Norfolk Safeguarding Adults Board

Safeguarding Adults Review:

Adult R

8 April 2024

FINAL REPORT

Suzy Braye
Independent adult safeguarding consultant
Emerita Professor of Social Work
s.braye@sussex.ac.uk

Nadean Marsh
Designated Nurse Safeguarding Adults BLMK ICB
RN BSc (HoNs) MSc
Nadean.marsh1@nhs.net

1. INTRODUCTION

1.1. Adult R, aged 82, died in Queen Elizabeth Hospital on 24th August 2021. Three months previously she had been hospitalised after experiencing a stroke that left her unable to care for herself. Prior to her stroke she had led a relatively independent life. She lived alone but enjoyed going out, walking her dog, meeting her friends and neighbours and keeping contact with her son and stepdaughter. She had not been receiving anything other than primary healthcare services. Sadly, her son had died three weeks prior to her stroke.

1.2. Both her bereavement and her subsequent stroke brought significant changes to her mood and to how she lived. Following a period of in-patient care and rehabilitation, she was discharged home, in line with her wishes, and received support from a range of agencies providing medical and nursing care, social care support and, on occasion, emergency responses to her needs. She experienced a further acute episode (a transient ischaemic attack), which necessitated a second, shorter, hospital stay, following which she again returned home.

1.3. Although some items of equipment had been provided to assist her in living at home and to enable the care workers to safely move her, she was largely confined to her bed. During her periods both in hospital and at home, her skin integrity deteriorated, and she developed pressure ulcers, becoming very unwell before the final admission that preceded her death. At her inquest the coroner concluded that she died of natural causes: sepsis and an infected sacral ulcer in the context of severe coronary artery atherosclerosis.

2. THE SAFEGUARDING ADULT REVIEW PROCESS

2.1. On 18th September 2021 Manorcourt Homecare, the agency commissioned to provide care and support to Adult R, submitted a safeguarding adult review (SAR) referral to the Norfolk Safeguarding Adults Board (SAB). The Board has a statutory duty (section 44 (1-3), Care Act 2014) to carry out a SAR when an adult with care and support needs has died as a result of abuse or neglect and there is reasonable cause for concern about how the SAB, its members or others worked together to safeguard the individual. The SAB sought information from agencies involved with Adult R and on 29th March 2022 concluded that the criteria for a mandatory SAR were met. Capacity in the SAB business team along with a national shortage in the availability of appropriately skilled lead reviewers led to a delayed start for the review, but in March 2023 the SAB appointed a suitably qualified independent lead reviewer[1]. Due to the focus on pressure ulcer care, a second reviewer with specialist knowledge in this field[2] was appointed to work alongside the lead reviewer.

[1] Suzy Braye, Emerita Professor of Social Work at the University of Sussex, is an independent adult safeguarding consultant. She has an MSc in Public Sector Management and has received an OBE for her contribution to the adult safeguarding field. She is an experienced SAR reviewer and works with SABs to ensure the resultant learning can inform improvement in safeguarding practice.

[2] Nadean Marsh, Designated Nurse Safeguarding Adults with Bedfordshire, Luton and Milton Keynes ICB, is a registered adult nurse experienced in working at senior level in an acute trust. She has an MSc in Patient Safety and Quality Improvement (University of Northampton).

2.2. The key lines of enquiry for the SAR were to explore:

- How well Adult R's needs were met;
- How well her views and wishes were respected;
- How well risks were identified and managed;
- How well her pressure ulcers were managed;
- How care quality was assured;
- Whether service structures or organisational features impacted on her care;
- How well agencies worked together to meet her needs and keep her safe.

2.3. The period under review was the eight-months between January and August 2021.

2.4. The independent reviewers worked with a Panel comprising senior representatives of the agencies involved in supporting Adult R.

2.5. In terms of parallel processes, an inquest was completed before the SAR started, with the coroner's verdict of death by natural causes available to the SAR.
In addition, Norfolk County Council provided a report from an enquiry under section 42, Care Act 2014, carried out by a Safeguarding Adult Practice Consultant and dated 20th December 2021.

3. THE REVIEW METHODOLOGY

3.1. Agencies initially submitted a chronology of their involvement with Adult R, providing detail on their contacts with her. Subsequently each agency submitted an internal management report (IMR) addressing specific questions from the reviewers. These comprised both general questions related to the key lines of enquiry and specific questions on individual agencies' actions.

3.2. The following agencies provided information.

Agency	Information
East of England Ambulance NHS Trust (EEAST)	EEAST attended Adult R on five occasions during the period under review. She was conveyed to hospital on three of those occasions and, on the remaining two, ambulance crew liaised with primary/community healthcare providers about her condition.
Howdale Surgery (GP)	The practice is situated in the NHS West Norfolk Integrated Care Board area and has a General Medical Services contract with the NHS. The surgery has an above average number of patients aged 65 and over, while income deprivation affecting older people is below average. Adult R had been registered as a patient since 2001 and since 2002 the surgery had monitored her for high blood pressure. During the period under review, they provided medication prescriptions and responded to healthcare needs notified by Adult R's care workers and by the ambulance service.

Agency	Information
Manorcourt Homecare	Manorcourt Homecare is a domiciliary care provider with multiple branches covering Norfolk, Suffolk and Essex. The company provided domiciliary care and support to Adult R, two care workers making 4 visits per day, 7 days per week. Manorcourt raised a safeguarding referral about the pressure ulcer care provided to Adult R and made the SAR referral following her death.
Norfolk County Council Adult Social Care (ASC)	ASC provides assessments under the Care Act 2014 to support people with eligible needs to access the appropriate care and support. ASC carried out a Care Act assessment of Adult R's care and support needs and commissioned the care and support she needed once discharged home.
Norfolk Community Health and Care NHS Trust (NCHC)	NCHC provides community-based NHS health and care across Norfolk: inpatient rehabilitation units, specialist palliative care, services for children, young people and families, therapies, community nursing and a range of outpatient services. The Trust is divided into 4 Places based on geography, each having their own management structure. Adult R was being cared for by the Community Nursing Team in West Place. The team provided follow- up pressure ulcer care to Adult R following her discharges from hospital, initially twice a week with visits later increased to three times a week.
Norfolk Police	During Adult R's initial hospitalisation, a safeguarding concern was raised about the care she received from a Health Care Assistant on the ward. The matter was addressed by the hospital at the time. The safeguarding referral was triaged in September 2021, after Adult R's death, with the conclusion that any action by the HCA was unlikely to have caused Adult R's skin deterioration.
Queen Elizabeth Hospital NHS Trust (QEH)	QEH is an acute hospital serving communities of West Norfolk, South Lincolnshire, and East (Fenland) Cambridgeshire. Adult R was an in- patient at QEH between 8th May and 8th July 2021, following her stroke, and between 28th July and 5th August following her TIA. Her final admission was on 22nd August; she died in hospital two days later.

3.3. Following preliminary analysis of the information received, all agencies were invited to attend an online learning event. Here the reviewers first presented the emergent learning from Adult R's case. SAR panel members then facilitated small group discussions that sought participants' views on the challenges now, two years on, of providing safe care at home to individuals in circumstances like Adult R's. Further small group discussions considered what changes would enable those challenges to be overcome.

3.4. Adult R's stepdaughter and her neighbour were informed about the review and invited to participate. They provided valuable background information about Adult R herself and shared their views on her needs and the support she had received. This information has been used at various points in this report.

3.5. The reviewers wish to express thanks to all who contributed to the review: Adult R's family and friends, the staff within agencies who provided chronological information and IMR reports, participants in the learning event and the members and chair of the SAR panel, who provided an important forum for discussion and accountability, as well as assisting with facilitation of the learning event. They are also grateful for the support of the SAB business manager and executive support assistant in steering the SAR process through all the necessary steps. The levels of openness to reflection and learning that were shown by all involved has enabled important priorities for improvement to emerge from the review.

4. ADULT R'S STORY: A CHRONOLOGY OF SIGNIFICANT EVENTS

4.1. Adult R had had lived in her home for over 20 years, having moved there when her partner died. She and her stepdaughter, who lived some distance away, kept in touch regularly by phone. She made friends easily, was very sociable and had several friends locally, including a neighbour whom she saw every day. She was very keen on keeping fit and eating healthily and walked her dog every day, enjoying the social side of this. Her stepdaughter describes her as a happy person.

4.2. On **8th May 2021** Norfolk Police, having been alerted by a neighbour, found Adult R on her bathroom floor. She was conveyed to QEH by ambulance having experienced a suspected cerebrovascular accident. The Stroke Team diagnosed an ischaemic stroke affecting the right hemisphere with consequent hemiparesis. She was admitted to the acute medical unit and transferred to the stroke unit the following day.
All pressure areas were intact, but risk of skin breakdown was identified and an Anjo air mattress was provided.

4.3. While in the stroke unit she received multidisciplinary support: medical, nursing, therapeutic (physiotherapy, occupational therapy, and speech/language therapy) and dietary interventions. It became known that her son had died just 3 weeks before her admission. She was observed to be low in mood and agreed to clinical psychology support. She had variable insight into how the stroke had affected her – at times recognising its impact and at others struggling to understand that she may not regain her mobility. She indicated she had felt very lonely and anxious since her son's death. Adult R's stepdaughter informed the review that her son's death was unexpected and that it had taken Adult R some time to acknowledge the loss. Her stepdaughter wonders if her absence of overt reaction contributed to her stroke only 3 weeks later.

4.4. Adult R remained in hospital for some weeks and, as time progressed, she developed a blister on her heel, assessed by a tissue viability nurse as a friction blister.

4.5. In discharge discussions, Adult R consistently indicated her desire to return home. She understood that she would not be able to move between bed and chair other than when assisted by care workers and that it was probable her dog would not be able to return to her. Cognitive assessment showed some deficits in attention, memory, number and praxis areas. She complained of pain on her left side, and a mood screen was positive. Her mental capacity was not thought to be in doubt.

4.6. On **2nd June 2021** the hospital therapy team made an environmental visit to her home to scope the equipment needed (hospital bed and mattress, hoist, slings, slide sheets, bedpan, keysafe and wheelchair). The occupational therapist ordered a Gantry Hoist, wheeled commode, slide sheets, 4 slings, upper limb splint, airflow, hospital bed and pressure relieving mattress. The physiotherapist sent a Community Response Team referral to Adult Social Care (ASC) indicating that Adult R was hoist dependent, unable to stand and incontinent, and required full assistance with all personal care. Pressure-relieving equipment would be required. ASC had no prior knowledge of Adult R.

