

CAMDEN SAFEGUARDING ADULTS PARTNERSHIP BOARD

SAFEGUARDING ADULTS REVIEW

IN RESPECT OF

YY

Date of birth: 02.11.1957

Date of death: 18.05.2016

Age at death: 58

FINAL REPORT

Report author: Chris Brabbs

Date of report: 23rd October 2017

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1. EXECUTIVE SUMMARY

Circumstances Leading to the Review

- 1.1 YY had many long standing complex health conditions including osteoporosis, ulcerative colitis, peripheral, vascular disease, and necrotic toes. He also experienced anxiety and periods of depression because of the problems these conditions caused him. YY had adopted a restricted diet and avoided the use of most analgesics as part of his self management of his various conditions. He often chose not to act on advice from health professionals, or attend appointments for secondary care investigations. This lack of engagement compounded some of his health problems, and it became a cycle which both YY, and professionals found difficult to break.
- 1.2 He was admitted to the Royal Free London NHS Foundation Trust (RFLNHSFT) on 22nd January 2016 following a fall at his mother's house where he had been living, which resulted in a non displaced fracture of the left femur.
- 1.3 On admission he was observed to be emaciated and professionals were concerned about the possibility of self neglect. Soon after admission, he was found to have a grade 3 sacral pressure ulcer which deteriorated to grade 4 during his stay. He also developed a pressure ulcer on his right hip, and left heel. From the outset PP frequently declined to be re-positioned, and increase his oral intake despite being informed of the risks. His self imposed restrictive diet was thought to stem from an undiagnosed obsessive compulsive disorder. In all assessments carried out, he was deemed to have mental capacity to make his own decisions about his care and treatment.
- 1.4 When YY was deemed to be medically stable, he accepted the plan to be discharged to a step down nursing bed to continue his rehabilitation although he had previously been hoping to return home. However, after the nursing home admission on 9th March, his previous pattern of responses to the care offered remained unchanged despite the advice provided by a range of professionals, and there were increasing concerns about his condition. Further assessments of YY's mental capacity were carried out because there were doubts as to whether he was able to understand the significance of information being provided about his care needs and discharge plans, or the likely adverse consequences if he did not follow professional advice. All these assessments, which included second opinions provided by mental health professionals, concluded that he had mental capacity.
- 1.5 The nursing home sent for an ambulance on 2 occasions on 4th and 11th May because of their concerns about a perceived deterioration in his physical condition, but on both occasions YY declined the offer to go to hospital. The lack of advance consultation with YY and his family before taking this step, added to the already tense working relationships which had developed between YY's family and many professionals.
- 1.6 On the morning of 12th May, YY was found in an unresponsive state, and he was re-admitted to University College London Hospitals NHS Foundation Trust (UCLH) where he was found to be seriously ill because of sepsis, malnutrition and dehydration. Despite the best efforts of hospital staff, his condition could not be reversed and YY died on 18th May 2016.

Summary of Key Findings

- 1.7 All the required clinical assessments and treatment were offered or carried out during YY's time in RFLNHSFT and UCLH. Professionals adopted a range of strategies to try and build YY's trust and secure his co-operation with the care offered but with limited success. The frequent decisions made by YY not to act on professional advice, despite being informed on several occasions of the potentially fatal consequences, created dilemmas for professionals in balancing YY's right to self determination with their duty to safeguard people from harm.

Safeguarding Issues

- 1.8 There were delays in raising safeguarding concerns about the development of the pressure ulcers through the RFLNHSFT internal reporting arrangements and the multi-agency safeguarding procedures, and in commencing formal safeguarding enquiries following the concerns raised by professionals and YY's sister. This appeared to be due to wide variation in the way that London boroughs are interpreting the requirements of the Care Act 2014 around the application of the thresholds and timescales for Section 42 safeguarding enquiries.
- 1.9 Throughout the time period under review, there were missed opportunities to raise a safeguarding concern about possible self neglect, and to refer YY to a specialist eating disorder service. In part this was due to professionals not showing sufficient "professional curiosity" to gather a full history to inform case planning. It also reflected a lack of knowledge about the referral pathways and the triggers which warranted an urgent assessment and possible hospital admission.

Mental Capacity

- 1.10 Professionals were able to evidence that they had justifiable reasons for calling into question the presumption of mental capacity, which led to a large number of Mental Capacity Act assessments being carried out which all concluded that YY had capacity to make decisions about his care and treatment. However, some of these were not sufficiently robust, and there was insufficient consideration as to whether YY's capacity to make these decisions might be affected by his having a low Body Mass Index (BMI).
- 1.11 The Review identified that there are wide variations in the approach adopted by different agencies / professionals, and in the evidence base used to reach professional judgements. Some professionals appeared to lack confidence in their own judgements which resulted in "second opinion" assessments being commissioned from mental health professionals. The arrangements for these were not well co-ordinated, and led to challenges that these did not take into account all relevant information.

Issues around Compulsory Treatment

- 1.12 When professionals made referrals for an urgent mental health assessment, they did not make it clear that they were requesting a formal Mental Health Act (MHA) assessment to establish if the criteria for compulsory admission were met. Mental health practitioners therefore interpreted the referrals as being a request for a general assessment of YY's mental health and / or mental capacity to make decisions about his care. It is possible that if a formal MHA assessment had been carried out, this might have resulted in a different outcome.

- 1.13 There were several occasions when professionals at RFLNHSFT considered the option of applying to the Court of Protection to request authorisation to provide compulsory treatment, and legal advice was obtained. The decisions not to pursue this step appeared to be unduly influenced by assumptions made as to what the court was likely to decide. The view reached by RFLNHSFT was that the the Court of Protection would decide it had no jurisdiction given the fact that YY had been assessed on many occasions by a range of professionals as having capacity to make decisions about his care and treatment,. After his admission to the nursing home, agencies did not seek legal advice despite professionals' increasing concerns about YY's health and his continuing decisions not to act on professional advice.

Co-ordination of Care

- 1.14 When YY was discharged from RFLNHSFT, the planned seamless transfer of support to community services to ensure continuity of care was not achieved, and there was some delay before these services commenced involvement. This might have been avoided had there been earlier notification of the planned discharge, and greater involvement of these agencies in the discharge planning process.
- 1.15 There was a lack of co-ordination of the multi-agency involvement when YY was in the nursing home which resulted in disjointed interventions. The lack of advance contingency planning created uncertainty for some professionals on how to respond when the situation did not improve. Professionals appeared uncertain about the pathways for escalating cases which are deemed to be high risk, and where decisions made by the service user not to act on professional advice could be life threatening.
- 1.16 There was insufficient leadership from managers to support staff who became increasingly concerned about the impact of YY's behaviours on his health, and the tensions which developed in the relationships with YY and his family. Convening a high level risk management meeting would have strengthened the decision making process for those involved. However, although Camden had in place a multi-agency high risk panel for considering such cases, the referral process and criteria were not well publicised.

2. RECOMMENDATIONS

- 2.1 Camden Safeguarding Adults Partnership Board (CSAPB) should develop a multi-agency toolkit which provides systems, processes and guidance to support professionals in recognising and responding to situations involving self neglect. This should be supplemented by multi-agency training to enable professionals to develop the required knowledge and skills;
- 2.2 CSAPB should seek assurance from agencies that:-
- they have quality assurance systems in place to ensure that where professionals have made a decision that a safeguarding concern should be raised, this is actioned and followed up;
 - relevant national and local clinical and safeguarding guidance is applied in reaching decisions on reporting the existence of pressure ulcers either through their internal serious incident reporting procedures and / or by raising a safeguarding concern through the multi-agency safeguarding procedures.

- 2.3 CSAPB should seek assurance from agencies that staff make use of national guidance issued by the National Institute for Health and Care Excellence (NICE) on the recognition and treatment of eating disorders, and are aware of the local referral pathways to access specialist eating disorder services.
- 2.4 CSAPB should explore methods of collecting qualitative data regarding the local application of the Mental Capacity Act 2005, taking into account information from all agencies on how they quality assure their organisation's work, and the results of their most recent audit.
- 2.5 CSAPB should develop a multi-agency protocol for escalation and challenge for safeguarding matters, which should include arrangements for forums where cases can be considered according to their assessed level of risk.
- 2.6 CSAPB should request agencies to review the composition, terms of reference, and referral process of the existing multi-agency high risk panel to ensure the necessary level of seniority in the core membership, and the involvement of other professionals as necessary depending on the nature of the risk of cases referred.
- 2.7 CSAPB should seek assurance that hospital discharge processes achieve a shared agreement with community based professionals on the arrangements for co-ordinating care post discharge, in order to ensure continuity of care and a rapid response where it is anticipated that a service user may decline care.
- 2.8 CSAPB should seek assurance from the CCG of arrangements in place to ensure appropriate levels of GP engagement in multi-agency work to safeguard adults.

PART 2: MAIN BODY OF THE REPORT

3. THE REVIEW PROCESS

Circumstances Leading to the Review

- 3.1 This Safeguarding Adults Review (SAR) was established under Section 44 of the Care Act 2014 which requires a Review to be carried out where:-

“An adult with care and support needs (whether or not those needs are met by the local authority) in the Safeguarding Adult Board’s area has died as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked together more effectively to protect the adult”
- 3.2 Three safeguarding concerns were investigated during 2016. Following a strategy meeting held on 18th May, a formal Section 42 investigation was completed in August which was considered at a case conference on 3rd August 2016.
- 3.3 The decision to commission a SAR was made by the Independent Chair of the Camden Safeguarding Adults Partnership Board (CSAPB) on 23rd August 2016, accepting the recommendation of the Serious Case Review Subgroup that the criteria for a SAR were met.
- 3.4 The Review commenced in late February 2017. The start had been delayed because of the imminent inquest, and some complications around the commissioning of a review chair, and independent author, arising from changes in key personnel within member agencies of the safeguarding board. The objective was to complete the review within 6 months.

Parallel Processes

- 3.5 A 2 day inquest was completed on 7th November 2016. The Coroner's determination was that YY died from the combination of the accidental fall, and natural causes stemming from several chronic conditions. The medical cause of death was:-
- Sepsis
 - Advanced decubitus ulcers, malnutrition and dehydration
 - Fracture of the left femur (January 2016)
 - Ulcerative colitis (on steroids), Hyposplenius, Peripheral Vascular Disease
- 3.6 A Serious Incident Investigation was carried out by Royal Free London NHS Foundation Trust following the safeguarding alert raised on 8th March 2016.
- 3.7 There are no ongoing police enquiries related to this case. The Police had previously followed up on a report that some care records had been removed from the nursing home without authority by a member of the family. The outcome was no further action.
- 3.8 A 2 day inquest was completed on 7th November 2016. The Coroner's determination was that YY died from the combination of the accidental fall, and natural causes stemming from several chronic conditions. The medical cause of death was:-
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Purpose of the Review

- 3.9 The purpose of the SAR, as set out in national guidance relating to the Care Act 2014, is not to apportion blame, but to:-
- determine what agencies and individuals involved might have done differently to prevent the harm or death;
 - review the effectiveness of multi-agency safeguarding arrangements and procedures;
 - identify the learning, including examples of good practice, and apply these to improve practice and partnership working to prevent similar harm occurring again in future cases.
- 3.10 The Review has been undertaken in line with the London Multi-Agency Safeguarding Adults Procedures, and CSAPB's SAR Framework.

Agencies Involved

- 3.11 The following agencies contributed to the Review:-
- Royal Free London NHS Foundation Trust (RFLNHSFT)
 - University College London Hospitals NHS Foundation Trust (UCLH)
 - Central and North West London NHS Foundation Trust (CNWL)
 - Camden and Islington Mental Health Trust (CIMHT)
 - Whittington Health NHS Trust
 - Camden Clinical Commissioning Group
 - Barnet Clinical Commissioning Group
 - LB of Camden (LBC)

- Orchard Care Homes (owner of St Johns Wood Care Centre)
- Jewish Care
- Hartwig Care
- Greenfield Medical Centre (Primary Care)
- The Abbey Medical Centre (Primary Care)
- London Ambulance Service

Review Team Membership

3.12 The Review Team, which was chaired by the Director of Quality and Clinical Effectiveness from the Camden Clinical Commissioning Group (CCG), comprised a representative of the above agencies with the exception of the Ambulance Service. Their presence in the Review Team meetings would have added to the quality of the review. The representation in respect of the GP practices was provided through the involvement of the two CCGs.¹

Independent Overview Report Author

3.13 Chris Brabbs was appointed as the Independent Overview Report Author, who is a former Director of Social Services with extensive experience of conducting both safeguarding adult reviews and children's serious case reviews. He had no previous involvement or connection with agencies involved in this Review.

Time Period

3.14 The SAR covered the period from 1st January 2015 to 30th September 2016. The reason for this start period was to place the analysis of the care provided at RFLNHSFT and the nursing home, in the context of the recent history of YY's circumstances and his response to professionals' input. The end date enabled the Review to take into account the subsequent formal safeguarding processes.

Key Issues

3.15 The scoping of the Review identified the following key issues, which were translated into a number of case specific questions which are attached at Appendix 2.

- the quality of assessments and delivery of person-centred care;
- the challenges flowing from YY frequently choosing not to follow professional advice or refuse the care and treatment offered;
- the robustness of mental capacity, and mental health assessments;
- the appropriateness of the rehabilitation plan, and effectiveness of arrangements to maintain continuity of care on discharge from hospital;
- what consideration was given to escalating YY's case given its complexity and high risks which were potentially life threatening;
- the reasons why YY was not admitted to hospital on 4th and 11th May;
- whether the raising of safeguarding concerns, and subsequent processes were timely and effective;

¹ GP practices are member agencies of the CCG

- whether previous learning from Camden SARs was reflected in agency and professional practice.

3.16 During the Review, two additional key issues were identified:-

- the response by professionals when a possible eating disorder was identified, and their level of knowledge about how to access specialist services;
- professionals' understanding of the differences between general assessments of mental health, and a formal assessment under the Mental Health Act 1983.

Methodology

3.17 The Review adopted a combination of an investigative approach and systems methodology. This former ensured sufficient focus on the specifics of YY's case, which was important given the concerns raised by the family. The latter assisted the identification of contributory factors which influenced the actions and decisions of professionals, and what these revealed about underlying "system" issues which needed to be addressed.

Sources of information

3.18 The scoping of the Review established that considerable information had already been provided by agencies to inform the safeguarding processes and the inquest. Therefore, to avoid unnecessary duplication, it was decided that each agency would not prepare a full management review, but instead provide a chronology of key events summarising actions / decisions taken, a commentary on whether practice standards had been met, and highlight any organisational issues which may have affected the services offered.

3.19 An integrated chronology was constructed as a working tool, supplemented by key documents from agency records, and the reports from the parallel investigations, including the RFLNHSFT serious incident investigation, statements prepared for the inquest, and a transcript of the inquest hearing. A decision was made that given the input from key professionals directly involved in the case within those processes, it would not be proportionate to carry out further individual discussions, but they would be involved in a learning event at the conclusion of the process.

Involvement of Family Members

3.20 Several approaches were made to YY's family to invite them to contribute to the Review and share their perspectives. Two letters were sent to YY's sister and mother at the outset of the review which did not elicit a response. In discussing whether further approaches should be made, the Review Team was mindful of the information received that the family had found the recent inquest proceedings difficult, and that they had also appeared stressed and upset during professionals contact with them when care was being provided to YY. The Review Team acknowledged there was a possibility that the family might prefer not to contribute as this could involve revisiting painful memories.

3.21 It was agreed therefore that given that further time had elapsed since the start of the SAR, a further letter should be sent to YY's sister prior to the review being finalised to provide an update on progress and extend a further invitation to contribute. This did not elicit an immediate response, but YY's sister attempted to make contact and left a voicemail with the Overview Report Author shortly before the report was due to be finalised and presented to the Safeguarding Adults Board. However, efforts to engage with YY's sister following that proved unsuccessful until a final letter was sent

following the report being presented to the CSAPB, when YY's sister took up the offer of a telephone call to hear about the findings prior to publication. Within this discussion, YY's sister explained how family circumstances had made it difficult for her to engage previously.

4. SUMMARY OF KEY EVENTS AND AGENCY INVOLVEMENT

Background Information

4.1 YY was registered with a GP practice in Barnet from 2007. The detailed notes show that the Barnet GPs had very frequent contact either through home visits or telephone consultations because YY was either unable, or unwilling, to be seen at the surgery. There was a long history of the following health problems related to degenerative bone conditions, leg ulcers, circulation problems and anxiety symptoms:-

- Ankylosing spondylitis since 1982 ²
- Haematuria 1990 ³
- Ulcerative colitis since 1991 ⁴
- Osteoporosis- previously treated with regular IV Pamidronate. ⁵
- Bilateral avascular osteonecrosis of both hips due to long term steroid use since 1991 ⁶
- Peripheral vascular disease ⁷
- Amputation of toe on right foot for gangrene 2006
- Pyoderma gangrenosum 2007 ⁸
- Chronic leg ulcers

Barnet GP Involvement from 1st January 2015

4.2 There were 18 recorded consultations, albeit that all but 2 of these were telephone contacts. These show that the GPs became extremely concerned about YY's various health issues, and his failure to engage with secondary care. They made referrals, and sought advice on his management, from a number of secondary care specialists, but YY's pattern of not attending appointments (DNAs), or declining the offer of referrals continued despite continual encouragement and explanation of the risks of his non engagement.

4.3 Two referrals were made for a mental health assessment in September and October 2015 to see if help could be provided for his anxiety, and also his obsessive compulsive behaviours around his limited diet and fear of getting infections. The latter resulted in any visiting health professional getting through several pairs of sterile gloves and copious amounts of hand gel. The podiatrist reported that that visits that

² *Ankylosing spondylitis (AS) is a long-term (chronic) condition in which the spine and other areas of the body become inflamed.*

³ *Presence of blood in the urine*

⁴ *Ulcerative colitis is a long-term condition, where the colon and rectum become inflamed.*

⁵ *Pamidronate is a member of a family of drugs called Bisphosphonates that reduce bone breakdown.*

⁶ *Avascular necrosis is the death of bone tissue due to a lack of blood supply.*

⁷ *Peripheral vascular disease (PVD) is a blood circulation disorder that causes the blood vessels to narrow through the build up of fatty deposits. It typically causes pain and fatigue in the legs.*

⁸ *Pyoderma gangrenosum is a rare skin condition that causes painful ulcers, usually in the legs.*

should have required 30 minutes care were taking between 2 and 3 hours because of YY's hypersensitivity and the need to allay his anxiety. Observations were recorded that his obsession with cleanliness was not matched by the condition of his room.

