Manchester Safeguarding Partnership

Safeguarding Adult Review

'Johnny'

This report was commissioned and prepared on behalf of the Manchester Safeguarding Partnership

Independent Reviewer: David Mellor

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Safeguarding Adults Review (SAR) – Johnny

Contents	Page number
Introduction	3
Terms of Reference	4-5
Glossary	6-9
Synopsis	10-37
Views of Johnny's family and friends	38-40
Analysis	41-62
Findings	63-70
References	71-72
Appendix A	73-74

1.0 Introduction

1.1 Johnny died in hospital in January 2018. He was 67 years of age. He had complex physical and mental health needs. He was entitled to Section 117 Mental Health Act aftercare having previously been detained under that Act. He had been supported to live as independently as possible in his own property which was situated in a neighbouring local authority area. When these arrangements came under strain he began to be repeatedly admitted to hospital until he agreed to a nursing home placement in the Manchester City Council area a little over a year prior to his death. Johnny never settled in this placement and repeatedly asked to leave. Opportunities to review his placement were not taken and in the months prior to his death, several safeguarding concerns were raised.

1.2 The then Manchester Safeguarding Adults Board (now Manchester Safeguarding Partnership) decided to undertake a safeguarding adults review (SAR) on the grounds that neglect may have been a contributory factor in Johnny's death and there were concerns that partner agencies could have worked together more effectively to protect Johnny. A description of the process by which this SAR was conducted is shown at Appendix A.

1.3 David Mellor was appointed as lead reviewer for the SAR. He is a retired chief officer of police and has eight years experience of conducting statutory reviews. He has no connection to any agency in Manchester. He chaired the Panel established to oversee the SAR. Membership of the SAR Panel is also shown at Appendix A.

1.4 An inquest will be held in due course.

1.5 Manchester Safeguarding Partnership wishes to express sincere condolences to the family and friends of Johnny.

2.0 Terms of reference

2.1 The timeframe of the review is from 1st March 2016 to 14th January 2018. Significant events which took place prior to March 2016 were also included.

2.2 The key areas of focus for the review are:

- How effectively were Johnny's physical and mental health needs assessed and addressed, whilst being supported to live in the community, during his hospital admissions and during his placement in Nursing and Residential Care Home 1?

- How effectively did practitioners respond to Johnny's apparent self-neglecting behaviour, including declining food, fluids and medication?

- Was Johnny's voice listened to? Were the reasons for his behaviour adequately explored?

- How appropriate was Johnny's placement in Nursing and Residential Care Home 1? Was the placement considered likely to meet his needs? Were placements in the neighbouring authority area (in which Johnny lived) fully considered?

- Did Johnny consent to his placement in Nursing and Residential Care Home 1? Was his mental capacity to decide to move into residential care and to choose a placement destination assessed?

- When Johnny began to object to his placement in Nursing and Residential Care Home 1, what action was taken in response? Were the Deprivation of Liberty Safeguards correctly applied?

- How well was the standard of care and support provided to residents of Nursing and Residential Care Home 1 monitored by Manchester City Council's Quality and Contracts team and by the commissioners of Johnny's placement there (Greater Manchester Mental Health NHS Foundation Trust/ the neighbouring local authority)?

- Given that Johnny had been placed in out of area residential care, how effective were the 'cross border' issues which arose addressed?

- How effectively were the series of adult safeguarding concerns raised in respect of Johnny in the months prior to his death dealt with?

- How were decisions taken in respect of end of life care for Johnny? Was an adequate legal framework in place? Was the Mental Capacity Act correctly applied? Was Johnny's family consulted?

- When concerns arose over the care and support provided to Johnny and/or the decisions taken in respect of Johnny, were concerns effectively escalated and was there sufficient professional challenge?

- To what extent did what was described as Johnny's challenging behaviour result in unhelpful assumptions being made about him which adversely affected the care and support provided to him?

- How effective was care planning and care co-ordination for Johnny?

- How effective was multi-agency working in respect of Johnny?

3.0 Glossary

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

Best Interests Assessors (BIA) are the key decision makers in respect of Deprivation of Liberty Safeguards (DoLS). They meet the person assessed under DoLS, consider their ability to make decisions about their lives and the necessity for the restrictions they live under. They work with the person, their family and friends, the staff in the relevant care home or hospital, those making their ongoing care decisions, psychiatrists and advocates. The BIA role is designed to offer an independent, professional critique of the care and treatment of those subject to restrictive care plans under DoLS.

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

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

- deciding whether someone has the mental capacity to make a particular decision for themselves
- appointing deputies to make ongoing decisions for people who lack mental capacity
- giving people permission to make one-off decisions on behalf of someone else who lacks mental capacity
- handling urgent or emergency applications where a decision must be made on behalf of someone else without delay
- making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration
- considering applications to make statutory wills or gifts
- making decisions about when someone can be deprived of their liberty under the Mental Capacity Act

Do not attempt cardiopulmonary resuscitation (DNACPR) Cardiopulmonary resuscitation (CPR) is a treatment that attempts to start breathing and blood flow in people who have stopped breathing (respiratory arrest) or whose heart has stopped beating (cardiac arrest). Everyone has the right to refuse CPR if they wish. People can make it clear to their medical team that they do not want to have CPR if they

stop breathing or their heart stops beating. Once a DNACPR decision is made, it is placed in the person's medical records, usually on a special form that health professionals recognise.

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

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

There are distinct differences between an IMCA and an Independent Advocate, introduced under the Care Act. Independent advocates cannot undertake advocacy services under the Mental Capacity Act, however where there is an appointed IMCA they may also take on the role of Independent Advocate under the Care Act.
The Local Authority must arrange an Independent Advocate to facilitate the involvement of a person in their assessments, preparation and review of their care and support plans and through safeguarding adult enquiries and reviews under the Care Act 2014 if they consider that the person would experience substantial difficulty in understanding the processes or in communicating their views, wishes or feelings and there is no appropriate individual to help them.

Independent Care Act Advocacy may be needed for assessments, care planning and review processes, and/or cases of a safeguarding enquiry or Safeguarding Adults Reviews.

Inherent jurisdiction is a doctrine of the English common law that a superior court has the jurisdiction to hear any matter that comes before it, unless a statute or rule limits that authority or grants exclusive jurisdiction to some other court or

tribunal. The High Court has gradually extended the use of the inherent jurisdiction to vulnerable adults who possess capacity but still require protection for certain reasons. The aim of the High Court in such cases is to prevent the circumstances within which an adult might not be able to exercise a free choice at some point in the future.

NHS continuing healthcare (CHC) is a package of care provided outside of hospital that is arranged and funded solely by the NHS for individuals aged 18 years and older who have significant ongoing healthcare needs. When someone is assessed as eligible for CHC, the NHS is responsible for funding the full package of health and social care. In 2015-16, almost 160,000 people received, or were assessed as eligible for, CHC funding during the year, at a cost of £3.1 billion. (1)

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

Mental Capacity Act (MCA): The Mental Capacity Act 2005 provides a statutory framework to empower and protect people who may lack capacity to make decisions for themselves and establishes a framework for making decisions on their behalf. This applies whether the decisions are life changing events or everyday matters. All decisions taken in the adult safeguarding process must comply with the Act.

The presumption in the MCA is that adults have the mental capacity to make informed choices about their own safety and how they live their lives. Issues of mental capacity and the ability to give informed consent are central to decisions and actions in adult safeguarding. All interventions need to take into account the ability of adults to make informed choices about the way they want to live and the risks they want to take. This includes their ability to understand the implications of their situation, to take action themselves to prevent abuse and to participate to the fullest extent possible in decision-making about

Parkinson's disease develops when cells in the brain stop working properly and are lost over time. These brain cells produce a chemical called dopamine. Symptoms start to appear when the brain can’t make enough dopamine to control movement properly. There are three main symptoms - tremor (shaking), slowness of movement and rigidity (muscle stiffness) - but there are many other symptoms too.

Secondary or Drug-Induced Parkinsonism

"Parkinsonism" is the umbrella term used to describe the symptoms of tremors, muscle rigidity and slowness of movement. Parkinson's disease is the most common type of parkinsonism, but there are also some rarer types where a specific cause can be identified.

These include parkinsonism caused by medication (drug-induced parkinsonism) – where symptoms develop after taking certain medications, such as some types of antipsychotic medication, and usually improve once the medication is stopped.

Section 42 Care Act 2014 Enquiry by local authority

This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there):

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

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

Self-Neglect covers a wide range of behaviour including neglecting to care for one's personal hygiene, health or surroundings, lack of self-care to an extent that it threatens personal health and safety, inability to avoid harm as a result of self-neglect, unwillingness to seek help or access services to meet health and social care needs and includes behaviour such as hoarding.

4.0 Synopsis

4.1 Johnny lived with his parents until his father died in 1986, followed by his mother's death in 1992. Thereafter he lived alone in the family home in a neighbouring authority area. He had a sister who moved to live in the USA.

4.2 He had been diagnosed with epilepsy at a very young age. He was first detained under the Mental Health Act in 1972. Deafness was documented from 2000. He was diagnosed with depression in 2005 to which financial pressures, inability to work and 'poor living conditions' were reported to contribute. He had a long standing history of schizophrenia and was diagnosed with paranoid schizophrenia in 2009, secondary Parkinsonism (when symptoms similar to Parkinson disease are caused by certain medicines, a different nervous system disorder, or another illness) in 2014, axonal sensorimotor neuropathy (damage to the nerves causing decreased ability to move or feel sensation) in 2014, congestive heart failure in 2015 and bipolar affective disorder in October 2017.

4.3 In 2006 Johnny's sister contacted his GP to express concern about his mental state. He was said to have become quite isolated and he reported that people were 'watching and listening' to him. Johnny's GP referred him to the local Community Mental Health Team (CMHT). This referral was accepted although the team was unable to engage with him particularly well and the following year his case was transferred to the Assertive Outreach Team.

4.4 In 2007 Johnny was again detained under the Mental Health Act. The grounds cited were his aforementioned long-standing history of schizophrenia, non-compliance with medication and support, delusions about his neighbours and poor selfcare. He suffered several falls on the stairs in his home and in 2008 he sustained a hip fracture. In 2012 he developed a problem with his foot which needed an operation. He was described as 'slow on his feet'. The following year there were further falls at home and his mobility was described as 'poor'. His GP assessed his repeated falls as being the result of Parkinsonian mobility issues. Johnny was said to have refused all aids and adaptations to help with his mobility.

4.5 From 2014 the police began to receive calls from Johnny in relation to disputes with his neighbours including tampering with his key safe and turning their heating up so high that he was unable to sleep. During the year his property received a 'badly needed' clean-up from social services and he agreed to consider viewing flats with extra care given the ongoing concerns about his mobility and risk of falls.

4.6 During 2015 Johnny was admitted to hospital on three occasions suffering from chest pains and shortness of breath. At one point it was documented that he 'did not

understand what he was being told'. The context in which this observation was documented is unclear.

4.7 Johnny's case was discussed at the neighbouring authority Adults at Risk Group meeting during February 2016 at which it was stated that a ground floor room in his home had been adapted to enable him to live downstairs. The room contained a bed and a commode. He had a pendant alarm. He was said to have made over 100 calls to the local authority Community Services, the nature of which is not known. Having reluctantly agreed to move out of his home in 2015, Johnny now wished to stay in his own home. He was supported with what was described as an 'intensive' home care package which entailed four visits daily by carers. Difficulty was experienced in sourcing a home care agency as Johnny had previously accused carers of theft.

4.8 On 31st March 2016 Johnny was conveyed to Hospital 1 A&E by ambulance following a fall at home. He was admitted to the acute medical unit (AMU) for further investigation and treatment of a possible chest infection. (He remained in hospital until 18th May 2016). A comprehensive geriatric assessment was completed. He reported a recent increase in falls, reduced appetite and 'general deterioration'. He was noted to be a little unkempt and possibly not managing at home. He appeared fatigued and lacked motivation. An occupational therapy assessment indicated that he was not at his mobility baseline.

4.9 On 4th April 2016 the hospital queried the origin of Johnny's Parkinson's disease diagnosis as he was not known to the Parkinson's nurse and his medications were prescribed by his GP rather than a consultant. He was referred for review by the Parkinson's team as it was suspected that his symptoms were more likely drug induced. (As stated above, Johnny's GP records indicate that he had been diagnosed with secondary Parkinson's in September 2014 and had never been referred to specialist Parkinson's services).

4.10 On 12th April 2016 Johnny was referred to the hospital Rapid Assessment, Interface and Discharge (RAID) service because of his low mood. Johnny's previous diagnoses of schizophrenia and depression were noted. He denied any thoughts of deliberate self-harm or suicide. RAID could find no evidence of hallucinations although he continued to express delusional ideas about his neighbours. It was planned to conduct a joint review with the CMHT in the area that Johnny lived. RAID liaised with the CMHT the following day and the latter service agreed to visit Johnny prior to his discharge.

4.11 On 15th April 2016 Johnny was transferred to a discharge to assess unit run by Hospital 1 at that time. During his stay on the unit Johnny was noted to be demanding and aggressive towards staff. Other patients having control of the TV

remote and having to wait for his breakfast due to staff attending to other patients appear to have been recurrent concerns. Delusions about his neighbour being a witch led to contact with Johnny's CMHT care co-ordinator 1. The plan for this period included a referral to the Parkinson's Nurse for review but there is no indication that this was done.

4.12 On 18th May 2016 Johnny was discharged home with a package of care. A discharge summary was sent to his GP which advised that Johnny had been treated for lower respiratory tract infection, multiple pulmonary embolisms for which he was now receiving anticoagulant treatment, his swallow had been assessed and deemed safe and a CT scan had disclosed an appendiceal mucocele (obstructed appendix) which would require an appendectomy, assuming he was assessed as fit for surgery. A general outpatient appointment was arranged for 31st May 2016 but cancelled and no further appointments were offered. It is not known why a further appointment was not offered. The appointment appears to have been cancelled because NWAS were called to Johnny's home on the date of the appointment after he fell backwards onto his sofa and was unable to get up. He was supported to his feet and was able to mobilise. Hospital admission was judged to be 'unnecessary' in respect of the fall. His home was noted to be 'cluttered with trip hazards' and NWAS made a safeguarding referral, the outcome of which is unknown.

4.13 District nurses visited him to administer Clexane daily. (Clexane is a medication which helps to reduce the risk of blood clots).

4.14 On 8th July 2016 Johnny was conveyed to Hospital 1 by ambulance after a 'community worker' visited him and was concerned over his shortness of breath and 'new confusion'. Johnny told A&E staff that he had been in bed since his previous hospital discharge. After blood tests and a chest X-ray, Johnny was discharged home the same day for GP follow up. Oral antibiotics were prescribed for a likely urinary tract infection.

4.15 On 13th July 2016 Johnny was again conveyed to Hospital 1 A&E after the ambulance service was contacted by Johnny's carers on the advice of the GP as they had been unable to get him out of bed for several days. Johnny was said to feel weak and unable to mobilise, although the clinician who assessed him following his arrival at hospital noted that Johnny had previously said he was unable to mobilise 'when he was easily able to'. He was transferred to a respiratory ward. An assessment notice (an assessment notice is necessary when the patient is unlikely to be safely discharged from hospital without arrangements for care and support being put into place first) was sent (unclear to whom) noting possible problems with his care package as Johnny was 'very unkempt' on arrival at hospital. A discussion later

took place with the CMHT who felt that Johnny's care package had been 'close to breakdown' for several weeks. Johnny also complained about his home carers.

4.16 During his admission, Johnny received regular physiotherapy input. He was unable to say when he last stood up or walked. He required equipment and the assistance of two or three staff in order to stand and minimal improvement in his mobility was noted throughout his stay.

4.17 Johnny was also seen in respect of his unkempt appearance on admission by a safeguarding nurse who was unsure about Johnny's capacity to make decisions about his care. It was decided that a formal capacity assessment needed to be carried out and if lacking capacity in respect of his planned discharge home, a Best Interests discussion would need to take place.

4.18 A mental health review was attempted by the RAID service but Johnny declined to answer any questions. A care co-ordinator review took place on 20th July 2016. Johnny was said to be reluctant to talk and appeared 'vague'. He had unrealistic expectations about his ability to manage some activities of daily living once discharged home. If he was deemed to have capacity to decide to return home, it was considered that a hoist would be required. A hospital bed was also to be provided.

4.19 It would appear that the hospital discharge social worker concluded that Johnny had capacity to decide to return home although a capacity assessment was not documented. However, Johnny was said to have retained information from previous discussions.

4.20 On 9th August 2016 Johnny was discharged from hospital. The discharge summary sent to his GP stated that he had been admitted with decreased mobility secondary to Parkinson's. (The earlier question mark against his Parkinson's diagnosis appeared to have remained unresolved).