4.7. Adult R was discharged on the Discharge To Assess pathway[3]. The original request was for 24-hour care, but this was rejected as her needs were not thought to meet Continuing Health Care criteria. The options available were a 4-times a day package of care or a residential placement. Adult R declined the latter and the hospital submitted a revised referral for 4- times a day double-up care at home. It was confirmed that the QEH community stroke team would be involved with Adult R on discharge and her care package would be provided by Manorcourt Homecare. The occupational therapist completed manual handling guidelines and a copy was provided for the care workers, with instructions on using the slings.

4.8. Adult R's discharge from hospital was delayed because equipment services were unable to install a ceiling gantry hoist, therefore a mobile hoist was needed. During this period a safeguarding concern arose about care offered by a healthcare assistant on the ward during one shift. This related to Adult R not being given a choice of positioning and made to lie flat in bed, being denied drinks on request, and her call bell being placed out of reach. The hospital itself immediately investigated the healthcare assistant's behaviour[4].

4.9. On **8th July 2023** Adult R was discharged home. She required assistance with personal hygiene, meals, and fluids. She was incontinent of urine and wore a pad and pants. She required a hoist to transfer to a wheelchair, which accompanied her on discharge. She had a healing category 2 pressure area to her left heel, with dry, thick, yellow skin to the back of the heel and a community nursing referral for pressure ulcer care was made to NCHC.

[3] This pathway applies where people who are clinically optimised and do not require an acute hospital bed are provided with short term funding support to be discharged to their own home or another community setting, pending further assessment of their longer-term care needs.

[4] The safeguarding concern was not triaged in MASH until 9 September 2021 (after Adult R's death). At that point, in discussion with Adult Social Care, the Police concluded it was unlikely that the allegations would have caused Adult R's skin integrity to be affected and therefore were not linked to the cause of her death.

4.10. Manorcourt Homecare completed an assessment of her care requirements and took note of her category 2 pressure ulcer. Care would include full assistance with personal care, medication administration, application of creams, and meal and drink preparation. Adult R was fully involved in how her support package would be provided.

4.11. The GP surgery received a discharge summary indicating that Adult R had been medically optimized and discharged and noting that ongoing support was needed. This would include physiotherapy for hemiparesis, occupational therapy and dietician input, and medical treatment for recurrent urinary tract infections, mouth care and constipation. The discharge notes also included the reduced strength and sensation in her left arm, pain if poorly positioned, left leg weakness, and reduced sensation. She had deficits in attention in all areas, writing and imitation. She required hoisting with the assistance of two people, help with washing, dressing, and grooming, and was unable to use stairs. She was described as having been fully mobile prior to her stroke and was noted to have been very low in mood during her hospital stay due to both the stroke and the loss of her son a few weeks before admission.

4.12. The day after her discharge the community stroke team visited Adult R. They noted she would like to be independent but lacked insight into the limitations she faced. Manual handling guidelines were left on the carers' paperwork and the hoist prescription was left on top of the hoist slings. Instructions were left for the carers to fit her hand sling for several hours per day and that she was not to sit out in a chair for long periods during the day due to fatigue and pressure areas. The hoist was not yet in place as furniture needed to be moved. The occupational therapist would work on a plan for an Oxford midi floor hoist and a ross return 7500 for the community team to use for rehab.

4.13. By **10th July 2021** Manorcourt carers had become concerned about the pressure ulcer on Adult R's heel and a sore area on her sacrum and requested a visit from community nursing. The NCHC triage nurse tried to contact the care worker to obtain further information but was unable to make contact and was unwilling to leave a message on an unidentified answer machine. The following day, Manorcourt reported to NCHC that Adult R had spilled hot tea on herself the previous day and now had blisters on her right upper arm and chest.

4.14. On **12th July 2021** a community registered nurse completed a holistic SSKIN review[5], identifying that Adult R required support with repositioning due to weakness and pain in her left side. Her appetite and fluid intake were noted as normal; the Malnutrition Universal Screening Tool was completed. Her Waterlow pressure risk score was 29. A profiling bed and dynamic mattress (premier 2) were already insitu, but she would require repose boots and a wedge. She also had episodes of incontinence, managed with pads. The scald to her left forearm was dressed.
Two pressure areas were identified.

[5] S = surface; S = skin inspection; K = keep moving; I = incontinence; N = nutrition

a) A suspected deep tissue injury to the left heel: the skin was noted to be dehydrated but with no signs of infection and was assessed to not require a dressing at this time;
b) A category 1 pressure ulcer to the sacrum: this was assessed as not requiring a dressing.

The same day Adult R was seen by the stroke team physiotherapist and occupational therapist at home. The furniture had been removed to make room for the hoist, but Adult R was unhappy as she could not see out of the window. She seemed low in mood, anxious and upset that she could not do more and was experiencing pain. The therapists reviewed her mobility and balance, but her pain prevented the placing of the resting splint on her left hand. They moved the bed so that she could see out of the window.

4.15. Between **13th and 22nd July 2021**, community nurses undertook three visits (15th, 19th and 22nd July). Adult R's sacrum was reported as red but without sign of infection. Her right heel remained intact. The left heel was identified as having a static suspected deep tissue injury. Repose wedge and boots were put in place. Community nursing staff relied on Manorcourt staff being present to assist with moving Adult R so that her pressure wounds could be reviewed but visits were not always synchronised to allow this.

4.16. Manorcourt and NCHC liaised about Adult R's skin integrity and continence pads. On some occasions, NCHC could not reach the care worker who reported concerns so nursing triage of concerns could not be completed.

4.17. Adult R's stepdaughter raised concerns with ASC that Adult R was not being moved sufficiently. ASC discussed this with Manorcourt, who indicated they were awaiting the moving and handling plan from the hospital. The carers were currently not allowed to hoist Adult R into her chair due to the length of times between calls. They had been advised to leave her in bed between calls as the intervening periods were too long to leave her out of bed when she had no suitable chair to sit in and no continence products were provided. The stroke team were ordering a tilting armchair due to her frail skin integrity. The care agency requested extra time with Adult R; this was agreed and added to the care package. ASC subsequently asked the hospital physiotherapist to follow up with Manorcourt on any changes to Adult R's treatment.

4.18. On **22nd July 2021** an ASC practitioner carried out a Care Act assessment[6] with Adult R by telephone. Adult R was full of praise for the care workers. From 25th July care was increased: morning visit 60 mins, lunch 45 mins, tea 30 mins and evening 30 mins - all double up care. In addition, 3 hours flexi time every 4 weeks were allocated to support shopping and medication collection.

[6] Under section 9 of the Care Act 2014, the local authority must carry out an assessment where it appears an individual may have needs for care and support

4.19. On **25th July 2021** the care workers reported to the GP that Adult R was experiencing generalised pain without her morphine, which had been stopped. The GP reassured them that the medication was awaiting collection from the chemist. A urinary tract infection was also suspected. The same day Manorcourt raised concerns with community nursing about Adult R's sacrum dressing, which had fallen off; the wound was leaking and bleeding. The triage nurse attempted to contact the care agency to discuss but again was unable to make contact. Community nursing visited and Waterlow assessment gave a score of 26. The care workers were noted to be repositioning Adult R and were given a repositioning chart to support how they documented this. Category 2 pressure ulcers were noted to the left and right buttocks, both 30 mm x 30 mm in size. The areas were cleaned and dressed. The surrounding skin was noted to be fragile but there were no signs of infection. The deep tissue injury to the left heel was noted to have necrotic black skin peeling away but no signs of infection and Adult R reported no pain. The wound was redressed and a Datix incident report was completed for the category 2 pressure ulcers to the sacrum.

4.20. The same day ASC queried with the stroke team whether Adult R still required the large care package. The stroke team advised that she remained under active stroke rehabilitation, but that little progression was likely – the care package would be required long-term. Pain was a barrier to progression and Adult R was reported by the therapist to be low in mood. There was a hoist in situ but it not being used at the time as suitable seating for her to be hoisted to had not arrived.

4.21. The stroke team occupational therapist made a home visit. The care workers reported that Adult R was confused, had a urine infection, and had not had her usual morphine as it has only been prescribed short term by QEH, although they were in contact with the GP for review of medication. The carers also requested a toileting sling and were advised that existing equipment could be used but the community team could provide alternatives. Adult R said she was feeling low and felt as if she had been taken somewhere else that wasn't her house. The target date for delivery of her new seating was 28th July – in the meantime she was to sit out in her wheelchair as far as she was able.

4.22. On **27th July 2021** Manorcourt care workers rang NHS 111. Adult R was complaining of pain in her right hand and was more sleepy than usual; she had cold fingers and the care worker was worried about morphine overdose. NHS 111 visited and checked Toxbase; Adult R was found not to be in the toxic range, but the care workers were advised to hold off Oramorph until she was seen by her own GP.

4.23. The GP reviewed the medication and found a recording error had occurred when the morphine prescription was transferred from the hospital discharge record onto the GP records. This had resulted in a prescription for '*two 5ml spoonfuls (10mls) when required as directed by the hospital'* when in fact the hospital discharge letter had stated '1*0mg in 5ml, 5mg four times daily when required*'. The GP arranged for the dose to be reduced to 2.5-5mls every 4-6 hours, adding the instruction 'only when required'.

4.24. The following day, **28th July 2021**, Manorcourt staff called 999, reporting Adult R had right-handed wrist weakness and was struggling to grip. Ambulance crew conveyed her to QEH, where she was admitted via the Emergency Department.
A CT head scan was performed and showed no acute changes, and her symptoms resolved within 24 hours of admission. In addition to the transient ischaemic attack, she was believed to have experienced, she also had a low-grade sepsis secondary to a urinary tract infection and antibiotics were prescribed. It was noted that she had a grade 3 pressure area to her sacrum and a category 3 to her left heel; blackish scuffs were seen over the area. Dressings were applied and she was placed on an Auralis mattress. A Datix was completed, and a tissue viability nursing referral made.
She was also referred to the stroke team. She complained of left-sided pain and morphine was administered. She was transferred to the QEH stroke unit and the following day to a medical ward.

4.25. On **2nd August 2021** the tissue viability nurse documented a large category, unstageable pressure area over the coccyx, around 3cm x 4cm, 100% sloughy. This was to be dressed every 2 days unless soiled. The nurse also noted a small category, unstageable area to the left heel, 2cm x 1cm, dry necrotic.

4.26. Adult R was discharged on **5th August 2021**, with Manorcourt resuming care immediately. QEH made a referral to community nursing for care of the sacral pressure ulcer and pressure ulcer to her left heel, with a request for alternate day dressings. NCHC created care plans and planned a visit for 7th August. The care plan noted that nursing visits should coincide with carer visits to assist with manual handling.

4.27. The following day, **6th August 2021,** Manorcourt advised community nursing that Adult R's wound dressing was coming off and that her wound appeared very deep. Again, NCHC was unable to make phone contact with the care workers to complete triage.