- 4.4 YY was unhappy that the first referral had been made without his knowledge, and he declined to be seen despite further encouragement from the GP, and his admission that he was mentally exhausted. YY initially agreed to a home visit after the second referral, but cancelled because he felt too tired. He said he was not suicidal but feeling anxious due to his health problems. The mental health service informed the GP that they would see YY when he was ready to be re-referred.
- 4.5 From September, the GPs provided advice on the management of a flare up of his colitis. In October, on the advice of secondary care, YY was referred for urgent investigation of possible colorectal cancer given the rectal bleeding, but he did not attend because the mention of possible cancer had made him anxious, and on occasions suicidal. Despite lengthy discussions, YY declined a further referral.
- 4.6 The Barnet GPs also made frequent attempts to gradually reduce the quantity of steroids, but YY did not act on this because of his fear that the colitis would return. This led to the GPs seeking advice in January 2016 from the consultant gastroenterologist on how to approach management of this condition in the community given YY's continuing reluctance to engage with secondary care.
- 4.7 On 13th January, the podiatrist reported her concerns to the Barnet GP from her recent visit, after months of YY not her allowing to, that YY needed an x-ray for possible osteomyelitis⁹ as the bone was exposed on his right 2nd toe, and the dorsum of his foot was slightly inflamed. She also reported that YY was extremely thin, he was finding it hard to get onto the bed, his feet had not been washed or the dressings changed, since her previous visit. A joint visit was agreed once the response from the consultant gastroenterologist was received to draw up a plan for his care. Shortly afterwards, the district nurse also reported to the Barnet GP that there might be safeguarding issues involved as YY had refused his foot care and seemed very underweight.
- 4.8 On 20th January, the Barnet GP declined YY's sister's request for a home visit and additional analgesia following his fall, explaining that his injury must be assessed and x-rayed at hospital because of a possible fracture. This decision was made with the support of other GP colleagues within the practice in the hope that this would force the family to take YY to A&E where his toe could also be x-rayed in the light of the podiatrist's concern. During that evening, YY sent for the paramedics again because his condition had deteriorated and he was taken to the Emergency Department (ED) at the Royal Free Hospital (RFLT) but refused analgesics offered by the paramedics.

CARE PROVIDED AT ROYAL FREE HOSPITAL

- 4.9 Initial examination referred to the leg ulcers, low blood pressure, his thinness and frailty. X-rays and CT scans confirmed that YY had a non displaced fracture of the right knee. He was then admitted under the care of the medical team rather than orthopaedics due to his many medical conditions.
- 4.10 In the first two hours of his admission he was advised on the importance of turning to relieve the pressure and to enable staff to check his pressure areas However YY declined to do this. He also refused IV antibiotics, an ECG, and analgesia. He was assessed as having full capacity. The orthopaedic team drew up a plan for the application of a back slab with conservative treatment of immobilisation of the knee

⁹ *Osteomyelitis is an infection of the bone*

for 4 to 6 weeks and referral to occupational therapy (OT) for a rehabilitation programme.

- 4.11 On the second day, a review by the medical team recorded that he had a pressure ulcer but the notes did not state where. He was stated to be emaciated and pale, and appropriate treatment was commenced when it was considered that he may have sepsis. A management plan was made to address his malnutrition and dehydration, organise a rehabilitation programme, and commission orthopaedic, vascular and endocrine reviews. He was also found to have anaemia due to bleeding from his rectum which required a transfusion. Plans were made for him to be placed in a side room which was his preference, and also because of his overall condition. The ED medical registrar recorded that YY had capacity but a psychiatric review would be requested for the following morning.
- 4.12 YY continued to decline alternative analgesia methods such as entonox via a mask, personal care, repositioning, and for his pressure areas to be checked but agreed to an ECG and I/V fluids. The back slab was removed after the medical registrar who noted discoloration of the 4th toe, and then reapplied. An orthopaedic review concluded that the discoloration was likely due to poor vascular status, and a referral was made to the vascular surgeons.
- 4.13 When reviewed by the medical team on 23rd January, YY's past history of DNA's in multiple clinics was noted, along with his self medicating with steroids. YY's explanation was that he had missed appointments because he had too much to deal with and was depressed. He said he was not eating much in hospital due to the unsuitable food. He said he had lost about 1 stone over 6 months, was very tired, and was not sleeping due to the continuous and significant pain, worry and noise. During this review, YY's mother said she could not manage YY at home in a micro-environment. YY was very tearful and wanted to go home, saying he hated hospital.
- 4.14 The possibility of self neglect was first noted 2 days after admission on 23rd January. However, despite the medical team recorded that a possible safeguarding referral would be made, they did not take this further. On the same day, although the occupational therapists ticked in the notes they had referred YY to a social worker for a safeguarding assessment for neglect, a safeguarding concern was not received.
- 4.15 At the initial assessment by the occupational therapist and physiotherapist on 24th January, YY agreed to be reviewed by the pain team, but did not wish to explore other medications other than paracetamol due to their side effects. They liaised with social care who agreed to explore the patient's background given the inconsistencies in his account of his home circumstances.
- 4.16 On transfer to Ward 8 North, it was noted that YY had a grade 3 pressure ulcer. A clinical incident report was completed, and a check made that he was on the right mattress. It was noted he was only eating food brought in by his sister and therefore was marked for review by the dietician. A referral was also made to the Tissue Viability Nurse (TVN).
- 4.17 The dietician's assessment identified that it would be difficult to meet his requirements because of his very restrictive diet which excluded any dairy products, wheat / flour of any kind, salt, or sugar. He also declined all supplement drinks. Although arrangements were implemented for YY to inform the diet chef about his preferred list of foods, YY's intake remained low.

- 4.18 On 25th January the medical consultant took a full history where YY said that he had been underweight for many years, and the recent bowel flare-up had caused him to lose more. YY stated that he lived alone, had been having difficulty coping, but could stay with his mother or sister. His reason for not engaging with secondary care was that he was afraid of “dirty hospitals”. He also seen by the weekend social worker who also noted that YY was frail, unkempt and had the appearance of self neglect. The outcome was for him to be referred to the in-house social work team, but there was no mention of this including the possibility of raising a safeguarding concern.
- 4.19 From 26th January, the Consultant in General and Geriatric Medicine (lead consultant) took over lead responsibility for YY’s care through to discharge, and had a lengthy first consultation with YY alongside the Tissue Viability Nurse (TVN) who concurrently assessed his pressure ulcers.
- 4.20 YY reported a good appetite but had a very restricted diet of fish, eggs, rice cakes, potatoes and soya milk only due to his bowel symptoms. He was not medically advised to do this, and there was no formal diagnosis of food intolerance or celiac disease.¹⁰ He reported weight loss of around 1 stone for the last 6 months. He rarely left his flat, and received support from his mother and sister without any formal social care package. He denied any previous psychiatric history but reported previously seeing a counsellor for stress and anxiety.
- 4.21 On examination, he was extremely cachectic, looked unkempt and had a single tooth but was not pale, not jaundiced, and not cyanosed. He had an ungradable decubitus ulcer on his right buttock the size of a 20 pence piece with no sign of infection.¹¹ The skin of his heels was intact. He was in pain when moved but declined strong analgesia. Although anxious, YY did not present as confused and there was no evidence of acute neurological deficits. The consultant recorded that YY had an anxiety/mood disorder regarding health issues manifested in his refusing medications including analgesia, food, food supplements, repositioning and nursing interventions. In addition, it was noted that the possible depression needed further clarification, and collateral history, from the family and acquaintances.
- 4.22 During the discussions, the consultant explained the impact of YY’s disengagement with out-patient services and he was at risk of dying if this continued. The management plan referred to a list of 10 health conditions with an action plan of 22 items covering all the necessary investigations and consultation with other medical specialities, and a move to a side room which was YY’s preference. He was moved to the lead consultant’s ward 3 days later.
- 4.23 In a session later with the physiotherapists, YY said he was feeling overwhelmed, and was frightened about the thought of losing his foot and was finding it hard not to focus on this. It was noted that the ischemic foot¹² would impact on discharge planning.

¹⁰ YY was subsequently tested for Coeliac disease which proved negative.

¹¹ A decubitus ulcer, also referred to as a pressure ulcer, is an open wound often occurring on the skin covering bony areas

¹² Ischemic foot refers to inadequate blood flow to the foot due to poor arterial circulation. Without sufficient blood flow, the foot does not receive the necessary oxygen and nutrients for the cells to function properly. As a result, sores on the foot may never fully heal, and if left untreated, the tissue may eventually die and require amputation

- 4.24 After a scan on 28th January which showed a stag horn calculus of his right kidney, YY again confessed that he was struggling to cope with the amount of problems and investigations. Although he did not want the anti-depressants offered, he agreed he would be willing to talk with a clinical psychologist regarding his anxiety symptoms in order to learn some coping strategies.
- 4.25 On 29th January the TVN found a deterioration in the sacral wound with underlying damage, and newly identified discolouration to the left heel. YY consented to photographs being taken and a plan was made to upgrade him to a Breeze Mattress. A review by the vascular consultant concluded there although the skin condition was poor, YY was not currently suitable for vascular intervention. A complete duplex scan was suggested once the cast was removed or replaced. The same day the senior registrar explained at length to YY and his family his multiple problems. YY stated he wanted to move to his mother's new home with support rather than the interim nursing home placement being proposed.
- 4.26 On 1st February, the complex management team (CMT) had a joint session with the psychologist to carry out a formal mental capacity assessment regarding the decision about his discharge destination and care arrangements. This was because decisions were being arrived at by YY that carried potentially life-threatening consequences, and professionals needed to be confident that he had the ability to cognitively process the options put before him. The presumption of capacity under such circumstances was brought into question but not pushed aside. A test was therefore done to establish whether capacity was indeed compromised or not.
- 4.27 The conclusion reached was that YY did not fulfil the criteria to be deemed incapacitous. He was able to describe his health issues, the importance of repositioning, and the discharge options. He asked appropriate questions, and was able to understand and retain the information provided about the risks of going home. YY said he was feeling "overwhelmed" by it all, and did not feel the turning regime was manageable. Although he was able to recognize the benefits of a temporary placement, YY's view was that a return home to a familiar environment would have a positive impact on his emotional well being. However he acknowledged that it might not be possible to provide all the necessary care at home to meet his needs. He agreed that more information about the care options was essential to making an informed decision.
- 4.28 Overnight ward staff spent a lot of time with YY because he was tearful and distressed. YY felt that he was not being listened to, and he did not want to live anymore. His low mood was discussed with his sister. He similarly expressed suicidal ideation to the occupational therapist the following day because he was feeling overwhelmed after 10 years of problems. On being informed of this, the psychologist and registrar requested a psychiatric assessment. By this point, YY said that he now agreed with the plan for an interim placement. A dietician review noted that YY's diet was still very restrictive, that his nutrition requirements were not being met, and he was likely to lose weight and become more malnourished.
- 4.29 The psychiatric assessment on 3rd February noted that YY appeared cachectic,¹³ but was fully oriented. YY's description of sustained suicidal ideation was more in the form of wishing he was dead rather than actively planning how he would end his life, and he remained hopeful that treatment would leave him pain free. His cognition was not formally assessed, but there was no evidence of delusional content or thought disorder. He showed insight in accepting that he might be depressed, but was indifferent as to whether treatment would be helpful as he stated he was taking

¹³ *Cachectic is physical wasting with loss of weight and muscle mass*

enough medication as it was. The conclusion was that YY had a reactive depressive state following the stressor of hospital admission and physical illness. There was insufficient evidence to suggest a diagnosis of depression, and YY declined anti-depressants or further psychiatric input. The outcome was for no further action unless his mood worsened, or the risk was deemed to have changed.

- 4.30 The complex management team continued to discuss strategies for working with YY around repositioning, pain relief, skin deterioration, anxiety, and food which met his preferences. An early discussion with the Camden Continuing Healthcare Team (CHC) identified that it was too soon to consider eligibility because he had not reached rehabilitation potential. This was in line with current CHC assessment guidelines. However, there was agreement that the care he would require could only be achieved in a nursing home. This information was shared with YY's sister.
- 4.31 When YY was examined by the lead consultant and the TVN on 3rd February, the sacral ulcer had deteriorated to grade 4, measuring 5.5 x 4 cms, with exposed bone and purulent discharge. He was again advised that if he refused re-positioning, treatment and medications, it would be difficult to help him and it was likely he would deteriorate. It was recorded that YY had capacity in declining to co-operate with the skin bundle regime.
- 4.32 Overnight on 6th February, the ward ran out of supplies of steroids, and the required amount was not available from other wards. Given YY's anxiety about this, his sister was contacted who brought some in from his home supply.
- 4.33 The psychologist carried out another capacity assessment on 8th February prior to a family meeting to ensure YY understood the purpose and decisions to be made about his future care. He was again judged to have capacity but was sometimes inconsistent in communicating his wishes. At the meeting, the lead consultant explained the consequences of YY's self restricting diet, refusal of analgesia, and the worsening grade 4 pressure ulcer. He explained that while the explanations about the possible fatal repercussions might cause distress, it was essential to try and get YY to engage. It was explained that staff could not use deceit, and everything had to be done with his consent. The family were counselled to be cautious about his prospects, and that he might continue to deteriorate unless he adhered to the treatment plans. It was made clear that there was no easy solution.
- 4.34 YY's sister contacted Jewish Care ¹⁴ the next day as she was not coping with the situation and was in "desperate" need for help for YY who had asked her to find support. She shared her perception that there was a lack of communication between herself and the hospital, and that was why she was seeking advocacy support for YY who was depressed and wanted to go home. YY's sister also shared information about her own health problems, and that she had no support. Jewish Care agreed to become involved.
- 4.35 A follow up dietician review on 10th February found YY more receptive to the need to increase his intake, and some adjustments were agreed to his diet. He also agreed to try the Ensure nutritional supplement. When a further review was carried out a week later, it was recorded that there had been no progress. This led to the multi disciplinary team meeting (MDT) making a plan to refer YY to the eating disorder team but this was not actioned. A CMT meeting the same day commenced active discharge planning.

¹⁴ *Jewish Care is the largest health and social care organisation serving the Jewish community in London and the South East. We run over 70 centres and services,*

- 4.36 On 17th February, the TVN review noted that the grade 4 pressure ulcer had become larger, but YY was still reluctant to be turned. A full advice plan was provided to staff for managing all the ulcers. Later, ward staff escalated their concerns to the ward manager that YY had refused hourly turns and several of his medications. Later that afternoon, YY's sister rang the ward to say she was upset as YY had rung to say that staff were not attending to his personal care. She was informed that this was not the case.
- 4.37 On the same day, the hospital social worker carried out a first assessment of YY's possible care needs post discharge. This covered YY's home circumstances, his health issues, and exploration of the signs of a possible eating disorder. It was recorded that YY had capacity, and that he agreed with the discharge plan which would be discussed at a family meeting the following week. However, during a medical review on 19th February, YY was in extreme distress and wanted his family to take him home. It was also noted that he had become "paranoid about cleanliness" and was fearful of contracting the Novovirus which was present on the ward. On the evening of 20th February, YY rang his mother to say he was left in faeces and could not reach his buzzer. It was recorded that neither of these claims were true and staff were with him at the time.
- 4.38 X-rays and an orthopaedic review on 22nd February showed that the fracture was healing with a decision being made that the immobilisation plan should continue for at least a further two weeks. When YY's sister was informed 3 days later that an interim placement was not yet available at the preferred nursing home, she contacted Jewish Care requesting he be moved out of hospital immediately. However, their enquiries found no placements available in Jewish Care homes.
- 4.39 A further TVN review on 26th February found that the sacral wound had increased to 9 x 7 cms and was down to the bone. The left heel was dry, but there was black necrosis and dry gangrene to the 5th toe and lateral aspect of the foot which was painful to touch. A vascular review on 1st March confirmed the dry gangrene of the left foot which did not need debriding.¹⁵ A CT Angio of his legs was suggested, and plastics to look at the sacral wound. When YY met with the Senior Registrar, he blamed the physiotherapy for the dry gangrene. It was explained that the cause was multi-factorial. When the dietician carried out a further review, it was noted that his intake had only improved slightly, and there was no further input that they could give.
- 4.40 The manager of St John's Wood Care Centre (SJWCC), a nursing home, assessed YY on 1st March, but made a decision not to admit him due to his being non weight bearing, the non compliance with pressure care, and the length of time that would be needed to support YY. YY's sister again asked for Jewish care's help in finding an alternative home as she felt YY was not receiving the care that he needed for his recovery.
- 4.41 A discharge planning meeting was held, with YY and his sister on 3rd March after YY had been deemed medically fit for discharge. In the discussion around his future care needs, RFLNHSFT staff shared their positive experiences that YY had become more compliant as he had become used to the routine and the carers. A key requirement therefore was giving YY the opportunity to build trust through staff giving him sufficient time and showing patience. The SJWCC Manager agreed to take YY subject to approximately 30 hours of 1 to 1 extra support being provided through 5 daily calls from an external home care provider so that 2 staff could help with repositioning. Input from the community TVN would also be required who would change the wounds on alternate days during the first week before SJWCC nurses

¹⁵ *Removal of all dead, contaminated, or adherent tissue that may promote infection and impede healing.*

took over that task. A specialised mattress would also need to be ordered with TVN advice. It was noted that YY's sister would bring in his meals. Funding for the additional support was approved the following day which was commissioned from Hartwig Care on 7th March.

