

Safeguarding Adult Review: Ben

EAST SUSSEX SAFEGUARDING ADULTS BOARD

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1. Introduction

- 1.1. In 2017 East Sussex Safeguarding Adults Board (ESSAB) published its first safeguarding adults review (SAR) under the mandate in Section 44 Care Act 2014. Known as Adult A, the SAR focused on the death of a 64-year-old man who had been a resident in a nursing home. He had a history of Korsakoff Syndrome, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis & ulceration. He had been placed in nursing care in East Sussex in September 2015, the placement being commissioned by West Kent CCG. No suitable placement had been found in what had been his area of ordinary residence.
- 1.2. Adult A died in July 2016. Cause of death was systemic sepsis, cutaneous & soft tissue infection of legs, diabetes mellitus, and idiopathic hepatic cirrhosis. The review's main findings were as follows, namely:
 - 1.2.1. Shortfall of placements for people with highly complex needs.
 - 1.2.2. Lack of proactive follow-up by West Kent CCG, resulting in a lack of case coordination and inter-agency communication. This was compounded by the challenges of working across borders. On no occasion did all relevant agencies, practitioners and managers meet together to agree a risk mitigation plan. Efforts that individual agencies and practitioners made to secure care and treatment for Adult A happened in isolation.
 - 1.2.3. Adult A lacked capacity to make decisions regarding his place of residence, care and treatment. The placement in the nursing home was made in his best interests and deprivation of liberty safeguards were used to ensure that he remained there. However, Adult A and his Lasting Power of Attorney opposed the placement and the absence of agreement about what was in his best interests was not referred to the Court of Protection for a determination.
 - 1.2.4. When the lasting Power of Attorney withdrew subsequently and played no further role, this was not referred to the Office of the Public Guardian. No consideration appeared to have been given either to the appointment of an Independent Mental Capacity Advocate.
 - 1.2.5. When the deprivation of liberty required renewal, the process was not finalised as West Kent CCG did not pick up the completed forms that had been returned by the nursing home.
 - 1.2.6. Adult A's daily refusal of care and treatment was respected by nursing home staff. Once again, no referral was made to the Court of Protection.
 - 1.2.7. There were missed opportunities to refer and assess Adult A's mental health, despite the recognition that it influenced his response to the care and treatment being offered. No formal assessment was conducted under the Mental Health Act 1983. This was not followed up by the nursing home, GP or psychiatrist and was a significant omission. The interface between physical health, mental health and mental capacity is complex and required more multi-agency discussion than it received.
 - 1.2.8. Safeguarding pathways were not used. The only safeguarding concern referral (Section 42(1) Care Act 2014) was submitted on the weekend when he died.
- 1.3. The review made recommendations about placements, case coordination, safeguarding, advocacy, mental capacity and mental health, and dissemination of learning.

- 1.4. Ben¹ died on 22nd November 2019, aged 60. He had been admitted into hospital in October 2019 requiring bi-lateral amputation due to deterioration of diabetic foot ulcers. The severity of Ben's condition meant that amputation could not be considered. The hospital raised a safeguarding concern on 22nd October 2019 in relation to neglect / acts of omission, expressing concern at Ben's presentation on arrival from the care home. Ben had a history of risks relating to self-neglect and non-compliance with medical care and treatment in relation to diabetes management.
- 1.5. Cause of death was infected foot ulcer, diabetes mellitus and schizophrenia. No Coroner inquest has been held. He had been living in a residential home in East Sussex for around 30 years, having been placed by West Sussex County Council (WSCC). The care home is registered for the care of people with mental health conditions and/or sensory impairment, and for care of older people. Since August 1993 he had been seen by the East Sussex Assessment and Treatment Service (ATS) for monitoring of his mental health and the administration of long-acting injection by a Community Psychiatric Nurse fortnightly. He was reported to be compliant with mental health medication.
- 1.6. He is reported to have been less compliant with physical health treatment, with secondary diabetic-related complications requiring ongoing monitoring of diabetic-related risks, for example concerning his feet, from at least 2016.
- 1.7. The SAR referral recorded diagnoses of learning disability, autism, paranoid schizophrenia and Type 1 (insulin dependent) diabetes². His next of kin was recorded as his sister.
- 1.8. A SAR referral was received by ESSAB on 24th February 2021 from the Learning Disability Review (LeDeR) programme lead at the CCG. ESSAB's SAR sub-group met on 22nd March 2021, and again on 25th May, and recommended that the criteria for a mandatory review had been met (Section 44(1) (2) (3) Care Act 2014) had been met. It further recommended that a proportionate methodology be adopted, to focus in particular on the outcome of the recommendations from the Adult A SAR but also on the delay in receipt of the SAR referral and on the Section 42 (Care Act 2014) enquiry that had apparently preceded it. The sub-group's recommendations were accepted by ESSAB's then independent chair on 14th July.
- 1.9. These recommendations were informed by the apparent similarities between the two cases, namely:
 - 1.9.1. An out of county placement.
 - 1.9.2. The complex interface between mental capacity, mental health, and physical health.
 - 1.9.3. Working with adults who self-neglect and who refuse care and treatment.
 - 1.9.4. An apparent lack of a coordinated multi-agency response.
 - 1.9.5. Apparent missed opportunities for early intervention.
 - 1.9.6. Apparent lack of knowledge of self-neglect and of adult safeguarding pathways.
 - 1.9.7. Lack of consideration of advocacy.
- 1.10. In consultation with the independent reviewer, the following terms of reference were agreed as key lines of enquiry, namely:

¹ Ben is a pseudonym.

² The independent reviewer has been informed that Ben was diagnosed with, and treated for type 2 diabetes.

- 1.10.1. Case coordination and inter-agency communication (including across geographical boundaries).
 - 1.10.2. Knowledge and practical application of the self-neglect procedures.
 - 1.10.3. How the Mental Capacity Act and Deprivation of Liberty Safeguards were understood and used in practice.
 - 1.10.4. The interface between the Mental Capacity Act and Mental Health Act in cases involving self-neglect.
 - 1.10.5. The challenges of non-engagement with adults experiencing self-neglect.
 - 1.10.6. How well the Section 42 process is used when a person dies during an enquiry, leading to that process ending, but where there remains potential risk to other adults.
 - 1.10.7. The extent to which the SAR referral process is understood by frontline practitioners and managers, including awareness of the need to make timely referrals.
- 1.11. It was agreed that the time zone for reflective analysis would be from December 2018 to November 2019. Detailed statements of involvement were received from the services involved. Services also responded to questions raised by the independent review, who also was given access to a Higher Learning Review Report completed by Sussex Partnership NHS Foundation Trust (SPFT). The services providing information for the review were as follows:
- 1.11.1. Sussex Partnership NHS Foundation Trust (SPFT)
 - 1.11.2. West Sussex County Council (WSCC)
 - 1.11.3. East Sussex County Council (ESCC)
 - 1.11.4. East Sussex Hospital Trust (ESHT)
 - 1.11.5. GP
 - 1.11.6. Care Home
- 1.12. Ben's sister was notified of the SAR and invited to contribute. No response was received initially.
- 1.13. A reflective learning event was held virtually, attended by representatives of all the agencies involved, including practitioners and operational managers who knew and had worked with Ben. The outcomes of the learning event were significantly enhanced by the involvement of practitioners who had worked with Ben over a significant time period, and the reflective openness that all those involved brought to the process.