4.28. On **7th August 2021** a NCHC Community Healthcare Assistant undertook a planned visit, completed a SSKIN assessment and identified a Waterlow score of 26. Adult R had a grade 3 pressure ulcer to the right buttock, measuring 40mm x 15mm x 2mm, covered with 100% slough with rolled/raw wound margins. No signs of infection were noted. Wound photographs were taken and added to records.
The suspected deep tissue injury to the left heel was reported to have 100% necrotic tissue, no exudate, and no clinical signs of infection. Adult R was noted to have a profiling bed and a dynamic mattress in situ. A repose wedge was in situ and at the correct inflation pressure. Carers reported that repose boots were in the property, but they could not be located at the time of the visit.

4.29. The same day Adult R was seen at home by the physiotherapist and the occupational therapist. She was hoisted into her wheelchair but complained of pain in her left leg and was very anxious. She was therefore returned to bed. The therapists determined that they would give the care workers further advice on moving and handling once Adult R's chair was available. They asked the GP to increase medication to manage her pain.

4.30. The following day, **8th August 2021**, Manorcourt notified community nursing that Adult R's dressing had come off and that her sacral ulcer was deteriorating. NCHC were unable to make phone contact so left a message for the carers to contact the Triage Hub.

4.31. On **10th August 2021** Manorcourt notified NCHC that Adult R's pressure ulcer dressing had come off the sacral ulcer and the area was leaking green pus. A registered community nurse, already scheduled to visit, attended to review both the heel ulcer and the sacrum ulcer, which was categorised as unstageable and covered in 100% slough. No clinical signs of infection were noted. A dressing was applied to assist with autolytic debridement and a note was left for the care workers emphasising the importance of positioning / turning. The nurse emailed the GP to request review of Adult R's pain relief. The surgery responded enquiring what sort of GP review had been requested and when care workers would be in to arrange an appropriate visit time or call. No reply was received, and the review did not take place.

4.32. Following the visit, the community nurse discussed Adult R with the NCHC clinical lead, expressing concerns about the frequency with which Adult R was being repositioned. A TOTO turning solution was considered, but due to Adult R's pain level this was not thought to be a viable solution.

4.33. The following day, **11th August 2021**, a NCHC Community Health Care Assistant made a planned visit for wound care. The left heel ulcer was noted to be dry with no exudate. The sacral wound remained covered with 100% slough with moderate amount of yellow exudate. No clinical signs of infection were reported.

4.34. At a NCHC team handover meeting on **12th August 2021**, concerns were discussed that care workers were not meeting Adult R's pressure ulcer care needs, although Adult R reported that she was very pleased with the carers. The NCHC team planned to monitor and report any concerns.

4.35. By **13th August 2021**, NCHC staff assessed the heel wound to be a deep tissue injury with 100% necrotic tissue. The sacral pressure ulcer remained covered in 100% slough. A minimal amount of exudate was present when cleaning the wound. Two days later, on **15th August 2021,** Manorcourt notified community nursing that the dressing had come off Adult R's sacrum ulcer and the wound appeared to be infected; they also reported blood clots and mucus in her stools. The Triage Hub were unable to visit that day due to capacity issues and asked the care worker to apply a clean dressing, which they did. The following day, **16th August 2021**, Manorcourt staff again notified community nursing that the dressing had come off. The care workers replaced the dressing and reported some anal bleeding, on which NCHC advised they contact the GP.

4.36. On **17th August 2021** a NCHC community health care assistant made a planned visit. The left heel wound remained static. The sacral wound was noted to have 60% darker slough coverage with the remaining 40% lighter in colour. Straw colour exudate was contained within the dressing. No clinical signs of infection were noted.

4.37. The same day. Manorcourt staff raised a safeguarding concern about the community nursing team having failed to respond when alerted that Adult R was in a lot of pain, had a pressure ulcer on her spine, and was taking reduced fluids. ASC advised Manorcourt to contact the GP for advice and to ask for a visit from either the GP or the Community Matron.

4.38. Responding to Manorcourt's concern, the GP visited and noted Adult R was in great pain, had a worsening pressure ulcer and was very low mood. They noted that she was alert with no signs of sepsis, undertook swab tests and increased her analgesia. They understood the care workers were trying to arrange respite nursing care. The GP left their personal mobile number so that the Safeguarding Co-ordinator and the care worker could contact them if required.

4.39. The following day, **18th August 2021**, Manorcourt raised concerns with the GP about Adult R's urine retention, with the GP advising a 999 call. While ambulance crew were in attendance, Adult R did pass urine. She was reluctant to return to QEH as she had not had a positive experience the previous time. The crew contacted NCHC, and it was agreed that a registered nurse would visit Adult R at home the following day to review her pressure ulcers and her current care.

4.40. The same day the QEH occupational therapist and physiotherapist also visited. The pressure ulcer on Adult R's sacrum was not visible as a dressing was in place but small blisters/redness was seen on her 4th and 5th finger. Her left side remained painful. She was rolled and repositioned onto her side to assist with the pressure area and her splint was applied. It was noted that the tilt in space chair was still awaited.

4.41. ASC spoke with the stroke rehabilitation team physiotherapist to ascertain the team's involvement and plans. The physiotherapist advised that Adult R was using a hospital bed and that she had an Oxford hoist instead of the gantry hoist originally intended. They had established that she was not able to use the Ross-return safely. They had tried transferring her to her wheelchair, but this was too uncomfortable, and she could not stay in it between care calls. A tilt in space chair had been ordered but the delivery date was unclear. The splint for her arm did not fit well and it was unclear whether the mattress she had was suitable. They indicated there was no real rehabilitation potential so once all equipment was in place and being used safely, they would no longer be visiting.

4.42. The next day, **19th August 2021,** Manorcourt informed the GP that Adult R had blood and mucus in her stools and a strong odour from her sacral wound. The Ambulance Service was called. Adult R was found to have low blood sugar, although this returned to normal levels after she was given something to eat. Other observations were normal. Adult R stated that she did not want to go to hospital and the ambulance crew assessed that she had mental capacity to make this decision. They advised the GP surgery that Adult R was declining hospital admission; the surgery advised that should more blood be passed an ambulance should again be called. The ambulance crew also rang NCHC and asked for a community nursing visit to check Adult R's pressure ulcers and to review her blood sugar.

4.43. The same day, the NCHC community operations manager and ASC discussed concerns about Adult R having unmet care needs. Clinical needs assessment was awaited from the visiting nurse that day. A NCHC registered community nurse made a planned visit. The left heel wound remained static. The sacral ulcer was starting to form a cavity with debridement. No clinical signs of infection were noted. The dressing was changed to assist with exudate management and support debridement. The surrounding skin was identified as vulnerable and required careful monitoring.

4.44. NCHC reported back to ASC, raising concerns that Adult R was not being re-positioned often enough to relieve the pressure on her affected areas and that it was not appropriate for the care workers to make 999 calls for pressure ulcer concerns. They also considered that Adult R needed support at night, but this was not something that could be put in on a regular basis. Community nurse visits were to increase to alternate days and a referral was made to the Community Matron for review and possible involvement. NCHC also requested community therapy team input, but this was rejected as West community therapy team are not commissioned to provide community stroke therapy. Referral back to QEH stroke team was advised.

4.45. ASC spoke to Manorcourt who confirmed there was a re-positioning chart in the house. The care workers reported, however, that when they left Adult R on her side, as advised, she would move herself back from that position between visits. Manorcourt considered both 999 calls were justified - one had been on GP's instruction and the other was about anal, vaginal and pressure ulcer bleeding. ASC relayed this back to community nursing.

4.46. On **21st August 2021** a NCHC Community Health Care Assistant made a planned visit. The sacral pressure ulcer was assessed as 70% brown slough and 30% thick yellow slough. The wound was now 40 mm by 35 mm, but the wound cavity was developing. No clinical signs of infection were noted but there was a moderate amount of exudate noted on the dressing.

4.47. The following day, **22nd August 2021,** Manorcourt contacted the Council's Emergency Duty Team (EDT) to advise of a serious deterioration in Adult R's health, that she was declining all fluids and her pressure ulcer was seeping badly. EDT advised calling for an Ambulance. Adult R's family also at this point contacted the NCHC hub reporting concerns about sacral ulcer deterioration. Ambulance crew attended and found Adult R in bed, pale and pyrexic, with a temperature of 38C. She had pressure sores to her sacrum and left heel with dressings that were wet, stained, and potent smelling. Her eating and drinking were reduced. Adult R was admitted to QEH via the Emergency Department. She had a category 4 pressure ulcer to her sacrum, which was black/necrotic. The ambulance crew informed hospital staff of the active safeguarding concern. Adult R was commenced on intravenous antibiotics, oxygen, and intravenous fluids for low grade pyrexia. She had an infected pressure ulcer and swabs were taken. She was placed on an Auralis airflow mattress. A Datix was entered, and a tissue viability nurse referral made. She was transferred to the acute medical unit for treatment.

4.48. On **23rd August 2021** NCHC learnt from QEH that Adult R would remain in hospital – all planned community nursing visits were therefore closed. ASC closed the safeguarding concern as Adult R was now in hospital. The QEH physiotherapist contacted NRS Healthcare (who were supplying the equipment ordered) to find out why delivery of Adult R's chair was taking so long. It emerged that the chair had in fact been available since 10th August, but NRS had not contacted Adult R's family to arrange delivery.

4.49. The following day, **24th August 2021,** medical staff completed a ReSPECT form with Adult R. She requested ward-based care, no escalation to intensive care and no resuscitation. She was assessed as having capacity to make this decision. During the day her condition declined, with a lowered temperature indicative of entering septic shock. Her stepdaughter was notified by the hospital of the significant deterioration and agreed that her comfort was the main priority. Adult R peacefully passed away in the late afternoon.

5. THEMATIC ANALYSIS

This section sets out the learning emerging from analysis of all the information available to the review. The findings are organised thematically and address the key lines of enquiry.

5.1. How well were Adult R's needs met?

5.1.1. Adult R's medical needs at the time of her original stroke were met appropriately. The care provided was sound and timely, following the stroke pathway process. Her first admission took place during pressures arising from the Covid pandemic, and although there was delay outside the hospital before she could be admitted, medical staff nonetheless attended her and commenced investigations in the waiting ambulance. She was already at this point outside the timeframe for thrombolysis. Once admitted, she benefitted from a wide range of medical, nursing, and therapeutic attention, including attention to her mental health needs through referral to clinical psychology. She was regularly and effectively repositioned. An environmental visit took place before she was discharged, ensuring that hospital-based therapists were familiar with her home environment when planning what equipment was needed to make her safe and comfortable.