- 4.42 On 4th March, a review by the Senior Registrar and TVN found that the sacral wound was slightly smaller, but new damage was noted on his right hip. This was ungradable, and described as unavoidable, because YY claimed he could not lie on his left hip due to the pain. A new Datix¹⁶ was completed and photographs taken. The TVNs attempted to make a telephone referral to alert the community TVN team of YY's planned discharge but were unable to make contact until 7th March. A written referral was subsequently sent on the day of discharge.
- 4.43 At a vascular review on 5th March, YY's refusal for the CT scan was discussed and the risk that he might lose his leg. There was extensive dry gangrene, and a duplex scan was planned to see if any clear vessels could be viewed. YY was informed that leg amputation was very likely, and he was advised not to discharge himself until the peripheral vascular disease had been reviewed. On 7th March, at a gastrology review, YY refused an endoscopy and a colonoscopy. It was noted that attempts would be made to reduce his steroids.
- 4.44 In preparation for the discharge the hospital social worker noted that a Breeze airflow mattress had been recommended by the TVN, but the SJWCC manager stated that their standard mattress was adjustable to any weight, and provided the same benefits as the recommended mattress. The Discharge Co-ordinator's view was this should be suitable.
- 4.45 On 8th March, the ward referred YY's case to the Serious Incident Reporting Panel (SIRP) because of the pressure ulcers. The conclusion from the meeting held that same day was that it should be classed as a "no harm" incident because all appropriate treatment had been offered, and the wounds were due to YY's lack of compliance with the skin bundle regime.
- 4.46 YY was discharged to SJWCC on 9th March following a MDT review which deemed that YY was stable for transfer. The fracture was healing but would need another 4 weeks in plaster. A lengthy discharge summary was sent to SJWCC, the Barnet GP, and the Camden GP practice who would be temporarily taking over oversight of his medical care while he was in the nursing home. They also received the care plan and care booklet from the CMT.

Care provided at St John's Wood Care Centre

- 4.47 A full skin assessment and body map were completed on the day of admission, and on the third day it was documented that nursing staff had discussed with YY his health conditions, and food choices to achieve good nutritional intake. A referral was sent to the community TVN service because their input had not commenced as agreed in the discharge plan.¹⁷ However, a TVN from RFLNHSFT carried out a follow up visit on 11th March.

¹⁶ *Datix is a web based incident reporting system which allows incidents to be reported in real-time reducing delays experienced with paper systems. The web form divides the incidents into clinical and non-clinical with categories appearing in dropdown lists to make selection and completion straightforward.*

¹⁷ *The referral made by RFLNHSFT was received by the community TVN service 2 days before YY's discharge, and full written referral information was faxed through on the day of discharge.*

- 4.48 On 11th March, the hospital social worker raised a safeguarding concern after a number of complaints were raised by YY's sister relating to aspects of the care at RFLNHSFT – the mix up over medication at discharge, 2 occasions when the ward ran out of steroids, and the discomfort of the cast which had not been changed despite being promised. She requested that YY be moved back home.
- 4.49 The same day, the Care Manager of Hartwig Care carried out a first review and noted YY's frailty, the issues around his pressure ulcers and poor oral intake. The Camden GP also carried out her first examination at SJWCC's request because of the pain YY was experiencing, and the leakage from the left heel of the cast. The GP noted that YY was emaciated and had dry gangrene of both feet. Additional pain management options were discussed¹⁸ which he declined as he felt the pain was manageable if he was positioned with adequate support. His oral intake was discussed and the reason given for not taking the prescribed supplements was that the Ensure was too sweet. He agreed to try Calogen neutral which did not have any flavour. The GP then reviewed his medication 4 days later.
- 4.50 On 12th March, it was recorded that SJWCC completed an MCA assessment and YY was deemed to have capacity to make decisions about his care. 3 days later, SJWCC requested an urgent social work review because of YY's non compliance with turning, his complaints about the mattress, the problems around food and pain management, and his wish not to stay at the home.
- 4.51 On 16th March, the community TVN made her first visit and redressed the wounds. She recorded that YY refused repositioning because of the pain despite his understanding that this would prevent his pressure ulcers healing. YY was said to be shocked when the severity of the wounds was explained, and that these could deteriorate and become infected which could result in hospitalisation and death. The TVN gave advice on his diet, and recorded her view that he showed signs of an eating disorder, and also suffered from OCD in relation to his insistence of professionals changing gloves and not contaminating things, particularly his table. The TVN was informed by staff that if something upset YY, he could then refuse care for the rest of the day. The TVN provided detailed instructions on how each wound should be managed with a plan to revisit in 2 weeks, and made a plan to make a referral to the community dietician.
- 4.52 The TVN also noted that YY was pre-occupied with having his mattress changed even though this was a full replacement mattress set to the correct height for his weight. The SJWCC manager told the TVN that replacing the mattress would not be possible as this would normally be supplied by the Clinical Commissioning Group (CCG). The TVN recorded that YY had capacity to make decisions about his care but that a strategy meeting would be needed if he continued to refuse all interventions and care. Following the visit, the TVN emailed the hospital social worker to explain her assessment of the risks and also to request provision of a Toto Lateral Turning Platform.
- 4.53 On 17th March, the Hartwig Care manager sent his first weekly report to the hospital social worker outlining YY's dissatisfaction with the mattress, his overall distress, and concerns regarding the possible weight loss due to his continued poor intake. The social worker rang the Camden GP to discuss the services being provided and that input was still awaited from the dietician. It was agreed that YY's eating disorder and OCD were part of the issues round his weight loss and poor healing. The Camden GP agreed to chase the dietician, and explained her attempts to get YY to accept the supplements.

¹⁸ YY was already on Fentanyl 75mcg patch and taking Aspirin for his peripheral vascular disease

- 4.54 After a further visit on 22nd March, the Camden GP made a referral for a mental health assessment given the on-going concerns about his oral intake, non-compliance with turning, and request to go home. The same day, a social worker from the community team was allocated to follow up the safeguarding concerns raised on 11.03.16, and to take over care planning.
- 4.55 In his second weekly review of 22nd March, the Hartwig Care manager informed the social worker that YY was declining personal care due to the pain, but was rejecting pain medication. The manager had raised the mattress issue with SJWCC who reaffirmed that it was appropriate. The email shared the concerns raised by both the Hartwig care worker, and nursing home staff, about the problems in seeking assistance from each other. On 24th March, a new manager took over at SJWCC.
- 4.56 The social worker made her first visit on 24th March noting that YY appeared extremely underweight, his cheeks were visibly very sunken even through his beard which extended down to his chest, as did his hair. YY appeared to have a very good relationship with the Hartwig carer but was critical of SJWCC staff alleging that they did not turn him as per the turning regime. The Hartwig carer explained that it was sometimes difficult to locate staff for assistance, and therefore he had sometimes turned YY single handed because YY had been "crying out" in pain and something needed to be done to alleviate his distress. The social worker advised that he should not do this, and should take this up with SJWCC. YY was very anxious and agitated throughout the meeting, and repeatedly said he was desperate to get home as he felt he would improve there.
- 4.57 During this visit, the TVN arrived and gave advice about the need to increase his oral intake and comply with the turning. The TVN said she would chase up the mattress issue with the new manager. The social worker and TVN agreed that a return home would be difficult to organise given the level of support required.
- 4.58 The Hartwig care manager sent his weekly report (and the previous ones) on 29th March to the social worker, which included the information that YY had now placed a duvet over the mattress. On the same day, the Jewish Care social worker emailed the social worker to say she was attempting to get background information from the Barnet GP about how his medical issues had been managed at home, and whether there had been any mental health diagnoses. The Barnet GP had agreed to do this subject to receiving the necessary consents.
- 4.59 The GP continued to maintain regular oversight with further visits made on 1st and 5th April, and there was a further TVN review on 6th April.
- 4.60 The first dietician assessment carried out on 8th April noted the appearance of self neglect, and YY's belief that his wounds would heal, and that he would be able to go home, despite often refusing to eat, or drink the supplements. The dietician emailed the GP about YY's loss of weight sharing her view that based on RFLNHSFT's previous estimate of his weight and height, YY's body mass index (BMI) would be 12.¹⁹ The dietician also contacted the Camden Mental Health Residential Liaison Team (CMHRLT) because her view was that YY required urgent mental health input, enteral feeding, or hospital admission. She shared her observation that such severe malnutrition could affect YY's ability to make rational decisions.

¹⁹ *The BMI (Body Mass Index) is used by the medical profession to determine a person's weight in regard to their height. The BMI calculation is used to determine if a person is underweight, of normal weight, overweight or obese.*

- 4.61 The Jewish Care social worker also contacted the Camden GP to request a mental capacity and mental health assessment because YY had said he wanted to 'give up' although he denied that he would act on these thoughts. The GP reviewed YY later who claimed to be eating a little better and was accepting 30mls of the nutritional supplement Calogen twice a day.
- 4.62 Although a referral had not been received from the GP, a mental health nurse from CMHRLT undertook an initial assessment to support SJWCC. YY denied any psychotic phenomena, achieved the maximum score on the Mini Mental State Examination test (MMSE), and displayed good insight into his conditions. The results were shared with the Camden GP who contacted the Jewish Care worker to see if 1 to 1 care could be provided at night.
- 4.63 On 18th April, the hospital dietician shared her perception with the community dietician that RFLT had experienced similar responses from YY in hospital, and that he would most likely refuse any enteral feeding. Her view was that the issue was more a mental health and psychological one, and while there had been discussion about a referral to the eating disorder clinic, the lead consultant thought this was better done in the community. She was not aware of whether his had been progressed since.
- 4.64 On the same day, the Camden GP sought the advice of the RFLT haematology registrar regarding YY's low Hemoglobin level ²⁰who advised that if this remained low after repeat tests, he should be sent to hospital. This was followed up with SJWCC the following day. The TVN and district nurse also made a joint visit when YY was shocked when shown photos of his wounds. He later told the Jewish Care worker who was present that he wanted to die and "end it all". This information was passed on to the social worker.
- 4.65 The mental health nurse carried out a follow up visit on 19th April when YY reported he was a little better, was taking more analgesia, and his intake had increased a little. He agreed to a weekly review.
- 4.66 At a professionals' meeting with the family on 20th April, the family were adamant that YY be allowed to return home despite being informed that the ulcers were life threatening, and had increased in size over the previous 2 weeks. The urgency of securing a replacement mattress and Toto platform was agreed. The mattress was ordered the following day, and delivered 4 days later, after further advice from the TVN, and the intervention of LBC's QA and Contracts Manager.
- 4.67 Also on 20th April, the Hartwig Care manager informed the social worker that YY was still not eating, and had lost further weight. The community dietician had a frank discussion with YY and informed him that a referral would be made to the eating disorder team via the Camden GP.
- 4.68 When the TVN carried out her review that day, she found no change in YY's level of co-operation, and he had placed a duvet on the mattress. The TVN continued to liaise with the district nurses and occupational therapists to plan for YY's possible return home. The district nurse agreed with the TVN's view that a regime of 2 hourly turning may not be achievable, and discharge home without adequate support in place was not going to be safe and achievable given the extent of pressure damage. During this discussion, the TVN expressed her surprise that RFLNHSFT had discharged him. The occupational therapists subsequently carried out an assessment in early May when they concluded that the use of hoists and slings would not be feasible.

²⁰ Hemoglobin is a protein in red blood cells that carries oxygen around the body.

- 4.69 On 21st April, the 2 social workers agreed that the CMHT's formal written assessment was needed regarding YY's capacity to discharge himself and his understanding of the associated risks. The mental health nurse planned the visit for 27th April and requested reports from all the professionals currently involved so she had a full picture.
- 4.70 On 25th April, YY's sister informed the Jewish Care worker that she had lodged a complaint about RFLNHSFT and SJWCC with the Care Quality Commission (CQC). The CQC sent a request for information to LBC the following day.
- 4.71 On 25th April, the mental health nurse informed the social worker that her visit was being brought forward to that afternoon because of a cancellation. The social worker provided verbal background information as the previously requested written reports had yet to be sent on. The social worker explained that she had found it difficult to assess YY's capacity, and it was important for professionals to be "absolutely sure" that YY had capacity and fully understood the risk of a return home.
- 4.72 Before seeing YY, the mental health nurse was informed by the SJWCC nurse that the hip was starting to heal and the sacral ulcer was now clean. During the assessment YY said he was eating more, and promised to co-operate with repositioning. He also responded positively to the suggestion of antidepressants. Although being in low mood, he did not have a death wish as mentioned by the social worker. The conclusion was that YY seemed marginally better, and did have mental capacity although this seemed to fluctuate. The plan was to hold an MDT meeting, and arrange a joint visit with the psychiatrist. YY also informed the Camden GP the following day that he was feeling better, and he again agreed to eat more, and to a referral being made to the haematology clinic.
- 4.73 On 26th April, the Jewish care worker sent a global email to the other professionals involved to check her understanding of the latest plans. The social worker replied that there would be a professional meeting the following week with the family, and the continuing healthcare assessment by Barnet CCG was scheduled for early May. YY's sister was said to be more accepting that YY could not return home until the care package was in place, but was pessimistic as to whether he would ever leave SJWCC given the lack of progress. The following day, YY's sister raised further concerns with the Jewish Care worker that YY was distressed by the way care was being provided by SJWCC staff who did not afford him the time he needed, and lacked understanding and patience.
- 4.74 During a review visit on 28th April, the mental health nurse was informed by the Hartwig carer that while there had been a slight improvement, YY was rude to him when providing personal care and his behaviour was unacceptable. He was advised to challenge YY about this, and report it to his supervisor.
- 4.75 The CHC assessment was carried out by the Barnet CCG Lead Nurse on 3rd May which took into account full information obtained from the Barnet GP practice. YY had not wanted to participate and gave consent for his sister to speak for him. The Lead Nurse's assessment, shared with the social worker, was that YY was extremely unwell and she doubted that YY could be managed at home, and that he perhaps needed admission to hospital.
- 4.76 The following day, the social worker discussed with the QA and Contracts Manager whether SJWCC could meet the extremely high level of care that YY needed, and whether hospital admission for a period of acute care should be arranged in light of the views expressed by the Barnet CCG Lead Nurse. The QA and Contracts manager discussed this with the SJWCC manager who also felt it was in YY's best interests to be nursed in hospital.

- 4.77 Later, the SJWCC nurse made a 999 call to request an ambulance. The control centre recorded that this was because of YY's poor oral intake, severe weight loss, and grade 4 pressure ulcers. On arrival, YY said that he was unaware they had been requested and did not want to attend hospital.²¹ SJWCC staff informed the paramedics that YY had the capacity to make decisions about his care.²² While the paramedics were there, YY's sister arrived and was angry that she had not been informed accusing the SJWCC manager of calling the ambulance to "cover his back". She subsequently left a note instructing staff that YY should not be taken to any hospital without her being contacted first. The outcome of the paramedics' visit was an agreement that YY could stay at SJWCC for 24 hours but would attend hospital the next day. This interval was designed to give YY the chance to come to terms with that step.
- 4.78 This episode resulted in YY's sister sending a detailed complaint to the LBC Chief Executive about the care provided, the delay in YY being returned home, and the distress caused to YY by the ambulance being called without the family being informed. YY's sister asked if YY could be moved to a Jewish care home until the necessary home support could be put in place. Her aim was to avoid the risk of a repeat of the ambulance episode. Jewish care made some initial enquiries which were unsuccessful. YY's sister also contacted the GP to ask about YY's HB levels.
- 4.79 The social worker informed the Barnet CCG Lead Nurse of the increasing tensions between SJWCC and the family arising from the paramedics' visit. The Lead Nurse emailed the Camden GP to raise her serious concerns regarding YY's mental and physical health, referring to the history of multiple secondary care DNAs, and his refusal to go to hospital the previous day.²³ The immediate concern was the lack of nutrition, and the belief he had lost further weight since admission. This was contributing to his becoming increasingly fatigued, which was impacting on his oral intake as he was frequently asleep during meals. Even when he was able to stay awake, it was taking up to two hours to eat minimal amounts. The Camden GP's views were sought as to whether in the light of this, and the recent blood tests, an acute admission to address feeding and haematology concerns would be a way forward. The Lead Nurse also shared her view with the social worker that YY was "clinically compromised" and needed urgent medical, psychological and dietary intervention. She doubted that the family had insight into how critical YY's condition was.
- 4.80. On 5th May, the psychiatrist carried out a mental health and mental capacity assessment. The mental health nurse and YY's sister were present. The psychiatrist recorded that YY appeared to have a sensible and understandable plan about how he would manage at home. YY stated that he did not feel depressed but was "fed up" with being in the care home and just wanted to get back to his own room with his books and music. The psychiatrist's conclusion was that there was no evidence of cognitive impairment or psychosis, and that YY had the capacity to make decisions about where he received care.