2. Chronology

- 2.1. Prior to the time zone set for detailed reflective analysis, there were episodes that began to establish a pattern. Ben had been in residential care since 1992. In September 2014, the care home raised an adult safeguarding concern regarding his lack of compliance with medical treatment, including refusal to attend hospital. The plan apparently was for the GP and consultant psychiatrist to visit Ben to assess his mental capacity. **Commentary:** the referral of an adult safeguarding concern was good practice.
- 2.2. Periodically thereafter the care home raised concerns about Ben's health and wellbeing. In December 2015, the care home raised concerns regarding his refusal to engage with treatment plans, his deteriorating physical health, and his self-neglect. His GP had been visiting. In early January 2016 Ben was diagnosed with Type 2 diabetes. Concerns were expressed about his mental capacity and whether it was necessary to use deprivation of liberty safeguards. District nurses were visiting, and the GP was requested to complete a mental capacity assessment. The chronology for East Sussex Health Trust (ESHT), provider of community nursing and podiatry, records daily contact with community nurses for diabetes management and foot treatment. On 14th January 2016, the diabetic foot clinic wrote to Ben's GP regarding a neuropathic foot ulcer and questioning whether he had capacity to make decisions regarding his health. The ESHT chronology also records that in January 2016 he was discharged from Eastbourne District General Hospital (EDGT) as he did not want to attend foot clinic. It appears, however, that he would see district nurses at the care home.
- 2.3. In May 2016 WSCC completed a review of Ben's placement. **Commentary:** placement reviews should be annual and more frequent when there are concerns about risk and/or whether placements remain appropriate. The next review was not held until December 2018.
- 2.4. In February 2017, another adult safeguarding concern was referred, again because of Ben's self-neglect and refusal to accept medical interventions. There was another request for the GP and consultant psychiatrist to assess his mental capacity. **Commentary:** referral of an adult safeguarding concern was good practice.
- 2.5. In early October 2017 WSCC received an email requesting best interest decision-making because of ongoing concerns.
- 2.6. In February 2018, a multi-disciplinary team meeting was held at the GP surgery as a result of ongoing concerns regarding Ben's mental health and non-compliance with treatment. It was agreed that it was in his best interests to have insulin and medications administered for him. It was noted that further mental capacity assessments were likely to be needed for key decisions, such as medical interventions. Information was shared with WSCC. WSCC contacted the care home.
- 2.7. At the same time EDGH referred Ben to district nursing for initiation of insulin treatment. It was stated that he would not leave the care home for appointments and that he lacked mental capacity for decisions about diabetes management. His diabetes was poorly controlled and there were concerns about how services could engage with him because of his behaviour and mental health. **Commentary:** as emphasised in the Adult A SAR, when there are significant concerns about the ability to act in someone's best interests, when

they do not have mental capacity for specific decisions, referral to the Court of Protection must be considered.

- 2.8. 24th September 2018 Ben had cellulitis of foot and suffered from frequent infections.
- 2.9. By 9th October the cellulitis had improved.
- 2.10. On 19th October Ben was assessed as not having capacity for decisions about medical treatment.
- 2.11. By 1st November, in a diabetic foot risk assessment, his right foot had completely healed.
- 2.12. On 4th December 2018 WSCC undertook a review and reassessment. It was prompted by a request from the care home, struggling to look after Ben, especially with diabetes management. This focused on how the desired outcomes of the support plan were being met, his wellbeing and physical health, changes in his needs for care and support, his behaviour and the number of incidents, family contact and community access, and staffing ratios. His support plan was updated. It was to support him to communicate his needs, maintain his personal hygiene and his physical health, and contact his sister. He was to have a clean and safe environment that maintained his mental health and responded to any change. Support was to be provided with respect to money management, good nutrition and hydration, and opportunities to engage in chosen activities. His sister offered two suggestions here, namely painting and fishing.
- 2.13. Following the review, the care home requested additional funding for the support plan. On 20th December WSCC emailed the service for additional information, especially how the additional support hours would be used. Additional funding was provided from 1st April 2019.
- 2.14. By 24th December both feet had a range of corns and wounds, but none look infected. Care staff noticed that he was picking at his wounds and scabs. The ESHT chronology records that he responded well with antibiotics, noting also a blister on his hand. A referral for podiatry was sent. **Commentary:** care staff reporting concerns becomes a running thread.
- 2.15. From 4th January 2019 onwards the ESHT chronology records predominantly daily visits for the purposes of diabetes and wound management, and the administration of insulin. This pattern continued until his final hospital admission at the beginning of October. **Commentary:** this level of care and treatment was good practice.
- 2.16. On 10th January, the ESHT chronology records a tongue ulcer and dry and scabbed fingers. On 14th January, his feet were better, just flaky skin being observed. On 20th January, a new GP took over the list of patients³. On 21st January it was noted that high blood glucose levels had been recorded for the last week⁴.
- 2.17. On 31st January, a diabetic foot examination took place. Ben had podiatry every 3 months. Missing toenail on his great toe and on left foot some dry skin were observed. The

³ GP statement of involvement.

⁴ ESHT chronology of involvement.

same day the GP chronology records a diabetic review by the surgery's specialist diabetes nurse. No current ulcers were observed but high risk was recorded.

- 2.18. On 3rd February, the ESHT chronology recorded a GP referral as Ben was declining insulin. Two days later the same chronology recorded a warning to staff that Ben was agitated. A podiatrist had visited and would review again in three months. Both feet were assessed at moderate risk. Ben was unable to advise when pressure was applied to his feet. **Commentary:** risks appear to be increasing, suggestive of the need for a multi-disciplinary meeting to review care and treatment.
- 2.19. On 7th February, the care home notified WSCC that it wished to cease being the financial appointee for Ben and requested that the placing local authority should assume this responsibility. This request was referred to CLDT (Community Learning Disability Team) North.
- 2.20. On 12th February, the ESHT chronology recorded that Ben had picked a scab in his right lower leg, surrounding skin was now red and scab was weeping serious fluid. Care home staff called his GP. This is also recorded in the GP chronology, with Ben having been seen by a specialist nurse and found to have pick at his wound and to have developed cellulitis. Antibiotics were prescribed and he was referred to district nursing for dressings. Two days later the ESHT chronology noted that he was receiving antibiotics four times daily for an infected right leg. A pressure area assessment on 19th February recorded problems with circulation, observing pink areas but concluding minimal risk of pressure damage. The assessment was repeated on 26th April, 26th June and 24th July. **Commentary:** continuity of focus on skin integrity was good practice.
- 2.21. A paramedic practitioner visited on 12th March and recorded Ben experiencing dizzy spells, related to antipsychotic medication⁵.
- 2.22. On 9th April WSCC recorded an email regarding a best interest meeting in relation to the management of Ben's finances. The ESHT chronology for 17th April recorded his right inside leg above the ankle appeared to have a local infection. The GP chronology recorded care staff concern for the same date, with a specialist nurse visiting. Antibiotics were prescribed for a hand wound and insulin was to be increased because of poor diabetes control. He was referred to district nursing⁶.
- 2.23. On 8th May the care home requested a best interest meeting. On 16th May the ESHT chronology recorded a podiatry assessment that found his feet in good health. However, Ben did not speak during the assessment. The same chronology for 24th May noted that care home staff had reported that Ben was refusing to have his skin checked.
- 2.24. By 5th June a traumatic wound, small skin tear on the front of his shin, was observed. On 7th June care home staff reported that he had picked at scabs and that the wound area was spreading. This report, however, does not appear to have been known to the healthcare assistant who visited and who recorded the following day that care home staff appeared unaware of the care plan to check his legs⁷. However, the GP chronology also recorded carer concern that his cellulitis was worsening at this time. The care home was

⁵ GP chronology.

⁶ The GP chronology records the same for 5th June.

⁷ ESHT chronology.

also requesting support with the administration of insulin. **Commentary:** this highlights the importance of information-sharing when service providers work together.