4.21 On 7th October 2016 Johnny was conveyed to Hospital 1 by ambulance after his carers raised concerns over his vomiting dark brown fluid and his 'very dark brown' urine. He was said not to have opened his bowels for three weeks and to be neglecting himself. (Johnny's care package had been transferred to a different care provider on 16th September 2016). It was noted that there was no food in the property and Johnny had no money to purchase any. CMHT care co-ordinator 1 was aware of this issue as a volunteer from the local church had been doing Johnny's food shopping until recently but had stopped because of 'accusations' by Johnny. The care co-ordinator had attempted to refer Johnny to 'client finance' but this had been declined owing to Johnny owning his own home.

4.22 When seen by a hospital clinician Johnny claimed that his carers had not been feeding him and had been poisoning him. (The hospital safeguarding team considered whether this was a safeguarding issue and after consulting a social worker, decided that there was no evidence that Johnny's carers had been neglectful).

4.23 On 10th October 2016 an assessment notice was issued to the neighbouring local authority in which Johnny lived and on 13th October 2016 a discharge notice (the hospital has to give the local authority notice of when it intends to discharge the patient. The discharge notice must specify whether or not the patient will receive any further health care services upon discharge, and if so, what those services will be) was sent to the hospital social worker identifying that a social work assessment was required to assist with discharge planning, and that Johnny had previously been cared for at home with a comprehensive care package and hoist transfers.

4.24 On 17th October 2016 Johnny met with the hospital social worker and CMHT care co-ordinator 1 and agreed to move into a 24 hour care placement. A nursing needs assessment (NNA) would be required which was completed the following day.

4.25 A copy of the NNA has been shared with this review. Under 'Primary Need/Diagnosis (active)' the assessor recorded Johnny's presentation on admission before adding that Johnny had a diagnosis of 'mental illness' which 'can affect his mood and behaviour'. Under 'Previous Medical History (inactive)' the following conditions were listed; epilepsy, PE (presumably pulmonary embolism), osteoporosis, Parkinson's, cardiac failure, prostate problems, frequent A&E admissions, schizophrenia, bipolar, inappropriate sexual behaviour and self-neglect. Under 'Present Medical History (active)' it was recorded that Johnny lived alone supported by a care package, had been bedbound, had been neglecting himself and was unkempt and had a reduced dietary intake. His frequent hospital admissions during 2016 were noted. It was recorded that Johnny 'can have challenging behaviour' which was further described as behaving in a sexually inappropriate manner to ward staff, being rude and aggressive and throwing bottles of urine on the floor. He was also said to display 'attention seeking' behaviour.

4.26 It is assumed that the NNA was written up after the subsequent RAID team assessment as the NNA states that the RAID team reported that he was 'not for EMI (Elderly Mentally Ill) nursing home'. The NNA stated that Johnny had capacity to make his own decisions. The list of professionals involved in Johnny's care in the past six months listed two consultants from Hospital 1 and the RAID mental health practitioner who subsequently carried out the EMI assessment. Earlier in the NNA the contact details of Johnny's social worker were recorded as the hospital social

worker. A Waterlow pressure ulcer prevention risk assessment was included which indicated that Johnny was at 'very high risk'. Johnny appears to have initialled the NNA and a charge nurse counter-signed as 'the patient was unable to sign but had indicated their consent'. (Johnny would not sign the assessment documents without speaking to his CMHT care co-ordinator first. The care co-ordinator visited Johnny on 24th October 2016. Johnny asked a friend from his Church to attend at the same time. Johnny asked his friend to leave before signing his consent to the proposed care).

4.27 On 20th October 2016 an EMI assessment was completed by RAID in consultation with nursing staff at Hospital 1. His medical history was given as epilepsy, osteoporosis, Parkinson's Disease, recurrent UTIs, a previous episode of congestive cardiac failure, bed bound and prostate problems. The assessment described complex physical health problems combined with schizophrenia. Johnny was said to have been falling at night when attempting to mobilise, he was self-neglecting, he had accused his neighbours of stealing from him, members of his church had been doing his shopping and he had carer support four times per day. Johnny was assessed as having capacity with regards to decisions about his accommodation.

4.28 The RAID assessment has been shared with this review. The mental health practitioner consulted with the hospital social worker and CMHT care co-ordinator 1. It was concluded that Johnny 'does not screen in for NHS Continuing HealthCare (CHC) funding as he does not meet the criteria'. No further details are included in the EMI assessment. (If a CHC decision support tool (DST) was used it has not been located in the Greater Manchester Mental Health NHS Foundation Trust (GMMH) notes) The EMI assessment recommended that Johnny should be placed in a general nursing home where he would have support from district nurses and the CMHT.

4.29 The mental health practitioner documented that Johnny 'seemed to have capacity' as 'he sustained a plausible discussion around the issues' involved in the assessment. It was documented that Johnny had instigated the assessment as he wanted 24 hour care. However, Johnny stated that he would only move into 24 hour care if he was allowed to take his CDs and retain his cable TV and telephone contract. He later declined to sign the EMI assessment until he had spoken to his care co-ordinator about spending further time in his house and possibly selling it first.

4.30 On 25th October 2016 an urgent clinical review of Johnny took place after a Modified Early Warning score (MEWS) of 8 was recorded which indicated a high risk of deterioration. A chest x-ray indicated hospital acquired pneumonia and Johnny was commenced on intravenous antibiotics. The clinical opinion was that escalation

to intensive care was inappropriate and that a DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) should be authorised on the basis of Johnny's multiple co-morbidities, specifically congestive heart failure, Parkinson's, epilepsy and 'new' sepsis. It was documented that there was 'no family' but Johnny had provided the name of a friend with whom the issue would be discussed.

4.31 By 28th October 2016 Johnny's condition was much improved and his MEWS score had returned to zero. He was stepped down from IV antibiotics to oral. He was later catheterised because of concerns around his skin integrity.

4.32 On 17th November 2016 the Integrated Discharge Team (IDT) Homefinder -a role which supports people who require a placement - contacted Johnny's new CMHT care co-ordinator 2 to discuss available vacancies for Johnny and it was recorded that the latter was unaware that a Nursing Needs Assessment had been completed or whether Johnny had capacity to make the decision in regards to his placement.

4.33 On 25th November 2016 the Homefinder sent the NNA to a number of nursing homes, including Care Home 1. On this date it was noted that the CMHT care co-ordinator 2 requested the occupational therapist to take Johnny to visit Care Home 1 but there is no record of whether this visit took place or what the outcome was. A care home near Blackpool, where Johnny had lived at one time, was also under consideration. It is not known whether care homes in the Council area in which Johnny lived were considered or approached in respect of Johnny.

4.34 During early December 2016 (no specific date recorded) Johnny's CMHT care co-ordinator 2 requested RAID to review their initial recommendation that Johnny required general nursing care, as hospital staff had reported that Johnny had been challenging and aggressive. Records indicate that RAID complied with this request and concluded that general nursing care remained appropriate as no challenging behaviour had been documented in Johnny's medical notes, and the nurse on shift that day reported that Johnny had been settled. The RAID team manager was also consulted.

4.35 It is understood that the fact that Johnny was in receipt of Section 117 Mental Health Act aftercare led to 'numerous discussions' as to whose responsibility it was to facilitate hospital discharge and arrange the funding of any placement. (Johnny was entitled to Section 117 Mental Health Act (MHA) aftercare funding to address those mental health needs which resulted in his earlier detention under the Act).

4.36 On 2nd December 2016 a healthcare admission assessment was completed for Nursing and Residential Care Home 1 (hereinafter referred to as Care Home 1). The

admission assessment assessed Johnny against the following domains; 'getting up', 'going to bed', 'night time needs', personal hygiene', 'bathing', 'dressing', 'continence/toilet needs', 'meals/appetite', 'mobility indoors/outdoors/use of stairs', 'hearing', 'vision', 'dentures', 'skin integrity', 'communication', cognitive behaviour', 'social activity', 'religious/spiritual needs', 'medical history', 'current medication', 'reason for admission', and 'other comments'.

4.37 Under 'medical history' bipolar, prostate problems, recurrent UTIs and Parkinson's was recorded. There was no reference to schizophrenia, epilepsy, osteoporosis, self-neglect or any challenging or inappropriate behaviours. Nothing was recorded under 'cognitive behaviour' and under 'communication', 'can hold conversation' was recorded.

4.38 The section of the assessment where a decision is recorded as to whether to offer or decline a placement was not completed. The telephone number of the CMHT care co-ordinator is recorded at this point of the assessment which suggests that the care provider may have consulted him before deciding whether to offer a placement. It is not known whether Hospital 1 nursing staff were consulted in completing the assessment.

4.39 Care Home 1 subsequently confirmed that they were able to accept Johnny and he would be able to be discharged there on 5th December 2016. The IDT Homefinder contacted CMHT care co-ordinator 2 who confirmed that he was aware of the placement and was waiting for funding to be approved, which it subsequently was. However, the GMMH chronology submitted to this SAR states 'CMHT duty desk received a call from a hospital social worker based at Hospital 1. Johnny was a delayed discharge, and a bed had been found available that day at Care Home 1. Placement made by Hospital Social Worker. CMHT not involved'.

4.40 On 5th December 2016 Johnny was transferred to Care Home 1 by ambulance and experienced considerable difficulty in mobilising. He was said to be hardly able to use the walking frame and the paramedics accompanying Johnny advised the carers to use a standing hoist. He was noted to 'very demanding and so impatient' overnight. He was 'buzzing' throughout and asking to be changed although his pad was completely clean and urine draining very well via his catheter.

4.41 On 8th December 2016 Johnny was reviewed by the neighbouring local authority area CMHT care co-ordinator 2 and was documented to be eating and drinking independently. His appetite was good although he was unhappy with the choice of meals. He accused staff of poisoning his meals at times.

4.42 The first documented incident of challenging behaviour took place on 10th December 2016 when Johnny became verbally aggressive towards staff and threw a towel in a carer's face whilst being assisted with personal care.

4.43 On 12th December 2016 Johnny was seen by Nursing Home Team (NHT) Advanced Practitioner 1. Johnny was said to be disorientated to time and place. A consultant medication review was to be arranged. A Mental Capacity Act (MCA) assessment was requested and an independent mental capacity advocate (IMCA) referral was made in respect of advanced care planning decisions. (The NHT is unique to this area and comprises consultants and advanced practitioners which precludes the need for GP involvement. The team is able to react very quickly to need (4 hours)).

4.44 On 23rd January 2017 Johnny was seen by NHT Consultant Geriatrician 1 who documented that he was unhappy at Care Home 1 and wanted to speak to a social worker to discuss leaving as soon as possible. The consultant recorded that there was no reason to doubt his mental capacity to make this decision. The following day the consultant referred Johnny to the neighbouring local authority area psychiatric unit - which, amongst other things, offers outpatient appointments - for a medication review and also made a referral to the neighbouring authority 'social services' requesting a placement review. (There is no reference to the receipt of either referral in the reports shared with this review by Greater Manchester Mental Health NHS Trust). It is not known if the referrals were received and if not received, why not.

4.45 On 31st January 2017 Johnny was visited by NHT Advanced Practitioner 1 following concerns about his behaviour and presentation. No further details of Johnny's behaviour and presentation and any outcome of the NHT visit have been shared with this review.

4.46 On 3rd February 2017 Johnny was seen by NHT Consultant Physician 1 and presented as verbally aggressive and refused his medications. He was angry about being at Care Home 1. The consultant told him that returning home was not an option as his house had been sold (It has been confirmed that this was not the case – see Paragraph 4.98). He calmed down through negotiation and agreed to take his medications. He did not appear to be able to weigh up or retain information, and so his capacity was questioned. (This entry does not specify what type of decision he may have lacked capacity to make). A Deprivation of Liberty Safeguards (DoLS) application was also considered to be appropriate.

4.47 On 6th February 2017 the NHT, having received no response to Consultant Geriatrician 1's referral to 'social services' (see Paragraph 4.44) sent a referral to Manchester Mental Health Services via Gateway.

4.48 On 7th February 2017 Johnny was seen by NHT Advanced Practitioner 1 over concerns relating to poor diet and fluid intake. Johnny continued to be verbally abusive to care staff, attempted to physically assault them, damaged his bed and throw his drinks on the floor. He periodically refused food and fluids saying he was on 'hunger strike'.

4.49 On 8th February 2017 Manchester Old Age Psychiatry contacted the NHT to advise that Johnny had a CMHT Care Co-ordinator and provided them with his contact details. The NHT documented that Johnny's placement had not been followed up as a concern, given that the Care Home 1 had been struggling to encourage him to take fluids. The Care Home 1 assistant manager contacted CMHT Care Co-ordinator 2 and expressed concern that Johnny had been refusing food, drink and medication, and advised they had become concerned that they were unable to manage his care needs as he was very complex. CMHT Care Co-ordinator 2 agreed to request a psychiatric review by the CMHT Consultant. The CMHT Care Co-ordinator advised Care Home 1 to call an ambulance if they were struggling.

4.50 On the same date CMHT Care Co-ordinator 2 sent an email to the CMHT Consultant requesting the transfer of Johnny to South Manchester Older Adult CMHT Manchester.

4.51 On 9th February 2017 NHT Advanced Practitioner 1 documented that a review was due to take place on 14th February 2017, but felt that the neighbouring authorities lack of support and follow up was concerning, as reports suggested that Johnny's needs were longstanding.

4.52 On 10th February 2017 CMHT Care Co-ordinator 2 telephoned the South Manchester Older Adult CMHT to request transfer of care as Johnny was in an Out of Area placement. A team manager from the South Manchester Older Adult CMHT responded by leaving a message setting out transfer expectations which were a care review by the current care team and any concerns around food/medication to be addressed. However, the South Manchester Older Adult CMHT would step in, in the patients' best interest, if there was an unreasonable delay in treating the patient. Following three months of stability in the placement care would then be transferred.

4.53 On 13th February 2017 Johnny was discussed in the neighbouring authority CMHT multi-disciplinary team (MDT) meeting when it was noted that the placement had requested a review, that the placement was out of area and that the

neighbouring authority had Section 117 responsibility. It was agreed that a consultant transfer would be arranged, and for CMHT Care Co-ordinator 2 to complete a joint review and then refer to South Manchester CMHT to take over care co-ordination. It was documented that South Manchester would only accept the transfer if the case was settled.

4.54 On 20th February 2017 the NHT were notified by letter from the neighbouring authority CMHT Care Co-ordinator 2 that Johnny had been reviewed on 16th February 2017 and his eating and drinking had improved and that he appeared more settled. The letter also advised that care management was to be transferred to South Manchester and that Care Home 1 had been advised to raise any concerns with South Manchester CMHT rather than the neighbouring authority. (There is no record of the 16th February 2017 review in the GMMH chronology submitted to this review).

4.55 The following day the NHT documented that Johnny had lost 10kg in weight and supplements were prescribed. He was said to often refuse food.

4.56 On 27th February 2017 Johnny began punching, spitting and swearing when carers were washing and dressing him and slapped a carer, necessitating a 'high level intervention'. From the information shared with this review by Care Home 1, it is not possible to say whether or not restraint was used on this occasion.

4.57 On 3rd March 2017 Johnny was seen in Care Home 1 by NHT Consultant Geriatrician 1 who documented that he had not eaten for five days and not taken fluid for 24 hours and was dehydrated. It was documented that Johnny refused examination and said that he would be 'better off dead, than in this prison'. He had not been out of bed for two days and had refused medication for the same length of time.

4.58 The same day he was admitted to Hospital 1 where he presented as paranoid. He declined clinical assessments, saying he wanted to be admitted to a ward. He was assessed as lacking capacity to consent to blood tests and IV access and was later physically restrained to enable these procedures to be carried out. When conducting the capacity assessment Johnny was stated to be known to have paranoid schizophrenia and was unable to understand, retain and repeat back information to the effect that not eating/drinking/taking medication would endanger his life.

4.59 By the following day Johnny was considered to be medically fit for discharge but remained in hospital to await a mental health review which took place on 6th March 2017 (RAID). During this review he appeared quite flat in effect but denied

being low in mood or having thoughts of self-harm or suicide. He was dwelling on the fact that his house had been sold and he had moved into a nursing home to which he said he did not want to return although he understood that he had no other placement at that time. The mental health practitioner gained the impression that Johnny had chronic schizophrenia and residual paranoid symptoms but no acute mental health issues. At this point Johnny was still not eating (contradicts Care Home 1 chronology entry that Johnny was eating and drinking well whilst in hospital) although he was drinking.

4.60 The discharge summary sent to Johnny's GP, and shared automatically with the NHT, stated that he had been admitted due to reduced oral intake. A urinary tract infection had been identified and treated with antibiotics. He had been reviewed by the mental health team during his admission and a CMHT post-discharge review was planned. Nutritional supplements had been prescribed. Hospital 1 psychiatry emailed the neighbouring authority CMHT to advise that Johnny was being discharged, and to request they liaise with Care Home 1 and provide input, as Johnny was still under their care.