²¹ *The SJWCC manager subsequently informed the QA and Contracts Manager that he had informed YY in advance that an ambulance was being requested, but he had not informed the family.*

²² *It was later alleged by the SJWCC manager that YY's refusal stemmed from the Hartwig carer intervening and saying he did not have to agree to go. This claim was subsequently rebutted by Hartwig care when responding to a formal complaint lodged by Social Care.*

²³ *the GP was not available to take the Lead Nurse's telephone call*

- 4.81 The following day, the Barnet CCG Lead Nurse emailed the mental health nurse and Camden GP to express her serious concerns that YY's mental health was impacting on his physical health to a point where he was at serious risk of harm. She requested an urgent MH assessment by a psychiatrist or a referral to the Westminster Rapid Response Team. The Lead Nurse then updated the social worker and agreed to contact YY's sister to explain how critical the situation was, and explain why hospital admission was required. ULCH would be suggested as this might be more acceptable to the family given their previous complaint about RFLNHSFT. During the subsequent telephone call, YY's sister accepted that hospital admission was now required.
- 4.82 The GP visited YY on 6th May after being informed about the ambulance call out. Although YY appeared frail, pale and cachectic, he was alert and eating a meal of rice and mincemeat brought in by family. The GP explained about the further blood tests and the haematology appointment on 13th May.
- 4.83 The GP replied to the Barnet CCG Lead Nurse on 9th May confirming that YY was not fit for discharge, and needed investigation due to the low Hb levels as well as other health issues, including his extremely low weight. She explained that the imminent haematology appointment might result in immediate admission if it was concluded that he was critically ill. In the light of this, the CCG Lead Nurse emailed the social worker to say that the professionals' meeting planned for the following day might no longer be necessary as YY might be admitted into hospital that week. The social worker explained that the meeting was not to plan YY's discharge, but to review recent events at SJWCC.
- 4.84 The same day, CNWL's Integrated Primary Care Service Manager, emailed the CMHT expressing serious concerns about the outcome of the capacity assessment carried out by the psychiatrist as she felt this did not reflect the critical nature of YY's health needs and the assessment was based on inaccurate information that YY's wounds were improving. Her view was that hospital admission was required. This email was copied to the social worker and Barnet CCG Lead Nurse. An internal discussion between the mental health nurse and the trust's safeguarding lead identified that a multi disciplinary team meeting would be appropriate, but the record did not identify how that would be progressed.
- 4.85 At the professionals' meeting on 10th May, all those present shared their concern that although YY required hospital admission, he had refused to go the previous week. It was noted that the sacral sore was not improving, and was increasing in size. Reference was made to the challenge raised to the psychiatrist's assessment. Hartwig Care raised their concern that SJWCC staff were not available when their carer required assistance to provide the doubled-up care, and that this was causing tensions, and potentially impacting on their ability to provide care to YY on a regular basis. The outcome was an agreement to await the outcome of the haematology appointment as this might lead to admission, but that in the meantime the social worker would seek legal advice. SJWCC and Hartwig would also meet the next day to resolve the staffing issues.
- 4.86 The Camden GP reviewed YY that day with the latest blood test results which remained low. YY said he was drinking the supplement and eating a bit more including cake. On examination there was marked emaciation but the sacral sore was clean. The plan made was for YY to keep the haematology appointment on Friday and he was aware that he may be kept in for iron infusion.

- 4.87 On 11th May, the community dietician sought an update from the Camden GP, and requested an urgent referral to the Eating Disorder Service as this had not been actioned when he was in the RFLNHSFT. Her view was that this might offer the possibility of his being admitted for treatment under the Mental Health Act. The GP agreed to make the referral depending on the outcome of the haematology appointment.
- 4.88 During that afternoon, the SJWCC nurse made a 999 call as YY had irregular breathing and oxygen saturations of 81%. A Fast Response Unit and ambulance were dispatched immediately, but on arrival ambulance staff found YY was not experiencing difficulty in breathing, and all clinical observations were normal. The outcome was that it was deemed not necessary for YY to go to hospital but that he should be seen by the GP. YY informed the GP that he had had a panic attack as he was choking on his medication and did not know whether to cough or attempt to swallow. The GP informed YY and his family that he was very malnourished and dehydrated, and therefore there was the option of going into hospital that day but YY declined this saying he would drink and eat more. It was agreed to adhere to the original plan of awaiting the outcome of the haematology appointment.
- 4.89 The following day, on 12th May, SJWCC sent for an emergency ambulance as the Hartwig carer had found YY semi conscious and unresponsive, and YY was taken to UCLH.

Summary of care provided at UCLH

- 4.90 On admission, the clinical impression was: hypoglycaemia due to malnutrition, severe cachexia, pressure ulceration secondary to immobility, volume depletion, anaemia, elevated liver enzymes of uncertain causes, sepsis and possible osteomyelitis of the sacrum and sepsis. There were extensive areas of skin ulceration consistent with pressure ulcers including a Grade 4 sacral sore. YY was immediately assessed by the Tissue Viability Nurse. A body map and photographs were taken. An incident report was completed for the pressure ulcers. A collective clinical discussion was made to admit SL to a medical bed at AMU for immediate and appropriate medical treatment. In the light of the severity of YY's condition, a safeguarding concern was raised by the UCLH Safeguarding Lead who informed the social worker that the pressure ulcers were amongst the worse ever seen, and that YY was critically ill and might not survive.
- 4.91 The following day, YY was fully conscious and able to conduct a conversation but remained in a precarious state. He refused the insertion of a naso gastric tube despite a long discussion about the ongoing risks of his poor nutritional state and the high risk of death in the absence of restoration of his nutritional needs. A discussion was held with the family. YY accepted that his refusal placed his life in danger. Although YY seemed unable to reconcile the two issues, the medical team felt he had capacity to refuse the intervention. As a compromise he was persuaded to try and increase his oral intake.
- 4.92 On 14th May, a "Do not attempt cardiopulmonary resuscitation" request was completed with YY who was deemed to have capacity to make this decision. On 15th May, YY agreed to have a naso gastric tube inserted and he was transferred to the gastroenterology ward. On 17th May, YY's conscious level deteriorated and his Glasgow Coma Scale was 10/15. His family were informed and he was prescribed with appropriate "end of life" medications. YY died the following day on 18th May.

Subsequent Safeguarding Processes

- 4.93 A professionals meeting was held at UCLH on 23rd May to allow UCLH staff to share their concerns and to learn about the previous safeguarding alerts. LBC made a decision not to class this as a strategy meeting because there was already a safeguarding process underway, and it was better to absorb the UCLH safeguarding alert within this. The UCLH safeguarding lead expressed disagreement with this decision.
- 4.94 Following completion of a Section 42 safeguarding investigation, a case conference was held at UCLH on 3rd August 2016.

5. ANALYSIS OF AGENCY INVOLVEMENT AND APPRAISAL OF PRACTICE

- 5.1 The Review Team's analysis and findings centre of the following themes:-
- Response to obsessive compulsive behaviours and possible eating disorders;
 - Response to possible self neglect;
 - Working with service users who choose not to act on professional advice;
 - Assessment of mental capacity;
 - Safeguarding thresholds and processes;
 - Hospital discharge planning
 - Case co-ordination
 - Escalating concerns;
- 5.2 Many of these are inter-related. Therefore for ease of presentation each theme will be covered in turn, with the links drawn together in an overall summary of the findings at the end of the report.

6. RESPONSE TO OBSESSIVE COMPULSIVE BEHAVIOURS AND POSSIBLE EATING DISORDERS

- 6.1 YY's obsessive compulsive behaviours and restricted diet were significant contributory factors to his poor health, and the challenges experienced by professionals in getting him to act on their advice.
- 6.2 The Barnet GP records showed that these behaviours, and their impact, were well known to both them, and a number of secondary care doctors at RFLNHSFT, over the 9 year period from 2007 when he registered with that practice. The following are examples of correspondence touching on these issues:-
- A letter from a senior dietician 23rd May 2008 referring to YY's restrictive diet, his nutritional requirements not being met despite advice, and his being underweight with a BMI of 16.5;
 - A RFLNHSFT dietician's letter of 3rd June 2008 which included YY's explanation for his limited intake. These included:-

- * concerns that certain foods might lead to a flare up of his ulcerative colitis;
 - * the links of certain foods to cancer, and high fat intake affecting heart health;
 - * his intolerances to sucrose leading to exhaustion, and extreme sensitivity to salt leading to fluid retention in his legs;
 - * the effect of certain foods on his bowels.
- A letter from the RFLNHSFT Nephrology Clinic of 27th August 2009 referring to YY's ongoing weight loss (one stone since 2007) and malnourishment;
 - A letter from a Neurology registrar at RFLNHSFT on 10th June 2011 referring to his chronically low weight, poor nutrition and low BMI.

6.3 Despite the frequent references to YY displaying OCD behaviours, a formal diagnosis was never sought until August 2013 when the Barnet GP made a referral to the local Community Mental Health Team (CMHT) on the advice of a hospital dietician who thought there may be an OCD element to his eating habits which were contributing to his malnourishment. However, YY subsequently declined this appointment because his view was that he did not have an obsession, but a genuine intolerance of certain foods.

6.4 Two years elapsed before the further 2 further referrals were made by the Barnet GPs to the CMHT in September and October 2015. This stemmed from their own concerns, and those raised by the podiatrist, about YY's obsessive behaviours in respect of the hygiene practices he insisted they adopted. However, these referrals did not refer specifically to a request for an assessment of a possible eating disorder. YY's decision not to engage meant that these efforts to obtain a possible diagnosis and treatment plan proved abortive. Although the offer of a re-referral was made in the feedback letter, neither the Barnet GP, or the CMHT practitioner, took the initiative to initiate further discussion to problem-solve his lack of engagement, and explore the degree of urgency of the situation.

Period YY was in the RFLNHSFT

6.5 The response to the referrals for mental health and psychology input was immediate at the RFLNHSFT, but their assessments were focused on issues around his depression, suicidal ideation, and mental capacity. There was no specific reference to his OCD behaviours in those assessments.

6.6 Although a plan was made for a referral to the eating disorder service, this was not followed through. A referral at this point would have been helpful given the difficulties hospital staff were experiencing in getting YY to increase his oral intake, which was hampering their efforts to treat his worsening pressure ulcers. When this oversight was picked up by the community dietician 6 weeks after discharge, she was informed that the view of hospital staff was that this referral would be best done in the community. The Review Team agreed that this was a missed opportunity and that when providing care in complex cases, it is important that acute hospitals look at the broadest picture and commission all potentially relevant investigations.

Period at the Nursing Home

- 6.7 A range of professionals tried to get YY to increase his oral intake without success. However, despite his continuing OCD behaviours and emaciated condition, it does not appear that either the Camden GP, or social worker, considered seeking specialist input, until this was raised by other professionals. In part this was due to SJWCC never raising the need for mental health input with either the social worker or the GP. From the evidence given by the SJWCC manager at the inquest, this stemmed from the home adopting a passive approach in relying on the advice and instructions of health professionals in providing care. SJWCC were welcoming of the offer of support subsequently made by the mental health residential liaison nurse. During this time, YY continued to lose weight and his BMI was 11 at the point he was admitted to ULCH. The significance of this BMI figure will be discussed later.

Issue of Compulsory Treatment

- 6.8 This possible step was the subject of several discussions at the RFLNHSFT involving the lead consultant, a psychiatrist, and the Trust's legal advisor. The view reached was that an application to the Court of Protection would be unlikely to be successful because a number of professionals had judged that YY had capacity – a conclusion which was supported by the family. In addition, from a clinical perspective there was little to be gained from taking this step, because the practicalities of enforcing treatment, with someone who was being resistant, would be difficult in respect of repositioning, giving intravenous drips or applying force feeding.
- 6.9 During YY's time at SJWCC, the issue was discussed between individual professionals on several occasions as concerns grew that there was little change in YY's condition and responses. However, there was no collective consideration of this until the professional's meeting on 10th May when it was agreed that the social worker would seek legal advice. However, the perception of one attendee was that the chair thought such a step was somewhat "heavy-handed". In any event, this step possibly came too late to have influenced the subsequent course of events.

Conclusions and Learning

- 6.10 A common theme running through government guidance, and that published by professional organisations, is the importance of early intervention to address OCD behaviours and possible eating disorders given their association with poor health, psychological health issues, social isolation, and the impact on family members. The impact of eating disorders can affect nearly every organ system and if left untreated, can lead to physical health complications which are often irreversible, and can be life-threatening - eating disorders have one of the highest levels of mortality of any psychiatric illness. The view of the Joint Commissioning Panel for Mental Health is that there is a critical window for intervention as the prognosis for all eating disorders worsens with time, and recovery is less likely if it remains untreated for more than 3 to 5 years.²⁴ There are also significant resource implications if the condition is not treated early because it may require multiple medical investigations as occurred in YY's case.

²⁴ *"Guidance for commissioners of eating disorder services" - published by the Joint Commissioning Panel for Mental Health - October 2013*

- 6.11 In addition to securing early intervention, access to specialist help is important to help with the recovery process which is complex because the person has rebuild themselves physically and psychologically. This is reflected in the observations made by Kings College London that:-

*“recovery from an eating disorder will never be easy, never be short, and never be painless. The gaining of weight, or relinquishing of unhealthy eating behaviour is a slow, long, arduous struggle full of emotional turmoil. The strength and mental willpower an individual needs to break free from their illness is immense. An individual cannot recover without support and guidance. For some, breaking free from an eating disorder may be their toughest challenge in life. They will feel lost, alone, and vulnerable.”*²⁵

- 6.12 The more weight that has been lost, and the more extreme the emaciation, the longer the recovery takes. Similarly, recovery is much harder the longer the illness has gone on before treatment starts, and if the illness has failed to respond to several attempts at treatment. As well as establishing a regular and balanced eating pattern, the underlying emotional problems need to be addressed and resolved. The Kings College London perspective is that the first, and perhaps most difficult step in treatment, is for the individual to acknowledge that eating is a problem. They have to want to change their life and give up their illness. Ambivalence will lead to an incomplete recovery or relapse.
- 6.13 In the light of the above observations, the several missed opportunities to refer YY to a specialist eating disorder service indicated a lack of awareness about when specialist help should be sought, the services available, and the referral pathways. As a result YY’s OCD behaviours and eating disorder remained undiagnosed.
- 6.14 Given the importance of this issue, the Review sought the input from a senior operational manager of the Barnet, Enfield and Haringey Eating Disorder Service to help draw out the learning from this Review.²⁶
- 6.15 This expert advice suggested that working with service users with eating disorders is challenging because in the majority of cases there are underlying characteristics such as an obsessive personality, anxiety disorder, and low self-esteem. These were traits displayed by YY in his anxiety around the effects of analgesia, certain foods, poor hygiene, and dirty hospitals. In addition, in her experience, many patients are extremely intelligent, and able to provide rational explanations as to why they have intolerances to certain food or restrictive diets. They also make countless promises to change behaviour but these are not followed through. These were features of YY’s behaviour and response to professionals.
- 6.16 In deciding how to address OCD behaviours, and eating disorders, it is important that professionals draw on the guidance issued by the National Institute for Health and Care Excellence (NICE). The 2005 NICE guidance on managing OCD explains how a “stepped care” approach should be offered at all levels of the healthcare system. While initial treatment may be best provided in primary care settings, in cases where people have more impaired functioning, higher levels of comorbidity, or poor response to initial treatment, the input of specialist expertise will be required. In patient care may be required where there is perceived risk to life.

²⁵ www.kcl.ac.uk/ioppn/depts/pm/research/eatingdisorders/treatment/treatment.aspx

²⁶ *The ED service comprises a large multi-disciplinary team offering out-patient services and has access to the Trust’s 20 bed in-patient psychiatric unit.*

- 6.17 In May 2017, NICE updated its guidance on eating disorders.²⁷ Although this is specifically directed at patients with anorexia and bulimia disorders, it includes advice that is applicable in addressing all kinds of eating disorders. Therefore it will be important to ensure that professionals are not put off from using this guidance which would be classed as atypical, such as YY's.

Referral Triggers

- 6.18 The 2017 NICE guidance stresses the importance of assessment and treatment commencing at the earliest opportunity, and the need to prioritise cases involving severe emaciation. Judgements as to whether to refer should take into account an unusually low or high BMI, rapid weight loss, restrictive eating practices, and the presence of any mental health problems commonly associated with eating disorders, including depression, anxiety, self-harm and obsessive compulsive disorder.
- 6.19 Although the NICE guidance advises that a patient's BMI should not be relied on as the sole trigger for making a referral, the expert consulted for the review explained that in practice it remains a key assessment measure on whether intervention is needed, and that as a rule of thumb, a BMI below 15 should be regarded as "really urgent". An further insight provided is that female patients appear to cope better with a low BMI than men who may come into that threshold with a higher BMI. A large or tall man with a BMI of 16 would be quite thin.
- 6.20 During YY's stay in RFLNHSFT, his BMI was said to be always above 15, but had dropped to 11 at the time of his death. During YY's time at SJWCC, the Community Dietician calculated that his BMI would be around 12 given the continuing loss of weight which she based on the previous RFLNHSFT estimate. This led to the dietician pursuing the referral for an urgent mental health assessment given her view that he needed enteral feeding and possible urgent hospital admission. However, there was some drift before this request was acted on.

Referral Pathways

- 6.21 The Review discussions identified that many professionals are not aware of the pathway into specialist services. In YY's case, professionals saw the GP as the conduit. However, the local specialist service accepts referrals direct from any professional. For patients in a community setting, outpatient appointments are usually offered in the first instance. If the service user declines to engage, the feedback letter to the referrer will ask what the referrer wants to do next, and whether the situation is serious enough to warrant a formal assessment under the Mental Health Act.
- 6.22 Where the patient is in hospital, referrals will usually come via the psychiatric liaison team, who should be involved where there are psychological complications such as moderate to severe depression, especially with suicidal ideation, a failure of current management, or diagnostic uncertainty. The Eating Disorder Service liaison team will then carry out an assessment visit at the hospital where experience has shown that it is harder for the patient to refuse to engage, and an appropriate plan can be formulated, including a formal Mental Health Act (MHA) assessment if necessary.
- 6.23 Patients can be admitted to the BEH Trust's psychiatric ward, but where the patient's medical treatment needs are greater than the ward can provide, treatment for the eating disorder will be provided within the general hospital where their treatment will be managed by the hospital's psychiatric liaison team, with an ED practitioner visiting

²⁷ *Eating disorders: recognition and treatment: NICE guideline ng69 Published: 23 May 2017*

at least once a week. This reflects the 2014 guidance issued by the Royal College of Psychiatrists on joint care arrangements.²⁸

Decisions on when to admit to hospital

- 6.24 The 2017 NICE guidance advises that acute medical care (including emergency admission) should be provided where physical health is severely compromised and there is a need to monitor risk parameters such as blood tests, physical observations and ECG, when medical stabilisation cannot be achieved in an outpatient setting. Indicators which may require this step include electrolyte imbalance, severe malnutrition, and severe dehydration. This is an important message in dealing with future cases given that the last 2 indicators were present in YY's case despite him being in a care setting with qualified nursing staff.
- 6.25 An issue which was pressed by the Coroner during the inquest was at what point consideration should have been given to re-admitting YY to hospital. The Review confirmed that unless specific triggers have been included in the discharge summary, this is a matter of professional judgement for community based staff including picking up any possible signs of sepsis in view of national and local initiatives to raise awareness on this.