- 2.25. By 10th June skin redness appeared to be resolving but on 4th July the ESHT chronology recorded that Ben was picking at his skin and that care home staff had dressed a wound on his hand. A body map was completed. **Commentary:** completion of the body map was good practice.
- 2.26. The GP chronology for 14th June noted that his main carer at the care home was leaving and that this could have an impact on his compliance with medication. The chronology also recorded that a capacity assessment had been done but would be reviewed. Care home staff requested a letter to the effect that Ben lacked capacity regarding decisions about his health. The GP provided this as the previous GP had done so. On 18th June, a specialist nurse visited and found the wounds to have fully healed.⁸ **Commentary:** capacity assessments are required to be time specific.
- 2.27. The GP statement of involvement for 26th July recorded renewed concern about wounds, with antibiotics prescribed and referral to district nursing. The ESHT chronology for 27th July recorded that Ben had been prescribed antibiotics as he had bitten into a blister leading to an open raw area on his hand. Sometimes he would remove the dressing. On 7th August he was refusing antibiotics. **Commentary:** Ben's acceptance of treatment fluctuated. This highlights the importance of keeping mental capacity continually under review, of distinguishing between macro and micro decisions when assessing mental capacity⁹, and of considering legal options, especially referral to the Court of Protection.
- 2.28. Care home staff reported a heal blister to ESHT practitioners on 24th August. This was recorded as not caused by pressure. A wound plan was drawn up. The GP chronology for 29th August recorded renewed concern about his left lower leg, with a specialist nurse visiting, prescribing antibiotics, and making an urgent referral to podiatry. By 31st August, the wound area was extensive. Ben had consented to the taking of a photograph but was non-compliant with keeping pressure off the affected area. An out of hours GP requested an urgent diabetic podiatry referral. By 2nd September he was receiving antibiotics. On 4th September, the ESHT and GP chronologies recorded podiatry involvement, with Ben being treated in his best interests and with an increased dose of antibiotics authorised as ulceration was now extending to his mid-calf and infection was spreading. He was continually reluctant to rest his foot. The GP was informed.
- 2.29. The GP chronology for 5th September recorded increasing care staff concern, with Ben being increasingly aggressive and refusing medications. The chronology recorded diazepam being prescribed and referral to the mental health provider team. This referral was a GP letter to the Assessment and Treatment Service in East Sussex, requesting an urgent review due to Ben's aggression towards district nurses and lack of compliance with antibiotic medication. On 8th September he would not take antibiotics and was picking at his leg. The infected area showed signs of worsening, on his left leg up to his knee. A GP visit was requested. The ulcerated left heel was being dressed each day. Ben was due to see a diabetic foot specialist, but care home staff were worried that they might not be able to take him due to his aggression. On 9th September, the GP chronology recorded a visit by a paramedic practitioner who found the left heel improved.

⁸ GP chronology.

⁹ Royal Borough of Greenwich v CDM [2019] EWCOP 32.

- 2.30. Indeed, he did not attend the foot clinic on 11th September and the GP was informed. Care home staff had been unable to take him due to his aggression, and his mental health was rendering intervention difficult. The foot clinic discharged Ben to his GP. **Commentary:** once again, fluctuating engagement and the challenges of acting in his best interests should have prompted a multi-agency meeting and/or referral of an adult safeguarding concern, with application to the Court of Protection also considered.
- 2.31. The GP chronology for 12th September recorded a visit to assess Ben, describing a “difficult situation” and raising the possibility that his learning disability and mental health were impacting on his decision-making about treatment. The GP assessed that he lacked understanding regarding his diabetes and had no insight into his current condition. He therefore lacked decisional capacity. He had not yet developed sepsis, but he could become septic. The GP was considering a planned hospital admission, as he was not so acutely unwell, and referrals were sent to mental health, learning disability and podiatry teams. The GP chronology also mentioned a Mental Health Act 1983 referral to the Emergency Duty team, which was apparently declined. Ben’s behaviour was becoming more challenging, and he was beginning to refuse mental health medication. **Commentary:** a planned hospital admission reflects the principle of a proportionate, least restrictive response.
- 2.32. The ESHT chronology for 12th September recorded that the GP was assessing Ben’s mental capacity and considering a referral to a psychiatrist. Ben was refusing antibiotics and sedation. The wound at the bottom of his heel was necrotic. Antibiotics had been prescribed. ESCC records note a referral from the care home to the Emergency Duty Team (EDT) Service, reporting concern for Ben’s wellbeing regarding his diabetes, inflected foot ulcer and compliance with diet and medication. EDT were informed of his mental health diagnosis. The care home was advised to inform WSCC. **Commentary:** whilst WSCC as the placing authority should have been notified of the concerns, this was one opportunity when an adult safeguarding concern could have been referred in order to prompt multi-agency information-sharing and planning.
- 2.33. On 16th September, a member of care staff asked a nurse to check his toe for a fungal infection. A district nurse informed podiatry, resulting in a joint visit on 19th September. Although antibiotics continued to be prescribed, Ben refused this treatment on 23rd September. Care staff were advised to inform the GP¹⁰. **Commentary:** good examples of information-sharing and working together. However, the pattern is continuing, and mitigating risks has proved difficult. A whole system meeting should have been considered.
- 2.34. From around this time the urgency and seriousness of the situation appears to escalate. The GP chronology recorded that Ben’s symptoms worsened. On 16th September, a consultant psychiatrist from the Assessment and Treatment Service responded to the urgent referral sent by the GP on 6th. A best interest meeting was suggested, On 17th September he was referred to a community learning disability team. On 20th September an urgent referral was sent to the diabetes team. The GP also notified a learning disability team, expecting a multi-disciplinary team discussion. No change was recorded on 24th September. The GP chronology recorded an urgent referral on 25th September to the diabetic foot clinic and on 26th September that care staff were reporting that Ben was refusing all medication, with increasing aggression. The mental health team had apparently not reviewed the case, which the GP chased up by writing again to the consultant

¹⁰ ESHT chronology.

psychiatrist. The mental health team requested another referral urgently. **Commentary:** there was a ten-day delay between the GP requesting urgent review by the Assessment and Treatment Team and the response from a consultant psychiatrist. The suggested best interest meeting was not convened.

- 2.35. The WSCC chronology for 26th September noted that Ben was still on the waiting list for allocation by CLDT North. The ESHT chronology for the same date recorded that Ben was agitated when his foot was redressed and that he was refusing all medication except insulin. The pattern continued the following day. The same chronology observed for 30th September that care staff believed the GP was contacting the mental health provider, and that on 1st October the GP and community psychiatric nurse were suggesting that a best interest meeting be held. **Commentary:** certainly a multi-agency, multi-disciplinary meeting had been necessary to consider how to act in Ben's best interests in light of the pattern that had become established and the difficulty in mitigating risks to his health and wellbeing.
- 2.36. On 2nd October a podiatrist found that his wound had deteriorated, and that cellulitis was spreading. The advice was that Ben should be in hospital, but it was expected that he would be aggressive if an ambulance was summoned. The GP was informed. He continued to refuse medications and the taking of photographs. The GP chronology recorded the referral from podiatry and concern about his leg, with urgent IV treatment required. The referral apparently reached the surgery late in the day, resulting in a duty doctor liaising with the care home. IV antibiotics were recommended but the registered manager is reported as suggesting that this could prove challenging. The chronology also observed that a community pharmacist cannot provide this treatment. **Commentary:** the GP was attempting to facilitate treatment in an environment familiar to Ben, which was good practice.
- 2.37. Also, on 2nd October the care home wrote to the GP and consultant psychiatrist expressing considerable concern. This prompted a priority response from the duty worker at the Assessment and Treatment Service. The following day a duty clinician spoke to Adult Social Care and the care home to arrange for two community psychiatric nurses to visit.
- 2.38. Also, on 3rd October a community nurse secured Ben's agreement to the insertion of IV cannulation. However, IV antibiotics cannot be prescribed in the community. On the same day, the GP emailed all the consultants involved requesting urgent support. The hospital diabetic team would not see Ben until he was an inpatient¹¹.
- 2.39. On 4th October Ben was seen by two community psychiatric nurses. Care home staff reported that his mental health was declining but the community psychiatric nurses could not detect psychosis as he would only engage for a short time. Care home staff reported that he was refusing treatment for a deteriorating heel ulcer, with consequent risk of gangrene, but he was refusing hospital admission. Ben admitted that his foot hurt but would not elaborate or say whether he was willing to accept medication. The community psychiatric nurses determined that he did not require a Mental Health Act 1983 assessment and advised care home staff to contact district nurses. **Commentary:** a further mental capacity assessment could have been completed at this point regarding his decision-making about treatment and hospital admission. There is some evidence to indicate that his mood was fluctuating due to pain from infection. His willingness to accept medication, specifically antibiotics, was fluctuating.

¹¹ GP chronology.