4.61 On 8th March 2017 Johnny was seen by NHT Consultant Geriatrician 2 as he continued to refuse food, fluid and medication. This was documented to be a behavioural problem, a manifestation of 'attention seeking behaviour'. It was decided that it was in Johnny's best interests for medication to be provided covertly if necessary. It was stated that this would be discussed with his next of kin (NOK)/IMCA at an Advanced Care Plan meeting at the next opportunity. An urgent psychiatric review was to be arranged. No record of an Advanced Care Plan meeting being held has been shared with this review.

4.62 On 9th March 2017 NHT Advanced Practitioner 1 was unable to complete an IMCA referral in respect of Johnny as there was 'no general consensus regarding capacity'. A Gateway referral was sent to Old Age Psychiatry.

4.63 On 10th March 2017 NHT Advanced Practitioner 1 had a discussion with the Care Home 1 manager who advised that Johnny's friend M did not wish to be involved in decision making in respect of Johnny.

4.64 On 13th March 2017 Johnny was discussed at the neighbouring local authority CMHT MDT where it was noted that a transfer to South Manchester was planned as Johnny had been at Care Home 1 for three months and was 'stable'. A referral from the neighbouring authority CMHT in respect of Johnny was received by South Manchester Older Adult CMHT.

4.65 The following day Johnny was seen by NHT Advanced Practitioner 1 who documented that he was eating and drinking well. On the same date South Manchester Older Adult CMHT rejected the referral from the neighbouring authority CMHT, agreeing only a Consultant outpatient service for Johnny. (Manchester services opened cases for Consultant only care where there was no identified need for support from other members of the CMHT. The neighbouring authority did not operate this system and it may therefore have led to some confusion between the services in Manchester and the neighbouring authority).

4.66 On 24th March 2017 Johnny was seen by NHT Consultant Physician 2. He was agitated and had not eaten and drank much. He was pulling on his catheter and had haematuria (blood in urine) and his urine was thick with a light green sediment. He was offered a drink of which he consumed half and threw the rest away. He was to be encouraged to drink fluids to flush his bladder.

4.67 On 27th March 2017 NHT Consultant Geriatrician 1 assessed Johnny's capacity and found that he was able to discuss, and understand, a conversation around his condition, and what to do if he deteriorated. It was documented that there was no reason to feel he lacked capacity. He expressed a wish to go to hospital for life prolonging treatment, but did not wish to be revived in the event of a collapse. DNACPR was completed.

4.68 On 28th March 2017 Johnny was reviewed by a Trainee Doctor in Old Age Psychiatry. Johnny refused to meet her so she interviewed Care Home 1 staff who reported 'verbal abuse/poor diet/refusal to take medication/bed bound/banging on bed frame/throwing things/objecting to personal care interventions.' She queried whether community psychiatric nurse (CPN) input was necessary to help Care Home 1 cope with caring for Johnny.

4.69 On 29th March 2017 Johnny was admitted to Hospital 1 as a result of reduced oral intake. It was said that he had chosen to stop eating and drinking almost entirely. He would not engage in discussions about the reason for refusing food and drink. No delusions in respect of food or drink were noted. The suggested plan was for blood tests, IV fluids, mental health review and consideration of nasogastric feeding. A DNACPR was completed with the rationale recorded as 'advancing frailty, patient's wishes'.

4.70 On 31st March 2017 Johnny was examined by a tissue viability nurse (TVN) after reddening was noted on his sacrum. This was identified as a grade 1 pressure ulcer caused by Johnny lying on his catheter tube. Johnny was noted to be non-compliant with repositioning and so it was decided to make a DoLS application as he

'lacked capacity and care was to be provided in his best interests on the ward'. There is no record of a DoLS application being submitted by Hospital 1.

4.71 On 3rd April 2017 Johnny was discharged to Care Home 1. The discharge summary stated that his bloods were normal, he had been treated for a UTI although no infection had been established via urine sample. Whilst admitted he had taken his medication and three quarters to full meals. The TVN service sent a letter to the NHT.

4.72 On 12th April 2017 CMHT Care Co-ordinator 2 contacted the South Manchester Later Life CMHT team manager to request handover of care co-ordination be completed as soon as possible.

4.73 On 19th April 2017 Johnny was seen by NHT Advanced Practitioner 1 who documented that he was eating and drinking well and there were no new concerns. Two days later, Johnny refused all medications during the day and kept removing his bedding and throwing it on the floor. He was described as very abusive and angry.

4.74 On 2nd May 2017 CPN 1 from Manchester Older Adults CMHT visited Johnny and he engaged well with her. He said he felt 'fed up' and wanted to return home. The CPN planned to liaise with the neighbouring authority CMHT about his wish to go home.

4.75 On 3rd May 2017 the neighbouring authority CCG Personalised Care Team, which is responsible for processing CHC applications in respect of patients with a GP in the neighbouring authority, was advised that Johnny had been discharged from hospital to Care Home 1. The team received a NNA and a CHC Checklist for Johnny on 10th May 2017. The documentation was reviewed by the team but the CHC application was not accepted because it was completed on 18th October 2016 whilst Johnny was an inpatient (Paragraph 4.28 states that Johnny was assessed as ineligible for CHC funding at the time of the EMI assessment). The team contacted Care Home 1 to request up to date documentation which was not subsequently submitted. There was no further involvement by the Personalised Care Team.

4.76 On 5th May 2017 Johnny was discussed at the neighbouring authority CMHT MDT. The plan remained unchanged in that his care was to transfer to Manchester services and the neighbouring were to manage Section 117 aftercare.

4.77 On 10th May 2017 Johnny received a follow up visit from CPN 1 from South Manchester Older Adult CMHT. He was reported to remain 'fed up' and wished to return home with support. He was noted to be under the care of the NHT and was

also being seen by the TVN. The Care Home 1 chronology entry states that the CPN was discharging Johnny from her team's care.

4.78 On 12th May 2017 CMHT Care Co-ordinator 2 documented that Johnny was settled at Care Home 1, although he could change suddenly. He had been informed that Johnny had requested to go home and responded by advising Care Home 1 to request a DoLS application. On the same date Care Home 1 documented challenging behaviour including throwing food and drink on the floor and refusing to take medication whilst asking to be allowed to go home.

4.79 On 16th May 2017 Johnny was seen by NHT Advanced Practitioner 1 and was documented to be eating and drinking well ('enjoying takeout pizza'). He continued on antipsychotics without any evident side effects.

4.80 On 17th May 2017 a South Manchester Psychiatry Trainee Doctor visited Johnny who declined to engage which led to the consultation being terminated. On the same date a liaison meeting took place with South Manchester Older Adult CMHT at which it was agreed that Johnny did not need CPN support and that the neighbouring authority had Section 117 responsibility and should therefore review Johnny. The Care Home 1 chronology states that they understood that the neighbouring authority held responsibility for reviewing the placement if needed, should his care needs not be met in the current setting. Also, on the same date Johnny's case was discussed at the neighbouring authority CMHT MDT where it was recorded that his care co-ordination needed to be transferred to Manchester. There is no record of Johnny's wish to return home being discussed.

4.81 On 20th May 2017 Johnny was visited by his solicitor who brought in a CD player and CDs were purchased. His solicitor had lasting power of attorney in respect of Johnny's property and finances. During May or June 2017 Johnny's niece made a series of visits to her uncle whilst on holiday in the UK. After she returned home to the USA, her Manchester based friend continued to visit Johnny until shortly before his death.

4.82 On 22nd June 2017 an email was sent by the neighbouring authority CMHT Care Co-ordinator 2, possibly to South Manchester CMHT, advising that Johnny's clinical care had now been handed over, confirming that the neighbouring local authority retained Section 117 responsibility but Manchester would need to take on the care co-ordination of Johnny. The care co-ordinator referred to Johnny's wish to return home and advised that Care Home 1 was applying for a DoLS as Johnny's 'physical needs had been assessed as requiring 24 hour care'. NHT Consultant Physician 1 later saw Johnny and in her view, he understood that he could not go home, and therefore no DoLS was required.

4.83 On 23rd June 2017 the neighbouring authority CMHT made a further referral to South Manchester Older Adult CMHT. The response from Manchester was to request Johnny's most recent care plan and to confirm that Johnny would continue to be reviewed by Consultant in Old Age Psychiatry 1.

4.84 On 26th June 2017 Johnny removed his catheter and refused to have it replaced. This situation appears to have been monitored until Johnny was re-catheterised on 20th August 2017.

4.85 The following day Johnny was seen by NHT Advanced Practitioner 1 who documented he was eating and drinking well and was said to recognise that he could not realistically go home due to his level of dependency.

4.86 During June 2017 a letter from Manchester CMHT CPN 1 stated that the neighbouring authority CMHT had initially informed her that Johnny was not entitled to Section 117 aftercare.

4.87 On 5th July 2017 Johnny's care plan was updated and it was documented that he continued to require 'lots of encouragement' before accepting medication.

4.88 On 20th July 2017 a nursing and residential care home review was carried out by the Old Age Psychiatry Trainee Doctor. Johnny said that overall, he was grateful for the care at Care Home 1 and acknowledged that he would need a lot of support if he were to return home. The trainee doctor planned to liaise with the neighbouring authority 'social worker' in respect of future plans for Johnny. Care Home 1 staff reported that Johnny now rarely asked to go home.

4.89 On 15th August 2017 Johnny was described as more settled and eating and drinking with encouragement when visited by NHT Advanced Practitioner 1. Johnny was documented to be 'keen to go home' although only infrequently asking to go home and occasionally stating in future he wished to go home. The advanced practitioner documented that there were still differences of opinion regarding Johnny's capacity to make informed decisions regarding his placement and future plans and that he needed listing for a formal MCA assessment from 'geriatricians', although he had been deemed to have capacity 'by a DoLS assessor'. There was no DoLS application until the following month so it is unclear who had deemed Johnny to have capacity. He was described as frail and having a number of co-morbidities.

4.90 On the same date a care programme approach (CPA) review was conducted by the neighbouring authority CMHT Care Co-ordinator 2's manager and the Consultant in Old Age Psychiatry from South Manchester. Johnny said that he needed help with

meals, personal care and mobility and said that he thought he needed medication for epilepsy and Parkinson's but not schizophrenia. Johnny said that in the long-term he wanted to go home and expected that his solicitor would help him. At the conclusion of this interview the legal framework for Johnny's continued stay at Care Home 1 was discussed and the Care Home 1 manager was advised to refer for a DoLS assessment.

4.91 On 3rd September 2017 Johnny was reported to have settled into a larger room at Care Home 1.

4.92 On 5th September 2017 Johnny was seen by NHT Advanced Practitioner 1. He was not eating or drinking and refusing medications. He was said to be constipated. Laxatives were prescribed. He was unhappy with the night staff as he had diarrhoea during the night and said that no-one had cleaned him for a while. This complaint was reported to a nurse although staff denied Johnny's complaint and said he had accused them of stabbing him.

4.93 On 8th September 2017 NHT Consultant Geriatrician 1 assessed Johnny as lacking capacity in respect of his ongoing care needs and preferred place of care. Johnny was noted to engage in conversation but was disorientated to place. He believed people had been staying at his house without permission. He appeared unsure why he had been admitted to Care Home 1 and lacked insight as to his care needs and how he would manage at home. He also lacked insight into the risks of managing without carers and did not appreciate the significant deterioration in his health. The consultant also conducted a constipation review and Johnny refused a second suppository.

4.94 On 13th September 2017 Johnny's care plan was updated to the effect that he was eating small amounts and that he liked cheese or jam sandwiches which were being supplied on demand in addition to main meal times. An email had been received from his niece in the USA which was shared with him. He was said to not be engaging with staff currently, saying he preferred to be left alone or to be in hospital. He was refusing laxatives, enema and/or suppository for his constipation. There were said to be no financial issues now he was communicating with his solicitor.

4.95 On 27th September 2017 a DoLS referral was sent to the neighbouring Council, documenting that Johnny lacked capacity to make decisions about his placement. It also noted that staff were monitoring his sleeping patterns as he had agitated episodes and also referred to Johnny being vulnerable due to his mental health which placed his safety at risk.

4.96 The neighbouring Council, as the supervisory body, approved a standard DoLS authorisation on 10th October 2017, attaching a condition that the managing authority (Care Home 1) must maintain an accurate record of all the occasions on which Johnny expressed a wish to leave the placement which would help assessors establish the frequency and intensity of any objections he had to residing in the care home. The relatively short period of the DoLS authorisation (it would expire on 2nd January 2018) would enable Johnny's objections to be monitored during this period. It was also recognised that Johnny required a paid RPR (relevant person representative) because the best interests assessor (BIA) had been unable to identify an eligible person to act as his representative. Johnny was therefore referred to the Manchester Advocacy Service. The DoLS assessment also advised a referral to a dietician regarding Johnny's poor diet choices as he was only eating small amounts of the same food.

4.97 On 4th October 2017 Johnny was reviewed by a Parkinson's Disease specialist. Medications were reviewed and amended. On 11th October 2017 Johnny was visited by NHT Advanced Practitioner 1 who documented that changes in medication would be reviewed for side effects and communicated to Hospital 1 Consultant 1.

4.98 On 16th October 2017 Johnny was visited by his solicitor to discuss the potential sale of his house and the increasing financial burden of retaining the property. The solicitor concluded that Johnny lacked the mental capacity to make decisions relating to the retention or sale of his property and initiated arrangements to dispose of it.

4.99 On 20th October 2017 Johnny was seen by an NHT Practitioner 2 as he had been vomiting but had since recovered to an extent. Care Home 1 staff were requested to monitor his bowels 'properly' and be clear regarding 'omissions' of medication.

4.100 On 23rd October 2017 Johnny was seen by NHT Consultant Geriatrician 1 regarding concerns that he was refusing food and fluids although he had accepted medication apart from lactulose. He appeared to be confused. A history of declining interventions from Care Home 1 staff but accepting same from NHT was documented. On the same date he was seen by the new paid relevant person's representative (RPR) but Johnny didn't talk to her 'as he needed to go to the toilet'.

4.101 On 25th October 2017 a safeguarding referral was received by the Manchester City Council contact centre from the paid RPR highlighting concerns following a visit to Johnny at Care Home 1. She observed Johnny requesting staff to support him to use the toilet. She also called for staff to support Johnny with the toilet due to him presenting as distressed. She observed a staff member responding to Johnny by

telling him to 'go in his pad' as he 'takes too long in the toilet'. The RPR raised this concern with a nurse at Care Home 1, suggesting an occupational therapy referral and possible use of aids/ adaptations. The RPR felt the nurse was as 'unconcerned as the carers' stating that Johnny refused a bed pan and struggled to sit on the toilet. The RPR highlighted Johnny's constipation as likely due to being unwilling to toilet using pads. The safeguarding referral was processed by the contact centre and passed to the emergency duty service (EDS) due to the time of day. EDS forwarded the referral to the Manchester Adult multi-agency safeguarding hub (MASH) team to address the following morning.

4.102 On 26th October 2017 the safeguarding referral was screened by a MASH senior social worker and sent to South Manchester locality social work team with a recommendation for a Section 42 enquiry given the nature of the concerns and the impact on Johnny's dignity and wellbeing. Johnny was noted to be the neighbouring local authority funded resident, however the Section 42 enquiry was to be undertaken by Manchester as the host authority. The case was allocated to social worker 1 who liaised with, and gathered information from, the referrer, neighbouring authority CMHT Care Co-ordinator 2 and the Care Home 1 manager and made an unannounced visit to the home where Johnny refused to speak with her. She viewed Johnny's care plan and records and confirmed that the following steps had been taken to address the concerns raised:

- The Care Home 1 manager had addressed issues with staff members individually, through provision of training and staff meetings regarding their approach and communication.
- A referral to occupational therapy for assessment had been made.
- There was ongoing monitoring by NHT.
- Change of medication to address constipation had been arranged.
- Ensured a bowel chart was in place.
- Johnny had been referred to the neighbouring authority CMHT to request a review of his care and support needs with regards to increased support planning regarding his mental health and his behaviours.

4.103 On 31st October 2017 Johnny was visited by NHT Advanced Practitioner 1 who noted variable compliance with medication, depending on his mood at the time. He agreed to further enemas to alleviate constipation which were prescribed. His last bowel movement had been on the previous day but prior to that he had not had a bowel movement since 18th October 2017.

4.104 On 1st November 2017 Care Home 1 contacted the NHT as they were concerned that Johnny was 'not himself'. NHT Consultant Geriatrician 1 documented that he appeared well but significantly frailer than during a visit several months earlier. Johnny appeared 'very rigid', 'switched off' and bradykinesic (slowness of

movement which is regarded as a symptom of Parkinson's). He declined further examination. Monitoring was required as his Parkinson's medication was noted to have been withdrawn.

4.105 The following day the consultant visited Johnny again who was described as not looking acutely unwell. It was documented that 'weaning Parkinson's medication may help with his low blood pressure'.

