

EAST SUSSEX SAFEGUARDING ADULTS BOARD SAFEGUARDING ADULTS REVIEW: ADULT A

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1. INTRODUCTION

1.1. Brief overview of the circumstances that led to this review

1.1.1. Mr A, aged 64 (date of birth 7th January 1952), died on 24th July 2016. A post-mortem established his cause of death as systemic sepsis, cutaneous and soft tissue infection of the legs, diabetes mellitus and idiopathic hepatic cirrhosis.

1.1.2. Mr A had Korsakoff Syndrome¹, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis and ulceration. Since 2013 he had been in receipt of continuing care funding from West Kent Clinical Commissioning Group (CCG). On 25th August 2015 he had been admitted to Maidstone Hospital from the Kent nursing home in which he lived, for treatment of his ulcers. The nursing home made it known that it was unable to manage his complex needs and challenging behavior, which included care and treatment refusal. As a result, when he was ready to be discharged from hospital in September 2015, he was placed in a nursing home in East Sussex. This was intended to be a short-term placement, pending a move back closer to his home in Kent, but such a move did not subsequently take place.

1.1.3. Mr A continued to refuse care and treatment. He did not feel the East Sussex placement was suitable and wished to move nearer to his home; a former colleague who held lasting power of attorney (LPA) supported him in this². Mr A was assessed as lacking capacity to make decisions about his care and treatment, and deprivation of his liberty was authorised in order to ensure his continued stay at the nursing home in his best interests. His health gradually deteriorated and a psychiatric assessment in March 2016 concluded that he required specialist care in a brain injury unit or specialist private hospital, or detention under the Mental Health Act 1983. In June 2016 he was referred (without outcome) to the Lishman neuropsychiatry unit at Bethlem Royal Hospital, London.

1.1.4. On Friday 22nd July 2016 the care home manager noted bilateral infestation in maggots in Mr A's ulcerated legs, and attempted to secure a Mental Health Act 1983 assessment and/or a general hospital admission. In the absence of either being possible, and having made a safeguarding referral to adult social care, the manager called for out of hours GP assessment, which took place the following morning. The GP attempted to secure admission to Kings Hospital, London, which was

¹ A chronic memory disorder caused by severe thiamine deficiency, commonly resulting from alcohol misuse (Alzheimer's Association, <http://www.alz.org/dementia/wernicke-korsakoff-syndrome-symptoms.asp>)

² Mr A signed to grant LPA over property & finance and health & welfare on 18th March 2013 and the LPA was registered with the Office of the Public Guardian on 11th June 2013. A 'replacement attorney' was also named in OPG records (KCC IMR).

in line with Mr A's wishes, but the hospital was unable to admit him. The following day, 24th July 2016, the nurse in charge became concerned about Mr A's laboured breathing and called an ambulance, which attended. Due to health and safety risks from Mr A's condition, and given he was by now breathing normally, the ambulance crew (having sought supervisory guidance) did not further enter his room, leaving him in the care of the nurse in charge. Mr A's condition later deteriorated again and he died that evening.

1.2. Statutory duty to conduct a Safeguarding Adults Review

1.2.1. A Safeguarding Adults Board (SAB) has a statutory duty³ to arrange a Safeguarding Adults Review (SAR) where:

- (a) 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
- (b) There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

1.2.2. 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 future⁴. The purpose is not to allocate blame or responsibility, but to identify ways of improving how 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.

1.3. East Sussex SAB decision to conduct a review

1.3.1. On 10th August 2016 Sussex Police made a SAR referral to the East Sussex Safeguarding Adults Board (ESSAB) Case Review Panel. The Panel at its meeting on 22nd August 2016 found that the case met the criteria for undertaking a SAR, and on 25th August the Chair of the ESSAB endorsed this decision. A SAR Panel was appointed to conduct a review that would help the Board achieve the outcomes set out in its SAR policy:

- To establish whether there are lessons to be learned about the way in which local professionals and agencies work together to safeguard adults;
- To establish what those lessons are, how they will be acted upon, by whom, and what is expected to change as a result;
- To improve multi-agency working to better safeguard adults.

1.3.2. The membership of the SAR Panel was as follows:

³ Sections 44(1)-(3), Care Act 2014

⁴ Section 44(5), Care Act 2014

- Chair of the Panel: Head of Community Safety, East Sussex Fire & Rescue Service
- Lead reviewers and overview report writers: Suzy Braye & Michael Preston-Shoot, independent consultants
- East Sussex Adult Social Care
- East Sussex Clinical Commissioning Group
- East Sussex Safeguarding Adults Board
- Kent Adult Social Care (also linking to Kent and Medway SAB):
- Owner, Nursing Home One
- South East Coast Ambulance NHS Foundation Trust
- Sussex Partnership NHS Foundation Trust
- Sussex Police
- South East Commissioning Support Unit Placement Team⁵ and West Kent CCG

1.3.3. The SAR Panel received administrative support from the East Sussex SAB administrator.

1.4. Terms of reference for the review

The SAR Panel's full terms of reference may be found at Appendix 2. The scope of the review was to focus on the events leading up to the death of Mr A and to consider engagement and intervention with him, as well as with his family/friends/attorneys. The following factors were to be a particular focus:

- (i) *Placements*: How these were organised, and reviewed; how was it ensured that they had the skills to meet specialist needs;
- (ii) *How health and social care professionals worked together*, including across borders;
- (iii) *How Adult A was engaged with*, including any family members/LPA, how his wishes were understood and to what degree they were met;
- (iv) *Mental capacity/Deprivation of Liberty*: How these were assessed and relevant issues considered, taking into account Mr A's condition and needs;
- (v) *The interface between the Mental Capacity Act and the Mental Health Act*;
- (vi) *Care and treatment plans*: how they were agreed and followed, and whether all professionals were aware of them.

1.5. Other investigations

1.5.1. East Sussex Adult Social Care have conducted a safeguarding enquiry under section 42 of the Care Act 2014⁶.

⁵ From 1st April 2017, the South East Commissioning Support Unit (SECSU in this report) became known as NEL Commissioning Support Unit.

⁶ Section 42 of the Care Act requires the local authority, where they have reasonable cause to suspect that an adult with care and support needs is being abused or neglected and as a result of their needs is unable to protect her or himself, to make such enquiries as are necessary to enable the authority to decide what action needs to be taken and by whom.

1.5.2. South East Coast Ambulance Service has completed a serious incident review process.

1.5.3. Mr A's death is the subject of a Coroner's investigation. At its first meeting on 28th November 2016, the SAR panel for the present review decided to proceed with this review concurrently to the Coroner's investigation.

2. THE REVIEW METHODOLOGY

2.1. The review model

The approach chosen by the ESSAB Case Review Panel was a review model that involved:

- Individual Management Reviews (IMRs) commissioned by the SAR Panel from each agency that had involvement with Mr A in the period leading up to his death;
- Appointment of an independent reviewer and report writer to work with the Panel, and provide an overview report and summary report containing analysis, lessons learnt and recommendations;
- A learning event attended by practitioners and managers in agencies directly involved in Mr A's care, to ensure that their perspectives were heard, to clarify outstanding matters, and to stimulate debate about learning. Forty participants reviewed the draft report, engaged in reflective discussion and made proposals about potential recommendations;
- Formal reporting to the Safeguarding Adults Board, development of an action plan, and monitoring of implementation across the partnership.

2.2. Individual Management Reviews

2.2.1. The panel received reports from the following agencies:

Agency	Nature of involvement with Mr A
East Sussex Adult Social Care (ESASC)	ESASC were contacted two days before Mr A died when the GP made a safeguarding referral.
East Sussex Healthcare Trust (ESHT)	The Trust manages Eastbourne District General Hospital, where Mr A was treated at the emergency department.
Eastbourne, Hailsham & Seaford Clinical Commissioning Group (EHSCCG)	The IMR (commissioned by NHS England from an independent GP) reports on the involvement of Mr A's GP, and the involvement of the out of hours GP service.
Nursing Home One, East Sussex	Mr A was resident at Nursing Home One from 15 th September 2015 until his death on 24 th July 2016.

Kent County Council Adult Safeguarding Unit MCA/DoLS Service (KCC)	KCC handled applications for deprivation of Mr A's liberty in the care homes in which he lived.
South East Coast Ambulance NHS Foundation Trust (SECAMB)	SECAMB responded to two 999 calls on the day of Mr A's death.
South East Commissioning Support Unit Placement Team (SECSU) ⁷ on behalf of West Kent Clinical Commissioning Group (WKCCG)	WKCCG funded Mr A's placement under its continuing health care arrangements. Care planning, commissioning and case management input was provided by SECSU (also known as Kent CHC) on behalf of WKCCG.
Sussex Partnership NHS Foundation Trust (SPFT)	SPFT provided community mental health services to Mr A: assessment by a consultant psychiatrist in March 2016 and on-going contact by the psychiatrist thereafter.

2.2.2. In addition, Sussex Police and Maidstone and Tunbridge Wells NHS Trust both provided information on their respective involvements.

2.2.3. Guidance was provided for IMR writers, setting out the purposes of the IMRs:

- To enable agencies to reflect on and evaluate their involvement with Mr A, identifying both good practice and systems, processes or practices that could be improved;
- To contribute the individual agency perspective to the SAR Panel's overview of interagency practice in Mr A's case;
- To identify recommendations for change, at either individual agency or interagency level.

2.2.4. IMR writers were asked to provide, on standard templates, a detailed chronology of their involvement with Mr A and a narrative report explaining and evaluating that involvement.

2.3. Synthesis, discussion and evaluation of evidence

2.3.1. From the agencies' chronologies, a consolidated chronology was produced, mapping the actions of each agency by date against the actions of others. From this cross-referencing emerged significant episodes and themes in how the agencies, singly and jointly, responded to Mr A's situation and needs. The narrative IMR reports allowed further exploration of these episodes and themes.

2.3.2. A learning event was held at which managers and practitioners from the agencies that had been involved with Mr A discussed the

⁷ Known as NEL Commissioning Support Unit From 1st April 2017

significant episodes and themes, in order to identify the emergent learning.

2.3.3. The SAR Panel met on three occasions for discussion and analysis.

2.3.4. Based upon this review process, this overview report contains:

- A summary of the circumstances of Mr A's case;
- A chronology detailing the key actions reported by the relevant agencies;
- A themed analysis of learning that emerges from the actions taken or not taken by individuals and agencies;
- A concluding evaluation of the ways in which Mr A's circumstances were responded to;
- A set of recommendations for the ESSAB as a whole concerning the areas in which policy, procedure and practice could be improved.

2.4. Participation by Mr A's family

One of Mr A's relatives and his attorney were invited to contribute to this review. No response was received to the letters sent.

3. Mr A THE PERSON

3.1. Sources of information

This section brings together background information and observations from the agencies' submitted chronologies and IMRs. It summarises their involvement with Mr A prior to the period under review in order to provide contextual background for the events that are the primary focus of the review.

3.2. A pen picture

3.2.1. Believed to be originally from London, Mr A had lived in Kent for some years⁸. He had worked as a company director for market research companies and had been married twice, with two children from his first marriage and three from his second marriage. He had two sisters⁹. Mr A was believed to be estranged from his family¹⁰ and not to have any contact with either his children or his sisters. He was an alcoholic but had been teetotal since 2013¹¹.

3.2.2. Mr A was believed to have had brain surgery 9 years previously and in 2013 a stomach bleed that necessitated intensive care¹². He had

⁸ SAR referral

⁹ SPFT IMR

¹⁰ CARE HOME ONE IMR

¹¹ SPFT IMR

¹² SPFT IMR

complex health needs arising from Korsakoff Syndrome, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis and ulceration. He commonly refused intervention to meet his health and personal care needs, and could at times be hostile and aggressive¹³. His attorney described him as having a lifelong trait of not wanting to follow the lead or recommendations of others¹⁴.

3.2.3. Mr A had some contact with Kent County Council Adult Social Care related to assessments in 2013 following hospital admission for health problems. On 25th July 2013 he was deemed eligible for NHS Continuing Healthcare, with West Kent Clinical Commissioning Group as the funding body. Infrequent contact with adult social care continued while he was in receipt of continuing care funding¹⁵.

3.2.4. He had a close friend who worked with him, whom he described as his next of kin¹⁶ although they were not a family member. The friend held lasting power of attorney (LPA) over health and welfare, and finance and property¹⁷. The LPA was granted by Mr A on 18th March 2013 and registered with the Office of the Public Guardian (OPG) on 11th June 2013. The OPG also lists the name of a replacement attorney¹⁸. In this report, where the attorney is referred to, the reference is to the lead attorney. Where relevant, the replacement attorney (of whom there is no mention in any IMRs) is referred to as second attorney.

3.2.5. Mr A was discharged to Nursing Home Two, located in Kent, on 20th August 2013. There he refused physical health interventions but appeared to settle into the nursing home, who managed his behaviour, which continued to fluctuate but became less challenging. However he was re-admitted to hospital on 25th August 2015 for care of his legs, and the home declined to have him return to their care¹⁹.

3.2.6. Mr A's hostility to and refusal of personal care, nursing care and medication remained consistent after his discharge from hospital to Nursing Home One, located in East Sussex. He consistently expressed a wish to live in Kent, and to be admitted to Kings Hospital London, where his brain surgery had previously taken place, for medical treatment. When advised in January 2016 of the professionals' view that his life was at risk as a result of his refusal of care he is reported to have stated that he "*had no life now so it would not matter*"²⁰.