- 2.40. Subsequently on 4th October Ben was taken to EDGH's emergency department with query sepsis. This appears to have followed a conversation between the GP and care home staff, with advice to call an ambulance. His diabetes was unstable as a result of lack of compliance with diet and medication. His physical health was declining. He had refused hospital admission but was conveyed in his best interests with police support. He was aggressive and febrile on arrival. He was admitted the following day with an infected diabetic left leg ulcer. IV medication was now available. WSCC learned of this admission on 7th October.
- 2.41. The seriousness of his condition is underlined by the fact that hospital staff considered bi-lateral amputation but concluded that this operation would not be in his best interests. That conclusion was reached after consultation with the hospital's legal team. The best interest decision was reached with the involvement of an independent mental capacity advocate. This arose after the hospital had contacted Ben's sister, who felt unable to advise what his wishes would be regarding amputation. His prognosis was poor and palliative care would be offered. **Commentary:** seeking legal advice and involving his next of kin and an advocate were good practice.
- 2.42. On 15th October hospital staff referred Ben to learning disability liaison. On 22nd October, the hospital formally referred an adult safeguarding concern. Concerns focused on neglect/acts of omission, raised because of the condition in which Ben arrived at the hospital, and doubts about the appropriate use of the Mental Capacity Act 2005 regarding treatment for Ben in the community. **Commentary:** this referral was good practice.
- 2.43. On 6th November, a CHC fast-track funding referral was submitted. On 8th November WSCC was contacted by East Sussex Adult Social Care with respect to the adult safeguarding enquiry. This was a request for information regarding what was being funded, what WSCC knew about Ben's care and support needs, suspected sepsis, and refusals to accept treatment, and if WSCC had been involved in mental capacity assessments and best interest decisions. WSCC responded to the request on 14th November, noting that a funding increase had been approved following the December 2018 review to reflect running costs, Ben's care and support needs, and the expectation of 1:1 work. WSCC believed that a community psychiatric nurse was visiting weekly. It had not been involved in best interest decisions regarding Ben's treatment and was unaware of his treatment refusals prior to being informed on 7th October of his hospital admission. **Commentary:** it is possible that Ben might have qualified for CHC funding earlier than November, had a referral been made. Earlier consideration of a CHC referral would have been helpful, given his fluctuating health needs and their complexity. This would have facilitated coordination of NHS treatment and other support. Practitioners should routinely consider whether a CHC referrals appears indicated.
- 2.44. Around 15th November consideration was given to transferring Ben to a hospice and to authorisation of deprivation of liberty. Neither were progressed. At this point also, the care home gave notice. Ben died on 22nd November. WSCC were notified of Ben's death on 27th November and attended a safeguarding planning meeting on 2nd December.

3. Comparative analysis

- 3.1. An initial review of the documentation submitted by the agencies involved with Ben has enabled a cross-case comparison that in the following table looks back to the Adult A SAR. Both individuals presented with multiple complex needs. In both cases practitioners confronted a dilemma of how to balance individual autonomy with a duty of care, and of how to act in the person's best interests.

Theme	Adult A	Ben
Self-neglect	Refusal of care and treatment	Refusal of care and treatment
Mental capacity	Lacked capacity for care and treatment but difficult to act in his best interests	Assessed as lacking capacity about his health but difficult to act in his best interests
Out of authority placement	Placing authority only involved with deprivation of liberty	Placing authority only involved with care package review
Mental health	GP requests support from psychiatry	GP requests support from psychiatry
Physical health	Tissue viability concerns	Tissue viability concerns
Safeguarding literacy	No section 42 referral until shortly before he died	No section 42 referral until his final hospital admission
Legal literacy	No referral to the Court of Protection	No referral to the Court of Protection
Multi-agency meetings	No meeting at which all services involved were present	No multi-agency, whole system meeting

- 3.2. Both cases involved out of authority placements into East Sussex. Both cases required practitioners to navigate a complex interface between mental health, mental capacity and physical health concerns. Adult safeguarding procedures were not used in either case whilst the individuals were alive and there was limited use of advocacy. Both cases raise concerns about the adequacy of multi-agency working particularly in terms of addressing risk, and regarding the assessment of mental capacity, and how to respond when capacity fluctuates and/or it proves difficult to act in someone's best interests when they do not have capacity.

4. Mapping learning against the key lines of enquiry

Case coordination and inter-agency communication

- 4.1. At an ESCC safeguarding adults at risk planning meeting on 2nd December 2019, in response to the hospital's adult safeguarding referral, there was an agreed outcome that clearer referral pathways were required to obtain the right level of care for service users, their families and for practitioners supporting them. This was acknowledged as a systemic issue. Also acknowledged at that meeting was apparent confusion regarding which agency should lead and/or implement the self-neglect procedures, and convene a multi-agency meeting. There are clear parallels here with findings from the Adult A SAR.
- 4.2. The same planning meeting recorded concerns about lack of communication with the GP from district nurses and podiatrists regarding their reviews of Ben's physical wellbeing. However, the meeting notes also record that district nurses did witness his deterioration and shared their concerns with podiatry and the GP.
- 4.3. At the learning event, practitioners observed that there was no occasion when all the agencies had come together, and that it was unclear which service was the lead agency, taking responsibility for coordinating the response to meeting Ben's needs and addressing risks. This was noted to be a longstanding systemic issue, that had also been a finding in the Adult A SAR.
- 4.4. Those attending the learning event felt that individual practitioners across services had worked well but not necessarily collaboratively. Moreover, there was a lack of clarity about how to escalate concerns when requests for support, advice and involvement did not result in more collaborative engagement. The importance of using multi-agency meetings was acknowledged but concern was expressed that practitioners across different services might not be aware of how to access multi-agency panels and complex case forum discussions. Similarly, whilst it was recognised that any practitioner could call a multi-agency or multi-disciplinary meeting, there were obstacles (people's diaries) and hesitation about whether "you are the right person" and the responsibility that might follow from taking the lead. Differences of opinion were expressed regarding whether the process was clear on which agency should take a leadership role.
- 4.5. Those attending the learning event emphasised the challenges of multi-disciplinary working. For example, they questioned who would coordinate decision-making when there were several health care professionals and services involved, alongside social care. There were references to a revolving door – physical health, mental health, mental capacity and learning disability needs and concerns, with uncertainty about which service was responsible for drawing everything together to ensure a more collaborative, holistic approach. To overcome the difficulties that had been experienced in convening multi-agency meetings and ensuring a coordinated, collaborative approach, they recommended that someone needed to be named as the keyworker in complex cases.
- 4.6. In their responses to the independent reviewer's question as to why no multi-agency meeting was convened prior to Ben's final hospital admission, there was acknowledgement that such a meeting should have been convened. ESHT reported that a podiatrist had recommended a multi-disciplinary meeting to the GP but by this time Ben had been admitted to hospital. The GP responded that a multi-disciplinary team meeting would have been helpful but unfortunately this could not be facilitated. The GP observed that, in their

experience, setting up such meetings in general and especially in an acute situation was challenging. One agency suggested the development of cross border guidance to help establish clear roles, responsibilities and expectations of how to best support people who are funded by another local authority. Thus, although there is evidence in the records of a degree of liaison between services, information was not triangulated to gain a holistic picture. **Recommendation One:** ESSAB should consider whether policies, procedures, and pathways for convening multi-agency risk management meetings are adequate. ESSAB should also consider what further steps are necessary to embed a culture of services meeting together to coordinate responses in complex and challenging cases.

- 4.7. ESHT, in its submission, notes that since this case there have been practice changes within both the community nursing and podiatry teams. Daily safety huddles offer a forum for staff to address any immediate concerns that they have about patients. Furthermore, team structures have altered to include clinical leads to provide greater oversight. Podiatry teams now participate in weekly multi-disciplinary meetings which comprise in addition to podiatry both diabetologists and vascular specialists. This may help to mitigate a risk that ESHT has also identified, namely how the use of different recording systems can result in information not being shared or accessible.
- 4.8. Ben's placement in East Sussex was commissioned and periodically reviewed by WSCC. It was questioned how familiar services and practitioners were with national guidance on out of authority placements. Given that question and the similarity with the Adult A SAR, those at the learning event felt that Pan-Sussex guidance on out of authority placements would be helpful.
- 4.9. The statutory guidance that accompanies the Care Act 2014¹² has a chapter on cross-border placements. As this guidance is statutory, it has legal force and must be followed unless there are reasons that justify a departure from it. It emphasises reciprocity and cooperation between authorities, the expectations of liaison between the first (placing) authority and second (host) authority, and the importance of clear arrangements for ongoing management of the placement.
- 4.10. ADASS has also issued an advice note on out of area placements¹³. This also emphasises the importance of clear arrangements between the placing and the host authority, the placing authority's responsibility for care and support reviews, and the provision of contact details so that the care provider knows who to speak with in the event of concerns.
- 4.11. ADASS has also issued practice guidance on out of area adult safeguarding arrangements¹⁴. This reinforces the statutory guidance, re-emphasising the roles and responsibilities of both the host and placing authority for Section 42 enquiries and for SARs. **Recommendation Two:** ESSAB should: a) consider conducting an audit to seek assurance that the statutory guidance on out of authority placements is being adhered to by East Sussex Agencies; b) write to Councils, CCGs and Partnership Trusts highlighting the SAR and encourage them to consider the learning points in respect of out of area placements.

