Safeguarding Adults Review – Robyn

safeguarding adults at risk
a cumbria partnership

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1.0 Introduction

1.1 A woman who will be referred to in this report as Robyn died in December 2018. She sustained a traumatic head injury in a fall at home in December 2015 which she was not expected to survive. After an artificial feeding tube was inserted during her hospital admission, she was discharged home into the care of her youngest son who had also been caring for her prior to her hospital admission. At the time she was discharged from hospital Robyn was in a minimally conscious state. She unexpectedly survived for a further three years. She died in a local hospice after the withdrawal of clinically assisted nutrition and hydration by order of the Court of Protection.

1.2 Cumbria Safeguarding Adults Board decide to undertake a safeguarding adults review as there were concerns that partner agencies could have worked together more effectively to protect Robyn. A description of the process by which this SAR was conducted is shown at Appendix A.

1.3 Louise Mason-Lodge, Deputy Director of Nursing and Designated Nurse for Safeguarding, North Cumbria Clinical Commissioning Group (CCG) chaired the Panel established to oversee the SAR. Membership of the SAR Panel is also shown at Appendix A. David Mellor was appointed as lead reviewer for the SAR. He is a retired chief officer of police and has over seven years experience of conducting statutory reviews. He has no connection to any agency in Cumbria.

1.4 An inquest was held on 12th June 2019 and recorded a verdict of accidental death. Robyn's cause of death was recorded as an intracerebral haemorrhage following an unwitnessed fall at her home address in December 2015.

1.5 Cumbria Safeguarding Adults Board wishes to express sincere condolences to the family of Robyn.

2.0 Terms of reference

2.1 The timeframe of the review is from April 2015 (when Robyn's GP reported that her youngest son was 'struggling in his caring role') until Robyn's death in December 2018. Significant events which took place prior to April 2015 will also be included.

2.2 The key lines of enquiry for the review are:

Family Functioning

- To what extent did agencies in contact with Robyn gain an understanding of family functioning, particularly the dynamics of the relationship between Robyn and her youngest son and between her youngest son and his siblings?
- Did Best Interests discussions take account of wider family views?

Safeguarding

- How effectively did agencies address adult safeguarding concerns in respect of Robyn up to and including the fall which caused her traumatic head injury on 21st December 2015?
- How effectively did agencies address adult safeguarding concerns in respect of Robyn during the period following her fall on 21st December 2015?
- Was the decision to discharge Robyn home from hospital in February 2016 taken in her Best Interests and was the decision informed by prior safeguarding concerns?
- How effectively were any adult safeguarding concerns enquired into?
- How effectively did agencies respond to concerns that her youngest son may be isolating Robyn from the care and support she needed?

Person Centred

- How effective were agencies in respecting Robyn's previously held views and Advance Decision? Were systems in place to ensure her wishes were respected?
- To what extent did agencies focus on the needs of Robyn and consider her lived experience?

Caring Role

- What support was offered to Robyn's youngest son as her primary carer following the decision to discharge Robyn home from hospital in February 2016?
- How effectively did agencies engage with the youngest son as carer for Robyn?
- How did agencies respond to concerns about the youngest son's capacity to provide appropriate care for Robyn? In particular how did agencies respond to indications that the youngest son's emotional and mental health may be affecting his care for Robyn?

Mental Capacity Act

- Was the Mental Capacity Act applied correctly in respect of Robyn?

3.0 Glossary

An **Advance Decision** (sometimes known as an advance decision to refuse treatment, an ADRT (advance decision to refuse treatment) or a living will) is a decision someone can make in the present to refuse a specific type of treatment at some time in the future. It lets their family, carers and health professionals know their wishes about refusing treatment if they are unable to make or communicate those decisions themselves.

Best Interests - if a person has been assessed as lacking mental capacity then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests.

Care Programme Approach (CPA) - is a framework to assess the care and support needs of people with mental health problems, develop a care plan and provide the necessary support. A care coordinator monitors the care and support provided.

The **Court of Protection** makes decisions on financial or welfare matters for people who lack the mental capacity to make decisions at the time they need to be made. Specifically, the Court is responsible for:

- Deciding whether someone has the mental capacity to make a particular decision for themselves
- Appointing deputies to make ongoing decisions for people who lack mental capacity

- Giving people permission to make one-off decisions on behalf of someone else who lacks mental capacity
- Handling urgent or emergency applications where a decision must be made on behalf of someone else without delay
- Making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration
- Considering applications to make statutory wills or gifts
- Making decisions about when someone can be deprived of their liberty under the Mental Capacity Act

Do not attempt cardiopulmonary resuscitation (DNACPR) Cardiopulmonary resuscitation (CPR) is a treatment that attempts to start breathing and blood flow in people who have stopped breathing (respiratory arrest) or whose heart has stopped beating (cardiac arrest). Everyone has the right to refuse CPR if they wish. People can make it clear to their medical team that they do not want to have CPR if they stop breathing or their heart stops beating. Once a DNACPR decision is made, it is placed in the person's medical records, usually on a special form that health professionals recognise.

Domestic violence and abuse is any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are or have been intimate partners or family members regardless of gender or sexuality. This can encompass, but is not limited to, the following types of abuse:

- Psychological
- Physical
- Sexual
- Financial
- Emotional

Controlling behaviour is a range of acts designed to make a person subordinate and/or dependent by isolating them from sources of support, exploiting their resources and capacities for personal gain, depriving them of the means needed for independence, resistance and escape and regulating their everyday behaviour.

Coercive behaviour is a continuing act or a pattern of acts of assault, threats, humiliation and intimidation or other abuse that is used to harm, punish, or frighten their victim.

Deprivation of Liberty Safeguards (DoLS) were introduced in 2009 and protect the rights of people aged 18 or above who lack the ability to make certain decisions for themselves and make sure that their freedom is not inappropriately restricted. No one can be deprived of their liberty unless it is done in accordance with a legal procedure. The DoLS is the legal procedure to be followed when it is necessary for a resident or patient who lacks capacity to consent to their care and treatment to be deprived of their liberty in order to keep them safe from harm. The DoLS can only be used if the person will be deprived of their liberty in a care home or hospital. In other settings, and for children aged 16 and above the Court of Protection may authorise a deprivation of liberty.

An **emergency care plan** allows clinicians to discuss and record patient preferences in advance, not only regarding cardiopulmonary resuscitation, but all aspects of care and treatment in an emergency. The emergency care plan provides recommendations for care and treatment for future scenarios when people might not have the capacity to communicate their preferences. The plan should be tailored to consider the most likely individual situations, such as a sudden acute illness, deterioration in a long-term condition, or sudden cardiac or respiratory arrest

Independent Mental Capacity Advocate (IMCA) - The purpose of the Independent Mental Capacity Advocacy Service is to help particularly vulnerable people who lack the capacity to make important decisions about serious medical treatment and changes of accommodation, and who have no family or friends that it would be appropriate to consult about those decisions. The role of the Independent Mental Capacity Advocate (IMCA) is to work with and support people who lack capacity, and represent their views to those who are working out their best interests.

Inherent jurisdiction is a doctrine of the English common law that a superior court has the jurisdiction to hear any matter that comes before it, unless a statute or rule limits that authority or grants exclusive jurisdiction to some other court or tribunal. The High Court has gradually extended the use of the inherent jurisdiction to vulnerable adults who possess capacity but still require protection for certain reasons. The aim of the High Court in such cases is to prevent the circumstances within which an adult might not be able to exercise a free choice at some point in the future.

NHS continuing healthcare (CHC) is a package of care provided outside of hospital that is arranged and funded solely by the NHS for individuals aged 18 years and older who have significant ongoing healthcare needs. When someone is assessed as eligible for CHC, the NHS is responsible for funding the full package of health and social care. In 2015-16, almost 160,000 people received, or were assessed as eligible for, CHC funding during the year, at a cost of £3.1 billion.

Making Safeguarding Personal - is a sector-led programme of change which seeks to put the person being safeguarded at the centre of decision making. It involves having conversations with people about how agencies might respond in safeguarding situations in a way that enhances involvement, choice and control as well as improving quality of life, wellbeing and safety. It is about seeing people as experts in their own lives and working alongside them. It envisages a shift from a process supported by conversations to a series of conversations supported by a process.

Mental Capacity Act (MCA): The Mental Capacity Act 2005 came into force in 2007. It is designed to protect and empower those vulnerable people who may lack capacity to make certain decisions, due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol. The MCA also supports those who have capacity and choose to plan for their future. The MCA applies to everyone working in social care, health and other sectors who is involved in the support and treatment of people aged 16 and over who live in England and Wales, and who are unable to make all or some decisions for themselves.

Minimally Conscious State: Where a person shows clear but minimal or inconsistent awareness they are classified as being in a minimally conscious state.
They may have periods where they can communicate or respond to commands, such as moving a finger when asked. A person may enter a minimally conscious state after being in a coma or vegetative state. In some cases, a minimally conscious state is a stage on the route to recovery, but in others it's permanent. As with vegetative state, a continuing minimally conscious state means it's lasted longer than 4 weeks.
In most cases, a minimally conscious state isn't usually considered to be permanent until it's lasted several years.

Obsessive compulsive disorder (OCD) is a common mental health condition where a person has obsessive thoughts and compulsive behaviours. An obsession is an unwanted and unpleasant thought, image or urge that repeatedly enters a person's mind, causing feelings of anxiety, disgust or unease. A compulsion is a repetitive behaviour or mental act that the person feels they need to do to temporarily relieve the unpleasant feelings brought on by the obsessive thought.

Section 42 Care Act 2014 Enquiry by local authority
This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there):

- Has needs for care and support (whether or not the authority is meeting any of those needs),
- Is experiencing, or is at risk of, abuse or neglect, and
- As a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case and, if so, what and by whom.

A **vegetative state** is when a person is awake but is showing no signs of awareness. A person in a vegetative state may:

- Open their eyes
- Wake up and fall asleep at regular intervals
- Have basic reflexes (such as blinking when they're startled by a loud noise or withdrawing their hand when it's squeezed hard)

They're also able to regulate their heartbeat and breathing without assistance. But a person in a vegetative state doesn't show any meaningful responses, such as following an object with their eyes or responding to voices. They also show no signs of experiencing emotions. If a person is in a vegetative state for a long time, it may be considered to be:

- A continuing vegetative state when it's been longer than 4 weeks
- A permanent vegetative state when it's been more than 6 months if caused by a non-traumatic brain injury, or more than 12 months if caused by a traumatic brain injury

If a person is diagnosed as being in a permanent vegetative state, recovery is extremely unlikely but not impossible.

4.0 Synopsis

4.1 In 2014 Robyn was 81 years of age. She was a former nurse who had cared for her mother during a prolonged illness and later nursed her husband who died of prostate cancer. She had four adult sons. She lived in quite a remote rural area.

4.2 From the summer 2014 there was a steady decline in Robyn's physical and mental health. She was catheterised, required a wheelchair because of poor mobility and was showing signs of cognitive decline which was later diagnosed as cerebral vascular disease. One of its effects on her was to upset her balance which left her at risk of falls. Her GP began doing regular home visits on request.

4.3 During July 2014 Robyn agreed an emergency care plan which included a Do not attempt cardio pulmonary resuscitation (DNACPR) form. The form was signed by Robyn and witnessed by one of her elder sons. Additionally, the Court of Protection Judgement referred to in Paragraph 1.1 states that on 24th July 2014 Robyn signed an Advance Decision, in which she indicated her refusal of treatment in certain circumstances.

4.4 Following Robyn's hospital admission for pneumonia in August 2014, her youngest son moved into her home to care for her. This was with the agreement of her other sons.

4.5 Also during August 2014 Robyn agreed an 'admission avoidance care plan' with her GP in which she indicated that she wished to die at home if possible. The GP noted that it was evident that she had capacity to make decisions about her care at that time. It is unclear whether the 'admission avoidance care plan' was a separate and distinct document (The GP practice has been unable to find the 'admission avoidance care plan'). Robyn's wish to die at home if possible was recorded in the personalised care plan agreed with her GP in which her 'preferred place of care' was stated to be 'home under all circumstances'.

4.6 During a GP home visit on 29th April 2015 Robyn said she had lost her confidence after falling and would now only walk if her youngest son was present to hold her. Whilst the youngest son was out of the room, Robyn became upset and disclosed that her youngest son was 'pushing her too far' and she felt 'afraid to challenge him'. She went on to say that they 'get upset with each other and sometimes shout'. She added that she wanted to be allowed to get old and thought her youngest son wanted her to be 'how she was'. She said that she would consider moving into a care home but didn't want to leave her cat. The GP subsequently spoke to the youngest son and discussed the possibility of getting Adult Social Care involved. The GP referred Robyn to Adult Social Care.

4.7 In response to the GP referral a social worker visited Robyn on 19th May 2015 and spoke to her and her youngest son. She did not repeat the disclosures she had made to the GP. Robyn was noted to be extremely fatigued due to her health conditions. Respite was discussed and both Robyn and her youngest son expressed a preference for Robyn attending day care activities rather than spending periods of respite in a care home. The son requested an occupational therapy assessment to identify whether Robyn would benefit from any further aids and adaptations. The social worker arranged for the youngest son to have a carer's assessment which was completed on 18th June 2015. As the youngest son decided not to contribute to this SAR, it was decided that it would not be appropriate for the contents of this carer's assessment to be shared with this review.

4.8 On 18th May 2015 Robyn collapsed whilst receiving respite care in a local care home whilst her youngest son was visiting his home in Scotland. The care home subsequently contacted Adult Social Care to express concerns about comments made by Robyn whilst in respite. She told staff that she didn't want to go home and implied that her youngest son bullied her. The matter was resolved by the care home agreeing to advise of any further concerns arising from a forthcoming period of respite for Robyn in June 2015. The care home did not advise of any further concerns.

4.9 On 14th September 2015 Robyn's neighbour contacted the GP to express concern that Robyn had told her that she was 'very unhappy' as her youngest son had been forcing her to eat more than she reasonably could and hit her if she didn't eat enough or was too slow in getting to the toilet. The GP made a home visit later that day and spoke to Robyn alone whilst her youngest son was upstairs. The GP noted bruising to her left forehead and left eye, her left wrist and forearm, her right forearm and on both shins. Robyn disclosed that her youngest son 'bashes her about if she doesn't stand to attention when told and do as she is told'. She added that her youngest son also threatened to harm the cat when she didn't complete tasks quickly enough. She said she was frightened of her son knowing she had disclosed abuse.

4.10 On the same day the GP reported the matter to the locality social work team safeguarding hub in Penrith where a safeguarding concern was logged. During the early evening two police officers accompanied by a social worker and her team manager visited Robyn's address and found no-one at home. After phone discussions with two of Robyn's other sons, who said it was rare for her to leave her home, the police gained access to the property with a key provided by the neighbour who had raised the concern with the GP earlier in the day. Robyn and her youngest son arrived home from Penrith where he had taken his mother for shopping and a meal. They were upset to find that the police had entered Robyn's home. She was spoken to alone. 'Significant' bruising to her hands and arms was noted which she said may have been caused unintentionally by her youngest son whilst helping her after she had fallen. She declined the offer of a place of safety for her and her cat at a nearby care home. Her youngest son was spoken to and said that his mother bruised easily as a result of her medication. It was documented that he had demanded the immediate return of his mother's house key from the neighbour.

