following her treatment'.*

15. The Trust further stated '*the Oncology follow up pathways are in line with nationally and regionally agreed management guidelines for treatment and follow up of all cancers produced by the National Institute for Health and Care Excellence (NICE). The relevant guidelines are, NICE Guideline Lung cancer: diagnosis and management 2011. The patient was regularly reviewed by the Oncology team in the Cancer Centre - in February, April, July, October and December 2015; in March, June and December 2016, in August and November 2017, and in July and September 2018. During this time, it was noted that she had responded well to her oncology treatment and there was no indication that her disease had returned. Follow up CT scans were carried*

out as per guidelines as well as a chest x-ray at each outpatient attendance. Additional scans were also organised to assess specific symptoms as required'.

16. The Trust confirmed '*During these follow up appointments it was noted the patient was experiencing several problems which included a new mole on her back, a dry cough, chest wall pain, swallowing difficulty, nausea, fatigue, and weight loss. These were recorded in the notes and investigated as appropriate, for example, she was referred to the dermatology service to investigate a mole on her back and when she experienced a dry cough, she was treated with steroid therapy. She was also referred to gastroenterology when she described swallowing difficulty and subsequently had a scan organised when she complained of chest wall pain. Her fatigue was felt to be due to the cardiology medication she was taking, therefore she was referred to cardiology for further opinion. The most persistent and difficult to control symptom was the nausea she experienced. Investigations including CT scans and an Oesophago-Gastro-Duodenoscopy [9](OGD) were performed. Anti-emetic[10] medication was adjusted in conjunction with her GP and a referral for specialist symptom control advice was made in September 2018'.*

17. The Trust stated '*The Consultant Clinical Oncologist reviewed the patient again as planned on 27 September 2018 following her CT scan to discuss her results with her. During the appointment, she described poor appetite, haemoptysis (coughing up blood), a cough with dyspnoea (breathlessness) over a six week period and fatigue. The CT scan completed on the 21 September 2018 suggested disease relapse in her lung however as this was inconclusive the Consultant Clinical Oncologist requested further investigations including a CT Brain and a PET-CT. He recorded in the medical notes that he had been advised by the family that the patient had also been referred for an OGD. At this appointment, the Consultant Clinical Oncologist*

[9] **OGD** stands for oesophago-gastro-duodenoscopy. It is also known as an endoscopy or gastroscopy. It is a test where an endoscopist looks into the upper part of your gut (the upper gastrointestinal tract). The upper gut consists of the oesophagus (gullet), stomach and duodenum. We use an endoscope to do this.
[10] An antiemetic is a drug that is effective against vomiting and nausea. Antiemetics are typically used to treat motion sickness and the side effects of opioid analgesics, general anaesthetics, and chemotherapy directed against cancer.

made an onward referral to the palliative care team (Palliative Medicine[11]) for further specialist support and advice with regard to the ongoing nausea for the patient' (Issue 2 refers).

18. In response to enquiries regarding admitting the patient to hospital, the Trust stated *'The patient attended an outpatient appointment with Consultant in Palliative Medicine on 13 November 2018. Consultant in Palliative Medicine assessed the patient after reviewing her electronic care record (ECR) as her oncology medical notes were not available. A follow up letter was dictated on 16 November 2018 and typed on 22 November 2018 for information on ECR and to the patient's GP. The patient was referred by Oncology to Palliative Medicine for symptom management and advice regarding nausea and likely relapsed lung cancer; she had a bronchoscopy[12] planned for 14 November 2018 in the Belfast City Hospital (BCH). During the medical assessment the Consultant in Palliative Medicine noted the patient had developed intermittent problems with her ability to speak (expressive dysphasia[13]) over the previous number of days, this symptom was referred to as "confusion" by her daughter.*

19. The Trust stated *'the Consultant in Palliative Medicine reviewed the results of an MRI from 5 November 2018 which suggested multiple brain infarcts (small strokes) possibly from a cardiac (heart) source and a PET scan report (October 2018) which suggested possible cardiac inflammation. There were no other physical signs of stroke such as loss of power to her limbs and her vital signs were recorded being within normal limits apart from a somewhat increased heart rate. The Consultant in Palliative Medicine attempted to contact colleagues in respiratory and general medicine on the BCH site to ask if they would consider admitting the patient for further investigations of these symptoms. However, a referral to the ED at RVH for possible admission to the stroke unit or possible admission to the cardiology ward, in light of recent scan*

[11] Palliative care is an interdisciplinary medical caregiving approach aimed at optimizing quality of life and mitigating suffering among people with serious, complex illness.
[12] Bronchoscopy is an endoscopic technique of visualizing the inside of the airways for diagnostic and therapeutic purposes. An instrument is inserted into the airways, usually through the nose or mouth, or occasionally through a tracheostomy
[13] disorder marked by deficiency in the generation of speech, and sometimes also in its comprehension, due to brain disease or damage.

results and speech difficulty was advised'.

20. The Trust further stated *'As the patient had attended the outpatient clinic unaided, and was assessed as medically stable during the appointment with no new acute symptoms, an ambulance transfer was not considered necessary at this time. The Consultant in Palliative Medicine recollects discussing immediate attendance at RVH versus returning home initially to sort things out, but advised that any delay should not be overly long. The Consultant in Palliative Medicine also recollects contacting colleagues at RVH re the patient the next day to ensure she had followed the advice given'.*

21. In relation to the patient's attendance to the ED, the Trust stated '*The patient attended the ED on 13 November 2018 at 18:41. Whilst in the ED, a repeat CT brain scan was performed and a decision made to discuss with the stroke team. The patient was assessed by a stroke doctor whilst in the ED at 01:00 on 14 November 2018 and the decision to admit her was made. The patient arrived onto the stroke unit from the ED where a nursing assessment was completed at 04:00 as part of her admission to the unit. We aim to admit patients to the stroke unit within 4 hours of attendance to the ED and we review this target regularly. Changes have been made to our systems since the patient's admission and whilst this is improving, access times remain a challenge. Patients are clinically prioritised when they arrive in ED and after assessment by a triage nurse. If the patient arrives by ambulance, it does not influence their time to assessment or admission times. The length of time to assessment in ED is dictated by a patient's clinical presentation'.*

22. In response to enquiries about the patient being admitted through the ED, the Trust stated '*the patient's symptoms were suggestive of recent strokes and it is appropriate for patients who present with these symptoms to be admitted through the ED. The Consultant in Palliative Medicine recalls contacting two different specialties on the BCH site to discuss admission to BCH. Although the patient was being investigated for disease progression, it was not thought she was imminently dying, so further investigation of the stroke symptoms was considered to be appropriate. Additionally, there was a planned*

investigation date for bronchoscopy on the 14 November 2018'.

Clinical Records

23. I considered relevant extracts from the patient's clinical records which are included at appendix five to this report.

Independent Professional Advice

Consultant Oncologist (CO IPA)

24. In relation to the patient's oncology care and treatment, the CO IPA advised '*The relevant NICE guidance states; offer all people with lung cancer an initial specialist follow-up appointment within 6 weeks of completing treatment to discuss ongoing care; offer regular appointments after this, rather than relying on the person requesting appointments when they experience symptoms; offer protocol-driven follow-up led by a lung cancer clinical nurse specialist as an option for people with a life expectancy of more than 3 months; ensure that people know how to contact the lung cancer clinical nurse specialist involved in their care between their scheduled hospital visits. The patient was thus followed up according to NICE guidance. I note that no guidance is provided as to the timing or type of investigations that should be performed at follow-up. This mirrors international guidance where sadly if the disease recurs after potentially curative treatment further management becomes purely of palliative intent i.e. largely to prolong life and improve symptoms. Furthermore, patients have to be well enough to have treatment and I note that even by August 2018 it was noted that the patient was becoming more fatigued and performance status two*[14] *and already at that time would have been deemed borderline suitable for aggressive chemotherapy treatments'.*

25. The CO IPA further advised '*the patient was seen three monthly from completion of chemotherapy/radiation in January 2015 for 18 months and then six monthly and then less frequently. I consider this consistent with international practice. The context of this complaint needs to be that whilst the*

[14] 1: Unable to do strenuous activities, but able to carry out light housework and sedentary activities. This **status** basically means you can't do heavy work but can do anything else. **2**: Able to walk and manage self-care, but unable to work. Out of bed more than 50% of waking hours.

CT scan suggested progression of the disease in September 2018 it was relatively small volume limited to the irradiated area around the right hilum[15]. Subsequent PET scan on 24 October 2018 was performed because the relapse was uncertain but also because of nausea and weight loss however showed the disease was much more extensive involving intrathoracic lymph nodes[16], additional pulmonary nodules[17] involvement of lymph glands within the abdomen and the adrenal gland[18]. The report concluded significant interval deterioration with recurrent disease and extensive mediastinal hilar[19] involvement contralateral hilar and right adrenal metastases[20]. In addition, the MRI scan in November 2018 showed multiple acute infarcts across vascular territories on a background of small vessel chronic ischaemia[21] and a gastroscopy showed gastro-oesophageal reflux disease. Further, the patient was admitted with fast nature fibrillation in July 2017 and required additional medication that indeed was changed because of her symptoms. There were thus a number of reasons why the patient would generally decline, become more fatigued and have nausea and intermittent vomiting. It was thus reasonable initially before the PET scan to assume it was not the cancer causing these symptoms given the relatively reassuring changes on the CT scan in September 2018 of limited progression'.

26. The CO IPA advised '*Of importance in this complaint is that the patient was appropriately referred to the stroke unit and investigated and managed there. The patient was appropriately referred by the GP to the gastroenterologists and seen in October 2018 and a further endoscopy arranged. I concur that it would not be normal practice for the unscheduled or emergency unit of an oncology department to see patients other than with the acute complications*

[15] The **hilum** is located on the medial aspect of each **lung** and provides the only route via which other structures enter and exit the **lung**.
[16] **Thoracic lymph nodes** are separated into two types: parietal **lymph nodes** located in the **thoracic** wall, and visceral **lymph nodes**, which are associated with the internal organs. Due to their location, abnormalities of the **lymph nodes** in the thorax, or chest, are not easily detected.
[17] A **pulmonary nodule** is a small round or oval-shaped growth in the **lung**. It may also be called a "spot on the **lung**" or a "coin lesion
[18] the **adrenal glands** (also known as **suprarenal glands**) are endocrine **glands** that produce a variety of hormones including adrenaline and the steroids aldosterone and cortisol. They are found above the kidneys.
[19] **Mediastinal lymph nodes** are **lymph nodes** located in the **mediastinum**. The **mediastinum** is the area located between the lungs which contains the heart, esophagus, trachea, cardiac nerves, thymus gland, and **lymph nodes** of the central chest. The enlargement of **lymph nodes** is referred to as lymphadenopathy.
[20] the development of secondary malignant growths at a distance from a primary site of cancer.
[21] an inadequate blood supply to an organ or part of the body, especially the heart muscles.

of treatment or shortly after completion of treatment. However, I note that the local unit will now assess patients who attend the hospital for other reasons.