¹³ SECSU IMR

¹⁴ CARE HOME ONE IMR

¹⁵ ESASC IMR His case was closed to adult social care in June 2014.

¹⁶ SPFT IMR

¹⁷ SECSU IMR

¹⁸ KCC IMR

¹⁹ SECSU IMR

²⁰ SPFT IMR

4. CASE CHRONOLOGY

This combined chronology of agencies' involvement with Mr A between 25th August 2015 and 24th July 2016 is taken from the chronologies submitted by those agencies as part of their IMRs. Footnotes identify the source of the information about each event.

4.1. On 25th August 2015 the SECSU nurse assessor visited the Kent nursing home, Nursing Home Two, to complete a routine review of Mr A's needs, having been advised by the home of concerns about his skin, and that his behaviour was deteriorating. Mr A refused to engage in discussion, and believed his needs could only be met at Kings Hospital London. The assessor, concerned about his ulcerated, oedematous legs, requested that the home seek an urgent review from the GP²¹.

Mr A was admitted to Maidstone Hospital later the same day by ambulance from the nursing home, following a telephone call from his GP. The medical concern was cellulitis in both legs. The IMR describes Mr A as having been included in discussions about his transportation to hospital and as having been calm and co-operative²². The GP notes mentioned that the nursing home felt unable to care for him, and considered hospital admission to "force a social review"²³. His treatment plan was to treat him for chronic lymphoedema, to encourage him to take antibiotics, and to discuss his treatment with his GP and with Kings College Hospital²⁴.

4.2. On 26th August 2015 and subsequently, Mr A refused to take antibiotics, believing he did not have an infection²⁵. The SECSU senior nurse assessor asked the ward to undertake a mental capacity assessment for Mr A's decision-making related to treatment for his leg oedema. The senior nurse assessor also advised the ward that the nursing home had been administering covert medication²⁶.

4.3. On 27th August 2015 Nursing Home Two advised SECSU that they would not take Mr A back, believing they were unable to meet his complex needs due to the impact his mental health was having on his physical health²⁷. Ward notes indicate that the nurse who discussed treatment with Mr A felt he did have mental capacity, but that the doctor was unsure about his ability to weigh relevant information²⁸.

4.4. On 28th August 2015 the SECSU nurse assessor advised the ward that she had assessed Mr A's capacity on 25th August and concluded that he did not

²¹ SECSU IMR and further information supplied by the CCG

²² SECAMB IMR

²³ Information from Maidstone Hospital

²⁴ Information from Maidstone Hospital

²⁵ Information from Maidstone Hospital.

²⁶ SECSU IMR

²⁷ SECSU IMR

²⁸ Information from Maidstone Hospital

have capacity to decide about moving to a different nursing home. The ward concluded that he had capacity in relation to medical treatment.

The same day, he was considered fit for discharge²⁹. The SECSU nurse assessor discussed Mr A with the hospital's discharge liaison coordinator, expressing concern that he was being considered for discharge without a mental health assessment³⁰. The hospital view was that his mental health should be assessed in his own environment, not on an acute ward³¹. The same day the SECSU nurse assessor emailed senior staff for advice. It was agreed that another nurse assessor would review Mr A³². The ward notes indicate that the hospital psychiatric liaison team reviewed Mr A that day, finding him neither confused nor disoriented, able to give a good account of his personal history, and focusing upon the need for a Kings Hospital referral. No further involvement from the psychiatric team was envisaged; the medical team were to assess his capacity³³.

4.5. Between 1st and 11th September 2015, the nurse assessor contacted 8 alternative placements, without success³⁴.

4.6. On 8th September 2015 the manager of a nursing home near Maidstone Hospital at the request of SECSU assessed Mr A's care needs, concluding that the home was not a suitable placement as Mr A was considerably younger than the majority of the home's residents. The manager recommended to SECSU that Nursing Home One (owned by the same company) would be a suitable placement due to their experience with a client group with needs similar to those of Mr A³⁵.

4.7. On 10th September 2015 the manager discussed her pre-admission assessment with Nursing Home One, who on 11th September undertook a pre-admission assessment with the ward at Maidstone Hospital³⁶.

4.8. On 11th September 2015 Nursing Home Two reassessed Mr A and confirmed they were unable to accept him back³⁷. The same day a staff member from the sister home to Nursing Home One attended the ward to assess Mr A and accepted him on behalf of Nursing Home One. The SECSU nurse assessor discussed this with Mr A's attorney, who stated that Mr A would prefer a younger person's placement, and that she (and Mr A) would prefer a placement in Ashford³⁸. The SECSU nurse assessor informed the hospital discharge coordinator that the attorney had objected to the East Sussex placement but was now in agreement if it was the only placement

²⁹ Information from Maidstone Hospital

³⁰ SECSU IMR

³¹ Information from Maidstone Hospital

³² SECSU IMR

³³ Information from Maidstone Hospital

³⁴ SECSU IMR

³⁵ CARE HOME ONE IMR

³⁶ CARE HOME ONE IMR

³⁷ SECSU IMR

³⁸ SECSU IMR

that could be found; however, the agreement was for a short period only and the attorney wanted it registered that she didn't really agree with the placement³⁹.

The same day a new consultant assessed Mr A's capacity, recording "it is clear that he doesn't fully understand the consequences of not taking his medications, made worse with paranoid thoughts and lack of proper insight". The need for psychiatric review was identified⁴⁰.

Mr A's next of kin family member was contacted, and indicated that they did not wish to be contacted unless in a life-threatening emergency and Mr A was dying⁴¹.

4.9. On 12th September 2015 Nursing Home One confirmed to SECSU its acceptance of Mr A's placement. There followed a detailed life story, history and care plan, drawn up with the involvement of Mr A's attorney⁴². The care plan records Mr A's medical history, allergies and interests. It covers such areas as communication, end of life care, hygiene, medication and mental well-being. It records that Mr A could be aggressive towards staff and residents. It notes that Mr A rejected medical staff views on his diabetes, leg oedema and leg ulceration, with fluctuating compliance regarding medication. It advises that he demonstrated fixed delusional ideas, for instance regarding treatment at Kings College Hospital, and showed limited insight into his mental health and physical condition. It offers guidance for management of his personal care and advises regular reviews by mental health professionals.

4.10. On 15th September 2015, the hospital Safeguarding Adults Matron gave advice on whether DoLS authorisation was required to move Mr A to Nursing Home One, advising that, if he lacked capacity to agree to the move, the least restrictive measures should be used to convey him under the MCA, and that the nursing home would require DoLS authorisation. A doctor on the ward conducted a mental capacity assessment, which is comprehensively documented, concluding that he lacked capacity to decide about discharge to Nursing Home One, was unlikely to regain capacity to make that decision, and that nursing home admission was in his best interests⁴³.

4.11. On 16th September 2015 Mr A refused his move to Nursing Home One, stating he would only go to Kings Hospital. Consideration was given to whether he should be given sedation during the move⁴⁴. One IMR⁴⁵ records that Mr A was delusional about going to Kings College Hospital.

³⁹ Information from Maidstone Hospital

⁴⁰ Information from Maidstone Hospital

⁴¹ Information from Maidstone Hospital

⁴² CARE HOME ONE IMR

⁴³ Information from Maidstone Hospital

⁴⁴ SECSU IMR

⁴⁵ KCC IMR

The same day Nursing Home One requested urgent and standard DoLS authorisations from KCC.

4.12. On **17th September 2015** Mr A was admitted to Nursing Home One⁴⁶. Sedation was administered to facilitate his move, with the documented agreement of his attorney. Mr A was advised in advance that sedation would be used and the ward took advice from a psychiatrist and the pharmacy on a suitable sedation regime⁴⁷. On arrival he was able to self-transfer, and appeared to enter the nursing home willingly. The nurse escort informed the receiving nurse at the nursing home that he had received sedation and had had a settled journey without the need for further sedation, but that continued observation would be necessary⁴⁸.

4.13. On **18th September 2015** KCC requested a mental health assessment for purposes of the DoLS application. The assessment by a consultant psychiatrist was received back on 23rd September⁴⁹. The KCC IMR records that by 23rd September 2015 Mr A was agreeable to placement at Nursing Home One, but viewed it as temporary.

4.14. On **15th October 2015** KCC requested a best interests assessment for purposes of the DoLS application. This was provided on 22nd October, with a recommendation for Nursing Home One to liaise with SECSU regarding a placement close to Mr A's home⁵⁰.

4.15. On **22nd October 2015** a best interests assessment was completed for the deprivation of liberty process. The best interests assessor contacted the SECSU nurse assessor to discuss the placement; Mr A wished to be placed in Kent, or near Epsom where he had friends. The SECSU nurse assessor explained the difficulties of securing a placement in Kent, and agreed to seek a placement near Epsom⁵¹.

4.16. On **3rd November 2015**, deprivation of Mr A's liberty was authorised to secure him at Nursing Home One in his best interests, on the grounds that he lacked capacity to make decisions about where to reside⁵²⁵³. Mr A's and his attorney's opposition to the placement were noted, and conditions were attached to the authorisation: that Nursing Home One engage with SECSU to support Mr A in exploring alternative residential options, and that Nursing Home One continue to explore socialisation options for Mr A to engage in activities beyond his room⁵⁴. Nursing Home One was advised of this outcome on 5th November⁵⁵.

⁴⁶ CARE HOME ONE IMR

⁴⁷ Information from Maidstone Hospital

⁴⁸ Information from Maidstone Hospital

⁴⁹ KCC IMR

⁵⁰ KCC IMR

⁵¹ SECSU IMR

⁵² NURSING HOME ONE IMR

⁵³ KCC IMR

⁵⁴ KCC IMR

⁵⁵ KCC IMR

- 4.17.** On **3rd November 2015**, an ambulance crew responded to a 999 call from Nursing Home One as Mr A had experienced a seizure. The IMR notes that Mr A was included in decision-making and his refusal of treatment was respected. He was physically and verbally aggressive to care home staff and the ambulance crew when refusing care and transportation to hospital⁵⁶.
- 4.18.** On **6th November 2015** KCC asked Powher⁵⁷ to provide a paid relevant person's representative⁵⁸ (PRPR) due to distance between Mr A's attorney and his placement⁵⁹. A PRPR was not allocated owing to a lack of suitable PRPRs within that organisation.
- 4.19.** On **10th November 2015** Mr A was taken to the Emergency Department at Eastbourne District General Hospital by ambulance, arriving at 06.39. When the ambulance crew had arrived, Mr A had initially refused advice, treatment and admission to hospital. However, he changed his mind and was transported to the Emergency Department⁶⁰. He presented there with a history of seizures and neglect due to refusal to take prescribed medication. Medical examination and investigations were undertaken. At 08.35 a doctor contacted Nursing Home One for further information, being advised of Mr A's refusal of care and medication. At 08.40 the doctor discussed with the registrar, who advised referral to Adult Social Care. Adult Social Care when contacted advised that Mr A should be returned to the nursing home, which could contact adult social care itself if they were experiencing difficulties. Having no acute medical needs, Mr A was returned to the nursing home (though stating he did not want to return there as he did not like it)⁶¹.
- 4.20.** On **12th December 2015**, Nursing Home One made a referral to Healogics Wound Healing Centre due to concerns about Mr A's leg ulcers. The Centre's assessment is dated 18th December 2015⁶². It records as urgent Mr A's cellulitis, which was deteriorating and painful. It notes that he was refusing all medication and that his diabetes increased the risk of infection. The management plan lists treatment and encouragement. The assessment includes photographs of Mr A's wounds and open areas, subsequently updated on 12th January 2016 and 17th May 2016.
- 4.21.** On **18th December 2015** the GP from the Medical Centre visited Mr A at Nursing Home One to conduct a new patient assessment. The GP considered that Mr A lacked capacity in relation to personal care, and

⁵⁶ SECAMB IMR

⁵⁷ Powher is an independent advocacy agency commissioned to provide PRPRs in the area

⁵⁸ The role of the RPR is to maintain contact with the individual subject to DoL, and to represent and support them in all matters relating to the DoLS. A paid RPR must be appointed where there is no one suitable in the individual's network able to take on that role.

⁵⁹ KCC IMR

⁶⁰ SECAMB IMR

⁶¹ ESHT IMR

⁶² NURSING HOME ONE IMR

agreed that a best interests meeting should be held. A tissue viability assessment was also undertaken⁶³. The section 42 enquiry report notes that this was done by a tissue viability nurse who recorded that Mr A had infected legs and was non-compliant with treatment.

4.22. On **29th December 2015**, the deputy manager at Nursing Home One wrote to Mr A's nurse assessor at SECSU outlining the problems experienced with Mr A's non-compliance on wound care, personal care and medication and requesting a best interests meeting. Mr A had also begun to experience seizures⁶⁴. The section 42 enquiry report notes that Nursing Home One had in fact requested a review of the placement. The SECSU IMR notes this contact, adding that it was the GP who had suggested to the nursing home that an urgent best interest meeting be held to establish how to proceed with Mr A's care⁶⁵.