4.11 On 22nd September 2015 the police obtained Robyn's initial account at her home address. A social worker was also present. She retracted the disclosures made to the GP. Her younger son was present in the house during the interview. A safeguarding strategy meeting was held the following day attended by Adult Social Care and the police with the GP giving his apologies although he provided information to the meeting. During the meeting it was stated that Robyn had capacity to make decisions about keeping herself safe. The known facts of the case were considered. During this discussion it was said that Robyn had reportedly expressed the wish not to return home whilst receiving respite care (Paragraph 4.8). The outcomes of the meeting included the police obtaining statements from witnesses and considering interviewing the youngest son. The social worker was to make enquiries with Robyn's cleaner who was thought to be able to shed light on when the bruises had first been apparent and check whether Robyn was prescribed medication which thinned her blood and increased the risk of bruising (The GP later confirmed this). A referral was made to Occupational Therapy to observe how the youngest son managed the manual handling of his mother. The date of the next meeting - a multi-agency safeguarding planning meeting at which all information gathered during the investigation would be presented and, if appropriate, a safeguarding plan agreed - was set for 14th October 2015 but did not take place as only the social worker attended.

4.12 The police later decided to take no further action on the grounds of insufficient evidence for a realistic prospect of a conviction. The youngest son had been interviewed and denied assaulting his mother, reiterating the explanation that the bruising had been caused by a fall. Whilst the youngest son was being interviewed at the police station, the police arranged for an officer to revisit Robyn to provide her with a further opportunity to repeat her disclosure of abuse whilst her son was not present in the house. Robyn did not repeat her earlier disclosures. The police also spoke to one of her other sons and his wife who confirmed that the youngest son had told them about the fall and that they had also seen the bruising. The police concluded that all reasonable lines of enquiry had been conducted and there was no prospect of further evidence to strengthen the case.

4.13 The occupational therapist visited Robyn on 22nd October 2015 and observed her youngest son appropriately and safely supporting his mother to mobilise around the home including ascending and descending the stairs.

4.14 On 26th November 2015 Robyn was taken to the local acute hospital emergency department (ED) by her youngest son who reported that she had fallen going from her bedroom to the toilet. Robyn added that she had twisted herself when falling and landed on her zimmer frame and the linoleum floor. She was diagnosed with a closed fracture of her pubic ramus and discharged home. She had sustained extensive bruising to her lower abdomen.

4.15 The following day (27th November 2015) the GP received the hospital discharge letter and visited Robyn who told him that she had fallen whilst walking to the toilet late on the previous Saturday evening (21st November 2015). The youngest son said that his mother had been 'really sleepy' but needed to go to the toilet so 'he rushed her so she wouldn't have an accident'. He hadn't sought medical attention until he was due to take her to hospital for a scheduled cardiology appointment five days later. He acknowledged that he had seen the bruising on her abdomen and noticed that she was unable to get down the stairs at home. The GP also noted a bruise on Robyn's lower chin. After telephoning Adult Social Care the same evening, the GP arranged for the district nurse to visit daily over the forthcoming weekend when Robyn was said to have been able to mobilise with the help of her youngest son and her zimmer frame between her bed and the en-suite on the first floor of the house. A general nursing review was carried out on 28th November 2015.

4.16 On 1st December 2015 the GP contacted Adult Social Care to raise a safeguarding concern in respect of the youngest son's delay in seeking treatment for his mother and visited her at home the following day. The GP found her mood to be flat and she appeared to be struggling with her memory. It is understood that the hospital may also have raised a safeguarding concern on 30th October 2015 although there is no reference to this in the records shared with this SAR by North Cumbria University Hospitals or Adult Social Care.

4.17 On 9th December 2015 the GP visited again and found Robyn to be 'slightly more upbeat'. She appeared very frail and needed help to stand and shuffled when she walked. The GP noted a small fading bruise on her left cheek and a larger one on her right upper arm.

4.18 On 16th December 2015 a safeguarding strategy meeting took place. Flooding had prevented the meeting taking place earlier. The police were not present and there is no indication that they had been advised of the most recent incident. Both GP's from the practice were present. Robyn was judged to have capacity to make decisions about her personal safety but was felt to be 'under considerable influence' which may be affecting her decision making. It was noted that the current safeguarding concern had not been shared with her. The September 2015 safeguarding alert was discussed. The GP expressed the view that it was 'highly abnormal' not to seek help following an incident of this seriousness. The GP also expressed concern that the hospital had discharged her 'back into the same situation' with no follow up. The GP added that the September 2015 safeguarding alert was included in Robyn's patient notes and could therefore have been accessed by ED staff. (This was incorrect as there was no system in place for advising ED staff of adult safeguarding concerns at that time). It was asked why the hospital had not questioned Robyn's late presentation at the hospital. The hospital's safeguarding lead had been invited to the meeting but had been unable to attend. However, the minutes of the meeting were to be sent to him. The GP confirmed that Robyn was prescribed steroid inhalers which could make her bruise more easily. One of the two GPs was a female and said that she had felt intimidated when she visited Robyn. The youngest son had let her into the house, locked the door behind her and put the key in his pocket. The youngest son's practice of making his mother go upstairs to use the toilet rather than use the downstairs toilet in order to 'keep her mobile' was mentioned. There was some discussion about whether coercion and control may be present in the youngest son's relationship with his mother and it was suggested that this may be case for Inherent Jurisdiction although it was said that in order to pursue this further, the case would need to be strong. It was agreed that the social worker would visit Robyn to enquire whether she needed any support. It was anticipated that the visit would take place in the New Year. It was also agreed that it would be helpful if Robyn went into respite care for a period which would provide an opportunity to talk to her. The youngest son would be asked about respite during the visit. It was noted that district nurses continued to visit weekly and so they could monitor for bruising. The next safeguarding meeting would be arranged after the social worker visit to Robyn.

4.19 At 8.31am on 21st December 2015 the ambulance service attended Robyn's home after what was recorded as an 'unwitnessed fall' at home which had been reported to them by her youngest son. She was conveyed to the local acute hospital ED. The hospital documented that Robyn had fallen whilst her son was taking her to the commode. She was diagnosed with an extensive subdural (acute) haematoma and intracerebral haemorrhage and transferred to the intensive care unit (ICU). An endotracheal tube was inserted to assist with her breathing. The DNACPR (do not attempt resuscitation) process was completed. Transfer to Newcastle Royal Victoria Infirmary was ruled out as it was judged that neurosurgical intervention would not be of any benefit. The plan was for Robyn to transfer from the ICU onto a ward to receive palliative care and after discussion with family members, it was agreed that the focus would be on her comfort and dignity. (In their contribution to this review the family – three of Robyn's son's and two daughters-in-law, state that they advised hospital staff of the existence of the Advance Decision on the day of her admission. The hospital has no record of this conversation). Intravenous fluids were stopped at this point. There was some concern that Robyn may have fractured her left tibia, but the family agreed that there was no need for an X-ray. It was noted that Robyn was still 'open to safeguarding' following the 1st December 2015 safeguarding alert.

4.20 On 23rd December 2015 it was decided that a safeguarding concern 'was to be made' following consultation with the hospital safeguarding adults lead in view of the extensive injuries Robyn had sustained and the belief that she would have been immobile at the time of her most recent fall, which cast doubt on the account of the mechanism of injury provided by the youngest son. The belief that Robyn would have been immobile may have been based on the ED notes relating to her treatment for the fracture of her pubic ramus on 26th November 2015 when it was documented that Robyn could not mobilise at all. Photographs were to be taken of her injuries. It was said that this concern was to be handled sensitively due to the palliative nature of the care being provided to her.

4.21 On 29th December 2015 a 'further safeguarding alert' was made by the hospital safeguarding adults lead on the basis that there was reason to doubt whether Robyn's injuries could have been caused by a fall as she was believed to have been immobile due to her fractured pubic ramus and as her head injuries were so extensive. Both Adult Social Care and the police were aware. It is assumed that this safeguarding concern was not in fact a further concern but the formalisation of the safeguarding concern which had been under consideration since 23rd December 2015.

4.22 Robyn's life expectancy was anticipated to be very limited but there was a slight improvement in her condition over the following days. On 31st December 2015 Robyn was documented to have responded to questions which required an indication of yes or no. On 2nd January 2016 Robyn was noted to be 'brighter' and the appropriateness of fitting a nasogastric (NG) feeding tube was discussed with her youngest son. (Nasogastric feeding is where a narrow feeding tube is placed through the patient's nose down into their stomach. The tube can be used to give fluids, medications and liquid food). However, when Robyn was seen by the palliative care team on 6th January 2016, they noted an initial response of raising her right eyebrow followed by no further signs of response over the period they observed Robyn (In their contribution to this review, the family state that Robyn's elder son had a telephone conversation with the consultant overseeing her care during which the consultant was advised of the existence of the Advance Decision (Paragraph 5.4). The elder son recalls this conversation taking place around ten days after Robyn's admission – which would have been at the end of December 2015 or beginning of January 2016. The hospital has no record of this conversation). The consultant continues to work at the hospital and was asked if he could recall this conversation with Robyn's elder son. He had no memory of the conversation.

4.23 From 7th January 2016 the youngest son began to argue that his mother be discharged so that she could die at home which he said was in accordance with her previously expressed wishes (see Paragraph 4.5). However, the clinical view was that the window for a safe and dignified transfer home may have been missed. At this point Robyn was considered to be 'very much end of life' and Cheyne-Stoke breathing, which is an abnormal pattern of breathing commonly seen as patients approach death, had been observed. The youngest son was unwilling to accept the advice provided and also raised concerns that hospital staff had not been monitoring his mother well enough as he felt that she had been experiencing altered states of consciousness. However, clinicians noted her to fluctuate only between complete unresponsiveness and periodic eye movements and facial grimaces and to have no speech. The youngest son's brothers disagreed with him, preferring their mother to continue to receive hospital based palliative care.

4.24 On 8th January 2016 a fresh bruise to Robyn's right arm was noted. The hospital safeguarding lead was informed. The youngest son was very unhappy with ward staff, claiming that his mother was being 'starved to death' and that professionals were allowing her to dehydrate.

4.25 On 11th January 2016 Robyn was reviewed by the palliative care team. The possible need for artificial nutrition was discussed but it was documented that this would require a Best Interests meeting (There is no record of such a Best Interests meeting being held). On the same date a hospital multi-disciplinary team (MDT) meeting took place which identified that if Robyn was to be discharged from hospital, a discussion was needed with the youngest son in relation to the ongoing safeguarding issues 'which will prevent her from being returned home'.

4.26 On 13th January 2016 a safeguarding strategy meeting took place at the hospital which was chaired by the ASC team manager. The earlier safeguarding concerns were referred to (Paragraphs 4.9 and 4.14). It was confirmed that Robyn's leg had not been fractured as first thought when admitted (Paragraph 4.19), but in addition to extensive bruising, what appeared to be a possible hand mark had been noted on her chest. It was noted that the youngest son had become angry about his mother 'being starved'. A decision had been taken to feed her on subcutaneous fluids but this had not been successful. Three or four attempts had been made to insert a nasogastric feeding tube. A further attempt was to be made the following day and arrangements were to be made for a further scan to assess Robyn's haemorrhage. It was documented that the dilemma for nursing staff was that Robyn was not alert enough to be fed but without food she would slowly decline. Mention was made of the bruise on her arm Robyn had sustained since her admission to hospital (Paragraph 4.24) and there were concerns that this may have been caused by her youngest son as he had closed the door to her room whilst visiting her on occasions. Robyn was not receiving any medication that would increase her susceptibility to bruising and the bruise was not consistent with normal moving and handling. It was questioned why her youngest son had been allowed unsupervised access to his mother given the prior safeguarding concerns. The response was that a collective decision had been taken that it would be wrong to deny him access given the expectation that Robyn was likely to die within a short time. It was also decided not to treat the fresh bruise as a safeguarding concern as it was a 'one off', although further bruises would be treated as such. The outcomes of the meeting were that a decision to return Robyn home would be reviewed depending on how she responded and that the family needed to be involved in that decision. The situation relating to discharge would be reassessed in one weeks time. A follow up safeguarding planning meeting would take place on 25th January 2016.

4.27 On 19th January 2016 the local postmaster contacted the GP to express concern that the youngest son had been withdrawing unusually large amounts of cash from Robyn's account (£2500 over the past two months compared with the usual pattern of £100 withdrawn weekly). This concern was reported to Adult Social Care and the police. A safeguarding strategy meeting took place on 19th January 2016 at which it was confirmed that the police would be investigating the allegation. A safeguarding planning meeting took place on 22nd January 2016 when it was noted that the police had spoken to one of Robyn's sons who had power of attorney in respect of his mother's finances who confirmed that he had authorised his brother to use Robyn's account and was aware of the transactions. The safeguarding enquiry procedures were then closed.

4.28 On 22nd January 2016 a referral was made for Robyn to be fitted with a percutaneous endoscopic gastrostomy (PEG) tube which is a procedure in which a flexible feeding tube is placed through the abdominal wall and into the stomach, allowing nutrition, fluids and/or medications to be put directly into the stomach, bypassing the mouth and oesophagus. This decision appeared to be taken by Robyn's consultant after a discussion with her youngest son during which it was stated that the NG tube was not a long term option if Robyn was to be discharged. On the same date Robyn's other sons telephoned the hospital to express their disagreement with the PEG referral, saying that they needed further information. This disagreement between the youngest son and his brothers appears to have prompted a telephone call from the sister on Robyn's ward to the GP on 26th January 2016 to establish whether Robyn had made an Advance Decision and what information it contained. The GP record states that he checked Robyn's notes and found that the Advanced Decision 'refers to 'resus' only not artificial feeding'. The hospital records state that the GP had noted the Advanced Decision 'but this only related to DNACPR'. In his contribution to this review, the now retired GP stated that he sent a copy of Robyn's Advance Decision to the hospital following the 26th January 2016 telephone call, although this is not confirmed in the GP or hospital records shared with this review. In view of the fact that Robyn was considered to lack capacity in respect of her treatment and care and there was a difference of opinion between her sons over whether artificial nutrition was appropriate, the hospital made a referral for an Independent Mental Capacity Advocate (IMCA).

4.29 The following day (27th January 2016) a consent form in respect of the PEG insertion was signed by Robyn's consultant and her youngest son. The hospital notes state that the PEG insertion was in Robyn's best interests medically and in terms of 'nutritional means'. It was also documented that it was not possible to wait any longer to determine whether Robyn's neurological condition would improve as she had already had many days without nutrition. (There is no indication that a Best Interests meeting was held). The PEG tube was inserted on 29th January 2016.

4.30 The referral for an IMCA (Paragraph 4.28) was declined by the provider of the service on the basis that Robyn 'had lots of family involved to support decision making', even if they were in disagreement. Additionally, the IMCA service appears to have declined to become involved as the Best Interest decision to insert the PEG had, by this time, been taken.