27. The CO IPA advised '*Outpatient department review at the end of August 2017 identified nausea and worsening breathlessness and appropriate imaging with CT scan of chest and abdomen was performed in September 2017. These investigations did not demonstrate progression of the malignancy and thus the oncologist would have been reassured at the appointment in November 2017 that the nausea may well have been caused by one of the other comorbidities. In July 2018, the GP was asked to follow-up regarding weight loss, CT scan was booked. Probable recurrence was diagnosed in September 2018 at which stage when seen symptoms over a six-week period of poor appetite haemoptysis cough with breathlessness and fatigue led to referral to palliative care which was appropriately made and a PET scan requested to see there was more advanced disease. As above the PET scan showed extensive recurrence and at around the same time the patient also suffered worsening intracranial problems'.*

28. The CO IPA concluded '*In my opinion even with earlier diagnosis of extensive progression given the patient's poor health would not have been suitable for any further treatment and thus the outcome is not affected. In summary, the Oncology care and treatment was reasonable, appropriate and line with relevant standards/guidelines with respect to outpatient review from July 2017 onwards, referral to GP for follow up investigations and appropriate referral for palliative care. The patient had a number of medical co-morbidities that were likely to cause her symptoms of general decline nausea and vomiting. In hindsight the CT scan of 21 September 2018 underestimated the extent of the recurrence was really only shown on PET scan. Given the patient's co-morbidities and general poor health she would not have been suitable for treatment in any event and purely palliative care administered as was in any event'.*

29. In relation to the Trust's response to the complaint, the CO IPA advised '*I have reviewed the Trust complaint documentation and also meeting minutes.*

The Trust complaint response dated 11 January 2019 is accurate and entirely reasonable'.

Consultant Neurologist IPA (CN IPA)

30. In regards to the patient's care and treatment for her stroke, the CN IPA advised '*It was unclear when the patient first developed new neurological symptoms with word-finding difficulties. This was mentioned as periods of "confusion". According to the medical notes, it could have started from the Monday, which would have been the 12 November 2018. Best practice would dictate that she should have been seen and assessed within hours of the onset of new neurological symptoms but the stroke was not recognised at that time. It was when the patient was assessed by the Consultant in Palliative Medicine on 14 November 2018 that this new symptom was reported. The Consultant in Palliative Medicine tried to discuss the patient's case with a number of other specialists and eventually the decision was made for her to attend the ED. For someone with new onset of new neurological symptoms that would be the most appropriate place, as acute strokes should be assessed to consider whether the patient is suitable for treatment known as thrombolysis*[22] *or clot retrieval. This is in an attempt to re-open blood vessels if the stroke is caused by blockage of an artery supplying blood to the brain. This has been shown to reduce long-term morbidity and mortality. According to NICE Guidelines, this should be carried out within four and a half hours of onset of neurological symptoms'.*

31. The CN IPA further advised '*In the patient's case with unclear duration of symptom onset, possibly lasting for days, such treatment is inadvisable. This is according to all the recent guidelines for stroke treatment. There was clearly a delay in the patient being admitted to the stroke ward. She had arrived just after 18.00 on 14 November 2018, eventually arriving on the stroke ward at 04.00 the next day. This is not ideal and it would appear that the Trust has*

[22] Thrombolysis, also called fibrinolytic therapy, is the breakdown of blood clots formed in blood vessels, using medication. It is used in ST elevation myocardial infarction, stroke, and in cases of severe venous thromboembolism.

accepted this failing and has implemented a new care pathway to make sure that those with a stroke are admitted into the stroke unit within four hours as much as possible. The patient's care on the stroke ward was complicated by the fact that she was known to have carcinoma of the lung with spread and she was also symptomatic with nausea as well as being in pain. She also developed hospital acquired pneumonia which needed treatment with intravenous antibiotics and a period of non-invasive ventilation. In my opinion, her care in the hospital was appropriate'.

32. The CN IPA also advised '*I do not think that the delay in the patient's admission to the stroke unit has made a significant difference to the eventual outcome but it clearly increased the distress felt by the family. The prolonged wait in the ED before admission to the ward was not ideal. Once she was in the stroke ward, her care was within the usual normal guidelines. Planning of her discharge appears to be complicated by miscommunication between the hospital and community palliative care teams and district nursing teams'.*

33. The CN IPA highlighted '*Since the complaint was raised, the Trust has implemented a new stroke ambulatory pathway to ensure patients with suspected strokes have access to the unit as quickly as possible. The pathway has reduced the need for admission of stroke mimics to the unit, thus freeing up beds for the most acute stroke patients to access in accordance with the Sentinel Stroke National Audit Programme[23] (SSNAP) and the identified target from ED to a specialist stroke unit in four hours. SSNAP data is gathered on a quality basis, presenting in ten domains, covering 44 key indicators of stroke care. Overall scores are based on patient and team centred performance. Since the inception of the new ambulatory pathway the RVH has improved its results from B to an A rating'.*

[23] The Sentinel Stroke National Audit Programme (SSNAP) aims to improve the quality of stroke care by measuring both the structure and processes of stroke care against evidence based standards. These standards are informed by the National Clinical Guideline for Stroke, and national and local benchmarks. The **SSNAP** aims to improve the quality of stroke care by measuring both the structure and processes of stroke care against evidence based standards. These standards are informed by the National Clinical Guideline for Stroke, and national and local benchmarks/ratings.

34. In relation to the Trust's response to the complaint, the CN IPA advised '*I thought the reply from the Trust was reasonable and they have made changes to speed up admissions into the stroke ward. I think it is a positive step to improve stroke care after the unfortunate events surrounding the patient's care was audited'.*

Nursing (N IPA)

35. In relation to the patient's nursing care and treatment between 14 November 2018 and 26 November 2018, the N IPA advised '*The patient was admitted with word finding difficulties thought to be related to a stroke, secondary to an underlying malignancy. She had palliative care needs as her cancer was not curable. A nursing assessment was started at 04:00 on 15 November 2018, at this time she did not have family present (note it was the early hours of the morning and family presence could not reasonably be requested). Due to her difficulties with speech, the assessment was not completed fully. This particular element of the assessment was in line with the Nursing and Midwifery Code (NMC) "Professional standards of practice and behaviour for nurses and midwifes, with regards to keeping a clear record of your actions or omissions during care provision"'.*

36. The N IPA also advised '*From the nursing assessment it is noted that her nursing care needs included nausea, nutrition/poor appetite. The patient was documented as being alert and self-caring with no problems with her bowels or bladder. It is indicated that she had 'no breathing difficulties identified' which was inaccurate as she was also documented as having a 'persistent cough' (in daily nursing evaluations documented on same day), being on oxygen therapy and she was a smoker. In line with national guidance and local policy, if you are unable to complete the assessment, the reason should be documented (which it was); but you should not 'guess' the responses, you should wait until an accurate assessment can be documented: NMC code "complete all records accurately and without any falsification, taking immediate and appropriate action if you become aware that someone has not kept to these requirements"'.*

37. The N IPA also advised *'smokers should be offered smoking cessation advice, have the Trust's smoking policy explained and should be offered nicotine replacement therapy[24] (NRT) to help them with their cravings over their hospital admission. This is in line with local policy. The patient indicated that she did not have any pain on assessment. With regards to the cough, there was no impact in omitting this from the assessment because on the same day within the daily nursing evaluations it is documented that: "usually takes cough med at home. Prescribed PRN[25] and ordered".*

38. The N IPA highlighted *'A malnutrition universal screening tool[26] (MUST) was completed which indicated a 'medium' risk of malnutrition. From this, food charts should be completed for three days in order to monitor intake, the patient should be reassessed in one week and they should be referred to a dietitian if any concerns are identified (this is in line with national and local policy). There are some food charts within the records which demonstrate a moderate/ poor intake. In accordance with the dietitian's notes, the patient was referred to a dietitian on 16 November 2018 and was seen by the dietitian on 21 November 2018. The patient's skin and risk of pressure area breakdown was assessed using the braden scale[27] which is a recognised risk assessment tool. She had a low risk. This was in line with national guidance'. The patient was referred to the speech and language team (SALT) as she 'failed her swallow assessment' on 14 November 2018 (in daily evaluation of nursing care). She was consequently given IV fluids and was nil by mouth (NBM). This was timely (within 24 hours of admission) and was in line with national guidance'.*

39. The N IPA further advised *'Referrals on 14 November 2018 included palliative care, MDT (multidisciplinary team – physio/OT/medics) and dietitian. These were appropriate in meeting the patient's needs. With regards to monitoring pain and nausea, scores were kept on the NEWS charts. Nausea was*

[24] **Nicotine replacement therapy** (**NRT**) gives you **nicotine** – in the form of **gum**, patches, sprays, inhalers, or lozenges – but not the other harmful chemicals in tobacco. **NRT** can help relieve some of the physical withdrawal symptoms so that you can focus on the psychological (emotional) aspects of quitting
[25] **PRN**" is a Latin term that stands for "pro re nata," which means "as the thing is needed.
[26] **MUST**' is a five-step screening tool to identify adults, who are malnourished, at risk of malnutrition. (undernutrition), or obese
[27] Scoring system. Evaluates patient's risk of developing a pressure ulcer.

intermittent and difficult to control, as had been the patient's experience for a number of months. Pain increased over 16 November 2018 and 17 November 2018 and on reviewing the records, this was escalated to medical staff. This is in line with NMC Code'.

40 In relation to the patient's pain management, the N IPA advised *'Analgesia was reviewed and increased on 16 November 2018 and fentanyl patch was increased on 18 November 2018 after which the patient's pain is documented as being 'much better' by the differing staff members that reviewed her.* The N IPA also advised *'shortness of breath became an issue for the patient during this admission and was escalated to medics by nursing staff on a number of occasions. This is shortened to ATSP 'asked to see patient'; Oxygen therapy was needed and non-invasive ventilation (NIV)[28] escalation was in line with NMC Code'.*

41. The N IPA further advised *'The patient's view was taken into account and her decision to 'risk feed' (have a normal diet despite the risks) were acknowledged. Her decision not to have a package of care at home was also acknowledged. This was in line with national guidance. Discharge was in line with national guidance, in that it involved the patient, family and the multidisciplinary team'.*

42. The N IPA concluded there was an *'in-accurate nursing assessment on 14 November 2018: nursing assessments should be completed in full. If it is not possible to do so (for example family needed to complete the assessment), the assessment should be left blank with a documented rationale as to why this has not been completed; Patients who smoke: they should be informed of the Trust's smoking policy and offered support and NRT'.*

43. In relation to the Trust's response to the complaint, the N IPA advised '*the letter dated 11 January 2019 is regarding the responsibility of the patient's care between the cancer centre and her GP, having read the response and*

[28] [28] Non-invasive ventilation is the use of breathing support administered through a face mask, nasal mask, or a helmet. Air, usually with added oxygen, is given through the mask under positive pressure; generally the amount of pressure is alternated depending on whether someone is breathing in or out

also the clinical records available this response appears accurate and reasonable'.

44. The Investigating Officer made further enquiries in relation to the patient's pain management by her nursing team. The N IPA advised '*With regards to monitoring pain from the perspective of the ward nurse, pain scores should be documented. National guidance recommends documenting pain scores on NEWS charts, if pain is identified, the nurse should give 'as required' analgesia if it has been prescribed. However, if pain is difficult to manage and the analgesia that has been prescribed is not effective, the nurse should escalate to either medics, pain management specialists or the palliative care team. On 17 November 2018 nursing staff have documented that the patient drank some oramorph[29] out of a bottle that she had in her own bag, thus indicating how much pain she was in. It was difficult to know how much morphine the patient was using to control her pain from admission to 17 November 2018 when her own oramorph was discovered. The patient's fentanyl patch was increased during this timeframe which resulted in a documented improvement in pain control from 18 and 19 November 2018'.*

45. The Investigating Officer made further enquiries of the N IPA in regards to this issue. The N IPA advised '*When a patient needs medications there are three options of administration in accordance with current standards. The storage and administration of the medicine remains the responsibility of the nurse/Trust; the storage of the medication remains the responsibility of the nurse/ Trust and the patient self-administers under supervision; and the patient maintains full responsibility of the storage and administration of their medication. The patient had the medication and no-one knew about it. The patient could potentially have over dosed. Furthermore, the medication may not have been safety secured in the patient's bag, thus putting other patients at risk. What should happen therefore is that an incident form should have been competed (Datix) and the prescriber (usually the doctor) should have been informed to review the medication (dose/ effectiveness/ side effects)'.*

[29] Oramorph is a liquid form of morphine, which is often used as a pain killer, in small doses oramorph is used for the relief of long term or chronic breathlessness.