5.1.2. Responsibility for meeting Adult R's needs once home was shared between Adult Social Care, Manorcourt Homecare, the QEH community stroke team, NCHC and her GP. At the point of discharge, it is not clear how or by whom the decision was taken that she did not qualify for 24-hour care. The review has been informed that Adult R was not eligible for the continuing care funding that this would require, but no details of a continuing care assessment have been provided and neither NCHC nor the local authority have been able to establish from their records how this decision was made. This remains a concern going forward.

5.1.3. Instead, Adult Social Care commissioned a care and support package from Manorcourt Homecare, consisting of 4 double-handed visits a day (said to be the maximum number possible under the discharge arrangements). This was arranged in a timely way on her discharge and the allocated hours were increased at a later date in recognition of her needs once the Care Act 2014 assessment had taken place. That assessment (on 22nd July) took place by telephone, and while the absence of a home visit may have been understandable in the context of Covid pressures[7], it must be acknowledged that the practitioner's decisions on what care and support was necessary were therefore made without the benefit of full information. Even when it was clear that Adult R's condition was deteriorating, no home visit was made by Adult Social Care. It was, however, good practice that her case remained open rather than the practitioner withdrawing once the care and support was in place.

5.1.4. Manorcourt care workers built a very positive relationship with Adult R, who valued their approach to looking after her. The care workers were proactive in monitoring her condition and in sharing their concerns with others, including the GP, the ambulance service, NCHC and ASC. They used escalation pathways, including 999 calls and a safeguarding referral, to secure responses they believed were necessary. They did, however, experience difficulties adhering to the positioning plan that was intended to protect Adult R's skin. Her level of pain and her tendency to move herself out of the required position between visits meant that the key objective of protecting her skin was compromised. It was not until concerns about their adherence to the positioning plan were raised with them that they shared the difficulties they were experiencing. Earlier and more proactive escalation of these challenges would have been appropriate.

5.1.5. NCHC provided pressure ulcer care when Adult R was discharged from hospital after both her first and her second admission. Pressure ulcer care is the focus of a discrete key line of enquiry for this review, and the detail is therefore covered in a later section of this report. At this point, in considering NCHC's contribution to meeting her overall needs, it can be noted that the equipment and care provided was appropriate and in line with standards. It was ultimately, however, not successful in managing her skin integrity and in that context missed opportunities were significant. The absence of referral to a tissue viability nurse, the absence of photography as a means of monitoring skin condition on all but one occasion, the failure to account for the impact of continence on skin viability and to address the impact of pain on the positioning plan, all indicate that more proactive attention to her needs was necessary. Ultimately nursing staff did conclude that the 4x daily package of care that was in place from Adult Social Care was not meeting Adult R's needs, and that further discussion with Adult Social Care would be needed, but there is no evidence that this discussion took place.

[7] Assessments by telephone were an approach outlined in government guidance for local authorities on implementing Coronavirus Act 2020 easements to their Care Act 2014 duties. The easements provision expired on 16th July 2021 and the guidance was withdrawn on 22nd July 2021.

5.1.6. The hospital community stroke team became involved with Adult R post-discharge, following on from hospital-based therapy colleagues to provide continuity of specialist therapeutic care. As her condition deteriorated, however, they were not proactive in considering how a combination of factors - her pain, the absence of a key piece of equipment (the tilt in space chair) and the challenges of the positioning strategy – could be managed in a way that might control the deterioration. Having assessed her potential for rehabilitation as minimal, the team were preparing to withdraw once all equipment was in place, although it was clear that the situation in her home was far from satisfactory.

5.1.7. Adult R's GP monitored her physical health, prescribed medication for pain management, and provided appropriate treatment for a urinary tract infection. They were also proactive when alerted to concerns by Adult R's care workers and by the Ambulance Service and carried out a home visit on 17th August, the day on which Manorcourt had raised a safeguarding concern. Prior to this, however, the surgery did make an error in recording medication information from the hospital, resulting in Adult R's morphine dose being wrongly administered. This was picked up by the care workers, who raised concerns with the GP about her drowsiness, and was rectified by the surgery. It was not, however, reported as it should have been to the then Clinical Commissioning Group. As part of the investigation undertaken for this review, the surgery has been advised that the incident must be reported to the NHS England Controlled Drugs Accountability Officer (CDAO). The surgery has since reported the incident to the CDAO, who has advised that no further action needs to be taken.

At the time the hospital had not yet transitioned to electronic prescribing but has since done so. In community-based agencies, manual transcription is still commonly used.

5.1.8. The Ambulance Service attended Adult R on five occasions, conveying her to hospital on three of those. On all visits, their approach was timely and the care they provided met expected standards.

5.1.9. Much of the focus while Adult R was at home was on her physical health and practical elements of her care and support. It is less clear how her mental health needs were monitored. These related to the psychological impact of her stroke as well as to the loss of her son three weeks prior to it and had been addressed in hospital on her first admission through referral to clinical psychology. Beyond the kindness and consideration shown by her care workers, there is little evidence that attention was given to her mental health by any of the agencies supporting her at home, although it is likely that both the bereavement and the significant change in her health posed challenges of adaptation.

5.1.10. A key element of meeting Adult R's needs was the provision of suitable equipment. Unable to stand, she was to be cared for in bed, on a prescribed mattress, with a hoist provided to lift her from her bed to seating. Despite the efforts of the hospital and community stroke teams to ensure that the equipment was suitable, its provision was not straightforward.

- Her original discharge was delayed as the hoist order had to be changed due to an initial ordering error. The Gantry hoist originally ordered on 16th June and delivered to Adult R's home on 22nd June could not be installed because the ceiling was not suitable for this type of hoist. A replacement mobile Oxford midi floor hoist was ordered but delivery was delayed due to stock shortage, and it was not delivered until 28th July.

- In addition, no suitable chair into which Adult R could be hoisted was available and despite efforts to secure one, no provision was made before she died. A tilt in space chair was ordered on 13th July but errors in the ordering caused delay and the order was eventually placed on 21st July. The supply company NRS twice attempted to arrange delivery but received no response, and on 2nd August were advised to place the order on hold. (Adult R was at this point on her second hospital admission.) NRS made a further attempt to deliver the chair on 25th August, but on delivery were advised that Adult R was deceased.

5.1.11. While this review has been advised that there are debates about the wisdom of 'sitting out' for someone being cared for in bed, the transfer into a chair was a key part of Adult R's care plan, and the failure to implement it due to a lack of suitable equipment should have been acted upon. It was not until 23rd August, the day Adult R was admitted to hospital for the final time, that the physiotherapist contacted the supplier NRS to find out why delivery was taking so long, only to find that the chair had been available since 10th August, but no delivery had been arranged.

5.1.12. Glide sheets were provided to facilitate Adult R's movement up and down the bed, but a splint provided for her arm did not fit well and was painful. Repose boots were provided as part of her care routine but appear not to have been regularly used. Manorcourt's daily notes show only a few entries where the care workers specifically recorded their use. NCHC have indicated that their use was discussed and explained with care staff, but Manorcourt have no record of any guidance or instruction being provided. The care workers requested a toileting sling but there is no evidence that this was supplied.

5.1.13. After Adult R's second discharge from hospital NCHC reviewed and changed her mattress[8], which was good practice. It was clear, however, that there were challenges in fulfilling a positioning plan that could minimise pressure damage. It was not until 10th that the use of a TOTO turning system was considered and having considered and rejected this as an option, it seems NCHC's only other action was to raise a complaint that Manorcourt Homecare were not adhering to the positioning plan. It was at this point that Manorcourt shared the difficulties they were experiencing due to Adult R repositioning herself between visits. This could and should have triggered a review of the care and support, taking account of the increasing level of risk from the deterioration in her skin integrity, but although Adult Social Care became aware of the difficulties no action was initiated.

5.1.14. **In summary**, while agencies supporting Adult R at home were providing active support and attempting to meet her needs, there were omissions and missed opportunities to monitor risk and to escalate action that could address it. Errors and delays in the provision of suitable equipment were also significant, and impacted on how safely she could be cared for. Also relevant here was the absence of any overall coordinating role. With each agency working within its own remit, monitoring and acting to coordinate the *interaction* between the various aspects of Adult R's care was no-one's responsibility. This is considered further in a later section of this report.

5.2. To what extent were Adult R's views ascertained and her wishes respected?

5.2.1. Patient-centred care requires practitioners to ensure that the individual's preferences and values guide clinical decisions, and that the care provided is respectful and responsive. This approach relies on services supporting the individual's knowledge development, so that informed choices are made. However, the challenges of balancing the demands faced by the NHS and local authorities with the needs of an increasing population requiring care and support can sometimes result in care being 'done to/for' a person rather than 'with them', resulting in some loss of person-centred focus.

5.2.2. During her admissions to hospital, Adult R clearly and repeatedly expressed her preferences. She was clear from whom she was prepared to have visits while in hospital, and equally clear about her wish to return to her own home, where she wanted to see her dog. The alternative of residential care was offered, but she declined and her wish to return home is what drove the discharge arrangements. It is not clear how fully the risks of her returning home were discussed with her, or indeed whether there was full exploration of what was driving her desire, or how realistic it was. There is reference to her not fully appreciating the restrictions on her abilities after the stroke and anticipating that she would soon be able to walk again, indicating that she did not have a full grasp of the challenges that would face her.

[8] The premier 2 dynamic mattress in situ since her first hospital discharge was replaced by a Quattro dynamic mattress, delivered on 11th August.

5.2.3. It was also clear that she was anxious about the prospect of returning home. She discussed her concerns with a clinical psychologist and was given reassurance that once equipment was in place she would be supported at home and that having mixed emotions was a normal reaction. Once ready for discharge, she asked to be referred for 24-hour care at home under continuing care arrangements, indicating that she felt she would need support at night. When this application was rejected in favour of a maximum offer of 4 visits per day, with no overnight provision, there is no evidence that:

- The implications of this departure from her preferred arrangement were discussed with her;
- Alternative options were revisited and discussed;
- Any attention was given to how her overnight needs would be met.

5.2.4. At this point there were thus gaps in fully exploring Adult R's wishes and feelings, particularly when it became apparent that her preferred option could not be provided. It is not evident that the practical and clinical implications were revisited with her, raising questions about whether she was sufficiently informed within the hospital to be able to make a decision regarding discharge home.

5.2.5. Once home, Adult R was fully informed about the level of care provision by Manorcourt Homecare and expressed her full satisfaction with the care provided. It is clear that here too her preferences were heard. Adult R had a positive relationship with the care workers and reported that she much preferred their care to being in hospital. Such a positive relationship further supported her wish to remain at home. Other practitioners also responded to her day-to-day preferences; for example, her wish to be able to look out of the window resulted in community stroke team practitioners moving room furniture, as well as listening and responding to her experience of pain.