4.31 A safeguarding planning meeting took place on 25th January 2016 at which the safeguarding enquiry in respect of the fall which had led to Robyn's hospital admission on 21st December 2015, was closed. After discussion it was concluded that there was no evidence of abuse. Concern was expressed that the ED had not recorded any explanation of how Robyn had sustained her head injury which was said to be 'surprising'. The hospital safeguarding lead was to take this matter up with the ED. There was also discussion about efforts to insert a nasogastric tube on 22nd January 2016 which Robyn had resisted, saying 'no' and 'sore'. She was said to have pulled it out after it had been inserted and 'continued to resist'.

4.32 On 5th February 2016 a meeting described as both an MDT meeting and a discharge planning meeting took place. It was noted that Robyn had been assessed as not meeting the criteria for NHS Continuing HealthCare (CHC) funding for her care at home. The CHC decision support tool was used to make the assessment and it was concluded that the nature of Robyn's significant subdural haemorrhage was not complex, intense or unpredictable. However, it was concluded that Robyn would qualify for NHS funded nursing care due to continence care, skin integrity and nutritional status via PEG feeding, which would be provided by the district nurses. It was confirmed that Robyn had been assessed as lacking capacity and unable to make any of her needs or wishes known. It was further stated that all those present, including her four sons, felt that her wish would be to return home and receive care from her youngest son, supported by carers to assist with using the hoist four times each day to fully support Robyn with her mobility. (In their contribution to this review, the family stated that they would not have agreed to their mother being discharged home to be cared for by the youngest son had they been made aware of prior safeguarding concerns including the delay in seeking medical attention to Robyn's pubic ramus fracture and the bruise Robyn sustained following her admission to hospital). The care package was to be purchased privately in view of the CHC decision. Robyn was noted to have a catheter and a PEG and to be incontinent of bowel movements which was to be supported through incontinence pads. Her youngest son was to be trained as the 'second carer'. Should he become unwell, the contingency plan would be for Robyn to access nursing home care. The meeting was not formally minuted although the Adult Social Care social worker has shared her note of the meeting with this review.

4.33 On 8th February 2016 the home care provider, who had also been providing home care to Robyn previously, contacted the hospital to express concerns about the youngest son being identified as the second carer as they felt that this could compromise the dignity with which Robyn's personal care was provided.

4.34 On 16th February 2016 a meeting to discuss the palliative care to be provided to Robyn in her home setting took place at the GP practice. The GP questioned whether it was appropriate to discharge Robyn to be cared for at home by her youngest son in view of the prior safeguarding concerns. The GP discussed his concerns with the safeguarding leads of the CCG and the hospital and also phoned Adult Social Care to register his concern. Robyn's social worker advised the GP that all of her family supported her discharge home and that all of the safeguarding concerns had been closed as unsubstantiated (No indication has been provided to this review that the safeguarding concern raised as a result of the delay in seeking medical attention for Robyn's fractured pubic ramus had been closed as unsubstantiated).

4.35 Robyn was discharged home on 29th February 2016 and the home care provider began delivering personal care to her four times daily (morning, lunch, tea and evening). Robyn was confined to the ground floor and the carers assisted the youngest son to transfer his mother from her bed to a reclining chair using the hoist and assist with her personal care needs such as washing, changing incontinence pads, changing catheter bags and applying creams.

4.36 On 7th March 2016 the GP contacted Adult Social Care to advise that the carers had expressed concerns about the impact of what were described as the youngest son's apparent obsessive compulsive tendencies on his care for his mother, his reluctance to contact the GP when Robyn was presenting as feverish and his threats to sack them (the home care provider). Robyn's social worker subsequently made a home visit with an occupational therapist and the youngest son was noted to be very attentive to his mother's needs throughout the visit. Adult Social Care assessed the risk of the youngest son cancelling the carers and concluded that there would be a severe risk of neglect including skin damage, unmet continence needs, her GP not being contacted when necessary and a high risk of harm to Robyn should he use equipment such as the hoist alone. It was documented that if the youngest son stopped carers from supporting his mother, the Best Interests decision would be for her to receive care in a nursing home due to the level of care she required.

Additionally, urgent contact would need to be made with the Court of Protection as nursing home care would likely be a disputed outcome.

4.37 During June 2016 the youngest son began objecting to district nurses visiting without giving sufficient notice and turning them away if they did not arrive at a time which fitted in with his schedule.

4.38 On 27th July 2016 the home care provider contacted Adult Social Care to advise that the youngest son had cancelled the morning and tea time care visits as Robyn was no longer being transferred from her bed to the chair. The provider said that they were not raising a concern over the youngest son's care of his mother which they considered to be very caring and of high quality but felt that Adult Social Care should know that he would now be supporting his mother in her bed for 18 hours a day without support. Any risks associated with this change were evaluated by an occupational therapist and it was decided that the youngest son's decision was reasonable and safe.

4.39 During August 2016 one of Robyn's sons contacted the GP to express concern that in exceeding the life expectancy anticipated at the time of her discharge from hospital, his mother was now in a situation he felt she would have hated. He was also worried about how the youngest son was coping with his caring responsibilities.

4.40 On 22nd August 2016 the GP met with Robyn's sons, including the youngest son who was unwilling to countenance withdrawal of his mother's PEG feeding. His brothers disagreed. They were also concerned that their mother would have found the intimate care provided by the youngest son undignified and degrading. The GP said he would contact Adult Social Care to enquire about a Best Interests meeting and was advised that ceasing artificial feeding could not be accomplished under a Best Interests framework and that legal advice would need to be sought from the CCG. The GP planned to hold a further meeting with Robyn's family and her new social worker made a referral for an IMCA to assist in the forthcoming meeting. The GP later documented within Robyn's patient notes that it was important to be aware that withdrawal of PEG feeding was not legal and that if the PEG tube blocked or came out then Robyn would need to be admitted to hospital. To remove PEG feeding would require an application to the Court of Protection. It was further documented that all other decisions relating to Robyn's medical care could be addressed under a Best Interests framework. It would appear that this information was not shared with other relevant health services, including out of hours services at that time.

4.41 On 21st September 2016 the GP and Robyn's social worker held a Best Interests meeting with her family. The GP recorded that the consensus view was that Robyn would not have wanted to be kept alive in her present state. With the exception of the youngest son, the brothers wished to approach the Court of Protection to stop PEG feeding. The youngest son said he did not want to have anything to do with this decision and became very upset recalling how his mother was in hospital when she was not being fed. It was agreed that Robyn would receive no active treatment for potentially life shortening illnesses such as a chest infection. The GP was to approach the CCG for legal advice. There is no indication that an IMCA was present at the meeting.

4.42 After a bruise was noticed on Robyn's forehead on 10th October 2016 a discussion took place between her social worker and the Adult Social Care single point of access (SPA) during which it was decided not to proceed to a safeguarding enquiry. The social worker made a home visit the following day and found Robyn to be well cared for and reminded the youngest son of the support available to him from the local carers organisation.

4.43 On 27th October 2016 the GP met the CCG medical director, the outcome of which was that Robyn would need expert neurological assessment which the CCG would arrange. The GP advised the youngest son and his brothers.

4.44 On 18th November 2016 the home care providers contacted Adult Social Care to express concern that the youngest son was not coping with his caring role and that he was dealing with all his mother's intimate personal care. Robyn's social worker liaised with the GP and decided that she would speak to the home carers in order to obtain a more specific account and also speak to the safeguarding team. No outcome of these conversations is recorded. The matter was also to be discussed with one of Robyn's sons but the outcome of any discussion is unknown.

4.45 On 20th November 2016 a consultant neurologist who had been instructed by the CCG examined Robyn at home and concluded that, based on prior medical records, she had been dementing prior to the traumatic head injury sustained on 21st December 2015 and that this dementing process involved many aspects of brain function. He concluded that she was in a 'minimally conscious state' and that the prognosis for any meaningful recovery was 'dismal'.

4.46 The youngest son continued to send district nurses away if they did not provide sufficient notice of their arrival and on 27th December 2016 he sent them away after they had provided two hours' notice, saying that 24 hours would be required in future.

4.47 On 5th January 2017 the GP documented that one of Robyn's sons advised him that the youngest son had a long history of 'medically diagnosed severe OCD'. The youngest son was registered with a GP in Scotland at that time. (During the family contribution to this review, this son said that he had also told the GP about the youngest son's OCD before this date).

4.48 On 17th January 2017 the district nurse contacted the GP to share concerns that the youngest son had stopped the home carers for one week and then re-started them again. The carers had described him as appearing unwell and dishevelled. The GP phoned the youngest son who assured him he was fine, that he had reinstated the carers and was happy that they were back.

4.49 On 3rd March 2017 the home care provider raised a safeguarding concern after the youngest son had tied pillows around his mother's arms using straps from the catheter instead of the prescribed wrist splints. When visited by the social worker the youngest son explained that he felt that the wrist splints could cause skin integrity issues. It was decided not to progress the concern to a safeguarding enquiry.

4.50 On 14 March 2017 a carer noted that Robyn had a bruise on the side of her face and two fingers strapped together. The youngest sons advised that the district nurses 'had done this'. The home care provider passed the information to Adult Social Care but there is no record of any outcome.

4.51 On 15th March 2017 the GP spoke to the youngest son during a home visit and the latter expressed anger at the recent safeguarding concern. The GP noted an old bruise to Robyn's right forearm and left temple for which the youngest son provided an explanation which satisfied the GP. The youngest son would not consider respite for himself and also disclosed that he had fallen out with two of his brothers who now had no contact or input into decisions about their mother's day to day care.

4.52 At the end of March 2017 the youngest son cancelled all visits from the home care provider and refused an Adult Social Care request to reinstate them. The home care provider had no further contact with Robyn. The youngest son said that they were too expensive, the care fees having been increased. Adult Social Care decided that this was not a safeguarding issue but the district nurses were asked to report any concerns arising from their home visits. The youngest son told the GP that he was happier without the carers because he could get into a routine with no-one to disrupt it.

4.53 As the months passed by there were a number of failed visits and difficulties in professionals accessing the address to visit Robyn and provide care. On 3rd August 2017 a palliative care nurse made a pre-arranged home visit and arrived four minutes early. The youngest son responded by angrily saying that she was 'ridiculously early'. He later apologised for his behaviour after the district nurse team leader visited him. The youngest son was offered respite for himself and his mother, both of which he declined. He said that he would never forgive himself if his mother died in respite care. The GP contacted one of Robyn's sons who said that the youngest son had stopped answering his phone calls. It is understood that this son subsequently visited the youngest son to give him advice.

4.54 Around this time district nursing staff expressed unease that Adult Social Care were not responding to their concerns that the youngest son was unable to consistently manage his mother's care without respite and he was restricting the access and input of health professionals, which was isolating Robyn from essential care and support.

4.55 From 17th August 2017 the youngest son began a practice of leaving professionals at the door for prolonged periods and it was reported that the nurses would often have to follow a pattern of knocking a certain number of times and waiting at least 10 minutes before the door was answered.

4.56 On 21st August 2017 a multi-disciplinary meeting was held to discuss the concerns raised by the district nurses. It was noted that the youngest son had begun leaving the district nurses waiting at the front door and seemed harassed and unhappy at their presence in the house. Disquiet was also expressed that he referred to his mother as 'sweetie pie', 'cheeky face' and 'honey pie'. It was questioned whether or not the youngest son caring entirely for his mother was in her best interests. It was noted that Robyn appeared unresponsive and may now meet the criteria for CHC funding. A follow up meeting was planned for two weeks later but there is no record of this meeting taking place.

4.57 On 17th October 2017 the consultant neurologist instructed by the CCG again examined Robyn at her home address and concluded that the movements she now displayed were all 'reflexive' and that there was 'no evidence of any conscious interaction'. He noted a deterioration over the intervening year since his previous examination in November 2016 when evidence of conscious interaction had been minimal.

4.58 On 30th November 2017 the district nurse noticed a small yellow bruise under Robyn's eye during a home visit. The youngest son said he could have easily have knocked his mother when rolling her. There was also a green bruise to Robyn's inner left foot which her youngest son reported to have been caused when he rubbed moisturiser on her feet. The incident was shared with the GP. It appears that the youngest son's explanation for the bruising was accepted.

4.59 In January 2018 district nurses continued to face challenges in making visits to Robyn. Her youngest son challenged them on the frequency of their visits which he felt should take place only monthly whereas the district nurses schedule required fortnightly visits.

4.60 On 11th January 2018 a new GP, who had taken over the practice, visited Robyn with the district nurse. They were concerned about reddening on her back as a result of being supine most of the time. The district nurse was to order a pressure mattress. The following week a district nurse contacted Adult Social Care to express concern that the youngest son's lack of compliance with advice regarding the repositioning of his mother was adversely affecting her skin integrity. The social worker later spoke to the GP and ascertained that the pressure mattress had been ordered.

4.61 On 28th January 2018 the district nurses expressed concern to Adult Social Care over what was described as the youngest son's highly anxious state and his tendency to overreact when the nurses were present. They questioned whether he would behave in this manner when caring for Robyn alone. Two days later the district nurses sought advice from the Cumbria Partnership Foundation Trust (CPFT) safeguarding team over the youngest son's non-compliance with nursing advice regarding positioning his mother and managing her continence needs. They were recommended to submit a safeguarding concern but there is no record of this happening. However, a multi-disciplinary team meeting took place involving Adult Social Care. Following that meeting the social worker and her manager subsequently visited the youngest son and offered him a range of support options all of which he declined.

4.62 On 5th March 2018 the GP was contacted about a forthcoming assessment of Robyn and was asked whether she had any concerns about the female consultant who would be conducting the assessment visiting alone. The GP replied that she had felt uncomfortable when visiting Robyn as her youngest son had locked the door behind her and added that the district nurses visited in pairs.

4.63 On 8th March 2018 the district nurses noted bruising on the bridge of Robyn's nose which her youngest son said had been caused by him washing her face.

4.64 On 15th April 2018 a consultant instructed by the CCG conducted a SMART (Sensory Modality Assessment and Rehabilitation Technique) assessment of Robyn. This assessment is used for the assessment and rehabilitation of people with prolonged disorders of consciousness following severe brain injury. The assessment report concluded that Robyn 'did not demonstrate any behaviours indicating awareness of herself or her environment, but had primarily reflexive responses with some spontaneous but non-purposeful behaviours'. The report went on to state that it was 'understandable how Robyn's responses, while non-meaningful, could be interpreted as purposeful'.

4.65 On 21st May 2018 district nurses noted bruises to Robyn's temples. Her youngest son claimed that his mother bruised easily. There is no indication that this was escalated.

4.66 On 6th July 2018 district nurses raised a safeguarding concern after the youngest son described how he helped his mother with her bowel movements. The GP visited him and he provided an explanation of how he assisted her to open her bowels which the GP found acceptable and the safeguarding concern was taken no further on the basis that there was no evidence of 'malpractice or lack of care'.