46. The N IPA further advised *'from 14 November 2018 the patient received pain monitoring and symptom control from the ward based medical and nursing teams but they struggled to control her symptoms which were complex. The patient needed specialist palliative care input to ensure optimum pain control which was why she was referred to palliative care from admission. In the patient's case, ward nurses acted in accordance with the national guidance by monitoring her pain, administering analgesia and escalating to medics when pain was uncontrolled'.*

The Complainant's Response to the Draft Report

47. The complainant provided a very detailed and extensive commentary on the draft report in which she indicated she does not accept elements of the evidence provided by the Trust and the advice of the IPA's. I have considered the complainant's comments in relation to the three issues of complaint accepted for investigation within the relevant analysis and findings section of the report.

The Trust's response to the Draft Report

48. The Trust stated it had no comments on the draft report. The Trust also indicated it accepted the findings and conclusions.

Analysis and Findings

Outpatient appointments

49. I note that the outpatient Oncology service reviewed the patient on twelve occasions between 12 February 2015 and 27 September 2018. I established the Trust recorded at the patient's outpatient oncology appointment's on 12 February 2015, 9 April 2015 and 2 July 2015 that she had '*a new mole on her back, a dry cough and chest wall pain'.* I also established on 3 March 2017, 30 June 2017, 2 November 2017 and 12 December 2017, the Trust recorded the patient had complained of '*fatigue'*. On 19 July 2018, the Trust recorded the patient complained about '*nausea and weight loss'*.

50. I further note the patient was referred by the Oncology service to the Dermatology on 12 February 2015 to investigate a mole on her back and Gastroenterology on 2 July 2015 and 19 October 2018. The patient was also

referred to Cardiology on 25 October 2018 to investigate her ongoing fatigue. The clinical records document the patient had a CT scan performed on 21 September 2018, a PET scan on 24 October 2018 and an MRI scan on 13 November 2018. The investigation also established an OGD was performed in November 2018. I also note a referral was made for the patient for '*specialist symptom control advice'* on 27 September 2018.

51. I refer to the Lung Cancer Diagnosis and Management Guidance *'offer all people with lung cancer an initial specialist follow-up appointment within 6 weeks of completing treatment to discuss ongoing care. Offer regular appointments after this…'.* I considered and I accept the CO IPA advice that in accordance with published guidance '*the patient was followed up according to NICE guidance'.*

52. I considered the CO IPA advice and accept *'the CT scan suggested progression of the disease in September 2018 was relatively small volume…however a subsequent PET scan on 24 October 2018 was performed and showed the disease was much more progressive'.* I also accept the CO IPA advice that the patient's MRI scan on 13 November 2018 identified '*multiple acute infarcts across vascular territories on a background of small vessel chronic ischaemia*[30] *and a gastroscopy showed gastro-oesophageal reflux disease'.*

53. I also note the CO IPA highlighted the patient had been admitted to hospital with '*fast nature fibrillation in July 2017'* which required a change to her medication. I considered and I accept the CO IPA advice that *'there were thus a number of reasons why the patient would generally decline... it was thus reasonable initially before the PET scan to assume it was not the cancer causing these symptoms given the relatively reassuring changes on the CT scan in September 2018 of limited progression'.* I considered the CO IPA advice and I accept '*the oncology care and treatment was reasonable, appropriate and line with relevant standards/guidelines with respect to outpatient review from July 2017 onwards and referral to GP for follow up investigations'.* I note the CO IPA advised '*given the patient's poor health*

[30] an inadequate blood supply to an organ or part of the body, especially the heart muscles.

would not have been suitable for any further treatment and thus the outcome is not affected'.

54. I note the complainant's response to the draft report she stated the oncology department did not keep her *'adequately informed, offered no information, guidance and it seemed likely that my mother* [the patient] *was coming to end stage'.* Upon examination of the clinical records, I consider the outpatient Oncology service was regularly reviewing and assessing the patient's condition, including making onward referrals for further investigations into her nausea, vomiting and weight loss. I consider the care and treatment provided by the outpatient oncology team was appropriate and reasonable and in accordance with guidance. Therefore, I do not uphold this element of the complaint. However this does not detract from the view expressed by the complainant as to the extent of her knowledge about her mother's condition. I would remind the Trust and the staff involved of the importance of frequent and clear communication with patients and where consent is provided their families.

Admission to the ED and Stroke Symptoms

55. The investigation established the patient was reviewed by a Consultant in Palliative Medicine in the BCH on 13 November 2018 who detected the patient '*had developed intermittent problems with her ability to speak over the previous number of days'.* I note the Trust stated the Consultant in Palliative Medicine reviewed the patient's most recent MRI and PET scans and attempted to admit the patient to the BCH for further investigations. However, the Trust stated '*a referral to the ED at RVH for possible admission to the stroke unit or possible admission to the cardiology ward was advised….'.*

56. The clinical records document the Consultant in Palliative Medicine discussed with the patient '*immediate attendance at RVH versus returning home initially to sort things out however advised to ensure there was no unnecessary delay in attending the RVH'.* I established from the clinical records the patient attended the ED at 18.41 on that same day where she was triaged at 19.24 and reviewed by an ED doctor at 21.10.

57. I note in response to the draft report the complainant raised concern about

the delay in the patient receiving a brain scan and indicated that she considered that staff had not noticed how quickly she was deteriorating. She was concerned about the delay in the patient being admitted to the stroke ward. The clinical records support the time line referred to by the complainant. They show that the patient was not assessed by *'a stroke doctor'* until 01.00 and was not admitted to a stroke ward until04.00 on 14 November 2018.

58. The complainant was also concerned about swelling in her mother's feet which she indicated that she raised with a doctor who did not take the issue seriously. I have not identified any record that this was recorded in the medical notes which is concerning or that anyone took the time to discuss the issue with the complainant. While appreciating that it may have been a busy time for staff, it is also a very stressful time for patients and their families and appropriate communication can help to alleviate some of the stress.

59. I considered the CN IPA advice and accept '*For someone with new onset of new neurological symptoms* [the ED] *would be the most appropriate place'.* I also considered and accept the CN IPA advice that *'there was clearly a delay in the patient being admitted to the stroke ward'.* I would highlight and I accept the CN IPA advice '*once she was in the stroke ward, her care was within the usual normal guidelines'.*

60. As noted above and accepted by the Trust there was a delay in admitting the patient to the stroke ward from the ED. I consider this delay to be a failure in the patients care and treatment. I therefore uphold this element of the complaint. I consider the delay in admitting the patient to the stroke ward to have caused the patient the injustice of upset and frustration. I also considered the CN IPA advice that '*I do not think that the delay in the patient's admission to the stroke unit has made a significant difference to the eventual outcome but it clearly increased the distress felt by the family',* I accept this advice and consider the failure identified caused the patient's family the injustice of distress. I welcome the Trust's acknowledgement of this failure to meet the accepted standard for admission to a stroke ward and the apology to the patient's family. I also welcome the Trust's implementation of a new care pathway to ensure that those with a stroke are admitted *'to the*

stroke unit within four hours of attendance to the ED and' and it reviews *'this target regularly'.* Upon examination of the Stroke Audit Programme, I established the results of stroke admissions has improved in the RVH since the care pathway was introduced. I note the CN IPA highlighted this service improvement. He advised that since its inception the RVH have improved its result from a '*B rating to an A rating'.*

61. In relation to the patient's nursing care and treatment on the stroke ward, I considered the N IPA advice and accept the patient's '*MUST tool was completed…..food charts completed within the record…..skin and risk of pressure area breakdown was assessed and referrals made to SALT, Palliative care, MDT, Physio, OT and Medics'.* I also accept the N IPA advice that the nurses were *'monitoring pain and nausea…. pain scores were kept on the NEWS charts….analgesia was reviewed and increased….the patient's views were taken into account and her discharge were all in line with national guidance'.* The clinical records also document the patient's pain had increased on 16 November and 17 November 2020. Nursing staff escalated this to the medical staff, which was in accordance with recommended guidance and standards.

62. I also note the N IPA advice that '*Smokers should be offered smoking cessation advice and should be offered nicotine replacement therapy (NRT)*'. Upon review of the patient's nursing assessment from 14 November 2018, I have not identified any record which indicates the patient was given any smoking cessation advice, had the Trust's no smoking policy explained, was offered NRT or referred to the smoking cessation service. It is my view the patient was diagnosed with terminal lung cancer and therefore unlikely to recover from her disease. Therefore, I consider these actions apart from not offering NRT were reasonable though I would have expected a record to have been created of this consideration. I also note the complainant expressed concern in response to the draft report that because the patient was a smoker the issues she raised were not taken seriously and that appropriate care was not provided by nursing staff. I have been unable to verify these concerns from the records avaliable.

63. I also considered and I accept the N IPA advice that elements of patient's '*nursing assessment was not accurate, there was no acknowledgment of oxygen therapy, persistent cough and smoking'*. The NMC Code states that all records should be completed '*accurately and without any falsification, taking immediate and appropriate action if you become aware that someone has not kept to these requirements*". I therefore find the failure to adequately complete the patient's nursing assessment on 14 November 2018 was a failure in her care and treatment. However, I do not consider the patient suffered an injustice due to this failure as she continued to be reviewed and observed by nursing staff who observed her coughing. I would however stress the importance of accurate recording of information in nursing assessments to ensure that patients receive safe and effective care.

64. I would draw to the Trust's attention the N IPA's comments the patient had '*drank some oramorph out of a bottle that she had in her own bag'*. I established from reviewing the patient's clinical records on 17 November 2018, the nurse recorded '*before the administration of pain medication, the health care assistant referred to me to "have seen the patient drinking something from her handbag". I walked in and asked the patient could I open the bag beneath the bed where I found a bottle of oramorph. The patient denied to have been drinking from it. Hospital policy for medication administrations explained to the patient. Nurse in charge made aware and oramorph put in the locker…other medications found in the same bag and put in the medications trolly…explained to the patient that we understand she is in pain and that the oramorph has been prescribed by the doctor…explained that it is very dangerous that she was taking it when I was providing prescribed dose'*.

65. In response to the draft report, the complainant said that she felt that the patient taking her own oramorph was due to the fact that her pain was not managed appropriately. The complainant was also concerned that this was allowed to happen and the risk of overdose. I note the N IPA advised '*the prescriber (usually the doctor) should have been informed to review the medication (dose/ effectiveness/ side effects)'*. Upon examination of the

clinical records, I established an F1 doctor '*was made aware of the incident'* and the patient was reviewed and monitored and the medication was removed from the patient and safely stored elsewhere. I note from the records the patient's pain relief was reviewed and assessed on 16 November 2018. Following the incident with the patient consuming her own oramorph on 17 November 2018, nursing staff advised medical staff and another review of pain relief was carried out on 18 November 2018. I note the complainant's clear concern about this issue and the importance of adequate pain relief being provided. However while sufficient evidence exits to indicate that the patient's pain was being reviewed this was without the benefit of HSSPCT who provide specialist advice on pain relief in patients where pain is difficult to manage. The delay in input from the HSSPCT is considered at paragraph 100.

