Cambridgeshire and Peterborough Safeguarding Adults Board

Safeguarding Adults Review – "Arthur" (5th October 1957 – 10th April 2018)

Professor Michael Preston-Shoot
Independent Overview Report Writer

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1. Introduction

1.1. Arthur[1] lived in first floor accommodation provided by Clarion (formerly Circle) Housing. He was registered disabled, having Type 2 diabetes and a below the left knee amputation. He is reported to have had limited mobility and to have used a wheelchair. This was stored in a hall cupboard for outside use as it was too big for the flat. He is reported as having been non-compliant with his strict diabetic diet.

1.2. Around the time the referral for a Safeguarding Adult Review was received, he is reported as having expressed a wish to move to alternative housing. He was unable to use his wheelchair indoors due to its size; it would not pass through the internal doorways. He was also unable to access the bathroom. He is reported to have neglected his own health and wellbeing, including hoarding. Paramedics had previously submitted a safeguarding referral regarding Arthur, having found his accommodation to be cluttered and in a "mess". Paramedics registered concern about him living in squalor when transporting him to hospital in August 2017.

1.3. The referral of Arthur's case for a Safeguarding Adult Review records that on hospital admission in August 2017 he had a pressure ulcer to the sacrum[2] and multiple leg dressings to wounds with significant maggot infestation. It records sepsis[3] and environmental concerns and further notes that he was known to have uncontrolled diabetes.

1.4. The referral records that consideration had been given to amputation of the right leg due to infection, gangrene and circulation. However, this decision had been suspended because his condition had improved with intravenous antibiotics (17th August 2017). The referral concludes that Arthur was a "vulnerable adult" with limited mobility, who had suffered significant harm due to potential neglect to his wounds. It was further complicated due to high blood sugars.

1.5. The referral questions whether agencies could have done more to prevent a significant decline in his health and whether he could have been re-referred to hospital sooner because of the breakdown in his wounds. It asks whether anyone noticed that he was becoming septic, which might have been impacting on his mental capacity, and whether anyone saw maggots from his wounds or ischaemia[4] in his leg and tracked how his vascular response was decreasing.

1.6. The referral contains other details. Arthur had been an inpatient at Peterborough City Hospital (PCH) in May/June 2017, being discharged on 1st June 2017 when his wounds are stated to have been superficial. The discharge plan included a referral to district

[1] Arthur is a pseudonym.

[2] Injury to the skin and underlying tissue resulting from prolonged pressure on the skin.

[3] Sepsis - also referred to as blood poisoning or septicaemia

[4] Restriction of blood supply to tissue with resultant damage.

nursing but it is stated that no visit took place until 23rd June and further that the district nursing service discharged Arthur on 27th June, with the expectation thereafter that he would attend the GP surgery. He had, however, consistently failed to attend, possibly due to limited mobility[5].

1.7. Arthur had apparently been compliant in hospital with respect to his care and treatment. A formal mental capacity was not undertaken but the referral from PCH stated that he lacked insight and was unable to keep himself safe. It refers to his hoarding traits and an admission that he bought "stuff" on his credit card. The referral asks whether, if other agencies believed him to have mental capacity, what was put in place to reduce the risks?

1.8. Subsequent to the referral for a review, health, housing and social care agencies continued to have contact with Arthur until his death in April 2018. Cause of death has been recorded[6] as cardiac arrest, peripheral vascular disease, hypertension, sepsis, type two diabetes[7] and hyperosmolar hyperglycaemic state[8].

2. Safeguarding Adult Reviews

2.1. The Cambridgeshire and Peterborough Safeguarding Adults Board (SAB) has a statutory duty[9] to arrange a Safeguarding Adult Review (SAR) where:

- An adult with care and support needs has died and the SAB knows or suspects that the death resulted from abuse or neglect, or an adult is still alive and the SAB knows or suspects that they have experienced serious abuse or neglect, and
- There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

2.2. The SAB has discretion to commission reviews in circumstances where there is learning to be derived from how agencies worked together but where it is inconclusive as to whether an individual's death was the result of abuse or neglect. Abuse and neglect includes self-neglect.

2.3. Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons in the future[10]. The purpose is not to allocate blame or responsibility, but to identify ways of improving how

[5] Sections 7.18 and 9.13.4 clarify the difficulties that Arthur would have experienced leaving his accommodation.

[6] PASC IMR

[7] Cardiac Arrest – the heart stops beating, Peripheral vascular disease – a build-up of fatty deposits in the arteries. Hypertension – high blood pressure. Type 2 diabetes - high blood sugar levels.

[8] Hyperosmolar hyperglycaemic state - high blood sugar that results in an emergency situation. Onset is typically over days to weeks.

[9] Sections 44(1)-(3), Care Act 2014

[10] Section 44(5), Care Act 2014

agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

2.4. A referral was submitted by the Safeguarding Lead Nurse at PCH on 25th October 2017. The SAB's SAR panel recommended that a review be commissioned on 16th November 2017. This was subsequently agreed by the Independent Chair of Cambridgeshire and Peterborough Safeguarding Adults Board. The panel met again on 18th January 2018 to finalise the terms of reference and the proposed methodology, and to make arrangements for the appointment of the independent overview report writer. I was confirmed as the reviewer and overview report writer on 9th February 2018.

2.5. The membership of the SAR Panel comprised the members of the Board's SAR sub-group, with the addition of co-opted members representing at senior level the agencies which had commissioned or provided services to Arthur.

- Independent overview report writer:
    - Michael Preston-Shoot
- Cambridgeshire and Peterborough SAB Business Manager
- Cambridgeshire and Peterborough SAB SAR Panel Independent Chair
- Peterborough Adult Social Care, Assistant Director
- Cambridgeshire and Peterborough Clinical Commissioning Group, Designated Nurse (Safeguarding Adults)
- Cambridgeshire and Peterborough Clinical Commissioning Group, Named Nurse Primary Care (Safeguarding Adults)
- Peterborough City Hospital, Lead Nurse Safeguarding Adults
- North West Anglia NHS Foundation Trust, Deputy Chief Nurse
- East of England Ambulance Service NHS Trust, Safeguarding Specialist Practitioner (Adults)
- Clarion (formerly Circle) Housing, Neighbourhood Officer
- Cambridgeshire and Peterborough NHS Foundation Trust, Named Nurse (Safeguarding Adults)

The SAR Panel received administrative support from the Cambridgeshire and Peterborough Safeguarding Adults Board Business Support Officer.

2.6. A referral for a section 42 (Care Act 2014) enquiry was sent from PCH on 14th August 2017. As identified in the chronology and thematic analysis of the case, this referral did not proceed to an enquiry.

2.7. A serious incident investigation was undertaken by PCH relating to the care and treatment that Arthur received on his final admission to hospital, in April 2018. This was concluded in August 2018. It found that, although Arthur received the correct treatment, he was acutely unwell with complex pre-existing co-morbidities. The investigation recommended

that the Trust's transfer policy should be updated. It found that clinical areas failed to communicate effectively with receiving areas, and that the Critical Care Outreach Team was not involved as it should have been prior to his transfer out of the Emergency Department/Medical Assessment Unit. There should have been a medical review prior to his transfer onto a hospital ward. However, concern about his deteriorating condition was subsequently escalated in a timely manner.

2.8. At the time when the SAR was commissioned, panel members were concerned about Arthur's apparent hoarding and the possible decline in his cognitive functioning. The panel agreed to request that Arthur's GP conduct a health and wellbeing check. The panel also sought additional information regarding whether Arthur had ever been referred to mental health services, and when he was last seen by district nurses and whether a future appointment had been made.

3. Review Process

3.1. The panel set the terms of reference, which range across hospital discharge, self-neglect, non-attendance at appointments, mental capacity, prevention and policies and procedures with respect to self-neglect and hoarding, as follows:

3.1.1. What discharge plans were agreed and how did each organisation respond? Are there any lessons to be learned? Could any agency/organisation have done more?

3.1.2. What was known about Arthur's potential for self-neglect? How was the risk of self-neglect mitigated?

3.1.3. What was known about his failure to attend appointments and how was the risk mitigated?

3.1.4. Were single and multi-agency policies, especially on self-neglect and hoarding, sufficient and followed? Is there any learning from this case with respect to the adequacy of single and multi-agency policies?

3.1.5. Did any agency have concerns about Arthur's mental capacity and what actions were taken? Was his mental capacity assessed, why, when and with what outcome?

3.1.6. Could any agency have done more to prevent the decline in his health?

3.2. Methodology

3.2.1. The SAR panel initially agreed that the timeframe for the review would cover the period from 1st January 2016 to 14th August 2017. However, in April 2018 the panel was informed of Arthur's death and the timeframe was subsequently amended to include the subsequent period up to his death.

3.2.2. Agencies were requested to provide Independent Management Reviews (IMRs) and a chronology of their involvement with Arthur within the agreed timeframe. They were advised to also include anything that they judged significant that fell outside the agreed timeframe for the review.

3.2.3. IMRs were received from Peterborough City Hospital (PCH), Peterborough Adult Social Care (PASC), Clarion Housing Association, GP Surgery, East of England Ambulance Service and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). One IMR[11] was not submitted on the template provided by the Cambridgeshire and Peterborough SAB and the author appears to have been given very little time to complete it due to work pressures and a short notice period, despite guidance and a briefing having been given by the SAB Business Manager. This IMR rather appears to have been an initial review, looking at the immediate needs for action rather than a considered analysis of learning from the case. Not all the IMRs were submitted on time, sometimes said to be the result of staff shortages, and the quality of the reflective analysis was variable.

3.2.4. Information was sought from Cambridge University Hospitals NHS foundation Trust (Addenbrookes). Little information was available from their records.

3.2.5. The learning event explored key episodes and events within the timeframe being reviewed based on issues and concerns emerging from the combined chronology and responses to the reflective questions.

3.2.6. A letter was received from the provider of the Wheelchair Service Cambridgeshire and Peterborough giving requested information about Arthur's contact with this service.

3.2.7. Thus, a hybrid methodology has been used, designed to provide for a proportional, fully inclusive and focused review.

3.3. Family involvement

3.3.1. The panel had originally envisaged that Arthur would be invited to participate in the review by meeting with the overview report writer. This could not be arranged prior to his death.

3.3.2. The Serious Incident investigation states that Arthur had no next of kin. Social housing records note that Arthur had stated that he had no next of kin.

3.3.3. The independent reviewer met with a neighbour who had supported Arthur. He stated that Arthur was estranged from his brothers, who live abroad, and that it

[11] CPFT IMR

had not been possible to trace them after Arthur died. Comments from the neighbour are included in this report.

4. Pen Picture

4.1. Little information has been available to the SAR panel and independent reviewer about Arthur. A tenancy check form provided by Circle Housing Association has recorded that Arthur was White British and had moved to his most recent accommodation, a one-bedroom flat, in 1998. Social housing records contain an entry that PCH staff had confirmed the suitability of the accommodation for Arthur's needs. The flat was on the first floor with a lift available. He is recorded as having been single and retired.

4.2. One IMR[12] has recorded that he had a below the knee amputation of his left leg in 1998. Another IMR[13] has recorded that it took place in 2011. Information obtained from Addenbrooke's includes admission in2010 for surgery to his right leg but no details thereafter relating to care of prosthetics. It is unclear what action in the form of health and social care assessments and interventions, if any, was taken at that time to ensure that he could manage at home, in his one-bedroom flat above shops. It is not known what led to the amputation or how Arthur responded to it. That IMR is, however, clear that his accommodation had not been adapted to meet wheelchair use standards and his bathroom facilities had not been adapted to respond to his disability. Apparently he had a local support network, with good neighbour relationships, and for most of the period under review he expressed a strong wish not to move.