4.67 On 24th July 2018 a Best Interests meeting was held at which all agencies involved in Robyn's case were present and all the brothers with the exception of the youngest son. It was noted that the PEG had initially been inserted to enable her to be transferred home where it was anticipated that she would most likely die soon as she was so weak and physically compromised. It was also noted that the youngest son was now the sole carer for his mother and that the standard of his physical care was generally not in doubt. Some safeguarding issues had been reported but these had not necessitated consideration of the removal of Robyn from her own home. Access for the remaining professionals involved in Robyn's care was noted to be 'hard' and often required negotiation. It was stated that the family, with the exception of the youngest son, felt that the current situation was not something Robyn would have wanted for herself. Several members of the wider family contributed to the meeting. The view of those present was that Robyn would not have wanted any active treatment including artificial nutrition or any emergency and/or recovery treatments for infections or medical crisis.

4.68 The meeting considered the following four options:

- Change nothing and allow Robyn to remain at home being cared for by her youngest son with the existing agreement that active medical interventions to recover any deteriorations in her physical health would not be attempted.
- Move Robyn to a nursing home to have her care needs met by experienced and qualified staff reducing the caring pressures on her youngest son and increase opportunities for wider family contact until such time as nature takes it course.
- That withdrawing the clinically-assisted nutrition and hydration (CANH) was in Robyn's best interests and in line with her previously held values, beliefs and views and that this should take place in her family home. Looking also at what support may be needed to accommodate this.
- That withdrawing the CANH was in Robyn's best interests and in line with her previously held values, beliefs and views and that this should take place in a hospice setting.

4.69 The latter option was the agreed way forward although the difference of opinion of the youngest son was acknowledged. It was agreed to seek legal oversight through a decision by the Court of Protection which would take a view on what Robyn's wishes would be if she could communicate them directly herself. Concern was raised around the youngest son's emotional wellbeing should a decision be made that didn't concur with his own views. Options for offering support to the youngest son were discussed.

4.70 On 16th August 2018 the youngest son became agitated when district nurses reiterated their advice not to use 'puppy pads' for continence management. These are intended for dog training and adversely affect a human's skin integrity.

4.71 On 13th September 2018 the youngest son refused district nurses access as they had not attended at the 'allocated time'. He had insisted on being given one hour time slots for their visits whilst they had been unable to offer anything less than four hour time slots. He insisted that all visits should be arranged through Adult Social Care. The district nurses raised a safeguarding concern and also contacted the CPFT safeguarding team.

4.72 On 27th September 2018 a professionals meeting took place at the GP practice to discuss the youngest son's unwillingness to follow professional advice in respect of the care of his mother. The district nurses summarised their concerns which included the youngest son providing 24 hour care without consideration of any support; Robyn's needs not being met in a compassionate way as he declined input without considering what his mother would have wanted; him undertaking rectal digital stimulation without any training, rationale or clinical indication; him attempting to irrigate the catheter tube without training and only contacting district nurses as a last resort; and him controlling all moving and handling of Robyn which was unconventional. Additionally, staff stated they felt very uncomfortable during home visits due to the youngest son's inability to negotiate and his heightened anxiety levels.

4.73 On 2nd October 2018 the district nurses raised a safeguarding concern after being denied access by the youngest son. The safeguarding concern did not progress to formal enquiry as the Adult Social Care SPA determined that there had been no deliberate obstruction or concerns about the care being provided by the youngest son which was described as 'meticulous'. It was documented that it was felt that the district nurses were disrupting his routines by calling announced at the property and that a time slot of 1pm-4pm every other Thursday had been agreed.

4.74 On 29th November 2018 the youngest son was described as very challenging and antagonistic throughout the district nurse visit, saying that they were 'lucky to get in the house' as they had played their part in the meeting which had 'condemned his mother to death'. He was verbally abusive throughout the visit, shouting on occasions and at the end of the visit, told them that they would not be welcome to return. A safeguarding concern was raised by the district nurses in respect of the youngest son being verbally abusive and not allowing them access to Robyn. On 3rd December 2018 the district nurse phoned the GP to say that 'things had deteriorated' with the youngest son as he was refusing them access to the house despite the fact that Robyn had a pressure sore on her left hip which needed weekly visits. The district nurse said that a safeguarding concern had been raised and a strategy meeting was to be held. The GP decided against ringing him to tell him to admit the district nurses as both she and the district nurse felt that this might inflame the situation further. It was decided to await a meeting to be arranged by the 'safeguarding team'.

4.75 On 5th December 2018 the district nurses raised a further safeguarding concern as the youngest son would not allow them to access Robyn's home consistently to treat her skin integrity issues. It was decided to progress this referral to a safeguarding enquiry. They continued to be denied access over the following days.

4.76 On 7th December 2018 a professor in neurorehabilitation, instructed by the CCG to examine Robyn for the forthcoming Court of Protection hearing to consider the proposed withdrawal of clinically assisted nutrition, examined her at home. Some difficulty had been experienced in arranging this examination as the youngest son had stated that the dates initially offered by the professor were inconvenient. The professor concluded that if a label were to be attached to Robyn's condition, then the correct one was 'persistent vegetative state', both because of the endurance of her condition and because of the ongoing twin pathology of advancing dementia. He went on to conclude that Robyn was most probably beyond pain and awareness.

4.77 A safeguarding planning meeting took place on 13th December 2018 to discuss the 4th December 2018 safeguarding concern. It was noted that the youngest son had denied the district nurses access to Robyn for two weeks but that following an interim hearing of the Court of Protection, district nurse access to Robyn had been ordered by the Court with which the youngest son was complying. Therefore, Robyn was no longer considered to be at risk and the safeguarding enquiry was closed.

4.78 On 21st December 2018 the Court of Protection heard the application in respect of Robyn and it was decided that her life should be allowed to conclude with dignity in a local hospice to which she was transferred on the same date. The transfer, which had involved detailed planning to prepare for contingencies was carried out by the ambulance service who were assisted by the district nurse service.

5.0 Family Contribution

5.1 Robyn's youngest son initially decided not to contribute to this review but at a late stage decided to offer his comments. Restrictions imposed as a result of the Covid 19 virus precluded a meeting between the lead reviewer and the youngest son but during two substantial telephone conversations the lead reviewer took the youngest son through the contents of the report and noted the latter's comments which are as follows:

5.2 He said that after his mother left hospital in August 2014 and he subsequently moved in to her home in order to care for her more or less full time, he felt that the impact of her cognitive decline had turned her into a 'little girl' who was no longer able to distinguish between fantasy and reality.

5.3 Turning to the investigation of his mother's disclosure of physical abuse (Paragraphs 4.9-4.11), the youngest son said that he did in fact absent himself from his mother's house when the police obtained her initial account. He said he went outside and sat on a neighbour's wall until the police had finished. He added that when he was subsequently interviewed by the police as a suspect, he was 'flabbergasted' at the weight given to the limited disclosure of abuse made by his mother and felt that to have treated what she said as a disclosure of physical abuse by himself, one would have had to have approached what she said with an 'immediate and overwhelming presumption of guilt' on his part.

5.4 He said that the fall which caused his mother to fracture her pubic ramus in November 2015 (Paragraphs 4.14–4.16) was not a serious fall and it was only after a day or so that she began to experience mobility problems as a result. He said he felt that his mother needed to be checked out at hospital but she begged him not to take her there because of her fear of dying in hospital. Although he felt he was going against her wishes, he took her to the hospital ED on a day on which she had a routine appointment in another hospital department. He said that the fracture was so tiny that the X ray technician couldn't see it. The facture was observed by a hospital doctor who advised that he should keep his mother as mobile as possible whilst giving her medication for the pain.

5.5 He rejected any inference that he was responsible for the bruise his mother sustained in hospital (Paragraphs 4.24 and 4.26). He said he shut the door to the hospital room in which his mother was being treated because a patient in a nearby hospital room had complained that the radio he was using to play music to his mother was too loud. He also closed the door to his mother's room for his privacy as he was often in tears whilst waiting by her bedside. He said that no hospital staff told him not to close the door to his mother's room. He added that his mother was on medication at that time which meant that she bruised more easily.

5.6 He said it was wrong to suggest or imply that he had been in any way instrumental in agitating for the insertion of the nasogastric tube following Robyn's admission to hospital after the fall which caused her traumatic head injury. He said that this possibility had been put to him by hospital staff after his mother's condition improved. He agreed with this course of action describing it as 'hope on a plate'. He didn't think it necessary to consult his brothers or advise them of his decision on his mother's behalf to agree to the insertion of the nasogastric tube.

5.7 He added that there had been no disagreement with his brothers over Robyn's treatment in hospital. He said that he had had a debate, rather than a disagreement, with one of his brothers over the advisability of inserting the PEG tube where he had argued in favour of this, as without the PEG, she could not be discharged home to die which he said he knew to be her 'fundamental' wish.

5.8 He said he had no knowledge of the making of his mother's Advance Decision. It had been his understanding that she had consented to a DNACPR and that that was all.

5.9 He strongly denied that he had ever isolated his mother. He felt that as the person who was looking after Robyn 24/7, he should have been given a little consideration by professionals. He said he never stopped her close friend visiting his mother three times each week to clean the house, ensure that bird feeders were topped up and organise birthday and Christmas cards and presents to be sent to family members on Robyn's behalf. He added that he never stopped neighbours 'popping in'.

5.10 He said that he found the four daily visits from the home care providers 'exhausting'. No sooner had the carers helped him hoist his mother from her bed to her chair in the morning than the doorbell would ring again and it would be 'round 2', quickly followed by 'round 3' then 'round 4'. He felt that this regime prevented him from doing the shopping, collecting prescriptions or even taking some time for himself. When he reduced the number of daily visits by the home carers from 4 to 2, he said he consulted his brothers, Adult Social Care, the district nurses, occupational therapist and the physiotherapist and they were all in agreement.

5.11 He said that he later decided to dispense with the home carers all together because they 'significantly' increased their charges and he felt that some of the carers were not effective. He could see no advantage to him, or his mother, to continue with their service. He felt that he could adequately manage his mother's hoist to transfer her from bed to her chair and back again without any assistance.

5.12 He felt that it was unreasonable for the district nurses to only give him a four hour window for their home visits to his mother. He said that this 'stole time from his day' and prevented him from sitting down to eat a meal or even visit the toilet as the doorbell might ring at any moment. When the district nurses visited he would have to disconnect the PEG tube to allow them to move his mother in order to thoroughly check her skin integrity. Disconnecting the PEG tube always made him fear that it would become damaged resulting in his mother being admitted to hospital where she might die, meaning that the 'whole business of getting her home' would have been 'blown out of the water'.

5.13 He said he regretted his behaviour towards the district nurses on one occasion when he sent them away after they arrived 15 minutes early to change his mother's catheter. He said he was having an absolute disaster of a day having slept in late and having to deal with an incident involving a cat. He said he raised his voice to the district nurses on this occasion and they may have been frightened as a result.

5.14 He felt that if he expressed an opinion to a professional with which they disagreed, he was seen as being difficult. Sometimes he felt that disagreement with the district nurses led to him being 'punished' by them making more frequent visits for a time.

5.15 He said that he didn't isolate his mother from the rest of her family as it was they who stopped visiting and effectively isolated themselves from him. He acknowledged that some animosity had arisen over his brothers' wish to cease the artificial feeding of his mother, with which he disagreed. He said he 'wanted out' of this decision-making process because he was so committed to caring for his mother.

5.16 He said that he declined offers of respite care for his mother because on a previous period in respite care, she had become unwell shortly before he arrived to collect her and they had to wait for 'hours and hours' for a locum doctor to visit the care home to attend to his mother. He said that after this incident, he 'vowed to himself' that his mother would not go into respite and be in that state again and that he would just have to look after her 24/7.

5.17 In the thirty four months he cared for his mother after her discharge from hospital, she had no infections and no pressure sores (Paragraph 4.74 refers to a pressure sore on Robyn's hip). He felt that he provided his mother with excellent care but despite this some professionals 'rubbished' him. He accepted that she sustained some bruising during this period but felt that this was 'par for the course' when a substantial amount of manual handling was necessary. He added that his mother had a tendency to cough 'at the wrong moment' as she was being hoisted from bed to chair and chair to bed. When she coughed, this would sometimes cause her to collide with him and the side of the bed. He felt that this not infrequent coughing was his mother attempting to communicate that she didn't like being hoisted, although he said that professionals 'pooh, poohed' this suggestion.

5.18 He flatly rejected professional concerns over the intimate care he provided for his mother. He said that this issue was repeatedly raised with him by some professionals. His response, then and now, was that it was a loving act, in terms of wanting his mother to be comfortable and clean. He found the concerns raised be to be very upsetting.

5.19 Overall, the youngest son felt that going through the findings of the SAR report had reopened old wounds, adding that he didn't know what he had to do to vindicate himself. He felt that he had been let down by many professionals who were only prepared to help him care for his mother on their terms.

5.20 Robyn's other three sons and two daughters in law decided to contribute to the review and met the lead reviewer as a group. They will be referred to as 'the family' in this section of the report.

5.21 Overall the family felt angry that their mother, after sustaining a catastrophic head injury, had been subjected to three years of care which she most definitely would not have wanted. They felt that decisions were made whilst she was being treated in hospital after sustaining the brain injury which were not in accordance with her previously stated wishes. They also felt that after her discharge from hospital when it became clear that she could survive indefinitely as a result of the artificial feeding which had been put in place, the family did not receive good advice from the Clinical Commissioning Group which had the result of unnecessarily prolonging their mother's suffering and caused the family a great deal of stress.

5.22 The family said that following their mother's admission to hospital on 21st December 2015 they shared the fact that their mother had completed an Advance Decision with hospital staff on at least three occasions. They said they told hospital nursing staff and the 'neuro' consultant about the Advance Decision on the day of their mother's admission.

5.23 Additionally the elder brother told the consultant who was caring for his mother about the Advanced Decision during a telephone call which took place around ten days after his mother's admission. The brother recalls that his mother was receiving palliative care only at that time. The consultant told him that it had been decided to reintroduce food and fluid for his mother by inserting a nasogastric tube. The brother responded by saying that his mother wouldn't want this to happen and again referred to the Advance Decision. The consultant responded by saying that the Advanced Decision was not clear and that they would be reintroducing food and fluid on ethical and moral grounds. The brother described the tone of the consultant as 'offhand and condescending'.

5.24 Another brother recalled advising a palliative nurse of the Advanced Decision but can't remember whether this was before or after the PEG tube had been fitted. He recalls having this conversation with the palliative care nurse whilst the youngest brother was not present.

5.25 In summary, the family wished to emphasise that they had advised the hospital of their mother's Advance Decision on the very first day of her admission and on two subsequent occasions. It was therefore incorrect for information to have been presented to the Court of Protection which stated that the hospital was only made aware of the existence of the Advance Decision in a telephone call between their mother's GP and the ward sister at the hospital on 26th January 2016.

5.26 Their understanding was that once the nasogastric tube was fitted and artificial nutrition had begun, this could only be reversed by order of the Court of Protection. As a result, the family acquiesced to the fitting of the PEG tube as artificial feeding had already begun by other means, they had been told that the Advanced Decision was not competent and allowing their mother to return home to die would not be possible without the PEG tube being inserted.