66. I refer to the Hospital Medicines Code which states '*Patient's own medicines on admission, these medicines are the property of the patient, and should not, be destroyed or otherwise disposed of without the agreement of the patient or their carer. Medicines brought in by the patient, patient's carer or Northern Ireland Ambulance Service (NIAS) should only be used in the hospital when they can be positively identified, meet defined quality criteria and are appropriately labelled. They should be approved for use by appropriately trained staff. Where this is not the case, the patient should be advised accordingly'.* I further note the Hospital Medicines Policy states '*The medicines must be securely stored. Patient's Own Drugs (PODs) should be stored in a POD locker if available or in medicine trolley / cupboard separated from ward stock, securely closed and labelled with patient details at ward level. The patient's own medicines must be stored in a separate area away from ward stock. This is to avoid the inadvertent administration of one patient's property to another patient'*. With this in mind I accept the patient's nursing staff removed the medicine from the patient and stored it safely and securely.

67. However, I accept the N IPA advice '*that an incident form should have been completed'*. I have not been presented with any evidence that an incident form

was completed. The Hospital Medicines Code also refers to the medication incident reporting, specifically '*The Trust is committed to developing a reporting and learning culture so that risks to patients and staff from preventable medication incidents are minimised. This relies on effective reporting and analysis of medication incidents and recognises that to improve safety, risks must first be identified. To ensure identification of medication risks, a Trust incident form should be completed for all medication incidents, ideally this is done online using datixweb*[31]*. Lessons can then be learned and, where appropriate, action taken to reduce recurrence. A medication incident is defined as any preventable medication related event that could have or did lead to patient harm, loss or damage. This definition encompasses 'near misses', that is, those medication related occurrences where the patient did not suffer harm, but there was the potential for harm, loss or damage'.* Therefore, I consider the failure to complete a Trust medication incident form to have been a failure and not in accordance with recommended guidance.

Issue 2 Whether the Palliative/End of Life care was managed appropriately, reasonably and in line with relevant guidance in November 2018?

Detail of Complaint

68. The complainant said the patient remained very unwell when she was re-diagnosed with lung cancer on 30 October 2018. The complainant believed when the patient was admitted to the RVH on 14 November 2018, she was dying. The complainant said the patient was discharged from the RVH on 26 November 2019 and subsequently passed away on 29 November 2018. The complainant believed the Trust failed to provide the patient with palliative and end of life care between 14 November 2018 and 29 November 2018.

Evidence Considered

Guidance

[31] Internal Trust Intranet

69. I considered the relevant extracts from the Palliative Care Guidelines which are included at Appendix eight.

70. I examined the DOH Palliative and End of Life Care Strategy and I considered the following section relevant to the investigation;

Section 6.21 *'Improving the pre-planning of care is one of the most important ways in which person-centred care can be achieved and communication and decision-making between clinicians and patients made more effective'.*

'The palliative and end of life care needs of patients families and carers are identified, addressed and regularly reviewed as a matter of course, including the need for physical, spiritual, psychological, financial and social support'.

71. I examined the DOH Discharge Guidelines and considered the following relevant extracts:

'Operating principles for effective discharge:

1. 'Discharge and transfer planning starts early to anticipate problems, put appropriate support in place and agree an expected discharge date'.

3. 'The care planning process is co-ordinated effectively'.

5. 'The multidisciplinary team works collaboratively to plan care, agree who is responsible for specific actions and make decisions on the process and timing of discharges and transfers'.

7. 'Patients and carers are involved at all stages of discharge planning, given good information and helped to make care planning decisions and choices'.

72. I examined the RCN Fundamentals of End of Life Care and considered the following relevant extracts:

'*There are some fundamentals of end of life care that apply to all care settings in England, Northern Ireland, Scotland and Wales.*

- *People should be seen as individuals, asked what is important to them and involved in all discussions and decisions about their wishes and care.*
- *Everyone should get fair access to care no matter where they live or what their circumstances.*
- *People should be supported to be as comfortable as possible and all care and treatment should be reviewed regularly to ensure that this happens.*
- *The care the individual receives should be coordinated so that everyone involved is aware of the plans; changes should be shared and transitions managed in a way that ensures the person and the people who are important to them are part of this. The individual should be able to access support from informed staff day or night.*
- *The individual should be assured that all staff involved in their care are competent, confident and compassionate.*
- *The community and the public also have a role to play. They should be able to have conversations about death and dying, including what can be done outside the health and social care systems'.*

73. I examined the Trust's Complaints Policy and considered the following relevant extracts:

    Objectives – '*To ensure complainants receive open, honest and proportionate responses to their complaints where mistakes are acknowledged, explanations provided for what went wrong and appropriate and proportionate measures are considered to put things right'.*

The Trust's response to investigation enquiries

74. In response to enquiries regarding the patient's palliative care, the Trust stated '*All patients receive "general" palliative care – to meet their physical, psychological, social and spiritual needs - from their clinical teams both in the community and hospital, but may also be referred to specialist palliative care teams if their needs are thought to be "complex*". *The patient was assessed by the Consultant in Stroke Medicine*[32] *on the post take ward round on 14*

[32] A **Stroke** Specialist is a physician with specialist skills in **stroke**.

November 2018 at 09:15. A review of the patient's records from ECR was undertaken. A history was taken from the patient and her complaints of nausea, weight loss (more than 1 stone) and recent haemoptysis[33] were noted. The Consultant in Stroke Medicine performed a clinical examination and a management plan was put in place. This included a referral to the Hospital Supportive and Specialist Palliative Care Team (HSSPCT). As the patient had reported significant weight loss, a referral was also made to the hospital dietician and intravenous multivitamins were commenced. On admission to hospital the patient was risk assessed, which confirmed she was unable to safely swallow food/fluids and was advised to not take any food or fluids orally. She was identified to be made nil by mouth and therefore her regular oral medications where prescribed via the intravenous route (IV) and this included IV metoclopramide[34] (an antiemetic)'.

75. The Trust stated '*the Consultant in Stroke Medicine reviewed the patient on 15 November 2018 and she reported ongoing nausea. A palliative review was recommended in the care plan. The Consultant in Stroke Medicine reviewed the patient on 16 and 17 November 2018 and again advised palliative review. On the 16 November 2018, the patient reported that pain was not controlled by her regular fentanyl patch and as required oramorph was prescribed. We recognise and acknowledge there was a delay in the patient being referred to the HSSPCT. We are extremely sorry for this and have apologised to the patient's daughters for this'.*

76. The Trust further confirmed '*on 17 November 2018, the patient developed signs of a chest infection and intravenous antibiotics were commenced. She deteriorated due to her chest infection on 19 November 2018 and required a period of NIV to help improve her respiratory status. The respiratory team assessed the patient. The HSSPCT received a referral from a staff nurse on ward 6F on 16 November 2018, as advised by the Consultant in Stroke Medicine. The referring nurse prioritised the referral as "non-urgent" and the*

[33] **Haemoptysis** is the coughing of blood. **Haemoptysis** originates from the respiratory tract below the level of the larynx

[34] Metoclopramide is a medication used mostly for stomach and esophageal problems. It is commonly used to treat and prevent nausea and vomiting, to help with emptying of the stomach in people with delayed stomach emptying, and to help with gastroesophageal reflux disease.

reason for the referral was "symptom management". According to an informal triage system used by the HSSPCT in the RVH, the nurse specialist discussed the patient with a ward nurse who was caring for the patient, who was of the opinion that the patient was not greatly symptomatic at that time. During a further triage discussion on 19 November 2018, the nurse specialist was advised the patient was in receipt of NIV and was having active medical management of her symptoms. Further reference to "awaiting Palliative Care review" was annotated in the patient's medical notes on 17 and 19 November 2018 and a further annotation by the Consultant in Stroke Medicine's team on 21 November 2018 noted "palliative care to see".

77. The Trust also stated '*The HSSPCT received a second referral on 21 November 2018 at 11:30 and a HSSPCT nurse specialist assessed the patient at 14.30 that day. As per the patient's medical notes, the HSSPCT nurse specialist met with the patient and two daughters, and advised medication for her nausea. The patient and family had no further issues at that time. A referral was placed to Bradbury DN Team on 22 November 2018 from ward 6E RVH requesting a commode to facilitate the patients discharge to her daughter's home. The communication requested the DN to contact the ward to discuss the patient's palliative care needs. The DN contacted the ward later that afternoon. At that time it was anticipated the patient would discharge from hospital on 26 November 2018, however a further referral would be sent from the ward to advise of final care needs. On 26 November 2018, the patient's discharge was confirmed following receipt of a referral requesting palliative care and review.*

78. The Trust stated *'As the patient had not been previously known to DN services prior to her admission, a palliative care assessment was planned for the following day 27 November 2018'.* The Trust also stated *'A second referral was placed to the team requesting the administration of clexane[35] that evening at 22.00. On reviewing the nursing documentation, it would appear the clexane injection was administered at 17.45 on 26 November 2018 on the*

[35] Enoxaparin sodium is an anticoagulant medication. It is used to treat and prevent deep vein thrombosis and pulmonary embolism including during pregnancy and following certain types of surgery. It is also used in those with acute coronary syndrome and heart

ward, due to the patient's late discharge that day. There was a final team review on 26 November 2018 when no symptoms were identified and the ward nursing staff were advised to make an onward referral to district nursing for "general palliative assessment"'.

79. The Trust confirmed '*On 27 November 2018 the DN visited the patient and undertook a palliative care assessment. Within this assessment, an offer was made for DN to assist the patient with her personal care needs. This offer was declined, as the patient's family wished to assist her at that time. The DN arranged daily administration of clexane injections and palliative support. The patient continued to receive daily support and palliative symptom control until the rapid deterioration of her condition in the early hours of 29 November 2018'.*

80. The Trust stated '*The team is very sorry there was a delay before a palliative care nurse came to see the patient. The feedback received from this complainant has been shared with the HSSPCT at the RVH site and has been discussed with the nurse specialists. The HSSPCT take feedback seriously and recognises that there were missed opportunities for assessment and management of the patient's symptoms, distress, and advance care planning. The team will use the learning from this complaint to improve the service (including HSSPCT triage system) we provide to patients and families within the BHSCT'.*

81. The Investigating Officer made additional enquiries of the Trust in relation to the referral process to the HSSPCT. The Trust stated '*The team administrator received the telephone referral on [*16 November 2018*], which was recorded in the message book and referral form. The patient had a diagnosis of Lung Cancer. Patients with Lung Cancer are referred onwards to the Lung Cancer Nurse Specialist. The referral form was therefore received by Nurse Specialist from the Generic Supportive & Specialist Palliative Care Team RVH site. The referring nurse prioritised the referral on [*16 November 2018*] as "non-urgent" and the reason for the referral was "symptom management".*

82. The Trust further stated '*the referring nurse's normal protocol would be to*

telephone through to extension for a palliative referral, leave a message on the answering machine notifying of referral. The Palliative care team then pick up the telephone referral and telephone back, complete a pro-forma for details of the patient then come out and review'. The Trust stated there was a further entry in nursing records on '*20th November "palliative care to see, contacted again today Nurse Band 6"".*

83. The Investigating Officer made further enquiries of the Trust in relation to communication between ward staff and the HSSPCT. The Trust stated *'the HSSPCT rarely receive emails regarding patient referrals at RVH site. Telephone Calls are recorded in message book. Communication and information is transcribed to the HSSPCT Referral Form. Weekly Activity sheets are completed detailing number of face-to-face visits patients receive per week per nurse. The Nurse Specialist discussed the patient with a ward nurse who was caring for the patient, who was of the opinion that the patient was not symptomatic at that time. During a further telephone discussion on Monday 19 November, the Nurse Specialist was advised the patient was in receipt of NIV and was having active medical management of symptoms. This interaction was recorded a "check" on the HSSPCT weekly activity sheet'.*

Clinical Records

84. I considered relevant extracts from the patient's clinical records which are included at appendix five to this report.