4.106 On 6th November 2017 the safeguarding referral in respect of Johnny was discussed at the neighbouring authority CMHT MDT meeting. It was noted that the referral was being dealt with by Manchester City Council.

4.107 The following day Johnny was seen by NHT Advanced Practitioner 1. He was documented to be frail and being nursed in bed but his carers reported no concerns at that time.

4.108 On 9th November 2017 Johnny again declined to speak with social worker 1, who was conducting the Section 42 enquiry, when she made an unannounced visit to Care Home 1.

4.109 On 19th November 2017 the paid RPR visited Johnny and raised concerns with care staff that his room smelled strongly of urine, his bed was wet, he was lying in bed uncomfortably with his head pressed against the wall, he had jam in his beard and was complaining that he had not been changed or washed in several hours. The RPR noted that his records showed that little or no pressure relief was being offered and Johnny was only consuming a litre of fluid a day and there was no record of food consumption.

4.110 The following day the Section 42 safeguarding enquiry was closed with an outcome of 'No further action' recorded. The rationale for this decision was that a request had been made to the neighbouring authority CMHT to undertake a review of Johnny's current needs and challenging behaviours to establish what support could be offered regarding his management. The outcome of the review was summarised as follows:

- Johnny has complex physical and mental health needs and had been supported at Care Home 1 for some time.
- Johnny had deteriorated in that time and continued to refuse to be supported outside of bed. This had impacted on his sitting balance and the support which could be provided to Johnny.
- Information had been received that Johnny required support in bed and would require a hoist and two carers to support him with his personal care

needs. Johnny was incontinent of faeces and his needs were met by a pad. Although the language used towards the paid RPR was not acceptable and more appropriate language should have been used, alongside the offer of comfort and support to Johnny, this on its own was not sufficient to constitute abuse.

- Care Home 1 staff had been spoken to and had reflected on their communication, all acknowledging their conduct and communication had not been of an acceptable standard and relevant training had been delivered to all staff involved in the incident, actions which would reduce the risk of this type of incident happening again.
- Care Home 1 staff had had internal training regarding the way in which they spoke in such situations.
- Johnny had been assessed by occupational therapy and equipment had been supplied to support his continence needs.
- A request had been made for additional planning support for Care Home 1 from the neighbouring authority CMHT including support with Johnny's behaviour.
- Johnny's file documented a lack of capacity and although he was requesting to leave Care Home 1, this could not be fulfilled without assessment of Johnny's capacity and any required best interest meeting and the identification of a further place of residence.

4.111 In an email to the neighbouring authority CMHT Care Co-ordinator 2, social worker 1 reiterated the need for a review of Johnny's care and support needs with regards to increased support planning regarding his mental health and behaviours. She went on to ask if this support would be 'under yourselves at 'the neighbouring authority' CMHT or has Johnny's ongoing care been transferred to Manchester CMHT?' The social worker emailed the Care Home 1 manager to advise that they would need to re-refer to the neighbouring authority CMHT for support with support planning due to Johnny's challenging behaviours.

4.112 On 21st November 2017 Johnny was seen by NHT Advanced Practitioner 1 as he had been constipated for two weeks. He was taking fluids well. Care Home 1 was advised to seek urgent advice from the NHT if Johnny stopped opening his bowels or displayed additional signs of concern such as vomiting or pain. A commode was purchased to support Johnny as he was currently being nursed in bed 24 hours per day and was said to be reluctant to change his position.

4.113 On 8th December 2017 the neighbouring authority CMHT Care Co-ordinator 2 phoned the Care Home 1 manager to request a capacity assessment and a Best Interests meeting. The NHT appeared to have considered an IMCA referral as 'no

friends or family involved'. A DNACPR was documented to have been signed by Consultant Geriatrician 1.

4.114 On 19th December 2017 the neighbouring authority DoLS team allocated Johnny's case for a review.

4.115 On 21st December 2017 a further safeguarding referral was received from the paid RPR due to ongoing quality of care issues noted during a visit to Care Home 1 on 8th December 2017 which included:

- Johnny reported that there was no longer any staff member supporting him to shave.
- He was always thirsty and not receiving adequate fluids. The referrer checked his fluid chart and confirmed this appeared to be the case.
- Johnny was bored and spent all day alone in his room. He would like a TV and the radio set to a specific station.
- Johnny had been told he would receive equipment to support him to use his toilet but this had not yet arrived. He was therefore still feeling distressed with regards to toileting in his bed.
- Staff kept leaving the call bell in places Johnny was unable to reach due to his restricted movement despite this having been raised with staff.

4.116 The safeguarding referral was processed by the contact centre and passed to the Manchester Adult MASH.

4.117 On 22nd December 2017 the NHT visited Johnny over concerns in respect of dehydration (no fluids for 24 hours) and his passing a lot of urine. Johnny was lying in bed and presented as much the same as during the last visit. Johnny said that his constipation was slightly better. He was documented to be low in mood and 'quite open' about his dislike of Care Home 1.

4.118 The safeguarding referral was screened by a MASH senior social worker and sent to Manchester South locality social work team with a recommendation for a 'safeguarding adult's response' given the nature of concerns and impact upon Johnny's dignity and wellbeing alongside ensuring continuity in view of the previous Section 42 enquiry. The rationale for this decision was that the information available suggested that harm had occurred and that the adult was also at risk of harm. A further response was required to establish the facts, gather further information, establish whether harm had occurred, the nature of any harm and why it had occurred.

4.119 The referral was received in the 'duty inbox' at Manchester South social work team. A case note was made by the duty social worker to the effect that following a discussion with the duty manager, the referral was to be shared with the neighbouring local authority 'social services' as they had placed Johnny, a psychiatric update was to be requested as were details of Johnny's care plan. The locality team assigned the referral to social worker 1 who was on leave over the Christmas period.

4.120 Also on 22nd December 2017 Johnny's care plan was updated to document that he was 'very poorly', had not eaten for the last week and was not drinking much. No DNACPR was said to be in place and no statement of intent (SOI). (A statement of intent may be issued by a GP confirming that if death occurs outside surgery hours he/she will be prepared to issue a medical certificate of cause of death).

4.121 Johnny's paid RPR contacted the neighbouring authority CMHT Care Co-ordinator 2 to say that the safeguarding referral had been closed and suggested that the care co-ordinator liaise with Manchester City Council about who would lead around the concerns raised and the possibility of Johnny moving. The paid RPR said that she was trying to access support for Johnny who, in her opinion, was being neglected. The paid RPR later emailed the care co-ordinator to say that she had spoken with Manchester Contact Centre who suggested that if Johnny needed to relocate then his 'social worker' would need to look into this. There is no response to this email on record. However, the Care Co-ordinator contacted the Care Home 1 manager to ask that the home agree a review of Johnny with Later Life Consultant 1 and the paid RPR.

4.122 On 27th December 2017 NHT Consultant Geriatrician 2 saw Johnny with a Care Home 1 nurse and recorded that he appeared to have weakened and that not eating or drinking was the result of his multiple morbidities. The consultant concluded that Johnny was dying, that artificial feeding was unlikely to change his prognosis and the focus should be on comfort and supportive care. Hospital escalation was not considered appropriate as 'nil reversible'. The consultant believed a statement of intent (SOI) was appropriate and contacted Johnny's niece in the USA who agreed that it was in Johnny's Best Interests to remain at Care Home 1. The consultant concluded, having looked through Johnny's file and seen email correspondence from her, that Johnny was 'befriended' by his niece. The consultant recorded that this was the reason that no advocate was required as part of the decision-making process. The Statement of Intent gave Parkinsonism as the advanced and irreversible illness likely to lead to Johnny's death. The consultant sought a second opinion from a colleague, a specialty trainee 6 doctor, who agreed with her diagnosis of terminal stage of advanced frailty. The decision was documented by a different doctor two days later, on 29th December 2017 on a

Nursing Home Service Patient Review Proforma on the basis of a verbal handover from NHT Consultant Geriatrician 2. The proforma consisted of the following management plan:

'I spoke to Johnny's niece today. Together we have decided it is in Johnny's best interest to have his preferred place of care and death in Care Home 1. Therefore, we have also decided that he is not for hospital escalation. A medical decision was made that he is not to be artificially fed'.

4.123 On 28th December 2017 Johnny was seen by the Consultant in Old Age Psychiatry. Care Home 1 documented the outcome of the consultation as Johnny was exercising his choice not to eat, drink or take medication.

4.124 On 29th December 2017 Care Home 1 held a telephone discussion with Johnny's niece who was informed of his poor prognosis. The SOI was also discussed.

4.125 On 3rd January 2018 the NHT Advanced Practitioner 1 conducted a medication review in respect of Johnny and requested cosmocol (laxative for chronic constipation).

4.126 On 4th January 2018 the NHT visited Johnny and requested a medication review as Johnny was not compliant with his medications. The Care Home 1 nurse was advised to continue to write 'unable to take' in Johnny's MAR chart.

4.127 A meeting between the paid RPR, Care Home 1 manager, a DoLS Best Interests Assessor (who had been commissioned by the neighbouring authority Council to conduct a review of Johnny's DoLS authorisation which had expired two days earlier) and CMHT Care Co-ordinator 2 had been arranged for 4th January 2018. However, the care co-ordinator was unavailable to attend and no replacement CMHT attendee was arranged.

4.128 On Friday 5th January 2018 the paid RPR emailed social worker 1 to say that 'things had escalated significantly' in respect of Johnny and that he was not expected to survive the weekend if he continued as he was. She also forwarded an email from the Best Interests Assessor and concluded by saying 'if there was anything your team could do to assist, please do. I just wanted to make you aware'. The Best Interests Assessor's email stated that Johnny's mental state and physical condition appeared to have rapidly deteriorated over the past three weeks and that he had refused food since 21st December 2017 and not drunk any fluids since early afternoon on 3rd January 2018. His mouth looked dry and he could barely speak. The assessor said that Johnny was refusing all medication and had not had a bowel movement for eight days. Johnny was said to be unwilling to engage with any

discussions about his care arrangements and repeatedly told her and the paid RPR to 'get away from me'. The Best Interests Assessor went on to express concern that at that time of the issue of the SOI by Consultant Geriatrician 2 on 27th December 2017 there was 'no evidence' of MCA or Best Interests considerations, in particular in respect of the option of covert administration of medication or artificial means of providing nutrition and hydration. The Best Interests Assessor also expressed concern that admission to hospital 'had not been considered' despite his most recent DNAPR stating that he was for hospital if suffering from a life-threatening illness. The Best Interests Assessor's third concern was that Johnny had been seen by the Consultant in Old Age Psychiatry on 28th December 2017 who informed Care Home 1 that Johnny was choosing not to eat, drink or take medication. The assessor was concerned that there was again no evidence of the assessment of Johnny's mental capacity to make this significant decision with potentially irreversible consequences or of Best Interests' considerations. She also expressed concern that Johnny's behaviour had been described to her as being 'on hunger strike' and 'a protest'. She concluded by acknowledging that Johnny was undoubtedly a difficult person to care for but she did not feel he had been afforded the full protection of the Mental Capacity Act. She said that the Care Home 1 acting manager had agreed to contact NHT Advanced Practitioner 1 and Consultant Geriatrician 2 the next day to discuss Johnny's case urgently. The assessor had also left a message for the neighbouring authority CMHT Care co-ordinator 1 to contact her as he had knowledge of Johnny from when he was his care co-ordinator. It was noted that Johnny's current Care Co-ordinator 2 was on leave until 14th January 2018.

4.129 Following receipt of this email, the Manchester MASH documented that the case was to be stepped up to a Section 42 Enquiry 'due to the complexity of the referral and the current situation'. Johnny was said to be currently receiving palliative treatment but there had been concerns raised regarding alleged neglect at the home and an alleged lack of documentation and failure to follow procedure with regard to mental capacity assessment and Best Interest process by the medics in charge of his care. Due to Johnny's current poor health, the risk was considered to be significant, including risk of his death and actions were required imminently. It was therefore decided to proceed to a Section 42 enquiry in order to ensure that due process was followed and information and evidence gathered about the concerns raised and meetings held as required.

4.130 The email from the Best Interests assessor was also sent to the neighbouring authority CMHT. Johnny's previous CMHT Care Co-ordinator 1 contacted the Best Interests assessor and visited Johnny the same day. On the same date (Friday 5th January 2018) the paid RPR advised the acting manager at Care Home 1 to call an ambulance for Johnny and it was her and social worker 1's understanding that an ambulance was on its way to take Johnny to hospital. However, it is understood that

the Care Home 1 acting manager cancelled the ambulance. The Care Home 1 chronology states that the acting manager had a conversation with NHT Consultant Geriatrician 2 who advised against hospital admission. It is understood that the DNACPR was 'redone' with a statement of intent. The consultant documented that Johnny was not for hospital and her rationale was that his niece was a good contact and that they agreed that Johnny had 'given up'. Johnny's preferred place of death was recorded as Care Home 1.

4.131 On 6th January 2018 the Manchester contact centre received a referral from Care Home 1 to inform that concerns of alleged neglect of Johnny had been raised about which they had notified the Care Quality Commission (CQC). A copy of the CQC notification was shared with the MASH and included the following:

- Johnny was refusing food and all interventions.
- The care home had referred Johnny to a dietician.
- Medication reviews had been completed and medications changed.
- Doctors had been called and attended the home on three visits.
- A statement of intent had been completed by consultant following discussion with the family
- Concerns regarding DNACPR had been raised by the DoLS Best Interests Assessor.
- Care Home 1 had requested copies of the Mental Capacity assessment and Best Interest decision
- Care Home 1 had requested a Doctor attend to see Johnny to 'consider hospitalisation and possible Section'.

The contact centre passed this information directly to the locality social work team and social worker 1.

4.132 On Monday 8th January 2018, when it was established that Johnny had not been taken to hospital, the Bests Interests assessor escalated the matter to the learning disability service manager at the neighbouring authority Council, who then discussed the issue with NHT Consultant Geriatrician 2. The learning disability service manager advised that she would make an urgent Welfare Application to the Court of Protection unless the consultant reconsidered her view that Johnny should not be admitted to hospital. (A 'personal welfare application' may be made to the Court of Protection in respect of a decision concerning treatment to which the person cannot consent, a decision which is difficult or complex, where someone disagrees with a course of action or the person needs ongoing help with decisions relating to personal health and welfare). It was at this point that an ambulance was called and Johnny was admitted to Hospital 1. The NHT chronology states 'Consultant Geriatrician 2 visit: Review visit and rationale. Contact with IMCA and request to hospitalise'.

4.133 On 9th January 2018, following his admission to Hospital 1, a Safeguarding Planning meeting was held at which it was confirmed that Johnny had been stepped down from a statement of intent and that he was being treated with IV fluids and antibiotics. In attendance was the Hospital Consultant, an IMCA, Senior social workers from the neighbouring authority Hospital Social Work Team, Hospital Trust Safeguarding Nurse and social worker 1 and her team manager. The meeting reviewed the recent safeguarding enquiries, the first of which had been completed and the second of which was ongoing. It was noted that the first safeguarding enquiry had resulted in a request to the neighbouring local authority CMHT for support planning. The 27th December 2017 SOI giving Parkinsonism as the advanced and irreversible illness likely to lead to Johnny's death was noted as was the discussion with Johnny's niece. The visit to Johnny the following date by the Consultant in Old Age Psychiatry was also noted. It was stated that the consultant had subsequently advised social worker 1 that there had been no information provided to him regarding 'hunger strike' or refusal to eat, or challenging behaviours. The Consultant in Old Age Psychiatry added that his assessment and advice may have been different had he received this information. The Hospital Consultant had previously seen Johnny in the community to complete the diagnosis of Parkinsonism in October 2017 (Paragraph 4.97) and she reflected that he presented as having much deteriorated from that time. The consultant noted that Johnny had a physiological age of around 20 years older than his chronological age and it was felt that he was at the end of his life. The consultant felt that any additional support at that time would not support any improvement in his outcome and would cause significant distress. After the Hospital Consultant contacted Johnny's niece, it was agreed that Johnny would not benefit from artificial feeding. The meeting agreed that Hospital 1 and the IMCA were required to consult legal services as to whether a Court of Protection Welfare Decision was required at that time. Due to concerns raised regarding Care Home 1, Johnny was to remain in the care of Hospital 1 and was subsequently placed on the end of life pathway. The hospital made a DoLS referral to Manchester Contact Centre.

4.134 Johnny was referred to RAID and on 10th January 2018 the RAID Consultant reviewed him on the hospital ward. No concerns were expressed about the decision to palliate, and the record of the discussion with Johnny's niece together with the community-based reviews conducted by Consultant Geriatrician 2 and Old Age Consultant Psychiatrist 1 were considered.