5.27 They felt that in taking the initial decision to insert the nasogastric tube, the hospital had ignored the wishes of their mother and her family, with the exception of the youngest son. The family's view is that the Advance Decision should have been viewed before any artificial feeding took place and that the fitting of the nasogastric tube and subsequently the PEG tube represented physical assaults on their mother. The family feel that before commencing artificial feeding in hospital, the decision should have been escalated to senior management and legal advice sought.

5.28 The family say that when their mother was discharged from hospital at the end of February 2016 they were told that her life expectancy was very limited – from two weeks to two months. They say that they were never advised that inserting the PEG could prolong her life.

5.29 The family went on to discuss what happened after their mother was discharged from hospital. They felt that the findings of the Court of Protection were contrary to the advice they received from North Cumbria CCG. The Court of Protection ruled that drawing a firm distinction between vegetative state and minimally conscious state is frequently both artificial and unnecessary*. The family said that this contradicted the approach adopted by the CCG which advised them that they couldn't approach the Court of Protection until their mother was assessed as being in a persistent vegetative state and so three assessments were carried out over a period of 18 months to determine that their mother had deteriorated sufficiently. What they were told by the Court of Protection indicated that they could have gone to the Court much earlier, potentially after the first examination of their mother by the consultant in October 2016.

* It should be pointed out that the Court of Protection decision in respect of Robyn, when noting that the importance of obtaining a precise and definitive diagnosis had reduced, referred to 'recent' Royal College of Physicians and British Medical Association guidance entitled 'Clinically- assisted nutrition and hydration (CANH) and adults who lack the capacity to consent' (2). This guidance had been published on 12th December 2018 just days before the Court of Protection decision and would therefore not have been available to guide CCG decision making over the preceding three years.

5.30 The family were also unhappy with the CCG's advice that their mother's Advance Decision was not competent. This was not the view of the Court of Protection which ruled that the initial insertion of the nasogastric tube was arguably incompatible with their mother's wishes and that there was little doubt that the insertion of the PEG was contrary to Robyn's Advance Decision. They felt that the CCG could have taken the case to the Court of Protection much sooner which would have greatly reduced the period their mother was being cared for against her wishes and would have greatly reduced the consequent pain and suffering endured by the family over those years including a major rift in a previously close family.

5.31 The family also felt that the situation that Robyn's youngest son found himself in as his mother's primary carer was another reason for the CCG to move much faster. Although he had worked in residential care (albeit for a short period, many years previously), the family felt that he found himself in a very exposed position in caring for their mother. They had visited him weekly until the final year of their mother's life when their relationship broke down. They felt that the youngest son had become obsessed with doing everything he could to avoid their mother succumbing to an infection and isolating himself and keeping professionals at bay was his way of reducing the possibility of infection. They felt that the prolonged period of caring for their mother adversely affected his pre-existing obsessive compulsive symptoms. The family said that they had advised their mother's GP of the youngest son's mental health issues far earlier than the entry in the GP notes dated January 2017.

5.32 When the lead reviewer took the family through the contact that agencies had had with their mother and her youngest son during the period of nearly three years following her discharge from hospital in February 2016, they were shocked by the number of safeguarding issues raised of which they said they were unaware and wondered why they had not been contacted to try and intercede.

5.33 The family felt that they should receive apologies from the hospital for deciding to provide artificial nutrition to their mother against their mother's expressed wishes and the disrespect shown to them when they alerted them to the existence of the Advance Decision, and the CCG for insisting that their mother's Advance Decision was defective and that they could not go to the Court of Protection until it could be clinically established that their mother was in a persistent vegetative state. They wished to be advised of the changes introduced to prevent what their mother and the family had been through happening to anyone else.

6.0 Analysis

6.1 In this section of the report the key lines of enquiry for the review will be considered.

How effectively did agencies address adult safeguarding concerns in respect of Robyn up to and including the fall which caused her traumatic head injury on 21st December 2015?

6.2 Robyn's disclosure to her neighbour and subsequently her GP that her youngest son had assaulted her causing visible bruising received a prompt multi-agency response. The GP made an immediate safeguarding referral, Adult Social Care notified the police and they jointly visited Robyn's address after arrangements had been made for her and her cat, without which it was felt she would be unlikely to wish to leave her home, to be provided with respite care. When they were unable to obtain an answer from Robyn's address, and having established via telephone contact with two of her other sons that it was unusual for her to be away from her home at that time of day (early evening), it was a defensible decision for the police to gain entry to her house after being provided with a key by the neighbour to whom Robyn had disclosed physical abuse. Entry was justified in order to check that Robyn was safe and well.

6.3 It is unfortunate that Robyn and her youngest son returned at this point because Robyn was understandably surprised and somewhat distressed to find the police in her house and social workers also present. She declined the offer of respite and did not repeat her earlier disclosures that evening or when spoken to subsequently. There was no doubt that she had sustained quite extensive bruising which was clearly visible to the police officers and social workers.

6.4 When the police visited Robyn to obtain her initial account on 22nd September 2015, her youngest son was present in the house. Given the suspicion that he may have assaulted Robyn he should not have been present. It may have been possible to arrange for one of Robyn's other sons to provide care for her on that date. However, practitioners who attended the learning event arranged to inform this review advised that when the youngest son was subsequently interviewed by the police at the police station an officer again visited Robyn to give her the opportunity to repeat her earlier disclosures of physical abuse which she declined to do.

6.5 The safeguarding strategy meeting ensured that all reasonable enquiries were initiated although the follow up safeguarding planning meeting did not take place after only the social worker attended. The purpose of this safeguarding planning meeting is to present all the information gathered during the investigation and, where appropriate, a safeguarding plan will be agreed (3). This meeting represented an opportunity to take stock following the conclusion of the police investigation and consider what further action needed to be taken to safeguard Robyn, if any.

6.6 The police had interviewed the youngest son who continued to contend that the bruises to his mother were accidental. The police were also in contact with two of his brothers who substantiated the youngest son's account to an extent in that they said that he had informed them of the bruising to their mother at the time it occurred. The police decided to take no further action. At the practitioner learning event the officers involved in the investigation confirmed that an evidence led prosecution had been considered. An evidence-led prosecution takes place without the support of the victim (4). It is therefore assumed that the evidence of bruising to Robyn and the statements from the GP and neighbour to whom Robyn had made the disclosures were insufficient to mount an evidence-led prosecution given the corroboration obtained for the youngest son's explanation that the bruising had been caused by a fall.

6.7 Assuming the bruising had occurred in a fall, it was appropriate to arrange for an occupational therapist to observe how the youngest son supported his mother to mobilise around the house.

6.8 A second safeguarding concern was raised by the GP after the youngest son failed to seek medical attention for a closed fracture of Robyn's pubic ramus for five days. There was clear evidence of neglect given the extensive bruising sustained in the fall which caused the fracture and the substantial pain and restriction in movement Robyn would have experienced. The youngest son was also demonstrating the reluctance to seek the assistance of health professionals and a tendency to 'go it alone' in the care of his mother which would become so pronounced over the following years.

6.9 When her youngest son eventually sought medical attention for his mother by taking her to the local acute hospital ED, her late presentation was not apparently questioned and no safeguarding concern was considered at the time or contact made with any other service in respect of Robyn, other than sending the standard notification of hospital attendance to the GP who again promptly raised a safeguarding concern. Nor did the hospital apparently consider whether it was safe to discharge her back to the environment in which she had fallen and sustained the fracture. (The hospital safeguarding lead may have raised a safeguarding concern some days later although this is not documented in the combined chronology).

6.10 The safeguarding strategy meeting was delayed by a week due to flooding. The prior safeguarding concern was noted and the question of whether Robyn was subject to coercive control was discussed. She was said to be 'under considerable influence' which may be affecting her decision making. The plan was for the social worker to visit Robyn and suggest a period of respite which would provide an opportunity to talk to her away from her younger son's influence. The SAR Panel questioned whether it was appropriate for a core element of the safeguarding plan for the district nurses to monitor Robyn for bruising (Paragraph 4.18) when their core role was to provide her with care.

6.11 The effectiveness of the care her youngest son was providing to his mother merited further attention at this point. Robyn had fallen and sustained the fracture whilst the youngest son had admitted to rushing her to the bathroom whilst she was sleepy. He appeared to have been rushing her to avoid her urinating before she reached the bathroom, which was an unwise order of priorities when supporting someone with mobility and cognitive issues. Given the previous safeguarding concern in which the youngest son claimed that Robyn's extensive bruising had been caused by a fall, concerns over Robyn's risk of falls in her youngest son's care merited further action including a falls risk assessment in which he could have been involved.

6.12 Before the social worker visit could be arranged, Robyn was admitted to hospital after a further fall at home in which she sustained a traumatic head injury. This led to a third safeguarding referral in three months which was made by the hospital safeguarding lead as there was reason to doubt whether Robyn's injuries could have been caused by a fall as she was (incorrectly) believed to have been immobile due to her fractured pubic ramus and as her injuries were so extensive.

6.13 A safeguarding strategy meeting took place to consider this safeguarding concern on 13th January 2016. The two earlier safeguarding concerns informed decision-making. The minutes of the meeting indicates that a wide range of issues relating to Robyn were discussed at this meeting which may have distracted from the original purpose of developing a multi-agency strategy for investigating safeguarding concerns. It was acknowledged that Robyn's extensive injuries were reportedly caused by a fall but that there was reason to doubt this. The police were present but stated that this was not an open investigation and that they had merely been made 'aware' of the safeguarding concern. It was decided that the situation should be managed as it was for the moment and would be reassessed in one week's time. The follow up safeguarding planning meeting took place on 25th January 2016. After discussion it was concluded that the safeguarding concern was unsubstantiated and safeguarding procedures were closed. Establishing that Robyn had been able to mobilise with support following the fracture to her pubic ramus appears to have been a significant factor in this decision, although the fall which caused her brain injury was subsequently recorded by the Coroner as unwitnessed which indicates that she was not being assisted by the youngest son at the time. Police records indicate that Robyn sustained the injury by falling from her commode. Concern was expressed that the ED had not recorded any explanation of how Robyn had sustained her head injury which was said to be 'surprising'. The hospital safeguarding lead was to take this matter up with the ED.

6.14 No safeguarding concern was raised in respect of the fresh bruise noted on Robyn during her hospital admission (Paragraph 4.24) which her youngest son was suspected of causing. This was not acceptable practice.

6.15 A fourth safeguarding concern was raised over concerns of financial abuse (Paragraph 4.25) but this was quickly resolved after the son with lasting power of attorney in respect of Robyn's finances confirmed that he had authorised the withdrawals by the youngest son from his mother's post office account.

6.16 Looking back at the response to the safeguarding concerns which arose in the months up to and including her admission to hospital following the traumatic head injury, it is unclear whether the concerns expressed by Robyn to the GP in April 2015 (Paragraph 4.6) informed the response to those subsequent safeguarding concerns although the comments she made whilst in a respite placement in May 2015 (Paragraph 4.8) were considered. It is unfortunate that the serious and prompt response to Robyn's disclosure of physical abuse in September 2015, which resulted in Robyn returning to her home to find the police had affected entry to her home, unsettled Robyn and may have inadvertently diminished the possibility of her repeating the disclosures she had made to her neighbour and the GP earlier in the day. Concerns that the fall from which Robyn sustained a traumatic head injury may have been non-accidental were eventually considered to be unfounded although the lack of record keeping about the circumstances of the fall in ED was unsatisfactory. As stated above the bruise Robyn sustained after her admission should have been treated as a safeguarding concern. The safeguarding concern in respect of Robyn's late presentation at hospital following her fractured pubic ramus clearly represented neglect by the youngest son and the response to this incident was delayed by severe weather and then overtaken by events, in that Robyn's fall from which she sustained the traumatic head injury took place before the safeguarding enquiry could be concluded. This failure to seek prompt medical attention should have informed the decision to discharge Robyn home in February 2015 and the subsequent care and support provided to Robyn but there is no indication that it did so. The impression gained is one of the 'slate being wiped clean' of the prior safeguarding concerns by the time it had been decided to discharge Robyn from hospital in February 2016.

How effective were agencies in respecting Robyn's previously held views and Advance Decision? Were systems in place to ensure her wishes were respected?

6.17 The Court of Protection Judgement states that on 24th July 2014 Robyn signed an Advance Decision, in which she indicated her refusal of treatment in certain circumstances. An advance decision (sometimes known as an advance decision to refuse treatment (ADRT) or a living will) is a decision a person with capacity can make in the present to refuse a specific type of treatment at some time in the future. It lets the person's family, carers and health professionals know their wishes about refusing treatment if the person is unable to make or communicate those decisions themselves. The treatments the person decided to refuse must all be named in the advance decision (5).

6.18 What Robyn stated in the document is as follows: "on collapse, I do not wish to be resuscitated by any means." She amplified this: "I am refusing all treatment. Even if my life is at risk as a result." Addressing the applicability of her decision, she identified her aspiration in these terms: "in all circumstances of collapse that put my life at risk, this direction is to be applied."

6.19 In their contribution to this review, Robyn's family have advised that they decided not to involve the youngest son in the process by which the Advance Decision was completed as it was felt that he would not be in agreement and so when Robyn signed the document it was witnessed by one of her other sons.

6.20 When Robyn was admitted to hospital on 21st December 2015, the Advance Decision was highly relevant to her circumstances. She had sustained a traumatic head injury which she was considered to be unlikely to survive. She was assessed as lacking capacity to make decisions about her care and treatment and was unable to communicate her wishes.

6.21 The Court of Protection Judgement concludes that it was plain, or at least it appeared, that the document was not available at the hospital at the time of Robyn's admission. There is no reference to the Advance Decision in the chronology provided to this SAR by North Cumbria University Hospitals until the telephone contact between the ward sister and Robyn's GP on 26th January 2016, over a month after her admission (Paragraph 4.28). As previously stated, following this phone call the GP recorded that the Advance Decision 'referred to 'resus' only not artificial feeding' and the ward sister recorded that it 'only related to DNACPR'. The Court of Protection took a different view, finding that the initial insertion of the nasogastric tube was arguably incompatible with Robyn's wishes and that there could be little doubt that the insertion of the PEG was contrary to Robyn's written decision.

6.22 In their contribution to this review the family have said that they informed the hospital of the Advance Decision on three occasions, when Robyn was admitted on 21st December 2016, in a telephone conversation between the consultant and one of Robyn's sons to discuss the insertion of the nasogastric tube around ten days after her admission and in a conversation with a palliative care nurse either before or after the PEG was fitted. The family say that during the telephone conversation with Robyn's son, the consultant advised him that the Advance Decision was not competent which suggests that the Advance Decision may have been viewed by the hospital prior to 26th January 2016.