Compulsory treatment

- 6.26 Within the Review Team discussions, there were different views as to whether taking steps to enable treatment to be given compulsorily would have been a feasible or appropriate step to take in YY's case, and whether this might have resulted in a different outcome. The option of compulsory treatment would have been to address the perception of professionals at the time, that YY knew that the consequence of the decisions he was making was that he might die, but this was not something he wanted to happen.
- 6.27 In looking at the possible routes as to how compulsory treatment might have been achieved, the Review agreed that YY's case did not fit the criteria for applying to the High Court to exercise its powers of inherent jurisdiction because this was not a case where he was being prevented from making a decision due to coercion or influence of a third party.
- 6.28 The Review heard that RFLT will make an application to the court of protection if they have any doubt about whether a patient has capacity, but that in YY's case, the view was that an application would fail because YY was deemed to have capacity. However, the Review heard that there had been cases which had been accepted by the High Court where a patient refused treatment due to a fear / phobia, and the Court has over-ruled the patient's decision and deemed that they lacked capacity.²⁹

Use of the Mental Health Act

- 6.29 What did not appear to feature in any of the discussions about the issue of compulsory treatment was the possible use of the legal framework provided by the Mental Health Act. The 2017 NICE guidance clarifies that this is the route to be followed where a person's physical health is at serious risk due to their eating disorder, they do not consent to treatment, and they can only be treated safely in an inpatient setting. Given the constraints professionals felt at the time because they had

²⁸ "Management of Really Sick Patients with Anorexia Nervosa" (MARSIPAN) – Royal College of Psychiatrists, Physicians & Pathologists – October 2014

²⁹ Re MB. 1997. 1 FCR 274

deemed that YY had capacity, it is important to provide a reminder that a person can be detained under the MHA regardless of whether they are deemed to have mental capacity.

- 6.30 In addition, the Eating Disorder specialist consulted for this Review also explained that even where a patient appears to have capacity, compulsory treatment will need to be considered if the patient does not co-operate with treatment, where the BMI is 13 or below. This is because their cognition will be impaired, and they will lack capacity because the brain is unable to function properly. The MHA allows treatment to be enforced, including restraining patients to insert a NG Tube. The perspective of the Review's expert advisor was that while this treatment is unpleasant and undesirable, the rationale for enforcing treatment is that once the BMI comes back up, and their cognitive functioning improves, patients will often then accept treatment and eat of their own free will.
- 6.31 In considering why a MHA assessment was not requested or carried out, a significant issue which emerged was that professionals did not appear to understand the importance of being clear what type of assessment they were requesting when they sought the input of mental health specialists. The latter's response will be very different depending on whether they are being asked to provide an opinion about a patient's overall mental health, or a request for a formal assessment under the Mental Health Act to establish if the criteria for compulsory admission are met.
- 6.32 This lack of understanding of terminology created misunderstanding and uncertainty amongst most professionals in YY's case. So while those asking for an assessment via the Camden GP may have been thinking an assessment would include whether there were grounds for compulsory admission, this was not stated explicitly, and was not how the request was interpreted, particularly as the referrals made great play on the second opinion being sought on whether YY had mental capacity in refusing treatment. The Review Team's experience is that the misunderstanding and uncertainty which featured in this case are not unusual.

7. RESPONSE TO POSSIBLE SELF NEGLECT

- 7.1 There were many aspects of YY's situation and behaviour which would lead to a view that he came within the definition of self neglect in the statutory guidance on the Care Act 2014:-

“self neglect covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding. It should be noted that self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.”

- 7.2 The previous section provided examples of the many occasions when health professionals in both primary and secondary care settings recorded their observations about YY's thinness and low weight, and how his behaviours and decisions were contributing to this. These could have resulted in a safeguarding concern being raised for possible self neglect taking into account his emaciated state, his reluctance to act on professional advice, and the recurring pattern of DNAs.
- 7.3 However the Barnet GP notes do not indicate that this step was ever considered. This may reflect that prior to implementation of the Care Act from April 2015, self neglect was not included in the categories of abuse under the safeguarding arrangements, and this may have created uncertainty where to share their observations.

- 7.4 After YY's admission to the RFLNHSFT in January 2016, neither the medical team, nor the therapists, followed through their intention to raise a safeguarding concern about possible self neglect.³⁰ There were then further opportunities when this step could have been considered when the weekend social worker noted his appearance of self neglect, and when this was listed as one of YY's multiple problems by the senior registrar on 29th January.
- 7.5 After this, possibly because YY was in either a hospital or care setting, there appears to have been little consideration as to whether to raise a safeguarding concern despite YY's frequent decisions not to co-operate with the skin bundle regime, or increase his oral intake, despite being informed of the potential serious consequences.

Conclusions and Learning

- 7.6 In exploring why the identification of possible self neglect were not brought into the formal safeguarding system, the Review identified that various factors may have come into play. As well as a lack of knowledge of the referral process, professionals may have been inhibited from raising a concern because YY was deemed to have capacity, and also because professionals are more used to responding to safeguarding issues where there is an alleged perpetrator. The fact that YY had been assessed as having capacity did not mitigate the risks, or address the issue of whether he could protect himself.
- 7.7 The issue of self neglect featured in a previous SAR carried out by Camden SAPB in relation to ZZ which was published in July 2015. Although the circumstances were different to those in this case, the SAR made recommendations to raise awareness and equip professionals with the requisite skills to recognise and respond to self neglect. However, the findings from this current Review would suggest that those planned changes have yet to be implemented fully to build in the necessary robust systems and processes to assist staff in identifying possible self neglect, and when this is identified as a concern, how to act on their concerns. It is important therefore to revisit this issue and highlight some of the key elements for effective practice.
- 7.8 The Review noted that there are a number of challenges facing professionals in dealing with cases involving possible self neglect because of its multi-dimensional nature, and the difficulties often encountered in achieving effective engagement - particularly where there are related mental health problems or cognitive impairments.
- 7.9 In self neglect cases, the negative impact is high, not just for the adult at risk, but also for professionals because of the time involved in addressing the non engagement, and the anxiety around the potential for a poor outcome. The perception that the person has the capacity to make an informed decision does not lessen that stress because these are not situations where professionals can just "walk away".
- 7.10 The 2015 Social Care Institute for Excellence (SCIE) report on self neglect policy and practice identified a number of key messages for achieving an effective response.³¹ High on this list is the need to locate strategic responsibility for addressing self-neglect with the Local Safeguarding Adults Board, which is best placed to oversee the development of:-

³⁰ *state of generally poor health, malnutrition, and weight loss.*

³¹ *Self-neglect policy and practice: key research messages - Written by Suzy Braye, David Orr and Michael Preston-Shoot – published March 2015*

- shared definitions of what constitutes self-neglect, and expectations of agency responses;
- joined-up systems to ensure coordination between agencies;
- organisational arrangements within agencies which ensure staff have time for longer-term involvement;
- data collection and analysis to inform service development;
- training which provides professionals with knowledge of self neglect, the ethical issues that arise, and the legal framework.

7.11 A number of safeguarding adults boards have developed a multi-agency toolkit for professionals to draw on, and the Review agreed that this should be a priority action. This would not provide any “magic bullets”, but could include vignettes about what constitutes self-neglect, the different levels of risk, and strategies for early intervention based on a range of factors which have been found to be key ingredients for effective intervention drawn from previous SARs and research published by SCIE.

7.12 Factors which relate to the learning from YY’s case, include:-

- The importance of robust multi disciplinary risk assessments, which probe the social history and family dynamics, to gain insights into the motivation and possible factors influencing decisions to decline services;
- A person centred focus which attempts to establish a relationship of trust at the person’s own pace which can facilitate greater acceptance of support;
- The need to adopt a pro-active approach through early information sharing and intervention before the self neglecting behaviour becomes more severe and entrenched;
- Not allowing issues around mental capacity to inhibit professionals’ response to the impact of the self neglect;
- Increased understanding of the legal framework, and the need to seek legal advice where the health risks are potentially life threatening;
- The need for practitioners and managers to challenge and reflect upon cases through the supervision process and training;
- assessing capacity at both a decision making and executive functioning level on a decision specific basis and reassessing capacity over time.

8. PROFESSIONALS’ APPROACH IN WORKING WITH YY AND HIS FAMILY

8.1 Despite YY’s physical presentation, and the immediate pattern of not complying with treatment offered, information was never sought from the Barnet GPs to find out more about YY’s background until very late on when the continuing healthcare assessment was completed.

8.2 Instead staff relied on YY and his family for obtaining background information. One contributory factor for this was that he was articulate, and a good historian, and could recount the appointments he had missed and the reasons for the choices he made about his treatment. This was in part due to how he had experienced treatment in the past, but also from extensive research on the internet and through reading magazines.

8.3 The danger of this over-reliance on YY in compiling the history was the unreliability of the information he provided. There were many inconsistencies in the accounts provided by YY in professionals' first encounter with him which included the following variations during the early part of his stay in the RFLNHSFT:-

- he had lived with his mother for many years, and she was his main carer;
- he had been staying with his mother for about four months;
- he lived alone but could stay with his mother and sister;
- he stayed with his mother for around 5 days every week;
- he rarely left his flat and received support from his family;
- he was usually independent but had recently required help from his sister.

The therapists recorded the need to question the consistency of his story, particularly his claim that he would normally be able to manage stairs to access the bathroom. However although there was an expectation that the social worker would make further enquiries, the social worker also only relied on information provided by the family.

8.4 During YY's time in the RFLNHSFT and SJWCC, practitioners adopted a range of strategies to secure YY's co-operation, which ranged from trying to work with his preferences to build up trust, to the other extreme of trying to shock him into changing his responses by spelling out the potentially fatal consequences of his decisions. The lead consultant gave evidence at the inquest that he had been "fairly blunt", and had told YY and his family on multiple occasions that he could die as a result of his refusal. The TVN showed YY photographs of his wounds to reinforce her warnings.

8.5 To a large extent these were a repetition of the different strategies adopted by the Barnet GPs and contact with them would have provided important insights into YY's explanations for the multiple DNAs, and the different strategies the GPs had applied to try and secure his engagement with secondary care. Their efforts show considerable patience and persistence in trying to secure YY's co-operation and engagement with secondary care. Sometimes when met with resistance, they would leave it with YY to come back when he felt able to engage, but they showed persistence in trying to progress urgent investigations or address his mental health issues.

8.6 Had there been knowledge of the different responses these invoked in YY, this could have pre-empted a repeat of previous unsuccessful strategies, and led to early discussions at the RFLNHSFT to agree a common approach to be applied by all those working with him which offered the best chance of achieving the necessary change. In making this observation, it is important not to under-estimate the enormous challenges that professionals faced in working with YY.

8.7 However during his time at the RFLNHSFT and SJWCC, the various strategies adopted did not secure any lasting change, just more promises from YY that were not sustained that he would co-operate with repositioning and try to increase his oral intake. While the use of honest explanations about the possibility of death was understandable, there was a need to be aware that this approach could potentially prove counter-productive. This had been the experience of the Barnet GPs who found that putting the potential risks to YY in stark terms caused what he experienced as "mental turmoil", and the additional anxiety and agitation resulted in an unwillingness to engage. They had therefore drawn back from this approach and avoided the use of emotive terms.

- 8.8 There was evidence to suggest YY displayed a controlling personality in several respects. He would only engage with care and treatment on his terms, and he also insisted that staff did not touch, or throw away anything in his room even when the state of the room raised staff concerns about hygiene issues. There were also reports of his rudeness towards staff both in the RFLNHSFT and at SJWCC.
- 8.9 A recurring message was that considerable time and reassurance was needed to overcome his anxiety, and minimise the pain and distress when providing care or treatment. This was highlighted by the RFLNHSFT staff at the discharge planning meeting that YY was more responsive if time could be provided, and he had become easier to treat as he became more familiar with the routine and there was an opportunity to build mutual trust.
- 8.10 However, the reality was that this was unlikely to be achievable in any sustained way given the restrictions on the time that the majority of practitioners and carers would be able to devote to YY in the face of competing demands. Even where staff could put in that time, such as the 1 to 1 Hartwig Care worker, the latter reported his unhappiness about YY's rudeness on occasions even when personal care was being provided in a person centred way.

Family dynamics

- 8.11 The review identified that the relationships between YY and his family were complex, and had a significant impact on how the situation developed, and professionals' work with them. YY appeared to exercise an element of control over his mother and sister whom he would regularly ring to share his complaints about the care he was receiving. YY's distress during these contacts, and the constant articulation of his wish to return home, would have put them under enormous pressure to go along with his wishes, and the way he did this, had the potential to make them feel guilty about his situation.
- 8.12 The pressure from YY regularly resulted in his family contacting professionals to voice their complaints and take issues up on his behalf. It was likely that YY knew that they would respond in this way. An example was that prior to the professionals' meeting on 3rd May, YY's sister showed the Jewish Care social worker 3 pages of notes describing YY's experiences in the RFLNHSFT. She was advised to channel her emotions in a constructive way, and focus on the purpose of the meeting of achieving YY's discharge, and talk about the techniques the family used to manage his behaviours, and that complaints could be raised after his discharge as necessary. However, YY's sister found this hard to manage within what proved to be a tense meeting.

Impact on the Family

- 8.13 Although YY's family, and his sister in particular, outwardly supported his wish to return home, behind this stance they had difficulties of their own. His elderly mother did not enjoy good health, and had previously told some professionals that she could no longer cope with YY living with her. His sister had also disclosed that she had health problems of her own including back problems for which she was having treatment. The task of caring for YY at home, even if he accepted professional help with turning, would have created immeasurable physical and psychological demands on them. However these implications did not seem to have featured prominently in YY's approach, and he displayed little insight on the impact on them both physically and emotionally.

- 8.14 A report by the Joint Commissioning Panel for Mental Health ³² makes the observation that the burden on carers is very high, particularly where people with eating disorders are ambivalent about treatment even in the face of severe illness which are potentially life threatening. It can result in family members experiencing a mixture of distress, anger, and guilt that they should be able to do more to improve the situation. The report also explains the importance of honest and open expression of thoughts and feelings between all family members. In these situations, professionals must be ready to offer support and help to relatives and carers. However, while professionals did attempt to provide support, there is no evidence that consideration was given to carrying out formal carer assessments of their needs. This was an important oversight.

Professionals' Relationships with the Family

- 8.15 There were tensions in the relationships between the family and a number of professionals, and reflected the frustration that YY and his family felt about aspects of his care, the intended placements, and the delay in achieving discharge both from the RFLNHSFT and SJWCC. This resulted in continual complaints from YY's sister that professionals did not understand YY's needs, his wishes and feelings were not being taken into account and insufficient regard was being given to her perspectives on why YY was not responding to professionals input, or steps which could be taken to improve his situation.
- 8.16 One example related to issues she raised about the food provided at RFLNHSFT. Although on a daily basis YY's choice of food was ordered specifically for him, having being agreed with the diet chef and dietician, YY's sister's perspective was that she had provided detailed information on the food that YY liked to eat at home but that this was not reflected in the menu choices offered. Her perception of poor communication was evident in the views she shared with the voluntary agency social worker, her written complaint to the LBC Chief Executive, and her statement submitted to the Inquest.
- 8.17 Many professionals found it hard to deal with YY's sister's frustration which could be expressed in behaviour which was sometimes highly charged. The Review noted that these difficult interactions often involved more junior staff such as nurses or care staff. In contrast, there was evidence of a more respectful and conciliatory approach from YY and his family towards senior staff. This was illustrated by the family not appearing to have any significant issues about the information provided by the lead consultant and his senior colleagues at the RFLNHSFT. Their detailed explanations, including reasons for the plans proposed, meant that every decision was made in consultation with YY and his family. YY's sister also accepted the explanation provided by the Barnet CCG Lead Nurse that the time had come for YY to be re-admitted to hospital.
- 8.18 Key factors which appear to have contributed to this more acquiescent response was the perceived status of the professionals involved, and senior staff having greater experience, and training, on how to defuse tensions and build open and effective working relationships with families.

³² "Guidance for commissioners of eating disorder services" - published by the Joint Commissioning Panel for Mental Health - October 2013

Conclusions

- 8.19 In providing person centred care, professionals must ensure that at all times they try to “hear the voice” of the service user and their families. In order to achieve this, leadership from senior staff is a key factor. However, the Review found that at times, there was insufficient support for staff in helping them manage their frustration with YY’s responses and not being able to achieve an improvement in his condition. More visible leadership might also have helped to de-escalate the tensions with the family, and avoided the occasions when professionals took action without advance discussion with YY or his family such as the ambulance call out on 4th May, and the GP referral in September 2015 for a mental health assessment.
- 8.20 The Review Team’s experience is that service users and families are becoming increasingly knowledgeable about health and social care and prepared to challenge professionals – particularly more junior staff. In the hospital setting, this can be a practical consequence of families visiting in the evenings and weekends when senior staff are less likely to be on the ward. Where the interface with families is not managed well managed, tensions can quickly develop - particularly if issues are raised in a highly charged manner as happened in this case.
- 8.21 In these situations, less experienced staff may be unsure how to respond partly through a fear that families will make a complaint if they challenge the family about the manner in which issues are being raised. It can also sometimes result in professionals dismissing their complaints, and early labelling of service users and families as “difficult and “unreasonable”. If these perceptions are then passed on to other professionals, it can cloud subsequent work and decision-making, and contribute to the development of a self perpetuating cycle of difficulties in the working relationships.
- 8.22 Notwithstanding the above observations, it is essential that professionals feel able to challenge families where their wishes could have a negative impact on the care provided or plans being made. This can prove harder to do when these views are presented in a calm and rationale manner which can result in staff feeling disarmed.
- 8.23 Key learning therefore from this Review, is the importance of training in managing conflict and challenge, and the need for visible leadership from managers to support staff in problem solving complex cases. Within the hospital setting, consultants can act as key influencers. This leadership should include guidance on how to maintain a focus on working in the patients’ best interests, the importance of taking account of any relevant cultural issues, and how to manage the interface with families, and other agencies. Staff also need guidance on how to set boundaries, and explain to families that there are limits to what issues they can be expected to field where these are not directly related to their own service. Where practitioners encounter challenges from families which either they are unable, or it is not “within their remit, to resolve, they must be clear on how to escalate matters internally to senior staff.