5.2.6. Again, however, it is not clear how fully the risks of her situation were spelled out for her by those monitoring rehabilitation and her skin integrity. She was known to reposition herself in bed between the care workers' visits, returning to positions that were potentially more damaging to her pressure areas. To what level of detail the risks of this were shared and explored with her is not clear and represents a missed opportunity to ensure that her decisions and actions were fully informed. Her possible lack of understanding became even more significant as her pressure ulcers deteriorated. It was not until the days before her final hospital admission that respite care was mentioned, and while there appeared to be a consensus among agencies about the need for it, it is again unclear how or by whom it was discussed with her.

5.2.7. During her periods at home Adult R's physical condition deteriorated, with development of a category 3 and later category 4 pressure ulcer, a urinary tract infection and sepsis. This review did not receive any evidence that information about the extent of the pressure damage, the associated risks and the rationale for repositioning was shared with her by those able to explain the clinical implications of her condition.

5.2.8. While a safeguarding referral concerning Adult Rs pressure area care was raised by Manorcourt Homecare on 17th August, no discussion took place with Adult A herself and the referral was closed on her admission to hospital shortly afterwards, without contact being made with her. This represents a missed opportunity to comprehensively review the care provision and to ascertain Adult R's understanding of the risks she faced, being safe and receiving safe care.

5.2.9. One key consideration relating to an individual's expressed views and wishes is the question of whether the individual has mental capacity to make the decisions in question. All agencies involved with Adult R considered that she did have capacity to decide about her care and treatment. In the absence of any indication that her capacity might be in doubt, agencies felt confident in assuming that her decisions were made with capacity, indeed there is no evidence that this confidence was misplaced. Notwithstanding this, two mental capacity assessments were in fact completed. On 19th August 2021, when Adult R declined hospital admission, the Ambulance Service formally assessed her capacity to make that decision (and found that she did indeed have capacity to make it). When she was finally admitted to hospital, QEH on 24th August 2021 completed a formal assessment during completion of a ReSPECT record noting her wish for ward-based care, with no escalation to intensive care and no resuscitation. Again, she was found to have capacity to make this decision. Such assessments, made in relation to decisions that have potentially far-reaching or high-risk consequences, are good practice. Given the knowledge that Adult R had unrealistic expectations of her recovery at home following her initial stroke, it would have been good practice for the hospital to carry out a formal assessment of her capacity in relation to her decision to return home, and for this question to be revisited by agencies as her condition deteriorated.

5.2.10. **In summary**, Adult R expressed a strong desire to return home with care following her stroke and her wishes were respected. What is missing is evidence of clear information- sharing with her about the risks involved. Equally, as her condition deteriorated, continuous risk assessment should have resulted in the options available to her being revisited, with full explanation of the risks she faced, and their potential consequences, if no alternative options were considered. Had her mental capacity been explicitly assessed, this would have triggered a fuller exploration of her understanding of information relevant to her decision to return and subsequently to remain at home.

5.3. How well were risks identified and Adult R safeguarded?

5.3.1. How well risks were identified and managed is a key line of enquiry in this review. The risks from Adult R's loss of mobility following her stroke and subsequently from her deteriorating skin integrity have been rehearsed in the previous sections. This section considers the use of formal safeguarding processes, which, while not the only way of safeguarding an individual, are nonetheless significant points at which risk management strategy becomes a key focus and decisive action can be taken. In Adult R's case there were two formal safeguarding referrals during the period under review.

5.3.2. The first of these (29th June) relates to her first period in hospital, when a health care assistant on the ward was alleged to have refused her a drink, placed her call bell out of reach and required her to remain flat in her bed. The hospital made an appropriate and timely response to this, investigating the work of the member of staff concerned and ensuring safety on the ward. The safeguarding referral itself, however, was not triaged in the MASH until September, a month after Adult R had died. At that point, it was concluded that the allegations were not linked to Adult R's death. The delay in triage, however, meant that Adult R's own perspective could not be sought.

5.3.3. The second safeguarding referral (17th August) was from Manorcourt Homecare and expressed concerns about NCHC's care of Adult R's pressure ulcers. Adult Social Care made some preliminary enquiries[9] to seek information from NCHC on Adult R's pressure ulcer care but closed the enquiry when Adult R was admitted to hospital on 22nd August. The assumption here was that she was now safe and receiving appropriate care, and that safeguarding action would no longer be necessary. This was problematic, as Adult Social Care have acknowledged, in that it denied the opportunity for Adult R's own views and experiences to be sought.
The enquiry was then reopened on 21st October, two months after Adult R died. This review has received the report of that enquiry, which concludes there were missed opportunities from health professionals, in particular district nurses, to carry out essential wound care that could have prevented the severe breakdown in pressure areas.

5.3.4. It must be noted, however, that opening or re-opening a s.42 enquiry after an individual has died falls outside the legal mandate within the Care Act. Indeed, by this date the local authority had already received a request from the Norfolk SAB for background information on its involvement with Adult R and was therefore aware that a SAR was under consideration[10].

[9] The safeguarding enquiry was initiated under section 42 of the Care Act 2014, which requires the local authority to consider what actions may be necessary to safeguard an individual with care and support needs who is at risk of abuse or neglect and who, because of their care and support needs, is unable to protect themselves from the abuse or neglect.

[10] Adult Social Care have advised this review that their safeguarding triage processes have since changed – details are provided in section 7.2 of this report.

5.3.5. Beyond the two safeguarding referrals relating to Adult R, there were times when safeguarding referrals could have been made but were not. Although her pressure ulcers were reported on Datix on several occasions, these were not escalated to safeguarding. No safeguarding referral was made by the hospital when she was readmitted on 28th July with a category 3 pressure ulcer to her sacrum, which had been acquired while being cared for at home, and a category 3 ulcer to her heel. Similarly, when the GP visited and examined Adult R on 17th August, noting the breakdown of her skin integrity, a safeguarding referral could have been expected. While the GP would have been aware of the referral raised by the Manorcourt Homecare, this does not negate responsibility for raising their own concerns through the appropriate channel.

5.3.6. **In summary**, formal safeguarding processes were not effective in keeping Adult R safe. On the one hand, referrals that were made were not pursued in a timely way and, by not involving Adult R herself, did not adhere to the principles of making safeguarding personal. On the other hand, there were times when safeguarding referrals might have been expected but were not made, raising concerns about how effective this pathway is as a means of managing risk.

5.4. How well were her pressure ulcers were managed?

5.4.1. Adult R died because of sepsis and an infected sacral pressure ulcer in the context of severe coronary artery atherosclerosis. A pressure ulcer is a localised skin/underlying tissue injury resulting from pressure over a bony prominence and can be classified based on severity into categories 1-4, unstageable and deep tissue injury[11]. Harm prevention is a continued priority for the NHS with 19% of all reported patient safety incidents being attributed to pressure ulcers[12]. Although national guidance in place during the period under review[13] recognises that not all pressure ulcers can be prevented, it can be argued that if appropriate measures for maintaining care are implemented then most pressures ulcers can be considered preventable[14]. This review has sought to investigate whether pressure damage was appropriately recognised, assessed, treated and escalated.

[11] EPUAP (2010) European Pressure Ulcer Advisory Panel 'European pressure ulcer', online accessed 2023.URL: www.epuap.org

[12] NICE (2015) Pressure ulcers: Quality Standard. London: National Institute for Clinical Excellence.

[13] Department of Health & Social Care (2018) Safeguarding Adults Protocol: Pressure Ulcers and the Interface with a Safeguarding Enquiry. London: DHSC. This guidance was withdrawn in June 2023 due to being out of date, but it was in place during the period under review. Although withdrawn, it is advised that local guidance based on its principles should still be followed.

[14] Moore and Van Etten (2011). Repositioning and pressure ulcer prevention in the seated individual. Wounds UK (3), 34-40.

5.4.2. It was QEH policy, for patients at risk of developing pressure damage, to carry out a daily inspection of the skin to monitor and maintain skin integrity. Outcomes were recorded each day, along with any actions taken in response. At various points during Adult R's first hospital admission, the inspections noted the sacrum and heels becoming red; these areas were treated appropriately with emollients and regular repositioning. She was regularly repositioned and was compliant with advice on this. Ten days into her admission, Adult R was noted to have a blister on her left heel. The following day the tissue viability nurse assessed this as a friction blister. Waterlow scores were monitored and by 22nd May the blister was noted to be improving. At her discharge on 8th July, it was described as a healing category 2 pressure area and a referral was made to NCHC for follow up care.

5.4.3. Following this first discharge, NCHC nurses visited Adult R twice a week. At the first nursing assessment, which took place 4 days after her discharge, she was noted to have a deep tissue injury to her left heel and a category 1 pressure ulcer to her sacrum. Repose boots and a repose wedge were provided to support pressure relief.

5.4.4. Deterioration of her skin integrity occurred whilst being nursed at home. By the time she was readmitted to hospital on 27th July, she had developed category 3 pressure ulcers to her sacral/buttock area and to her heel. Tissue viability nurse assessment in hospital on 2nd August identified large category unstageable pressure area over her coccyx and a small category unstageable area to her left heel. At discharge on 5th August a further community nursing referral for follow up care was made.

5.4.5. NCHC visiting frequency was increased to three times a week and nursing staff discussed the need for positioning both with Adult R and with the carers, but the extent of these discussions is not clear, particularly whether the consequences of not relieving pressure were fully explained and understood. There appears to have been no discussion about what should happen during the long overnight period when there were no care worker visits. And because Adult R was telling nursing staff that she was very happy with the care she was receiving, the decision made was to observe and monitor the situation. Escalation at this point could have taken place, either to ASC, the GP or the NCHC safeguarding team.

5.4.6. There was no overall review of the dressing regime undertaken. Reviews were conducted on a visit-by-visit basis. A review looking at the care plans and the number of referrals into the nursing hub for dressing concerns would have provided opportunity to include the tissue viability specialist nurse both in reviewing the dressings and in the wider aspects of ongoing care.

5.4.7. By the time of her final admission on 22nd August, Adult R was found to have a large discharging grade 4 pressure sore to her sacrum, which was black/necrotic around the edge.

5.4.8. Susceptibility to pressure ulcers can vary from person to person and thus assessment is important when predicting level of risk. One key question for this review, therefore, is whether there was evidence of risk assessment that could or should have highlighted preventative actions. Professionals from agencies in both primary and secondary health care did recognise poor mobility, reduced appetite, pain, incontinence and low mood as risk factors for Adult R. Within the hospital a nationally recognised pressure ulcer prediction tool (Waterlow) was completed as appropriate every 7 days. This highlighted Adult R to be at high risk with a score between 20-26. With a high-risk score appropriate signposting of pressure relieving equipment, dietician and therapist referrals were prescribed.