4.23. The best interests meeting took place on **12th January 2016**. Attendees were the nurse assessor from SECSU⁶⁶, Mr A's GP⁶⁷, and the deputy manager and the nurse in charge at Nursing Home One. Apologies were received from Mr A's attorney. The meeting discussed the risk to Mr A's life of his continued refusal to accept care, with Mr A said to be in denial of his medical condition. Care home staff stated that they have been unable to coax or manage him, and that they felt frustrated in the absence of advice about how to assist him. They expressed concern that they would one day find him dead in his room. A mental health section and psychological intervention were discussed, alongside the difficulty of finding an alternative placement. After the meeting the representatives from SECSU⁶⁸ and the manager of Nursing Home One also discussed matters with Mr A. Mr A is recorded as saying that he was happy with the care received and as acknowledging that his legs were not good. He is noted as declining treatment, believing it to be wrong. When concerns are raised about potentially fatal risks from refusing treatment, Mr A was noted to have commented that "*had no life now so it would not matter*"⁶⁹. He did agree to wound care from one specific nurse but disputed the diagnosis of diabetes and rejected the GP's advice. He is recorded as stating that he wanted a placement in Kent and contact with his children, and that he would not rule out psychological support. The Nursing Home One IMR, the SECSU IMR and the EHSCCG IMR note the resultant outcomes: the SECSU nurse assessor was to (a) to discuss with Mr A's attorney the question of private hospital care for Mr A's legs, and the involvement of a psychologist and (b) to continue to explore a potential Kent placement^{70 71}

⁶³ EHSCCG IMR

⁶⁴ NURSING HOME ONE IMR

⁶⁵ SECSU IMR

⁶⁶ accompanied by a newly appointed nurse assessor as part of her induction (SECSU IMR)

⁶⁷ For the second half of the meeting (EHSCCG)

⁶⁸ NURSING HOME ONE IMR

⁶⁹ SPFT IMR

⁷⁰ NURSING HOME ONE IMR

⁷¹ SECSU IMR

⁷². Notes of the meeting with Mr A conclude with the statement that he lacked insight and that psychiatric review was necessary.

4.24. On **22nd January 2016** Nursing Home One by email requested an update from the SECSU nurse assessor on the actions agreed at the best interests meeting⁷³. The email notes that Mr A's denial, refusal of treatment and seizures continued. It stresses that the situation was deteriorating and an urgent decision was required.

4.25. On **28th January 2016**, Nursing Home One by email noted the absence of any reply to the email sent on 22nd January 2016. The email states that the care home was unable to meet Mr A's needs and required instructions on how to proceed. The email concludes by stating that a notice period would commence on 4th February 2016⁷⁴. The nurse assessor contacted the nursing home the following day, noting the difficulty in finding Mr A an alternative placement and indicating that the GP should refer Mr A to the community mental health team and advise on a private hospital stay. She informed Nursing Home One that she was transferring responsibility for Mr A to a colleague, and that future possibilities included either a mental health bed in Kent or a neuro-psychiatry bed in London⁷⁵. The nurse assessor left a message for the GP requesting CMHT referral. The nurse assessor also contacted Mr A's attorney, who indicated she was struggling to make decisions in Mr A's best interests and would like support from an independent mental capacity advocate (IMCA); the nurse assessor made an IMCA referral⁷⁶.

4.26. An experienced SECSU nurse assessor was now involved, and explored placement at Kent & Medway Partnership Trust continuing care facilities. No bed was available, and it was thought that placement might anyway be difficult due to the facility being intended for patients with dementia⁷⁷.

4.27. On **3rd February 2016** Nursing Home One spoke to the second SECSU nurse assessor to emphasise the need for an alternative placement⁷⁸.

4.28. On **12th February 2016** Nursing Home One requested authorisation from KCC for renewed deprivation of liberty, the previous authorisation having expired on 2nd February 2016⁷⁹. The email refers to Mr A's resistance to care and treatment, and to the recent referral to a mental health team for assessment. The Kent MCA/DoLS Service has no record of

⁷² EHSCCG IMR

⁷³ NURSING HOME ONE IMR

⁷⁴ NURSING HOME ONE IMR

⁷⁵ NURSING HOME ONE IMR

⁷⁶ SECSU IMR

⁷⁷ SECSU IMR; Korsakoff syndrome is classified separately from dementia in the World Health Organisation International Statistical Classification of Diseases (SECSU IMR)

⁷⁸ NURSING HOME ONE IMR

⁷⁹ NURSING HOME ONE IMR

this request⁸⁰, but it clearly was received because the service responded by sending new forms back to Nursing Home One for completion on **15th February 2016**. These were diverted into Nursing Home One's junk mail and not dealt with.

4.29. The same day the second nurse assessor discussed Mr A by phone with the GP, who agreed to refer to the Community Mental Health Team (CMHT) for an opinion on diagnosis, capacity and treatment options⁸¹.

4.30. On **16th February 2016** KCC sent a letter to Mr A indicating that the original deprivation of liberty had been granted⁸². The same day the SPFT consultant psychiatrist received a referral letter from Mr A's GP⁸³.

4.31. On **3rd March 2016** the second nurse assessor contacted Mr A's attorney to discuss the difficulties Nursing Home One were experiencing in caring for Mr A, and to discuss the difficulties securing an alternative placement. He advised her of the CMHT referral⁸⁴.

4.32. On **4th March 2016** Mr A was assessed by the consultant psychiatrist, who supported the need for an alternative specialist unit and suggested placement at a brain injury unit for people with challenging behaviour⁸⁵. The consultant found he could be considered for assessment under the Mental Health Act or the Mental Capacity Act, but found no evidence of florid psychosis, anxiety or depression, suicidal thoughts or plans. A diagnosis of Korsakoff Syndrome was given and short-term memory impairment noted. A capacity assessment confirmed he lacked capacity regarding his care needs and medication. Risk of serious physical injury or even death was noted as moderate to high due to his refusal of care, assistance and medication. Care needs were not met at the placement, and review was required. Mr A wanted to be moved back to Kent. He refused advice on his treatment because he did not accept the diagnosis and was adamant he would only take treatment from Kings College Hospital, who had conducted his brain surgery some years earlier⁸⁶. The section 42 enquiry largely repeats this picture but suggests that the psychiatrist had concluded that assessment under the Mental Health Act was inappropriate.

4.33. The GP visited Nursing Home One on **15th March 2016** and her notes record that she was awaiting the outcome of the assessment by the psychiatrist.

4.34. On **22nd March 2016** the second nurse assessor discussed Mr A with Kerwin Court brain injury unit in West Sussex, who agreed to consider him

⁸⁰ KCC IMR

⁸¹ SECSU IMR

⁸² KCC IMR

⁸³ SPFT IMR

⁸⁴ SECSU IMR

⁸⁵ SECSU IMR

⁸⁶ SPFT IMR

for assessment. Follow up by the nurse assessor on 31st March and 7th April failed to secure further discussion of his case⁸⁷. The section 42 enquiry concluded that there was no clear outcome to this contact regarding Mr A's suitability for that service.

4.35. The section 42 enquiry notes that the psychiatrist reiterated his advice of 15th March 2016 again on **23rd March 2016**.

4.36. The second nurse assessor contacted Nursing Home One on **31st March 2016**, sending a psychiatrist's assessment and indicating that enquiries for alternative placements were in hand; details of one possible placement at a brain injury unit were given, with a suggestion otherwise of referral to a neuropsychiatry unit⁸⁸.

4.37. On **14th April 2016** the brain injury unit advised the second nurse assessor that they were unable to accept Mr A; they suggested a Kent project specialising in the management of Korsakoff-related behaviours. The nurse assessor sent a referral⁸⁹. GP notes record the GP as having visited the same day and that Mr A was continuing to refuse treatment. She was still hoping that a new placement would be found.

4.38. On **3rd May 2016** the GP visited and recorded that Mr A was continuing to refuse all care and medical input. He would continue to be encouraged to engage with treatment.

4.39. On **12th May 2016** a professionals' meeting took place at Nursing Home One, attended by the consultant psychiatrist, the GP, the manager and a nurse from the nursing home and two nurse assessors from SECSU. Mr A continued to refuse care; his legs were very oedematous, with an offensive smell; dressings were required but he refused support. He had been seen by a tissue viability nurse but refused their advice also.

4.40. On **17th May 2016** Nursing Home One rang and emailed the second nurse assessor requesting an update on alternative placements. He informed them that a specialist project in Kent would visit to assess Mr A⁹⁰.

4.41. The same day the SPFT consultant psychiatrist and charge nurse visited Mr A at Nursing Home One. The care home staff updated them on SECSU's search for alternative accommodation. There was no change in Mr A's presentation; he continued to refuse care.

4.42. On **19th May 2016** the GP contacted the consultant psychiatrist to clarify whether Mr A could be sectioned under the MHA 1983. She was advised that the Mental Health Act could only be used for enforcing

⁸⁷ SECSU IMR

⁸⁸ NURSING HOME ONE IMR

⁸⁹ SECSU IMR

⁹⁰ NURSING HOME ONE IMR

psychiatric care, not physical care⁹¹. Nursing Home One was advised by SECSU of a project (Upstreet) that might accept Mr A and of a possible referral to a neuropsychiatry unit⁹².

- 4.43.** On **20th May 2016** Nursing Home One sent an email to SECSU advising of a conversation with Mr A's attorney to the effect that Upstreet had been tried previously⁹³.
- 4.44.** On **23rd May 2016** the GP received a report indicating that the consultant psychiatrist had visited Mr A and expressed concern that he was at risk of neglect and death. Mr A had been referred for assessment at a neuropsychiatric unit⁹⁴.
- 4.45.** On **25th May 2016** Mr A asked to see his GP about his legs. The GP recorded a significant deterioration, with malodorous wounds. He refused to allow his bedroom windows to be opened and he asked the GP to leave. She recorded her considerable concern about his refusal to allow care and treatment and her intention to ask the psychiatrist to consider sectioning as Mr A was putting himself at risk⁹⁵.
- 4.46.** On **26th May 2016** the Kent specialist project visited Nursing Home One to assess Mr A⁹⁶. The outcome was that while they could offer engagement and stimulation, they would be unable to support his physical needs and immobility⁹⁷.
- 4.47.** On **27th May 2016** the second nurse assessor discussed Mr A with the Lishman Unit at Bethlem Royal Hospital. He was advised that Mr A was likely to be suitable for admission⁹⁸. He advised the consultant psychiatrist that a referral form was required from either the GP or the consultant⁹⁹.
- 4.48.** On **31st May 2016** the second nurse assessor advised the consultant psychiatrist that the Kent specialist project (Upstreet) could not take Mr A because of his physical health and mobility problems¹⁰⁰.
- 4.49.** On **2nd June 2016**, the second nurse assessor passed to Nursing Home One a query about pellagra, raised by the Upstreet Project¹⁰¹.
- 4.50.** On **3rd June 2016** the consultant psychiatrist referred Mr A to the Lishman Unit¹⁰² requesting in-patient neuropsychiatric services for Mr A

⁹¹ EHSCCG IMR

⁹² Additional information provided by Nursing Home One

⁹³ Additional information provided by Nursing Home One

⁹⁴ EHSCCG IMR

⁹⁵ Additional information provided by EHSCCG

⁹⁶ NURSING HOME ONE IMR

⁹⁷ SECSU IMR

⁹⁸ SECSU IMR

⁹⁹ SPFT IMR

¹⁰⁰ SPFT IMR

¹⁰¹ NURSING HOME ONE IMR

and emphasising the risk of serious physical injury or even death¹⁰³. The section 42 enquiry report notes that no response was received to this referral, and SPFT have indicated that it was not followed up by the consultant¹⁰⁴. It further records that the psychiatrist remained of the view that use of the Mental Health Act was inappropriate as Mr A's needs were physical.

4.51. On **16th June 2016** the GP visited as Mr A had fallen and lost a toenail in the process. Mr A refused to allow the GP to provide clinical care. A discussion took place between the GP and Nursing Home One staff about the safeguarding concerns raised by the home's inability to provide care (although no safeguarding referral was made by either party). The GP sought further advice from the consultant psychiatrist¹⁰⁵.

4.52. On **1st July 2016** the GP wrote to the consultant psychiatrist requesting advice on management of Mr A and raising safeguarding concerns¹⁰⁶. Nursing Home One's records for the following date note Mr A's swollen legs and a malodorous smell. This record is repeated on **13th July**, with the addition that worms had been found in his wounds¹⁰⁷.

4.53. On **14th July 2016** Nursing Home One raised the question of hospital admission with the GP, who felt that Mr A's refusal of care would continue in a hospital setting. She recognised that his mental health needs were interfering with his acceptance of care, but noted that the consultant psychiatrist had not thought he needed treatment¹⁰⁸.

4.54. On **15th July 2016** the GP expressed to Nursing Home One the view that Mr A required nursing care rather than hospital admission¹⁰⁹.

4.55. On **19th July 2016** the consultant psychiatrist responded to the GP's request for advice (letter of 1st July), stating that a further best interests meeting would be appropriate. There had been no response from the Lishman Unit¹¹⁰.

4.56. On **22nd July 2016** (a Friday) Nursing Home One contacted Mr A's psychiatrist suggesting hospitalisation under the Mental Health Act 1983; the psychiatrist advised that such admission would only be possible for treatment for mental disorder, not to treat a physical health problem or provide personal care¹¹¹. The psychiatrist considered that Mr A required

¹⁰² SECSU IMR

¹⁰³ SPFT IMR

¹⁰⁴ Additional information provided by SPFT

¹⁰⁵ EHSCCG IMR

¹⁰⁶ SPFT IMR

¹⁰⁷ Additional information provided by Nursing Home One

¹⁰⁸ EHSCCG IMR

¹⁰⁹ NURSING HOME ONE IMR

¹¹⁰ EHSCCG IMR

¹¹¹ NURSING HOME ONE IMR

acute medical treatment and advised Nursing Home One to contact emergency services and the GP to seek admission¹¹².