4.3. According to the social housing association, there were some issues with rent arrears over the year and some concerns about anti-social behaviour, mainly in the form of smells emanating from the flat. Self-neglect concerns had first been recorded in 2011. It is not clear whether self-neglect and hoarding pre or post-dated his amputation. The information does, however, underscore the importance of knowing the history in cases of self-neglect and hoarding[14]. In the combined chronology, it is noted that the ambulance crew on 5th September 2016 had recorded Arthur as being partially sighted. This is not referred to anywhere else in the documentation. There are also some passing references to Arthur experiencing low mood and "depression."

4.4. It is now known that GP records contain mention of depression in April 1992 and again in December 2007. The GP records also contain mention of deep vein thrombosis of a lower limb in 1992 and again in 1998 and 2003, a below the knee amputation in October 1998, a diagnosis of Type 2 diabetes in February 2002 and references to other physical health issues including arthritis and ulcerative colitis. In 2012 there are references to his legs being at moderate or high risk and to non-attendance at hospital appointments or

[12] PCH IMR

[13] Clarion Housing IMR

[14] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' *Journal of Adult Protection* (2015) 17 (1), 3-18.

reviews by GPs. There are references to wound infections, for example in July and December 2015, and to his inability to tolerate statins in March 2013 and November 2015.

4.5. A detailed search of Adult Social Care records did reveal some background information, as follows:

4.5.1. Arthur was 49 years old when he was first known to Adult Social Care in 2007 when housing officers referred him due to foul smells from his flat. Arthur lived alone in a first floor flat. He had diabetes and had had a partial leg amputation in 1998. He had moved to this flat in 1999. A Community Support Worker became involved in 2007 although Arthur was reluctant due to his anger at having had no support when his leg was amputated. There were concerns around hoarding and lack of ability to cope with some aspects of personal care.

4.5.2. Throughout 2007/2008 the support worker slowly gained some rapport and actions resulted such as starting to help Arthur make decisions about de-cluttering the house, applying for benefits and getting him out and about a little more. His low mood was identified and Arthur was encouraged to ask the GP for referral to counselling services. This was also in relation to identification of attachment issues about his mother. There was no apparent contact or involvement with family or friends.

4.5.3. Throughout this time Arthur was mobile with his prosthesis but this gave him continual difficulties with ulcers and pain in his leg. He did have a new cast taken for a new prosthesis but there were still some difficulties with the new one and this was often the stated cause of lack of motivation.

4.5.4. Arthur was generally isolated and did not see many people, did not get out much and watched a lot of TV. Although registered with housing he was not engaged in trying to bid for properties. The support worker did achieve supporting him to go to a gym at times. By contrast to Adult Social Care records, GP, District Nurse and social housing records indicate that neighbours provided a circle of friends who went out with him.

4.5.5. During Nov /Dec 2008 there needed to be a change of support worker and Arthur began to disengage from contact with professionals - not responding to phone calls or letters. The Adult Social Care team arranged that the housing support worker would continue with support weekly and that Adult Social Care would close their involvement.

4.5.6. Around March 2009 issues arose from tradespeople making deliveries about bottles of urine being around the property and a severe smell. By October 2009 Environmental Health services were involved. Around this time it seemed he was mobilising with walking aids and there was a likelihood of further

operations on his leg to remove ulcers. Case notes do record that he was still able to drive.

4.5.7. Around April 2010 Arthur had an operation and plans were made to provide some personal care after discharge but Arthur continued to be unresponsive to calls and letters and after many attempts the referral was closed.

4.5.8. There was no contact on ASC systems between April 2010 and February 2016.

4.6. The neighbour told the independent reviewer that he had known Arthur for ten years. He knew something about Arthur's background, namely that he had worked as a technician for one of the armed services, having been discharged following an industrial accident. In his job, he had travelled the world. Around the time of his amputation his mortgaged three-bedroom house had been repossessed and he had moved into his one-bedroom flat with much of his furniture, resulting in some overcrowding. He was a keen collector.

4.7. The neighbour described Arthur as cantankerous, angry, miserable and embittered regarding the change in his circumstances but over time the two had struck up a mutually supportive relationship and Arthur had "come out of himself." He had assisted Arthur to go out on many occasions and there were other neighbours who also offered friendship.

4.8. The limited and somewhat contradictory information about Arthur as a person may be illustrative of the focus of the work undertaken with him by the agencies involved, with an emphasis on presenting problems. It underscores the importance of taking a chronology and history in order to begin to understand presenting problems.

5. Timeline of Agency Involvement

5.1. The original time frame for the SAR was between January 2016 and August 2017, the latter date determined by when Arthur was admitted to hospital seriously ill and the original SAR referral was raised. The timeframe was subsequently extended to the date of his death in April 2018. To assist with the thematic analysis of the lessons to be learned from this case, the chronology of agency involvement is presented in three parts, focusing first on 2016, then January to August 2017 and finally September 2017 to April 2018.

6. Time Episode January – December 2016

6.1. Clarion Housing IMR notes that no concerns were raised during 2016. It records one tenancy sustainment visit, on 10th December 2016, when Arthur requested help with cleaning and shopping. He consented to a referral to adult social care and stated that he did not want to move. This referral was chased on 9th January 2017.

6.2. The absence of information in this IMR is interesting given the quite substantial involvement that Arthur had with health and social care providers during 2016, some of which contained explicit reference to his accommodation. This may be reflective of how housing providers have (not) been embedded in adult safeguarding and care and support systems, a theme of working together further elaborated in section 7 of this report.

6.3. During January 2016 Arthur was seen, including at home[15], by GPs who requested ultrasound scans of his limbs, noted leaky valves in some of his veins and prescribed water tablets and antibiotics.

6.4. East of England Ambulance Service had three contacts with Arthur in 2016. On 29th January 2016, Arthur was transported to PCH, following liaison between a GP and an orthopaedic doctor, and subsequently returned home from the Emergency Department. Trust records contain reference to the hospital having been unable to diagnose the problems arising from his amputated leg. When he was transported home, the ambulance crew observed that the flat was a "mess", cluttered with rubbish. Arthur had been using milk bottles as a toilet. It was recorded that Arthur could not use his wheelchair or crutches in his accommodation and it proved very difficult to get the wheelchair through the front door. A safeguarding concern was referred, which the IMR observes contained a good level of detail, being concise and with clearly stated concerns. The theme of section 42 (Care Act 2014) referrals is discussed in section 9 of this report.

6.5. The PCH IMR observes that Arthur was examined in the Emergency Department on 29th January 2016. He had a swollen and painful amputation stump and diabetic leg ulcers. It is recorded that the GP had prescribed a course of antibiotics that had been completed. Arthur's heart rate was slow and the records state that a drug used for cardiovascular disease had been discontinued. Arthur is reported to have been orientated in time and place. He was discharged home as no emergency input was required. Arthur himself received a letter on 9th February from a consultant vascular and endovascular surgeon to the effect that there was no significant disease in his arteries but leaky valves in the veins of his right leg which could be the cause of infection. He was advised to see his GP for compression stockings to expedite healing, with a follow-up review to take place in three or four months. The GP was asked to refer Arthur to a prosthesis clinic. The GP IMR records that this referral was sent. GP records seen by panel members and the independent reviewer contain reference to a referral to a plastic surgeon on 11th February, followed by referral for rehabilitation (18th February). The 11th February GP referral has also been recorded on the electronic patient record held by Addenbrookes.

6.6. The PASC IMR picks up the narrative at the point of Arthur being returned by an ambulance crew from PCH on 29th January 2016. It too observes that the flat was not accessible from his wheelchair due to the size and width of the doorways, there were no

[15] The GP Surgery IMR makes no reference to home conditions when GPs saw Arthur at home.

walking aids and that he appeared to live in an armchair. It too records the presence of milk bottles containing urine and that the flat was messy, crowded and cluttered. Arthur had apparently refused the offer of a return to the hospital. Occasional help from a friend was recorded. The ambulance crew had referred the case to the Emergency Duty Team and to adult safeguarding, with a copy to the GP.

6.7. The GP IMR also picks up the narrative subsequent to Arthur returning home from PCH. On 8th February 2016 a GP requested that swabs be taken from his stump and on 11th February a GP provided information when requested by Adult Social Care regarding his mobility. He refused a safeguarding referral by the GP. GP notes record OT and Duty Social Worker involvement. The GP IMR records that the surgery referred Arthur to the Emergency Department on 25th February. A telephone discussion between the GP and staff at PCH concluded that Arthur did not require admission and an outpatient appointment was arranged instead. On 26th February a GP requested a wheelchair referral after having seen Arthur and also physiotherapy. Also noted is that he would require transport to keep his appointment at Addenbrookes Hospital on 2nd March.

6.8. On 2nd February 2016 the local authority Adult Social Care safeguarding lead discussed the adult safeguarding referral with Arthur who declined referral for a care and support needs assessment but did agree to a referral to occupational therapy. Over time a repeating pattern emerges of Arthur agreeing and declining assessment and this is explored further in section 9. He did not see his home environment as a concern. The Adult Social Care safeguarding lead subsequently contacted the GP who agreed to visit and who was asked to re-refer if concerned. The safeguarding referral was closed as Arthur did not wish to continue with an investigation. The outcome of safeguarding referrals is explored further in section 9 below.

6.9. The Occupational Therapist (OT) for Adult Social Care made contact with Arthur by telephone to begin an assessment. He rejected a commode but did agree to a care and support assessment and the OT made the referral. The OT informed Arthur that a full home assessment would take place in about six weeks' time. Section 9 returns to the theme of assessment, including the challenge of balancing waiting times with urgency and the use of telephone assessments. Between 8th and 19th February there were discussions between the OT and GP regarding referral to the community rehabilitation team. The GP discussed concerns regarding Arthur with the safeguarding team but was advised that the referral had been closed and the case would be dealt with via care management.

6.10. On 19th February 2016 Arthur rejected a care and support assessment when contacted by telephone. He was given advice and the case was closed. Ten days later the OT attempted to visit but could not see Arthur as he could not mobilise to let the OT into the flat. This circumstance does not appear to have generated referrals, either to adult safeguarding, the housing provider or the Fire and Rescue Service. Four further

assessment attempts were made[16] but the case was closed on 4th April 2016, with Arthur's apparent agreement that he would re-refer himself if necessary[17]. Apparently he wished to wait for the outcome of an appointment with Addenbrookes Hospital regarding his left leg and prosthesis. In the event he did not attend appointments with consultants from Addenbrookes on 1st April and again on 15th April, on this second occasion because of pain in his legs. An appointment on 3rd May appears to have been cancelled by the hospital. There is no subsequent reference to Arthur on the electronic patient record system held by Addenbrookes.

6.11. There is no further adult social care involvement until 17th June 2016[18] when the GP re-referred urgent concerns about the need for personal care and support in the home environment. Arthur was contacted and only requested assistance with cleaning and shopping. There is no record of what advice was given or of any feedback to the GP. Recording is a theme explored further in section 9 of this review. The final 2016 Adult Social Care involvement was during August when Arthur declined assistive technology support.

6.12. On 5th September 2016, East of England Ambulance Trust transported Arthur to PCH. Nothing significant is noted in the Ambulance Trust IMR regarding this episode. However, in the combined chronology the ambulance crew are recorded as reporting Arthur to have evidence of ischaemia[19] on admission. The PCH IMR explores this hospital admission in some detail. Arthur had been treated with antibiotics for three weeks but on admission diabetic leg ulcers were found on both legs. There was extensive damage to his right leg. Although the wounds had begun to heal, maggots were found. It is recorded that District Nurses had been dressing his legs. It is evident that there was already a repeating pattern regarding the condition of his legs and this is a theme picked up again in section 9.