¹² Department of Health and Social Care (2018) *Care and Support Statutory Guidance: Issued under the Care Act 2014*. London: The Stationery Office.

¹³ ADASS and LGA (undated) Advice Note for Directors of Adult Social Services: Commissioning Out of Area Care and Support Services.

¹⁴ ADASS (2016) *Out of Area Safeguarding Adults Arrangements*.

- 4.12. Prior to the December 2018 review by WSCC, the last one was conducted on 5th May 2016. Between the two reviews there are 32 case notes recorded on activity on the case, of which 9 relate to direct contact with the home via email or telephone. There is no record of WSCC staff directly seeing Ben between the two reviews or, indeed, subsequently. Nor did WSCC proactively monitor the outcomes of the care and support plan following the December 2018 review. There was, therefore, no quality assurance regarding the outcomes following the additional funding that had been agreed. In early February 2019, the care home requested that WSCC take on appointeeship responsibility for Ben. This request was not allocated until concerns were raised for the purpose of completing the necessary referral to the financial adult safeguarding team. At the time of his death care home staff were continuing to act in their long established role of appointee.
- 4.13. At the learning event it was recognised that resource pressures had meant that statutory responsibilities for annual reviews were not being met. There did not appear to be a failsafe mechanism for identifying high risk and complex cases, which should be prioritised for review, and that practitioners conducting reviews were unlikely to have in-depth knowledge of the case that comes from continuity of involvement. As was observed at the learning event, the seriousness of risks can escalate quickly, for instance when patients have diabetes and are non-compliant with dietary advice and treatment. Care home practitioners and GPs in such situations need a timely outreach response from diabetes specialists to prevent deterioration, and the placing authority needs to respond with robust care planning. As observed at the learning event, where out of authority placements are necessary, risks should be mitigated by robust care planning and clearly named practitioners to contact.
- 4.14. There are two records of ESCC ASC forwarding emergency duty service referrals to WSCC ASC on 13th September and 7th October 2019. Both emails indicate an expectation for WSCC to respond to the concerns. WSCC did not respond and has stated that, for example, it had no prior knowledge of Ben refusing treatment for his diabetes until informed by the care home on 7th October that he required hospital treatment. WSCC hold a case record dated 24th October noting that a best interest meeting had been held a day earlier and that the seriousness of the situation had led to the information being passed to the hospital's legal team for consideration. It appears that Ben's case was not open to an allocated worker but closed pending review. The level of complexity and escalating concern, had it been fully appreciated by the placing/funding authority, should have indicated the need to allocate the case.
- 4.15. The care home in its written responses to the independent reviewer has referred to several occasions when staff felt that WSCC did not respond to concerns that were raised, and to breakdowns in communication. The importance of all commissioners ensuring responsive support for care home providers is, however, a system-wide issue and is not unique to a single local authority. At the learning event, care home staff voiced generic experiences of feeling under pressure to accept referrals and of not receiving the fullest picture possible of a proposed resident in order to determine suitability of placement. They then were unclear "where the buck would stop" and were sometimes left feeling that they had to "beg" for support.
- 4.16. More positively were accounts at the learning event of ASC practitioners attending GP surgeries and multi-disciplinary team meetings, and plans for colocation of community nursing with ASC to enhance joint working. ESHT staff reported work to combine some

recording systems to improve communication and information-sharing. The GP practice had held a multi-disciplinary team meeting after Ben's death to reflect on the lessons to be learned.

Knowledge and practical application of self-neglect procedures

- 4.17. Those attending the learning event felt that greater understanding was needed of self-neglect, including where the adult safeguarding pathway was appropriate because the person was unable to protect themselves¹⁵. A sense of confusion was conveyed, not helped it was said by how statutory guidance highlights that self-neglect may not prompt a Section 42 enquiry, with assessment expected on a case by case basis, and a decision on whether a safeguarding response is required dependent on the adult's ability to protect themselves by controlling their own behaviour without external support.
- 4.18. Statements of involvement, which included chronologies, provided by services at the outset of this review suggested that GPs may not be aware of self-neglect procedures and that self-neglect is included within safeguarding adults. It also emerged that care home staff had not been advised to refer Ben's situation as a safeguarding concern.
- 4.19. After publication of the Adult A SAR, procedures in East Sussex on self-neglect had been revised and promoted, but those attending the learning event still felt that the nuances were not well understood when determining whether an incidence of self-neglect should fall within adult safeguarding.
- 4.20. Those present at the learning event advised that policies and procedures were in place but staffing changes led to incoming practitioners and managers not being fully aware of the frameworks for practice, both in respect of self-neglect but also of out of authority placements.

Understanding and use of the Mental Capacity Act 2005 and Deprivation of Liberty Safeguards

- 4.21. There are only two records of consideration being given to referral to the Court of Protection, since it was proving difficult to treat Ben in his best interests. The first instance arose as part of advice given by emergency duty services to the GP on 12th September, which also recommended liaison with consultants on whether current medical issues were the result of mental disorder. No decision was reached on whether or not to refer. In a written submission the GP has explained that during Ben's acute presentation this was not done, mainly because the aim was clear that he needed treatment. This appears to reflect a misunderstanding since emergency orders can be sought from the Court of Protection. Indeed, SPFT's higher learning review report records the GP as contacting agencies regarding perceived dilemmas in treating Ben and as feeling that insufficient advice was given regarding how to make progress. There are clear parallels here with the findings from the Adult A SAR. As it was Ben was not admitted to hospital for several weeks.
- 4.22. The second occasion occurred whilst Ben was an inpatient. University Hospitals Sussex has advised the independent reviewer that legal advice on the question of amputation was sought. This followed a suggestion from an IMCA that the decision should

¹⁵ Section 42(1) Care Act 2014.

be referred to the Court of Protection. As there was no apparent disagreement that amputation was not in his best interests, referral to the Court of Protection did not appear indicated¹⁶. Further conversations with Ben involving another capacity assessment by a learning disability nurse and a doctor, together with liaison with an IMCA, confirmed the decision not to amputate.

- 4.23. This is the only occasion when legal advice appears to have been sought during the period under review. It has been suggested to the independent reviewer that there is some reluctance to seek emergency orders from the Court of Protection.
- 4.24. This is the only occasion when an IMCA was involved, a referral appropriately made by University Hospitals Sussex. Ben's sister had been consulted with regard to his initial surgery but had not been in touch with him for several years and was not confident to advocate regarding the amputation. Hospital records are detailed with respect to the involvement and contributions of the IMCA. Ben was unable to give a view on whether or not he wanted an amputation. In the past he had often refused medical interventions. On the ward he had been non-compliant with interventions tried. He wished to return to the care home.
- 4.25. Information provided by the care home, for instance at the WSCC placement review in December 2018, indicated that Ben was inclined to refuse to attend meetings with unfamiliar people. He was reluctant to participate in reassessments and reviews. He could also become agitated if he felt unable to communicate his needs. Combined with refusals of some medication and treatment, this suggests missed opportunities to refer Ben for advocacy. WSCC has advised that the practitioner completing the reassessment in December 2018 considered whether Ben lacked capacity to be involved in the reassessment. They felt it was unclear whether he lacked capacity to attend the meeting or whether he chose not to attend. They formed the view that he was likely to lack capacity in making decisions with regard to his care and support, but it is unclear why they did not pursue the need for advocacy further. A view was expressed at the learning event that advocacy was underused. Once again then, there are parallels with findings from the Adult A SAR. **Recommendation Three:** ESSAB should consider seeking assurance about use of advocacy for people who lack capacity in respect of assessments, reviews and safeguarding activity.
- 4.26. An SPFT case note for 27th September from a registered mental health nurse (RMN) states that the care home were attempting to organise a best interest meeting. No meeting was held before Ben's final admission to hospital. SPFT has also advised that, when RMNs visited the care home on 4th October, care staff shared a GP letter from 2017 stating that Ben lacked capacity for health decisions and stated that the GP's view was that he lacked capacity to make health decisions at this time. The mental health practitioners encouraged the care home staff to contact the district nursing team that afternoon and call an ambulance if a medical emergency occurred.
- 4.27. Of note is that SPFT has records of best interest meetings being held previously on 28th February 2018 and 19th October 2018 with regard to Ben's diabetes management, attended by his then GP, care home and SPFT learning disability services. The notes record that Ben did not fully understand his condition and therefore did not have capacity for

¹⁶ In NHS Trust v Y [2018] UKSC 46, the Supreme Court ruled that, unless there is agreement from all parties regarding medical intervention, cases must be referred to the Court of Protection.

decision making around his physical health. Whilst mental capacity assessments must be decision and time specific, these earlier meetings could have laid out the pathway to follow in the event that acting in his best interests proved challenging.