Nursing Home One contacted the GP for advice as Mr A's leg wounds now contained maggots and there were concerns for the health and safety of residents as he was dropping maggots while walking round the home. The GP's records confirm this and refer to Mr A needing to be sectioned. The GP spoke to on-call consultant at the Medical Assessment Unit at Eastbourne & District General Hospital, who advised that if Mr A continued to refuse care it could not be imposed, and felt hospital admission would not help. The GP raised a safeguarding referral, and also sought advice from the consultant psychiatrist about sectioning Mr A under the Mental Health Act 1983¹¹³. No request for AMHP/MHA assessment was made¹¹⁴.

The ESASC Social Care Direct Service¹¹⁵ noted the referral from the GP's surgery by phone at 16.10, noting the concerns as being Mr A's ulcerated legs and his refusal of care. At 16.58 details were forwarded to the Emergency Duty Service (EDS). Having attempted without success to reach the GP, the EDS rang Nursing Home One and gained further detail of Mr A's situation. The EDS practitioner advised the nursing home to make further contact with the GP to discuss action under the MCA. The EDS practitioner notified the Social Care Direct service of the need to initiate a safeguarding enquiry during office hours on Monday morning¹¹⁶.

The same evening Nursing Home One requested an out of hours GP visit¹¹⁷.

4.57. On **23rd July 2016** (a Saturday) the out of hours doctor visited Nursing Home One but was unable to persuade Mr A to agree to hospital admission. Mr A expressed willingness to be admitted to Kings Hospital London, but that hospital would not accept him¹¹⁸. The out of hours doctor considered that Mr A had mental capacity and was making a 'bad decision'. He secured Kings Hospital agreement to review Mr A in the diabetic foot ulcer clinic on 25th July following contact from his GP¹¹⁹.

4.58. On **24th July 2016** (Sunday) the consultant psychiatrist was contacted again, advising again that detention under the MHA was not appropriate as Mr A required urgent medical care, and that emergency services should be called¹²⁰.

Nursing Home One called the ambulance service. At around 12pm, the paramedics attended but did not enter Mr A's room due to perceived risks

¹¹² SPFT IMR

¹¹³ EHSCCG IMR

¹¹⁴ SPFT IMR

¹¹⁵ This was ESASC's contact centre at the time (ESASC IMR)

¹¹⁶ ESASC IMR

¹¹⁷ NURSING HOME ONE IMR

¹¹⁸ NURSING HOME ONE IMR

¹¹⁹ EHSCCG IMR

¹²⁰ SPFT IMR

from doing so. They reported they had received a supervisor's instruction to leave Mr A in the care of the nursing home. The Nursing Home One IMR notes discrepancy between ambulance service documentation, which states the Nursing Home One nurse in charge agreed with this, and the care notes made by that nurse on the day¹²¹.

The IMR from the Ambulance Trust concludes that Mr A was not treated or transported to hospital in line with his expressed wishes as communicated to the crew by care home staff. The ambulance crew did not engage directly with Mr A. The crew completed a vulnerable person referral on the grounds of self-neglect and treatment refusal¹²².

Nursing Home One contacted the county council's EDS raising a safeguarding alert and requesting urgent support. They also (at 16.21) requested a Mental Health Act assessment¹²³. Between 16.21 and 19.00 EDS tried unsuccessfully to contact Nursing Home One by phone¹²⁴.

At 19.53, Nursing Home One called for an ambulance again; Mr A had collapsed and was described as not breathing. The SECAMB IMR notes that it was stated during the call that no defibrillator was available at the home¹²⁵. Resuscitation had not been started and Mr A was pronounced dead¹²⁶.

Some time later (between 19.00 and 21.20) the EDS made contact with a staff nurse at Nursing Home One who advised that Mr A had died. EDS updated the notification of the previous day to the Social Care Direct Service, requesting initiation of a safeguarding enquiry

- 4.59.** On **25th July 2016** the ESASC Social Care Direct Service asked the Mental Health Duty and Assessment Team to undertake a safeguarding enquiry¹²⁷.
- 4.60.** On **26th July 2016** SECSU learnt that Mr A had died.
- 4.61.** On **19th August 2016** KCC learnt that Mr A had died.

¹²¹ NURSING HOME ONE IMR

¹²² SECAMB IMR

¹²³ ESASC IMR The IMR also notes that NURSING HOME ONE did not have standing to request such an assessment, which must be requested by a GP, mental health professional or nearest relative. It also notes that consideration would usually first be given to whether the sought objectives could be achieved using authority under the MCA.

¹²⁴ ESASC IMR

¹²⁵ It was clarified at the learning event that Nursing Home One does have a defibrillator.

¹²⁶ NURSING HOME ONE IMR

¹²⁷ ESASC IMR

5. KEY EPISODES

Reading of the chronology enables identification of six significant episodes, within each of which a number of key themes emerge. Some of the key themes appear in more than one episode, for which reason the detailed analysis of findings will be thematic (section 6). First, however, the six significant episodes are outlined.

5.1. Significant episode 1 is the *initial placement*. Reading the combined chronology and the IMRs highlights the question of resources, for example hospital discharge pressures and the difficulty finding an appropriate placement for Mr A. Thus, this key episode opens up a continuing theme, namely the commissioning and subsequent quality assurance of placements. As elsewhere in the chronology, the question of Mr A's involvement, and that of his attorney, in decision-making emerges, linking to the assessment of mental capacity and mental health. Thus, was Mr A regarded as having the mental capacity to determine his living arrangements? If not, to what degree were he and the attorney involved in best interests decision-making? How were any differences of opinion regarding best interests resolved? This is one of several occasions where a best interests meeting and referral to the Court of Protection might have been considered, given his opposition to placement at Nursing Home One.

5.2. Significant episode 2 is the application for, and eventual approval of, deprivation of liberty. The theme of resources is again highlighted, referring to the volume of demand on the team responsible for the approval process, the long delay in notifying Mr A that deprivation of his liberty had been authorised and the lack of advocacy provision. The theme of involvement also re-emerges, with questions about the role in this process of the attorney and how any differences of opinion were resolved in the absence of a best interests meeting or referral to the Court of Protection, given Mr A's continued opposition to this placement. A theme of interagency communication and coordination emerges from the circumstances surrounding the failure to renew Mr A's deprivation of liberty, and the apparent absence of progress in meeting the two conditions that were attached to the original order.

5.3. Significant episode 3 covers the early months of placement, from September to December 2015, a time where Mr A became increasingly resistant to accepting care and treatment. Mr A's GP does not appear to have visited him until late in this period, despite concerns about his mental health and physical well-being, which resulted in one visit to a hospital emergency department. Whether Mr A consented to this visit and his subsequent return to the nursing home, or how his wishes were overridden, and the degree to which the attorney was involved in decision-making about his care and treatment, highlight the on-going themes of involvement and of mental capacity. The theme of interagency communication and coordination emerges with respect to information-sharing between the commissioning CCG, the nursing home and the GP with respect to Mr A's care and treatment. As time passed, any one of a

number of practitioners might have made a referral for a section 42 (Care Act 2014) safeguarding enquiry, but did not. A mental health assessment is mentioned but not undertaken.

5.4. Significant episode 4 is the January 2016 *best interests meeting*. Mr A was involved in a discussion on the day of the meeting but the attorney was not present and the GP could only attend for part of the meeting. Interagency communication and coordination are highlighted again here in terms of who was and was not invited. The theme of recording re-emerges, with comment that the minutes were poorly written and not circulated to everyone involved, for example the GP. There is on-going delay with respect to a mental health assessment and the provision of advocacy. The meeting concluded with only two recommendations despite the complexities of the case, which would have merited an action plan with respect to management of his refusal of care and treatment.

5.5. Significant episode 5 covers the later months of placement, from the end of January to July 2016. Nursing Home One gave notice of termination of placement at the end of January and the period is characterised by a failure to find an alternative placement and an advocate, highlighting again the theme of resources. Mr A's on-going refusal of care and treatment posed increasing risks to his health and life. The attorney expressed difficulty in making decisions on his behalf but there appears to have been no consideration of involving the second attorney, or of holding a second best interests meeting, or of referral to the Court of Protection. This highlights the theme of legal literacy as does the absence of a section 42 referral, lack of clarity about whether Mr A lacked capacity to take specific decisions and, if so, how to act in his best interests, and on-going delays in obtaining a mental health assessment. Throughout there does not appear to have been a review of the approach being taken by the agencies involved.

5.6. Significant episode 6 is the weekend of Mr A's death. Once again there are questions about the involvement of the attorney, and of resources in terms of the on-going absence of an advocate. The theme of legal literacy is highlighted in the uncertainty about whether to make a section 42 referral and what benefits it might bring, and whether, if Mr A lacked capacity to make decisions about his deteriorating physical health, he could be conveyed to hospital. Legal advice might have been sought at this point by the CCG or an urgent referral made to the Court of Protection. The theme of recording again emerges: the Out of Hours GP did not have access to Mr A's GP's notes and insufficient information appeared available in the care plan held by Nursing Home One to indicate the then current assessment of Mr A's decision-making capacity.

6. THEMED ANALYSIS

6.1. Introduction

The following section reports on findings that emerge from the combined chronology of events, from evidence provided to the panel in the agencies' IMRs and from discussions held at the learning event. The analysis addresses key areas of enquiry that are central to the terms of reference for the review, and considers both single and joint agency actions, with an emphasis on how the various agencies worked together to help and protect Mr A.

6.2. Mental capacity

6.2.1. There seems to have been a general agreement between professionals involved that Mr A lacked capacity to make decisions about his place of residence, and about his medical, nursing and personal care. In the documentation supplied to this review, there are eight explicit mentions of capacity having been assessed:

- By the SECSU nurse assessor on 25th August 2015, as part of a review of Mr A's placement at Nursing Home Two (finding that he did not have capacity to decide about moving to a different nursing home);
- At Maidstone Hospital on 27th August 2015 (a nurse found that he had capacity to decide about medical treatment, although a doctor was unsure about his ability to use and weigh relevant information);
- At Maidstone Hospital on 11th September 2015 (a consultant doctor found that he did not have capacity to decide about his medication);
- At Maidstone Hospital on 15th September 2015 (a doctor found that he did not have capacity to decide about the proposed move to Nursing Home One);
- By the Kent MCA/DoLS office in granting authority for deprivation of liberty on 3rd November 2015 as he lacked capacity to decide where to live;
- By the GP during a new patient assessment on 18th December 2015 (finding that he did not have capacity to make decisions about personal care);
- By the consultant psychiatrist on 4th March 2016 (finding that he did not have capacity to decide about care needs and medication);
- By the out of hours GP on Saturday 23rd July (finding that he had capacity to decide about care and treatment).

6.2.2. On all but two occasions, Mr A was considered to lack capacity: the first, by a nurse in Maidstone Hospital, was reversed on subsequent assessments two weeks later; the second – by the out of hours GP who determined that Mr A's refusal to go to hospital was a capacitous decision, and therefore could not be overruled – was more influential on events. No detail of this assessment has been provided and it is

unclear whether the GP was aware of the previous specialist assessments that had found Mr A lacked capacity over similar decisions. The section 42 enquiry concludes that the out of hours GP was probably unaware of previous assessments. Awareness of these would not have absolved the GP of the responsibility to undertake his own assessment, as capacity must be assessed about a specific decision at a specific time, but it was a finding that did not take account of the views of others who had addressed the question in similar circumstances, and can be seen as influential in the subsequent course of events.

- 6.2.3. At other key points in the chronology, while there is one example of robust practice in relation to mental capacity (at Maidstone Hospital, where three explicit assessments of capacity for different decisions were undertaken and documented within a space of 3 weeks), the absence of recorded capacity assessment is striking. For example a nurse assessor visited Mr A at the Nursing Home Two on 25th August 2015 to undertake a review of his placement, and Maidstone Hospital have a record of her telling them she had assessed Mr A's capacity at that point, but the SECSU IMR found "*no evidence that MCA had been considered to determine whether or not he had capacity to understand his needs*"¹²⁸. The care plan to which Nursing Home One subsequently worked contains no mention of previous mental capacity assessments although it does refer to the need to make an application with respect to deprivation of liberty¹²⁹. The Ambulance Trust IMR¹³⁰ notes that it is unclear whether Mr A's wishes were taken into account when he was transported to the Emergency Department that same day. The SECSU IMR expresses concern that a capacity assessment took place after the best interests meeting on 12th January rather than before it.
- 6.2.4. In relation to attendance by ambulance crew on 3rd November 2015 it is unclear if Mr A's capacity was considered or an assessment conducted when he refused care and transportation to hospital¹³¹.
- 6.2.5. In relation to Mr A's attendance at the emergency department at EDGH on 10th November 2015, there is "*no evidence of a repeat of mental capacity assessment of the patient by the examining junior doctor, indicating that legal guidance was not adhered to or fully understood*"¹³².
- 6.2.6. The Nursing Home One IMR states that the nursing home was of the view that Mr A lacked capacity in relation to medication and had fluctuating capacity in relation to personal care. It is not clear what assessment lay behind this view. The IMR states: "*His capacity in*

¹²⁸ SECSU IMR

¹²⁹ NURSING HOME ONE IMR

¹³⁰ SECAMB IMR

¹³¹ SECAMB IMR

¹³² ESHT IMR

relation to personal care fluctuated and he acknowledged that he needed support with his personal care needs and on occasions said that he would accept it. However when staff tried to help and support him and offered personal care on a daily basis he refused and became physically aggressive with any attempt to help with his personal care.” This seems to imply that he was deemed to have capacity when he agreed and to lack capacity when he refused. Perhaps the variability in his apparent consent, rather than indicating fluctuating capacity, indicated an inability to translate intent into action – a common feature in self-neglect that can be associated with impairment of executive brain function, but which does not appear to have been considered here.