4.135 The Section 42 Enquiry in respect of the third safeguarding referral (Paragraph 4.129) had commenced on 8th January 2018. A referral was made to the GMP public protection investigation unit (PPIU) who ultimately decided that there was no role for the police. Liaison, information gathering and case discussions were taking place between social worker 1, her team manager, Care Home 1 acting

manager and the clinical commissioning group (CCG) safeguarding lead. Further information was required from a number of sources across Manchester and the neighbouring local authority.

4.136 On 14th January 2018 Johnny died in Hospital 1. His cause of death was recorded as:

1a. Bronchopneumonia, frailty

1b. Secondary Parkinson's (drug induced)

1c. Schizophrenia

5.0 Contribution of family and friends

5.1 Johnny's sister and her daughter (Johnny's niece) live in the USA. They decided not to contribute to the review whilst it was in progress, but at the conclusion of the review, Johnny's niece discussed the findings and recommendations arising from the review in a video conference call with the lead reviewer. However, a friend of Johnny's niece has contributed to the review and her account is summarised in the following paragraphs.

5.2 The friend knew Johnny through her friendship with his niece from the age of eleven. She was aware of his diagnoses of epilepsy and schizophrenia which she felt contributed to his parents adopting quite a protective approach towards him which may have limited his opportunity to lead a more independent life. She said that he found it difficult to look after himself after his parents died. She recalled him working for Remploy and as a park keeper although he had long periods out of work.

5.3 The friend renewed contact with Johnny after many years when his niece visited the UK in May or June 2017 and stayed at the friend's home in Greater Manchester. She said that the niece had lost contact with Johnny and when she visited the UK in 2017 didn't know whether he was alive or dead. Together, they visited Johnny's home which they found to be up for sale and apparently cleared of his possessions. They contacted the estate agent who put them in touch with Johnny's solicitor and they were able to establish Johnny's whereabouts in Care Home 1.

5.4 The niece and her friend visited him in Care Home 1 and found him to be bed bound and reliant on 24 hour care. In the view of the friend, Johnny definitely had mental capacity at this point as he talked very knowledgably about current political affairs and listened intently to his radio to keep up to date. She described him as 'very strong willed' at that time. She added that he seemed to enjoy the visits from his niece and when she returned to the USA at the end of her holiday, the friend decided to continue visiting Johnny in Care Home 1. She continued to visit him until shortly before his death and began taking notes from early December 2017 to relay back to his niece in the USA.

5.5 Drawing upon these notes, the friend said that she visited Johnny on 3rd December 2017 and took him a parcel from his family in the USA. She noted that he did not have the strength to lift a drinks bottle to his mouth and she had to help him eat a jam doughnut.

5.6 When she next visited Johnny on 24th December 2017 she said she was quite shocked by his deterioration. She said he was in a very poor state, was not interacting with others or eating and drinking. She was later told by Care Home 1 staff that Johnny had begun a 'hunger strike' on this date.

5.7 Her next visit took place on 28th December 2017 after she had received a telephone call from Consultant Geriatrician 2 the previous day in which the latter had told her that Johnny was dying and that she thought he had 'given up'. During the 28th December 2017 visit, the friend noted that Johnny was able to drink two glasses of cordial and half a chocolate bar she had taken in. She noticed a plate of cheese sandwiches lying on his bed which looked 'very stale'. She noted that Johnny said that he would like something to eat to a carer but his request was either not heard or overlooked.

5.8 The friend continued to visit him regularly until her final visit on 4th January 2018 when she felt that Johnny just wanted to be left alone. On 8th January 2018 the friend received a telephone call from Consultant Geriatrician 2 who told her that 'social services' and an IMCA had assessed Johnny and recommended his admittance to hospital. She gained the impression that there was a disagreement between the Consultant Geriatrician and 'social services' over how Johnny's end of life care was to be managed. The friend said that her stance was that she would agree with whatever the professionals advised.

5.9 Reflecting on her contact with Johnny whilst he was placed in Care Home 1, she felt that he was disadvantaged by not having a family member around to be his advocate and speak up for him. She felt that Care Home 1 staff could have done more to encourage Johnny to eat whilst accepting that he could be 'very obstructive'.

5.10 She said that during her visits, Johnny regularly talked about wanting to go home and that once he came to the conclusion that this wasn't possible, he mentally gave up.

5.11 She noticed that his room at Care Home 1 did not contain any items from his home such as family photos although part of his 'huge music collection' had been taken to his room.

5.12 When this report was complete, the friend and Johnny's niece held a video conferencing meeting with the lead reviewer. This provided an opportunity for the lead reviewer to go through the findings and recommendations arising from the SAR report with Johnny's niece and her friend. They both expressed satisfaction with the report and fully supported the findings and recommendations.

5.13 Johnny's solicitor also contributed to this review. He had lasting power of attorney (LPA), which allows for the appointment of one or more people to help someone make decisions or to make decisions on their behalf. There are two types

of LPA – 'health and welfare' and 'property and financial affairs'. The solicitor had LPA in respect of Johnny's property and financial affairs.

5.14 The legal practice's file in respect of Johnny was opened on 28th November 2016, which was the point at which a suitable nursing placement was being sought for Johnny. The solicitor advised that he became involved in Johnny's case from 15th June 2017 and in August of that year he brought some items from Johnny's home into Care Home 1 to help personalise his room. The solicitor discussed the sale of his home with Johnny but he was adamant that he did not wish to sell it. However, by the time he saw Johnny on 16th October 2017, the latter's funds had 'depleted dramatically' because of the high costs of unoccupied property insurance, a condition of which was that the property should be visited regularly. These visits were also costly as the legal practice charged their hourly legal rate to carry them out. The solicitor confirmed that Johnny did not make any financial contribution to the cost of his care at Care Home 1, adding that according to his records the placement was fully funded under Section 117.

5.15 On 16th October 2017 the solicitor decided that Johnny lacked capacity to make decisions in respect of the disposal of his property as he appeared unable to understand that he was never going to be able to return to his home, that his ability to meet the cost of keeping the property was diminishing and that in these circumstances the property needed to be sold. The solicitor then initiated arrangements to dispose of the property.

5.16 The solicitor said that in concluding that Johnny lacked capacity, he applied the principles of the Mental Capacity Act but it was essentially a judgement call on his behalf. Whilst the interests of Johnny as his client were paramount, he also had to consider the interests of any future beneficiaries of Johnny's estate, adding that he liaised with the niece periodically.

5.17 The solicitor observed that Care Home 1 seemed to struggle to cope with Johnny.

5.18 When this report was complete, relevant extracts from the report which related to Johnny's contact with his solicitor were sent to the solicitor for any comment he wished to make. No comments were received.

6.0 Analysis:

6.1 In this section of the report the areas of focus set out in Section 2 of the report will be considered in detail.

How effectively were Johnny's physical and mental health needs assessed?

6.1 During the period under review four key assessments of his needs took place. They all took place whilst he was a patient in Hospital 1 between October and December 2016. A Nursing Needs Assessment (NNA) (Paragraphs 4.24-4.26) concluded that he was eligible for nursing home care, an Elderly Mentally Ill/Infirm (EMI) assessment (Paragraphs 4.27-4.29) determined that he did not meet the criteria for an EMI placement, an NHS Continuing Healthcare (CHC) assessment found him to be ineligible for CHC funded health care (Paragraph 4.28) and the healthcare admission assessment assessed him as suitable for a placement in Care Home 1 (paragraphs 4.36-4.39).

6.2 The NNA was a vital assessment because, once it had been determined that Johnny was ineligible for an EMI placement, the NNA was the document which was circulated to nursing homes in an effort to secure Johnny a placement to meet those needs. The NNA was completed briefly and inaccurately. His 'previous medical history' includes Parkinson's rather than secondary Parkinsonism, includes bipolar disorder which does not appear as a prior diagnosis in the information shared with this review, excludes depression, axonal sensorimotor neuropathy and the apparently unaddressed appendiceal mucocele. The NNA correctly observed that Johnny's mental illness could affect his mood and behaviour, although this is not further explored, before the assessment goes on to document challenging behaviour, sexually inappropriate behaviour toward staff and 'attention seeking behaviour'.

6.3 The NNA was largely hospital focussed with only two Hospital 1 consultants and the RAID mental health practitioner who subsequently carried out the EMI assessment included in the list of professionals involved in Johnny's care in the past six months. Johnny's social worker was recorded to be a hospital social worker and it was to this hospital social worker that the discharge notice had been sent shortly after Johnny's admission (Paragraph 4.23). The only apparent involvement of the neighbouring authority CMHT arose when Johnny declined to sign the assessment until he had spoken to his CMHT care co-ordinator.

6.4 The NNA included no recommendations although it acknowledged that, in parallel, Johnny had been assessed as not meeting the criteria for an EMI nursing home placement.

6.5 The EMI assessment was completed by a RAID practitioner and was also extremely brief. However, Johnny's neighbouring authority CMHT care co-ordinator 1 was consulted. No justification for why Johnny did not meet the criteria for an EMI placement was documented. The assessment simply recommended 'General nursing home where he would have support from district nurses and community mental health teams'. NHS advice to people undergoing a mental health assessment (2) states that during an assessment, the following points will be considered (where relevant):

- their mental health symptoms and experiences
- their feelings, thoughts and actions
- their physical health and wellbeing
- their housing and financial circumstances
- their employment and training needs
- their social and family relationships
- their culture and ethnic background
- their gender and sexuality
- their use of drugs or alcohol
- their experiences, especially of similar problems
- issues relevant to their or others' safety
- whether there's anyone who depends on them, such as a child or elderly relative
- their strengths and skills, and what helps them best
- their hopes and aspirations for the future

The duration of the EMI assessment was documented to be '130'. Whilst it is unclear whether this was one hour thirty minutes or 130 minutes, this does suggest much more was covered than is documented in the record of the assessment shared with this review.

6.6 The RAID practitioner's assessment also concluded that Johnny did not 'screen in' for NHS Continuing Healthcare (CHC) funding although once again no justification for this decision was recorded and there is no indication that the CHC decision support tool, the completion of which is required to determine eligibility, was utilised, or if utilised there is no record on Johnny's file. To have met the criteria for CHC funding, Johnny's primary health need would have to have been assessed as one related to the treatment, control, management or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional)

(3). Full assessments for NHS continuing healthcare should be undertaken by a multidisciplinary team (MDT) made up of a minimum of two professionals from different healthcare professions (4). Although the RAID practitioner conducting the EMI/CHC assessment consulted with Johnny's CMHT care co-ordinator, a multi-disciplinary approach was not otherwise in evidence.

6.7 The CHC decision was followed up by the neighbouring local authority CCG Personalised Care Team, which is responsible for processing CHC applications in respect of patients with a GP in that area, six months later when they requested that Care Home 1 submit up to date information to enable them to reconsider Johnny's CHC eligibility. No information was forthcoming from Care Home 1 although this *may* have been because his placement was fully funded under Section 117 of the Mental Health Act). Care homes may lack an incentive to apply for CHC funding if residents are already receiving funding from another source, as in Johnny's case. CHC funding may have made a difference to Johnny's care in that he would have been fully assessed and his placement considered to see if it was suitable and he would have had more access to nursing care.

6.8 The RAID recommendation that Johnny required general nursing care was revisited just prior to his placement in Care Home 1 at the request of Johnny's CMHT care co-ordinator 2 as hospital staff reported that Johnny had been challenging and aggressive (Paragraph 4.34). The RAID team concluded that general nursing care remained valid for Johnny although in reviewing their initial recommendation they appeared to rely exclusively on his presentation whilst in hospital and were therefore dependent on what had been recorded by staff caring for him in the hospital setting.

6.9 The Healthcare agency that ran Care Home 1 assessed Johnny's suitability for a placement in Care Home 1. This brief and incomplete assessment largely focussed on Johnny's physical needs. There was no reference to schizophrenia, epilepsy, osteoporosis, self-neglect or any challenging or inappropriate behaviours. Parkinson's was recorded as opposed to Secondary Parkinson's. The apparently erroneous bipolar disorder diagnosis from the NNA was repeated.

6.10 Overall the standard of assessments which determined and subsequently informed the provision of Johnny's future care appears to have been extremely limited and represented a crucial contributing factor in the Care Home 1 placement not meeting his needs satisfactorily. Overall, there was a much stronger emphasis on Johnny's physical needs as opposed to his mental health needs and the inter relationship between his mental and physical health needs, though highlighted in the NNA, went largely unexplored. The practitioners conducting the assessments had no prior knowledge of Johnny and the neighbouring authority CMHT, which had had substantial involvement with Johnny over several years, was involved primarily as a

consultee to hospital-based assessments. Additionally, hospital settings are not appropriate places in which to assess people's needs. Johnny had spent over a month in Hospital 1's then discharge to assess unit prior to an earlier hospital discharge in May 2016 (Paragraph 4.11) which was a far more appropriate environment in which to assess his needs.

6.11 The SAR Panel which has overseen this review noted a general tendency for physical health needs to 'trump' mental health needs possibly because there are a greater range of physical health services to refer service users to whilst there is not an abundance of specialist mental health placements and they tend to be more expensive.

6.12 None of the assessments made any reference to Johnny's eligibility for Section 117 Mental Health Act aftercare, or sought to specify which aspects of his care fell under the definition of his Section 117 aftercare, despite the fact that it appears to have been an important factor in discussions about the funding of Johnny's placement (Paragraph 4.35). Section 117 aftercare is NHS funded care which aims to prevent the mental health condition which led to a person being sectioned under the Mental Health Act from worsening and to avoid re-admission to hospital. It is understood that Johnny's Section 117 aftercare never terminated and *may* have fully funded his placement in Care Home 1.

The response of agencies to Johnny's dissatisfaction with his placement in Care Home 1.

6.13 The transition from being supported to live in his own home to being placed in a nursing home seemed likely to be a difficult adjustment for Johnny. In 2015 he had reluctantly agreed to leave his home before changing his mind the following year and being supported by an 'intensive' home care package which by July 2016 was described as 'close to breakdown' (Paragraph 4.15).

6.14 He appeared to find communal living difficult when cared for in the discharge to assess unit from April 2016 where he was noted to be demanding and aggressive towards staff. Other patients exercising control over the TV remote and having to wait for his breakfast whilst staff attended to other patients appear to have been recurrent concerns (Paragraph 4.11).

6.15 His lack of insight into the substantial challenges he would face in sustaining a return to live in his own home, even with a substantial support package in place, was a recurring theme (Paragraph 4.18 and others).

6.16 Johnny's dissatisfaction with his placement in Care Home 1 and wish to speak to a social worker in order to discuss leaving as soon as possible was first documented on 23rd January 2017 by a Consultant Geriatrician from the NHT (Paragraph 4.44). The consultant responded by referring Johnny to a psychiatric unit in the neighbouring authority and to the neighbouring authority 'social services' for a placement review. The neighbouring authority CMHT do not appear to have been notified of the first, or received the second referral.

6.17 When the NHT received no response to the referral to the neighbouring authority 'social services', they sent a referral to Manchester Mental Health Services via Gateway on 6th February 2017 (Paragraph 4.47). (At that time mental health services in the neighbouring authority and Manchester were provided by separate organisations). On 8th February 2017 the NHT were advised that Johnny had a CMHT Care Co-ordinator who was contacted by the Care Home 1 assistant manager to express concern that they were unable to meet his needs and it was their understanding that the care co-ordinator would request a psychiatric review of Johnny by the neighbouring authority CMHT consultant (Paragraph 4.49). Some form of review appears to have taken place on 16th February 2017 (Paragraph 4.54) which concluded that Johnny's eating and drinking had improved and that he appeared more settled. However, as will be discussed later in this report, the focus of the neighbouring authority CMHT was almost exclusively on transferring responsibility for Johnny's case to mental health services in (South) Manchester.

6.18 Contrary to the findings of the neighbouring authority CMHT's 16th February 2017 'review', on 3rd February 2017 Johnny was documented to be angry about being at Care Home 1 by a different NHT consultant who incorrectly advised him that returning home was not an option as his house had been sold (Paragraph 4.46). Johnny's solicitor did not proceed with arrangements to sell Johnny's house until eight months later (Paragraph 4.98). Johnny's dissatisfaction with his placement appeared to be directly linked to what was often to be described by practitioners as 'challenging behaviour'. On this occasion he presented as verbally aggressive and refused his medications.

6.19 Four days later (7th February 2017) Johnny's behaviours – verbal abuse and attempted physical abuse of care staff, damage to his bed and throwing drinks on the floor – were attributed to Johnny being on 'hunger strike' (Paragraph 4.48). This was the first of many times the term 'hunger strike' was used, implying that Johnny's refusal of food and fluids represented some form of protest. If his behaviour at this time was motivated by some form of protest, it seems reasonable to assume that he was protesting against his placement at Care Home 1. Over time, the term 'hunger strike' came to be utilised by practitioners in ways which appeared to be harmful to Johnny, which will be discussed later in the report.