5.4.9. In the community, Adult R received regular community nursing visits at the intervals necessary for her pressure ulcer care. Waterlow scores were similarly used to identify level of risk, but as her skin integrity deteriorated risk-prevention actions are less evident. While her analgesia was reviewed when she experienced uncontrolled pain episodes, other factors in her daily functioning did not receive full or timely attention. Several concerns can be noted.

5.4.10. Although they followed guidance on repositioning her in bed, Manorcourt care workers reported that between care worker visits Adult R would revert to resting on her back, removing the pillow used for support. It is not clear to what extent the risks of this were discussed with her. Nor is it clear what consideration was given to how her pain impacted on her positioning. Consideration was given (10th August) to use of a TOTO automated turning system, but this was thought to be unsuitable due to the degree of pain that Adult R experienced on her left side. No practical alternatives to the repositioning problem appear to have been considered.

5.4.11. Appropriate pressure relieving and repositioning equipment was prescribed for her at home - hospital bed, autologic mattress, repose boots, glide sheets, hoist, tilt-in-space chair – but not all equipment was delivered or used effectively. Repose boots were left in the home without accompanying instructions for the carers, highlighting a potential a gap in prevention. The hoist was not in use because the tilt-in-space chair (to which she would be hoisted, thus spending time out of her bed) was not delivered.

5.4.12. Adult R was incontinent, a condition that can lead to inflammation and damage of the skin, resulting in adverse symptoms such as itching, discomfort/pain and secondary fungal infection[15]. Continence products were used to manage Adult R's continence needs, but further consideration was needed of the interaction between her incontinence and her skin integrity, in terms both of its impact and the risk of infection from contamination. Her incontinence contributed to her dressings becoming detached, and while this was addressed by community nurses adding an extra, secondary dressing to prevent continual detachment, the underlying cause (the impact of Adult R's incontinence) was not addressed. NCHC have acknowledged this as important learning.

5.4.13. On many of the multiple occasions when Manorcourt staff raised concerns with NCHC it proved impossible for NCHC to gather sufficient information to assist their triage and therefore to assess the urgency of the concern. This communication problem between the two agencies is considered in more detail in a later section. Suffice to say here that information-gathering for NCHC triage was sub-optimal as a result.

5.4.14. There was limited escalation of the concerns that were recognised. Although all concerned knew that Adult R's skin integrity was deteriorating to a dangerous level, and although NCHC raised concerns about how frequently she was being repositioned, little else was attempted by way of escalation or change. While several agencies acknowledged that respite care would be helpful, no initiative was taken by any agency to arrange this. The care strategy therefore remained 'more of the same'.

5.4.15. Review of the agencies' chronologies and IMRs indicates a lack of consistency in ulcer descriptors. Terminology of 100% sloughy, necrosis and wound dimensions were evidenced by the tissue viability nurse assessments in hospital, but accompanying photographs that could be shared across agencies caring for Adult R do not appear to have been used. Community nursing used photography relatively late in their care of Adult R. Earlier use could have ensured accurate mapping of wound location and deterioration, supporting any escalation of concern that was being raised by Manorcourt staff.

[15] Bliss et al (2017) Incontinence-Associated Skin Damage in Nursing Home Residents with New Onset Incontinence. Journal of Wound, Ostomy and Continence Nursing, 44(2):165-171.

5.4.16. Manorcourt care workers were proactive in raising their concerns about Adult R's ulcers and their dressings and liaised extensively with other agencies to seek responses to Adult R's pain and distress, including calls to NCHC, Adult Social Care and 999. It seems, however, that they had not been well informed on what to expect by the nursing practitioners, who may have made assumptions about the extent to which the care workers knew and understood the treatment protocols that were being followed. So, while community nursing staff were following dressing regimes for Adult R's pressure ulcers, there was little interaction with Manorcourt staff about what was to be expected within that treatment regime and the rationale for the use of particular dressings appears not to have been well explained to the care workers. This led to the care workers repeatedly escalating concerns about dressings falling off or leaking, with worsening ulcer descriptions, when in fact this was to be expected within the treatment plan to remove devitalised tissue. It is to be acknowledged that the coroner concluded that the wounds and dressing products used were appropriate and were applied appropriately, but there is learning to be noted here; with less specialist knowledge, care workers would not necessarily understand the rationale for a particular approach unless it was clearly explained, and therefore could be alarmed by the appearance of ulcers 'worsening' whilst the process of devitalization occurs. Nonetheless, it can be argued that as Adult R's condition continued to deteriorate, the alarm felt by the care workers was justified. It is significant that Adult R's presentation on 17th August, which led to the care workers making a safeguarding referral about her pressure ulcer care, followed a missed nursing visit[16], which meant that Adult R had not been seen by nursing for four days, during which time her condition declined further.

5.4.17. A further key question for this review relates to the interface between pressure ulcer care and formal safeguarding pathways. Department of Health & Social Care guidance in place at the time Adult R was receiving her treatment[17] advises that staff observing category 3, 4 and unstageable pressure ulcers, or multiple occurrences of category 2 pressure ulcers, should report these to their organisation's safeguarding team who, in a minority of cases, will raise a safeguarding concern with the local authority. Not all incidences would require investigation under section 42 of the Care Act 2014, as not all pressure ulcers result from abuse or neglect. A safeguarding decision guide exploring the pressure damage would provide a score, with a calculated score 15 or higher indicating the threshold for raising a safeguarding referral with the local authority.

[16] NCHC missed one nursing visit to Adult R during their care of her – 15th August – due to operational pressures.

[17] Department of Health & Social Care (2018) Safeguarding Adults Protocol: Pressure Ulcers and the Interface with a Safeguarding Enquiry. London: DHSC. This guidance was withdrawn in June 2023 due to being out of date, but it was in place during the period under review. Although withdrawn, it is advised that local guidance based on its principles should still be followed.

5.4.18. Except for Manorcourt Homecare, safeguarding considerations were predominantly absent across agencies involved in Adult R's care. None of the Datix reports raised by QEH and NCHC were escalated. This review asked whether agencies were aware of the DHSC guidance in place at the time and it emerged that not all were aware, including NCHC as the agency most directly involved in providing Adult R's pressure ulcer care.

5.4.19. Understanding of safeguarding thresholds for pressure damage are evidently inconsistent. It may also be the case that awareness of involvement from community nursing teams dissuaded others from raising a safeguarding referral, on the assumption that all necessary care was being provided. When a safeguarding was raised by Manorcourt Homecare on 17th August, it was closed five days later by the local authority on the grounds that Adult R was by then safe in hospital. This represents a significant missed opportunity to respond quickly on receipt of the referral and then to secure Adult R's own perspective on her safety. During the same period a further opportunity was missed when the GP, having seen Adult R at home and observed her condition, did not consider safeguarding or independently raise a referral.

5.4.20. Safeguarding is everyone's responsibility and taking a proactive approach can prevent or reduce harm. Whilst the level of pressure damage noted at the point the safeguarding referral was made can be considered irreversible, earlier opportunities to raise concerns about her skin deterioration and to implement a review of her care were missed. Thus, Adult R's voice was missing in terms of how she understood the extent of the damage, how it was affecting her quality of life and the associated risk of sepsis.

5.4.21. **In summary**, Adult R's skin integrity deteriorated significantly after her hospital discharge. Risk assessment, care plans and equipment were all in place and her pressure ulcers were recorded in line with national guidance via the Datix reporting system. However, delays/failures of equipment delivery and failure to consider the interaction between a range of risk factors resulted in a lack of holistic approach to risk management. The agencies involved in managing her pressure care did not work together as a multi-disciplinary team and their failure to share associated care plans and to act on escalated concerns contributed to her deterioration.

5.5. How was the quality of the care provided assured?

5.5.1. A key line of enquiry was whether ways of ensuring care quality were effective in Adult R's case. Agencies gave a variety of responses on the mechanisms they would normally use to ensure quality of care. Management scrutiny, multidisciplinary team meetings, staff training and supervision, team handover, specialist advice and clinical lead oversight would all play a role. When quality was questionable, internal reviews or significant event analysis might be used. Escalation was seen as important, but a lack of clarity was noted on the appropriate routes for use in different situations.

5.5.2. Meeting external standards is an important feature of care quality. The Care Quality Commission (CQC) is the regulator of all the agencies involved in Adult R's care, apart from Adult Social Care and the Police. It monitors, inspects, and rates health and social care services. The hospital's acute stroke pathway is also audited under the Sentinel Stroke National Audit Programme, a national project covering England, Wales and Northern Ireland that measures the quality of care and the structure of stroke services against national stroke care standards and guidelines.

5.5.3. Manorcourt Homecare advised CQC of the safeguarding referral that they made on 17th August, making contact initially with their assigned inspector the same day and, on receiving no response, with CQC itself on 21st August. As a result of the concerns raised, on 6th September CQC asked NCHC to review and provide assurance on their pressure ulcer care of Adult R. They subsequently considered NCHC's response alongside information that had been shared at the coroner's inquest and concluded that there were no specific concerns about the input of NCHC.

5.5.4. **In summary**, appropriate structures were in place for ensuring care quality and indeed Adult R's care by individual agencies did meet expected standards. What was missing was
(a) coordination of the interventions by different agencies,
(b) recognition that the care provided was not achieving the sought outcomes and
(c) use of pathways for escalation.

5.6. To what extent did service structures or organisational features impact on Adult R's care?

5.6.1. This review was tasked with investigating whether structural changes within the community nursing services, which were recent at the time, had impacted on the care Adult R received. The restructure involved community nursing being withdrawn from GP surgeries and provided from four geographically based hubs, allowing a more streamlined and efficient response that minimised nurse travelling and increased productivity. Referrals are managed from a single point of contact followed by clinical triage that involves a call back to the referrer. From a NCHC perspective the restructure had no impact on service delivery to individual patients, and indeed the majority of agencies responding in this review raised no comment about impact, either positive or negative. The GP surgery, however, believed that removing community nursing's physical presence from GP surgeries had impacted negatively on the flow of information and case management discussions that could take place between the surgery and nursing practitioners. In Adult R's case, this had been exacerbated by community nursing's non-attendance at the surgery's multidisciplinary team meetings during the period under review.

5.6.2. The disconnect between GP surgery and community nursing in Adult R's case was exacerbated by their use of different IT systems, which acted as a barrier to information- sharing. While both services now use SystmOne and shared care records have been introduced, patient consent for data recorded by one service to be accessed by the other is still required.

Further details on the current position are provided in section 7.2.