9. ASSESSMENTS OF MENTAL CAPACITY

- 9.1 There were 18 occasions where a detailed record was made of mental capacity assessments carried out - 7 during his time in the RFLNHSFT, 10 at SJWCC, and 1 at ULCH. Of these 2 were carried out by a psychologist, and 5 by mental health practitioners.
- 9.2 The above figure does not reflect all the occasions on which YY’s capacity was assessed. The lead consultant at the RFLNHSFT explained at the inquest how the assessment of YY’s capacity was “repeated and continual”, with a formal capacity

assessment being made every time there was a key decision to be made. However, a written record was not made of every assessment carried out because it would have been unrealistic to expect nursing staff, or therapists, to record the process and outcome of these each time treatment was provided or declined.

- 9.3 Given the number of assessments, and that there needs to be grounds upon which a patient's capacity is brought into question to justify invoking the Mental Capacity Act (MCA), the Review explored why the presumption of capacity laid down in the MCA was called into question in YY's case, and the robustness of the assessments carried out.

Period at RFLNHSFT

- 9.4 The Review heard that the reason for the MCA assessments being carried out was that decisions were being arrived at by YY that carried potentially life-threatening consequences, and professionals needed to be confident that he had the ability to cognitively process the options put before him. The presumption of capacity in these circumstances was brought into question (but not pushed aside) and assessments were carried out to establish whether capacity was compromised or not.
- 9.5 The outcome of all the assessments, which also on occasions involved psychiatrist and psychologist input, was that YY did not fulfil the criteria to be deemed incapacitous. There was never any change in YY's cognition, or any doubt that he had capacity to make decisions about his care and discharge destination. Although assessments found that YY showed poor insight into how his behaviours influenced his health outcomes, this was judged not to be due to his cognitive functioning or neurological deficits, but stemmed from his anxiety and OCD tendencies.
- 9.6 The Psychologist's view from the joint assessment carried out with the Lead Consultant on 1st February was that while YY was displaying depressive symptoms in the context of his medical co-morbidities, there were no cognitive impairments. YY was able to understand the information put to him about the recommended discharge plan, and asked appropriate questions.
- 9.7 The consequence was that although YY had been consistent in expressing his firm wish to return home, he understood the explanations from clinicians that his health and care needs could not be met there in the short term, and YY accepted the plan for an interim nursing home placement which was the best option for being discharged from hospital which was his immediate aim. A further assessment by the psychologist on 8th February prior to a meeting with the family again concluded that he had capacity to participate in treatment options, and showed considerable insight but was sometimes inconsistent in communicating his wishes.

Period at SJWCC

- 9.8 When YY was at the nursing home, several professionals questioned whether YY had capacity to make decisions about his future care and discharge. These doubts were around whether he was able to understand the explanations provided about the practical difficulties he would face in managing in that environment. YY appeared to minimise these problems and often referred to how he had successfully managed his conditions at home previously. Professionals were concerned that YY was being unrealistic, and did not appear to recognise that the situation was now very different given his immobilisation and the pressure ulcers. There seemed to be little comprehension of the level of care which these conditions would require, or the risks to his recovery because it would not be possible to replicate the 24 hour care that had been available in hospital and the nursing home.

- 9.9 As a result of this, and concerns about YY's low mood, the input of mental health professionals was sought - partly to assess his mental health but also to provide a second opinion as to whether YY had the mental capacity to make decisions around his future care. The psychiatric nurse concluded from her 2 visits that YY had capacity, but this seemed to be fluctuating. She asked a psychiatrist to provide a further opinion who concluded that there was no evidence of cognitive impairment or psychosis, and YY had capacity to make decisions about where he received care. The Review identified a number of issues relating to the arrangements for these second opinion assessments of YY's capacity.
- 9.10 The effectiveness of the psychiatric nurse's assessment on 25th April was affected by the assessment being brought forward at short notice which meant it was carried out before the requested background reports had been provided, and was therefore reliant solely on a telephone briefing from the social worker on the day. This meant that the psychiatric nurse did not have the latest overview of YY's current health condition from the community health professionals overseeing YY's care such as the TVN, dietician and GP. Instead she had to rely on information provided by the nurse at the nursing home. The latter's explanation that the pressure ulcers, and YY's oral intake was improving, did not reflect the most recent clinical assessments of community health professionals.
- 9.11 Therefore the psychiatric nurse did not have an accurate context when undertaking the capacity assessment, and appeared to accept at face value YY's promises that he would eat more and co-operate with being turned - promises which had been made to other practitioners previously but with little effect. It also meant she did not have the perspectives of those health professionals on all the relevant matters which needed to be taken into account, and put to YY, on the decision about his future care needs and placement. The nursing home was not in a position to present these on their behalf.
- 9.12 Similarly when the psychiatrist provided a further opinion, the reports had still not been received, his assessment again did not take into account the first hand perspectives of other professionals. His main source of information on the day was YY's sister. The review heard that the psychiatrist was concerned that he had not received the reports. If that was the case, the assessment could have been delayed until this had been provided. This may have avoided the challenge to the psychiatrist's finding by staff within Barnet CCG and CNWL that his conclusion that YY had capacity did not take all relevant information into account.

Independent Advocacy

- 9.13 In all the MCA assessments carried out, there was no evidence that consideration was given to engaging an independent mental capacity advocate. The Review heard one perspective that the local advocacy provider would have refused support in YY's case because his family were involved, and they felt he had capacity.
- 9.14 However, in the light of the earlier analysis about the family relationships, and the personal circumstances of YY's mother and sister, there is a strong case to suggest there was a potential conflict of interest in relation to the decision to be made about his wish to return home and his capacity to understand the associated risks. In addition, the way in which the family, particularly his sister, "championed his cause" would call into question whether they would be able to take a step back and consider YY's best interests in a sufficiently detached and considered manner. There were several references to professionals commenting that they did not think YY's family understood the seriousness of YY's condition, and the life threatening implications arising from his refusal to engage with treatment.

Advance Decision to refuse treatment

- 9.15 YY's decision that resuscitation should not be attempted, was made in discussion with doctors at UCLH on the second day after admission when he was deemed to have decision-making capacity. The timing of this discussion stemmed from a professional judgement that there would be little value in administering CPR due to nature of the serious presenting medical conditions. However, although the timing and approach adopted by doctors reflected best practice, YY's family were very unhappy that they had not been involved in the process, and a major disagreement ensued.
- 9.16 It is acknowledged that it may have come as a shock to the family to discover that the provisions of the MCA meant they had no inherent right to be involved in advance decisions to refuse treatment. Their reaction is not unusual, and the lack of public awareness was reflected in the evidence given to the House of Lords Committee looking at mental capacity³³ by national carers' organisations and the organisation "Compassion in Dying". The latter's research had found that 53% of the public wrongly believed that they had the legal right to make end of life treatment decisions for their next of kin.

Conclusions and Learning

- 9.17 This analysis of mental capacity issues in this case has highlighted a number of issues which should be taken into account in managing future cases. A number of these mirror the findings in the July 21017 report commissioned by the London Safeguarding Adults Board on learning from safeguarding adults reviews.³⁴
- 9.18 The conclusion of the review carried out by the RFLNHSFT to support the Section 42 enquiry was that YY's mental capacity could have been tested more rigorously on a number of occasions by using the RFLNHSFT's two page capacity assessment form. This would also have provided consistency in the approach to assessments, and made it possible to review what had been tested, and the responses given.
- 9.19 A recurring issue throughout the case is the importance of applying all 4 parts of stage 2 of the functional test set out in the MCA Code of Practice. In YY's case, while the records usually referred to his capacity to understand and retain information about the decision to be made, and the associated consequences, it was less apparent as to whether there was sufficient focus on his capacity to "use and weigh" the information not only in making a decision, but also the ability to act on those choices to keep himself safe. As time went on, and YY became more frail, his ability to do this was likely to have become impaired.

Balancing Safeguarding and Mental Capacity Act Requirements

- 9.20 YY's case brings into sharp focus the challenges that professionals face in grappling with a fundamental principle of the MCA that "*A person is not to be treated as unable to make a decision merely because he makes an unwise decision.*"³⁵ This right to make an unwise decision is at the heart of the empowering ethos of the MCA, but poses major challenges for professionals in balancing this with their professional duty

³³ *House of Lords Select Committee on the Mental Capacity Act 2005: Report of Session 2013–14 post-legislative scrutiny published 13 March 2014*

³⁴ *Learning from SARs – A Report for the London Safeguarding Adults Board; Suzy Braye and Michael Preston-Shoot – 18th July 2017*

³⁵ *Section 1(4), Care Act 2014*

of care to keep people safe where the consequences of the decision could have serious adverse effects on a person's health, and in this case, be life threatening.

- 9.21 Moving from an approach based on safeguarding and paternalism to enablement and empowerment remains a major challenge for professionals. The House of Lords Select Committee report ³⁶ identified that

“a consistent theme was the tension between the empowerment which the Act was designed to deliver, and the tendency of professionals to use the Act for safeguarding purposes. Prevailing professional cultures of risk aversion and paternalism have inhibited the aspiration of empowerment from being realised”.

- 9.22 The House of Lords report referred to the evidence of British Psychological Society that the right to make an unwise decision runs counter to the traditional cultures in health and social care of risk aversion, and that there was still a tendency for professionals to act in a paternalistic / authoritarian fashion. The concept of best interests as defined by the Act was not well understood, in part because it was at odds with the concept of best interests in a clinical sense. In these situations, the report found that there was a risk of the best interests principle becoming a tool to justify professional decisions to safeguard people.

- 9.23 The Government's response to the House of Lords report ³⁷ acknowledged the inter-dependencies between safeguarding and the MCA, and the need for professionals to ensure the empowering ethos of the MCA is built into the safeguarding discussion. Professionals' work with YY showed that they strove hard to achieve this, but there is a possibility that in adopting an empowering approach, professionals placed too much weight on respecting YY's autonomy. As outlined in earlier sections of the analysis, there were missed opportunities to bring YY's case within the formal safeguarding arena.

- 9.24 The potential life threatening nature of YY's decisions tested professionals' efforts to the limit in ensuring the MCA principles were reflected in their approach. The ever present anxiety and frustration from their inability to secure lasting change in YY's responses is evident in the records of professionals' actions and case discussions. This was also reflected in decision made by SJWCC to send for an ambulance on 4th May without advance discussions with YY and his family, and the social workers agreeing to ask mental health specialists to provide a second opinion to make “absolutely sure” that YY had capacity to make a decision about his future care.

Commissioning of second opinions

- 9.25 The outcome of those second opinions which provided confirmation of the original assessors' conclusions that YY had capacity to make decisions about his care and placement, raises issues as to when it is appropriate to go down this route, and arrangements which need to be put in place to enable these to achieve the purpose intended. The evidence presented to the House of Lords Committee revealed that many of the criticisms raised about the way in which capacity is assessed, appear to result from assessments being carried out by professionals who are not closely involved with the care of the person affected.

³⁶ *House of Lords Select Committee on the Mental Capacity Act 2005: Report of Session 2013–14 post-legislative scrutiny published 13 March 2014*

³⁷ *Government response “Valuing Every Voice” June 2014.*

- 9.26 The report commented that this “professionalisation” of capacity assessments, conducted by those with no established link to the person concerned, had led to some requirements of the Act being more difficult to fulfil in practice, such as the need to ensure that assessments are time and decision-specific. This was picked up by the psychologist who carried out an assessment at the RFLNHSFT who recorded that while he could give his opinion, the judgement as to whether YY had capacity rested with the doctors treating him.
- 9.27 The tendency on occasions to direct requests for MCA assessment towards people who are viewed as having the required expertise because of their professional status such as doctors, psychologists and mental health professionals, often stems from other professionals not feeling equipped, or lacking confidence, to undertake capacity assessments, even through they may be best placed to do these through having the most knowledge of the service user.
- 9.28 With regard to the dissatisfaction voiced by some professionals about the outcome of the psychiatrist’s assessment at SJWCC, the Review considered this a legitimate step to take because it is important that all practitioners feel able to challenge the findings reached by other professionals regardless of any perceived imbalances in professional status. Where this occurs, it is essential that those challenged are not defensive, and do not take it personally, so that there can be open and honest discussions about the differences in professional opinion.
- 9.29 Where it is agreed that other professionals should be drawn in to give an opinion, the importance of providing full advance information is essential to assist preparation for the assessment to avoid the difficulties which arose in this case. Consideration should always be given to the possible advantages of joint assessments which will not only assist with information exchange, but also involve the professional who would be leading on any best interests decision needing to be made. This joint approach often occurred in the RFLNHSFT, but not within the community setting.

Legal Advice and Recording

- 9.30 In complex cases, where a service user is making decisions to refuse care and treatment which could be life threatening, legal advice should be sought at an early stage in order to explore the options available, and apply any advice on how to approach management of the case. In all cases, it is essential to document fully all care offered, and the service user’s response in order to provide an audit trail.

Variations in approach across agencies

- 9.31 The Review identified that one of the problems around addressing mental capacity is that wide variation in approach adopted by agencies on when, and how, assessments are carried out, and the evidence base for making professional judgements. This can create uncertainties for practitioners on how to proceed when the input of other agencies is required. It can also mean service users and families have different experiences of the assessment process if they are in contact with several agencies. The Review saw value in exploring these reported differences to see if there was scope for developing a more common approach.

10. SAFEGUARDING PROCESSES

- 10.1 The Review identified several issues on the lack of timeliness in raising safeguarding concerns, and how safeguarding processes were applied. Prior to the first safeguarding alert made on 11th March 2016, there were several missed opportunities to bring YY’s case into the formal safeguarding arena. Section 6 has previously referred to these in relation to the perceived self neglect.

Response to Discovery of Pressure Ulcers

- 10.2 The earlier narrative confirmed that clinical practice met all expected agency standards in terms of the depth and timeliness of assessments, and the treatment plans which were developed. The difficulty professionals faced was that frequently YY would not co-operate with these.
- 10.3 However, there were oversights by staff within the RFLNHSFT in not following local procedures and reporting cases when the pressure ulcers were assessed as grade 3. The review heard from the RFLNHSFT that it was not clear why a safeguarding concern was not raised before 8th March, and this was unusual given the number and severity of the pressure ulcers. The failsafe that would normally operate is that any unusual wounds should come through to the safeguarding team even if the safeguarding box is not ticked.
- 10.4 The first oversight was on transfer to the ward on 24th January. Although a Datix was completed, and a referral made to the tissue viability nurse, a safeguarding concerns forms was not completed. Safeguarding concerns were also not raised when this was judged to have deteriorated to a grade 4 on the 4th February and after the assessments on the 17th and 26th of February which found that the wound had increased in size.
- 10.5 It is possible that safeguarding concerns were not raised because staff may have assumed this had been done previously. It may have also stemmed from the fact that over time, the “accepted story” changed as to when the ulcers developed. Therefore although no detail was recorded about these until 3 days after admission, as time went on, the accepted story became that YY had a grade 3 pressure ulcer on admission which deteriorated to grade 4. Evidence of this understanding appears in the note made by the therapists that YY was admitted with sacral sores, the report considered by the SIRP on 8th March, 38 and the case conference minutes of 3rd August 2016.³⁹

Action already taken

- 10.6 The Review heard that the RFLNHSFT had already taken action to implement the learning that Datix reports should be logged for pressure ulcers which are present on admission, or which develop whilst under the care of a ward, even where staff may feel these were unavoidable. In addition, re-positioning documentation should be completed fully, particularly where patients are declining to change position. The impact of this awareness raising work is that the Trust’s safeguarding lead reported that her team is now receiving notifications immediately.
- 10.7 In addition, the RFLNHSFT’s Clinical Governance Team had recently launched the Pressure Ulcer Practice and Prevention Initiative (PUPPI). Its aim is to eradicate all grade 4 pressure ulcers, and ultimately all grade 3s, by maintaining a continual focus not just on care being provided to patients with these, but also patients with grade 2 ulcers to ensure all appropriate steps are being taken to prevent these worsening. The group carrying out these weekly reviews includes the CCG and a dedicated

³⁸ *the report considered by the SIRP on 08.03.16 stating that “the pressure ulcer was a grade 3 on admission and deteriorated to a grade 4”.*

³⁹ *the minutes of the case conference on 3rd August 2016 state “on arrival at RFLT, YY presented with grade 3 sacral pressure to the right hip and left heel - all of which hospital records state that YY acquired while living at home”.*

member of clinical governance. The cases where patients have pressure ulcers are picked up from the Datix on which every grade 1 and 2 pressure ulcer has to be reported. The Governance team follows through on each one. Reports are run off monthly, and quarterly, and reviewed by divisional directors.

The safeguarding process

- 10.8 Although a social worker was allocated to follow up the safeguarding concerns raised on 11th March, no formal safeguarding strategy meeting was held until 18th May after the safeguarding concerns were raised by UCLH and the London Ambulance Service on 12th May following YY's admission. This may have reflected the fact that since the introduction of the Care Act 2014, there is no longer a requirement to have an immediate strategy meeting. The outcome of the strategy meeting was that no further investigation was required other than gaining answers to some specific questions in relation to complaints raised by the family about YY's care at SJWCC which would be dealt with at a further meeting.
- 10.9 There was some initial concern raised by UCLH about the status of the professionals' meeting held on 23rd May as to why this had not been badged as a strategy meeting. Social Care saw the purpose of this meeting as an opportunity for UCLH staff to share their concerns, but also to hear about the safeguarding enquiries already in progress because UCLH staff had not been present on 18th May. Social Care's decision was based on the view that to avoid duplication, the UCLH and London Ambulance Service alerts should be absorbed into the existing safeguarding process.
- 10.10 UCLH's concern was that this down-played the seriousness of the concerns surrounding YY's presentation when admitted to UCLH. The UCLH perception was that there was a risk that professionals had become influenced by taking the standpoint that as YY had been deemed to have capacity, there was nothing more that could be done if he refused the care or treatment offered.
- 10.11 Following this meeting, the case was closed by Social Care until a social worker was allocated the case on 8th June 2016 to carry out a formal Section 42 safeguarding enquiry in response to YY's sister's earlier complaint to the LBC Chief Executive, and against the background of the forthcoming Inquest.
- 10.12 There was also a delay in the RFLNHSFT sending a response to the Care Quality Commission's request for information following the complaint lodged by YY's sister. Although the safeguarding lead had sent out an information request to relevant staff, this was not tracked, or followed up, when the information was not supplied. The RFLNHSFT provided assurances that the omission in this case was a "one off" oversight due to changes which were taking place within the safeguarding team.