6.23 The hospital has no record of viewing the Advance Decision and they also have no record of being notified by the family of the Advance Decision on the date of Robyn's admission or in subsequent conversations between the family and the consultant and a palliative nurse other than the discussions which prompted the ward sister to telephone the GP on 26th January 2016. The now retired GP has advised this review that he sent a copy of Robyn's Advance Decision to the hospital following the 26th January 2016 telephone call although this is not confirmed by the GP or hospital records. However, the hospital records document two attempts by the two of Robyn's sons (not the youngest son) to telephone the consultant to argue against the insertion of the PEG tube on 22nd January 2016. The hospital records document a failed attempt to connect one son to the consultant by telephone and the subsequent provision of the consultant's secretary's telephone number to his brother. The family state that neither son spoke to the consultant on this occasion as a meeting took place at the hospital soon afterwards at which they were able to express their concerns. The hospital has no record of any telephone conversations between the consultant and either brother, either on or around 22nd January 2016 or earlier in Robyn's admission as stated by the family. The family have confirmed that they did not have a copy of their mother's Advance Decision to share with the hospital at that time.

6.24 Hospital staff were faced with a very challenging set of circumstances. Robyn was not expected to survive her injuries and it was decided to provide palliative care. There were slight signs of improvement and in response to this, and the urgings of her youngest son who appears to have been a more or less constant presence in the hospital at this time, artificial feeding began to be attempted. After a nasogastric tube was successfully fitted a PEG was later inserted. It was documented that there was disagreement between the youngest son and his brothers on the treatment to be provided to their mother and reference to the need for Best Interests meetings but there is no indication that any Best Interests meeting took place during Robyn's admission.

6.25 The aforementioned Royal College of Physicians and British Medical Association guidance entitled 'Clinically- assisted nutrition and hydration (CANH) and adults who lack the capacity to consent' contains the following key principles:

- CANH is a form of medical treatment;
- CANH should only be provided when it is in the patient's best interests;
- Decision-makers should start from a strong presumption that it is in a patient's best interests to receive life-sustaining treatment, but this can be rebutted if there is clear evidence that a patient would not want CANH to be provided in the circumstances that have arisen;
- All decisions must be made in accordance with the Mental Capacity Act 2005;
- All decisions must focus on the individual circumstances of the patient and on reaching the decision that is right for that person; and
- As per General Medical Council (GMC) guidance, a second clinical opinion should be sought where it is proposed, in the patient's best interests, to stop, or not to start CANH and the patient is not within hours or days of death (6)

6.26 It is inappropriate for this SAR to attempt to 'second guess' decision making in respect of Robyn's care during her hospital admission following the 21st December 2015 fall. However, it is pertinent to note the principle that CANH should only be provided when it is in a patient's best interests. No Best Interests meetings are documented to have taken place in respect of Robyn's care and treatment during her hospital admission. Had such meetings taken place it may have been possible to more fully explore Robyn's wishes and resolve the conflict apparent between the youngest son and his brothers. The Best Interest process would also have allowed earlier and more careful consideration of Robyn's Advance Decision which may have led to the conclusion that there was in fact 'clear evidence' that she would not have wanted CANH.

Was the Mental Capacity Act applied correctly in respect of Robyn? Did Best Interests discussions take account of wider family views?

6.27 A fundamental principle of the Mental Capacity Act (MCA) and English law generally is that adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so, unless it is proven otherwise. The responsibility for proving that an adult lacks capacity falls upon the person who challenges it.

6.28 Following her traumatic head injury Robyn was assessed as lacking mental capacity to consent to her care and treatment although she was noted to be able to respond to 'yes' and 'no' questions on occasions during her hospital admission and appeared resistant to the fitting of the nasogastric tube.

6.29 At the heart of the MCA lies the principle that where it is determined that individuals lack capacity, any decision or action taken on their behalf must be in their best interests. A crucial part of any best interests judgement will involve a discussion with those close to the individual, including family, friends or carers. During Robyn's hospital admission from 21st December 2015 to 29th February 2016 one would have expected to see a series of Best Interests discussions taking place as decisions were made in respect of palliative care, artificial nutrition and hydration via the nasogastric tube and subsequently via the insertion of a PEG, the destination to which she should be discharged from hospital etc. Whilst the need for Best Interest meetings to take place was frequently documented no such meetings appear to have taken place. The Mental Capacity Act Code of Practice states that 'where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker' (7). So, for the decisions relating to Robyn's medical treatment, including artificial hydration and nutrition, it would be 'the doctor or other members of the healthcare staff' who were responsible for ensuring that Best Interests meetings took place.

6.30 The MCA provides a non-exhaustive checklist of factors that decision-makers must work through in deciding what is in a person's best interests including:

- Take into account all relevant circumstances
- Take into account the individual's past and present wishes and feelings, and any beliefs and values likely to have a bearing on the decision
- Consult as far and as widely as possible.

Additionally, it is considered vital that Best Interests decisions are recorded. Not only is this good professional practice, but given the evidence-based approach required by the MCA, this will provide an objective record should any decision or decision-making processes later be challenged (8).

6.31 As previously stated, had Best Interests meetings taken place there would have been greater opportunity to fully explore Robyn's wishes, consider her Advance Decision, seek a second opinion or specialist advice on the Advance Decision as necessary and take the views of family members into account. It is almost certain that the youngest son would have taken a different view to his brothers in respect of artificial nutrition and in an effort to resolve this conflict a referral for an IMCA was made but rejected by the provider of the IMCA service on the basis that family members were involved. This was an unfortunate decision which appears to conflict with General Medical Council (GMC) guidance treatment and care towards the end of life: good practice in decision making (9). This guidance recommends that in order to resolve disagreements an independent advocate could be involved or local mediation services used.

Was the decision to discharge Robyn home from hospital in February 2016 taken in her Best Interests and was the decision informed by prior safeguarding concerns?

6.32 The decision to discharge Robyn to her home address was taken in a meeting held on 5th February 2016 (Paragraph 4.32). There was some confusion as to the purpose of this meeting and it was not minuted. It was assumed by both professionals and Robyn's family that she was returning home to receive primarily palliative care as her life expectancy was considered to be short. Robyn had previously expressed the wish to die at home if possible (Paragraph 4.5). There is no indication that the decision to discharge Robyn home to be cared for by her youngest son was informed by prior safeguarding concerns as they were said to have all been closed as unsubstantiated. It is difficult to see how the safeguarding concern arising from the delayed presentation of Robyn at ED following the fracture of her pubic ramus could be considered to have been unsubstantiated. Additionally, further concerns had arisen during Robyn's hospital admission including an unexplained bruise to Robyn which her youngest son was suspected of causing, 'pouring water into his mother's mouth' after being advised not to give her a drink as she was not being very responsive and not bringing in clean clothes or night clothes for his mother.

6.33 However concerns were subsequently registered by the GP, who had not been involved in the discharge planning meeting, and the home care providers. The GP shared his concerns with the CCG safeguarding lead, the hospital safeguarding lead and Adult Social Care but this did not result in any substantial response such as a multi-agency meeting to discuss the GP's concerns and potentially develop a plan to address any risks. This review has been advised that Cumbria Safeguarding Adults Board does not currently have a process for resolving professional disagreements.

6.34 Robyn's needs had been assessed to ascertain whether she was eligible for NHS funded Continuing HealthCare (CHC) by the NHS Cumbria CCG Continuing Health Care Team. Despite her very substantial needs, she was assessed as ineligible which was a decision which surprised the practitioners who attended the learning events arranged to inform this review. The CHC decision support tool (DST) used at the time has been reviewed to inform this SAR. It was found to lack the documentation of evidence necessary to reach conclusions and was considered to be of 'poor quality'. The absence of CHC funding had important implications. It meant that the provision of the home care package considered necessary to support the youngest son as 'second carer' was privately funded. Had this care been CHC funded it would have been subject to management and review. Nor would it have been possible for the youngest son to unilaterally cancel CHC funded care as he subsequently did in respect of the privately funded home care. Additionally, had Robyn been assessed as eligible for CHC, then the CHC team would have led the discharge planning process and provided a focus for decision making when issues arose in respect of Robyn's care at home.

How effectively did agencies address adult safeguarding concerns in respect of Robyn during the period following her discharge from hospital on 29th February 2016?

How effectively did agencies respond to concerns that the youngest son may be isolating Robyn from the care and support she needed?

6.35 Safeguarding concerns began to be raised by professionals within days of Robyn being discharged home (Paragraph 4.36). In March 2016 the home care provider expressed concern about the impact of the youngest son's OCD tendencies on his care of his mother, his reluctance to contact the GP when she was unwell and his threats to sack them. This concern did not appear to prompt a formal safeguarding enquiry but Adult Social Care responded by assessing the risk of the youngest son cancelling the home care provider and documented that it would be in Robyn's Best Interests to be transferred to nursing home care in those circumstances. They also noted that the youngest son would likely dispute that course of action which would necessitate the involvement of the Court of Protection.

6.36 The second safeguarding concern following Robyn's discharge from hospital arose in October 2016 when a bruise was noted on her forehead (Paragraph 4.42). It was decided that this should not progress to a safeguarding enquiry.

6.37 There appears to have been a discussion between Robyn's social worker and the GP in November 2016 (Paragraph 4.44) after the home care provider expressed concern that the youngest son was not coping with his caring role and dealing with all of his mother's intimate personal care. The outcome of the proposed discussion with the home care provider was not documented.

6.38 There was a further safeguarding concern from the home care provider in March 2017 (Paragraph 4.48) after the youngest son tied pillows around his mother's arms using straps from the catheter instead of the prescribed wrist splints. After the social worker visited the youngest son it was decided to close the safeguarding concern as his actions were not considered to have compromised the care provided to his mother. At the practitioner learning events, an occupational therapist described the youngest son's approach to providing care to his mother as unconventional at times whilst being well intentioned.

6.39 When a bruise was noted on the side of Robyn's face in March 2017 (Paragraph 4.50-51) there is no indication that a safeguarding concern was made. This and other bruising was noted by the GP the following day who was satisfied by the explanation given by the youngest son.

6.40 The youngest son cancelled the home care provider at the end of March 2017 after previously reducing their daily visits from four to two. This should have triggered the best interests discussion envisaged which Adult Social Care had earlier decided would be necessary (Paragraph 4.36). Instead they decided that this was not a safeguarding issue and the district nurses, who the youngest son had been restricting access to since June 2016 (Paragraph 4.37) were asked to report any concerns arising from their home visits. This was not an appropriate response. The risks to Robyn's care arising from the cancellation of home carers had been explicitly set out in April 2016. These risks had been mitigated to an extent by the diligent care the youngest son had been observed to provide to his mother but given the safeguarding concerns which had arisen in September and December 2015, the risk that he was isolating Robyn from professional care and the opportunity for professionals to regularly observe her, and the concerns about the youngest son's obsessive compulsive behaviours, a safeguarding strategy meeting should have been held at this point. Contact should also have been made with Robyn's other sons to discuss the issue.

6.41 In August 2017 a multi-disciplinary meeting was held to discuss persistent concerns that the youngest son was restricting the access of the district nurses. It seems unlikely that the issue was recorded as a safeguarding concern. Concern was expressed as to whether the youngest son caring entirely for his mother was in her best interests. It is documented that a follow up meeting was to take place but there is no record of this. It was also noted that because of the apparent deterioration in Robyn's consciousness she may have become eligible for CHC funding but there is no indication that this was followed up.

6.42 Bruising noted on Robyn in November 2017 (Paragraph 4.58) did not generate a safeguarding concern.

6.43 No safeguarding concern appears to have been made when the district nurse expressed disquiet that the youngest son's lack of compliance with professional advice was adversely affecting his mother's skin integrity (Paragraph 4.60).

6.44 It is unclear whether the district nurses followed the January 2018 advice from the CPFT safeguarding team and submitted a safeguarding concern when they expressed unease about whether the behaviour he displayed towards them could be present in his relationship with his mother when professionals were not present (Paragraph 4.61). However, a multi-disciplinary team meeting took place which led to a visit to the youngest son to offer him support which he declined.

6.45 Bruising on Robyn's face noted by the district nurses in March and May 2018 did not lead to safeguarding enquiries (Paragraph 4.63 and 4.65).

6.46 In July 2018 the district nurses raised a safeguarding concern after the youngest son described how he helped Robyn with her bowel movements. He later provided descriptions of the assistance he provided to his mother to open her bowels which the GP found acceptable although the fact that he had given a different and more concerning account of his actions to the district nurses does not appear to have been given sufficient weight in deciding to take the safeguarding concern no further.

6.47 In September 2018 what is described as a professionals meeting took place (Paragraph 4.72) at which district nurses set out the range of concerns they had about the youngest son's repeated denial of access to Robyn and his care of his mother. Again, this was not a formal safeguarding strategy meeting and there is no clarity about what the outcome was.

6.48 In October 2018 a safeguarding concern from the district nurses relating to denial of access was closed by Adult Social Care on the grounds that there was no deliberate obstruction and that the district nurses were disrupting the youngest son's routines by calling unannounced (Paragraph 4.73). It is not possible to understand how this view could have been taken given the prior documented efforts of the district nurses to offer time slots to the youngest son (Paragraph 4.71) and his repeated efforts to isolate his mother from professionals.

6.49 Further safeguarding concerns were raised by the district nurses on 3rd December 2018 (Paragraph 4.74) and 5th December 2018 (Paragraph 4.75) after the youngest son denied them access to treat Robyn's pressure sore. For the first time during the thirty four month period Robyn was cared for at home, these safeguarding concerns progressed to a formal safeguarding enquiry and a safeguarding planning meeting was held on 13th December 2018 (Paragraph 4.77).

6.50 The repeated safeguarding concerns which arose whilst Robyn was being cared for at home following her traumatic head injury began to demonstrate that her youngest son, a person who was believed to have mental health needs and was observed to be struggling to cope with his caring responsibilities at times, was increasingly isolating his mother from professional care. He gradually reduced the opportunities for professionals to observe her and ensure that her substantial care and support needs were being met. His behaviour towards professionals was frequently hostile and sometimes aggressive which gave rise to concerns about how he may have treated his mother.

6.51 Safeguarding concerns appear to have been responded to as separate events and accumulating issues do not appear to have been picked up on. From the incomplete records provided it is difficult to be precise but formal safeguarding procedures do not appear to have been followed at times. MDT or professionals meetings were held from time to time from which outcomes were often less than clear. There is no indication that Adult Social Care's policy of reviewing a case if three safeguarding 'contacts' had been received and not progressed to a formal safeguarding enquiry was implemented in Robyn's case.

6.52 During the period following Robyn's discharge from hospital in February 2016, she was not in receipt of services from, or commissioned by, Adult Social Care but it was decided to allocate a social worker to her case. This was an appropriate decision. The social worker concerned provided an invaluable link between the various professionals involved in the youngest son's care although the focus of the role appears to have been on conflict resolution which may have been entirely appropriate at times but may have been a less appropriate approach as concerns escalated.

To what extent did agencies focus on the needs of Robyn and consider her lived experience ?

6.53 Robyn's decision making whilst she had mental capacity indicates that she would have wished to die at home if possible. However, the wording of her Advance Decision strongly indicates that, whatever awareness she may have had of being cared for at home by her youngest son for the final 34 months of her life, she is most unlikely to have wanted this to happen.

6.54 Generally the professionals involved in her care were acutely conscious of Robyn's needs and the home carers, the district nurses, the palliative nurses and her GP, prior to his retirement at the end of 2017, showed considerable determination to gain access to Robyn and ensure her care and support needs were met. The GP in particular worked very hard to engage with the youngest son in a constructive manner to try and overcome his resistance to professional involvement in Robyn's care.