- 4.28. More positively, medical records held by University Hospitals Sussex contain detailed accounts of three best interest meetings held whilst Ben was an inpatient. These meetings were well attended, evaluated the different treatment options, and agreed clear plans.
- 4.29. Care home staff who attended the learning event stated that mental capacity assessments had been requested and a referral to the GP also made regarding deprivation of liberty. Staff were uncertain how far the referral had progressed. Some of those attending the learning event felt that there was a lack of understanding, confidence and experience of using the Mental Capacity Act 2005. GPs, for instance, were perhaps less familiar with the Court of Protection and not aware of the possibility of seeking legal advice via the CCG. It was acknowledged, however, that before the period under review a very experienced GP had convened a best interest meeting.
- 4.30. An example of lack of understanding was given at the learning event. Ben had declined treatment for physical health concerns but had agreed to medication for his mental health. Mental capacity had been assumed as a result of that agreement. It may not have been fully understood by all practitioners involved that capacity assessments are decision and time specific. One conclusion to emerge was that practitioners had assumed capacity too quickly. Another was that records should clearly indicate how capacity was assessed. A third concerned the availability of senior, specialist, and experienced staff to support the process of assessment.
- 4.31. Recommendations from those attending the learning event, given their concerns about lack of knowledge and understanding of the Mental Capacity Act 2005, included training for pre-registration nurses and for trainee doctors, and the inclusion of briefing on the use of the Act in guidance on the responsibilities of placing and host commissioners for out of authority placements. **Recommendation Four:** ESSAB should consider seeking assurance from partners that legal literacy is included in single agency safeguarding training, and commissioning multi-agency training on law relating to mental capacity, mental health and care and support. Where training is provided, outcomes should be evaluated over time to ensure that learning has been consolidated in practice. **Recommendation Five:** ESSAB should share the outcome of the learning from the SAR with the Royal College of General Practitioners, the Royal College of Psychiatrists, the British Medical Association, and the Nursing and Midwifery Council with a view that formative and post-qualifying education and training ensures that candidates have sufficient knowledge and understanding of mental capacity, mental health, care and support and adult safeguarding law.
- 4.32. In the record of the ESSAB SAR sub-group's discussion of the referral there is reference that the registered manager of the care home was advised around December 2018, when WSCC completed a formal review of Ben's placement, to check if deprivation of liberty safeguards should be used. There is no further reference in any of the statements of involvement provided by the agencies involved.
- 4.33. In follow-up responses to a question asked by the independent reviewer, neither WSCC nor the care home could find any reference to a request for, or consideration of

deprivation of liberty safeguards between December 2018 and November 2019. WSCC did locate a deprivation of liberty safeguards referral from the care home manager on 21st February 2017 This was apparently prioritised but was not acted on based upon the priority of the triage. The team contacted the care home and an email on 1st November 2018 from the care home manager described the application as “odd” and not needed. The referral was then closed.

- 4.34. The previous section contrasts with the information provided at the learning event by care home staff that they had requested the GP consider deprivation of liberty. The formal pathway for such a request would have been to the placing authority.
- Recommendation Six:** Given the findings of this review and the Adult A SAR, ESSAB should consider: a) writing to every care home in the County reminding them of their duties and responsibilities in respect of the appropriate use of deprivation of liberty safeguards within those settings; b) conducting an audit of selected cases to ensure that deprivation of liberty safeguards are being used appropriately in care settings.

Interface between Mental Capacity Act 2005 and Mental Health Act 1983

- 4.35. SPFT mental health practitioners were working with Ben around management of the mental illness component of his presentation. As he was compliant with his mental health treatment throughout, SPFT has stated that staff did not have a direct reason for initiating processes around mental capacity/ best interests. SPFT has acknowledged a duty to work proactively with other agencies to safeguard patients from any form of harm, but has concluded that there is evidence that SPFT clinicians gave consistent advice to the care home and GP on how to address Ben's lack of compliance with physical health treatment.
- 4.36. A GP referral to SPFT assessment and treatment service was received on 6th September (Friday). The concerns related to aggression towards the district nurses trying to dress Ben's leg ulcers and lack of compliance with his antibiotics medication. The service is not commissioned to provide a crisis response and is open for office hours Monday-Friday. On 9th September (Monday), a registered mental health nurse (RMN) called the care home to seek information and give advice. On 12th September, the GP called and spoke with another RMN, who sought advice from their team leader. The team leader suggested the GP contact ESCC via emergency duty services (EDS) to discuss how to manage the deterioration in Ben's physical health. ESCC records show that EDS suggested a clear pathway forward that day using the MCA framework to facilitate admission to a general hospital for treatment. A consultant psychiatrist responded by letter on 16th September.
- 4.37. The mental health team visited Ben in the care home on 17th September and 30th September to administer his prescribed medication and used these appointments to review his mental health. There was no noted deterioration of his mental health in this period, and he was compliant with mental health treatment. The mental health team were aware of the ongoing issues around non-compliance with physical health treatment, and reiterated the advice given to the care home and GP by EDS, namely, to proceed with treatment under the Mental Capacity Act 2005. Two RMNs visited Ben in the care home on 4th October following reports of significant deterioration in his mental state two days earlier from the care home and GP. Care home staff reported that Ben was "psychotic" and were of the view that he needed admission to hospital under the Mental Health Act 1983. The mental health practitioners saw no evidence of psychosis and did not feel Ben met the criteria for assessment under the MHA 1983. Their view was that his fluctuation in mood was a result

of his physical health in terms of infection and the pain he was expressing. The mental health practitioners reported their assessment back to the team who agreed an MHA assessment was not indicated. The mental health practitioners updated the consultant psychiatrist and tried to contact GP, who was not available.

- 4.38. SPFT's written response to the independent reviewer correctly observes that consent to treatment is decision and time specific rather than a universal characteristic. It therefore needs to be assessed by the person who is providing/proposing a particular treatment or procedure. The consultant psychiatrist was not therefore best placed to make arrangements for matters related to physical health interventions and provided advice to the GP as requested.
- 4.39. There are clear parallels between this sequence and the findings of the Adult A SAR, namely discussions between GPs and consultant psychiatrists about how to secure physical healthcare treatment for a patient without decisional capacity, and how to support GPs to act on the advice given. Advice that had been given over several weeks had not been acted upon. That might have suggested that a whole system response was needed to construct a risk management/mitigation plan. As it was, secondary services appear to have been working in silos, focusing just on their discrete contribution to Ben's co-occurring healthcare needs.
- 4.40. Those attending the learning event believed that some practitioners lacked understanding and confidence about the requirements of, and duties within the Mental Health Act 1983, and the scope of treatment that was permitted when a person was detained under section. Equally, there was a lack of clarity about how the two pieces of legislation linked together, and which Act it was appropriate to use when. In that context, it was acknowledged that the day before Ben's final hospital admission, the GP had spent three hours on the telephone seeking advice and support.
- 4.41. Community psychiatric nurses did visit Ben to administer medication to manage his mental health, but concern was expressed at the learning event as to whether they had time to complete or review assessments of his mental wellbeing.
- 4.42. Recommendations from those attending the learning event included provision in medical education and pre-registration nurse training on mental health legislation, the inclusion of mental health practitioners in primary care multi-disciplinary team meetings, and the use of case studies in multi-agency training locally.