6.13. During this admission Arthur was observed to be alert and orientated in time and place. His blood glucose level was within normal limits. He was discharged on 8th September 2016, with referrals for long-term outpatient management and community physiotherapy for continued mobilisation and rehabilitation. He was referred also to the district nursing service for compression dressings (four layer bandaging) and oral antibiotic administration. On discharge his left leg prosthesis was fitting. The record

[16] Entry details and a key code to gain access were on the GP record that would have allowed entry assuming the front door keys were available or Arthur could open the door. Arthur does not appear to have given these details and code to other practitioners attempting to make contact with him.

[17] Agreement that Arthur would re-refer is a recurring theme and one that does not appear to have been picked up as the case unfolded.

[18] However, a CPFT entry into the combined chronology records that ARTHUR contacted adult social care on 2nd June 2016 to cancel his reablement package.

[19] A restriction of blood supply to tissues.

states that he had been prescribed amitriptyline[20] but was not taking it. This raises the theme of non-compliance which is further explored in section 9 of this review report.

6.14. There is no reference in the PCH IMR to discussions with or a referral to adult social care during this admission, although existing support from home help and a carer is mentioned. An assessment of his care and support needs might have been appropriate at this juncture, a theme explored under hospital discharge in section 9.

6.15. There is no reference either in the PASC IMR regarding contact with Arthur around the time of the September hospital admission. Indeed the IMR observes that there was a gap in involvement with him between August 2016 and January 2017.

6.16. The CPFT IMR does not focus on 2016 but there are CPFT entries into the combined chronology for this period that refer to District Nurse and Physiotherapist involvement. In early March a re-referral is made to wheelchair services, as the original GP referral was incomplete, recorded above on 26th February. The Wheelchair Service has recorded receipt of this referral on 3rd March 2016 and it was triaged within three working days. The Service has advised that because of his weight, a wheelchair could not be issued immediately and an assessment was booked. Arthur requested an update on this referral on 9th March and by 23rd March is reported as having been disgruntled at the lack of progress. He is reported as stating that he was trapped in his flat. He was assessed on 30th March. The Wheelchair Service has recorded that the internal space in the flat was severely restricted and a wheelchair would be difficult to manoeuvre because of the doorway widths. Arthur is recorded as having already privately purchased a self-propelling wheelchair for outdoor use. He wanted a wheelchair as small as possible and was assessed for the narrowest wheelchair possible that would not compromise his skin integrity.

6.17. Arthur chased up the order for delivery the day following this wheelchair assessment. The chronology does not state when, if at all, the wheelchair was delivered and whether there was a review of its suitability. The Wheelchair Service letter does not indicate when the wheelchair was delivered but there was no further contact with Arthur until late August 2017. Overall this sequence of events is one instance where the panel and independent reviewer have highlighted the delay in obtaining for Arthur appropriate equipment. The recommendations include therefore an action regarding how agencies work together to ensure timely responses for providing and then reviewing the provision of wheelchairs and other equipment.

6.18. There was extensive physiotherapy involvement from 18th May 2016 onwards, once the OT had made contact with Arthur by telephone on 12th May and gained his agreement to a referral as he was unable to mobilise. The combined chronology records

[20] This is used to treat depression and in lower doses pain. In Arthur's case, it was prescribed to control nerve pain post amputation. There could have been several reasons for not taking the medication, including its side effects. Clearer recording would help practitioners to understand case management.

two Physiotherapy visits in May, two in June, two in August, four in September, three in October, three in November and two in December. Early on concern has been recorded about clutter, for example in the hallway, making it difficult for reablement exercises to take place. From the August visits onwards this concern is replaced by frequent comments that Arthur's stump was swollen, that he was unable to fit his prosthetic leg and that physiotherapy was therefore not possible. There are references periodically to his wounds leaking and being infected, and one reference (25th October) to Arthur becoming depressed because of the impact of his swollen stump. Antibiotics do not always appear to have improved the situation. In December a repose cushion[21] is ordered. At no point does this on-going situation appear to have triggered a multi-disciplinary meeting of healthcare professionals. The theme of working together is explored further in section 9.

6.19. The first reference to district nursing is a referral on 28th April 2016. On 4th May the GP referred Arthur to CPFT out of hours nurses as there were weeping open areas on his legs. The GP IMR also references urgent referrals to District Nurses on 4th May and to Physiotherapy on 5th May, after a case review on 25th April for knee swelling, Arthur's failure to attend appointments, and subsequent appointments with various GPs when he was seen. The combined chronology does not record any district nursing visits for May or June 2016[22]. A GP referral to orthopaedics was sent on 4th June, with subsequent telephone discussion with Arthur about treatment compliance for his leg ulcers.

6.20. The GP IMR records considerable activity during the months of June, July and August. A Tissue Viability Nurse visited to conduct a leg ulcer assessment on 29th June and recommended to the GP a referral to the vascular team, which the GP IMR records as having been sent[23]. In mid-June the same IMR observes that the GP practice was advised that Arthur cancelled his appointment with Addenbrookes Hospital, reportedly because he felt that both his legs were "bad." Prescriptions for collection by a carer were written, a referral to a cardiologist made, and antibiotics prescribed for the leg ulcers. Water tablets were given in late June, reviewed and the dosage increased in later July. Antibiotics were prescribed again in mid-August following the results of a swab.

6.21. There are five visits recorded of District Nurses or out of hours' nurses to change dressings in July and four in August. A Community Matron appears to have visited just prior to Arthur's hospital admission on 5th September, noting that his stump was inflamed, that his other leg also appeared infected, that maggots had been observed and that he was unable to fit his prosthesis. A review by District Nurses is requested. He did not appear to be eating or taking his medication. There is no evidence of a mental capacity assessment having been carried out regarding his nutrition and control of his

[21] Designed to reduce the risk of pressure damage to an area of the body.

[22] Analysis of CPFT records reveals that there were 11 District Nurse visits for wound care between 4th May 2016 and 27th June 2016. There is some evidence of communication between day and evening staff but this consists of handing over Arthur if there had been no time to visit during the day. There is no evidence of detailed handover/information regarding Arthur's self-neglect between Day and Out of Hours Teams.

[23] There is no record in the GP notes of the outcome.

dietary intake. He was admitted to PCH through the Emergency Department the same day, the GP having also sent an urgent FAX to the orthopaedic doctor on call regarding maggot infestation, ulcerated right leg and left leg oedema.

6.22. On hospital discharge (8th September) a referral to the district nursing service is made on the same day but he does not appear to have been visited before 29th September when the District Nurse was unable to change the compression bandages. There are recorded visits to change his dressings on one or both legs on 27th October, 2nd November and 17th November. The GP IMR records that antibiotics were prescribed on 3rd October. On 28th October the GP IMR records an urgent District Nursing referral for swabs and observes that workload pressures on District Nurses at the time meant some uncertainty about when they would be taken.

6.23. On 24th November 2016 the GP again requested that swabs be taken. The GP IMR records that this referral was chased on 29th and 30th November as the situation was deemed urgent[24]. The swab was done on 1st December and antibiotics given by the GP based on the results. Further antibiotics were prescribed on 7th December. District Nurses ordered a repose cushion[25] on 15th December and contacted the GP for more antibiotics. The stump is reported as being painful, wet, red and swollen. The following day the GP requested a further swab before prescribing antibiotics. This was performed on 19th December. On 22nd December Arthur declined dressing to his left leg and repeated the lack of consent, this time for his right leg on 28th December. It is not clear what advice was given here.

7. Time Episode January – August 2017

7.1. The GP IMR records that a GP saw Arthur on 5th January 2017 as a District Nurse, who was applying dressings twice weekly, was concerned about his stump. A GP recommended an urgent referral to the prosthesis team and Arthur apparently agreed to make contact with the team, something which he did not do. Entries on the combined chronology from CPFT record that physiotherapy visits were undertaken on 5th January, when the pressure relieving repose cushion was in place and treatment with antibiotics had been completed, and again on 18th January, when the stump had improved and Arthur was able to do his exercises. He is recorded as saying that he would continue with these exercises and would contact physiotherapy again when he was able to fit his prosthetic limb and to commence rehabilitation. He was therefore discharged at this point. He does not appear to have contacted physiotherapy again and there is no record of this having been followed-up.

[24] CPFT's entry onto the combined chronology notes that Arthur himself contacted the district nursing administration hub to say that no District Nurse had visited for this purpose on either 28th or 29th November.
[25] Repose cushion and boots reduce the pressure to the heels and can be used/worn in bed.

7.2. The PASC IMR notes receipt of a referral on 9th January 2017 from Clarion Housing[26] for a care and support needs assessment, especially with regards to personal care and shopping. He is recorded as being housebound. Contact by telephone is attempted and one message is left. Telephone assessments will be a theme further explored in section 9 below. A letter is sent on 14th January as Arthur has not responded. He responded ten days later and requested only an OT assessment to enable him to use the bathroom and toilet. He was referred for occupational therapy assessment, for which there was a six weeks' waiting list, and the care and support assessment referral was closed.

7.3. On 26th January an entry on the combined chronology from CPFT records that Arthur was referred to the diabetic service and a letter sent for an appointment for 29th March. There is no mention of whether Arthur attended this appointment or of any further follow-up[27].

7.4. Also on 26th January a new Housing Neighbourhood Officer visited. Arthur stated that he had not left the property for over a year and that District Nurses were visiting twice weekly. The flat was cluttered. Arthur stated that he did not want to move despite concerns about the suitability of the property. The GP advised that Arthur would be a wheelchair user for the foreseeable future. On 6th February a joint visit was arranged with the Fire and Rescue Service to address hoarding and Arthur's ability to evacuate the flat in the event of fire.

7.5. On 10th February, apparently following concern from a District Nurse about his stump, a GP saw Arthur after swabs had been taken and antibiotics prescribed. The GP IMR records liaison with the occupational health team about the possibility of a new prosthesis but does not comment on the outcome. On 3rd March this same IMR records that Arthur was seen by a Practice Nurse.

7.6. Between 24th and 31st March an OT assessment took place. A glide-about commode was issued and there was liaison with the GP and district nursing team concerning his prognosis regarding mobility and the impact of this on decisions regarding adaptation of his property. Shower adaptations were not progressed at this time because Arthur could not take a shower as a result of his leg dressings. On 4th April Arthur agreed to the OT making a referral for a care and support needs assessment. The OT also requested property repairs, which were done to the doorway levels.

7.7. The PCH IMR records that hospital records for 27th April 2017 refer to a local authority OT as being concerned about the lack of manoeuvrability in the flat and the need to widen the doors for access. There is no further mention of this in the hospital records. The same record notes that Arthur's stump problems were unresolved and that Arthur had discussed with his GP whether to recommence with statins[28] for his cardiovascular

[26] Paragraph 6.1 above.

[27] There was an annual review on 17th September 2017.

[28] A group of medicines that can help lower the level of cholesterol in the blood.

system. These were agreed by both the GP and Arthur as effective and re-prescribed. The PASC IMR for the same date records that Arthur was frustrated at the lack of progress on property repairs and the care and support needs assessment. The OT chased these referrals and also referred the case to the Fire and Rescue Service because of the risks arising from the clutter and Arthur's poor mobility. The OT discussed Arthur with the GP who concluded that Arthur's statement, "leave me a gun", was evidence of frustration rather than a mental health problem. The OT also contacted Addenbrookes Hospital who advised that Arthur had cancelled his appointment scheduled for 1st April 2016.