6.2.7. The Ambulance Trust acknowledges that the ambulance crew on the first call-out on 24th July 2016, having been told by care home staff that Mr A was refusing intervention and had capacity to take that decision, did not then pursue this with him¹³³. The same IMR notes that the crew found fly infestation and a pungent smell in his room and were advised about maggots and rotting flesh in his legs. The IMR concludes that it would have been pertinent to conduct a mental capacity assessment at that time, focusing on Mr A’s decision-making regarding treatment and transportation to hospital. It is unclear whether Mr A knew that his condition had worsened. It is unclear what his response would have been if advised of the severity of the condition and that the absence of treatment might end his life. The IMR concludes that it was inappropriate for the crew to have relied solely on care home staff but acknowledges also that, even if a mental capacity assessment had been done, the crew may not have subsequently transported Mr A to hospital because of his previous choices when he had had capacity.

6.2.8. Given the general consensus about Mr A’s lack of capacity in relation to his residence and care needs, a further question becomes how decisions made on his behalf secured his best interests.

6.2.9. He was subject to deprivation of liberty between 3rd November 2015 and 2nd February 2016. The request for renewal from Nursing Home One to the Kent MCA/DoLS office was not made until the 12th February 2016, and the reply on the 15th February, which attached new forms for completion, was filtered into Nursing Home One’s junk mail folder. Nursing Home One did not pick up on the absence of reply; it is unclear whether they assumed without checking that the authority had been renewed. A further complication arises in that the Kent MCA/DoLS office have no record of receipt of Nursing Home One’s request¹³⁴, although the fact that they replied on 15th February indicates that it must have been received. The office did not notice the absence of forms expected from Nursing Home One. The combination of these factors resulted in Mr A continuing to be deprived of his liberty (from 2nd February to his death on 24th July 2016) without legal authority.

¹³³ SECAMB IMR

¹³⁴ KCC IMR

6.2.10. The finding that Mr A lacked capacity in relation to residence and care needs might have been expected to result in best interests decision-making. Two key omissions emerge. First, there appears to have been no best interests meeting held at the time his placement in Nursing Home One was proposed while he was in Maidstone Hospital (although his discharge to the placement was deemed to be in his best interests by the doctor who undertook a capacity assessment of his ability to make that decision for himself and found it lacking). Both Mr A and his attorney were opposed to the move to East Sussex, and the attorney's opposition was only reluctantly withdrawn on the basis that the placement was for a short period only. In this context, it would have been appropriate for SECSU to convene a formal best interests decision-making process, with consideration given to application to the Court of Protection if the decision remained contested. Equally, it appears the hospital relied on an assumption that due processes had been followed rather than seeking evidence. Second, in July 2016, when the deterioration in Mr A's condition became such an acute concern, no best interests meeting took place, despite the consultant psychiatrist's advice (expressed to the GP but not elsewhere) that one should be called¹³⁵.

6.2.11. Following Mr A's admission to Nursing Home One, just one best interests meeting was held - on 12th January 2016. The outcomes were for SECSU nurse assessor to explore alternative placements, and to discuss with Mr A's attorney the possibility of admission to private hospital for care of his legs, and the involvement of a psychologist. While valid actions in themselves, these cannot be called best interests decisions related to the presenting problem of Mr A's self-neglect, refusal of care and the resultant risk to his life, all of which had been recorded on the care plan that was compiled for his admission to Nursing Home One. Despite his lack of capacity, Mr A appears to have been treated as someone who had capacity and whose refusal was therefore determinative - i.e. care could not be provided. The view of the nurse assessor is reported as: "*the same pattern had arisen in his previous care home resulting in his admission to hospital; she was unable suggest anything that could be undertaken to improve the situation as Mr A would not listen to her advice, and the treatment could not be forced on him*"¹³⁶.

6.2.12. He was at this point subject to deprivation of liberty, yet even without deprivation of liberty the Mental Capacity Act permits restraint to facilitate treatment in the best interests of someone who lacks capacity to consent, where necessary to protect them from harm and provided the restraint is proportionate to the likelihood and seriousness of that harm. If it was deemed that restraint to impose care and treatment would not be proportionate, then the Court of

¹³⁵ SPFT IMR

¹³⁶ NURSING HOME ONE IMR

Protection could at this point have been asked to consider the need for care and treatment and, if deemed in his best interests, to provide the authority for it.

6.2.13. There were other points at which consideration might have been given to an application to the Court of Protection, and indeed the Nursing Home One IMR recognises in retrospect that an application could have been made. Such intervention at any point during January to July 2016 may have assisted in resolving some of the dilemmas being experienced by those attempting to care for Mr A. Even in the final days of Mr A's life, when the scale of infestation of his leg wounds became clear, urgent application in such circumstances could have been sought. There is, however, no evidence that any of the agencies involved sought legal advice that would have enabled them either to be confident in pursuing a best interests intervention that would ensure treatment, or to seek authority from the Court. Of course the Court of Protection may have determined that to intervene to prevent Mr A from dying was not appropriate: the judgement in *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60 demonstrates the complex moral reasoning to be applied in such situations. But even such a decision would have provided a legitimacy that was otherwise lacking.

6.2.14. The missing assessments, the absence of appropriate action to secure best interests on occasions when capacity had been assessed, the deprivation of liberty without authority and the failure to seek authority for care and treatment, all indicate that Mr A's mental capacity was not appropriately addressed and the legal requirement for decisions therefore to be made in his best interests not met.

6.3. Involvement of Mr A and his attorney

(a) Mr A's involvement

6.3.1. Mr A consistently expressed the view that he wished to be placed in a nursing home in Kent, and that in relation to medical treatment he wished to attend Kings Hospital London (where it is understood he underwent brain surgery some years previously). Mr A's views and wishes were accorded primacy in the question of whether his care needs could be met. This was the case both on a daily basis in the care home and at key points when discussion took place. The problems with this approach are outlined in the preceding section relating to mental capacity; in many respects, having assessed Mr A as lacking capacity, the professionals involved proceeded to treat him as if he had capacity and did not use powers that would have enabled them to act in his best interests.

6.3.2. Clearly a finding of lack of capacity over a particular matter does not mean that the individual's perspective should be overruled indiscriminately. The Mental Capacity Act requires those making decisions on their behalf to pay close attention to their wishes,

feelings, beliefs and values. But they are one factor to be taken into account among many others in the pursuit of best interests.

6.3.3. One of the key mechanisms for facilitating involvement is advocacy. Following confirmation of Mr A's deprivation of liberty on 3rd November, Kent MCA/DoLS office on 6th November asked Powher¹³⁷ to provide a Paid Relevant Person's Representative¹³⁸ (PRPR). This was because of recognition that the distance between Mr A's placement and where his attorney lived made it difficult for her to be as involved as she might have chosen to be. Despite being chased up on 7th and 22nd January, and 11th February 2016, no PRPR was appointed by Powher because of a shortage suitable PRPRs.

6.3.4. Had an advocate been involved, it is likely that a number of subsequent shortcomings could have been identified and resolved: the absence of appropriate authority for the on-going deprivation of Mr A's liberty after 2nd February 2016; the absence of a care plan that drew on the authority of the Mental Capacity Act to ensure Mr A's care and treatment while an alternative placement was being sought; advocated for interagency best interests or complex case meetings to take place.

6.3.5. Arguably one of features of Mr A's situation was that he was isolated from his Kent networks, including his friends and attorneys. There was no one individual within the professional network around him with whom he had a relationship that could have provided the foundation for securing his agreement to accept care. An advocate was not the only person who could have performed this role, but in the absence of active case management (see below) an advocate could have been well placed to build the relationship of trust that is often at the heart of effective intervention in self-neglect (Braye, Orr & Preston-Shoot, 2014).

(b) Involvement of Mr A's attorney

6.3.6. Possessing lasting power of attorney over both finance and property and health and welfare, Mr A's attorney was in a position to make decisions on all matters on which Mr A lacked capacity to decide for himself, including giving consent to treatment and care¹³⁹. Yet her involvement was not consistent during the period under review.

6.3.7. She was involved in placement discussions in September 2015 while Mr A was in hospital in Maidstone, stating that he would prefer placement in Kent, and in a unit designed for younger people. Prior to Mr A's move to Nursing Home One she provided life history

¹³⁷ Powher is an independent advocacy agency commissioned to provide PRPRs.

¹³⁸ The role of the PRPR is to maintain contact with the individual subject to DoL, and to represent and support them in all matters relating to the DoLS. A PRPR must be appointed where there is no one suitable in the individual's network able to take on that role.

¹³⁹ Subject to any advance decisions made by Mr A, of which we have heard no mention.

information to the nursing home, and participated in developing a care plan. She was consulted during the Deprivation of Liberty Safeguards process in October 2016, when her opposition to Mr A's placement was noted.

6.3.8. However, she was not involved in the best interests meeting on 12th January 2016, having sent her apologies, and it is not clear that her views were relayed to the meeting.

6.3.9. The second nurse assessor, who became involved at the end of January 2016, contacted her two weeks after the meeting, and learnt that she was having difficulty making decisions in Mr A's best interests and would like support from an independent mental capacity advocate. It is not clear what the difficulties were, or whether the support was for herself or for Mr A, and this cannot be clarified as the attorney has declined involvement in this review. The nurse assessor made the referral but no IMCA was appointed because of a shortage of suitable IMCAs within the organization providing the service. He contacted her again on 3rd March to discuss the difficulties experienced in providing care for Mr A, and to advise her of the mental health referral.

6.3.10. On the last weekend of Mr A's life, when East Sussex Adult Social Care became involved, they were not made aware of the attorney's existence. Their IMR makes the point that had they known, they would have made contact with her.

6.3.11. Thus it seems that the attorney's role became far less prominent as time went on. It is not clear whether she herself withdrew or whether professionals omitted to involve her, but again as with the absence of an advocate for Mr A himself, her absence removed one crucial resource for ensuring Mr A's best interests. When it became apparent at the end of January that she was experiencing difficulty making decisions on his behalf, it may have been important to discuss with her whether the Office of the Public Guardian needed to be informed.

6.4. Mental health

6.4.1. Although Mr A's diagnosis of Korsakoff Syndrome was established and known to those involved in his care, and although it was commonly accepted that his mental health affected his ability to care for himself, and to allow others to do so, his mental health needs were not consistently addressed. Although a mental health assessment was undertaken at Maidstone Hospital in August 2015, this did not result in any ongoing mental health care, or referral to community mental health services on his discharge to Nursing Home One.

6.4.2. The SECSU IMR comments that the nurse assessor should have called for a mental health assessment during the early weeks of Mr A's placement at Nursing Home One. That she did not is described as an oversight, and its impact was twofold: Mr A did not receive the

attention his mental health warranted, and the absence of an assessment made securing an alternative placement more difficult.

- 6.4.3. Again no mental health assessment was called for at the best interests meeting on 12th January 2016, despite the presence of the GP and the SECSU nurse assessors and there was a further month's delay before the nurse assessor discussed referral to the community mental health team with the GP.
- 6.4.4. The SPFT consultant psychiatrist assessed Mr A on 4th March 2016, confirming the diagnosis of Korsakoff Syndrome with short-term memory impairment, and finding no evidence of florid psychosis, anxiety, depression or suicidal thoughts. He was deemed to lack capacity in relation to care, assistance and medication, and the risks of serious physical injury or even death as a result of his care refusal were seen as high. The psychiatrist noted that Mr A's needs were not being met at Nursing Home One and that an alternative, specialist brain injury placement was needed. There is no evidence that any treatment plan was put in place following this assessment, although the consultant psychiatrist remained available for advice.
- 6.4.5. The consultant psychiatrist re-assessed Mr A again on 17th May 2016 and wrote a referral letter to the Lishman Unit at Bethlem Royal Hospital.
- 6.4.6. Both the GP and Nursing Home One at various points took advice from the consultant psychiatrist, particularly in relation to a question that arose as Mr A's physical condition deteriorated, with no change to his refusal of care: whether he might be detained under the Mental Health Act 1983. The consultant psychiatrist's view (in a letter of 10th March following the assessment on 4th March was reported as: *"he could be considered, if deemed appropriate, to be assessed under the MHA, which may facilitate the treatment for his physical health that could be treated under the Mental Capacity Act. However he is not currently presenting with florid psychotic symptoms and it seems that he has fixed beliefs about his treatment and medications. Also the MHA will not give the power to treat his physical condition and he is likely to physically resist medical treatment"*.
- 6.4.7. This appears to leave the way open for assessment under the Mental Health Act 1983 to have taken place, and indeed the SPFT IMR writer expresses the view that such assessment would have been appropriate. The consultant had suggested it (along with action under the Mental Capacity Act in relation to Mr A's physical health care). It is not clear why neither of these routes was pursued.
- 6.4.8. The omission may be related to the absence of coordination and case management, a theme explored later. But a further pertinent factor may be the interpretation of the consultant psychiatrist's advice. Nursing Home One understood the psychiatrist to have said that while

it would be possible to section Mr A to facilitate mental health treatment, sectioning was not possible on the grounds of his need for physical treatment or personal care. The GP also asked the consultant psychiatrist about use of the Mental Health Act, and understood from the advice given that it could only be used for enforcing psychiatric care, not physical care¹⁴⁰. This of course is correct, but is not the whole story, as it over-simplifies the consultant's advice, and omits the important consideration of whether mental health treatment could have resolved the barriers to Mr A accepting physical treatment. What is more, the psychiatrist had identified the Mental Capacity Act as authority for physical care and treatment (on the same ground as those indicated in section 6.1 above). The SPFT IMR writer makes the point that: "*there are certain circumstances where the patient's mental disorder i.e. Korsakoff's Dementia affects their ability with regard to refusal of physical health conditions, where the Mental Health Act can be used to treat both mental and physical health needs*"¹⁴¹.