Independent Professional Advice

Nursing (N IPA)

85. In relation to the patient's referral to the HSSPCT, the N IPA advised '*The Trust defines palliative care as "the active, holistic care of patients with advanced, progressive illness. Palliative care aims to improve the quality of life for patients facing serious illness and for their families, through the assessment and management of physical symptoms, and psychological, spiritual and social issues". Palliative care can be provided by ward based nurses and medics, however the patient had 'complex symptoms' that she*

had been experiencing since July 2018 and thus should have received specialist palliative care from admission. The need for specialist palliative care from this admission is evidenced by the fact that the plan was to refer her to the specialist palliative care team on 14 November 2018'.

86. The N IPA further advised '*On reviewing the medical records, on 14 November 2018 at 09:15 it is documented that a "referral [was] made to palliative care" this was mainly concerning the symptom of nausea that was not responding to 'usual' treatments. This is reiterated on 15 November 2018 whereby "referral made to palliative care" is further documented. On 16 November 2018 "awaiting palliative care review" is documented. Within the nursing notes from 15 November 2018 overnight and into the 16 November 2018 it is documented that a palliative care team referral had been made. It is very unclear therefore from the clinical records when the actual palliative team referral was made. It appears to have been 14 November 2018. This could be an explanation for the delay in providing specialist palliative care – poor communication between the medical team and the nursing team, with no clear indication of when the referral was made to specialist palliative care within the patients notes'.*

87. The N IPA advised '*The patient's main symptoms warranting specialist palliative care review were "nausea not responding to cyclizine or ondansetron[36]." In addition to this, from 16 November 2018 nurses contacted medics to review the patient due to pain. It is documented by the reviewing doctor at 19:00 that the patient reported "normal cancer pain but much worse". Despite the addition of another analgesia (codeine), medics were called again to see the patient at 00:15 with "ongoing pain LHS [left hand side] chest". Nebulisers, oral steroids (prednisolone[37]) and chest physio were arranged'. At 04:23 on 17 November 2018, medics were again called as the patient was "in severe pain". Later on that day it is documented that "pain since yesterday" and "awaits palliative care referral made". At this point, the Consultant is*

[36] **Ondansetron** (**Zofran**) is used to prevent nausea and vomiting that may be caused by surgery or by medicine to treat cancer.
[37] Oral steroid

questioning if the referral has actually been made due to the time that has elapsed since the initial reference to a referral being made (now three days)'.

88. The N IPA also advised *'On 17 November 2018 nursing staff have documented that the patient drank some oramorph out of a bottle that she had in her own bag; thus indicating how much pain she was still in. The patient's fentanyl patch was increased on 18 November 2018 from 87.5mcg to 100mcg. On 19 November 2018 on review, it is noted the patient is needing increased doses of PRN[38] (pro re nata, as required) oramorph to control her pain but that it does appear to have improved. "Palliative referral re: pain and nausea" is once again documented. On 20 November 2018 it is documented that "nausea [has] improved". However, on 21 November 2018 during consultant review it is documented that the patient remains in pain and has "persistent nausea"'.*

89. The N IPA further advised '*Nursing staff escalated the patient to medics for these ongoing symptoms and analgesia was added or amended. Escalation was timely and medication was given as needed as per the medication charts and evaluations. In accordance with the NEWS charts, there appears to have been an improvement in the patient's pain on 18 November 2018. This is when her fentanyl patch was increased. In conclusion, from 14 November 2018 the patient received symptom control for pain and nausea from the ward based medical and nursing teams but they struggled to control her symptoms and she did not receive specialist palliative care until 21 November 2018. Her pain was poorly controlled from admission through until 18 November 2018 and she needed frequent doses of oramorph to control her pain thereafter. Nausea was persistent and as it was not responding to the usual treatments specialist advice was needed. In summary, whilst ward based staff responded to the issues of pain (improved control from 18 and 19 November 2018 with increase in fentanyl patch) and nausea (not controlled, ongoing) experienced by the patient, her symptoms were 'complex' and she needed specialist palliative care, which she did not receive'.*

[38] **PRN** (pro re nata) or 'when required' dose can treat many different conditions.

90. The N IPA also advised *'Pain management from a palliative care nurse perspective is 'specialist'. They will provide advice on the management of pain when ward nurses and medics are struggling to control and manage a patients 'palliative' pain (pain which is secondary to an incurable condition). The palliative care nurse will give advice on which analgesia to use and at what dose. They will review the patient until pain is adequately controlled from the patient's perspective. The ward nurses will continue to monitor pain (using pain scores) and administered prescribed analgesia. The patient was referred to palliative care nurses on 14 November 2018. She was not seen until 21 November 2018 by which time her pain was documented as controlled. She therefore struggled with uncontrolled pain, warranting self-administration of oramorph (unbeknown to staff) until 17 November 2018. On the 18 and 19 November 2018 following an increase in the strength of her fentanyl patch, the patient's pain was 'much better'.*

91. The N IPA advised '*Specialist palliative care was not afforded to the patient until 21 November 2018. She was then seen on three occasions prior to discharge. On 21 November 2018 the patient does not complain of pain and it is documented by the palliative care nurse that her fentanyl patch (100mcg) and one or two 20mg doses of oramorph per day were having a good effect. However, she was still suffering from nausea. The palliative care nurse recommends reintroducing a medication that the patient was taking in the community to control her nausea, but this is not prescribed until 26 November 2018 (the day of discharge) and is thus not given'.*

92. The N IPA advised '*On 22 November 2018 the patient is seen again by the palliative care nurse, again she complains of ongoing nausea. The following is documented "please clarify/ inform family type of antiemetic medication on discharge". It is very unclear, but it appears that the specialist nurse intended to change the type of medication to control the patients nausea but that she did not know what she had been using previously and if or why it had been stopped. The palliative care nurse should have endeavoured to contact the patient's GP for this information. The Trust maintain that their palliative care team liaises with GP's and community services to ensure that the patient receives the care that they need: the specialist palliative care team "also*

liaises with GPs, community nursing services and other palliative care providers to ensure that appropriate information is transferred in a timely manner"".

93. The N IPA also advised '*Levomepromazine[39] is a broad spectrum anti-emetic for intractable nausea/vomiting, often used second or third line[40]. It is noted that this was the medication considered by the specialist nurse but that it was not prescribed until the day of discharge and consequently it was not administered. The patient was reviewed again on 26 November 2018 but no further action was taken. It is documented that 'emotional support' was given. In summary, the palliative care nursing and treatment from 21 November 2018 was not in line with national guidance. This is because, despite complaining of ongoing nausea, no changes were made to the patient's medication regime until the day of discharge which was five days after she was initially reviewed by the palliative care nurse. This is inadequate and outside of general nursing care standards'.*

94. In response to the patient's discharge, the N IPA advised '*Discharge, from the perspective of the ward based team, was in line with national guidance in that it involved the patient, family and the multidisciplinary team. In accordance with the clinical records, the palliative care nurse advised 'refer to DN for palliative assessment' which is what the ward staff did. However, given the patients' complex symptoms this referral should have been completed by the palliative care team outlining the difficulties that they had experienced whilst the patient was an inpatient in controlling her pain and nausea'.*

95. The N IPA advised '*It is very difficult to say in retrospect, however it appears on reviewing the documentation that the specialist palliative care nurse should also have raised the issue of anticipatory medications within the referral to DNs. This is because, given the symptoms experienced by the patient, she could have been entering the last days of her life (increased pain, increased nausea, poor appetite, fatigue). The specialist nurse should have discussed*

[39] **Levomepromazine** is a phenothiazine used widely in palliative care to treat intractable nausea or vomiting, and for severe delirium/agitation in the last days of life.
[40] **Treatment** that is given when initial **treatment** (first-**line therapy**) doesn't work, or stops working.

and documented what the patient's wishes were for end of life care (often referred to as 'advanced care planning') in line with national guidance'.

96. The N IPA further advised '*as per the Trusts own description of their specialist palliative care team, more should have been done to ensure that the patient had the services she needed in place on discharge. This would include referring to the DNs in order to include the level of detail needed for a smooth transfer of care (rather than the ward team doing so), liaising with the patients GP to find out exactly what antiemetic (anti-sickness) she had in the community and why it was stopped and referring to the community based palliative care team for ongoing specialist support; Anticipatory medications: It is more challenging when a patient is new to you and you do not know their 'baseline' and if they have deteriorated. However, anticipatory medications should be organised when the patient is displaying obvious signs that they are nearing the end of their life such as those displayed by the patient'.*

97. In response to the impact the patient's palliative care had on her the N IPA advised '*The patient did not receive specialist palliative care support as an in-patient until 21 November 2018 (seven days after admission and the first documented reference to a referral). When she did receive specialist palliative care, it was not in line with the standards and guidance. The failings identified here meant that the patient's end of life symptoms (nausea, pain, breathlessness) were uncontrolled. The patient and her family were unsupported'.*

98. In relation to the Trust's response to the complaint, the N IPA advised '*the responses are contradictory*. *With regards to the palliative care referral, the Trusts response 5 January 2019 states* "*the Stroke Unit Discharge Coordinator, made a referral to the specialist palliative care team on 15 November 2018". The meeting minutes (15 May 2019) state the palliative care referral was made on 16 November 2018 and received on 19 November 2018. The Trust's final response dated 19 December 2019 stated that on 14 November 2018 at 09:15 the Consultant in Stroke Medicine on the post take ward round made a referral to the hospital palliative care team. On reviewing the records it appears more likely that the referral was made on 14 November*

2018 at 09:15 as it is documented that a "referral [was] made to palliative care".

99. The N IPA further advised *'It took a number of responses however for the Trust to give an accurate response, or indeed to apologise that they could not be certain when the referral was made. The Trust have apologised for the delay in referring the patient to the palliative care team and the delay in her being seen by a specialist nurse. They have said that there were missed opportunities for assessment and management of the patient's symptoms, distress, and advance care planning. Again, such apologises were only received within the final response dated 19 December 2019 and were not identified and discussed by the MacMillan team leader during the meeting. The responses contradict each other and it took a long time before the issues of advance care planning were identified'.*

Analysis and Findings

Referral to the HSSPCT

100. The investigation established that between the 14 November 2018 and 21 November 2018, the patient's medical and nursing team referred her to the palliative care team on three occasions: 14 November 2018, 16 November 2018 and 17 November 2018. I considered and I accept the N IPA advice '*the patient wasn't seen by palliative care until 21 November 2018 one week after the initial referral. This was not timely. Good clinical care and treatment is for hospital based palliative care teams to review the patient within 24 hours of a referral being received'.*

101. I refer to the NMC Code '*make sure that any treatment, assistance or care for which you are responsible is delivered without undue delay*". I also refer to the DOH strategy "*the palliative and end of life care needs of patients, families and carers are identified, addressed and regularly reviewed as a matter of course, including the need for physical, spiritual, psychological, financial and social support*". I consider the delay in the patient being reviewed by the HSSPCT to be a failure in the patient's care and treatment and not in

accordance with recommended guidance and standards. I therefore uphold this element of the complaint.