Responding to non-engagement

- 4.43. Those attending the learning event concluded that Ben's non-compliance with components of his care and support, and treatment, could have been escalated more often than it was. However, referral pathways were not necessarily well known, leading to recommendations for a briefing that would outline what action was expected when an individual was not engaging and at risk of self-neglect, and a directory of contacts.
- 4.44. The spectre of financial austerity entered here, with recognition of the challenges of maintaining a person-centred approach when resources were "so stretched." However, there were other obstacles to sound referral practice. One was felt to be the absence of a "no wrong door" culture between services, meaning the absence of a holistic view of the

seriousness of Ben's situation. A second was uncertainty about what information might be needed and concern about the absence of a shared language between practitioners and services, making it difficult to convey the seriousness of the risks involved and what was felt to be needed. A third was a concern about the robustness of risk assessment and contingency planning when endeavouring to find the least restrictive alternative for Ben. A fourth resided in different recording systems, which meant that there was no clear process for providing a joint alert, for triggering concerns simultaneously to all partner agencies.

- 4.45. One conclusion to emerge from the learning event was a felt need for a culture of "joining up" when one service required the input from other agencies, for example to facilitate a comprehensive assessment. Another conclusion was the need for accessible advice and support for practitioners, including GPs and care home staff, from safeguarding specialists, who could assist in taking concerns forward. Currently, the pattern of available support, for instance in GP surgeries, was inconsistent.

Understanding and use of Section 42 Care Act 2014

- 4.46. One concern to emerge at the learning event was expressed by care home staff, namely that they were deterred from referring adult safeguarding concerns because of the fear that this might reflect negatively on the provider. However, in Ben's case, several other concerns also were expressed, particularly by care home practitioners and managers.
- 4.47. The first was that they were not advised to raise a safeguarding referral, for example when alerting WSCC to their concerns about Ben's deteriorating mental and/or physical health. The second reflected "the endless emails" that the care home sent, causing doubt about what a safeguarding referral would add, especially when community psychiatric nurses, a psychiatrist and a GP were also involved.
- 4.48. Additionally, care home staff were also concerned that an adult safeguarding referral would be perceived and interpreted by others involved as the care home saying that they were not being helpful. What care home staff wanted to communicate was how bad they thought the situation had become and feeling that other services did not fully appreciate or recognise this. It emerged that GPs may have felt this also and not recognised the need for, and importance of referring an adult safeguarding concern. Had a referral been made, it might have prompted greater coordination.
- 4.49. Finally, it was observed at the learning event that, when a safeguarding referral was made after Ben's final admission to hospital, the rationale for this not being taken forward as an enquiry was not shared with the referrer. This meant that the decision could not be challenged. This was seen by some participants as a systemic issue, Section 42 referrals being declined without reasons being given, resulting in a lack of escalation.
- 4.50. Indeed, the hospital had raised the safeguarding concern on 22nd October 2019 in relation to neglect/acts of omission, expressing concern at Ben's presentation on arrival from the care home. This raised the prospect of risk to other residents. An ASC case note for 11th February 2020 records that, since this safeguarding referral concerned neglect, risks to other adults needed to be considered. It further recorded that this would be considered as part of a "serious case review" (sic) to identify the learning from this case and how services could work together in future to reduce the risk of such incidents occurring in the

future. This decision is questionable. The onus was on ASC to establish whether or not there were risks to other residents.

- 4.51. WSCC has confirmed that the case of the one other resident at the care home for which it was the responsible placing authority was reviewed and the individual remained in the placement.
- 4.52. More positively, at the learning event were reports of improved cohesive working between ASC and health services, based on agenda prompts and guidance, to ensure that all agencies were involved and meeting minutes routinely shared. Contact with GPs had improved but challenges remained – timing of meetings to facilitate their attendance and assumptions that they would not attend.
- 4.53. Agency responses to the independent reviewer have also reflected on the question why adult safeguarding concerns were not referred earlier than Ben’s final hospital admission. WSCC would expect the provider to contact the funding authority or raise a safeguarding concern with the host authority at the earliest opportunity. WSCC agreed that closer working arrangements through multi-agency meetings might have improved joint working and communication of the concerns. ESCC ASC, however, found no activity on the case record from 14th September to 3rd October in the period leading up to admission to hospital. It appears the ASC response to the GP’s referral on 12th September was focused on mental health and mental capacity. The concerns raised by the GP were referred to WSCC ASC the following day with the expectation that WSCC would respond. No safeguarding enquiry was started at the same time indicating it was not considered. This appears to reinforce the conclusion above that placing and host authorities must agree on roles and responsibilities and ensure that care providers are aware of the pathways to follow.
- 4.54. ESHT staff appeared to have viewed Ben in the context of his physical health and the interventions that were being provided as a result; it is possible that this was as a result of him being within a care setting. The GP reflected, drawing on subsequent experience, that referral of an adult safeguarding concern could have been done sooner by anyone involved in this case. Care home staff, as an outcome of their involvement in this review, have recognised the need for increased knowledge of safeguarding pathways and confidence in pressing for a safeguarding response. Once again there are clear parallels with findings and conclusions in the Adult A SAR, suggesting that concerns surrounding understanding and use of Section 42 might be a systemic issue.
- 4.55. Of significance here is SPFT’s records for 3rd March 2017. The notes describe a discussion of a potential safeguarding referral between SPFT’s mental health services, learning disability services, adult social care, and the care home. This was following several incidents when paramedics attended to Ben. An attached document indicates the safeguarding referral was not subsequently taken forward as it was not felt to meet thresholds. Ben at this time was described as generally compliant with his diabetes medication, but not with physical health observations. Best interest meetings were subsequently held in 2018 to address management of his diabetes.

Understanding of the SAR process

- 4.56. Ben died in November 2019, but the SAR referral was sent in February 2021. The delay occurred because the referrer had been trying to establish information from the local

authority to confirm whether the Section 42 enquiry process, commenced in October 2019, had been concluded and what the outcomes of that investigation were, particularly around receiving assurance on how the actions agreed at the safeguarding planning meeting held in December 2019 had been taken forward. The SAR referrer understood that a recommendation had been made for a SAR and had been in contact with senior mental health service managers over many months to seek clarity as to whether another statutory review was planned.

4.57. A decision is documented in the local authority's adult social care records confirming that the safeguarding enquiry would be closed as an active safeguarding plan was no longer required since Ben had died. It was recorded¹⁷ that the follow up actions from the safeguarding planning meeting would be looked at as part of a Serious Case Review. However, no referral for a SAR was made by ASC and the SAB then became aware of the case on receipt of the referral from the LeDeR programme lead on 24th February 2021.

4.58. At the learning event it was noted that ESSAB had never received a SAR referral where a person had survived significant harm in a context of concerns about how services had worked together to prevent and/or protect an individual from abuse/neglect.
Recommendation Seven: ESSAB should consider the need to raise awareness of timely SAR referrals and of the mandate for reviews in Section 44 Care Act 2014.

4.59. At the learning event there was positive appreciation of learning briefings from completed SARs and accounts of how they had been used. Also referenced was learning from the Adult A SAR being embedded in multi-agency training and safeguarding supervision. Other methods of disseminating SAR findings were also suggested, such as blogs. It was also recognised that useful learning and assurance could be gained from briefings about cases where services had worked well together to prevent and protect individuals from abuse/neglect, including self-neglect.

¹⁷ Case notes for 11th February 2020.