6.4.9. Thus the absence of attention to Mr A's mental health needs in the early months of his placement at Nursing Home One represents a missed opportunity to engage proactively with the source of his resistance to physical care. Equally, the failure to implement active consideration of the Mental Health Act, alongside the potential that the Mental Capacity Act offered for securing physical treatment, represents a missed opportunity to act decisively in his interests.

6.5. Legal literacy

6.5.1. There appears to have been a lack of legal literacy in relation to a number of relevant powers and duties that were engaged in Mr A's case.

(a) Section 42, Care Act 2014: safeguarding enquiry

6.5.2. For the duty to enquire to be triggered (section 42, Care Act 2014), three requirements have to be met. The individual must have needs for care and support, whether or not the local authority is meeting any of those needs; the individual must be experiencing or be at risk of abuse and neglect (including self-neglect); as a result of those needs, the individual must be unable to protect himself or herself against abuse or neglect or the risk of it. The local authority must make, or cause to be made, whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case and, if so, what and by whom.

6.5.3. Although the possibility of making a section 42 referral was discussed periodically throughout Mr A's placement at Nursing Home One, a referral was only finally made by Mr A's GP over the weekend

¹⁴⁰ EHSCCG IMR

¹⁴¹ SPFT IMR

that he died. As one IMR concludes¹⁴², this was too late. The section 42 enquiry notes that the GP raised safeguarding concerns with Nursing Home One on 21st June 2016 but not with the local authority's safeguarding team. This was a missed opportunity. Staff at Nursing Home One could have made a section 42 referral from the point where Mr A began refusing care and treatment. The tissue viability nurse, who assessed him in December 2015 and May 2016 and noted his non-compliance with treatment, could have raised this as a safeguarding concern. Either the GP or the psychiatrist could have made a referral, for example in March 2016 when Mr A was assessed as at 'moderate to high risk' of death, in May 2016 when a referral was made for neuropsychiatry or in June after Mr A experienced a fall and when it was becoming clear that Mr A's refusal of care and treatment was endangering his life. Indeed following a fall in June there was a misunderstanding about who would make a referral, with the result that none was made. Staff in the Emergency Department of Eastbourne District General Hospital, instead of or in addition to advising Nursing Home One to refer Mr A to adult social care, might also have made a section 42 referral given that his transportation to hospital appears to have been triggered by seizures as a result of refusal to take medication and self-neglect.

(b) Mental Health Act 1983

6.5.4. A key challenge presented by Mr A was his refusal of care and treatment. The GP in particular, concerned about his refusal, explored with the psychiatrist whether mental health legislation could be used to override his wishes. The psychiatrist correctly advised that mental health legislation could not be used to impose treatment for physical ill-health¹⁴³. The GP appears to have been uncertain about what (more) could be done with respect to ensuring that Mr A received care and treatment. Further exploration of the relevance of mental health legislation has been detailed above.

(c) Mental Capacity Act 2005

6.5.5. From the GP's first contact with Mr A, in December 2015, she believed that he did not have capacity to make decisions about his care and treatment, and agreed with the consensus view confirming this at the best interests meeting in January 2016. The GP has since clarified that Mr A could present in discussion as if he had capacity, and that as a result it was difficult to come to a firm conclusion. Her response to her increasing concern about the consequences of his on-going refusal was to request a mental health assessment, which was eventually begun in March 2016. This is one of several points at which mental capacity assessments should have been done and/or updated with respect to the specific decisions facing Mr A.

¹⁴² SPFT IMR

¹⁴³ EHSCCG CCG IMR

6.5.6. There were in fact from the very beginning of the period under review two individuals to whom Mr A had given lasting powers of attorney (only one of which had been activated) to cover his financial affairs and his health and well-being. Their involvement, or lack of it, has been discussed above. Here it is relevant to note that the attorney expressed her difficulty in acting on behalf of Mr A in late January 2016. The response was to make a referral for an Independent Mental Capacity Advocate, who was never in fact appointed. Whilst such a provision might have been helpful, no consideration appears to have been given to the involvement, or standing, of the second attorney, or to seeking guidance from the Court of Protection at this point¹⁴⁴.

6.5.7. As noted earlier, there were a number of points at which mental capacity assessments should have been completed. That such assessments were not done indicates that knowledge and understanding of the Mental Capacity Act is not as well integrated within practice as it needs to be.

6.5.8. Neither Mr A nor his attorney was supportive of the placement at Nursing Home One when it was suggested¹⁴⁵. This is the first occasion when, in the absence of agreement about what was in Mr A's best interests, legal advice should have been sought and a referral to the Court of Protection considered. Legal advice and referral to the Court of Protection might also have been sought prior to discharge from Eastbourne District General Hospital Emergency Department, when it is clear that Mr A was refusing care and treatment and did not want to return to Nursing Home One. Equally, it was a route to consider in response to what was described as an "horrific situation" in March 2016 when a psychiatrist observed his continued refusal of care and treatment, and the deterioration of his physical health¹⁴⁶. Finally urgent requests for legal advice and referral to the Court of Protection could have been made over the weekend during which Mr A died, especially as there was uncertainty about whether the Mental Capacity Act 2005, and acting in the best interests of someone lacking capacity to decide about his care and treatment, included the power to convey to hospital. Legal advice was not sought¹⁴⁷. Had it have been, then there may have been a counterbalance to the belief¹⁴⁸ that "there was no way that the GP could ensure that Mr A received care".

6.5.9. The Deprivation of Liberty Safeguards are an important protection of an individual's Article 5 (ECHR) right to liberty. It appears that a Deprivation of Liberty authorization expired on or around 30th September 2015. Best interest assessments were completed by 22nd

¹⁴⁴ KCC IMR

¹⁴⁵ SECSU IMR

¹⁴⁶ SPFT IMR

¹⁴⁷ SPFT IMR

¹⁴⁸ EHSCCG IMR

October 2015 and renewal was authorized on 3rd November 2015, a timeframe outside what is normally expected¹⁴⁹. Neither Nursing Home One nor relevant staff in Kent appear to have triggered the process for further renewal prior to the expiry of the authorization on 2nd February 2016¹⁵⁰. Nor did anyone appear to question the on-going apparent delay in seeking renewal, with the consequence that Mr A may have believed that he was deprived of his liberty when in fact he was not lawfully so deprived. Nor does there appear to have been any review of the conditions that were set at the time, namely exploration of more suitable placements and the involvement of Mr A in socialization activity outside his room.

6.6. Interagency communication, coordination and ownership

- 6.6.1. Given the complexities of this case, the role of a lead agency, and a lead professional within it, was crucial for the effective coordination of the multi-agency effort. Continuing care guidance (DH, 2012) indicates clearly that responsibility for ongoing case management for someone in receipt of continuing care funding resides with the CCG. In this case, it is SECSU that provided care planning, commissioning and case management on behalf of the West Kent CCG.
- 6.6.2. The section 42 enquiry records that the CCG policy was to review placements after three months and then annually unless circumstances indicated that more frequent reviews were necessary. A formal review was certainly indicated by 29th December 2015 when Nursing Home One requested a best interests meeting because the care home could not meet Mr A's needs.
- 6.6.3. Yet there was no occasion when all the agencies and professionals involved in the provision of placements, care and treatment came together. Only one best interest meeting was held, despite several IMRs noting that others had been recommended, for example prior to Mr A's discharge from hospital to Nursing Home One¹⁵¹, or subsequently by the psychiatrist involved. Moreover, the one meeting that was held did not involve everyone responsible for his placement, care and treatment, did not provide a clear plan for staff at Nursing Home One and did not agree a way forward. The focus was almost exclusively on seeking an alternative placement. The meeting does not appear to have offered advice to care home staff about how to manage Mr A, despite their expressed anxieties about his refusal of care and treatment. Given the challenges that Mr A presented with his on-going and consistent refusal of care and treatment, and his opposition to the placement, it is perhaps surprising that a multi-agency meeting was not held, perhaps using complex case procedures that were available. This course of action has certainly been recommended by other SARs

¹⁴⁹ KCC IMR

¹⁵⁰ KCC IMR

¹⁵¹ SECSU IMR

and SCRs involving adults who self-neglect (Braye, Orr and Preston-Shoot, 2015).

- 6.6.4. Given the cross-border nature of this situation, involving agencies and professionals in Kent and in East Sussex, nomination of a lead agency might have facilitated case coordination¹⁵². As it was, agencies and professionals worked in isolation, reflected in part by the IMRs not cross-referencing significant events, such as Mr A's admission to and discharge from EDGH Emergency Department, which is only referred to in one IMR¹⁵³.
- 6.6.5. Closer multi-agency and multi-professional working together might have highlighted the need to review the approach to Mr A's placement, care and treatment: in November 2015, when he was admitted to hospital and a safeguarding referral could have then been made; in February 2016 when it was clear that he lacked decision-making capacity for his medical needs and his care needs were not being met; or in May 2016 when his continued refusal to accept care and treatment had resulted in a deterioration of his health.
- 6.6.6. Communication between professionals and agencies was also unclear. The GP was unaware of the dates for Mr A's deprivation of liberty. The psychiatrist apparently suggested that a section 42 safeguarding concern be raised in later May 2016 because of Mr A's self-neglect and risk of death but no-one appears to have taken responsibility to activate this referral. No-one took responsibility for convening a best interest meeting when the psychiatrist advised that this was appropriate in July 2016. In June 2016 neither staff at Nursing Home One, the GP nor the psychiatrist made a safeguarding referral because of misunderstanding over who would take responsibility to do so¹⁵⁴.
- 6.6.7. The process of referral for a mental health assessment was longwinded, with one IMR noting that Mr A's mental health was assessed seven weeks after the best interests meeting and 24 weeks after his placement at Nursing Home One, the need for it having initially been recognised whilst in hospital and prior to his final placement¹⁵⁵. There also appears to have been a lack of follow-up or escalation on actions that were initiated but not completed, for instance in relation to the appointment of a Paid Relevant Person's Representative, progress on the conditions set when Mr A's deprivation of liberty was authorised in November 2015, decisions from the best interests meeting in January 2016, and the referral to the specialist Lishman Unit in June 2016.

¹⁵² SPFT

¹⁵³ ESHT IMR

¹⁵⁴ EHSCCG IMR

¹⁵⁵ SECSU IMR

6.7. Resources

- 6.7.1. Lack of resources emerges as a significant theme from several IMRs. The team responsible for Deprivation of Liberty Safeguards was experiencing a significant workload following the massive increase in applications after the Supreme Court decision in Cheshire West. As the IMR points out, this is not unique to Kent¹⁵⁶. However, it certainly meant that in Mr A's case the process of authorisation of his deprivation of liberty in October 2015 took longer than the 7-14 days normally allowed, and he was not actually informed of the authorisation until after the order had actually expired. The resource pressures on the team may also have affected the absence of follow-up of the conditions set in the authorisation and also when an expected renewal request did not emerge from Nursing Home One.
- 6.7.2. The same IMR also notes that due to a shortage of suitable staff Powher could not meet the request for a Paid Relevant Person's Representative. The same is also true in relation to the IMCA request.
- 6.7.3. The SECSU IMR notes the shortage of Registered Mental Health Nurses in the placement team and the dislocation caused by the team working out of two different sites.
- 6.7.4. The same IMR also emphasises the frequent difficulties in finding appropriate placements. This meant that Mr A was placed in Nursing Home One when some professionals involved at the time believed that he would be better placed in a mental health specialist unit. Subsequent attempts to find alternative placements nearer to Ashford or Epsom, locations that Mr A and/or his attorney had identified as preferred, were unsuccessful, either because no beds were available or because the combination of needs and challenges presented by Mr A meant that he did not meet a residential care facility's admission criteria. What, arguably, is surprising is that no multi-agency meetings were called, involving Mr A and/or his attorney, when efforts to find alternative placement providers were proving fruitless. There did not appear to be a Plan B, even after Nursing Home One had given notice of their intention to terminate the placement.
- 6.7.5. Responses by ambulance crews were within target response times except for the first call-out in July 2016. The IMR¹⁵⁷ concludes that the absence (since rectified) of a mental capacity assessment tool might have assisted crews to complete assessments and record their decision-making, especially during the first call-out in July 2016.
- 6.7.6. One further element of resources relates to staffing. Adults who self-neglect in the sense of Mr A's resistance to care and medication will have challenged the knowledge and skills of many staff involved with

¹⁵⁶ KCC IMR

¹⁵⁷ SECAMB IMR

him. His refusal of care and treatment meant significant deterioration over time of his skin integrity and aggravated other health care needs, such as diabetes. Working with adults who self-neglect requires an understanding of the phenomenon and appreciation of the growing knowledge-base about effective ways of working with people who neglect their health and well-being (Braye, Orr and Preston-Shoot, 2014). It is specialist work, especially when placed alongside the other mental health and physical health needs that Mr A presented. It is unclear the degree to those involved in Mr A's care were supported by the placement commissioners and others to ensure that knowledge and skills were in place. Equally, it is acknowledged¹⁵⁸ that Mr A's nurse assessor at SECSU had very little mental health experience. The impact of this was compounded by the fact that the SECSU Placement Team were working from two different bases; the mental health nurses were all based in one office and Mr A's nurse assessor was based in the other. Thus experienced oversight of case management was difficult to ensure until a second more experienced nurse assessor became involved.