Conclusions

- 10.13 Given the missed opportunities to bring YY's case into the formal safeguarding arena earlier, it will be important that the Safeguarding Board is assured by all agencies that they have effective quality assurance and tracking systems in place for managing safeguarding processes which are not reliant on individual initiative.
- 10.14 In examining the possible contributory factors as to why it took so long to start the formal safeguarding enquiry process, the Review identified a number of issues around the way safeguarding processes are being applied, which are creating difficulties and uncertainties for agencies. A significant challenge is that there is wide variation in the way that London boroughs are interpreting the requirements in the Care Act around application of the thresholds and timescales for Section 42 safeguarding enquiries. The RFLNHSFT referred to an audit which showed that in

one quarter it had shared safeguarding concerns to 18 boroughs all with different ways of referring safeguarding issues into the RFLNHSFT and different expectations of how these should be processed.

- 10.15 The secondary care NHS Trusts shared their perspective that many requests for them to contribute to Section 42 enquiries relate to patients already discharged, as was the case with YY. These involve a large amount of time consuming retrospective work to gather the information, and interview relevant staff. They therefore questioned how much value was gained from these retrospective investigations given that the situation had moved on, and there would be more benefits of the case being looked at in the “here and now”.
- 10.16 A contributory factor to the wide variations is that the current pan-London safeguarding procedures only provide a loose framework on timescales. There is therefore, currently, a London wide initiative to try and achieve a common approach to the section 42 threshold. This may help to address the reported uncertainty within agencies as to the value of initiating the formal safeguarding process.
- 10.17 With regard to raising safeguarding concerns about pressure ulcers, the Review heard that all the NHS Trusts involved in this case adhere to the NHS England guidance which has been adapted and applied on a pan London basis. This guidance explains that safeguarding concerns should not be raised automatically when all appropriate care has been provided, and / or the deterioration is related to self neglect. The guidance explains that other issues, rather than the grading of the pressure ulcers, should determine whether to proceed with a safeguarding referral, such as poor personal hygiene or living environment, poor nutrition and hydration.
- 10.18 While adhering to the pan London guidance, it was noted that there are variations in how individual NHS Trusts apply their own internal reporting arrangements as part of their overall quality assurance system. For example, the RFLNHSFT apply a strict policy of reporting all cases where there are hospital acquired grade 3 and 4 pressure ulcers to their Serious Incident Reporting Panel (SIRP) although not all of these will go on to be dealt with as Serious Incidents requiring further investigation and a formal report.

11. HOSPITAL DISCHARGE

The Decision to Discharge

- 11.1 The decision to discharge from the RFLNHSFT was an issue which was explored in depth within the inquest because the Coroner had initially had concerns about this when reading the initial information received about YY’s death. However, she was reassured after hearing the evidence of the lead consultant that it was a carefully planned decision. The consultant explained that given that there was nothing more that could be done for YY in hospital, discharge to a step down nursing bed, where he would receive 1 to 1 care, was seen as offering the best chance of securing YY’s co-operation in a setting which was more acceptable to him. However, it was acknowledged at time that this might not work, and YY’s condition might continue to deteriorate.
- 11.2 However, the rationale for the decision, and the possibility of further deterioration was not shared with all community professionals who became involved in YY’s care after his discharge. Although the detailed discharge summary referred to YY’s lack of engagement, there was no explicit mention of the rationale for the discharge. This initially led to the new GP having doubts about the decision, but changing her mind after reading the history of YY’s time in the RFLNHSFT in the discharge report. The

Community TVN also voiced her surprise at the discharge in her discussions with district nursing colleagues.

Discharge Planning Process

- 11.3 Although the manager of the nursing home was involved in the Discharge Planning Meeting, it did not include any other community based health professionals who would be involved in picking up YY's care. Action to transfer case responsibility to community services appears to have been initiated only very shortly before discharge, or immediately afterwards. This adversely affected the agreed plan of achieving a seamless transfer to community services to ensure continuity of care.
- 11.4 There is no record of direct liaison with the Camden GP who received the discharge summary on the day of discharge. While this reflected standard practice, direct contact might have been considered advantageous given YY's circumstances, the potential risk of further deterioration in his condition, and consequently the importance of immediate follow up in the community. This need was reflected in the urgent request made to the Camden GP by SJWCC to see YY 2 days after discharge.
- 11.5 Although the hospital TVN made a review visit in the first week, this did not match the agreed discharge plan for the community tissue viability service to provide intensive input from day 1. Their first visit was not made until 7 days after admission, and again followed an urgent referral from SJWCC because the service had not commenced. There was a 3 week gap before the community dietician made a first visit, and a 2 week delay before the community social work team were able to allocate the case and make a first visit because of pressures caused by staff holidays or sickness.

Appropriateness of the Placement

- 11.6 With the benefit of hindsight, the new SJWCC manager told the inquest that he would not have admitted YY had he been in post at the time. The Review also heard that the Barnet CCG Lead Nurse, who carried out the continuing healthcare assessment, shared her concerns about the placement, and speculated as to how much information had been given to SJWCC when they agreed to admit YY about the challenges caring for YY would pose.
- 11.7 However, at the time, there is evidence that considerable work went into planning this placement, and the SJWCC manager at the time was aware of the full picture. This is evident from his initial decision to decline the placement after carrying out an assessment, because of the high level of YY's nursing needs, and the history of non compliance. However, he reversed his decision once the arrangement for additional 1 to 1 care was agreed. As a result, there was a cautious confidence that SJWCC would be able to provide the required care with the input of health professionals.

Conclusion and Learning

- 11.8 Given the lack of seamless transfer of support in this case, a key finding is that in cases where it can be anticipated that a patient may decline care, it is important that the discharge plan sets out agreed arrangements to deliver rapid follow up. The Review heard that this has already been established as a priority by the Safeguarding Board and is being progressed through the Learning and Communications sub-group who would take into account some parallel work being undertaken by the Islington Safeguarding Adults Partnership Board. The perspectives of agencies providing community-based support will be important in taking this forward to agree how they can be involved at an early stage of discharge planning.

12. CASE CO-ORDINATION

- 12.1 It is evident that there was considerable liaison, and high levels of information sharing between professionals, which included 2 meetings with the family. However, the narrative covering the period when YY was in SJWCC, showed the challenges of co-ordinating care, and planning discharge, with 9 services being involved. Although there was a huge amount of committed input from professionals, the effectiveness of their intervention was undermined by much of their activity being disjointed.
- 12.2 Although meetings and professional liaison identified actions required, there were many instances where there was a lack of clarity on who would take responsibility for progressing matters, and the timescale. A key contributory factor was that there was never an explicit decision, and shared understanding, as to which professional would be the lead professional for co-ordinating care.
- 12.3 It was clear that the Camden GP was seen as having the lead role on overseeing YY's overall health care. This was evident from the SJWCC manager explaining at the inquest that the home was reliant on her advice. It was also reflected in the approaches made by the dietician, Barnet CCG lead nurse, and social workers asking the Camden GP to make the referral for a mental health assessment.
- 12.4 It also appears from the agency records that there was a tacit understanding that the co-ordination of YY's care, and the "direction of travel", should be routed via the LBC social worker. However, there were several instances where this did not occur, and professionals acted on their own initiative to move the case forward. One example was the TVN contact with the district nurses and OTs to prepare for YY's possible return home.
- 12.5 A further issue around co-ordination was that as the case developed during YY's time at SJWCC, there appears to have been some blurring of the boundaries of the roles of the LBC and voluntary agency social worker. The latter was originally involved to provide advocacy support for YY and the family, but at times appeared to take on a more pro-active case management role alongside the LBC worker, or during the latter's holiday.

Provider Joint Working Arrangements

- 12.6 From the outset, there were problems in the working relationship between SJWCC staff and the Hartwig Care carer in implementing the agreement that they would work together to ensure 2 staff carried out repositioning. Both agencies complained about the non availability of the other's carer when required. The alleged frequent unavailability of a SJWCC worker to assist with turning, resulted in the unsafe practice of the Hartwig carer sometimes attempting to turn YY unaided. However, although the difficulties were apparent from day one, the issue was not addressed until the professionals meeting on 10th May, 2 months after admission, when it was agreed that there would be an urgent meeting the following day to resolve this.
- 12.7 The problems about the working relationship may have stemmed from the Hartwig Care input only being commissioned 2 days before the service commenced, leaving little time for any advance discussions as to how the arrangements were to be put into practice. In addition, the Review heard the Hartwig Care perspective that they did not receive full information about the complexity of SL's case, and more direct involvement in planning for YY's care would have been beneficial. It was also pointed out that any difficulties in delivering the care specified has contractual implications.

- 12.8 More direct involvement at the planning stage would have provided the opportunity to sort out any issues relating to the role of the home carer, and may have avoided the situation which led to the formal complaint being lodged by Social Care that the Hartwig carer had not maintained neutrality in the discussions about planning for YY's discharge, and YY's decision not to go to hospital on 4th May.

Other Commissioning Issues

- 12.9 The discharge planning meeting had identified that discharge would be dependent on a special mattress being ordered for SJWCC. However SJWCC said their standard mattress was suitable and claimed that the TVN had endorsed this. The subsequent long running saga related to the complaints by YY and his family that this needed to be changed, proved a major distraction. This was because the mattress became the focus for YY's explanations for not complying with repositioning and not eating due to the pain the mattress caused him. The drift in resolving this issue made it hard for professionals to challenge him over his non co-operation during this period. As it was, the change of mattress made no difference because YY continued to place a duvet over it thus eliminating any possible benefit.
- 12.10 There was similar confusion over the TVN's attempts to secure provision of a Toto turning platform which remained unresolved. Again, the drift stemmed from the new SJWCC manager not being aware of what had been agreed previously, and as with the mattress issue, differences of opinion as to which agency had responsibility for funding this.

Conclusions and Learning

- 12.11 Although there was a huge amount of committed input from professionals, the effectiveness of their intervention was undermined by much of their activity being disjointed. The analysis leads to the following learning for the management of future cases. First is the need for early agreement between agencies as to who will be the lead professional for co-ordinating care. Where leadership is to be shared for co-ordinating different aspects of care, this needs to be explicit and shared with other agencies involved so that communication channels are understood. Second, where there are 2 or more care providers involved, the commissioning process should ensure that the joint working arrangements are in place at the outset, and that there is a system for checking that these are working as intended;
- 12.12 The Review also identified that it would be important to explore what steps could be taken to strengthen GP involvement in safeguarding, and case co-ordination. These might include looking at how best use can be made of the role of care navigators within GP practices who have a role in brokering services to meet patients' assessed needs.
- 12.13 It was also agreed that there may be scope to make use of EMIS codes in the GP Patient records system to place a "flag" on a patient record to quickly enable staff to identify where someone is considered to be "at risk" which would assist in cases receiving the right priority response.⁴⁰This "flag" would be reviewed at least once a year. A flag could also be used to indicate where someone is a carer. However, it is important to add a cautionary note that if the flag system is applied too liberally, it will dilute its effectiveness because the high risk cases would no longer be immediately apparent on the system.

⁴⁰ *EMIS is an electronic patient records system used by many GP Practices. The EMIS codes are used to classify different types of information such as social circumstances; ethnicity and religion; clinical signs, symptoms and observations; laboratory tests and results; diagnoses; diagnostic, therapeutic or surgical procedures performed;*

13. ESCALATING CONCERNS

- 13.1 During the review, the Barnet GP acknowledged that when their concerns increased, and their strategies had not achieved a change in YY's responses, they should have considered escalating the case so that it was discussed in a multi-agency setting. Possible points when this could have been considered might have been when YY did not engage with the urgent need for investigation of possible colorectal cancer, or either of the occasions when he cancelled the mental health appointment. However, the Barnet GPs were unsure of how, and where, to escalate their concerns. This lack of knowledge reflects that some GP practices are not sufficiently connected to the local multi agency network.
- 13.2 At the RFLNHSFT, there was evidence of staff raising their concerns with senior medical and nursing staff, which resulted in continuing efforts to achieve a breakthrough in gaining YY's engagement through the leadership of the lead consultant, the involvement of the complex management team, and the many MDT meetings. This reflected the clear arrangements at the RFLNHSFT for handling the small number of very complex cases which have similar features to those in YY's case. However, the Review agreed that when there were internal discussions to explore the option of compulsory treatment, this could have been the trigger for convening a multi-agency meeting where agencies could have brought to bear their different expertise in handling high risk cases.
- 13.3 The structured approach within the RFLNHST was less evident in how community based professionals responded to their increasing concerns when YY was at SJWCC, and there were missed opportunities to escalate YY's case to senior managers, seek the advice of agency safeguarding leads, or refer the case for consideration within the existing multi agency arrangements for considering high risk cases.
- 13.4 The apparent lack of management involvement in YY's case was surprising given the high level of risk, and the extent to which professionals' were struggling in achieving change. The only reference to line management input on the social care files was the team leader recording that the case would be raised with a senior manager if there was a further delay to the continuing healthcare assessment. Nor was there any reference to management input from the owners of SJWCC, the TVN, and dietician services.
- 13.5 The only evidence of more senior staff involvement came quite late on. The LBC QA and Quality Assurance Manager was drawn in to resolve the delay in securing a replacement mattress, and then engaged with the social worker's uncertainty as to whether SJWCC remained an appropriate placement given YY's complex care needs, and the increasing tensions between the nursing home and the family. The Lead Nurse from Barnet CCG, pursued her concerns from the continuing healthcare assessment, to press the GP to commission an urgent mental health assessment, and to seek the GP's views as to whether the time had come for re-admission to hospital.
- 13.6 There were a number of points while YY was at SJWCC where his case might have been escalated both within agencies, and through a high level multi agency approach. Key points where this could have been considered include:-
- after the GP's initial visit on 11th March when YY was observed to be emaciated and was already not complying with the care offered;

- on receipt of any of the weekly reports sent by the Hartwig Care manager to Social Care which referred to YY declining personal care, his poor oral intake and continuing loss of weight;
 - the TVN's second visit on 24th March when she found no change in YY's response following her original advice around oral intake and repositioning;
 - the professionals meeting of 20th April when information was again shared that if there was no change in YY's responses, the consequences could be life threatening.
- 13.7 The dietician did escalate her concerns following this meeting by contacting the Camden GP to ask that an urgent mental health assessment be commissioned. However the GP did not appear to act on this immediately but waited to see if YY acted on his previous assurances that he would increase his oral intake. In the meantime, the dietician made direct contact with the mental health service.
- 13.8 The challenges from senior staff in Barnet CCG, and CNWL to the validity of the psychiatrist's assessment of 5th May resulted in several professionals sharing their thinking about the possible value of holding another multi disciplinary team meeting. However, the records of those conversations reveal a lack of shared understanding and agreement as to who would take responsibility for convening this, who should be invited, and what the objective of such a meeting would be.
- 13.9 The uncertainty about how to escalate concerns, and who held the lead role for co-ordinating care, may have been a contributory factor to SJWCC unilaterally sending for an ambulance on 4th and 10th May. It is clear from the evidence given by the SJWCC manager at the inquest was that there was a fear there that they would be blamed if YY became seriously ill.

Conclusions and Learning

- 13.10 The analysis would suggest that some professionals were not clear as to when and how to escalate their concerns internally, or with partner agencies, and that care plans did not routinely include agreed crisis and contingency arrangements. A contributory factor appeared to be that Camden does not have a multi-agency framework around challenge and escalation.
- 13.11 It was agreed that developing a protocol and supporting procedures should be a priority. This would include clear processes on when and how professionals should escalate cases, and would provide endorsement of the value and legitimacy of challenging the actions of others. There will be advantages in the same framework being adopted by both the adults and children's safeguarding boards as this will provide consistency for those professionals who work across all age ranges.
- 13.12 The multi agency framework should also clarify the arrangements for a forum where complex and high risk cases can be considered. Potential triggers for referring cases might include:-
- where it is proving difficult to engage the service user and there are serious concerns around health and well-being which require an immediate response;
 - uncertainty arising from assessments as to whether a person has mental capacity;
 - where compulsory treatment under the Mental Health Act, or other enforcement action, may need to be considered;

- 13.13 The Review heard that there is already a “High Risk Panel” but this was not well known across agencies, and very few cases were being referred. At present there is a review of the terms of reference taking place, which will provide an opportunity for the findings from this SAR to be taken into account in finalising the revised arrangements.
- 13.14 The multi agency framework will need to be complemented by individual agencies having arrangements in place on how cases should be escalated internally. The Review heard that the RFLNHSFT have clear arrangements in place which have been strengthened further by involving the safeguarding lead at a very early stage. Similarly, ULCH are considering adopting the Southampton model for managing complex cases which involves a core group of professionals.