7.8. On 5th May the Fire and Rescue Service reported back to the OT. The Fire and Rescue Service recommended a move due to Arthur's poor mobility, hoarding and fire risks. He is noted to smoke and use candles. As a result of Arthur's hoarding behaviour, it was agreed that the OT would request a support worker to clear the flat. The referral to adult social care for a care and support needs assessment was still awaiting allocation. The Housing Neighbourhood Officer visited and knew that the OT had recommended the fitting of a level access shower, which was not ultimately progressed apparently because the bandages apparently prevented him taking a shower. Arthur was using milk bottles to store urine. He had leg dressings. The flat was cluttered.

7.9. Between January and Arthur's hospital admission on 10th May, according to the entries from CPFT on the combined chronology, District Nurses visited on ten occasions – three times in January, twice in February and March, once in April and finally on 8th and 10th May. It is unclear what determined the frequency of the visits, which were reported as twice weekly[29][30]. The pattern established in 2016 continues. On five of these occasions Arthur refused to allow dressings to be changed, usually with respect to his right leg. The reasons for this are not recorded on three occasions. Record keeping is a theme explored further in section 9. On one further occasion the record is incomplete with respect to the District Nurse response to his requests about bandaging. Swabs were taken when his stump wound was wet on one occasion but the results do not appear in the chronology. On one occasion also Arthur is recorded as being unhappy with the lack of progress regarding his stump, which is frequently described as leaking, purple, requiring cleaning and wet[31]. On another occasion (22nd January), because a urine sample could not be obtained, he was asked to bring one to the surgery. Elsewhere in the chronology it is recorded that he was housebound at this time.

[29] Further analysis of CPFT records found that 35 visits were recorded by District Nurses between 3rd January 2017 and 8th May 2017. The visits were twice weekly. The leg had two layer bandages on and was reasonably dry. The stump was swabbed 27th February 2017 as it had become wet, which is documented on other occasions also ("leaking").

[30] The panel and independent reviewer have observed that the wounds could have been improving and therefore the dressings would require changing less frequently. Clearer recording in case notes would have been helpful to understand case management.

[31] The GP IMR records that Arthur called the surgery on 15th June because his wound was leaking and the District Nurse had no visited as he expected. A GP is recorded as having requested an urgent District Nurse visit.

7.10. On 13th March the District Nurse is recorded as having discussed the case with the GP, antibiotic treatment having concluded. The outcome of this discussion is not recorded by CPFT on the combined chronology nor referenced in their IMR. The GP records note the discussion with the District Nurse and suggest a further review the following day with a possible referral to the surgeons or more antibiotics. He was reviewed the following day but no new vascular compromise was noted. On 2nd May the GP is recorded on the combined chronology as advising that Arthur would be an on-going wheelchair user and that, therefore, his flat would require adaptation. A new referral to the prosthetic clinic at PCH would be required from the GP as Arthur had cancelled his last appointment. On 10th May hospital admission was arranged to facilitate intravenous antibiotics.

7.11. East of England Ambulance Trust had two contacts with Arthur in this period. The first, on 10th May 2017, contained the reported statement from Arthur that he had not been out of his flat since January as his prosthetic leg was not fitting due to swelling and cellulitis[32]. This information does not appear to have prompted a section 42 (Care Act 2014) referral or any other action but this information was given by the Ambulance crew to PCH on arrival. Neither does this information appear to have been checked out whilst Arthur was in hospital when PCH records state that he had both an indoor and outdoor wheelchair and was able to transfer independently from bed, chair and commode.

7.12. The PCH IMR records that this admission which followed a joint GP and District Nurse visit when they found Arthur's stump to be excoriated and ulcerated. Oral antibiotics had been prescribed. On arrival at the Emergency Department intravenous antibiotics were given. Arthur was generally compliant with treatment when in PCH but sometimes refused personal care and weighing. The infections were successfully treated and he was discharged to the district nursing service on 1st June 2017. An outpatient follow-up with the vascular team was recommended to the GP.

7.13. Adult Social Care failed to make contact with Arthur on 12th May, not knowing that he was in hospital. The referral to Adult Social Care had been made on 4th April. The themes of delayed assessments and of how agencies worked together are explored in section 9. The duty worker discussed reablement with the OT but concluded that it was not an option due to hoarding concerns. A referral to the Transfer of Care Team at PCH was made. On 19th May a reablement caseworker assessed Arthur on the hospital ward and a multidisciplinary team meeting was arranged. The PASC IMR observes that there is no record of the details of that meeting. The panel and independent reviewer understand that this may have been a consultant ward round, the outcome of which was continuation of intravenous antibiotics and review the following week. The theme of recording is explored in section 9. The OT liaised with the Fire and Rescue Service. Arthur rejected the idea of moving.

[32] A common bacterial skin infection, often painful.

7.14. Arthur was discharged from PCH on 1st June with a reablement package which he declined the following day, rejecting also care over the weekend. The reablement case was closed. Recommendations from Clarion Housing and the Fire and Rescue Service were not progressed.

7.15. The Neighbourhood Housing Officer referred Arthur again to the Fire and Rescue Service on 22nd June because of his hoarding. Fire and Rescue Service advised that Arthur had been visited on 4th May following an OT referral. He had been adamant that he could vacate the flat in the event of fire. A move had been recommended but he was unlikely to consent to this. His hoarding had been noted with fire control.

7.16. On 27th June the OT tried unsuccessfully to contact Arthur by telephone and to progress adaptations to the property. The OT prepared a handover summary for a new OT. There is then a gap in OT involvement to 15th August 2017.

7.17. There appears to have been some improvement in the smell and condition of his property in late June and early July. District Nurses are reported to be visiting two or three times' weekly. Fire and Rescue Service had checked and fire alarms were working appropriately and a hoarding risk assessment was completed on 31st July[33].

7.18. Indeed, the district nursing service picked up the re-referral on 2nd June, after Arthur's hospital discharge from PCH, but he was not seen until 23rd June when he said he was sleeping on a settee because a friend was staying. There was a further visit by a District Nurse on 25th June when he said he was going out. Since he did not appear to be housebound, he was discharged by the district nursing service on 27th June and expected to see the Practice Nurse at the GP surgery[34]. The panel and independent reviewer understand, not least following descriptions from the neighbour regarding what Arthur had to negotiate when leaving his flat in order to exit the building, that he would have needed assistance with the corridor and entrance doors, and the lift, with the result that it was only possible for Arthur to visit the GP surgery if someone was available to assist. The panel and independent reviewer have concluded that there could have been flexibility in terms of thresholds for District Nurse home visits given these circumstances and a recommendation is made later to that effect.

7.19. As part of a repeating pattern throughout the period under review, he did not attend an appointment with the Practice Nurse on 1st August but no follow-up has been recorded, perhaps because he was assumed to have the mental capacity to make

[33] This information is gleaned from Clarion Housing IMR.

[34] Further analysis of CPFT records found reference to 13 District Nursing visits from 6th June 2017 to 27th July 2017. Although the District Nurses booked Arthur's subsequent first appointment with the Practice Nurse, there is no documentation that they discussed Arthur's history of self-neglect. Arthur's mobility was considered as he is recorded as having informed the District Nurses he was going for a coffee "most days" and they knew he used a wheelchair. However, there was no probing as to how he did this in great detail and it appears he also relied on a friend. The Practice did not notify the District Nursing Service that Arthur had stopped attending the practice.

decisions about his treatment. It is unclear whether his difficulties regarding mobility were factored into decision-making at this, or any other point; indeed whether his mobility was assessed at all in reaching the decision to discharge Arthur from the district nursing service at this time. There does not appear to have been a plan to manage the risk of non-attendance at the GP surgery, at least until after the August 2017 hospital admission, itself an omission given the history in this case.

7.20. On discharge from PCH on 1st June Arthur was also referred to the podiatry service. He did not attend an appointment on 22nd June. A letter was sent advising Arthur of the risks associated with non-attendance and likely discharge if he did not attend. There is no further contact with the podiatry service in this time episode. There was further podiatry service activity in the next time episode, from September 2017.

7.21. An ambulance crew also transported Arthur to PCH on 14th August 2017, having been alerted by his neighbour. Arthur would not allow the crew to cannulate and was assessed to have mental capacity to make this decision. A pre-alert was sent to PCH. His living conditions on this occasion were recorded as being unclean but no safeguarding referral was made to adult safeguarding by the ambulance crew because their assessment was that the threshold for a notification of concern was not met. The panel and independent reviewer understand that references to his living conditions here concern excessive clutter. The detail of his living conditions was handed over to PCH.

7.22. The PCH IMR indicates that this hospital admission followed a friend of Arthur asking the GP to visit, concerned that his dressings had not been changed for some time. On admission Arthur was recorded as having sepsis markers from the infection in his right leg, with fever and signs of confusion. He was doubly incontinent and had a sacral sore[35]. His blood glucose levels were high for which he received an insulin infusion. He was given intravenous antibiotics and Arthur gave consent for the emergency amputation of his right leg if that proved necessary, which ultimately it did not as he responded well to treatment. He was extremely unwell.

7.23. Hospital records refer to District Nurse support and to a friend having stayed in his flat. The hospital identified Arthur as a vulnerable adult and an adult safeguarding referral was submitted on 16th August following discussion with the PCH safeguarding team and advice that an environmental health assessment of Arthur's home would be necessary prior to discharge. A social care referral was also sent for an environment assessment due to his hoarding behaviour. There is no evidence that either assessment was undertaken. He was discharged on 25th August 2017 with a referral to the district nursing service, a first visit booked for 28th August. Arthur was given advice about the use of his prosthesis, bandaging, elevation and outpatient review. There is no record of an outpatient review and the theme of recording is explored further in section 9 below. The hospital recommended that the district nursing regime for Arthur was completely revised, suggesting new dressing every two days.

[35] Injury to the skin and underlying tissue resulting from prolonged pressure on the skin.

7.24. The PASC IMR gives further detail relating to the actions taken during this hospital admission. A safeguarding referral was received on 15th August. There were maggots in his wounds, with no treatment for the previous ten days. An amputation might be required to his right leg. He was septic and very ill. His housing environment was described as "catastrophic." This environment - hoarding and unhygienic - was exacerbating his poor health[36]. Discussion between members of the safeguarding and district nursing teams established that Arthur's wounds had been dressed twice weekly until 27th July when it was agreed that Arthur would visit the GP practice as his wounds were healing by then. This decision appears to have been taken by the district nursing service in isolation. District Nurses were aware of his poor hygiene and the hoarding, and had advised him of the risks, but he had contacted people before (for instance regarding his leaking wounds or with queries about equipment) and it was felt that he would again if necessary. Although this decision was made with Arthur, wider discussion with the GP and Practice Nurse would have been useful in order to review the history of the case (including repeating patterns) and to coordinate intervention. The Adult Social Care safeguarding team spoke to the GP who was not so confident that Arthur would attend the practice because he was known to be non-compliant at times.

7.25. The Transfer of Care Team assessed Arthur on the ward on 22nd August and arranged a reablement package with his agreement. He was discharged on 26th August and refused support from the Red Cross. He said that a friend would clear his property.

7.26. An entry on the PASC IMR for 25th August notes that Arthur would only answer the telephone if he knew who was calling. On 29th August the Reablement OT visited. Some clearing up had been done but there was still clutter, hoarding and faeces on the floor. This was reported to the Reablement Social Worker due to previous concerns. Arthur declined help with personal care and meal provision. The OT explored with housing practitioners possible avenues of support.