102. I note and accept the N IPA advice that the impact of receiving inadequate palliative care meant *'the patient's end of life symptoms (nausea, pain, breathlessness) were uncontrolled. The patient and her family were unsupported'.* I consider the patient suffered the injustice of loss of opportunity to have her condition adequately assessed and reviewed by specialist palliative care earlier. I also consider this failure in care and treatment caused the patient's family the injustice of uncertainty, lack of support and frustration over the appropriateness of the care and treatment received by the patient. I note the Trust recognises and acknowledges the delay in the patient being referred and reviewed by the HSSPCT. I welcome the Trust's apology to the patient's family for this failure. I further welcome the HSSPCT's shared learning and it's action plan which includes a review of its triage system and assessing referred patients, inter-hospital transfers between the Trust and its HSSPCT teams and advanced care and end of life planning.

103. The clinical records document a nurse made a referral to the HSSPCT on 16 November 2018 and this was received by the HSSPCT on the same day. The Trust stated a HSSPCT nurse[41] '*discussed the patient with a ward nurse* [on 19 November 2018]. However, the HSSPCT weekly activity sheets between 16 November 2018 and 20 November 2018 do not provide any evidence of conversations between ward staff and the HSSPCT staff. Whilst I note the Trust stated *'this interaction was recorded as a "check" on the HSSPCT weekly activity sheet',* I do not consider a tick to be a record of a conversation between ward staff and the HSSPCT. I would remind the Trust of the need to ensure that appropriate systems are in place for recording of clinical discussions between colleagues regarding decisions on a patients care and treatment, I would also remind the nursing staff involved of the need to comply with the requirement of the NMC Code to '*keep clear and accurate records relevant to your practice; complete records at the time or as soon as possible after an event, recording if the notes are written sometime after the event'.*

[41] Specialist Palliative Care Nurse

104. I note in response to the draft report the complainant stated that neither the patient nor her family were informed she was nearing the end of life. A detailed examination of the clinical notes from 14 November 2018 to 26 November 2018 do not indicate that this was discussed with the patient and her family as indicated by the complainant. This issue and the impact is considered further as part of issue 2.

105. However, upon a detailed examination of the patient's clinical notes, I established the patient's palliative care needs were discussed with the patient on 6 November 2018. I further established the patient's palliative care needs were discussed with the patient's clinical team and DN on 22 November 2018. The evidence also indicates the HSSPCT reviewed the patient three times between 21 November 2018 and 26 November 2018. Prior to discharge on 26 November 2018, the patient was referred to the community palliative care team and the DN service was scheduled to complete a palliative care assessment on 27 November 2018. The clinical records indicate the DN completed the patient's palliative assessment on 27 November 2018 and '*an offer was made for DN to assist the patient with her personal care needs. This offer was declined, as the patient's family wished to assist her at that time'.* Therefore, the records indicate a referral to palliative care had been made.

Pain Management and Nausea

106. I considered how the delay in being reviewed by the HSSPCT impacted on the patient's pain management. I note and accept the N IPA advice that '*from 14 November 2018 the patient received symptom control for pain and nausea from the ward based medical and nursing teams but they struggled to control her symptoms'.* I also considered and accept the N IPA advice '*Her pain was poorly controlled from admission* (14 November 2018) *through until 18 November 2018….nausea (not controlled)…..her symptoms were 'complex'…the patient's pain could have been controlled sooner than 18 and 19 November 2018 had she been reviewed by the palliative care nurse as "they offer specialist advice on complex symptoms such as pain, nausea and breathlessness".*

107. I refer to the Palliative Care Guidelines which state '*accurate assessment of pain is essential to plan appropriate interventions or treatments. Uncontrolled pain limits a person's ability to self-care, affects their response to illness and reduces their quality of life'.* It is my view the delay in the patient being reviewed by the HSSPCT impinged on the patient receiving specialist palliative support for her pain management. For that reason, I consider the patient did not receive specialist palliative support for her pain management between 14 November 2018 and 18 November 2018. I consider the failure to provide specialist palliative support for her pain management to be a failure in her care and treatment. I therefore uphold this element of the complaint.

108. I also considered and I accept the N IPA advice *'it appears that the specialist nurse intended to change the type of medication to control the patients nausea but that she did not know what she had been using previously and if or why it had been stopped….the palliative care nurse should have endeavoured to contact the patient's GP for this information'.* I refer to the Trust's guidance on palliative care which states '*the specialist palliative care team liaise with GPs, community nursing services and other palliative care providers to ensure that appropriate information is transferred in a timely manner".* I further accept the N IPA advice *'the palliative care nursing and treatment from 21 November 2018 was not in line with national guidance….despite complaining of ongoing nausea, no changes were made to the patient's medication regime until the day of discharge…five days after she was initially reviewed by the palliative care nurse. This is inadequate and outside of general nursing care standards".*

109. In accepting the N IPA advice, I found that despite the patient complaining of nausea and it being the intention of the palliative care nurse at her review on 21 November 2018 to change the patient's nausea medication, it took five days before this was changed on 26 November 2018. I refer to the NMC code which states '*make sure that any treatment, assistance or care for which you are responsible is delivered without undue delay'*. I therefore consider the delay in changing the patient's nausea medication to be a failure in her care and treatment. I consider the failures identified caused the patient to suffer the injustice of loss of opportunity to receive specialist palliative support for her

pain management and not having her nausea medication reviewed earlier. I also consider the patient's family suffered the injustice of uncertainty over the appropriateness of the care and treatment received by the patient.

Discharge Planning

110. In relation to discharge planning and having considered the advice of the N IPA I am concerned that the discharge planning was carried out by ward based nursing staff. I accept the advice of the N IPA that '*given the patients' complex symptoms this referral* (to the DN's) *should have been completed by the palliative care team'.* I further accept the N IPA advice that '*the specialist palliative care nurse should also have raised the issue of anticipatory medications within the referral to DN's….anticipatory medications should be organised when the patient is displaying obvious signs that they are nearing the end of their life such as those displayed by the patient'.* I further accept the N IPA advice*…'the specialist nurse should have discussed and documented what the patient's wishes were for end of life care....more should have been done to ensure that the patient had the services she needed in place on discharge'.*

111. I refer to the RCN Fundamentals of End of Life care which states *"People should be seen as individuals, asked what is important to them and involved in all discussions and decisions about their wishes and care".* I also refer to the NMC code '*respect the skills, expertise and contributions of your colleagues, referring matters to them when appropriate, work with colleagues to preserve the safety of those receiving care and make a timely referral to another practitioner when any action, care or treatment is required'.*

112. I note in the complainant's response to the draft report, she states *'every medical professional ignored those signs* [of her condition worsening] *and refused to issue us with the relevant anticipatory medications'.*

113. In accepting the N IPA advice, it is my view the HSSPCT did not adequately assess or plan for the patient's discharge in relation to providing the DNs with sufficient information on the patient's condition, liaising with the patient's GP in regards to her anti sickness medication, planning for anticipatory medications and discussing/documenting what the patient's wishes may have been for her

end of life. I consider the failure to have an adequate discharge plan to be a failure in the patient's care and treatment. I am satisfied the failure to have an adequate discharge plan caused the patient to experience the injustice of uncertainty, worry and loss of opportunity to have her advanced care planning and end of life wishes considered and to have benefited from the anticipatory medications at the appropriate point. I am also satisfied the failure to have an adequate discharge plan caused the patient's family to have suffered the injustice of upset and frustration as they struggled to cope with the patients symptoms in the last few days of her life. I am conscious of the very significant impact that this lack of planning had on the patient's family at a very difficult time and the pressure that this also put on other Trust services. This is dealt with further under Issue 3.

End of Life Care

114. I further considered the N IPA advice that '*on 27 November 2019, the patient was struggling with breathlessness and was unable to sleep from the initial community nursing assessment'*. The N IPA advised '*national guidance states that oxygen at the end of life should only be used if the patient is hypoxic and morphine sulphate is more commonly used*'. I considered and accept the N IPA advice that '*the patient was already using oramorph for breathlessness, there may have been scope to increase the dose and/or frequency of this. This should have been escalated to the patient's GP that day*'.

115. I refer to the NMC Code, nurses should '*accurately identify, observe and assess signs of normal or worsening physical and mental health in the person receiving care and make a timely referral to another practitioner when any action, care or treatment is required'.* I further refer to the DOH palliative and end of life care strategy which states '*the palliative and end of life care needs of patients families and carers are identified, addressed and regularly reviewed as a matter of course, including the need for physical, spiritual, psychological, financial and social support'.*

116. I note in the complainant's response to the draft report, she said '*her mother was having extreme difficulty breathing from when she was discharged from*

hospital on 26th November 2018'. It is my view that by the DN not informing the patient's GP on 27 November 2018 that she was struggling to breathe and escalating her care in accordance with recommended guidance that this was a failure in the patient's care and treatment. However, upon examination of the GP clinical records, I established the patient's GP carried out a visit on that same day and undertook an examination of the patient including arranging oxygen and reviewing medication. Therefore, I do not consider the patient suffered any injustice as a result of this failure.

117. I would highlight the N IPA's recommended learning development to the Trust, particularly that *'palliative care specialist nurse: the team should consider contacting the patients GP as 'standard practice' when there are uncertainties regarding the patients medications. Specifically when the patient has uncontrolled symptoms. It should be a fundamental aspect of their role and they should be able to prove that this is their standard practice; palliative care specialist nurse: should be more involved in discharge planning; considering it to be a crucial part of the role, to ensure that the patients care is seamlessly transferred from the hospital to the community. It should be a fundamental aspect of their role and they should be able to prove that this is their standard practice; palliative care specialist nurse: in situations such as the patient's, advanced care planning should be discussed by the specialist nurse. It should be a fundamental aspect of their role and they should be able to prove that this is their standard practice; and DN, anticipatory medications: It is more challenging when a patient is new to you and you do not know their 'baseline' and if consequently they have deteriorated from that baseline. However, anticipatory medications should be organised when the patient is displaying obvious signs that they are nearing the end of their life such as those displayed by the patient'.*

118. I note and welcome the Trust's acknowledgement that this element of the complaint was shared amongst the HSSPCT and nurse specialists who will use the learning to improve the service (including HSSPCT triage system) provided to patients and families within the Trust.

Observation

119. I would highlight that complaints handling was not an issue that was within the scope of the investigation. However, I would draw to the Trust's attention the N IPA advice that '*the responses [during the Trust's handling of the complaint] contradict each other and it took a long time before the issues of advance care planning were identified'*. It is important that complainants have faith in the investigatory process followed by the Trust. This is undermined when the robustness of that investigation is called into question by contradictions in the evidence quoted in responses to complainants I would draw the Trust's attention to its complaints policy where it acknowledges the importance of ensuring that 'complainants receive open, honest and proportionate responses. I would ask the Trust to reflect on the N IPA comments and take appropriate action to address the concerns raised.

Issue 3 Whether the care and treatment from the Out of Hours service was appropriate, reasonable and in line with relevant practice?