6.20 By 20th February 2017 Johnny had lost 10kg in weight and was said to often refuse food (Paragraph 4.55). An unspecified 'high level intervention' was required to respond to behaviours documented as punching, spitting and swearing at Care Home 1 carers on 27th February 2017 (Paragraph 4.56) and four days later he was admitted to Hospital 1 after becoming dehydrated after not taking fluid for 24 hours and eating for five days. Johnny said he would be 'better off dead, than in this prison'. It must have been obvious to practitioners that Johnny remained deeply unhappy in his placement.

6.21 His unhappiness in his placement was very apparent during the RAID assessment which took place during his Hospital 1 admission, when he was said to be dwelling on the fact that his house had been sold and he had moved into a nursing home to which he said he did not want to return. (During the first half of 2017 Johnny's contact with his solicitor appears to have been limited and so he may have taken the consultant's advice that his house had been sold (Paragraph 4.46) at face value). A post discharge review of Johnny by the neighbouring authority CMHT was envisaged in the hospital discharge summary but there is no indication that this took place. Therefore the only response to Johnny's repeatedly and on occasions forcibly expressed unhappiness with his placement remained the apparently superficial 16th February 2017 CMHT review.

6.22 On the day following his discharge back to Care Home 1, Johnny's continued refusal of food, fluid and medication was documented by Consultant Geriatrician 2 as a behavioural problem and a manifestation of attention seeking behaviour (Paragraph 4.61). This was the third different NHT consultant to see Johnny in a little over six weeks which may have prevented a deeper understanding of Johnny's presenting behaviour being obtained. However, an urgent psychiatric review and an Advanced Care Plan meeting were to be arranged although no indication that either of these interventions took place has been shared with this review.

6.23 Johnny refused to see a trainee doctor in Old Age Psychiatry on 28th March 2017 and was documented to be verbally abusive, refusing to take medication, banging on the bed frame, throwing things and objecting to personal care interventions (Paragraph 4.68). The response to his presentation was to arrange (South Manchester) CPN input.

6.24 When the CPN visited Johnny on 2nd May 2017 Johnny told her that he felt 'fed up' and wanted to return home. Her response was to liaise with CMHT about Johnny's wish to go home (Paragraph 4.74). This liaison appears to have led to some form of involvement by Johnny's CMHT care co-ordinator who documented that Johnny was settled at Care Home 1, although he could change suddenly

(Paragraph 4.78). The need to present Johnny as settled in the placement in order to achieve the transfer of his case to Manchester appeared to be a significant factor in his wish to leave Care Home 1 going unaddressed. GMMH takes the view that another factor was that CMHT care co-ordinator 2 misunderstood how services were configured in Manchester, assuming that they mirrored the way in which mental health services were delivered in the neighbouring authority and that it was therefore necessary to arrange for Johnny to receive the support of a care co-ordinator in South Manchester.

6.25 During June 2017 Johnny's continued desire to return home appeared to result in his CMHT care co-ordinator proposing an application for a DoLS authorisation which was inappropriate given that Johnny had not (yet) been assessed as lacking capacity to make decisions about his placement (Paragraph 4.82).

6.26 By late June 2017 Johnny appeared to have become more reconciled to remaining in Care Home 1. NHT Advanced Practitioner 1, who was the practitioner he had most regular contact with other than Care Home 1 staff, documented that he recognised that he could not realistically go home due to his level of dependency (Paragraph 4.85) and on 20th July 2017 Johnny told the Old Age Psychiatry Trainee Doctor that, overall, he was grateful for the care he was receiving at Care Home 1 and acknowledged that he would need a lot of support if he returned home (Paragraph 4.88). Care Home 1 staff were reporting that Johnny now rarely asked to go home (Paragraphs 4.88 and 4.89). Johnny may indeed have come to the realisation that returning home was no longer a viable option but it seems possible that he may simply have given up asking to leave Care Home 1 because asking the question for the past six months had achieved no genuine review of his placement and nothing had changed for him.

6.27 Thereafter doubts about Johnny's capacity to make decisions about his ongoing care needs and his preferred place of care led to an assessment of his capacity which concluded that he lacked capacity in respect of these decisions (Paragraph 4.93).

The response of agencies to Johnny's 'challenging' behaviour

6.28 Whilst placed in Care Home 1, Johnny's 'challenging' behaviour appeared to be inextricably linked to his unhappiness in his placement. Having said that, agencies had experienced challenges in supporting him prior to his placement in Care Home 1.

6.29 When living in his own home, the police were frequently called to complaints Johnny made about his neighbours such as tampering with his key safe and turning

their heating up so high that he was unable to sleep (Paragraph 4.5 and 4.11). Delusions about his neighbours appeared to have contributed to his 2007 detention under the Mental Health Act (Paragraph 4.4). In 2016 difficulty was experienced in sourcing a home care agency as Johnny had previously accused carers of theft (Paragraph 4.7). However, it is not unusual for people to make accusations against carers and neighbours whilst confused, experiencing stress or mentally unwell. Johnny had been diagnosed with paranoid schizophrenia in 2009, a condition which changes how a person thinks and behaves and is not infrequently characterised by hallucinations and delusions (5).

6.30 However, assumptions about Johnny's behaviour created a risk that concerns he raised were not given due consideration. For example Johnny, who had been documented to be 'very unkempt' on arrival at Hospital 1 in July 2016, complained about his carers during his admission (Paragraph 4.15). It is unclear how his complaint was dealt with although there was a discussion with the neighbouring authority CMHT who felt that his care package had been 'close to breakdown' for several weeks and his care package was transferred to a different provider in September 2016 (Paragraph 4.21). He complained about his new care provider when admitted to Hospital in October 2016, saying that they had not been feeding him and had been poisoning him (Paragraph 4.22). On this occasion, the hospital safeguarding team considered whether this was a safeguarding issue and after consulting a social worker, presumably his CMHT care co-ordinator, decided that there was no evidence that Johnny's carers had been neglectful.

6.31 Practitioners began to perceive his presentation as negative behaviour rather than the manifestation of a physical or mental health need. During his July 2016 admission to Hospital 1, Johnny was said to feel weak and unable to mobilise, although the clinician who assessed him noted that Johnny had previously said he was unable to mobilise 'when he was easily able to' (Paragraph 4.15). Yet during this admission, Johnny required equipment and the assistance of two or three staff in order to stand and minimal improvement in his mobility was noted throughout his stay, despite regular physiotherapy input (Paragraph 4.16).

6.32 Labels began to be applied to Johnny. In the NNA he was said to display 'attention seeking' behaviour (Paragraph 4.25), a phrase also used by NHT Consultant Geriatrician 2 on 8th March 2017 (Paragraph 4.61). Johnny was reported to have begun saying he was on 'hunger strike' when refusing food and fluids on 7th February 2017 (Paragraph 4.48). In the weeks prior to his death practitioner references to Johnny being on 'hunger strike' (Paragraphs 4.133 and 5.6) may have led to an acceptance that he had made a choice and therefore efforts to support him to take food and fluids did not need to be persisted with. His capacity to make such

a 'choice' and understand the consequences of not eating and drinking was not assessed.

6.33 The use of labels such as 'attention seeking' and 'hunger strike' imply that the presenting behaviour is wilful as does the use of the broader term 'challenging behaviour'.

6.34 SAR Panel members felt that nursing and care homes can sometimes struggle to respond to 'challenging behaviour' appropriately. In Johnny's case, Care Home 1 care staff found him to be 'demanding and impatient' from the outset (Paragraph 4.40) without apparently considering the high level of anxiety he may be experiencing at the beginning of a residential placement he had been very reluctant to commit to. NHS guidance on how to deal with challenging behaviour in adults (6), which the guidance defines as putting those around them (such as their carer) at risk, or leading to a poorer quality of life or impacting on their ability to join in everyday activities, advises carers to try to understand why the person they are looking after is behaving in this way, adding that the person may be feeling anxious, bored or in pain. Generally, Care Home 1 staff did not appear to have the skills to understand or indeed respond to Johnny's presenting behaviour. The NHS guidance stresses the importance of recognising early warning signs which could assist the carer in preventing behavioural outbursts (7). Care Home 1 has only been able to share limited records of the care received by Johnny with this review and so it has not been possible to examine how they responded to his 'challenging behaviour' including the use of recommended antecedent – behaviour – consequence (ABC) charts to understand the causes of his behaviour.

6.35 The NHS guidance goes on to advise that if a carer is finding it hard to cope with the behaviour of the person they look after, then professional help should be sought (8). However, Care Home 1 management and staff did not receive the support they needed to address Johnny's presenting behaviour. The NHT did not benefit from the input of dedicated mental health support at that time, as they now do, and Care Home 1 did not receive effective support from the neighbouring authority CMHT whose overriding focus, once Johnny's placement in Care Home 1 had commenced, was on transferring responsibility for addressing Johnny's mental health needs to South Manchester. One unacceptable outcome of this state of affairs was that Care Home 1 carers sometimes found themselves facing behaviour from Johnny which was unpleasant and threatening.

6.36 As long ago as 2007 the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists argued in their *Challenging behaviour: a unified approach* (9) for the phrase 'challenging behaviour' to be redefined owing to the way in which that terminology had become a label to

describe either a diagnosis or a problem owned by an individual which represented an obstacle to the provision of appropriate and effective support. As a result, people were being excluded from mainstream society and segregated into inappropriate services. The report went on to say that challenging behaviour is socially constructed and is a product of an interaction between the individual and their environment and therefore assessment and intervention must address the person, the environment and the interaction between the two. In Johnny's case, much of what was documented as challenging behaviour could be attributed to an adverse interaction with his environment in Care Home 1.

6.37 Many argue that it would be preferable to replace the term 'challenging behaviour' with 'distressed behaviour' as the latter term would encourage practitioners to focus on the cause of the distress.

6.38 Had practitioners focussed on the cause of Johnny's distress this could have led to a stronger focus on reviewing the extent to which the placement in Care Home 1 was meeting his needs but it could also have surfaced other issues. For example the appendiceal mucocele disclosed by a CT scan in May 2016 (Paragraph 4.12) which may have required an appendectomy, remained unaddressed. Symptoms may have included chronic pain, weight loss, nausea, anemia or the presence of blood in urine and the passing of blood through the anus. It seems possible that Johnny's untreated appendiceal mucocele may have affected his presentation and consequently his behaviour.

6.39 A tendency on the part of practitioners to perceive aspects of Johnny's presentation as challenging behaviour and/or related in some way to mental health diagnoses such as paranoid schizophrenia may have led to diagnostic overshadowing which has been defined as '..once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed' (10).

Mental Capacity Act

6.40 Practitioners began to doubt Johnny's capacity from 2015 when it was documented that he 'did not understand what he was being told' (Paragraph 4.6). During his July 2016 hospital admission both the safeguarding nurse (Paragraph 4.17) and the RAID practitioner (Paragraph 4.18) questioned Johnny's capacity to make decisions about his care and whether he could be supported to live at home. It was initially decided that a capacity assessment would be necessary but, in the event, the hospital discharge social worker concluded that Johnny had capacity to return home (Paragraph 4.19). To what extent it might have been expedient to reach this conclusion is unclear.

6.41 Of the key assessments which led to Johnny being placed in Care Home 1, the NNA stated that he had capacity to make his own decisions (Paragraph 4.26) and the RAID EMI assessment found that Johnny seemed to have capacity (Paragraph 4.29). The Healthcare assessment for Care Home 1 did not address the issue of capacity.

6.42 In the early months of Johnny's placement in Care Home 1, different NHT practitioners questioned his capacity (Paragraphs 4.43 and 4.46) whilst others felt there was no reason to doubt his capacity (Paragraph 4.44). A capacity assessment was 'requested' by the NHT and a referral for an IMCA was to be made – in respect of advanced care planning decisions - but by 9th March 2017 it was documented that there was 'no general consensus' regarding Johnny's capacity (Paragraph 4.62). It is unclear whether a formal capacity assessment took place but the proposed IMCA referral did not proceed.

6.43 However, one day before the NHT documented that there was 'no general consensus' regarding Johnny's capacity, a NHT consultant decided that it was in Johnny's 'best interests' for medication to be administered covertly if necessary (Paragraph 4.61). CQC guidance on the covert administration of medicines (11) states that covert administration is only likely to be necessary or appropriate where:

- a person actively refuses their medicine
- that person is judged not to have the capacity to understand the consequences of their refusal
- the medicine is deemed essential to the person's health and wellbeing

6.44 The guidance goes onto state that covert administration of medicines should be a last resort and reasonable efforts must be made to give medicines in the normal manner. Alternative methods of administration should also be considered, such as liquid rather than solid dose forms. The guidance points out that administering medicines in food or drink can alter their therapeutic properties and effects and they could become unsuitable or ineffective. There is no indication that Johnny's capacity to understand the consequences of refusing medication had been assessed. It is also unclear whether medication was, in fact, ever covertly administered to Johnny.

6.45 During a short admission to Hospital 1 around the same time as the NHT concluded that there was no consensus over Johnny's capacity, he was assessed as lacking capacity to consent to blood tests and IV access, and was physically restrained to allow these procedures to be completed. He was documented to be unable to understand, retain and repeat back information to the effect that not eating/drinking/taking medication would endanger his life (Paragraph 4.58).

However, the hospital was treating him for a UTI at this time which could have given the impression of confusion.

6.46 Johnny was assessed as having capacity to discuss, and understand a conversation around his condition and what to do if he deteriorated by an NHT consultant on 27th March 2017 (Paragraph 4.67).

6.47 Two days later Johnny had again been admitted to Hospital 1 (Paragraph 4.70) and when he was non-compliant with repositioning in order to avoid lying on his catheter tube, the tissue viability nurse assessed him as lacking capacity. This was the second hospital admission in short succession when Johnny's lack of compliance with medical procedures or advice was overcome by assessing him to lack capacity in respect of those decisions.

6.48 Differences of opinion within the NHT over Johnny's capacity to make informed decisions over his placement and 'future plans' continued into August 2017 and he was listed for a formal MCA assessment by 'geriatricians' although he was said to have been deemed to have capacity by a 'DoLS assessor' (Paragraph 4.89). It is not known how Johnny came to have his capacity considered by a DoLS assessor as Care Home 1 did not make a DoLS referral until the end of the following month (27th September 2017).

6.49 On 8th September 2017 an NHT consultant assessed Johnny as lacking capacity in respect of his ongoing care needs and preferred place of care. Johnny was noted to engage in conversation but was disorientated to place. He appeared unsure why he had been admitted to Care Home 1 and lacked insight as to his care needs and how he would manage at home. He also lacked insight into the risks of managing without carers and did not appreciate the significant deterioration in his health (Paragraph 4.93).

6.50 On 16th October 2017 Johnny was visited by his solicitor who concluded that Johnny lacked the mental capacity to make decisions relating to the retention or sale of his property and initiated arrangements to dispose of it. (Paragraph 4.98 and 5.14). The solicitor had LPA in respect of Johnny's property and financial affairs. In his contribution to this review, the solicitor said that in concluding that Johnny lacked capacity, he applied the principles of the Mental Capacity Act but it was essentially a judgement call on his behalf. There is no indication that a Best Interests discussion took place. Had such a discussion took place, potential consultees would have been Johnny's sister and niece in the USA, although they may have faced a conflict of interest as potential beneficiaries from the sale of the property. Other potential consultees would have been those involved in Johnny's care. The decision to sell Johnny's home was a pragmatic one, given the cost of

insuring and maintaining the property but does not appear to have been consistent with his desire to retain the property which had been his position whilst he had capacity.

Mental Capacity Act and decisions in respect of end of life care

6.51 On Wednesday 27th December 2017 NHT Consultant Geriatrician 2 saw Johnny at Care Home 1 and concluded that he was dying, that artificial feeding was unlikely to change his prognosis and the focus should be on comfort and supportive care (Paragraph 4.122). The consultant contacted Johnny's niece in the USA who was documented to have agreed that it was in Johnny's Best Interests to receive end of life care at Care Home 1 and not be admitted to hospital as his condition was 'nil reversible'.

6.52 This decision does not appear to have been documented until Friday 29th December 2017 when a colleague of the NHT consultant recorded the following: 'I spoke to Johnny's niece today. Together we have decided it is in Johnny's best interest to have his preferred place of care and death in Care Home 1. Therefore, we have also decided that he is not for hospital escalation. A medical decision was made that he is not to be artificially fed'.

6.53 There is no evidence that an assessment of Johnny's capacity to decide whether he wished to receive artificial nutrition and whether he wished to be transferred to hospital for treatment took place. The consultant could not rely on the most recent capacity assessment conducted on 8th September 2017 as capacity assessments are decision and time specific.