7.27. In fact housing practitioners had attempted to visit Arthur on 14th and 24th August[37], on one occasion with the Fire and Rescue Service, to discuss concerns about hoarding and fire safety. Neighbours advised housing officers on 29th August that Arthur had been in hospital. The theme of how all agencies were working together is explored in section 9.

7.28. Upon this latest hospital discharge from PCH, Arthur was readmitted onto the district nursing service caseload on 30th August. However, the GP IMR records that District Nurses did not visit before 5th September when Arthur was seen by a GP. A diabetic care plan was created and a pressure relieving cushion ordered. The CPFT IMR

[36] The panel and independent reviewer concluded that a quick deterioration of the home environment was possible owing to the impact of sepsis. This highlights the importance of monitoring cases where there is a history of self-neglect and non-compliance, with resultant risk of significant harm.

[37] Clarion Housing Association IMR.

and entry into the combined chronology also records that Arthur referred himself for a new wheelchair as the existing one was hard to manoeuvre through his front door.

7.29. Information provided by the Wheelchair Service records Arthur's re-referral on 29th August 2017. He was reviewed by the same technician who had assessed him in March 2016. Arthur apparently wanted a narrower wheelchair, stating that the present one was uncomfortable and had several times become stuck due to the widths of the doorways. He was advised that this was not possible because an even narrower wheelchair would increase the risks of pressure points. He was advised to contact the GP, Housing and Community Therapy team to pursue relocation to a wheelchair accessible property. Arthur was unhappy with this outcome and lodged a complaint. The risks of a narrower wheelchair were explained to him again, which he acknowledged. The Wheelchair Service had no further contact with Arthur.

8. Time Episode September 2017 – April 2018

8.1. One IMR[38] refers to concerns being raised with relevant agencies regarding Arthur's health problems and to numerous meetings and case conferences regarding his poor mental health. It also refers to Environmental Health having issued a notice to clear the property and reduce the hoarding. The combined chronology does not contain details of dates when these meetings and actions occurred and outcomes are therefore unclear. The panel and independent reviewer understand that Environmental Health were also involved in 2007. The neighbour has also stated that on several occasions he and others helped to clean and de-clutter the property.

8.2. Another IMR[39] similarly refers to joint working between Community Matron, a safeguarding lead and Tissue Viability personnel, including the ordering and delivery of pressure relieving equipment, transfer of wound care to the GP practice and liaison between the surgery and community nursing team to confirm whether Arthur had kept appointments with the Practice Nurse. It notes that sometimes, when attending the GP practice, his dressings were wet with urine, prompting referral to the continence service. When the wound was not healing, a referral was sent to the Tissue Viability Nurse. However, greater detail is to be found in CPFT entries into the combined chronology.

8.3. The Clarion Housing IMR is non-specific regarding dates of contact with Arthur in this time episode. It records simply that there were problems with respect to Arthur's hoarding and that smells emanating from his flat were causing problems for neighbours. Nonetheless, tenancy enforcement action was not considered. However, from January 2018, he appears to have been more prepared to move to ground floor accommodation. The process to attempt to arrange this was begun but not completed before his death.

[38] Clarion Housing IMR.

[39] CPFT IMR

8.4. On 4th September 2017 a right heel grade 3 pressure ulcer was observed by a District Nurse who referred Arthur to the tissue viability service. Arthur was complaining that his prosthesis was too small. His stump did not appear infected. Some water retention was noted. The following day Arthur saw his GP and the District Nurse ordered repose boots. Adult Social Care completed a reablement review. Arthur declined reablement, only wanting help with cleaning, for example faeces from the floors. He confirmed this decision on 7th September and the reablement service was ended because Arthur was judged to have mental capacity to make his own choices at that time. He had stated that he was managing shopping for food. Contact details for Age UK with respect to cleaning were given[40].

8.5. The Fire and Rescue Service visited on 4th September and reported that hoarding was evident although the situation had improved. Wheelchair access was still difficult.

8.6. Also on 5th September the safeguarding referral made by PCH during his August admission was not progressed by Adult Social Care because Arthur was able to make his own decisions, he did not want to engage and he was receiving health care support. GP and District Nurse were informed. In a context of repeating patterns and increasing complexity, the panel and independent reviewer have questioned who might raise questions about mental capacity, at what point, and whether staff would feel confident in escalating concerns

8.7. On 7th September Arthur kept an appointment with the Practice Nurse and therefore on 9th September he was discharged from the district nursing service. Also on 7th September, the local authority OT discussed tenancy issues with Arthur, specifically whether he would move or wished to have adaptations to his flat. No action was initiated immediately, awaiting a decision from Arthur.

8.8. As Arthur was under the care of the Practice Nurse, it was decided on 11th September that referral to the tissue viability service was not required[41]. However, two days later the District Nurse and Tissue Viability Nurse planned a joint visit to assess his heel pressure ulcer. This may have been prompted by a meeting[42] involving a Community Matron, District Nurse, CPFT Neighbourhood Team Manager and Named Adult Safeguarding Nurse where a response was planned if Arthur did not keep appointments with the Practice Nurse and the District Nurse was to visit to assess the pressure relieving equipment and to apologise for the heel pressure ulcer. The chronology does not report whether all these visits took place. Rather, on 18th September, the Tissue

[40] The panel and independent reviewer have concluded that, given the repeating patterns involving self-neglect, a focus on prevention would have been appropriate rather than just providing telephone numbers of services to contact since Arthur was unlikely to use them.

[41] CPFT IMR.

[42] The meeting occurred on 12th September 2017. Those present discussed visiting Arthur to check pressure areas and pressure relieving equipment as Arthur was now using his bed. A verbal apology was to be given regarding treatment of his pressure ulcer on his heel. It was agreed to hold a meeting with Practice staff to develop a plan if Arthur failed to attend Practice Nurse appointments.

Viability Nurse asked the Practice Nurse to observe the heel and provide feedback. The combined chronology does not record that this happened.

8.9. Meanwhile, Arthur declined a pressure relieving mattress but did accept repose boots on 14th September. A District Nurse explained the risks and judged that he had decision-making capacity. He was advised to re-refer if necessary. The following day Arthur kept an appointment with the Practice Nurse.

8.10. Between 21st September and 16th November the OT attempted to discuss with Arthur equipment and adaptation issues but, owing to his lack of response, the case was closed. Arthur contacted the wheelchair service to request an appointment and review, following up the referral he had made on 29th August. He was seen on 9th October but there was no suitable smaller wheelchair, about which Arthur expressed unhappiness. He was advised to move.

8.11. On 3rd October he was referred to the podiatry service but the case was closed on 11th October as he did not keep an appointment. He was referred again on 13th November but he was discharged on 22nd November at his own request.

8.12. On 11th October the safeguarding lead in Adult Social Care checked with the district nursing service that Arthur's dressings were being changed. A further check was made on 13th December when a District Nurse stated that it was presumed that he was keeping appointments with the Practice Nurse as no report had been received to indicate the opposite. Checks were also apparently made with the GP practice and with the housing provider, the latter reporting less concern about the hoarding and fire risks as the exits were clear. However, the Fire and Rescue Service were reported to be concerned still due to Arthur's lack of mobility.

8.13. On 19th January 2018 the GP IMR refers to a PCH Safeguarding Lead Nurse discussing concerns regarding Arthur's memory with a GP. The GP referred Arthur for urgent bloods and a urine sample. When Arthur attended the surgery further antibiotics were prescribed. On 26th January the GP referred Arthur to Adult Social Care, having seen him at surgery, but when Arthur did not answer the telephone a 14 day letter[43] was sent. The GP referral was accompanied by a medical summary that referred to health care concerns. The GP made an urgent referral to the diabetic nursing service, with an observation that he was not eating well or coping with meals. His presentation is recorded in the GP IMR as "sleepy", with concerns about his diet and compliance with medication. There is no further Adult Social Care involvement until April.

8.14. Following the GP referral to the diabetic nursing service a letter was sent to Arthur on 6th February 2018 for a clinic appointment with a consultant for 29th March 2018. This is done through "Choose & Book" and transport for the first appointment is

[43] Such letters indicate to the service user that the case will be closed unless the person responds within 14 days.

arranged through the GP practice. Therefore, the Diabetes Service would not have arranged transport. Arthur did not attend the appointment. On 3rd April 2018 a "did not attend letter" was sent with a new date booked (21st June 2018). Arthur died 10th April 2018.

8.15. On 26th January the Housing Neighbourhood Officer visited and requested a Fire and Rescue Service welfare visit. Arthur expressed reluctance to move.

8.16. On 16th February the GP referred Arthur to the continence service due to urine incontinence. An appointment letter was sent for 9th March. On 20th February the Practice Nurse referred Arthur to the Tissue Viability Nurse because of the delayed healing of his pressure ulcer. The GP IMR refers to missed appointments being followed up with telephone messages that appear to have prompted attendance at appointments. The referral for urine incontinence followed an appointment that Arthur kept. Before the end of February a re-referral is made to the diabetes team.

8.17. East of England transported Arthur to PCH on 27th February 2018. Nothing significant is recorded in their IMR for this particular contact. This admission, according to the GP IMR, appears to have followed Arthur's friend having visited the GP surgery to express concern and to highlight Arthur's falls. A GP conducted a home visit and made the referral to PCH. The PCH IMR observes that this admission was initiated by the GP who had been alerted by one of Arthur's friends. He had experienced a couple of falls, was possibly suffering from sepsis and his dressings required changing. He was incontinent of urine and his blood sugar levels were high. He was at risk of skin damage. He responded to treatment in hospital, including intravenous antibiotics, but was occasionally uncooperative. His wounds were redressed and he was discharged on 4th March to the GP for on-going wound care. The PCH IMR could not find evidence of a referral to district nursing. There is a repeating pattern regarding the condition in which Arthur was being admitted to hospital and this theme, along with the adequacy of discharge planning, is picked up again in section 9 below. No section 42 (Care Act 2014) referral was made and this too is addressed further in section 9 below.

8.18. On 7th March Arthur attended the surgery for wound dressing by the Practice Nurse and a referral was made to the Tissue Viability Nurse. On 19th March the Tissue Viability Nurse discussed the case with the Practice Nurse and a joint visit was planned for April. Arthur attended all his appointments for dressings until 28th March when, according to the GP IMR, a care planning meeting was held. A reminder system was set up, a referral to the memory clinic agreed and a re-referral to the incontinence team. After 28th March he did not respond to telephone calls. On 29th March Arthur did not keep an appointment with the diabetes service and a letter with a new appointment was sent. On 4th April he did not keep an appointment with the Practice Nurse who notified the Tissue Viability Nurse. The Practice Nurse called on all numbers provided without success and then passed it to the reception team to keep trying.

8.19. On 6th April the Fire and Rescue Service were called to his flat and had to force entry. Arthur had fallen. There was evidence of low level hoarding plus damp. Arthur requested a care plan for assistance with cleaning and daily living. A referral was sent for a care and support assessment, received by Adult Social Care on 13th April, three days after Arthur had died.

8.20. Also on 6th April Adult Social Care reviewed the 14 day letter that had been sent on 26th January. The case was closed because the risks were judged to be low. Also on 6th April the GP IMR notes that District Nurses were asked to undertake a welfare check but this had not been done by the 9th April.