5.6.3. A further organisational feature that affected communications was the nature of the telephony system used by Manorcourt Homecare in the context of NCHC's triage system. Nursing triage involved calls into the nursing hub being first screened by an administrator, then passed to a clinician for triage, which then involved calling the referrer back for further information. Manorcourt's phone system did not have a voicemail message recorded, and NCHC staff were therefore not confident, when calling back and being transferred to voicemail, that this was a trusted location in which to leave messages. Had this been escalated, it would have been easily rectified, but instead there were multiple failures to make a connection in which patient information could be shared, resulting in sub-optimal information being available to inform nursing triage. The problem has now been resolved with a new telephony system in place at Manorcourt Homecare.

5.6.4. A final and major consideration in relation to organisational pressures is that of the Covid pandemic. The period under review in this SAR coincides with the tiered restrictions that were introduced under the government's 'roadmap out of lockdown', which was operational between the end of the third national lockdown on 8th March 2021 and 19th July 2021. Since early 2020, all agencies had been under extreme pressure from unprecedented demands on services due to the pandemic, while also experiencing staffing capacity issues. There were some impacts for Adult R. Restrictions on face-to- face visits meant that all her contacts with Adult Social Care were conducted by phone, with the practitioner therefore unable to make direct visual observations of her circumstances. NCHC experienced constraints on the timing of community nursing visits, although only one visit was missed altogether. Pressures on staff time also meant that communications in nursing team handovers were restricted, resulting in less of a shared team perspective on specific individuals. Manorcourt Homecare has identified staffing pressures, although all visits to Adult R were appropriate staffed. For the hospital, contact times with other agencies were sometimes lengthened where practitioners were working from home, and staffing was also impacted by high levels of staff sickness and/or the need to isolate.

5.6.5. I**n summary**, the agencies involved experienced quite significant challenges at the organisational level, with some clear constraints on their actions arising from features of their organisational systems. Most notable, however, were the pressures that all were under because of the challenges of the Covid pandemic, in the context of which Adult R's care was nonetheless maintained.

5.7. How well did agencies work together to meet her needs and keep her safe?

5.7.1. Discharging home a person who has specialised care needs can be complex and as such, planning and involvement of all concerned is required. Guidance in place at the time of Adult R's discharge[18] emphasises the need for considered risk management approaches and co-operation between services and the individual, their carers and family. It supports the Discharge to Assess model as an effective way to support discharge, by ensuring it is timely, when the individual is clinically ready and has appropriate support in place. NHS England's Acute Hospital Discharge 100-day Challenge (July 2022[19]) includes multidisciplinary engagement in early discharge plans as one of the ten identified best practice initiatives for systems to deliver against.

5.7.2. Throughout this review, evidence of proactive communication between agencies has been identified, including liaison between NCHC, ASSD and QEH regarding Adult R's needs, dialogues between Manorcourt Homecare, the Ambulance Service and the GP regarding physical health concerns and communications from Manorcourt Homecare to NCHC about skin integrity.

5.7.3. Despite the good practice in sharing information, some frustrations were nonetheless experienced. There is evidence that hospital discharge arrangements did not run smoothly. It remains unclear what assessment took place to determine that Adult R did not need 24-hour care and was not eligible for continuing healthcare. Her first discharge was delayed due to equipment not being available and in place in her home. The hospital has reflected also that their liaison with Adult R's family could have been more proactive during the period leading up to her discharge.

5.7.4. Close liaison between NCHC and Manorcourt Homecare was missing. It was necessary for nursing visits to coincide with care worker attendance, in order to assist with positioning Adult R, but this did not always happen. There were times when the two agencies arranged times to meet but these appointments were then missed. As identified in an earlier section, Manorcourt care workers raised multiple concerns about the condition of Adult R's pressure ulcers and dressings, but NCHC staff were often unsuccessful in reaching the care workers, resulting in sub-optimal information being available to inform nursing triage. Yet even after numerous unsuccessful attempts the service did not re-strategise or escalate communication issues.

[18] Hospital Discharge and Community Support Guidance, first issued August 2020 and last updated in January 2024: https://www.gov.uk/government/publications/hospital-discharge-and-community-support- guidance/hospital-discharge-and-community-support-guidance

[19] https://www.england.nhs.uk/publication/acute-hospital-discharge-100-day-challenge

5.7.5. Beyond those time-sensitive communications, a more strategic communication channel between the two services was needed, through which nursing staff could explain the rationale for clinical decisions to enable the care workers to be better supported in their understanding of the dressing regime. Such explanations would have gone some way to ensuring a shared understanding of the approach being taken to Adult R's pressure ulcer care, with care workers more supported as the rationale for clinical decisions could have been explained. NCHC have acknowledged that this lack of communication and coordination with the care agency is an important point for learning.

5.7.6. Challenges have been highlighted concerning utilisation of different IT systems, for example between the GP surgery and community nursing. This led to delays in viewing records in real time, thus creating a reliance on verbal communication with its inbuilt inherent contact delays, which contributed to missed opportunities for professionals as a system team to discuss, update and professionally challenge decisions and to review the level of care Adult R required as her care needs changed.

5.7.7. Multi-disciplinary team working is essential to managing risk when supporting in their home an individual who has significant and potentially deteriorating health and care needs. Individual care needs may and often do change and therefore processes should be in place to ensure continual review and appropriate provision of care and support is being received[20]. Prior to structural changes to community nursing services, the GP practice had strong links to the service, facilitating discussion about patient concerns. Service changes have replaced this function with practices being requested to submit a referral form into the community nurse hub. Attendance of community nurses to multi- disciplinary team practice meetings declined during the period under review here, further exacerbating the potential communication gap.

5.7.8. Adult R was dependent on professionals to provide for her care and support needs and although this review acknowledges that each individual agency supported Adult R in what they considered to be the best and most appropriate way, it is clear that a 'silo approach' to working hindered opportunities for joined up thinking and system challenge. At no point did all the agencies involved in supporting Adult R convene together for discussion of how best to manage the risks in her situation. Holistic multi- professional assessments and reviews of need did not take place. Equally, no leadership was exercised - no one agency was coordinating the services being provided or taking the initiative for change. This review has identified that no guidance on case coordination was in place at the time and that multiagency case review practice may have been impacted by the Covid pandemic.

[20] Department of Health and Social Care (2022) Hospital Discharge and Community Support Guidance. London: DHSC. www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance

5.7.9. One example of the absence of coordination and clarity on responsibilities for action is in the perceived need for respite care which, despite being believed to be necessary, was not taken forward. The GP believed Manorcourt Homecare were arranging it; the Ambulance Service understood from the GP surgery that the surgery was arranging it. The safeguarding referral from Manorcourt on 17th August notes that respite care might be needed but ASC did not take this forward. ASC records show that on 19th August NCHC too expressed to them the view that Adult R should not be at home on her own and needed support at night, but that this was not something that could be put in on a regular basis. Despite all this discussion, there is no evidence that any initiative was taken to discuss alternative care arrangements with Adult R. Even in the light of mounting evidence that her condition was deteriorating, agencies continued to provide 'more of the same'. No-one took responsibility for seeking a holistic review of her situation or questioning whether a different strategy for her care needed to be devised.

5.7.10. Joint accountability across health and social care can be evidenced as leading to better outcomes[21]. In complex cases such as Adult R's, where multiple agencies are involved, coordination and leadership are essential. The organisational and interagency structure in this case required the involvement of, and coordination between, multiple agencies to meet her needs. In this context, one agency needs to be nominated to coordinate the strategy for meeting needs. Instead, in this case limited system ownership and responsibility for review and intervention are evidenced.

5.7.11. The distinction between health care needs and social care needs may also have played into this. On 19th August NCHC referred Adult R to the Community Matron nursing service in the hope they would offer additional help and support, particularly if Adult R maintained her preference for remaining at home. The community matron declined the referral on the grounds that Adult R had no healthcare requirement and advised that the patient be referred back into adult social care for additional care provision. It is not clear why her pressure ulcer care would not be seen as a healthcare need but, beyond that, the response is indicative of an unhelpful compartmentalisation of needs that does not reflect the reality of patients' lives and certainly does not reflect Adult R's experience.

5.7.12. **In summary** professionals were all working with the desire to provide safe care to Adult R. Complexity, system structure and workload pressures can be highlighted as potential root causes of silo working. But there was no one agency taking ultimate responsibility or accountability for Adult R's care. This was a significant gap resulting in limited co-ordination of services and care provision, causing fragmentation and frustration for agencies and, more significantly, a failure to pursue a shared risk management and intervention strategy.

[21] Department of Health and Social Care (2022) Hospital Discharge and Community Support Guidance. London: DHSC. www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance

6. A FAMILY AND FRIENDS' PERSPECTIVE ON ADULT R'S EXPERIENCE

6.1. Adult R's stepdaughter indicated that the stroke was clearly a life-changing tragedy for Adult R but that she had initially remained positive. She had plans and tried to understand how she could live with her limitations, using equipment that might help her to live as normal a life as was possible. She had high expectations, initially thinking she would be walking and driving again and that although she wouldn't be 100%, she would be better than she was initially. She had talked about getting a disability scooter.

6.2. While her family, friends and neighbours did everything they could to make her comfortable and happy, there was only so much that they could do in the context of the limitations she faced. They felt the care workers provided excellent care and that they seemed to really care for Adult R. However, as she got progressively worse, she became depressed and frustrated due to pain and problems with the supply of equipment. There was a failure of communication, with the family not advised that furniture needed to be moved, so the first hoist could not be delivered. The second one could not be used. Had the correct hoist been in place in the beginning, she could have used it to sit out, as at that point she didn't have the level of pain that developed later. The special chair that would have enabled her to sit out more safely was never delivered.

6.3. Adult R couldn't get out of her bedroom, which she desperately wanted to do; she couldn't remember what her bungalow looked like. She started to fade away as she couldn't connect with real life and her state of mind suffered. She found it hard to be without support during the long periods overnight; her inability to do things such as retrieve a dropped phone, or the TV remote made her feel vulnerable and helpless. At the time of her final admission to hospital, she was talking about paying for carers overnight.

6.4. Once the pressure ulcers became so much worse and the care workers began to make multiple calls to express concerns, Adult R's stepdaughter felt that agencies didn't respond with sufficient urgency. She believes this contributed to the speed of Adult R's deterioration. The equipment being used to position her was not entirely suitable either. The care workers were using an inflatable wedge to position her on her side, but she would remove this between visits as she preferred not to be on her side when talking on the phone. The wedge was too easy for her to move, but the more permanent wedge that was awaited, and which would have helped her to follow the advice on positioning, did not arrive. Her stepdaughter indicated that although Adult R wanted to do what was necessary to help her condition, she may not have been fully aware of the extent of the damage in her skin. She and the care workers had tried not to discuss the condition of the pressure ulcers in front of her and she was therefore perhaps not fully informed of the risks she faced.