5. Concluding discussion

- 5.1. At the learning event it was suggested that the cases of Adult A and Ben raised familiar issues and demonstrated how quickly longstanding needs could become acute risks. It was suggested that similar cases were more common than agencies might think. Accordingly, participants hoped that the learning would be disseminated widely to enhance case management in future. Cross-border cooperation with this review has been commendable. There was similar good cross-border collaboration for the Adult A SAR. The groundwork has been laid to take forward the recommendations at least regionally. **Recommendation Eight:** ESSAB should share the outcome and learning from the SAR with the other SABs in the region (and beyond) so that they can compare and contrast practice and service responses to individuals in placements with similar needs.
- 5.2. It was also suggested that ESSAB should disseminate learning from out of authority placements, and from cases involving multiple and complex physical and mental health needs, where practice outcomes had been positive, and services had worked well together. **Recommendation Nine:** ESSAB should consider multi-agency audits of practice as a prelude to disseminating the lessons to be learned from positive practice outcomes.
- 5.3. One feature in the Adult A SAR was the shortage of available placements. The care home that accepted Adult A from hospital was the only placement available when he was medically fit for discharge. Neither he nor the person who held lasting power of attorney wanted that placement to proceed and the SAR identified practice shortcomings with respect to decision-making about the out of authority placement and subsequent support for care home staff.
- 5.4. Whilst Ben's out of authority placement was different in one sense, since he had been a longstanding and settled resident, those at this learning event once again heard evidence about the shortage of placements for individuals with multiple and complex needs, which could result in care homes not receiving all available information in order to determine suitability. Care home practitioners and managers also questioned the support being given to enable them to manage individuals with multiple and complex needs, and challenging behaviours. Both Adult A and Ben had complex physical and mental health needs. Ben also had been diagnosed as having a learning disability and being on the autistic spectrum. Finding appropriate placements for individuals with such co-occurring conditions is a system-wide challenge. Similarly, system-wide is the challenge of ensuring that practitioners have the required knowledge and skills to provide the best care and treatment possible. **Recommendation Ten:** ESSAB should consider recommending that a summit of commissioners and providers is convened to review gaps in placement and staff training provision, and decision-making on placements and staff support.
- 5.5. Ben does not appear to have been registered at the GP practice as a patient with learning disabilities. The independent reviewer has been advised that the reason for this is unclear. The surgery has reviewed its coding system and undertaken searches to identify more adults with mental health issues who also might have a diagnosis of learning disability. A few more patients with learning disability had been identified who have benefited from learning disability yearly reviews during the pandemic.
- 5.6. Some discussion at the learning event focused on annual health checks by GPs of patients with learning disabilities. Concerns were expressed that workloads restricted the time available for reviews, where robustness was required especially for patients who were

ageing and who also presented with physical and mental health concerns. Improving standards, and the focus on prevention, is the aim of the quality assessment framework.

Recommendation Eleven: ESSAB should consider requesting assurance from the NHS as commissioners of the service that processes are in place to monitor and manage the outcomes of annual health checks.

- 5.7. Ben was initially admitted to ESHT, whose records held a learning disability passport for Ben. However, the days he was in the acute wards at ESHT were a weekend and some services such as the learning disability nurse would not have been available. He was then transferred to University Hospitals Sussex, where he was reviewed by a learning disability liaison nurse, although transfer notes from ESHT had not explicitly communicated the need for a referral. The learning disability liaison team do not work weekends but response to the referral met the hospital's target. Ben was reviewed regularly by learning disability liaison nurses following this.
- 5.8. Some agencies, for example ESHT, have reported improvements in the safeguarding training offered to their staff. Services have also advised that provision of training is complicated by operational demands, and by staff sickness and turnover. **Recommendation Twelve:** ESSAB should consider seeking assurance from individual agencies on the outcomes of their monitoring of the provision of training provided for staff, and the implications for the need for multi-agency training, in response to the findings of this review and the Adult A SAR.
- 5.9. ESSAB's SAR sub-group, when discussing the original referral, observed that there appeared to be shortfalls in a coordinated multi-agency response, missed opportunities for early intervention, and lack of knowledge about self-neglect and adult safeguarding. Responsibilities regarding out of area placements appeared unclear and there were further lessons to be learned regarding understanding and use of mental capacity legislation, and the importance of robust assessments and responses to risk. There are clear parallels here to the conclusions of the Adult A SAR.
- 5.10. SPFT's higher learning review report identified five practice shortfalls, namely:
- 5.10.1. Exchanges between the GP and consultant psychiatrist were not fully recorded in patient notes, potentially compromising communication and continuity of care;
 - 5.10.2. Summaries of fortnightly monitoring by community psychiatric nurses were limited and there was little evidence of holistic review to include Ben's physical health care needs and treatment alongside his mental health;
 - 5.10.3. Risk assessment did not include the risks arising from his physical health needs and their impact;
 - 5.10.4. Ben's care plan did not include physical health;
 - 5.10.5. Delays in hospital admission impacted on prognosis.
- 5.11. SPFT's higher learning review report made recommendations for mandatory training on mental health, mental capacity, and deprivation of liberty law; recording in patient notes of email communications; monitoring of physical health when monitoring a patient's mental health, with registered general nurses supporting mental health practitioners; and improving the use of care plans and multi-agency risk management meetings.
- 5.12. This review endorses these findings and recommendations.

The impact of COVID-19

- 5.13. Ben died before the onset of the pandemic. However, those attending the learning event referred to its impact on staff shortages, recruitment, training, use of agency staff and routine checks of placements. Also reported was an increasing number of cases where legal advice was being sought. Work with GPs on capacity assessments for decision-making about vaccine administration had been undertaken, which had raised awareness about referral pathways and use of the Court of Protection. **Recommendation Thirteen:** Lack of knowledge regarding, and referrals to the Court of Protection, were identified in the Adult A SAR and this review has reported similar findings. ESSAB should consider how to raise awareness of the role of the Court of Protection across health and social care services, and also of pathways to obtain legal advice regarding complex cases. Where different services seek legal advice independently on the same case, EESAB should seek assurance that services coordinate subsequent decision-making through multi-agency risk management or complex case meetings.
- 5.14. Whilst remote working had made it easier to convene and attend multi-agency meetings, in other respects it had interrupted joint working. For individuals like Ben the pandemic had disrupted established and familiar routines.

6. Recommendations

Recommendation One: ESSAB should consider whether policies, procedures, and pathways for convening multi-agency risk management meetings are adequate. ESSAB should also consider what further steps are necessary to embed a culture of services meeting together to coordinate responses in complex and challenging cases.

Recommendation Two: ESSAB should: a) consider conducting an audit to seek assurance that the statutory guidance on out of authority placements is being adhered to by East Sussex Agencies; b) write to Councils, CCGs and Partnership Trusts highlighting the SAR and encourage them to consider the learning points in respect of out of area placements.

Recommendation Three: ESSAB should consider seeking assurance about use of advocacy for people who lack capacity in respect of assessments, reviews, and safeguarding activity.

Recommendation Four: ESSAB should consider seeking assurance from partners that legal literacy is included in single agency safeguarding training, and commissioning multi-agency training on law relating to mental capacity, mental health and care and support. Where training is provided, outcomes should be evaluated over time to ensure that learning has been consolidated in practice.

Recommendation Five: ESSAB should share the outcome of the learning from the SAR with the Royal College of General Practitioners, the Royal College of Psychiatrists, the British Medical Association, and the Nursing and Midwifery Council with a view that formative and post-qualifying education and training ensures that candidates have sufficient knowledge and understanding of mental capacity, mental health, care and support and adult safeguarding law.

Recommendation Six: Given the findings of this review and the Adult A SAR, ESSAB should consider: a) writing to every care home in the County reminding them of their duties and responsibilities in respect of the appropriate use of deprivation of liberty safeguards within those settings; b) conducting an audit of selected cases to ensure that deprivation of liberty safeguards are being used appropriately in care settings.

Recommendation Seven: ESSAB should consider the need to raise awareness of timely SAR referrals and of the mandate for reviews in Section 44 Care Act 2014.

Recommendation Eight: ESSAB should share the outcome and learning from the SAR with the other SABs in the region (and beyond) so that they can compare and contrast practice and service responses to individuals in placements with similar needs.

Recommendation Nine: ESSAB should consider multi-agency audits of practice as a prelude to disseminating the lessons to be learned from positive practice outcomes.

Recommendation Ten: ESSAB should consider recommending that a summit of commissioners and providers is convened to review gaps in placement and staff training provision, and decision-making on placements and staff support.

Recommendation Eleven: ESSAB should consider requesting assurance from the NHS as commissioners of the service that processes are in place to monitor and manage the outcomes of annual health checks.

Recommendation Twelve: ESSAB should consider seeking assurance from individual agencies on the outcomes of their monitoring of the provision of training provided for staff, and the implications for the need for multi-agency training, in response to the findings of this review and the Adult A SAR.

Recommendation Thirteen: Lack of knowledge regarding, and referrals to the Court of Protection, were identified in the Adult A SAR and this review has reported similar findings. ESSAB should consider how to raise awareness of the role of the Court of Protection across health and social care services, and also of pathways to obtain legal advice regarding complex cases. Where different services seek legal advice independently on the same case, EESAB should seek assurance that services coordinate subsequent decision-making through multi-agency risk management or complex case meetings.