8.21. East of England transported Arthur to PCH for the final time on 9th April 2018. The PCH Serious Incident investigation states that the GP did not leave paperwork or instructions for the Ambulance Service but did fax notes to the hospital. The GP IMR states that this followed a GP home visit, having been alerted by Arthur's friend to the state of the flat and Arthur's ill-health. Nothing significant is recorded in the East of England Ambulance Trust IMR for this particular contact. However, the Serious Incident investigation records that equipment failure meant that the crew could not monitor oxygen saturations but that they did pre-alert PCH. The PCH IMR records that the admission was once again initiated by the GP. Arthur was very ill, admitted in a hyperosmolar hyperglycaemic state[44]. He was possibly suffering from sepsis and his diabetes was out of control. He had a grade 2 pressure sore in the sacral area and the risks of skin damage were assessed as being very high. His blood sugar levels were very high but the medical team managed to stabilise this. He required constant supervision. Once again the repeating pattern stands out. He died of a cardiac arrest the next day.

9. Thematic Analysis

9.1. The themes are derived from the terms of reference and from reading the combined chronology and from the additional information supplied by the agencies involved.

9.2. Hospital discharge

9.2.1. The ambulance crew were sufficiently concerned about the condition of Arthur's flat that they offered to return him to hospital on 29th January 2016. Arthur declined this offer.

9.2.2. The PCH IMR concludes that discharge plans were clear but that the referral processes for on-going care were not followed through in all instances. It notes that there is no reference in the June 2017 discharge arrangements that Arthur had not been out of his flat for several months. It observes that there was little in the clinical notes about his lifestyle and any links to his ill-health, and little

[44] A complication of diabetes mellitus in which high blood sugar levels develop through a combination of illness or infection and dehydration.

exploration of his home life and care and support needs. This IMR recommends that the discharge checklist form should be completed and filed on all occasions.

9.2.3. The Clarion Housing IMR observes that housing was not included in the discharge plans when there were concerns about the suitability of Arthur's accommodation and it was known that he was reluctant to move. This IMR recommends that discharge plans should consider the suitability of accommodation.

9.2.4. The PASC IMR observes that OT guidance had been clear that reablement was not suitable, particularly because of the state of Arthur's accommodation. This advice does not seem to have been heeded as reablement featured in the June 2017 discharge plan. This IMR also notes the absence of a multi-agency approach, observing that this could have led to greater engagement with Arthur and better outcomes by combining assessments and planning.

9.2.5. The PASC IMR found no evidence that the history of this case was considered in discharge planning. Nor were there contingency plans. In January 2016 he declined a care and support needs assessment and safeguarding involvement after his discharge. In June 2017 and August 2017 he declined reablement. This pattern was not recognised in discharge plans. Nor were his home conditions seen as part of this planning despite the evidence of self-neglect, including hoarding. All this meant that there was no comprehensive programme and opportunities were lost.

9.2.6. In summary, discharge planning arrangements do not appear to have changed despite repetitive patterns surrounding his admissions to hospital, often seriously ill with sepsis, infected wounds and uncontrolled diabetes, and with a history of rejecting services.

9.3. **Responses to risk of self-neglect**

9.3.1. The risks should have been well known to the agencies involved, with self-neglect dating from 2007. Less well known is when the self-neglect and hoarding began and the reasons for it. This highlights the importance of taking a history. The Neighbourhood Housing Officer and the OT were persistent in their attempts to tackle Arthur's hoarding, especially during the first half of 2017 and Fire and Rescue Service were appropriately involved in assessing his hoarding and his ability to vacate the flat in the event of fire. Measures such as alarms were in place but the risks from clutter remained.

9.3.2. East of England Ambulance Trust submitted a safeguarding referral in January 2016 but none thereafter. Ambulance crews did, however, pass on information regarding their observations to PCH. PCH submitted a safeguarding referral in August 2017. No other agency formally notified adult safeguarding of their

concerns. Noteworthy here is that Arthur was seriously ill on his final hospital admission. The panel and independent reviewer have observed that, although pertinent information may be recorded by professionals within their own agencies, there is no method for linking information across the differing record systems.

9.3.3. The CPFT IMR and entries into the combined chronology note the repetitive refusals to have his right leg dressed in the first half of 2017 but there is no evidence that this prompted exploration as to why. Indeed, the PASC IMR observes that there is no evidence that anyone sought to understand the rationale behind any of Arthur's decisions.

9.3.4. No agency was appointed as the lead organisation to coordinate assessment and planning. No lead worker was appointed. There do not appear to have been any multi-agency meetings to consider his self-neglect and how to address it; instead agencies worked largely on parallel lines, although the district nursing service and the Practice Nurse did liaise from September 2017 onwards to monitor whether Arthur kept appointments. A multi-agency meeting may have been appropriate in February 2016 when he is reported as saying that he did not see his home environment as a concern, and again in August 2017 when his home conditions were descried as "catastrophic" and exacerbating his poor health.

9.3.5. It is possible to conclude that there was no effective plan to help him manage well at home. The PASC IMR observes that he was not able to mobilise well , that all daily tasks were difficult, his mood was known sometimes to be low with an absence of motivation, he was socially isolated and had difficulties coping, and his diet was poor. Evidence of risk assessment, however, is limited, which this IMR relates to the need to strengthen risk assessment tools on triage documentation.

9.3.6. The PASC IMR concludes that referrals were closed because of his expressed wishes and an apparent ability to make his own choices but without a risk assessment other than to recognise that risks were high but that health care professionals were in contact with him. This IMR concludes that decisions post hospital discharges may have been strong on making safeguarding personal but this was not balanced with a focus on ascertaining the level of risk, using risk assessment indicator tools. It observes that the greater the risk, the greater the need to try to resolve or mitigate the risks and it questions whether the balance between risk and self-determination was appropriately struck in this case and whether it is appropriately considered more generally. To achieve such a balance requires a long-term approach to try to understand and respond

creatively rather than just accepting his choices. This conclusion accords with research on effective ways to work with adults who self-neglect[45].

9.4. Responses to lack of engagement

9.4.1. The PCH IMR notes that Arthur was mainly compliant with treatment when in hospital. The panel and independent reviewer have hypothesised that this might have been because hospital staff were assertive. Nonetheless, this IMR also observed that he had a long history of declining services and staff involved at the time with him observed in the learning event that they suspected that Arthur had little or no intention of engaging with professionals once he left hospital. Indeed, Arthur declined services at several points, including reablement, care and support assessments and podiatry. He also failed to keep appointments or cancelled them. This history does not appear to have triggered multi-agency consideration of how to mitigate the risks arising from declining services and failing to keep appointments. It does not appear to have prompted use of available risk assessment tools and a recommendation regarding their use is consequently made later.

9.4.2. The CPFT IMR observes that Arthur often failed to take advice or to keep appointments, and that he also did not answer the phone, especially if he did not know who was calling. It is unclear who knew this to be the case, especially when Adult Social Care Adult Early Help team frequently used telephone calls for assessment.

9.4.3. The PASC IMR found twelve references to Arthur declining personal care and support assessments and yet there does not appear to have been a change in approach towards him. The IMR observes that the rationale behind his refusals does not appear to have been explored. It was not unusual for him to fail to respond to telephone calls or letters. Non-attendance at, or cancelling of appointments, were not routinely followed-up. However, the approach taken, for example by Adult Social Care, did not change. Two IMRs[46] refer to the working context for staff, including workloads and staff shortages. This context may have been a factor alongside organisational workflow arrangements. Research[47] and SARs[48] have drawn attention to the importance of ensuring that the working context is aligned with evidence that identifies best practice for working with adults who self-neglect and hoard.

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[45] Braye, S., Orr, D. and Preston-Shoot, M. 2014 *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. (2014) London: Social Care Institute for Excellence.

[46] CPFT IMR and PASC IMR.

[47] Braye, S., Orr, D. and Preston-Shoot, M. 2014 *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. (2014) London: Social Care Institute for Excellence.

[48] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' *Journal of Adult Protection* (2015) 17 (1), 3-18.

9.4.4. The aim may have been to respect his choices and to promote his independence but the approach taken underplayed the apparent risks. There were occasional windows of motivation, when he complained about delays in assessments, but these opportunities were not really exploited by the agencies involved. The Housing Neighbourhood Officer and an OT took a more robust and persistent approach, visiting him at home. A more assertive outreach approach, coupled with an exploration of his choices and the history behind them, may have proved more effective. It would also have enabled an assessment of the degree to which his lack of mobility lay behind his failure to keep some appointments.

9.4.5. The panel and independent reviewer have questioned whether risk assessment tools, available in the self-neglect policy, were used and embedded in practice. Participants at the learning event concluded that Making Safeguarding Personal was misunderstood by some practitioners; professional curiosity about a person's desired outcomes and decisions should be a core part of practice.

9.5. Use of policies and procedures

9.5.1. Clarion Housing IMR points to the organisation's policies on safeguarding, tenancy management and vulnerable residents. However, it concludes that staff need to be up-to-date on its safeguarding policy in order to understand their responsibilities. Clarion housing did not make a safeguarding referral.

9.5.2. The CPFT IMR questions the understanding within the primary care team about leadership and responsibilities in complex cases. It asks who was responsible for Arthur's health care and whether a key worker should have been appointed.

9.5.3. The PCH IMR for the hospital admission in April 2018 notes that the managing patient in sepsis protocol was followed.

9.5.4. The PASC IMR devotes considerable space to critical reflection on procedures. It observes that the multi-agency policy and procedures for supporting people who self-neglect were in place but that there was only partial compliance. The risk assessment indicator tool in the policy was not used when it would have indicated that a section 42 enquiry was appropriate. Use of the policy and especially the risk assessment indicator tool would have provided a focus for multi-agency work, for example when he was seriously ill in August 2017 with the potential for loss of life. Once again this IMR notes that Making Safeguarding Personal[49] was the approach taken but without the necessary accompanying assessment and tackling of the risks of significant harm.

[49] Making Safeguarding Personal involves developing a safeguarding culture that focuses on the personalised outcomes desired by people with care and support needs who may have been abused or neglected (including self-neglect). It is a key operational and strategic goal. https://www.scie.org.uk/care-act-2014/safeguarding-adults/safeguarding-adults-boards-checklist-and-resources/making-safeguarding-personal.asp

9.5.5. The PASC IMR also refers to the multi-agency protocol for working with people who display hoarding behaviours. It concludes that this protocol too was only partially used, with no apparent consideration of whether his behaviour and lifestyle amounted to hoarding.

9.5.6. The PASC IMR also observes that there is no policy on oversight of case closures in Adult Social Care or written and clear guidance on the criteria surrounding the use and follow-up of 14 day letters when a person does not keep appointments or respond to attempted contacts.

9.5.7. Overall the PASC IMR concludes that the multi-agency policies are adequate but require more practical detail to support practitioners to creatively engage with service users. It recommends training on self-neglect, risk, non-compliance and case closures but research[50] has found that workforce development must be accompanied with workplace development if effective, evidence-based practice is to be embedded.

9.5.8. The GP IMR asserts that staff were aware of self-neglect guidance but there is no evidence in that submission as to when and how such awareness influenced the action taken in response to Arthur's presenting needs and the risks inherent in his situation.

9.5.9. Participants at the learning event wondered whether policies and procedures would achieve greater traction if they were simplified or shortened.

9.6. **Mental capacity assessment**

9.6.1. The PASC IMR concludes that Arthur's mental capacity was never formally assessed and observes that his behaviour and circumstances could have been considered reason enough to question his decisional capacity. It also comments that there was a lack of recognition that Arthur was unable to carry out his own good intentions at times throughout the period under review, an indirect reference to the need to consider executive capacity. Instead there was a presumption of mental capacity throughout, even when he was clearly not coping or when sepsis and other infections were present.