6.7.7. Finally, it is acknowledged¹⁵⁹ that the ambulance crew did not physically observe, assess or interact with Mr A during the first call-out in July 2016 because they did not have infection control equipment in their vehicle (it had not been checked earlier) and they did not use the equipment at Nursing Home One that was being used by care home staff.

6.8. Recording

6.8.1. One IMR observes that the documents concerning the best interests meeting held in January 2016, and those relating to mental capacity assessments were poorly written¹⁶⁰. The minutes of the best interests meeting do not appear to have been circulated to all those in attendance for part or all of the meeting, nor to those who were not invited, such as the tissue viability nurse, or those unable to attend, such as the attorney. The same IMR also notes that the minutes of the meeting do not record the rationale for the decisions that were reached or why the current placement was to be continued when Nursing Home One were clearly indicating that staff there could not meet his needs.

6.8.2. Although Nursing Home One were handed notes concerning Mr A's care and treatment on his admission, these do not provide detail with respect to his capacity to take specific decisions or how his physical needs were being treated by the GP. They refer to the need to apply for authority to deprive Mr A of his liberty and advise liaison with a mental health team for regular review and consideration of therapies

¹⁵⁸ SECSU IMR

¹⁵⁹ SECAMB IMR

¹⁶⁰ SECSU IMR

and activities to improve his mood and cognitive function. The notes refer to his fluctuating compliance regarding medication, his limited insight into his mental and physical well-being, and to his fixed delusional ideas. Despite the fact that several capacity assessments had been undertaken while he was in Maidstone Hospital, there is no reference to any of these. Certainly if the Out of Hours GP who attended Mr A during the weekend he died consulted the records held by Nursing Home One, he did not find sufficient information about mental capacity, and assessed Mr A as having capacity to decide about his care and treatment. He appears not to have known about previous mental capacity assessments¹⁶¹. Given that the Out of Hours GP did not have access to the GP's own medical records, the care and treatment record held at Nursing Home One would have been the crucial link in ensuring that he had sufficient knowledge on which to base his assessment and intervention.

- 6.8.3. Over time a number of mental capacity assessments were completed with respect to questions of Mr A's residence, medication and personal care. These do not appear to have been held in one accessible location or to have been available to all those who were endeavouring to support Mr A.
- 6.8.4. With respect to the deprivation of Mr A's liberty, the chronology has already observed that he was only advised after its expiry of the authorisation completed in early November 2015. The chronology has also noted that no record appeared available at the time of Nursing Home One's request for renewal even though it was actually responded to with a request that the correct forms were completed¹⁶². Staff at Nursing Home One were not checking junk mail at the time, so a completed renewal request was not in fact submitted. In this case recording regarding renewal of the deprivation of liberty is incomplete¹⁶³.
- 6.8.5. The GP's recording of her consultations with hospital staff on 22nd July 2016 do not appear to contain how and why particular decisions were reached. There are no records at the hospital of the conversation between the GP and the on-call consultant.
- 6.8.6. At crucial points - such as the handover to Nursing Home One at the time of his admission under sedation, and the dialogue between ambulance crew and nursing home staff during the final weekend of Mr A's life - perceptions (and in some cases records) of the content of conversations differ between the agencies involved. In the absence of an agreed and verified record, reliance cannot be placed on one or other version.

¹⁶¹ EHSCCG IMR

¹⁶² KCC IMR and Care Home One report

¹⁶³ KCC IMR

7. CONCLUSIONS

7.1. Introduction

The review has identified how a number of different systemic factors contributed to the circumstances in which Mr A died. No single factor in isolation influenced the outcome; it is their interaction with each other that was significant. And in each case, the influences at work are related both to the direct practice of the interagency network and to the broader context in which it took place.

7.2. Placement

7.2.1. The difficulties locating an environment in which Mr A's care and treatment could be managed started well before the period under scrutiny here. SECSU had been searching for an alternative placement to the Nursing Home Two in Kent for some time prior to Mr A's admission to Maidstone Hospital on 25th August 2015, but Nursing Home Two's refusal to have him back forced the issue.

7.2.2. There was pressure for his discharge from Maidstone Hospital once he was considered medically fit on 28th August. Despite being deemed (following mental capacity assessment) to be in his best interests, Mr A's placement at Nursing Home One contravened what was known about his wishes and feelings, which were to remain in Kent (or to be admitted to Kings Hospital London). His attorney supported him in this. For someone already mistrustful and resistant to care and treatment, this was problematic, and potentially compromised the care that the nursing home could provide from the start.

7.2.3. The broader context too was one in which clinical commissioning groups were relatively new arrangements and pressures on hospital discharge were acute. This review has identified a shortfall of placements suitable for people with highly complex needs of the kind shown by Mr A, demonstrating a commissioning gap and potentially a need for proactive market shaping.

7.3. Case coordination and interagency communication

7.3.1. The unsuitable nature of the placement was compounded by a lack of proactive follow up by SECSU and a resultant failure of case coordination. Challenges of working across borders and therefore at a distance may have also played a part¹⁶⁴. It is the absence of proactive

¹⁶⁴ Guidance to CCGs recognises cross-border challenges, requiring them to notify host CCGs when placing patients out of area, to support partnership working. It recognises the need to improve communication and co-ordination between commissioning CCGs and localities in order to monitor the quality and continuity of care (National Protocol for Notification of NHS Out of Area Placements for Individual Packages of Care (including Continuing Healthcare) (2012). ADASS (2016) has also published

case coordination in such a complex case that is one of the most telling features of the case. On no occasion did all relevant agencies and professionals come together to determine a shared plan for best interests intervention. Without strong leadership of the interprofessional and interagency network, the efforts that individual agencies made to secure care and treatment for Mr A were undertaken in isolation. As one learning event participant observed: “accountability was invisible and silent”.

- 7.3.2. Beyond this, there were numerous examples of communication failures, and failure to agree who would take action such as safeguarding referral or best interests meetings when concerns were identified. Equally, there are points at which perceptions of the same event or conversation differ markedly between agencies.
- 7.3.3. The absence of shared or mutually visible records was significant, making it difficult for an out of hours GP to access prior notes about Mr A’s case. The review has learnt that assessments (including mental capacity assessments) undertaken in one agency are not routinely passed to other agencies involved, making it difficult to ensure coordination, let alone integration, of health and social care perspectives and plans. Equally, the review has found instances where significant conversations or discussions were not entered in records, or where records contained insufficient detail to provide a clear audit trail of decision-making.
- 7.3.4. These gaps were sometimes exacerbated by technology. The fact that an important communication from the MCA/DoLS office could be filtered into Nursing Home One’s junk mail system, and lie undiscovered, with no mechanism built in to either agency to trigger an alert to an unresolved application, resulted in Mr A being deprived of his liberty without lawful authority.

7.4. Mental capacity

- 7.4.1. There was a serious failure to implement decisions about how care and treatment in Mr A’s best interests could be provided in the light of his lack of capacity to make such decisions for himself.
- 7.4.2. Mr A was, by all accounts, an articulate man who could forcefully express his views on where he wanted to live, and whether or not he accepted care and treatment. Information from a number of sources indicates that he did not believe what was told about his medical conditions, and remained fixed on the belief that the only treatment he required was from Kings Hospital London, where he had received treatment in the past (though he could not explain what that treatment was). Thus his treatment refusal was logical within the context of his

beliefs about his health, although those beliefs failed to take account of his medically established diagnoses. The logic of his reasoning could cause him to present as if he had capacity to make decisions, resulting sometimes in different opinions being expressed at the same time in relation to the same decision. In addition, he could at times be assertive, even aggressive, in his communications with those caring for him, making it even more difficult to challenge his beliefs and to persuade him to accept treatment.

- 7.4.3. At most points at which capacity was assessed, he was found to lack capacity to make decisions relating to his living situation, and to his care and treatment. His lack of capacity to decide on a suitable living environment resulted in the decision to place in him Nursing Home One, and to authorise the deprivation of his liberty to ensure that he remained there. However, despite the conclusion that he also lacked capacity to decide on care and treatment, his refusal of care and treatment on a daily basis in the nursing home was respected by staff, and endorsed at the best interests meeting in January 2016. Given he was deemed to lack capacity to give agreement, this is a paradoxical position.
- 7.4.4. Two factors made it possible. First, the best interests meeting that took place in January 2016, in confirming the plan to continue to search for an alternative placement, did not address the question of how daily care and treatment was to be secured. Second, throughout the ensuing period, as his condition deteriorated further, lawful means of either securing care and treatment or addressing the factors underlying his refusal were not actively sought. Best interests interventions using the protections of the MCA were not actively pursued, and no consideration was given to referring Mr A's case to the Court of Protection, when such a referral would have been entirely appropriate at various points during the final six months of his life. With one exception (in January 2016) there was an absence of explicit best interests decision-making processes, representing missed opportunities to take a more proactive approach to setting in place a strategy for securing his best interests, if necessary through application to the Court of Protection.
- 7.4.5. The final assessment of mental capacity, which the out of hours GP conducted the day before Mr A died, concluded that he did have capacity to decide about his care and treatment. Given the complexity of Mr A's history and situation, access at this point to his medical notes, or to information about previous assessments and the resultant multidisciplinary consensus, would have given the out of hours GP a more comprehensive picture of his ability to understand, retain, use and weigh relevant information. It was a highly influential determination of capacity, which also affected events the following day when the GP's view was reported by Nursing Home One staff to the ambulance crew, contributing to the ambulance service's decision not to engage or discuss hospital admission directly with him. While it is

recognised that mental capacity is time and decision specific, in highly complex cases where decisions lie with multidisciplinary teams, the importance of specialist mental capacity assessment that takes account of a range of professional perspectives cannot be underestimated.

7.4.6. In addition to the assessments above, there were numerous points at which mental capacity should have been assessed, with an outcome recorded, indicating that either explicit attention was not given to capacity or, if it was, that there are oversights in recording.

7.4.7. There were shortcomings too in how the deprivation of Mr A's liberty was managed. Due to pressures from a greatly increased number of DoLS applications there was delay in processing Nursing Home One's application to deprive Mr A of his liberty, and indeed formal notification to Mr A himself that he was deprived of his liberty was not sent until after the authorisation had expired in February 2016. Conditions attached by the Kent DoLS/MCA office when authorising his deprivation of liberty in November 2015 were not actively monitored, raising questions about how these are overseen within the DoLS system. Authority for Mr A's deprivation of liberty at Nursing Home One expired without completion of arrangements to renew the authority. In the absence of checks and balances within the management system at either the DoLS office or the nursing home, which would have triggered timely follow-up, the disappearance of an email from the MCA/DoLS office into the nursing home's junk mail system resulted in Mr A being deprived of his liberty unlawfully between February 2016 and his death in July.

7.5. Interface between mental capacity, mental health and physical health

7.5.1. There were missed opportunities to engage proactively with Mr A's mental health, despite the recognition that it affected his ability to allow others to care for him. Given his diagnosis, it is surprising that no community mental health referral was made at the time of his discharge from Maidstone Hospital, where a psychiatric assessment had been undertaken and closed. A referral by the SECSU nurse assessor would have been appropriate during the early months of his placement at Nursing Home One, and again following the best interests meeting in January 2016, but no psychiatric assessment took place until March 2016. Even then, no treatment plan ensued, despite the recognition by the psychiatrist that Mr A was at risk of serious injury or even death. The third assessment, in May 2016, resulted in more proactive referral for specialist neuropsychiatric care, although no such resource materialised before Mr A died. Despite advice by the consultant that assessment could be considered of whether Mr A met the grounds for hospital admission under the Mental Health Act 1983, (which could have facilitated treatment (using the MCA) for his physical health), no such assessment took place – a significant omission - and thus the impact of his mental health as a potential underlying cause of his refusal of care and treatment was not tested.

7.5.2. The interface between physical health, mental health and mental capacity is complex, and required more explicit interagency discussion than it received in Mr A's case. Again the absence of case coordination, either under continuing healthcare arrangements or adult safeguarding arrangements, contributed to the absence of any such discussion. Equally, a greater level of legal literacy and the timely provision of legal advice could have resulted in more decisive action.

7.6. Safeguarding

7.6.1. The review revealed that safeguarding processes were not effectively used in Mr A's case. A safeguarding referral was not made until the weekend he died, whereas safeguarding referrals could and should have been made at numerous earlier points by any of the people involved in his care and treatment. Just one such referral, made in timely fashion, could have resulted in a stronger multiagency coordination of efforts to safeguard him by securing his care and treatment, particularly important given the absence of proactive coordination by SECSU, which held the continuing healthcare coordinating and monitoring role on behalf of the West Kent CCG.

7.7. Involvement

7.7.1. Although Mr A was placed (in his best interests and deprived of his liberty) in a location to which he and his attorney were opposed, his views in relation to his care and treatment once there were, in contrast, accorded primacy. His consistent refusal of intervention was respected, despite the view that he lacked capacity to make that decision. Thus instead of being one factor to be taken into account in determining his best interests, his wishes, feelings, beliefs and values were allowed to determine the actions that professionals took (or omitted to take). To comply with best interests decision-making requirements, a more nuanced balance of a range of factors, including the risk to his life, was required.