6.54 Assuming that any assessment of Johnny's capacity carried out on 27th December 2017 would have concluded that he lacked capacity to make the relevant decisions, then any action taken, or any decision made for, or on behalf of Johnny, had to be made in his Best Interests. Amongst the factors which should be taken into consideration in deciding what was in Johnny's Best Interests were the individual's past and present wishes and feelings, and any beliefs and values likely to have a bearing on the decision. In terms of hospital admission, at the time a NHT consultant had last discussed the issue with him nine months earlier, Johnny expressed a wish to go to hospital for life prolonging treatment, but did not wish to be revived in the event of collapse (Paragraph 4.67). On 27th December 2017 NHT Consultant Geriatrician 2 concluded that his condition was 'nil reversible', which in her judgement made hospital admission unnecessary as it would not change or improve the outcome for Johnny.

6.55 Turning to the decision not provide artificial nutrition to Johnny, the Royal College of Physicians and British Medical Association guidance entitled 'Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent' contains the following key principles:

- CANH is a form of medical treatment;
- CANH should only be provided when it is in the patient's best interests;
- Decision-makers should start from a strong presumption that it is in a patient's best interests to receive life-sustaining treatment, but this can be rebutted if there is clear evidence that a patient would not want CANH to be provided in the circumstances that have arisen;
- All decisions must be made in accordance with the Mental Capacity Act 2005;
- All decisions must focus on the individual circumstances of the patient and on reaching the decision that is right for that person; and
- as per General Medical Council (GMC) guidance, a second clinical opinion should be sought where it is proposed, in the patient's best interests, to stop, or not to start CANH and the patient is not within hours or days of death (12)

6.56 In Johnny's case, the consultant sought a second opinion, although the person from whom the second opinion was sought, a specialty trainee 6 doctor, was a more junior colleague. No justification for departing from the 'strong presumption' that it is in a patient's Best Interests to receive life sustaining treatment was documented other than 'a medical decision was made that he is not to be artificially fed'.

6.57 A crucial part of any best interests judgement will involve a discussion with those close to the individual, including family, friends or carers. The consultant spoke with Johnny's niece having checked his Care Home 1 file and noted the contact which had been taking place between them in recent months. She also spoke with the niece's friend who had continued to visit Johnny after the niece returned to the USA (Paragraph 5.7). However, the niece lived in the USA and until the summer of that year appeared to have had no involvement in her uncle's life for a number of years. In these circumstances it would have strengthened the decision making process for an IMCA to have been involved or the paid RPR who had been working with Johnny since 23rd October 2017. Johnny's solicitor could also have been consulted.

6.58 The statement of intent was also completed inaccurately as it gave Parkinsonism as the advanced and irreversible illness likely to lead to Johnny's death despite his diagnosis of Secondary Parkinson's (drug induced) which had led to changes in his medication on 4th October 2017 the effects of which were being monitored by the NHT (Paragraph 4.97).

6.59 The imminent expiry of the DoLS authorisation in respect of Johnny's placement in Care Home 1 does not appear to have been considered.

6.60 The decisions taken by the NHT consultant on 27th December 2019 were challenged by the paid RPR and a DoLS Best Interests Assessor who attended a meeting at Care Home 1 on 4th January 2018. The Best Interests Assessor expressed concerns that the decisions taken by the NHT consultant on 27th December 2017 were not consistent with the requirements of the Mental Capacity Act nor was justification provided that the decisions were taken in Johnny's Best Interests. Concern was expressed that artificial nutrition had been ruled out and covert administration of medication had not been considered. The Best Interests Assessor also expressed concern that Johnny had not been admitted to hospital despite his most recent DNACPR stating that he was 'for hospital' if suffering from a life-threatening illness.

6.61 This was an entirely legitimate professional challenge. However, when the Care Home 1 manager, who had been present at the 4th January 2018 meeting at which the above concerns had been raised and a decision taken to summon an ambulance to convey Johnny to hospital, consulted with the NHT consultant, the latter firmly restated the position she had adopted on 27th December 2017 and the ambulance was cancelled (Paragraph 4.130). Given the serious weaknesses in the decision making process and documentation of that process on 27th December 2017, one would have expected the challenges made by the DoLS Best Interests assessor and the paid RPR to have merited a careful review of the original process by the NHT consultant including the seeking of a second opinion from a senior colleague. There is no indication that this happened.

6.62 The NHT consultant reviewed their 27th December 2017 decision following a discussion with the neighbouring local authority Council learning disability service manager who advised the consultant that she planned to make a Welfare Application to the Court of Protection (Paragraph 4.132). Johnny was then admitted to hospital – on 8th January 2018 – where he died six days later.

6.63 Whilst the focus of this review is on learning rather than criticism, it must be stated that the challenge to their decision making in respect of Johnny could have been responded to in a more open manner by the NHT. Professional challenge is an essential element of adult safeguarding and it should be welcomed and encouraged because it is overwhelmingly in the interests of adults who are at risk of abuse or neglect.

Deprivation of Liberty Safeguards

6.64 A standard DoLS authorisation in respect of Johnny was approved by the neighbouring authority Council on 10th October 2017. A condition was attached that Care Home 1 must maintain an accurate record of all the occasions on which Johnny expressed a wish to leave the placement. It was envisaged that this would assist in establishing the frequency and intensity of any objections he had to residing in Care Home 1. The short period of the DoLS authorisation would enable Johnny's objections to be monitored during this period. A paid RPR was arranged to act as Johnny's representative.

6.65 It is unclear whether Care Home 1 arranged to record Johnny's objections to the placement. In any event, his objections had become much less frequent by this time and his health began to decline markedly.

6.66 Johnny's case was allocated for review by the neighbouring authority DoLS team on 19th December 2017 but this had not been completed before the expiry of his DoLS authorisation on 2nd January 2018. Given the forthcoming Christmas and New year holidays, it would have been preferable to allocate his case for review earlier.

6.67 Prior to the approval of the standard DoLS authorisation in October 2017, there had at times been some confusion about the circumstances in which DoLS could be applied. In response to Johnny's objections to his placement at Care Home 1, DoLS applications were thought to be appropriate in February 2017 (Paragraph 4.46) and June 2017 (Paragraph 4.82) despite the fact that on neither occasion had his capacity to decide where he was supported to live been assessed.

6.68 Although Johnny's view of his own ability to cope at home was unrealistic, it was inappropriate to focus on depriving a person of their liberty who retained the capacity to make decisions about where he lived and was not consistent with Article 5 of the Human Rights Act which states that 'everyone has the right to liberty and security of person. No one shall be deprived of his or her liberty [unless] in accordance with a procedure prescribed in law'.

The extent to which Johnny's voice was listened to

6.69 Johnny had been extremely reluctant to give up his relative independence and move into nursing care. He struggled to adapt to life in Care Home 1 and began expressing his unhappiness there from an early point in his placement. Although providing him with care and support whilst he lived in his own home had presented challenges to practitioners and others over the years, Johnny's unhappiness in his placement at Care Home 1 manifested itself in a range of behaviours which signalled his distress and put himself and those caring for him at risk at times.

6.70 Johnny's transition from his home to residential care did not appear to have been managed in a person centred manner. When he agreed to a nursing home placement in October 2016 he would only do so if he was allowed to take his CDs and retain his cable TV and telephone contract (Paragraph 4.29). Although this request was agreed to at the time, there seems to have been a lengthy delay before it was actioned. It was not until May 2017 that CDs and a CD player were brought in to Johnny by his solicitor (seven months later) and August 2017 before his solicitor brought in some items from his home to personalise his room at Care Home 1 (Paragraph 5.14).

6.71 There is a sense that Johnny was very much 'on his own' when he first moved into Care Home 1. His case had been allocated from his longstanding CMHT care co-ordinator who knew him well to a different care co-ordinator who was primarily focussed on transferring responsibility for his case to South Manchester. He appeared to have lost contact with his relatives in the USA at that time and in order to understand his needs, the care staff at Care Home 1 and the members of the NHT were reliant on the limited assessments undertaken by practitioners who did not know him well and which were completed in a hospital setting.

6.72 It is difficult to reach any other conclusion than that Johnny was profoundly unhappy and often distressed for much of the final year of his life. His concerns were not acted upon (until his paid RPR became involved), his placement was not properly reviewed and when he began to exhibit distress, instead of the sources of that distress being explored with him, professionals largely focussed on his presenting behaviour and began to think in terms of restricting him.

6.73 If, as the Care Act 2014 states, the core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life (13), Johnny was clearly comprehensively failed.

How effectively were the series of adult safeguarding concerns raised in respect of Johnny in the months prior to his death dealt with?

6.74 Safeguarding concerns were raised by the paid RPR on 25th October 2017 (Paragraph 4.101) and on 21st December 2017 (Paragraph 4.115) and by the paid RPR and Best Interests DoLS assessor on 5th January 2018 (Paragraph 4.129). Each concern led to a Section 42 Enquiry and the second and third safeguarding concerns remained in progress at the time of Johnny's death on 14th January 2018.

6.75 There had been prior safeguarding concerns raised in respect of Johnny during the period under review (Paragraphs 4.12, 4.17 and 4.22) but these had not progressed to a Section 42 Enquiry.

6.76 Turning to the one completed section 42 enquiry – in respect of the first safeguarding concern raised by the paid RPR – the safeguarding concern was addressed the following morning by the Manchester MASH and promptly allocated to a social worker in the relevant locality team. The social worker quickly made an unannounced visit to Care Home 1 where Johnny declined to speak to her. However, the social worker viewed Johnny's care plan and identified a number of actions which had been taken in response to the concerns raised. Information was gathered from the referrer, CMHT care co-ordinator 2 and the care home manager. There is no indication that information was gathered from the NHT. A safeguarding planning meeting could have been arranged at this point in order to assess risks and develop an interim safeguarding plan, amongst other things, but this did not happen. The Manchester Safeguarding Adults Board (MSAB) multi-agency policies and procedures (14) do not state that a planning meeting is compulsory, acknowledging that planning is sometimes a process which can be undertaken through telephone conversations etc.

6.77 However, by the time the safeguarding enquiry was closed on 20th November 2017, no multi-agency meeting had been held. Given that this was a case with some complexity, involving 'cross border' issues and that a key action – a review of Johnny's care and support needs -was to be undertaken by the neighbouring authority CMHT - a service from outside the Manchester City Council area, it would have been beneficial for a multi-agency meeting to have been held in order to ensure that the actions necessary to safeguard Johnny were put in place and made the necessary difference.

6.78 The aforementioned MSAB multi-agency policy and procedures state that following the completion of the Section 42 enquiry, an outcomes meeting *may* be held, ideally, within 21 days of the completion of the enquiry (15). Amongst the objectives of an outcomes meeting are to consider the extent to which the outcomes identified by the person or their advocate have been met and the person's ongoing needs for care and support. No outcomes meeting was held in this case.

6.79 Prior to the closure of the first safeguarding concern there were indications that things were not improving, or improving sufficiently for Johnny (Paragraph 4.109). There is no indication that the CMHT reviewed Johnny's care and support needs. However, this particular outcome of the safeguarding enquiry appeared to have been articulated as a request from the social worker carrying out the Section 42 enquiry rather than an agreed outcome of the process and, in the absence of an

outcomes meeting, there seemed to be no mechanism for ensuring that the review of Johnny's care and support needs actually took place.

6.80 When the second safeguarding concern was raised, it was appropriately considered by the Manchester MASH and promptly allocated to the same social worker, although the imminent Christmas/ New Year holiday period meant that there was some delay in the enquiry being commenced. However, the content of the safeguarding concern indicated that Johnny continued to experience neglect in his placement and that the issues raised in the first safeguarding concern had not been addressed sufficiently.

6.81 This second safeguarding concern in fairly quick succession could have prompted questions about the standard of care provided at Care Home 1. During Johnny's placement there, the establishment had been inspected by the CQC on two occasions. In January 2017 the CQC found that insufficient improvement had been made in response to the seven breaches of the Health and Social Care Act Regulations identified in the previous inspection in May 2016 and further concerns were identified in respect of insufficiently robust risk assessments, lack of detail in care plans, administration of medicines, physical safety hazards and application of the Mental Capacity Act. Care home 1 was rated 'Requires Improvement' overall and inadequate for 'well-led'. In September 2017 the CQC inspected the establishment again and found that improvements had been made in the areas of concern although a new breach was identified in respect of safe recruitment of staff and a continued breach in respect of safe care and treatment.

6.82 The CQC report on the second inspection they undertook of Care Home 1 following Johnny's death – on 10th December 2018 - stated that whilst completing the inspection, the CQC received a notification from HM Coroner that a Regulation 28 Notice (Prevention of Future Death Reports) had been served on the provider of Care Home 1 in respect of failures which preceded the death of a resident of Care Home 1 in November 2017 – which was two months prior to the death of Johnny. During the inquest into this earlier death, the current manager of Care Home 1 had indicated that between September and November 2017 there were inadequate numbers of staff employed at the home and that this led to a delay in reviewing and reassessing care plans for all residents.

6.83 It is understood that there had been longstanding concerns about the standard of care provided at Care Home 1 and that support had been provided by MCC Performance and Quality Improvement which had led to improvements which the nursing home had been unable to sustain beyond the period during which support was offered. This review has received no indication that the longstanding concerns about the standard of care provided by Care Home 1 were discussed by the host

local authority with the neighbouring authority CMHT although there had been several adverse CQC inspection reports which were publicly available.

Given that Johnny had been placed in out of area residential care, how effectively were the 'cross border' issues which arose addressed?

6.84 The placement of a neighbouring authority resident Johnny in a nursing home in the Manchester City Council area, albeit under a mile away from the neighbouring Council boundary, created a great deal more cross border complexity than was merited.
The RAID EMI assessment which concluded that Johnny's needs would be met in a nursing home placement envisaged that any such placement would be supported by a community mental health team. The community mental health team support provided to Johnny's placement was severely limited by the focus of the neighbouring authority CMHT on transferring Johnny's case to South Manchester, a task which absorbed an inordinate amount of effort, yet remained incomplete at the time of Johnny's death. This adversely affected care co-ordination and care planning for Johnny.

6.85 The extent of the CMHT's involvement in the decision to place Johnny in Care Home 1 is not completely clear. They were consulted in respect of the RAID EMI assessment and later requested that that assessment be revisited after hospital staff had reported that Johnny had been challenging and aggressive (Paragraph 4.34). At the practitioner learning event organised to inform this SAR it was suggested that the placement may have been made with a degree of haste which meant that it bypassed the neighbouring authority CMHT's usual systems although Johnny's care co-ordinator promptly carried out an initial review of his placement in Care Home 1 (Paragraph 4.41).

6.86 However, from early February 2017 the focus of the CMHT shifted to transferring Johnny to the Older Adult CMHT in South Manchester (Paragraph 4.49 and 4.50). The latter service responded by stating that prior to any transfer being accepted, the CMHT needed to conduct a review of Johnny's care needs, the placement needed to be settled and concerns in respect of 'food/medication' needed to be addressed (Paragraph 4.52). South Manchester added that should there be any unreasonable delay in treating Johnny, they would 'step in' in his Best Interests.

6.87 The neighbouring authority CMHT conducted a review on 16th February 2017, of which no detail has been shared with this SAR, which concluded that Johnny's eating and drinking had improved and that he appeared more settled, which appears to have been a highly optimistic view of the state of the placement given the concerns documented by other practitioners at that time. Indeed, the chronology

submitted to this review by GMMH indicates that a more positive view of Johnny's placement than was actually the case may have been generally provided to the various neighbouring authority CMHT MDT meetings at which his case was discussed during his Care Home 1 placement (Paragraphs 4.64 and 4.80).

6.88 The neighbouring authority CMHT continued to hold responsibility for Johnny's case but it is unclear whether they carried out a further review of Johnny's placement as envisaged at the time of his discharge from Hospital 1 following a short admission in March 2017 (Paragraph 4.60).

6.89 South Manchester Older Adult CMHT rejected the transfer of Johnny's case on 14th March 2017 however a clinical transfer to the Consultant Outpatient service was agreed (Paragraph 4.65). When service users are transferred out of area and their care is commissioned and purchased by the Local Authority, transfer to the new locality Mental Health Service may be indicated when care co-ordination is still required. Appropriate measures would need to in place to review the placement as required.

6.90 Notwithstanding South Manchester Older Adult CMHT rejecting the transfer of Johnny's case, a CPN from that team became involved in Johnny's case for a short time in May 2017 but after establishing that the neighbouring authority CMHT retained responsibility for Johnny's Section 117 aftercare, it was decided that CPN support was not required by Johnny.

6.91 Confusion over whether Johnny's case had been transferred from the neighbouring authority to Manchester CMHT was apparent during the Section 42 enquiry into the first safeguarding concern in November 2017 (Paragraph 4.110).

How effective was multi-agency working in respect of Johnny?