9.6.2. The Clarion Housing IMR notes that those involved considered Arthur to have mental capacity but also comments that assessment of mental capacity is not a statutory duty for landlords. The panel and independent reviewer have observed that assessment of mental capacity could fall to a landlord when they are in the best position, by virtue of their knowledge of the person and of the

[50] Braye, S., Orr, D. and Preston-Shoot, M. (2013) *A Scoping Study of Workforce Development for Self-Neglect*. Leeds: Skills for Care.

question to be decided, to determine whether an individual does indeed have the mental capacity to take a specific decision at a specific time.

9.6.3. The CPFT IMR states that he was discharged by the district nursing service because he stated that he could leave his flat. It does not appear that he was asked to demonstrate how he managed this, in a context where he had previously said that he had not left his flat for months. A "show me" approach might have indicated whether or not he could execute his stated decisions. Lack of mobility, possibly accompanied by lack of motivation, may have been behind his failing to keep some appointments with Podiatry and the Practice Nurse.

9.6.4. The PCH IMR states that Arthur had mental capacity on most admissions but how this was assessed and what best interest decisions were taken when he did not have mental capacity are unclear in the documentation provided for the review. This IMR recommends that mental capacity should be assessed in hospital. The panel and independent reviewer have concluded that compliance with recording decisions about the need for and outcome of mental capacity assessments needs to improve. A mental capacity assessment tool is available in every admission pack but was not completed in this case. He may well have been delirious as a result of infection, at least on his final hospital admission.

9.6.5. The GP IMR refers to Arthur's mental capacity having been formally assessed on 26th January 2018 when he was brought in by his friend. An abbreviated mental test score was completed and his medication compliance checked. However, it is unclear for which decision his mental capacity was being assessed and whether his executive capacity, especially the frequent gap between his stated intentions and his actual behaviour, was addressed. Participants at the learning event noted that his ability to act on decisions did not appear to have been tested.

9.6.6. There is reference in the documentation to his mental health but this does not appear to have been assessed either and therefore its impact on his mental capacity is unclear. Given that some records refer to low mood and "depression", it is unclear whether this was ever formally assessed. There is no evidence as to how Arthur perceived his situation and had responded to his amputation and subsequent difficulties.

9.7. **Prevention of health decline**

9.7.1. When admitted to hospital twice in 2017 and twice in 2018, Arthur was seriously ill. Until the final admission hospital staff were able to stabilise him. As the repetitive pattern became clearer there were, arguably, opportunities for agencies to reflect together on how to attempt to mitigate the risks, such as non-compliance with medication which was noted in September 2016 and the presence of clutter and faeces on the floor. The omission of multi-agency meetings has already been noted.

9.7.2. On discharge from PCH in August 2017 PCH recommended that the district nursing regime with respect to Arthur was completely revised. The PCH IMR questions whether maggot-infested wounds and the risk of them were managed actively. This raises the question of whether the arrangement reached between the Practice Nurse and the district nursing service regarding notification of missed appointments was sufficiently robust.

9.7.3. As observed above, Arthur's rejection of treatment for his right leg during the first half of 2017 was a warning sign of self-neglect and the reasons for his refusals do not appear to have been explored or factored into any risk assessment.

9.7.4. After Arthur cancelled his appointment at Addenbrookes Hospital with respect to his stump, no assertive outreach followed.

9.7.5. Both the panel and participants at the learning event observed that greater flexibility within the district nursing service with respect to home visits would be helpful.

9.8. **Safeguarding**

9.8.1. There were only two safeguarding referrals during the period under review, one from East of England Ambulance Trust and one from PCH. It has already been observed that the multi-agency policy on self-neglect should have prompted a multi-agency approach through the medium of an enquiry.

9.8.2. The PASC IMR concludes that there is insufficient awareness of the need to progress safeguarding in self-neglect cases. The Clarion Housing IMR suggests that a safeguarding referral may have been appropriate. The PCH IMR concludes that a "vulnerable adult" referral should have been made on other occasions than just in August 2017, for example during the February 2018 admission.

9.8.3. Both safeguarding referrals were closed in apparent respect for Arthur's choices but without, as has been noted above, balancing this sufficiently with a risk assessment. When, on the first occasion, Arthur subsequently declined care and support assessment, there was no review of the safeguarding decision or reassessment of risk.

9.8.4. No feedback was provided to the Ambulance Trust regarding the outcome of their referral in January 2016 and the history of Arthur's case does not appear to have been gathered before this decision was made.

9.8.5. The PASC IMR recommends that the safeguarding triage process should use the risk assessment indicator tool contained within the multi-agency policy on

working with people who self-neglect. It further recommends that a multi-agency section 42 process should be used for high risk cases and for those of medium risk a multi-agency approach outside of section 42.

9.8.6. The GP IMR provides ample evidence of repeating patterns of self-neglect, difficulties with activities of daily living as a result of his disabilities, wound ulcers that may respond to antibiotics but are recurring. However, this evidence did not prompt any formal notifications of safeguarding concern or change in approach. This IMR concludes that more safeguarding meetings should have been held with the primary care team in order to ensure continuity of care and information-sharing. Although Arthur is said to have been on the surgery safeguarding list, it is unclear what this actually achieved in terms of reviewing the approach to Arthur's presenting problems. Indeed, the GP IMR concludes that there is a need for (more) multi-disciplinary team meetings for patients on the safeguarding list and requiring community care.

9.9. **Working together**

9.9.1. The Clarion Housing IMR observes that the Neighbourhood Housing Officer was not routinely informed of Arthur's hospital admissions, leading to abortive visits. It also notes that when concerns were raised with other agencies, these were not always fully addressed. There does appear, however, to be some good collaboration with an OT during the first half of 2017 and with the Fire and Rescue Service. This IMR recommends clearer procedures for managing complex cases to avoid agencies working in isolation. It also recommends improved communication with health and social professionals regarding adaptations and alternative housing options.

9.9.2. The PCH IMR concludes that there was some inter-agency communication but that this was not consolidated. Multi-agency meetings might have overcome this apparent deficit and appointed both a lead agency and key worker. This IMR also concludes that agencies did not have a holistic view of Arthur, his lifestyle or his care and support needs, and the approach did not change when he was admitted to hospital critically ill in 2017 and 2018.

9.9.3. As commented in the previous section, it is possible to conclude from the GP IMR that the overall approach to Arthur's ill-health did not change throughout the period under review. This IMR also observes that communication between the GPs and members of the primary care team, for example District Nurses, could have been more effective, and that communication between all the agencies involved could have been more efficient and timely. It also concludes that proper handovers between professionals are required in order to ensure continuity of care. That Arthur was seen by a considerable number of GPs during the period under review highlights the challenges faced by this surgery, the need

to improve communication between members of the primary care team and the importance of care continuity.

9.9.4. The PASC IMR found a lack of discussion with and feedback to the GP, who referred Arthur in January 2018, when the case was closed in early April 2018. The same occurred previously, it appears, in June 2016. From 2016 onwards this IMR concludes that there was no recognition that a multi-agency response might have achieved more and that assumptions, for example in June 2017, that District Nurses were in regular and close contact with Arthur were not checked out. It warns that information and outstanding actions regarding a case can become lost when there are transfers between teams within Adult Social Care.

9.9.5. The PASC IMR recommends that assessment should include consideration of a person's history and face-to-face contact in the individual's home environment. It also recommends closer engagement between Adult Social Care, GP and health services.

9.9.6. Participants at the learning event concluded that hitherto agencies have not been good at coming together and that multi-agency meetings need to be used more frequently when working with complex situations.

9.10. **Assessment**

9.10.1. There are only two records of a multi-disciplinary team meeting involving some primary care personnel, in early September 2017 and again on 28th March 2018 in what the GP IMR refers to as a care planning meeting following missed appointments.

9.10.2. There does not appear to have been an assessment of Arthur's mental health despite one IMR[51] referring to "significant mental health problems" and another[52] noting a history of low mood and depression, other than reference in the GP IMR to assessment using the abbreviated mental test score in late January 2018. The focus fell entirely on his physical health, perhaps indicating a lack of parity of esteem between physical and emotional wellbeing.

9.10.3. The PASC IMR observes that the history of this case was not consolidated, and that Arthur's rationale for his behaviour was not explored, with the result that there was no recognition of patterns and the need for a multi-agency approach. It comments that earlier records, between 2001 and 2010, recorded similar

[51] Clarion Housing IMR
[52] PASC IMR

concerns and issues of risk. Research on SARs involving cases of self-neglect has commented on the importance of considering history[53].

9.10.4. The PASC IMR is critical of a number of aspects revolving around assessment, namely:

- Adult Social Care staff responsible for care and support assessments did not observe the home environment;
- OT advice that Arthur was not suitable for reablement was not heeded by other health and social care practitioners, especially at the point of hospital discharge;
- There were assessment delays – a waiting time of six weeks for a full OT assessment in the home, an incontinence referral on 16th February 2018 with an appointment offered for 9th March, delayed allocation for care and support needs assessments, and Arthur chasing his own referral for wheelchair assessment;
- The absence of in-depth engagement by Adult Social Care staff with Arthur when he was in hospital;
- Lack of contact with the friend who was said to be undertaking some caring responsibilities, such as shopping or clearing clutter;
- There was no assessment of his social isolation[54], even when Arthur had commented that he had not been out of his flat for months because of access difficulties combined with lack of mobility;
- There do not appear to have been any conversations involving Adult Social Care social work or social care assessors with respect to how to enhance his independence and to manage the risks, his difficulty coping and his possibly unrealistic expectations;
- Reliance on telephone contact[55] in Adult Social Care Adult Early Help when the home should have been seen, which contributed also to the absence of assertive follow-up when he declined assessment and/or services.

9.10.5. Periodic reviews were completed of the need for adaptations but there was ultimately no progress, sometimes because Arthur wanted to wait for assessment of his stump, partly because the OT and Housing Officer wanted a long-term prognosis regarding his mobility and the implications of this with respect to whether to attempt to persuade Arthur to move. This meant that

[53] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' *Journal of Adult Protection* (2015) 17 (1), 3-18.

[54] There are potential human rights implications here with respect to the definition of the right to private and family life (R (Bernard and Another) v Enfield London Borough Council [2002] 5 CCLR 577).

[55] Department of Health Statutory Guidance (2017) relating to implementation of the Care Act 2014 advises against wholesale reliance on telephone assessment, especially in complex cases.

throughout the period under review, his flat was not suitable to meet his needs[56].

9.10.6. Participants at the learning event observed that there was a lack of face-to-face work with Arthur, for example when he was in hospital, which might have provided an opportunity to challenge or explore his decision-making and to attempt to work with him to build a discharge plan that would address the many physical and emotional challenges that he faced. It was also noted that there were missed opportunities to assess his mental health when he was in hospital.

9.11. **Recording**

9.11.1. The chronology presented in the three time episodes notes occasions where the records kept by agencies were incomplete or unclear. For example, there is no record in the PCH notes of a referral to Adult Social Care when Arthur was in hospital during February 2018. There are some discrepancies about when District Nurses were or were not visiting. As the PASC IMR points out, it is not always clear what advice was given to Arthur, it is possible that multi-disciplinary meetings when Arthur was in hospital were not recorded, and Adult Social Care files contain no account of senior manager oversight.

9.11.2. The GP IMR refers to the need to keep patient details up-to-date. He was not seen by the Tissue Viability Nurse at one point because District Nurses had incorrect contact details for Arthur. The same IMR observes that written communications from District Nurses would assist GPs to judge a patient's condition.

9.11.3. Participants at the learning event reiterated that IT systems restrict rather than facilitate access to information, making it difficult for professionals to be informed of the full history of the case and current concerns.