14. FINAL CONCLUSIONS

- 14.1 The Review has shown that YY had been struggling for many years with his many debilitating long term conditions, which not only caused him considerable pain and physical problems, but also high levels of anxiety about the symptoms he was experiencing and the fear that these could get worse. These contributed to YY experiencing periods of depression when he was uncertain whether he could carry on. He was frequently tired, had difficulty moving about his accommodation, and rarely went out. This was one factor he cited for not attending medical appointments.
- 14.2 YY had however developed strategies which had allowed him to just about cope within his home environment. However, some of these such as his restrictive diet, his avoidance of most analgesics, and decisions not to follow the Barnet GPs’ advice or attend secondary care investigations, only served to further compound some of his health problems. It became a cycle which both he, and professionals found difficult to break. Over many years, YY had an enormous amount of input from clinicians and other professionals who were persistent in their efforts to try and improve his health and well-being, but sadly all too often with little effect.
- 14.3 It was against this background of YY struggling to maintain his independence that YY suffered the fracture which resulted in his hospitalisation for several weeks. The necessary immobilisation, the number of assessments he had to undergo, and the large number of staff involved in his care in unfamiliar surroundings all added to his already high levels of anxiety. These made it even harder for him to change his established pattern of behaviours and engage with the care and treatment required to secure his recovery. This contributed to the development and deterioration of pressure ulcers and his decisions not to comply with advice to increase his oral intake, or agree to turning, resulted in further deterioration during his time in hospital and subsequently the nursing home. When YY was admitted to ULCH with acute sepsis, the pressure ulcers, malnutrition and dehydration were identified as being contributing factors. Sadly, despite the hospital’s best efforts, his condition could not be reversed.
- 14.4 The Review has shown that YY’s death was predictable, and the potentially fatal consequences of his decisions were explained to him on several occasions. Although he stated he did not want to die, he was unable to act on advice from professionals and his pattern of behaviour continued. As to whether YY’s death was preventable, the Review heard different perspectives. One perspective was that even if a formal safeguarding process had been commenced at an earlier stage, this would have been unlikely to have affected the subsequent case planning because all the appropriate care was already being offered or provided.

- 14.5 However, there was also the perspective that it is possible that there might have been a different outcome if a referral had been made to a specialist eating disorder service when efforts to get YY to increase his oral intake proved unsuccessful. While the specialist service would also have faced challenges in treating the disorder given the long standing anxiety and obsessive compulsive behaviours around his diet, their experience may have resulted in more focused consideration of whether a formal assessment should be carried out under the Mental Health Act to establish if the criteria were met for compulsory admission for assessment or treatment

15. **SUMMARY OF KEY FINDINGS AND ACTIONS TO IMPLEMENT THE LEARNING**

- 15.1 This section summarises the key findings from the SAR. Appendix 1 lists the proposed priority actions identified by the Review Team to implement the learning in respect of each finding which are reflected in the recommendations. and will be translated into a formal Action Plan to be led and monitored by CSAPB.

Self Neglect

- 15.2 The missed opportunities throughout the time period under review to raise safeguarding concerns indicates that professionals were uncertain on how to recognise and respond to signs of self neglect. Professionals did not appear to recognise the importance of gathering a full history from other agencies, as well as probing YY's own accounts, to gain insights into the root causes of the symptoms in order to inform development of an appropriate plan.
- 15.3 There was not always sufficient acknowledgement of the impact of self neglect on family members, and the vital role they can play in working with professionals to promote the honest and open relationships which are an important ingredient for challenging harmful behaviours. There was no evidence that carer assessments were offered which would have an important element of providing support for their needs, and securing their engagement.

Safeguarding Processes

- 15.4 The missed opportunities to raise safeguarding concerns either in respect of self neglect, or the worsening pressure ulcers, meant that the appropriate formal enquiries were not made at an early enough stage which might have led to the development of a protection plan if this was deemed necessary.
- 15.5 The Review heard that professionals are sometimes uncertain about when safeguarding concerns should be raised, or their contribution to safeguarding enquiries which are initiated. This is a particular challenge for agencies such as the police and NHS Trusts who interface with many local authorities who have varying approaches to safeguarding. The Review also highlighted how GPs are often not sufficiently integrated into local safeguarding arrangements.

Mental Capacity

- 15.6 Although the many capacity assessments carried out concluded that YY had capacity, there was insufficient consideration of whether YY might be experiencing fluctuating capacity, and whether this was affected by a low BMI. Some professionals did harbour doubts as to whether YY had capacity when decisions needed to be made about his future care when he was at the nursing home, but appeared to lack confidence in their own judgements. The process around the preparation and conduct of some of the second opinion assessments sought, affected their effectiveness and value.

Case Planning and Co-ordination

- 15.7 The lack of co-ordination of the multi-agency involvement when YY was in the nursing home, and absence of advance contingency planning, resulted in disjointed interventions and uncertainty about how to respond when the situation did not improve. In exploring the reasons for this, the Review noted that in cases which are managed within the formal safeguarding processes, the protection plan will normally include arrangements for co-ordinating action. However, for cases which sit outside the safeguarding arena, the arrangements were less clear.

Hospital Discharge Planning

- 15.8 The discharge planning arrangements resulted in a lack of continuity of care through the delays which occurred before community-based professionals became actively involved.

Escalation of Concerns

- 15.9 There were several points during YY's time in the nursing home where professionals could have escalated their concerns about the increasing risks to his health, and their inability to secure a change in his response. The fact that a professionals meeting was not held until 2 months after his admission suggests that professionals either did not see the need to raise the situation with more senior managers, or were unclear how to raise their escalate their concerns, either internally, or with partner agencies.

Leadership

- 15.10 The Review findings re-affirm that leadership is an essential component in enabling staff to maintain a focus on working in the patients' best interests, and problem solving the management of complex cases. However, although this was apparent within RFLT, once YY moved to the nursing home, there was little evidence of managers providing support to staff with case planning, or to assist in mediating difficulties which arose in the relationships with YY's family.

16. RECOMMENDATIONS

- 16.1. Camden Safeguarding Adults Partnership Board (CSAPB) should develop a multi-agency toolkit which provides systems, processes and guidance to support professionals in recognising and responding to situations involving self neglect. This should be supplemented by multi-agency training to enable professionals to develop the required knowledge and skills;
- 16.2. CSAPB should seek assurance from agencies that:-
- they have quality assurance systems in place to ensure that where professionals have made a decision that a safeguarding concern should be raised, this is actioned and followed up;
 - relevant national and local clinical and safeguarding guidance is applied in reaching decisions on reporting the existence of pressure ulcers either through their internal serious incident reporting procedures and / or by raising a safeguarding concern through the multi-agency safeguarding procedures.

- 16.3. CSAPB should seek assurance from agencies that staff make use of national guidance issued by the National Institute for Health and Care Excellence (NICE) on the recognition and treatment of eating disorders, and are aware of the local referral pathways to access specialist eating disorder services.
- 16.4 CSAPB should explore methods of collecting qualitative data regarding the local application of the Mental Capacity Act 2005, taking into account information from all agencies on how they quality assure their organisation's work, and the results of their most recent audit.
- 16.5 CSAPB should develop a multi-agency protocol for escalation and challenge for safeguarding matters, which should include arrangements for forums where cases can be considered according to their assessed level of risk.
- 16.6 CSAPB should request agencies to review the composition, terms of reference, and referral process of the existing multi-agency high risk panel to ensure the necessary level of seniority in the core membership, and the involvement of other professionals as necessary depending on the nature of the risk of cases referred.
- 16.7 CSAPB should seek assurance that hospital discharge processes achieve a shared agreement with community based professionals on the arrangements for co-ordinating care post discharge, in order to ensure continuity of care and a rapid response where it is anticipated that a service user may decline care.
- 16.8 CSAPB should seek assurance from the CCG of arrangements in place to ensure appropriate levels of GP engagement in multi-agency work to safeguard adults.

APPENDIX 1: PRIORITY ACTIONS TO IMPLEMENT THE LEARNING

Review Finding	Priority Actions
Self Neglect	
<p>There were missed opportunities to raise a safeguarding concern about possible self neglect, and to refer YY to a specialist eating disorder service. This reflected a lack of knowledge about the referral pathways and the triggers which warranted an urgent assessment and possible hospital admission.</p> <p>There was not always sufficient acknowledgement of the impact of self neglect on family members, and carer assessments were not offered.</p>	<p>To develop a multi-agency self neglect toolkit which will provide robust systems and processes to support staff include guidance on definitions, identification, prevention, thresholds for intervention and timescales. It could also include guidance on a number of key issues which featured in this case:-</p> <ul style="list-style-type: none"> - the need to apply “professional curiosity” and probe accounts provided by service users and their families to gather full information to inform case planning; - the ethical issues that can arise in achieving a balance between safeguarding service users, and their right to self determination; - the need to make use of NICE guidance in responding to indications of eating disorders and OCD behaviours; - the impact of eating disorders, and a low BMI, on mental capacity; - the pathways to access specialist eating disorder services, and triggers for considering when a referral should be made; - the legal framework, and the possible legal options which should be considered when service users refuse to engage with treatment and the consequences could be life threatening; <ul style="list-style-type: none"> - how to initiate a formal assessment under the Mental Health Act, the process that a formal assessment involves, and the importance of using the correct terminology so that it is clear what kind of assessment is being requested and why. -
Safeguarding	
<p>Missed opportunities to raise safeguarding concerns either in respect of self neglect, or the worsening pressure ulcers.</p>	<p>CSAPB should also seek confirmation from agencies that their quality assurance processes ensure that decisions on whether to raise a safeguarding concern are made promptly, and take account of relevant national guidance.</p>
<p>Uncertainty about when safeguarding concerns should be raised, or their contribution to safeguarding enquiries which are initiated.</p>	<p>CSAPB should use the learning from this SAR to contribute to the pan London work on developing a common approach to applying safeguarding thresholds, timescales and processes.</p>
<p>GPs are often not sufficiently integrated into local safeguarding arrangements.</p>	<p>CSAPB will also explore methods to secure increased GP engagement in local safeguarding arrangements, which could include a greater role for the existing care navigators within GP Practices, and holding more case conferences in GP surgeries.</p>

Review Finding	Priority Actions
Mental Capacity	
<p>Mental capacity assessments were not always sufficiently robust, and there was insufficient consideration of possibility of fluctuating capacity, and whether this was affected by a low BMI.</p> <p>Some professionals appeared to lack confidence in their own judgements when carrying out MCA assessments.</p> <p>The process around the preparation and conduct of some of the second opinion assessments sought, affected their effectiveness and value.</p>	<p>All agencies should carry out an audit of their arrangements and practice around mental capacity assessments, and share the findings with CSAPB including their arrangements for ongoing scrutiny of the quality of their MCA work. This should have a particular focus on the approach adopted by professionals in managing complex cases, including those where fluctuating capacity may be an issue.</p>
Hospital Discharge Planning	
<p>Discharge planning arrangements resulted in a lack of continuity of care because of delays before community-based professionals became actively involved.</p>	<p>A multi agency review of hospital discharge planning should be carried out to ensure that at the point of discharge, there are agreed arrangements for a rapid response where it is anticipated that a service user may decline care. These arrangements, and agreed agency responsibilities for co-ordination of post discharge care, should be specified in the hospital discharge summary, including the responsibility for procuring and funding any equipment required.</p>
Case Planning and Co-ordination	
<p>After YY moved to the nursing home, there was a lack of co-ordination of multi-agency involvement, insufficient advance contingency planning, and little evidence of managers providing support to staff with case planning, or to assist in mediating difficulties which arose in the relationships with YY's family.</p>	<p>The self neglect toolkit should include templates for care plans which set out arrangements for co-ordinating care, including allocation of responsibilities within a shared care plan.</p> <p>CASPB should request all agencies to review their arrangements and provide information on how they ensure that managers and senior clinicians exercise their leadership role effectively.</p>
<p>There were recurring problems in implementing the joint working arrangements between the nursing home and the home care agency to provide additional support which created the potential for unsafe working practices when providing care.</p>	<p>Commissioners should review their commissioning arrangements to ensure that the joint working arrangements are agreed at the outset, these are included within the contract, and there is a system for checking that these are working as intended.</p>

Review Finding	Priority Actions
Escalation and Challenge	
<p>The missed opportunities to escalate concerns about the increasing risks to YY’s health, and inability to secure a change in his response suggest that some professionals are uncertain about how and when this should be done either internally, or with partner agencies. .</p>	<p>CASPB will adopt a multi-agency protocol on escalation and challenge. This will provide clarity on triggers for escalating cases where there are safeguarding issues which are deemed to be high risk, and / or where professionals are not satisfied with decisions made by other agencies. The protocol will provide a clear endorsement of the legitimacy of agencies raising appropriate challenges to the actions and decisions of others.</p> <p>CASPB should explore with the Camden Children’s Safeguarding Board the possibility of adopting the same general approach to escalation in order to provide consistency for those professionals who work with individuals across the lifespan.</p> <p>To complement the multi-agency protocol, all agencies should ensure that they clear procedures for escalating cases within their own agencies, and staff are aware of when these should be applied.</p>
<p>Although Camden had in place a multi-agency high risk panel for considering such cases, the referral process and criteria were not well publicised.</p>	<p>CSAPB should request agencies to review the composition, terms of reference, and referral process of the existing multi-agency high risk panel to ensure the necessary level of seniority in the core membership, and the involvement of other professionals as necessary depending on the nature of the risk of cases referred.</p> <p>For cases which do not meet the threshold for the high risk panel, CSAPB should check that agencies have identified other multi agency forums where cases can be considered according to the perceived level of risk. Work to take this forward might include identifying existing forums which might be the vehicle for considering cases where concerns are beginning to appear.</p>

APPENDIX 2: EXTRACT FROM THE SAR TERMS OF REFERENCE

SPECIFIC ISSUES TO BE CONSIDERED THROUGH THE SAR

Quality of Assessments and Delivery of Person-Centred Care

- 11.1 In relation to YY's stay in Royal Free Hospital, St John's Wood Care Centre, and University College London Hospital:-
- 11.1.1 To what extent did agencies / professionals seek, and make use of, historical information about YY's medical conditions, and his previous responses to professional advice provided, and proposed care / treatment plans?
 - 11.1.2 Were all appropriate assessments, tests and treatments commissioned, and carried out promptly, to address YY's health needs, including the pressure sores, and concerns about his oral intake?
 - 11.1.3 How was YY's overall medical condition, and weight, monitored, and was there sufficient focus on the overall deterioration in YY's physical condition?
 - 11.1.4 Was information shared promptly with all relevant professionals / agencies about YY's frequent refusal of advice / care offered, and the perceived impact on his health and weight?

YY's Reluctance to Act on Professional Advice or Decline Care Offered

- 11.2 In relation to YY's care and treatment, including that related to the pressure sores, improving his oral intake, and pain management:-
- 11.2.1 What strategies did professionals adopt in trying to get YY to act on advice and plans?
 - 11.2.2 What factors, and strategies, appeared to be influential on the occasions when YY's co-operation was achieved?
 - 11.2.3 How did his refusal to act on advice, or accept the care offered, affect professionals' subsequent approach?
 - 11.2.4 To what extent was YY, and his family, involved in discussions about the options and proposed solutions to address his condition, and their wishes taken into account?
 - 11.2.5 How did professionals approach working with YY, and his family, to explain the consequences, and potentially fatal risks for YY, stemming from his decisions to decline to follow advice or refuse aspects of the care offered?
 - 11.2.6 What consideration was given on the possible impact of family relationships, and their views, on YY's decisions?

Mental Capacity and Mental Health Assessments

11.3 In relation to assessing YY's mental capacity, and mental health:-

- 11.3.1 Were MCA assessments carried out at all appropriate points when there was a decision to be made about YY's care and / or treatment?
- 11.3.2 How robust was the assessment process, and to what extent were other agencies, and family members, involved;
- 11.3.3 What was the evidence to support the assessment conclusions that YY had capacity?
- 11.3.4 How, and to what extent, was information regarding YY's mental health, and any formal diagnoses, taken into account to inform MCA assessments?
- 11.3.5 Did mental health and psychology assessments seek, and take into account, historical information to provide a broader context to the assessment of him in his placement at the time?

Hospital Discharge / Continuity of Care / Rehabilitation Plan

11.4 In relation to the decision to discharge YY from Royal Free Hospital on 9th March 2016, to a step down nursing bed at St John's Wood Care Centre (nursing home):-

- 11.4.1 What was the rationale for the rehabilitation plan, and how realistic was this? What degree of influence did the views of YY, and his family, have on the plans made?
- 11.4.2 Was YY medically fit for discharge given the pressure sores had worsened and been assessed as grade 4?
- 11.4.3 Was the timing appropriate for YY to be discharged immediately after a safeguarding alert had been raised?
- 11.4.4 Was full information shared about YY's health, and response to treatment during his hospital stay,
- 11.4.5 Were all required services arranged prior to discharge to ensure continuity of care?
- 11.4.6 Was adult social care the right agency to take the task on of organising an assessment of YY's eligibility for continuing healthcare, or should this have been fast-tracked by the Royal Free Hospital?
- 11.4.7 How timely was the response of community services following YY's admission to St John's Wood Care Centre?

Escalation of Concerns

- 11.5 In the light of the deterioration in YY's medical condition, and increased risks arising from YY's frequent decisions not to follow professional advice:-
- 11.5.1 What consideration was given, or action taken, to escalate concerns about the risks?
 - 11.5.2 What multi agency discussions took place, and did these include all appropriate agencies either currently, or previously, involved;
 - 11.5.3 Was consideration given to seeking legal advice as part of any escalation process, and if so what was the outcome?
 - 11.5.4 Would YY's case have met the criteria for consideration by the "High Risk" panel, and was this a step considered?

Assessments carried out by London Ambulance Service

- 11.6. In relation to the visits made by the London Ambulance Service on 4th May, 11th May, and 12th May 2016:-
- 11.6.1 What information did they LAS staff have, or receive, during their assessments?
 - 11.6.2 What were the reasons for decisions made, and were the outcomes in line with their assessments of YY's needs?
 - 11.6.3 Was consideration given to consulting / involving other health professionals, when YY declined to go to hospital?

Safeguarding processes

- 11.7 How effectively did the safeguarding processes address the concerns raised, and were there clear outcomes?
- 11.7.1 Were safeguarding alerts raised promptly in line with single, and multi agency procedures? If not, what was the reason for any omissions?
 - 11.7.2 Was all relevant information considered, and given due weight, in the subsequent safeguarding processes?
 - 11.7.3 Was there appropriate involvement of family members, and all agencies, who were, or had, been providing services to YY?
 - 11.7.4 How robust and effective were the safeguarding meetings in investigating the issue of whether YY's needs were neglected during his time in RFH and SJWCC?
 - 11.7.5 Were the safeguarding processes, and any follow up actions, clear and well co-ordinated?

Learning from Previous SARs

- 11.8 What evidence is there relevant learning from previous SARs carried out locally or nationally, has been embedded in the approach adopted by agencies and professional practice.