6.55 However, the focus gradually shifted away from Robyn's needs to managing her youngest son's behaviour including the demands and restrictions he continually sought to place on professionals. Managing him began to soak up an inordinate amount of professional attention and there were occasions when a desire to avoid inflaming the situation may have resulted in giving higher priority to placating him than ensuring Robyn's needs were met.

6.56 Prior to sustaining the traumatic head injury Robyn appeared to have been in a situation of some vulnerability as a result of her increasing care needs and her reliance on her youngest son. It is clear that there was a strong bond between mother and son but the youngest son's assumption of the primary carer role for his mother created a new dynamic in their relationship and it seems clear that conflict arose from time to time. The safeguarding concerns which arose from September 2015 generated professional concern that coercive control may be present in the youngest son's relationship with his mother.

6.57 Coercive control consists of behaviours perpetrated by one person against another with whom they have an intimate or family relationship and is exercised in situations where the behaviour of an individual is shaped into conformity to the wishes of another person (10). Professional awareness of coercive control has been most prominent in the area of physical abuse in intimate relationships although the criminal offence of coercive and controlling behaviour introduced by the Serious Crime Act 2015 relates to both intimate and familial relationships.

6.58 In this case there is evidence that coercive control may have been present when the youngest son deprived his mother of access to medical care for five days following the fracture of her pubic ramus. He also demonstrated controlling behaviour whilst his mother was being treated in hospital. Coercive control may also have been present in his subsequent behaviour in gradually isolating her from care and support by dispensing with the home care provider and continually restricting access for district and palliative care nurses.

6.59 Female professionals frequently felt intimidated by the youngest son. One of the two GP's who cared for Robyn until the end of 2017 described the youngest son letting her into the house, locking the door behind her and putting the house key in his pocket. (Paragraph 4.18). When the subsequent (female) GP was contacted about the forthcoming SMART assessment of Robyn and was asked whether she had any concerns about the female consultant who would be conducting the assessment visiting alone, she replied that she had felt uncomfortable when visiting Robyn as the youngest son had locked the door behind her. She added that the district nurses visited in pairs. At the practitioner learning event the district nurses confirmed that they visited in pairs and felt their vulnerability was increased by the rural location of Robyn's home and the lack of mobile phone network coverage. They added that they always ensured that a further colleague was aware of their visits to Robyn in order to check on their welfare as necessary. By January 2018 the district nurses expressed concern to Adult Social Care about whether his hostile behaviour towards them might be present in his relationship with his mother (Paragraph 4.61). In his contribution to this review Robyn's now retired (male) GP pointed out that the youngest son was not accommodating to professionals and that he'd personally experienced this behaviour which could be intimidating to either sex.

6.60 When Robyn disclosed physical abuse by her youngest son support from an Independent Domestic Violence Advocate (IDVA) should have been considered as could advocacy.

What support was offered to the youngest son as the primary carer for Robyn following the decision to discharge Robyn home from hospital in February 2016? How effectively did agencies engage with the youngest son as carer for Robyn? How did agencies respond to concerns about the youngest son's capacity to provide appropriate care for Robyn? In particular how did agencies respond to indications that the youngest son's emotional and mental health may be affecting his care for Robyn?

6.61 When Robyn was discharged from hospital on 29th February 2016, the discharge planning arrangements considered the practical elements of support required by the youngest son but there appeared to be little consideration of the personal impact of being in a very challenging carer's role. However, the assumption at the time was that Robyn's life expectancy was limited and therefore her youngest son's caring responsibilities would probably not extend beyond a short number of months. When his caring role continued for much longer than anticipated there was an opportunity to review the youngest son's needs as a carer.

6.62 After Robyn returned home, the district nurses began to express concern in respect of carer fatigue and the impact of being a sole carer on the youngest son. When the nurses attempted to engage in conversation with him regarding support this sometimes increased the strain in their relationship with him as he appeared to see any offer of help as a judgement on his ability to cope. There were concerns that his apparently fragile mental health could be deteriorating under the strain of caring for his mother.

6.63 The youngest son's strong focus on caring for his mother with increasingly restricted input from health and social care services also appears to have isolated him from receiving support as a carer. His medical records have not been shared with this review. His family had advised the GP that he had been diagnosed with obsessive compulsive disorder but it has not been possible to confirm this. In his contribution to this review, Robyn's now retired GP advised that he was concerned for the youngest son's well-being and tried to persuade him to register with a local GP, however, he was unwilling to do so.

6.64 Over the past two decades there has been increasing recognition of the needs of family carers whose rights were first given legislative effect in the 1995 Carers (Recognition and Services) Act which was followed by the National Carers Strategy in 1999. More recently, the Care Act 2014 substantially replaced and consolidated existing legislation for carers and those they support. The Act introduced parity of esteem between carers and service users, strengthened carer's rights to an assessment of need and placed a new duty on local authorities to fund support for carers 'eligible needs'.

6.65 A carer's assessment had been completed in June 2015 at a time when the youngest son was caring for his mother in very different circumstances from those which applied from 29th February 2016. As he decided not to contribute to this review it has not been possible to seek his consent to view the carer's assessment but it seems certain that, as part of the assessment, he would have been made aware of the options available for support and respite for himself as a carer. The extent to which he availed himself of support or respite is unclear although Robyn spent two periods in respite care during 2015. Practitioners who attended the learning events arranged to inform this review could not recall the youngest son accessing respite or support during the thirty four month period he cared for his mother at home following her discharge from hospital in February 2016. In October 2016 he had been reminded of the support and advice offered by a local carer's organisation and in February 2018 he declined a referral to the same organisation.

6.66 Given the much more demanding caring role he began fulfilling from February 2016, he could have been offered a further carer's assessment, particularly when he fully dispensed with the support of the home care provider at the end of March 2017.

6.67 The decision making in respect of his mother's future, from which he eventually absented himself, also appeared to have an adverse effect on his emotional health and wellbeing, particularly as the Court of Protection hearing drew nearer.

6.68 That his mother lived for so long beyond the initial prognosis and did not succumb to any infections is testament to the meticulous physical care her youngest son provided and may have been a factor in his apparent desire to isolate her from contact with professionals. Keeping her alive may have become an obsession which adversely affected his own health and wellbeing and caused a serous rift in his relationship with family members, further isolating him.

Information sharing to support adult safeguarding

6.69 The safeguarding concern in respect of Robyn's disclosures of physical abuse in September 2015 was not available to ED staff who treated her for the fracture of her pubic ramus two months later. There was no system for flagging adult safeguarding concerns to hospital ED staff and it is understood that this remains the case.

6.70 Additionally, the fact that withdrawal of PEG feeding for Robyn was not legal and that if her PEG tube blocked or came out then she would need to be admitted to hospital was not shared by her GP with other relevant health services, including out of hours services (Paragraph 4.40).

Good practice

6.71 There are many examples of good practice in this case including:

- The GP did much excellent work, including referring Robyn to Adult Social Care in April 2015 when she disclosed that her youngest son was 'pushing her too far', promptly raising a safeguarding concern after Robyn disclosed physical abuse by her youngest son in September 2015 and when there was a substantial delay in her youngest son seeking medical attention for his mother's pubic ramus fracture in November 2015. The GP also raised legitimate concerns about the decision to discharge Robyn to the care of her youngest son in her home in February 2016. The GP's recording of his contact with Robyn and her youngest son was very detailed which has been of invaluable assistance to this review. It is worth noting that the narrow 'resus only' view he took of the Advance Decision appears to be out of character with his general approach to record keeping. However, it should be pointed out that notwithstanding the judgement taken by the Court of Protection, it is undeniable that Robyn's Advance Decision was very brief.
- The response of Adult Social Care and the police to Robyn's disclosure of physical abuse in September 2015 afforded the disclosures an appropriate level of priority and the joint working between the two agencies was complementary.
- The determination of district and palliative care nurses to gain entry to Robyn's home in an effort to ensure her care needs were met despite the persistent and intimidating efforts of her youngest son to restrict their access.
- The persistence of the district nurses in continuing to raise safeguarding concerns over the thirty four month period during which Robyn was cared for by her youngest son at home, despite the less than satisfactory response the concerns attracted.
- The contingency plan for the removal of Robyn from her home to a local hospice following the Court of Protection Judgement was implemented sensitively and effectively.

7.0 Findings and Recommendations

7.1 This Safeguarding Adults Review focusses on how partner agencies worked together to prevent Robyn from being harmed during the last four years of her life. For the vast majority of this time she was cared for in her own home by her youngest son.

7.2 As a result of a fall in her home in December 2015 Robyn suffered a traumatic head injury which she was not expected to survive. Prior to this head injury Robyn's health had been declining and she had become increasingly dependent on her youngest son to care for her. During this earlier period safeguarding concerns arose. Robyn disclosed physical abuse by her youngest son which she quickly retracted and she also suffered neglect when he delayed seeking medical attention for five days after she sustained a fracture of her pubic ramus in a fall at home.

7.3 The fall from which Robyn sustained the traumatic head injury, which left her in a minimally conscious state, led to a safeguarding concern which was not substantiated. After Robyn was discharged home to be cared for by her youngest son she substantially outlived the brief life expectancy which had been anticipated and her family, with the exception of her youngest son, initiated an application to the Court of Protection which ruled that artificial nutrition and hydration should end and that Robyn should be allowed to die with dignity. However, this was a lengthy legal process during which the youngest son cared for Robyn for thirty four months. Professional opinion was divided over the quality of care he provided. There is little doubt that his meticulous care prevented Robyn developing infections which may have ended her life. However, he increasingly isolated Robyn, and himself, from the care and support of professionals, frequently behaving in a hostile manner towards them and concerns arose over the dignity of care Robyn was receiving. With the exception of the youngest son, her family felt that the circumstances in which she was cared for over the final thirty four months of her life were not in accordance with her wishes and this view was confirmed by the Court of Protection Judgement.

Adult Safeguarding

7.4 During the period prior to the fall from which she sustained a traumatic head injury, safeguarding concerns were responded to effectively by her GP, Adult Social Care and the police to an extent. However, it was not appropriate for the police to obtain Robyn's initial account about her prior disclosures of physical abuse whilst the suspected abuser, and the person on whom she was entirely dependent for her daily care and support, was present in the same house. Additionally, the fall from which Robyn sustained a fracture of the pubic ramus should have led to a falls risk assessment and the safeguarding concern that Robyn had suffered neglect because her youngest son had delayed seeking medical attention for the fracture should have been substantiated and more fully informed the professional view of the care provided by the youngest son to his mother over the following months and years.

7.5 However it is of concern that the hospital to which the youngest son took his mother following the fracture of her pubic ramus did not question her delayed presentation or consider raising a safeguarding concern at that time.

7.6 Therefore Cumbria Safeguarding Adults Board may wish to seek assurance from North Cumbria Integrated Care NHS Foundation Trust (the provider of acute hospital services since 1st October 2019) that late presentation of patients which indicate neglect or abuse on the part of the patient's carer, will be enquired into and a safeguarding concern raised where justified.

Recommendation 1

That Cumbria Safeguarding Adults Board seeks assurance from North Cumbria Integrated Care NHS Foundation Trust that late presentation of patients at hospital which indicates neglect or abuse on the part of the patient's carer, will be enquired into and a safeguarding concern raised where justified.

7.7 When Robyn was treated for her fractured pubic ramus in the hospital ED in November 2015, the ED staff would have been unaware of the recent safeguarding concern raised after Robyn had disclosed physical abuse by her youngest son. Contrary to the expectations of Robyn's GP, there was no system for flagging prior adult safeguarding concerns to hospital ED staff. It is understood that this remains the position.

7.8 Cumbria Safeguarding Adults Board may wish to seek assurance from North Cumbria Integrated Care NHS Foundation Trust that they have a system in place to ensure that hospital ED staff are alerted to adult safeguarding concerns in respect of patients attending at ED.

Recommendation 2

That Cumbria Safeguarding Adults Board obtains assurance from North Cumbria Integrated Care NHS Foundation Trust that they have a system in place to ensure that hospital ED staff are alerted to adult safeguarding concerns in respect of patients attending at ED.

7.9 The safeguarding concern arising from the fall from which Robyn sustained the traumatic head injury was eventually judged to be unsubstantiated but a bruise sustained by Robyn after her admission to hospital, which was considered to be incompatible with normal moving and handling of patients, did not result in a safeguarding concern. This was an error.

7.10 Therefore Cumbria Safeguarding Adults Board may wish to seek assurance from North Cumbria Integrated Care NHS Foundation Trust in respect of the raising of safeguarding concerns when unexplained bruises are sustained by patients post admission.

Recommendation 3

That Cumbria Safeguarding Adults Board seeks assurance from North Cumbria Integrated Care NHS Foundation Trust in respect of the raising of safeguarding concerns when unexplained bruises and injuries are sustained by patients post admission.

7.11 Practitioners began expressing disquiet about the care provided by the youngest son to his mother within days of her discharge from hospital on 29th February 2016. Looking back at the thirty four month period during which he cared for his mother following her discharge from hospital, one of the key areas of concern was that the youngest son gradually isolated her from the necessary care she required from professionals, reducing then completely dispensing with the home care provider just over a year after his mother's hospital discharge, repeatedly restricting access to district nurses and isolating Robyn from the remainder of her family. He assumed control over every aspect of his mother's care including care he was not trained to provide such as catheter care. Concern was also expressed about whether being cared for exclusively by her youngest son, including all personal care, was in Robyn's Best Interests and consistent with dignified care. Additionally, it was questioned whether the hostility that the youngest son frequently demonstrated to primarily female professionals may be present in his relationship with his mother who was no longer capable of communicating her wishes in any way. However, the youngest son continued to provide meticulous, if occasionally unconventional, care to his mother which prevented her succumbing to any infections and possibly prolonged her life.

7.12 When safeguarding concerns were raised, Adult Social Care took the view that they did not merit formal enquiry with the exception of two concerns raised by district nurses in December 2018, shortly before the Court of Protection hearing. There was insufficient consideration of psychological abuse which the Care Act 2014 guidance defines as including 'deprivation of contact', 'isolation' and 'unreasonable and unjustified withdrawal of services or supportive networks' (11). Adult Social Care had decided that the cancellation of the home care provider by the youngest son would expose Robyn to risks which would necessitate a Best Interests meeting to consider the transfer of Robyn to a care home but didn't follow through on this when the youngest son did, in fact, cancel the care provider.

7.13 Adult Social Care took the positive step of allocating Robyn's case to a social worker even though she was not receiving care and support commissioned by the local authority but the focus of their involvement appeared to be primarily around conflict resolution as the need to manage and placate the youngest son inadvertently began to assume greater importance than ensuring Robyn's needs were met. The various issues raised about the youngest son's care for his mother were considered in isolation and Adult Social Care's policy of reviewing a case after three safeguarding concerns have been received and not led to a formal safeguarding enquiry was not applied in Robyn's case. Adult Social Care appear to have lost sight of their duty to promote wellbeing when carrying out any of their care and support functions in respect of a person. Wellbeing relates, amongst other things, to personal dignity, including treating the person with respect as well as protection from abuse and neglect.