7.7.2. The person who held LPA on behalf of Mr A was known to find this role difficult, both because of the distance to Mr A's placement and because she was struggling anyway to make decisions in his best interests. Not all agencies were aware of her existence. No consideration appears to have been given to whether her difficulties should have been notified to the OPG, which has responsibility for overseeing the work of those holding LPA. No mention is made of attempts to involve the second attorney. Neither a PRPR nor an IMCA was appointed, due to a shortage of suitable people within the agency from which the services were commissioned. The combined outcome of these omissions meant that there were significant gaps in how Mr A's rights to representation and support were observed in the final months of his life.

RECOMMENDATIONS

7.8. Introduction

Review of the findings and conclusions at the learning event resulted in the shared view that Mr A's case was not a unique case. Participants recognised systemic patterns and interlocking systemic factors that could, if unchecked, affect other cases. The recommendations that follow are designed to strengthen how agencies work together in similar cases in the future. Some agencies indicated in their IMR a commitment to make certain internal changes. These are not addressed in the recommendations below, but are included for information in Appendix 3.

7.9. Recommendations

Arising from the analysis undertaken within this review, it is recommended that the East Sussex Safeguarding Adults Board:

In relation to placements:

1. Promotes the development of a database of specialist placements capable of managing people with complex needs and challenging forms of behaviour;
2. Promotes work between relevant CCGs to address the commissioning/market shaping gap relating to provision for people with complex needs and challenging forms of behaviour;
3. Seeks reassurance that commissioning processes are robust in identifying the degree to which recommended placements have the capacity and resources to meet an individual's identified care and support needs.

In relation to case coordination

4. Seeks reassurance that there is now a system in place for notification of, and monitoring all out of county placements, both those where agencies in East Sussex are the placing organisation and those where East Sussex is the receiving location, in line with available guidance;
5. Undertakes an audit of out of county placements to identify the volume of such placements and to evaluate whether there are systemic patterns to be addressed;
6. Reviews complex case procedures to ensure that all agencies are aware of when and how to convene a multi-agency review of a complex case, with particular reference to ensuring that all available information is shared across all the agencies involved, with access to advice and guidance from legal practitioners, and agreeing and following through on a multi-agency action plan;

7. For all care and nursing home residents, promotes the use of one shared record held at the care home by all professionals involved, to ensure that all practitioners are aware when visiting a resident of the key issues within the chronology of the case;
8. Establishes a task and finish group to review record-keeping and information-sharing between agencies and to make proposals regarding the transfer of information, with particular reference to hospital discharge planning and admissions to care homes, and complex cases involving concerns about self-neglect and mental capacity;
9. Develops a protocol on the management of cross-border cases in partnership with neighbouring Safeguarding Adults Boards, with the aim of ensuring that all agencies are clear about:
 - a. Lead agency responsibility for case management, for supervision of case management and for placement reviews
 - b. Link persons in the receiving area
 - c. Escalation processes when there are concerns about placement suitability or case management.

In relation to safeguarding:

10. Produces briefings to promote and refresh safeguarding literacy in the context of the Care Act 2014, with particular reference to the referral pathways and thresholds for section 42 safeguarding enquiries and the use of complex case procedures and multi-agency meetings in challenging cases, as well as awareness of, and confidence in, understanding factors contributing to self-neglect.
11. Seeks reassurance that practitioners and managers across agencies understand and use pathways for seeking advice from, and escalating concerns to, safeguarding leads within their own organisation, and are able to use appropriately safeguarding referral pathways;

In relation to mental capacity and mental health

12. Reviews the effectiveness of single and multi-agency training in raising awareness and confidence, and strengthening knowledge with respect to the Mental Capacity Act 2005, referrals to the Office of the Public Guardian and the Court of Protection.
13. Conducts an audit of cases to evaluate the outcomes of best interest decision-making, with particular reference to assessing multi-agency involvement and clarity about leadership responsibility;
14. Reviews guidance on mental capacity assessment to include a process for securing multidisciplinary capacity assessment in complex cases where multidisciplinary teams are responsible for decision-making;

15. Reviews guidance for staff on working with those holding LPA;
16. Conducts regular workforce surveys to assess staff confidence in their legal literacy and safeguarding literacy, using the results to inform proposals about further workforce development initiatives;
17. Seeks reassurance through audits that systems are effective for tracking renewals of Deprivation of Liberty Safeguards, for monitoring conditions attached to DoLS authorisations, and for ensuring that individuals and their representatives have been notified in a timely way when orders have been made;
18. Reviews guidance on legal options for intervening in self-neglect, with and without capacity, to include consideration of the interface between the Mental Health Act 1983 and the Mental Capacity Act 2005, and the use of the Court of Protection and of inherent jurisdiction.

In relation to advocacy

19. Reviews with commissioners and providers of advocacy services (including PRPRs and IMCAs) measures to address shortfall in the number of available advocates, and monitors further developments in advocacy provision;

In relation to disseminating the learning from this review:

20. Produces briefings for agencies that summarise the learning from this case, with an accompanying feedback template so that East Sussex SAB can be informed how all agencies have disseminated the learning by means of team meetings, learning events and/or workshops;
21. Reconvenes a learning event one year on from the publication of its action plan to report on progress made and learning embedded in practice;
22. Sends this review to Kent and Medway SAB with a request that it considers the above recommendations and advises East Sussex SAB regarding what action it also proposes to take to ensure that lessons are translated into service and practice development;
23. Shares this review with neighbouring West Sussex SAB, Brighton and Hove SAB and Surrey SAB to inform their consideration of cases relating to out of county placements, mental capacity and self-neglect.

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APPENDIX 1: Acronyms used in this report

AMHP	Approved Mental Health Professional
CCG	Clinical Commissioning Group
CMHT	Community Mental Health Team
DoLS	Deprivation of Liberty Safeguards
EDGH	Eastbourne District General Hospital
EDS	Emergency Duty Service
EHSCCG	Eastbourne, Hailsham & Seaford Clinical Commissioning Group
ESASC	East Sussex Adult Social Care
ESHT	East Sussex Healthcare Trust
ESSAB	East Sussex Safeguarding Adults Board
GP	General Practitioner
IMCA	Independent Mental Capacity Advocate
IMR	Individual Management Review
KCC	Kent County Council Adult Safeguarding Unit MCA/DoLS service
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act 2005
MHA	Mental Health Act 1983
NHS	National Health Service
OPG	Office of the Public Guardian
RPR	Relevant Person's Representative
SAB	Safeguarding Adults Board
SAR	Safeguarding Adults Review
SCR	Serious Case Review
SECAMB	South East Coast Ambulance NHS Foundation Trust
SECSU	South East Commissioning Support Unit Placement Team
SPFT	Sussex Partnership NHS Foundation Trust
WKCCG	West Kent Clinical Commissioning Group

APPENDIX 2

Safeguarding Adults Review (SAR) Adult A: Terms of Reference

1. Introduction

- 1.1. The purpose of this review is to identify what lessons are to be learnt about the way in which local agencies worked together to ensure they are responding appropriately to people who self-neglect within care settings, particular where there are complexities around behavioural and capacity issues.
- 1.2. The review has its statutory underpinning within section 44 of the Care Act.
- 1.3. Ethos of the Review: This review will be considered in a fair and open manner. It will be objective in its approach and will be thorough, rigorous, and evidence based. All contact with individuals and stakeholders will be respectful, recognising any circumstances and religious diversity or other protected characteristics in accordance with the Equality Act 2010.

2. Scope of the Review

- 2.1. The review will focus on the events leading up to the death of Mr A and will consider the service interventions for Mr A, as well as the engagement with Mr A and any family/friends/attorneys. The review will have a particular focus on the following factors in this case:
 - *Placements*: How these are organised, and reviewed; How it is ensured that they have the skills to meet specialist needs.
 - *How health and social care professionals work together*: including across borders.
 - *How was the adult engaged with?* Including any family members/LPA, and how X's wishes were understood and to what degree they were met
 - *Mental capacity/DoLS*: How these were assessed and consideration of these issues, taking into account X's condition and needs.
 - *Mental capacity and the interface with the Mental Health Act*
 - *Care and Treatment plans*: How they were agreed, followed, and if all professionals were aware of them.
- 2.2. Agencies that were in contact with Mr A will be asked to contribute to this review, as well as agencies that were not in contact but might have been expected to respond. Those are as follows:
 - East Sussex Adult Social Care
 - Sussex Police
 - East Sussex Clinical Commissioning Group
 - West Kent Clinical Commissioning Group
 - Kent & Medway NHS and Social Care Partnership Trust
 - Kent MCA DoLS Office
 - South East Coast Ambulance NHS Foundation Trust
 - East Sussex Healthcare Trust

- Sussex Partnership NHS Foundation Trust
- Nursing Home One
- GP surgery
- Out of hours primary care

2.3. Time Period: Having considered the relevant events, the focus of the review will run from a hospital admission in Maidstone hospital on 25th August 2015 until Mr A's death on 24th July 2016.

3. Methodology

- 3.1. A review panel will be established involving representation from the agencies outlined in 2.2 above.
- 3.2. The Chair of the Safeguarding Adults Review will be the Head of Community Safety, East Sussex Fire & Rescue Service, supported by the Head of Safeguarding (ASC), and the Safeguarding Adults Board Development Manager. Members of the SAR panel will also assist in the process.
- 3.3. The lead reviewers are Michael Preston-Shoot and Suzy Braye who will be responsible for the overview report and facilitation of learning events.
- 3.4. The Chair of the Review will write to the relevant agencies, requesting they review their organisation's involvement with Mr A. These reviews should not be undertaken by those involved in the case.
- 3.5. The lead reviewers will produce an overview report will be produced for the Safeguarding Adults Board, and the case review panel will translate the recommendations into an action plan.
- 3.6. The review will also undertake a reflective learning event, which will attempt to understand how practitioners were making sense of the case at the time. A key principle of this approach is to avoid the bias of hindsight: to be able to consider what would be done the same, and what would be done differently.
- 3.7. The SAR will establish links with any internal reviews being undertaken in cross border agencies, as well as external review processes running in parallel, as follows:
 - individual section 42 enquiry
 - coroner's investigation
 - Serious Incident (SI) process of South East Coast Ambulance NHS Foundation Trust
 - Any other out of area review

APPENDIX 3

Actions taken or planned within individual agencies as a result of their IMR process

South East Commissioning Support Unit Placement Team (SECSU)

1. The Placement Team has ensured all nurse assessors have received appropriate MCA training.
2. Further MCA workshops specific to their role within the placement team are being introduced by senior staff.
3. All reviews and MCA documents are verified by senior staff, in line with the National Framework, MCA and NMC code of professional conduct.
4. There has been a considerable increase in the numbers of Best Interest decisions made before support plans are applied.
5. Prior to discharge we now ensure a Best Interest discussion had taken place which encompasses all the individual's needs.
6. A thorough discharge plan is developed with agreement from specialist community services to support individuals following discharge.
7. The Placement Team are all based in the same office and have more opportunity to discuss more complex cases face to face with colleagues and if necessary individual case responsibility is handed to nurses experienced in particular needs.
8. Frequent 1:1 meetings between nurse assessors and their line managers allow nurses the opportunity to reflect and discuss more complex cases.
9. Audit process permits us to identify concerns, if these have not been identified beforehand.
10. This change in process will identify any staff inexperience and ensure staff with the appropriate skills and knowledge to appropriately case manage any specific need is initiated at a much earlier stage.
11. Further training has been provided around MCA and best interest Decisions and is on-going.
12. All key stakeholders are invited formally in writing to best interest meetings. Relevant guidance is followed and meetings are fully minuted. Actions are planned and completed in a timely fashion.
13. Nurse Assessors are given dedicated time each week to manage their caseloads.
14. The support structure for complex decision making has now been significantly strengthened.

Kent County Council MCA/DoLS (KCC)

1. The safeguarding unit within which MCA/DoLS is located is currently reviewing management of cases not prioritised for assessments to reduce levels of risk.
2. The MCA/DoLS Policy Manager and Senior Line Manager of the administrators within the KCC/MCA/DoLS Service have shared this example to highlight the importance of completion of administrative tasks.
3. The need for an automatic email response to be generated from the generic nhs.net and kent.gov generic email boxes to those emailing information in, to confirm that their email has been received, has been reviewed.

4. Communication of outcome by letter to the Relevant Person and Interested Parties is monitored and does not exceed four weeks.
5. The MCA/MCA/DoLS Service reviews management of cases not prioritised for assessments in order to reduce risks and increase safeguards while the assessment is awaited. An outgoing message advises managing authorities of what will happen and what action they should take, for example if the person moves, or their situation changes.

East Sussex Healthcare Trust (ESHT)

1. Assessment of the patient's mental capacity on admission into the ED needs to be accurately recorded.
2. The patients voice must be evident in the medical documentation.
3. Front-line staff are to receive support and training with the application of the Mental Capacity Act.
4. Training in MCA is to be mandatory for clinical staff at induction and every 3 years.

Sussex Partnership NHS Foundation Trust (SPFT)

1. Clinicians must seek advice on legal matters relating to the use of the Mental Health Act and Mental Capacity Act from either the Deputy Director, Principal Social Worker or Manager of the AMHP Service.
2. The Medical Director is to issue instruction to ensure that when advice is given to use the statutory framework of the Mental Health Act or Mental Capacity Act this is followed up by the person, team or both, that gives and receives the guidance.

East Sussex Adult Social Care (ESASC)

1. Staff guidance for Health & Social Care Connect should include the requirement to ensure that when receiving a referral staff confirm that the referrer, or an alternative contact, is available for further follow up contact.