Detail of Complaint

120. The complainant said that upon returning home from hospital on 26 November 2018, the patient remained very unwell and was in a great deal of pain. The complainant contacted the OOH service on 29 November 2018 to request a home visit by the OOH DN and OOH GP. The complainant said the OOH DN did not attend and there was a delay in the OOH GP attending. The complainant believed the care and treatment provided by the OOH GP and DN service on 29 November 2018, was inadequate.

Evidence Considered

Guidance

121. I examined the DNS Information Leaflet and I considered the following sections relevant to the investigation:

'District nurses are specialised registered nurses who have completed

additional training to provide care to patients who are housebound and require a home visit. The frequency of home visits will be assessed and changed according to your nursing needs.

District nurses are based in health and wellbeing centres. They work closely with other health care professionals and agencies e.g. GP's McMillan nurses, Marie curie nurses and social services, occupational therapists and physiotherapists'.

122. I examined the referral criteria for DN Service and I considered the following sections relevant to the investigation:

Prioritisation of Visits
'The service does not operate a waiting list therefore patient's visits will be prioritised on their identified need. Urgent: Nursing intervention is required to prevent a potential serious risk. The District Nurse will contact the patient within 4 hours of receiving the referral. All urgent referrals should be followed up immediately by a telephone call to the Trust Call Management Centre. Routine: The nurse will schedule a visit for the patient according to priority unless a date has been specified. On receipt of the referral a trained nurse will triage the call to ensure appropriately categorised and may contact the referrer to discuss further.

District nursing services aim to maintain patients in their own home by enabling them to cope with acute long term episodes of ill health and disability utilising a wide range of clinical and support services.

This referral criteria is designed as a guide to improve the referral process to the district nursing service. On receipt of a referral district nursing staff will exercise their professional judgement to assess if the patient is appropriate for the service'.

The Trust's response to investigation enquiries

123. In relation to enquiries relating to the patient's OOH care, the Trust stated '*In*

relation to the patient's family contacting the OOH DN team in the early hours of 29 November 2018 for support, we would again like to offer our deepest condolences and offer our unreserved apologies for the distress and anxiety the patient and her family experienced that night. The records indicate that a telephone call was received from the patient's family to OOH DN at 04.30. Following discussion with her daughter, the nurse ascertained that the patient was not prescribed anticipatory injectable drugs and that the OOH GP needed to visit to assess and prescribe the relevant drugs before they could be administered by the nurse'.

124. The Trust further stated '*the OOH nurse on duty did leave a communication for the day staff commencing at 08.00 to advise that the patient's condition had deteriorated overnight and that OOH GP had been contacted. A request was made for assessment and prescription of anticipatory drugs. The DN immediately made contact with the complainant to get an update on her condition and to ascertain if the OOH GP had visited. On speaking with the complainant it became apparent that the OOH GP had not yet visited. The DN contacted the patient's own GP to alert them of her deterioration and to advise that an urgent visit may be required following their assessment. On arriving at the complainant's home, it became apparent the OOH GP had just left the patient. The DN's supported the patient's family and provided care to the patient in an effort to make her comfortable, they remained with the patient until she became settled. Further arrangements were made by the DNs with the patient's own GP to prescribe medication via a syringe driver for symptom control. In the time between the DNs leaving the patient to collect the prescription medication via a syringe driver, a phone call was received from her family advising of her death. The DNs returned to the home to comfort her family and prepare the patient for the GP to verify her passing'.*

125. In response to enquiries regarding the OOH GP, the Trust stated *'In relation to calls to the OOH GP, the records indicate that a first call was received at 04.34, symptoms noted on the patient records indicate the patient was terminal and had SOB. An OOH GP returned the family's call at 05.04, viewed the patients ECR and prescribed the medication required. The OOH GP*

advised that the family needed to collect the prescription from the Belfast on-call community pharmacist as it included controlled drugs. Regrettably during the overnight shift OOH period there are only two GPs covering the wider North & West and South & East Belfast geographical area. The patient's daughter was advised that they should re-contact the OOH GP when this was completed'.

126. The Trust confirmed *'the OOH GP do not stock controlled drugs, but have access to request urgent medications from a community pharmacy on-call service. Unfortunately this service which is co-ordinated by the Health and Social Care Board (HSCB), is often not provided in pharmacies located close to the patient. The medication would not have been available to the OOH GP to administer from the OOH GP base or during a home visit without this arrangement, which would be the usual process during the out of hours period'.*

127. The Trust further stated '*A further contact was made to notify the OOH GP the family had collected the medication and a home visit was required. Syringe drivers are normally set up in the community by the nursing team, and the request for this visit was passed to the nursing team at 06:59. At 07:16 the OOH GP was advised the OOH nursing team where unable to visit the patient due to their workload, however the OOH GP involved at that stage advised the call should be passed to the day nursing team as there was insufficient time left in shift to attend to the patient'.* The Trust clarified *'the OOH service transfers care back to the day time teams at 08.00'.*

128. The Trust stated '*The OOH GP who had initially spoken with the family, then became aware that the call request was not being fulfilled by the DN team and she attended to the patient in her home at 08:20, she has noted there was no prescription or use of a syringe driver, or breakthrough doses of pain relief. The OOH GP examined the patient, noted her distress and administered subcutaneous morphine and hysoscine*[42] *to assist. The OOH GP has then*

[42] Hyoscine, also known as scopolamine, is a medication used to treat motion sickness and postoperative nausea and vomiting.

noted this appeared to settle the patient. As it was now after 08.00, it was noted that the patient's own GP would need to follow up her care. Any communications with a patient overnight go directly through to the patient's own GP practice electronically'.

129. The Trust stated *'On reflection, this is a regretful sequence of events and is not in keeping with best practice or with the expectation of care at end of life. We apologise this was the family's experience and acknowledge the traumatic effect this had upon the patient's family. Since receiving this complaint, the service has implemented learning from the feedback of the family's experience. If a call is received by the OOH team for a patient with palliative or end of life needs they are visited to be assessed and the family are supported by a registered nurse before referring to another service'.*

130. The Investigating Officer made further enquiries about the Trust's OOH DN service. The Trust stated '*the regional referral guidance identifies a four hour expectation for the nurse to make contact if the referral is considered urgent. A routine visit requires a suitable date and time to be arranged with patient. There are no waiting lists, patients are prioritised according to clinical need.'* The Trust confirmed it's OOH District nursing referrals are triaged based on *"clinical need" and this can sometimes be difficult to assess as there can, at times, be competing "demands". The assessment of these needs can be easier if the nurse is already familiar with the patient's needs, particularly if end of life. Often high priority calls would include: End of life care, time critical medications or an intervention that would be considered life preserving'.* The Trust also stated '*there was one registered nurse on duty for the night service and she was supported by one senior nursing assistant (non-registrant). They work together at night due to lone working issues. A referral had already been received for a scheduled visit at 07.00* (on 29 November 2018), *this was for the administration of a time critical medication and therefore would also have been considered a priority. I understand the night service had not visited this patient earlier and would therefore have gained an insight into the urgency of this. The service recognises they should have attended with the initial referral and assessed the patient at that time. The night staff finished at 08.00,*

therefore they liaised with the day staff to pass over information for them to provide the necessary medications and nursing support to the patient.'

Clinical Records

131. I considered relevant extracts from the patient's clinical records which are included at appendix five to this report.

Independent Professional Advice

GP IPA

132. In relation to the patient's OOH care and treatment, the GP IPA advised *'The only contacts with the patient and the OOH service were on 29 November 2018. In the initial contact a call back was made 30 minutes after the initial call was received. A prescription for injectable medication for end of life care was issued and arrangements made for it to be collected from an out of hour's pharmacy within 16 minutes of the doctor phoning the family. When the call from the family was received to indicate the drugs were available at 06.21 the call was sent on for a DN visit as 'routine'. The records indicate this call was dispatched to the DN service at 06.59. A call was received from the DN's indicating there would not be capacity to respond to this call at 07.16 and at 07.28 the arrangement for the daytime DN (from 08.00) to visit was made. An OOH GP visited at 08.20'.*

133. The GP IPA also advised *'The initial actions were timely and appropriate, the response to the call was 30 minutes which is reasonable. Immediate action was taken to prescribe medication and arrange for this to be collected. The Trust letter explains that the medication was not available to be administered from OOH. It is usual practice that medication is prescribed and collected from a pharmacy and this was arranged in a timely fashion. When the medication was available and immediate allocation to DN visit was arranged. The status was routine when it would have been more appropriate to set the status as urgent. At this point a medication chart should have been written up and signed by a doctor as it would not be possible for a DN to administer medications if this had not been done'.*

134. The GP IPA further advised *'the second call regarding the lack of capacity in the DN service, this was dealt with in a timely and appropriate manner in passing the call to the daytime DN. Once again, at this point, the medication chart should have been made available to enhance care provision. It would appear from the Trust response that the OOH GP decided to attend which resulted in appropriate management of the patient's symptoms in a timely fashion. It is not clear if this was an individual professional decision or if the OOH GP's responsibilities included visiting and the OOH GP took the decision to visit as well as involving the daytime DN. It was an appropriate decision'.*

135. In response to the impact on the patient, the GP IPA advised *'There was no detriment to the patient from the failing identified above as, although the medication chart should have been made available, it was actually completed by the OOH GP before the DN attended'.* The GP IPA concluded *'the patient's family called OOH in the early hours of 29 November 2018. The doctors on call provided a timely and appropriate response, taking a full history and providing appropriate medication with arrangements for that to be collected urgently. The records show appropriate liaison with the DN service and appropriate doctor visit when a possible DN delay was identified. A medication chart was not provided in a timely fashion but in this instance did not impact care as it was finally provided before DN were able to attend'.*

136. In relation to the Trust's response to the complaint, the GP IPA advised '*The Trust response of 19 December 2019 comments on the OOH doctor's role but this is not mentioned in either the response of 11 January 2019 or the meeting 15 May 2019. The Trust response does not reflect the absence of a medication chart but does outline the DN response and how this interacted with the OOH doctors'.*

Nursing (N IPA)

137. In response to the OOH nursing care, the N IPA advised '*The complainant phoned the OOH community nursing team at 04:30 on 29 November 2018 as her mum had deteriorated. She was advised to contact OOH GP for anticipatory medications which she did at 04:34. The OOH nurse left a message for day staff who started at 08:00 to advise that the patient had*

deteriorated. In the meantime the OOH GP had contacted the family by phone and asked them collect some medications from the OOH pharmacy, this was at 05:04. At 08:20 the OOH GP attended and administered some medications which were reported to have settled the patient. Community nurses visited shortly after'.

138. The N IPA further advised '*The OOH community nurse received a call at 04:30 on 29 November 2018 as the patient had deteriorated. At this point, the nurse should have visited the patient. It is understood that anticipatory medications had not been prescribed, and thus is was reasonable to advise contacting OOH GP, however this should have been in addition to a community nursing visit and not instead of a community nursing visit. There are more things that can be done in addition to medications for easing symptoms; changing the patients position, supporting the patient and the family emotionally, giving practical calming advice and support at a very difficult time. These interventions would have improved the patients, and her daughters' end of life experience. This is because there is more a nurse can do to help their patient and their family than administer medications. The nurse who took this call should receive further training or supervision in end of life care in order to understand the impact of her inaction on the patient and her daughter*'.