6.92 Despite Johnny repeatedly expressing his unhappiness in the placement at Care Home 1, despite his 'challenging behaviour' which the home struggled to address, despite the lack of any meaningful review of his placement, despite the long running but ultimately unsuccessful attempts to arrange the transfer of Johnny's case from the neighbouring authority CMHT to South Manchester Older People's CMHT, despite the safeguarding referrals made and the concerns that Johnny may be experiencing neglect, despite end of life decisions being made in respect of Johnny largely outside an MCA framework, no multi-agency meeting of practitioners took place until the safeguarding planning meeting in Hospital 1 five days prior to Johnny's death. As a practitioner asked at the learning event arranged to inform this SAR, 'How bad do things have to get for a multi-agency meeting to be held?'

6.93 The case was escalated to an extent. Johnny was discussed on several occasions at the neighbouring authority CMHT MDT meetings but this does not appear to have altered the focus on transferring the case to South Manchester. When this proved to be unsuccessful, the CMHT did not raise the issue of case transfer with senior managers in the neighbouring authority area Mental Health Services. This resulted in stalemate between the neighbouring authority and Manchester, and a lack of understanding between the two services as to why the referrals continued to be made and why they were not accepted. Additionally safeguarding referrals were made once the paid RPR became involved. However, the frustrations not infrequently expressed by practitioners could have led to earlier escalation of concerns to management level.

Resource issues

6.94 The impact of austerity is often highly visible when services are cut or decommissioned. At other times the impact is much more subtle. This SAR discloses some of the more subtle impacts of resource pressures which may have been a factor in the lack of a safeguarding planning or safeguarding outcomes meeting in the first Section 42 Enquiry, the lack of any multi-agency meeting to discuss escalating concerns about Johnny's placement in Care Home 1 and the focus of the neighbouring authority CMHT on transferring Johnny's case to South Manchester at the earliest opportunity.

Good practice

- Effective joint working between RAID and the neighbouring authority CMHT in April 2016 when RAID conducted a joint review of Johnny with CMHT prior to his discharge from hospital (Paragraph 4.10).

- Effective communication between Johnny's GP and his carers in July 2016 which led to the calling of an ambulance to convey him to hospital (Paragraph 4.15).

- The two safeguarding concerns raised by the paid RPR when she became involved in supporting Johnny.

- The joint work between the paid RPR and the DoLS Best Interest assessor in challenging the end of life decision making by the NHT and submitting a further safeguarding concern.

7.0 Findings and Recommendations

7.1 This report follows the journey of Johnny, a man with a complex combination of mental and physical health needs, *from* support by community mental health team and a home care package to live in his own home in the neighbouring Council area - arrangements which gradually became unsustainable - *into* hospital followed by discharge to a nursing home placement in the Manchester City Council area where he spent the last year or so of his life.

7.2 This review found that he was not well served by the range of agencies with which he came into contact, or by the systems designed to ensure that his assessed needs were addressed; his placement reviewed; that legal safeguards to ensure he was not subject to unlawful restrictions on his liberty were consistently applied; that decisions were taken in his best interests; that he was safeguarded from neglect; that his voice was listened to and his wishes respected.

Assessments for placements in 24 hour residential and/or nursing care

7.3 The standard of assessments which determined and subsequently informed the provision of Johnny's care in Care Home 1 appeared to be extremely limited and represented a crucial contributing factor in the Care Home 1 placement not meeting his needs satisfactorily. Overall, there was a much stronger emphasis on Johnny's physical needs as opposed to his mental health needs and the inter relationship between his mental and physical health needs went largely unexplored. The practitioners conducting the assessments which resulted in his placement in Care Home 1 had no prior knowledge of Johnny and CMHT, which had had substantial involvement with Johnny over several years, was involved primarily as a consultee to hospital-based assessments.

7.4 Both Manchester Safeguarding Partnership and the neighbouring Safeguarding Partnership may wish to consider an audit of the standard of relevant assessments, including those carried out in hospital settings, because the implications of a failed placement or needs not being met for the service user can be significant, as in this case.

7.5 Both Manchester Safeguarding Partnership and the neighbouring Safeguarding Partnership may also wish to audit the extent to which assessments conducted in hospital settings are sufficiently informed by community based services, including those who hold statutory responsibilities for the service user.

Recommendation 1

That Manchester Safeguarding Partnership commission audits of the standard of assessments of service users, including those carried out in hospital settings, in respect of whom a residential 24 hour care placement is being considered.

Recommendation 2

That Manchester Safeguarding Partnership commission audits of the extent to which assessments conducted in hospital settings are sufficiently informed by community based services, including those who hold statutory responsibilities for the service user.

Out of Area Placements

7.6 The placement of a neighbouring local authority resident Johnny in a nursing home in the Manchester City Council area, albeit under a mile away from the Council boundary, created a great deal more cross border complexity than was merited. As a result of the cross border issues described in Paragraphs 6.83 to 6.90, Johnny's placement was not meaningfully reviewed by the neighbouring authority Community Mental Health Team or the quality of care monitored by the commissioners of the placement.

7.7 Additionally, the advanced practitioner from the NHT who had the most contact with Johnny commented to this review that when people are placed in a residential setting out of area, as they often are within Greater Manchester, practitioners supporting those residents often feel that they have insufficient knowledge of the person's history and physical and mental health conditions. In this case, the South Manchester NHT relied heavily on the limited assessments carried out just before Johnny was placed in Care Home 1. Improving the quality of assessments (Recommendations 1 and 2) could make a difference to this problem.

7.8 There is an additional risk that the placing authority in out of area placements will be insufficiently aware of concerns about the placement known to the host authority. In this case, CQC concerns about Care Home 1 were publicly available but the review has received no indication that the neighbouring local authority sought information held by Manchester in respect of the longstanding concerns about Care Home 1.

7.9 Manchester Safeguarding Partnership and the neighbouring Safeguarding Partnership may wish to obtain assurance in respect of the oversight of out of area placements, in particular that responsibilities are not passed from services in the placing to the receiving local authority area until the placement is assessed as stable and meeting the needs of the service user.

7.10 Additionally Manchester Safeguarding Partnership and the neighbouring Safeguarding Partnership may wish to obtain assurance that any concerns the host authority may hold about a placement are sought out by the placing authority before a placement is agreed.

Recommendation 3

That Manchester Safeguarding Partnership obtain assurance in respect of the oversight of out of area placements, in particular that responsibilities are not passed from services in the placing to the receiving local authority area until the placement is assessed as stable and meeting the needs of the service user.

Recommendation 4

That Manchester Safeguarding Partnership obtain assurance that any concerns the host authority may hold about a placement are sought out by the placing authority before a placement is agreed.

Placement Reviews

7.11 The neighbouring authority CMHT did not complete a substantial review of Johnny's placement in Care Home 1 until August 2017 (Paragraph 4.90). They conducted an initial review shortly after Johnny's placement began (Paragraph 4.41) and a review in February 2017 which prematurely concluded that he had settled in Care Home 1 (Paragraph 4.54). They did not carry out a review of Johnny's placement when requested to do so as a result of the first Section 42 Enquiry.

7.12 It is therefore recommended that Manchester Safeguarding Partnership and relevant authorities seeks assurance from Greater Manchester Mental Health NHS Foundation Trust, which is the provider of community mental health services in those areas, that reviews of service user placements are carried out in a timely and thorough manner.

Recommendation 5

That Manchester Safeguarding Partnership and relevant authorities seeks assurance from Greater Manchester Mental Health NHS Foundation Trust, which is the provider of community mental health services in those areas, that reviews of service user placements are carried out in a timely and thorough manner.

Listening and responding to the wishes of service users

7.13 Paragraphs 6.13 to 6.27 describes the lack of response by professionals to Johnny's repeated objections to his placement in Care Home 1. Whilst his wish to be supported to return to live at home was probably unrealistic and his insight into his ability to sustain such an arrangement was limited, his unhappiness in the placement should have led to a review of the placement but as stated above no meaningful review took place until August 2017.

7.14 Practitioners also considered restrictions on Johnny at times when he retained the capacity to make decisions about where he lived which was inconsistent with Article 5 of the Human Rights Act.

7.15 If, as the Care Act 2014 states, the core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life Johnny was clearly comprehensively failed.

7.16 When Manchester Safeguarding Partnership and the neighbouring Safeguarding Partnership disseminate learning from this review they may wish to take the opportunity to emphasise the importance of listening to service users and responding appropriately to their wishes. It would also be of value to gather and disseminate good practice in respect of listening to service users at that time.

Recommendation 6

When Manchester Safeguarding Partnership disseminate the learning from this review, that they emphasise the importance of listening to service users and responding appropriately to their wishes.

'Challenging' Behaviour

7.17 Whilst placed in Care Home 1, Johnny's 'challenging' behaviour appeared to be inextricably linked to his unhappiness in his placement. The term 'challenging behaviour' has become a label to describe either a diagnosis or a problem *owned by the individual* and has become an obstacle to the provision of appropriate and effective support. In Johnny's case he was also described as 'attention seeking' and on 'hunger strike' which implied that his presenting behaviour was wilful. Such labels can have very harmful effects. For example, in the weeks prior to his death references to Johnny being on 'hunger strike' may have led to an acceptance that he had made a choice and therefore efforts to support him to take food and fluids did not need to be persevered with.

7.18 Many argue that it would be preferable to replace the term 'challenging behaviour' with 'distressed behaviour' as the latter term would encourage practitioners to focus on the cause of the distress.

7.19 SAR Panel members felt that nursing and care homes can sometimes struggle to respond to the type of distressed behaviour with which Johnny frequently presented and that carers may lack the training, support and time to explore why the person is behaving in this way or recognise early warning signs which could assist in preventing behaviour escalating. Being equipped with the necessary skills would contribute to a safer working environment for carers.

7.20 It is therefore recommended that Manchester Safeguarding Partnership promote the replacement of the term 'challenging behaviour' with a less judgemental term such as distressed behaviour in order to encourage practitioners to explore why the person is behaving as he/she is. Practitioners should also be encouraged to challenge the use of the term 'challenging behaviour'.

7.21 It is also recommended that Manchester Safeguarding Partnership and the neighbouring Safeguarding Partnership audit the extent to which the providers of nursing homes have policies, supported by training which provide support to care staff in addressing distressed behaviour by residents.

Recommendation 7

That Manchester Safeguarding Partnership promote the replacement of the term 'challenging' behaviour with a less judgemental term such as distressed behaviour in order to encourage practitioners to explore why the person is behaving as he/she is.

Recommendation 8

That Manchester Safeguarding Adults Partnership commission an audit of the extent to which the providers of nursing homes have policies, plans which are informed by the use of ABC charts and supported by training which provide support to care staff in addressing distressed behaviour by service users.

Mental Capacity Act

7.22 The Nursing Home Team (NHT) carries out emergency visits for residents in the eight South Manchester Nursing Homes including Care Home 1 and plays an important role in reducing hospital admissions by supporting nursing home residents to access the care they need in the community. The NHT is also committed to supporting the delivery of high quality end of life care for residents of nursing homes in South Manchester.

7.23 However this SAR has disclosed a lack of compliance with, and understanding of, the Mental Capacity Act in respect of the NHT's approach to the administration of covert medication, the provision of artificial nutrition, end of life care and Best Interests discussions.

7.24 Manchester Safeguarding Partnership may wish to seek assurance from the Manchester University NHS Foundation Trust, which is the provider of the Nursing Home Team, that members of the team receive the necessary training and support to enable them to confidently apply the Mental Capacity Act.

Recommendation 9

That Manchester Safeguarding Partnership seeks assurance from the Manchester University NHS Foundation Trust as provider of the Nursing Home Team that members of the team receive the necessary training and support to enable them to confidently apply the Mental Capacity Act.

Advocacy

7.25 By the time his placement in Care Home 1 began in December 2016, Johnny had become quite isolated. His closest relatives lived in the USA and appeared to have lost contact with him at that time, his relationships with supportive friends from the churches with which he was involved had come under strain, the providers of his home care package had recently changed and his case had recently been transferred from the CMHT care co-ordinator who knew him well.

7.26 It wasn't until the paid relevant person's representative became involved in his case that concerns about the care and support Johnny was receiving were articulated and safeguarding concerns appropriately raised. This case demonstrates the vital role of advocacy in preventing abuse and neglect in residential settings which should be highlighted in any dissemination of learning from this case.

Safeguarding concerns

7.27 When safeguarding concerns were raised in respect of Johnny, they were dealt with in accordance with multi-agency policy but the only Section 42 Enquiry completed prior to Johnny's death was not successful in achieving the desired outcomes including a review of his placement by the neighbouring authority Community Mental Health Team. In complex cases such as this, there would have been benefit in holding discretionary safeguarding planning and/or safeguarding

outcomes meetings. This could have assisted in holding partner agencies to account and given the safeguarding enquiry greater 'clout'.

7.28 In the experience of this lead reviewer, the lack of multi-agency meetings - physical or virtual - when the circumstances appear to demand such a discussion, is a frequent feature of safeguarding adults reviews. In this case no multi-agency meeting took place until five days before Johnny's death. As one practitioner asked at the learning event arranged to inform this SAR, 'How bad do things have to get for a multi-agency meeting to be held?'

7.29 Manchester Safeguarding Partnership may wish to audit the extent to which safeguarding planning and safeguarding outcomes meetings are held in respect of Section 42 Enquiries in order to establish whether such meetings are held when justified.

Recommendation 10

That Manchester Safeguarding Partnership audit the extent to which safeguarding planning and safeguarding outcomes meetings are held in respect of Section 42 Enquiries in order to establish whether such meetings are held when justified.

Escalation of professional disagreements

7.30 It is understood that Manchester Safeguarding Partnership has no multi-agency process for resolving professional disagreements in respect of adult safeguarding issues. In this case the professional disagreement between the paid RPR and Best Interests DoLS assessor and the NHT consultant geriatrician was not resolved elegantly. The situation degenerated as the NHT adopted an entrenched position and the needs of Johnny and the potential distress to his relatives may have been lost sight of for a time. It is understood that a similar issue was highlighted in an earlier SAR and that an 'escalation policy' is being developed.

7.31 Manchester Safeguarding Partnership may wish to consider developing a process (or refining the proposed escalation policy) for resolving professional disagreements in respect of adult safeguarding issues or adapting the process currently used for resolving professional disagreements in respect of safeguarding children issues. The neighbouring Safeguarding Partnership has advised the review that this recommendation should also apply to them.

Recommendation 11

That Manchester Safeguarding Partnership develop processes for resolving professional disagreements in respect of adult safeguarding issues.

Communication between acute hospital and community mental health services

7.32 During the period covered by this review Johnny was admitted to hospital on several occasions. The review noted that when he was discharged from hospital, a discharge summary would be sent to his GP but not the community mental health team co-ordinating his care. The SAR Panel felt that this was a missed opportunity for community mental health teams to review a service user's care plan in the light of their hospital admission. It is understood that this is an issue which is not limited to the care of Johnny. It is therefore recommended that Manchester Safeguarding Partnership seeks assurance that all agencies working with people in receipt of a complex multi-agency hospital discharge plan contribute to the information sharing and action planning to ensure the person's needs are met.

Recommendation 12

That Manchester Safeguarding Partnership seeks assurance that all agencies working with people in receipt of a complex multi-agency hospital discharge plan contribute to the information sharing and action planning to ensure the person's needs are met.

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

(14) Retrieved from https://www.manchestersafeguardingpartnership.co.uk/adults/Safeguarding

(15) ibid

Appendix A

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

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

Role	Organisation
Panel Member	Manchester City Council Multi-Agency Safeguarding Hub
Panel Member	Manchester Health and Care Commissioning
Panel Member	Manchester University Hospitals NHS Foundation Trust
Panel Member	Greater Manchester Mental Health NHS Foundation Trust
Panel Member	Greater Manchester Police
Panel Member	Manchester Advocacy Service
Safeguarding Partnership Co-ordinator	MSP
Independent Reviewer and SAR Panel Chair	David Mellor

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

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

- Homecare provider
- Greater Manchester Mental Health NHS Foundation Trust Greater Manchester Police
- Manchester City Council Multi-Agency Safeguarding Hub

- Manchester City Council Quality and Contracts Team
- Manchester Health and Care Commissioning – in respect of GP services
- Manchester University NHS Foundation Trust – in respect of Hospital 1 and the Nursing Home Team
- The neighbouring authority Clinical Commissioning Group – in respect of the Personalised Care Team and Local Care Organisation
- The neighbouring Metropolitan Borough Council – in respect of the Deprivation of Liberty Safeguards.

The SAR panel analysed the chronologies and identified issues to explore with practitioners and managers at the learning event facilitated by the lead reviewer which was very well attended by representatives of nearly all of the various disciplines involved in this case.

A friend of Johnny's niece contributed to the SAR as did Johnny's solicitor. At the conclusion of the review, Johnny's niece and her friend discussed the findings and recommendations arising from the SAR report with the lead reviewer. Johnny's solicitor was also provided with an opportunity to comment on those sections of the report which related to the involvement of the solicitor.

The lead reviewer then developed a draft report which reflected the chronologies, the contributions of practitioners and managers who had attended the learning event and the contributions of Johnny's friend and his solicitor.

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