7.14 It is therefore recommended that Cumbria Safeguarding Adults Board seek assurance from Cumbria County Council Adult Social Care in respect of their management of cases in which there are a number of safeguarding concerns raised. In particular the extent to which they analyse the concerns in order to identify an accumulation of issues and the extent to which they consistently apply their system for reviewing a case when three safeguarding referrals have been made which have not led to a safeguarding enquiry.

Recommendation 4
That Cumbria Safeguarding Adults Board seek assurance from Cumbria County Council Adult Social Care in respect of their management of cases in which there are a number of safeguarding concerns raised. In particular the extent to which they analyse the concerns in order to identify an accumulation of issues and the extent to which their system for reviewing a case when three safeguarding referrals have been made which have not led to a safeguarding enquiry is consistently applied.

7.15 It became apparent that not all safeguarding concerns which arose during the thirty four months during which the youngest son was caring for his mother following her discharge from hospital were raised in accordance with the Pan Lancashire and Cumbria multi-agency safeguarding adults policy and procedures. Additionally, safeguarding concerns were often addressed informally via multi-disciplinary meetings from which the outcome was sometimes less than clear.

7.16 Therefore Cumbria Safeguarding Adults Board may wish to remind professionals of the importance of following the multi-agency safeguarding adults policy (which is due to be updated imminently) by using the formal route for raising, and responding to adult safeguarding concerns and promoting the use of formal safeguarding strategy and safeguarding planning meetings.

Recommendation 5
That Cumbria Safeguarding Adults Board reminds partner agencies of the importance of following the multi-agency safeguarding adults policy (which is due to be updated imminently) by using the formal route for raising, and responding to, adult safeguarding concerns and promoting the use of formal safeguarding strategy and safeguarding planning meetings.

Discharge Planning

7.17 When Robyn was discharged from hospital on 29th February 2016, the discharge planning arrangements were not robust. There was confusion amongst practitioners over the purpose of the discharge planning meeting, the meeting was not minuted, the GP was not invited, the prior safeguarding concerns were said to be unsubstantiated when one of them was not (late presentation at hospital following fracture to pubic ramus), and there was insufficient consideration of the risks associated with Robyn's return home to the care of her youngest son. There was also no consideration of the emotional impact on the youngest son of caring for his mother in a minimally conscious state although at that point, Robyn's life expectancy was considered to be very short.

7.18 Cumbria Safeguarding Adults Board may wish to seek assurance from North Cumbria Integrated Care NHS Foundation Trust in respect of the effectiveness of discharge planning arrangements including the overall management and recording of discharge planning meetings, consideration and management of any risks associated with the hospital discharge and ensuring that all relevant professionals are invited.

Recommendation 6
That Cumbria Safeguarding Adults Board seeks assurance from North Cumbria Integrated Care NHS Foundation Trust in respect of the effectiveness of discharge planning arrangements including the overall management and recording of discharge planning meetings, consideration and management of any risks associated with the hospital discharge and ensuring that all relevant professionals are invited.

Advance Decisions

7.19 The Court of Protection ruled that the initial insertion of the nasogastric tube by the hospital in January 2016 was arguably incompatible with Robyn's wishes and that there was little doubt that the insertion of the PEG was contrary to her wishes as expressed in her Advance Decision.

7.20 The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life (12). The outcome desired by Robyn and articulated in her Advance Decision was not achieved. A number of factors contributed to this. Firstly, there appears to have been only one copy of the Advance Decision and this was placed in Robyn's GP records. There should be a system in place, subject to the consent of the person making the Advance Decision, to ensure that Advance Decisions are shared with other parts of the healthcare system which may have a need to view the Advance Decision at some stage. It would also be helpful for the person making the Advance Decision and her family to retain a copy. In this case Robyn's family were not in possession of a copy of the Advance Decision which could have assisted them in their discussions with hospital staff following their mother's admission in December 2015.

7.21 Professionals may also need guidance on how to advise people who wish to make Advanced Decisions to ensure that they state their wishes as clearly and comprehensively as possible. Professionals may also need guidance on how to interpret and apply what is written in Advance Decisions to the circumstances which subsequently arise for the maker of the Advance Decision. In this case the GP, to whom Robyn was very well known, interpreted the Advance Decision more narrowly than did the Court of Protection.

7.22 In this case there is disagreement between the family and the hospital over whether the former mentioned Robyn's Advance Decision to the latter. The family are adamant that they notified the hospital of the Advance Decision on three separate occasions. There is no record of these notifications in the hospital records shared with this review. Professionals need to be advised to record any reference to an Advance Decision and then make enquiries to locate the document.

7.23 When the hospital decided to investigate Robyn's Advance Decision, they relied on the GP's interpretation of the contents of the document rather than requesting a copy to consider, although the now retired GP has advised this review that he sent the hospital a copy but this is not confirmed by the GP or hospital records. This is an insufficiently robust approach to considering such an important document. Professionals need to be advised to obtain a copy of any Advance Decision and to seek advice on the interpretation of the content of the document where necessary.

7.24 Cumbria Safeguarding Adults Board may wish to arrange for the learning arising from the handling of Robyn's Advance Decision to inform national guidance, specifically in respect of the need for professionals to advise people who wish to make Advanced Decisions to ensure that they state their wishes as clearly and comprehensively as possible, the need for a system, subject to the consent of the person making the Advance Decision, to ensure that Advance Decisions are shared with other parts of the healthcare system which may have a need to view the Advance Decision, the need for professionals to record all references to the existence of Advance Decisions and the need to obtain a copy of any Advance Decision and to seek advice on the interpretation of the content of the document where necessary.

Recommendation 7

That Cumbria Safeguarding Adults Board makes arrangements for the learning arising from the handling of Robyn's Advance Decision to inform national guidance, specifically in respect of:

- *The need for professionals to advise people who wish to make Advanced Decisions to ensure that they state their wishes as clearly and comprehensively as possible,*
- *The need for a system, subject to the consent of the person making the Advance Decision, to ensure that Advance Decisions are shared with other parts of the healthcare system which may have a need to view the Advance Decision,*
- *The need for professionals to record all references to the existence of Advance Decisions and*
- *The need to obtain a copy of any Advance Decision and to seek advice on the interpretation of the content of the document where necessary.*

Mental Capacity Act (Best Interests)

7.25 At the heart of the MCA lies the principle that where it is determined that individuals lack capacity, any decision or action taken on their behalf must be in their best interests. During Robyn's hospital admission from 21st December 2015 to 29th February 2016 one would have expected to see a series of Best Interests discussions taking place as decisions were made in respect of palliative care, artificial nutrition and hydration via the nasogastric tube and subsequently via the insertion of a PEG, the destination to which she should be discharged from hospital etc. Whilst the need for Best Interest meetings to take place is frequently documented within hospital records no such meetings appear to have taken place.

7.26 Had Best Interests meetings taken place there would have been greater opportunity to fully explore Robyn's wishes, consider her Advance Decision, seek a second opinion or specialist advice on the Advance Decision as necessary and take the views of family members into account.

7.27 Cumbria Safeguarding Adults Board may wish to work with partner agencies to raise awareness of the need for Best Interests meetings and the importance of fully documenting them. Developing a case study based on the learning from this SAR could represent a valuable contribution to any awareness raising.

Recommendation 8

That Cumbria Safeguarding Adults Board work with partner agencies to raise awareness of the need for Best Interests meetings and the importance of fully documenting them. Developing a case study based on the learning from this SAR could represent a valuable contribution to any awareness raising.

7.28 When it became clear that there was a disagreement between the youngest son and his siblings over the care of their mother the hospital considered the involvement of advocacy and could have considered the involvement of mediation. It may be helpful for the commissioners of the IMCA service to discuss this case with the provider of the IMCA service and consider whether any changes to referrals and the response to referrals are justified.

Working with family carers

7.29 Concerns arose over the impact on the youngest son of meeting his mother's very substantial care needs, particularly during the thirty four month period he cared for Robyn at home following the traumatic head injury she sustained in December 2015. During this period, he increasingly isolated his mother from the care and support of professionals and, in doing so, isolated himself from support. His relationship with his brothers also broke down during this period. Limiting the involvement of professionals in his mother's care appeared to meet his needs for an uninterrupted routine and a high degree of control over the situation. However, professionals began to express concern that his mental health and wellbeing may have been adversely affected.

7.30 The youngest son declined offers of support including respite care for his mother. In doing so he appeared to be motivated in part by a desire to isolate her from the risk of infection and thereby prolong her life. He had received a carer's assessment in 2015 but a further carer's assessment should have been offered to him when it became clear that Robyn had outlived the limited life expectancy anticipated at the time of her discharge from hospital. However, it seems likely that such an offer would have been declined. It is worthy of note that discharge planning arrangements focussed only on the practical support the youngest son would need to care for his mother, omitting consideration of his emotional needs as a carer.

7.31 It is therefore recommended that Cumbria Safeguarding Adults Board remind agencies of the need to offer a further carer's assessment to a family carer when the demands upon them change or, as in this case, continue for an extended period. It is further suggested that when the learning from this Safeguarding Adults Review is disseminated, practitioners are invited to consider how they might support a carer as resistant to support as the youngest son appeared to be.

Recommendation 9

That Cumbria Safeguarding Adults Board raise the awareness of agencies of the need to offer a further carer's assessment to a family carer when the demands upon them change or, as in this case, continue for an extended period.

Resolving professional disagreements

7.32 A professional disagreement arose over the decision to discharge Robyn from hospital to be cared for by her youngest son at her home address in February 2016. This issue did not appear to be satisfactorily resolved. This SAR has been advised that currently there is no formal process for resolving professional disagreements in respect of adult safeguarding issues.

7.33 It is understood that the lack of formal process for resolving professional disagreements has been commented upon in a previous SAR (Adult B). Cumbria Safeguarding Adults Board may wish to implement a formal process for resolving professional disagreements and disseminate this to partner agencies.

Recommendation 10

That Cumbria Safeguarding Adults Board implement a formal process for resolving professional disagreements and disseminate this to partner agencies.

Coercion and Control

7.34 The safeguarding concerns which arose from September 2015 generated professional concern that coercive control may be present in the youngest son's relationship with his mother. Professional awareness of coercive control has been most prominent in the area of physical abuse in intimate relationships. It would therefore be of benefit when disseminating the learning from this SAR, if Cumbria Safeguarding Adults Board raised professional awareness of domestic abuse, including coercion and control in familial relationships and in family caring relationships.

Recommendation 11

That Cumbria Safeguarding Adults Board widely disseminates the learning from this case including the raising of awareness of domestic abuse, including coercion and control in familial relationships and in family caring relationships.

NHS Continuing Healthcare (CHC)

7.35 Prior to her discharge from hospital in February 2016 Robyn had been assessed as ineligible for NHS funded Continuing HealthCare (CHC) despite her very substantial needs. The quality of the CHC assessment has been questioned by this review. Had Robyn been assessed as eligible for CHC funded care, this could have prevented or mitigated the subsequent isolation of Robyn from care and support. It was recognised that the CHC assessment needed to be revisited but this was never actioned.

7.36 North Cumbria Clinical Commissioning Group may wish to seek assurance in respect of the quality of assessments of CHC eligibility and also seek assurance that professionals are aware of the need to revisit the cases of people to whom they are providing care and support who had been assessed as ineligible for CHC funding should their needs change.

Recommendation 12

That North Cumbria Clinical Commissioning Group (CCG) obtain assurance in respect of the quality of assessments of CHC eligibility completed by their Continuing Health Care Team. The CCG should also seek assurance that professionals are aware of the need to revisit the cases of people to whom they are providing care and support who had been assessed as ineligible for CHC funding should their needs change.

8.0 References

(1) Retrieved from **https://www.nao.org.uk/report/nhs-continuing-healthcare-investigation/**

(2) Retrieved from **https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/clinically-assisted-nutrition-and-hydration-canh-guidance**

(3) Retrieved from **https://www.cumbria.gov.uk/elibrary/Content/Internet/327/949/4305415121.pdf**

(4) Retrieved from **https://www.app.college.police.uk/app-content/major-investigation-and-public-protection/domestic-abuse/investigative-development/**

(5) Retrieved from **https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/**

(6) Retrieved from **https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/clinically-assisted-nutrition-and-hydration-canh-guidance**

(7) Retrieved from **https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf**

(8) Retrieved from **https://www.scie.org.uk/mca/practice/best-interests**

(9) Retrieved from **https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/working-with-the-principles-and-decision-making-models#paragraph-47**

(10) Retrieved from **https://coercivecontrol.ripfa.org.uk/wp-content/uploads/Evidence_scope_coercive_control.pdf**

(11) Retrieved from **https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance**

(12) Retrieved from **https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance**

Appendix A

Process by which safeguarding adults review (SAR) conducted and membership of the SAR panel

*see also Performance Monitoring

A panel of senior managers from partner agencies was established to oversee the SAR. The membership was as follows:

Role	Organisation
Chair - Deputy Director of Nursing and Designated Nurse for Safeguarding	North Cumbria Clinical Commissioning Group
Panel Member	Cumbria County Council
Panel Member	Cumbria Constabulary
Panel Member	North Cumbria Clinical Commissioning Group
Panel Member	Cumbria Partnership NHS Trust and North Cumbria University Hospitals which subsequently merged to become the North Cumbria Integrated Care NHS Foundation Trust
Business Manager	CSAB
Business Support	CSAB
Independent Reviewer	David Mellor

It was decided to adopt a systems approach to conducting this SAR. The systems approach helps identify which factors in the work environment support good practice, and which create unsafe conditions in which unsatisfactory safeguarding practice is more likely. This approach supports an analysis that goes beyond identifying what happened to explain why it did so – recognising that actions or decisions will usually have seemed sensible at the time they were taken. It is a collaborative approach to case reviews in that those directly involved in the case are centrally and actively involved in the analysis and development of recommendations.

Chronologies which described and analysed relevant contacts with Robyn were completed by the following agencies:

- The GP practice
- Cumbria County Council
- Cumbria Constabulary
- Cumbria Partnership NHS Trust (North Cumbria Integrated Care NHS Trust since 1.10.2019)
- North Cumbria University Hospitals (North Cumbria Integrated Care NHS Trust since 1.10.2019)
- Beacon Homecare Services
- North West Ambulance Service
- Cumbria Health on Call (CHOC)

The SAR panel analysed the chronologies and identified issues to explore with practitioners and managers at the learning event facilitated by the lead reviewer which was attended by representatives of nearly all of the various disciplines involved in this case. Robyn's GP until his retirement in September 2017 was also provided with an opportunity to contribute to this review in a telephone conversation with the lead reviewer.

Three of Robyn's sons and two daughters in law contributed collectively to the review and were provided with an opportunity to comment on a late draft of the SAR report. Robyn's youngest son contributed separately to the review.

The lead reviewer then developed a draft report which reflected the chronologies, the contributions of practitioners and managers who had attended the learning event and the contributions of the family of Robyn.

With the assistance of the SAR panel, the report was further developed into a final version and presented to Cumbria Safeguarding Adults Board.