139. In relation to the Trust's response to the complaint, the N IPA advised *'the letter dated 11 January 2019 is regarding the responsibility of the patient's care between the cancer centre and her GP. Having read the response and also the clinical records available this response appears accurate and reasonable'.*

Analysis and Findings

140. The investigation established the complainant contacted the OOH DN service on 29 November 2018 at 04.30. The complainant said the patient was very unwell and in a great deal of pain. The clinical records indicates the OOH DN advised the complainant to contact the OOH GP as they would have to assess and prescribe medication before they could be administered by the

nurse. The clinical records also indicate the complainant rang the OOH GP at 04.34. The records indicate the OOH GP rang the complainant at 05.04 and prescribed the patient anticipatory drugs. I note the Trust stated the OOH GP informed the complainant the family would have to collect the prescription from the community pharmacy on call service as the OOH GP service '*did not stock controlled drugs and would not be available to administer from the OOH GP base'*.

141. The Trust stated when the family collected the prescription for anticipatory drugs the complainant informed the OOH GP that a home visit was required. The clinical records document the OOH GP made a request at 06.59 for a home visit by the nursing team. The evidence further indicates at 07.16 the OOH DN's informed the OOH GP they were '*unable to visit the patient due to their workload*'. The Trust stated the OOH GP advised the OOH DNs to pass the request to the day nursing team as there was *'insufficient time left in the shift to attend the patient'.* The clinical records document the OOH GP '*spoke to call management*' and asked '*day DN starting at 08.00 to attend'*, as there '*was insufficient time remaining in shift to travel to/from visit and administer meds'*. The clinical records document this referral was set as '*routine'.* The investigation established the OOH service transfers back to the day time services at 08.00.

142. The investigation established that as the OOH DNs were unable to attend to the patient, the OOH GP attended the patient at 08.20. The OOH GP assessed the patient and administered pain medication. The evidence also indicates the daytime DN visited and assessed the patient at 08.58. I note the DN had arranged with the patient's GP to '*prescribe medication via a syringe driver for symptom control'.* However, I established when the daytime DN left to collect the prescription for the syringe driver from the GP Practice, the patient sadly passed away.

143. I considered and I accept the GP IPA advice *'The initial actions were timely and appropriate, the response to the call was 30 minutes which is reasonable. Immediate action was taken to prescribe medication and arrange for this to be collected….when the medication was available and immediate allocation to*

DN's visit was arranged…..at this point a medication chart should have been written up and signed by a doctor…'. I note the GP IPA advised '*when the medication was available* [at 06.21] *an immediate allocation to DN visit was arranged…..the status was routine when it would have been more appropriate to set the status as urgent'.* The investigation established the Trust's DN service will aim to visit a patient within four hours if it is prioritised as an urgent visit and schedule a date and time with the patient if it is prioritised as a routine visit.

144. I considered the GP IPA advice and accept that '*The OOH doctors provided a timely and appropriate response, taking a full history and providing appropriate medication with arrangements to be collected urgently. The records show appropriate liaison with the OOH DN service and appropriate doctor visit when a possible OOH DN delay was identified'.* Therefore, I consider the care and treatment from the OOH GP service was appropriate, reasonable and in line with relevant practice.

145. However, I considered and I accept the GP IPA advice that '*a medication chart was not provided in a timely fashion'.* I refer to the GMC Guidelines, *record your work clearly, accurately and legibly; documents you make (including clinical records) to formally record you work must be clear, accurate and legible. You should make records at the same time as the events you are recording or as soon as possible afterwards'.* I consider that by not completing a medication chart when the OOH DN's home visit was requested, to be a failure in the patient's care and treatment. I do not however consider there was any injustice to the patient as a medication chart was commenced and provided when the OOH GP attended at 08.20, a view supported by the GP IPA.

146. I considered and accept the N IPA advice that '*the nurse should have visited the patient'.* I further accept the N IPA advice that as anticipatory medications had not been prescribed, it '*was reasonable to advise contacting OOH GP, however this should have been in addition to a community nursing visit and not instead of a community nursing visit'.* I also considered the N IPA advice that '*there are more things that can be done in addition to medications for*

easing symptoms; changing the patients position, supporting the patient and the family emotionally, giving practical calming advice and support at a very difficult time'.

147. The clinical records indicates the family informed the OOH service they had collected the medication at 06.21. The clinical records further indicate the call was '*dispatched to the OOH DN service at 06.59' by the OOH GP*. The OOH GP prioritised the referral as routine and therefore there was no requirement on the OOH DN to attend the patient within four hours. I note the level of priority attached to the OOH DN's referral was made by the OOH GP and the Trust state the level of priority is based on '*clinical need'*. I note in response to the draft report the complainant does not agree and states '*I cannot comprehend how the status was set to routine, when I was collecting end of life medication… my mother* [the patient] *should have been classed as an urgent case and the delay was unacceptable'.* I considered and I accept the GP IPA advice '*The status was routine when it would have been more appropriate to set the status as urgent'*. I consider the patient was very unwell and therefore would have required her medication as early as possible, after the referral was made to the DN service at 06.59. I therefore consider the failure to prioritise the referral as urgent to be a failure in the patient's care and treatment. I note the patient was visited by an OOH GP at 08.20 when the medication was administered. In the situation where a distressed family are waiting for the administration of medication to make their loved one comfortable it is imperative that all staff involved act as promptly as possible to reduce the pain of the patient and the anxiety of the family.

148. Examination of the clinical records indicate the OOH DN service had one registered nurse and one nursing assistant who were due to attend a scheduled appointment with another patient at 07.00. Therefore, I accept and consider it reasonable the OOH DN service were unable to attend to the patient at 07.00 due to a previously scheduled appointment. However, I refer to the NMC code which states '*treat people with kindness, respect and compassion, make sure you deliver the fundamentals of care effectively and recognise and respond compassionately to the needs of those who are in the last few days and hours of life'.* In accepting the N IPA advice, I consider there

was more the OOH DN could have done, particularly in providing support to the patient and her family when the complainant contacted the OOH DN service at 04.30. I note this was a view supported by the complainant in her response to the draft report that *'the DN could have done a lot more in assisting our family with getting the help my mother* [the patient] *so obviously required'.* I also note the complainant expressed concern that the workload of the OOH nursing team prevented the patient being visited.

149. I consider the failure of the OOH DN to visit the patient, to be a failure in the patient's nursing care and treatment. Therefore, I uphold this element of the complaint. I consider the patient suffered the injustice of worry and uncertainty. I also consider the patient's family suffered the injustice of anxiety and distress at witnessing the patient's decline and loss of opportunity to receive emotional comfort and support. As referred to earlier, I note an OOH GP visited the patient at 08.20 and a daytime DN visited and comforted the patient at 08.58 in the hours before her death. I would draw the Trust's attention to the N IPA's observation that *'the nurse who took this call should receive further training or supervision in end of life care in order to understand the impact of her inaction on the patient and her daughter'*.

150. I note the Trust has apologised to the patient's family for this failure. I welcome the Trust's confirmation that it recognises they should have attended with the initial referral and assessed the patient at that time. I further welcome the Trust's confirmation that the service implemented learning when a patient requires palliative or end of life care, they will be visited, assessed and the family supported by the OOH service before being referred to another service.

CONCLUSION

151. The complainant submitted a complaint to me about the actions of the Trust.

152. The investigation of the complaint found that the care and treatment provided by the patient's oncology service at her outpatient reviews was appropriate and reasonable. In addition, the investigation did not find a failure

in the the care and treatment provided by the OOH GP service. The care and treatment provided was appropriate, reasonable and in line with relevant practice.

153. However, the investigation of the complaint found failures in the patient's care and treatment in relation to the following matters:

i. Delay in admission to the stroke ward
ii. Failure to adequately complete nursing assessment
iii. Failure to complete medications incident form on 17 November 2018
iv. Delay in completing HSSPCT review
v. Delay in receiving support for managing pain
vi. Delay in changing nausea medication
vii. Failure to have an adequate discharge plan
viii. Failure to escalate care to the patient's GP
ix. Failure to commence a medication chart
x. Failure to prioritise the referral as urgent
xi. Failure to carry out an OOH DN home visit

154. I am satisfied that the failures in care and treatment I identified caused the patient to experience the injustice of upset, frustration, anxiety, worry, uncertainty, lack of support and loss of opportunity. I am also satisfied these failings caused the patient's family the injustice of worry, uncertainty, upset, anxiety and distress, being unsupported and frustration over the appropriateness of the patient's care and treatment.

155. I note the Trust apologised to the patient's family for the delay in admitting the patient to the stroke ward, the delay in performing the patient's HSSPCT review and the failure in the OOH's care. I consider the Trust's apology for these failures was appropriate. It is clear from my investigation of this complainant that the failures in palliative care planning particularly concerning anticipatory medications had a very significant impact on the patient and the complainant at a very difficult and stressful time. I consider that this is the fundamental failure in this case which as outlined had very significant

consequences. I am also concerned that there were still opportunities for the patient and the complainant to be better supported by the Trust out of hours services and that these services also failed to provide the necessary support.

Recommendations

The Trust implemented the following learning:

Stroke Services:
A New Stroke Ambulatory Pathway
Quarterly reports on Sentinel Stroke National Audit Programme data
Introduction of an advice line in the 'Same Day Assessment Service' (SDAS)

HSSPCT:
Awareness Stroke helpline
Assessing Referred Patients
Inter-hospital Transfer between Trust HSSPCT Teams
End of life Planning

Out of Hours:
Review of Beldoc Call Management and Processes between Doctors on duty during the overnight shifts.

I recognise the Trust implemented a number of improvements by way of acknowledging the failures identified in this report otherwise further recommendations would have been made.

I therefore recommend:

i. In accordance with NIPSO guidance on issuing an apology, the Trust should provide a written apology to the complainant for the injustice identified in this report. The Trust should provide the apology to the complainant within one month of the date of my final report.
ii. The Trust provide evidence of the implementation of the shared learning and actions identified above.

iii. I consider there are a number of lessons to be learned which provide the Trust with an opportunity to improve its service. In particular, the Trust share the outcome of this investigation with relevant nursing staff highlighting the learning outcomes identified in regard to the completion of nursing assessments, offering NRT and completing medicine incident forms.

iv. I recommend the Trust share the outcome of this investigation with relevant HSSPCT staff highlighting the learning outcomes identified in relation to palliative care reviews, organising anticipatory medications for advanced care planning and ensuring adequate discharge planning.

v. I recommend the relevant HSSPCT staff should reflect on the findings from this report and discuss this with their appraiser as part of their next scheduled appraisal.

vi. I recommend the Trust share the outcome of this investigation with the relevant DN staff highlighting the learning outcomes identified in relation to escalating care to a patient's GP and commencing a medications chart.

vii. I recommend the Trust should arrange end of life care training for the relevant OOH DN staff highlighting the impact of not visiting the patient on 29 November 2018.

vii. I recommend the relevant DN staff should reflect on the findings from this report and discuss this with their appraiser as part of their next scheduled appraisal.

I recommend the Trust comply with my recommendations within three months of the date of my final report.

I am pleased to note the Trust accepted my findings and recommendations.

MARGARET KELLY
OMBUDSMAN

March 2021

APPENDIX ONE

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 TWO

PRINCIPLES OF GOOD COMPLAINT HANDLING

Good complaint handling by public bodies means:

Getting it right

- Acting in accordance with the law and relevant guidance, 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 learnt from complaints.
- Including complaint management as an integral part of service design.
- Ensuring that staff are equipped and empowered to act decisively to resolve complaints.
- Focusing on 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.

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 co-ordinating responses with any other bodies involved in the same complaint, where appropriate.

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.

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 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.

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.

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 the learning from complaints.
- Regularly reviewing the lessons to be learnt from complaints.
- Where appropriate, telling the complainant about the lessons learnt and changes made to services, guidance or policy.