9.12. **Case closure**

9.12.1. The PASC IMR questions whether case closure of reablement on 5th September 2017 was wise given the history of the case and observes that the result of case closure, without multi-agency discussion, meant that at times there were no open referrals. It also questions the reasoning behind closing down both safeguarding referrals, where Arthur's choices were respected without adequate consideration of risks. The same IMR, for the same reasons, questions the OT manager's decision to close down OT involvement in November 2017, and the decision taken on 6th April to close the referral for assessment made by the GP three months earlier without speaking to the GP.

[56] Clarion Housing IMR.

9.12.2. The PASC IMR recommends that records should include a detailed rationale when closing a case, with clarification also of processes surrounding the use of 14 day letters.

9.12.3. Research on SARs[57] and on self-neglect[58] cautions against case closure without multi-agency consideration as this can result in a person at risk being someone no agency "owns." In this case the panel and independent reviewer have concluded that the GP should have been contacted for up-to-date information prior to case closure decisions.

9.13. **Recognition and assessment of carers**

9.13.1. At various points in the chronology it is clear that Arthur was reliant upon and assisted by a neighbour. The combined chronology records that the neighbour sometimes accompanied Arthur to the GP surgery and sometimes alerted the GP with concerns about Arthur's health and wellbeing. On one occasion at least the neighbour called the ambulance. It was indeed this neighbour who alerted the GP prior to Arthur's final admission to PCH.

9.13.2. It does not appear that this neighbour was recognised as a carer or the extent established of the care and support that he was offered.

9.13.3. It does not appear that this neighbour was asked for information regarding Arthur's past and present living situation when he might have held useful information.

9.13.4. When speaking with the independent reviewer, the neighbour provided detailed information about the challenge facing Arthur each time he wished to leave his flat – difficulty weight bearing, an entry door to the building which he could not open, partly because of a bad arm and shoulder, a step to negotiate on entry/exit, interlocking corridor doors and a lift. Entry ways were narrow. It was, the neighbour described, a struggle for him to leave the building and even more difficult to get in unaided. Sometimes therefore he would not go out. He was embarrassed about his legs and incontinence. Such information would have been useful to District Nurses when deciding whether he could visit the Practice Nurse, and to other agencies with responsibility for meeting his care and support, and housing needs.

9.13.5. Reference has been made in this review to a period when someone stayed in Arthur's flat. Clarion Housing were aware of this. The neighbour commented

[57] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' *Journal of Adult Protection* (2015) 17 (1), 3-18.

[58] Braye, S., Orr, D. and Preston-Shoot, M. 2014 *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. (2014) London: Social Care Institute for Excellence.

that Arthur felt exploited by this person but the neighbour was not approached for information and for his support to help agencies engage with Arthur.

9.13.6. Other safeguarding adult reviews have stressed the importance of seeking information from carers and ensuring that they are offered carer assessments[59].

9.14. **IMR process**

9.14.1. Not all IMRs were submitted on time or in the appropriate format. Despite a briefing for IMR writers, one agency[60] appears to have appointed an author very late and to have allowed little time for them to complete the IMR. Not all potential IMR writers attended the briefing.

9.14.2. The degree of critical analysis and reflection is variable across the IMRs.

9.14.3. Panel members and participants at the learning event agreed that further training for IMR writers would be helpful.

10. Agency Context

10.1. The CPFT IMR refers to out of hours' nurses being used sometimes for changes of dressings. This was because the district nursing service was under pressure regarding workload capacity. The panel and independent reviewer have questioned whether information-exchange between these services is sufficiently robust.

10.2. The GP IMR refers to workload pressures facing District Nurses. With reference back to section 9.9.3, the panel observed that the reliance on locum GPs in this surgery was illustrative of the challenges surrounding GP recruitment. Arthur was unable to have one designated GP who could have provided continuity of care.

10.3. The PASC IMR refers to the very high volume and throughput of work, and to staffing shortages in some teams. It refers to an organisational culture where there was an expectation to move work on quickly, with a high turnover of cases and telephone assessment as the norm within Adult Early Help.

10.4. The PASC IMR also refers to audits, on self-neglect, on multi-agency safeguarding hub arrangements and adult social care safeguarding. Good practice on self-neglect was found in all instances, focused on capacity assessment, person-centred and comprehensive enquiries, gathering of relevant information, including history, and effective multi-agency working. However, further development was required with respect to increasing organisational awareness of multi-agency policies on self-neglect,

[59] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' *Journal of Adult Protection* (2015) 17 (1), 3-18.
[60] GP surgery.

improved management oversight, training, working jointly with other agencies and analysing why some people do not engage or accept support.

10.5. Audits of multi-agency safeguarding hub arrangements found good practice in terms of timely responses, identification of risk, management oversight, consideration of mental capacity and proportionate decision-making. However, development areas were identified, namely recording the rationale for decisions, reflecting the risks that had been identified, and consistent completion of assessment of risks and a person's strengths.

10.6. The audits of adult safeguarding found good practice in the effective identification of risks, needs and protective factors, consideration of mental capacity, an outcome focused approach that drew on making safeguarding personal practice, multi-agency working and person-centred early engagement. Further development was needed in effective management oversight, and considering all aspects of a person's identity.

10.7. These audits took place during 2016 and 2017. They provide an interesting perspective when considered alongside the thematic analysis of this case.

10.8. Participants at the learning event observed that demanding workloads can impede communication between agencies and finding the time to discover and then address a person's history, or to drop by a person in order to maintain contact.

11. Good Practice

11.1. During the first half of 2017 OT practice with Arthur was persistent, what the PASC IMR calls "diligent."

11.2. The Neighbourhood Housing Officer maintained consistent contact with Arthur and liaised closely with the Fire and Rescue Service and the OT.

11.3. Ambulance crews arrived within expected timescales.

11.4. Health and social care practice ascertained Arthur's wishes and respected his decision-making.

11.5. The GP Surgery acted on the advice of CPFT after the August 2017 hospital admission to ensure that Arthur had a care plan in place where by the Practice Nurse would alert other members of the primary care team when he did not keep appointments for wound dressing. The GP Surgery does have a designated staff member whose role includes following up people who do not keep appointments.

11.6. PCH notification and escalation of concern prompted the commissioning of this review because of the severity of Arthur's condition on admission in August 2017.

11.7. There was positive liaison between the Tenancy Support Worker and the OT.

11.8. As participants in the learning event concluded, some professionals invested considerable time with Arthur but much of this effort occurred in isolation and not as part of a co-ordinated multi-agency effort.

12. Concluding Discussion

12.1. Participants at the learning event endorsed and developed the thematic analysis that has been presented herein and concluded that, without policy and practice development, such a case could re-occur.

12.2. The learning from this case and from previous SARs, references to which have been included in this report, means that it is now possible to identify what good single and multi-agency practice should consist of with respect to people who self-neglect and hoard. For example, in the domain of direct practice this case yet again reinforces the importance of relationship-building and face-to-face communication, professional curiosity in relation to a person's history and decision-making, and detailed risk and mental capacity assessments.

12.3. In the domain of multi-agency working together, this case illustrates the importance of multi-agency meetings and the appointment of a lead agency and key worker. In relation to primary care, GPs and other members of the primary care team involved in the case need to determine who will co-ordinate and monitor the care plan. Primary and secondary healthcare agencies need to come together around hospital discharge and work closely with Adult Social Care and Housing. Escalation policies, which this SAB has introduced, need to be utilised when there are concerns about how agencies are working together.

12.4. Nonetheless, the strain nationally on health and social care services must be acknowledged – the growing volume and complexity of demand. That forms a backdrop to this and other cases.

12.5. The recommendations have been formulated with these conclusions in mind.

13. Recommendations

13.1. Review of the findings and conclusions at the learning event and panel meetings resulted in the shared view that Arthur's case was not unique. Interlocking systemic factors are recognisable that could, if unchecked, reappear in other cases. The recommendations that follow are designed to strengthen how agencies work together in similar cases in the future.

13.2. Arising from the analysis undertaken within this review, the SAR Panel recommends that the Cambridgeshire and Peterborough Safeguarding Adults Board:

Hospital Discharge

13.2.1. Reviews with partner agencies how hospital discharge care and support plans are arranged in complex cases with repeating patterns of risk.

Responses to Risk of Self-Neglect

13.2.2. Arranges a programme of multi-agency training on self-neglect, involving practitioners, operational managers and strategic managers to ensure whole system change as well as workforce development; this training to include skills of expressing professional curiosity, the importance of ascertaining a person's history and a chronological account, and how staff should respond when there is a tension between a person's autonomy or self-determination and the likelihood or risks of significant harm as a result of their decision-making and self-neglect.

Responses to Lack of Engagement

13.2.3. Reviews the provision of outreach to people who do not attend appointments and/or who decline assessment or services having previously agreed to them.

Use of Policies and Procedures

13.2.4. Reviews existing policies on self-neglect and hoarding, escalation and the use of multi-agency risk management meetings to ensure that they provide clear and accessible guidance to staff.

13.2.5. Disseminates the revised policies and procedures through learning and service development events and team briefings.

13.2.6. Conducts multi-agency case file audits to explore how embedded the policies and procedures are in practice.

Mental Capacity Assessments

13.2.7. Works with NHS Trusts and Adult Social Care to ensure that mental capacity assessments are undertaken in secondary care settings, using the templates and tools already available.

13.2.8. Works with providers of social housing on undertaking mental capacity assessments.

13.2.9. Provides guidance on consideration of executive capacity in mental capacity assessments, especially where there are repeating patterns of presentation.

Prevention of Health Decline

13.2.10. In partnership with the CCG, provides guidance for GPs and other professionals within primary care on leadership and co-ordination of health care provision in complex cases involving multiple needs and repeating patterns.

13.2.11. Conducts audits on the timeliness of response to urgent referrals, for example by providers with respect to assessment for the provision of equipment

and by NHS Trusts and Adult Social Care for review of health and social care needs.

13.2.12. In partnership with CCG, reviews the thresholds used by the district nursing service for home visiting.

Safeguarding

13.2.13. With Adult Social Care, clarifies the circumstances when a notification of concern would be appropriate in order to prompt a section 42 enquiry in self-neglect and hoarding cases to ensure a co-ordinated multi-agency response.

Working Together

13.2.14. Reviews guidance on multi-agency arrangements to avoid agencies working in isolation with complex cases, including the use of network meetings, case conferences and risk management meetings.

13.2.15. Ensures that guidance addresses the requirement for lead agencies and key workers to be appointed in complex cases to ensure a co-ordinated response.

Assessment

13.2.16. Conducts multi-agency audits of the use of risk assessment tools in complex cases, as already required by procedures/policies.

13.2.17. Works with Adult Social Care to clarify the circumstances where home visits rather than telephone contact and assessments are appropriate with respect to persons with care and support needs, and a history of declining care and support, and safeguarding concerns.

Recording

13.2.18. Works with partner agencies to explore how to facilitate information-sharing through interlocking IT systems.

13.2.19. Works with CCG to ensure that GP and primary care record systems clearly flag where there are safeguarding concerns and are accessible to primary care team members.

Case Closure

13.2.20. Strengthens current guidance on working together in complex cases to emphasise that GPs should be contacted and multi-agency meetings should be held prior to case closure where there are safeguarding concerns.

13.2.21. With Adult Social Care, reviews the use of 14 day letters.

SAR Process

13.2.22. Reviews current guidance, training and support for IMR writers.

13.2.23. Initiates discussion with other SABs and with the Department of Health and Social Care on accountability of a SAB for ensuring the well-being of an adult with care and support needs and at risk of further significant harm where a SAR has been commissioned.