7. WHAT HAS CHANGED SINCE ADULT R's DEATH AND WHAT IMPROVEMENTS REMAIN TO BE MADE?

7.1. It is to be expected that agencies do not wait for the outcome of a SAR before making changes they feel are necessary in their approach or practice. This is particularly important when the learning from individual circumstances may be delayed, as has been the case here. This SAR has therefore sought to capture what has been done in the intervening period since Adult R's death. Agencies were asked, when returning their IMRs, to include information about changes they had implemented in response to their own reflection and learning from Adult R's circumstances. The focus of learning event, held in November 2023, was to enable the reviewers to hear from practitioners, managers, and senior leaders about current practice in caring for people in similar circumstances to Adult R – i.e., those who are fully dependent on health and social care provision at home to meet all their daily needs. This section of the report therefore brings together evidence from both these lines of enquiry to explore how the provision of safe care at home is being managed now, 2½ years on from Adult R's death.

7.2. **Changes already implemented by agencies:** A number of agencies have made changes to their practices in the intervening time since Adult R's death.

7.2.1. **ASC** have reviewed the decision to close the safeguarding referral on 17th August 2021 and have, as a result, changed procedure on referrals that do not proceed to a s.42 enquiry. In such cases, the practitioner making that decision must record their rationale, and management sign-off is required, with the manager consulting the MASH where necessary. The revised policy and procedure have been communicated to all staff and the local authority completes audits to check the quality of decision-making.

7.2.2. The **GP surgery** has reviewed its Safeguarding Adults policy and ensured all staff are familiar with the policy and how to access it. They have also highlighted for staff the importance of following up fully on email exchange with community nursing teams and allied health professionals.

7.2.3. **Manorcourt Homecare** has invested in a new telephony system, which now ensures all calls are managed appropriately. A new Electronic Call Monitoring system and alert system makes the reporting of concerns more immediate, in real time. A discharge checklist has been implemented giving more detailed information around changes to mobility, medication, skin integrity and acquired infections.

7.2.4. **NCHC** have established a regular, complex case meeting to which patients' circumstances can be brought for discussion and escalation. This meeting is attended by a wide range of professionals across the disciplines and often Safeguarding are present. NCHC West Place have a daily escalation call attended by all primary care network teams which is used for escalation of issues such as unallocated visits and cross- border / team working. An additional full-time allocator has been employed to manage allocation within this primary care network. SystemOne has an 'awaiting call back' list, used to monitor any return communications that are required.

7.2.5. The **Norfolk & Waveney Integrated Care System** has introduced arrangements for patient records to be shared between services using the SystmOne Electronic Health Record. The Integrated Care Board has provided the following information. Sharing of records for the majority of GP practices works on the basis of implied consent. The GP practice where the patient is registered will advise the patient that their records will be shared unless they opt out. Some practices, however, may seek explicit consent on registering the patient. With either type of consent, the patient's record is only shared at the point at which they are seen by/referred to another SystmOne healthcare service. If a patient dissents, no records are shared with any other SystmOne organisation caring for the patient.

On becoming a patient of another SystmOne provider, that provider will ask the patient two questions: (i) are they happy for the service to view their GP record and (ii) are they happy for the service to share back to their GP record. The patient's decision should be recorded by the service. If a SystmOne organisation is viewing the patient's GP record, access will end at the point the service's care is ended.

7.3. In addition, agencies have identified further actions that they intend to take:

7.3.1. **ASC** will promote learning for staff about the importance of active liaison with community nursing teams where concerns about skin integrity are identified. It will be expected that, where skin integrity concerns have arisen during risk assessment, case records provide evidence that direct contact has been made with community nursing and the risks taken account of in care planning. ASC will also look to its Principal Social Worker to take a lead on promoting joint health and social care planning, in line with Care Act 2014 Statutory Guidance[22].

7.3.2. **EEAST** will issue a reminder to staff to ensure that contacts with external agencies are recorded and a summary of the content of discussions documented.

[22] 22 Parag. 20.34 "Providing joint care and support and health plans will avoid duplication of processes and the need for multiple monitoring regimes. Information should be shared as quickly as possible with the minimum of bureaucracy. Local authorities should work alongside health and other professionals where plans are developed jointly to establish a 'lead' organisation which undertakes monitoring and assurance of the combined plan. Consideration should be given to whether a person should receive a personal budget and a personal health budget to support integration of services.

7.3.3. The **GP practice** will promote the importance of consistent attendance at multidisciplinary team meetings when invites are shared. The practice will also review NICE guidance on pressure ulcers (https://cks.nice.org.uk/topics/pressure-ulcers/) and will invite the Named GP for Safeguarding Adults to present the findings of this SAR to the practice.

7.3.4. **Manorcourt Homecare** will ensure new team members understand the importance of keeping accurate and clear records, especially where the involvement of another agency may be required. Weekly team meetings will monitor service users' changing care needs and actions taken to meet them.

7.3.5. **NCHC** has a business case under development to expand the tissue viability service. In addition, learning hubs are to be established within each Place to assist with learning across a range of subjects including pressure care, tissue viability and other subjects that have a co-dependency and impact on the holistic care of patients.

8. THE LEARNING EVENT – A TEMPERATURE CHECK ON CURRENT PRACTICE

8.1. The learning event was attended by over 40 people representing some of the agencies most closely involved with Adult R but also agencies currently working in the same field. The independent reviewers presented the learning themes emerging from the SAR. They then invited participants to work in break-out rooms, facilitated by members of the SAR panel, to discuss two questions:

- What is working well now in health and social care provision at home to people who are dependent on services to meet all their daily needs?
- What are still challenges in providing care in this way – what could be improved?

8.2. Participants felt that when things work well, this is due to (a) good communication and (b) the individual being placed at the heart of what is done.

- Capturing the voice and thoughts of the individual prior to hospital discharge is prioritised.
- The shared care record has made a real, positive improvement in internal communication and helps to develop more comprehensive risk assessment.
- The knowledge and training of care workers, their understanding of the person and their adherence to personalised guidance are much valued.
- Person-centred care is recognised as providing better outcomes.
- Family involvement is prioritised.
- Care agencies having on-call systems for staff to use out of office hours is valuable.

- While multidisciplinary working had suffered during the height of the Covid pandemic, this is now improving.

- There is now better understanding of what constitutes a safeguarding referral (but see also below).

8.3. There remain, nonetheless, multiple challenges:

- The constant pressure on resources, particularly on staffing, impacts on responses from teams and results in practice become reactive rather than proactive. There is an ongoing mismatch between demand and capacity to meet it. Faster responses were sought in particular from physio and occupational therapy teams.

- Hospital discharge is sometimes disjointed, with a lack of information to providers on what care is required. Pressure to discharge can lead to poor exchange of information or referrals lacking information on the level of care required. It was also noted that there is often a difference between what people can do while in hospital and what they can do at home.

- There is a belief that more complex needs are being met at home now than prior to the Covid pandemic.

- Equipment delivery remains problematic, with delays and poor communication. Equipment sometimes arrives after discharge.

- The quality of referrals in relation to risk is also variable; there is a need to find ways of reaching shared understandings of risk level in any individual case. What is urgent to one organisation is not urgent to another making emergency responses difficult.

- Ease of communication is not uniform across agencies; it can be difficult for practitioners on the ground to contact other agencies. This was particularly the case for care providers needing to speak to adult social care when no practitioner is allocated to the individual.

- Some opposition is experienced from others when raising safeguarding concerns and there remains some lack of understanding about what constitutes a referral. Safeguarding meetings are sometimes not well attended. Safeguarding is experienced by some as too complicated and dispersed, with calls for a centralised hub.

- When people are returned home by ambulance, it appears ambulance crew are not trained to use equipment to put them safely in bed, requiring home care staff to be present before this can be done.

- Feedback on referrals or queries to other agencies is often lacking, making coordination of services difficult – specifically mentioned here were GP surgeries, community nursing and safeguarding.

- Separate IT systems and lack of interaction between them remains problematic in some contexts. Access to ambulance service records would help with the delivery of care, as often they are the first point of contact, and access to Norfolk & Suffolk NHS Foundation Trust records would also improve patient care.

- The community nursing restructure has made it more difficult for GPs to communicate with nursing staff. Communication is now via a central hub rather than direct.

- Where an individual no longer has a social care practitioner allocated there can be a lack of communication about concerns that a provider might experience but which do not reach a safeguarding threshold. This is exacerbated when reviews by social care do not take place.

- Care logs located in people's homes are not being updated by all visiting professionals.
- Getting one's voice heard by other professionals can be difficult, and there is a need for awareness of escalation routes for facilitating professional curiosity and respectful challenge. Staff on the front line may not be invited to attend multidisciplinary teams, or if they are their voice may not carry weight.
- Home care providers have a wealth of knowledge and experience, and their voice is sometimes not being heard. They should more routinely be asked for feedback and involved in multidisciplinary team discussions.
- There is ambivalence about the virtual working environment. MS Teams has helped with efficiency and use of time but has changed the focus away from home visits and convening the professional network in a person's home can now be difficult.

8.4. Participants were then asked to break again into small groups to discuss how safe care at home can be improved going forward. Three specific questions were posed:

- What can you do yourself in your own practice?

- What actions would you like to see others take?

- What actions would you like to see the SAB take?

8.5. Many priorities for change were put forward. At a personal level, practitioners emphasised the importance of:

- Not becoming de-sensitised to an individual's circumstances;

- Escalating concerns more readily;

- Not working in a silo but constantly communicating across to others;

- Taking timely action;

- Being clear, relevant, and accurate when giving information;

- Better use of mental capacity assessments (and recording them), to ensure that individuals do fully understand the risks of their health condition and the significance of advice and care provided.

8.6. In terms of aspirations for actions that others might take and/or that the SAB might offer leadership on, practitioners called for:

- Improved information to be included on referrals to avoid having to seek clarification;

- Using a common language and a single channel/format for sharing information;

- Possible development of an 'escalation map', specific to each individual, containing key contact details for varying avenues of communication about aspect of their care, and identifying a communication coordinator;

- Better communication around hospital discharge, and clear leadership of the need to coordinate discussion between agencies in the 72 hours following discharge;

- Equipment to be installed prior to discharge – this involves a better understanding of the necessary timelines for this and the need sometimes for an interim care plan;

- Improved use of technology for keeping people safe and use of photography for monitoring their condition. Also needed is skill development to build these facilities into care planning;

- A renewed focus on face-to-face assessments that can build a relationship with the individual;

- Better information from community nursing on dressings – what they do, how long they can be used, when should concern be raised;

- Better awareness of clinical care that is available over weekends;

- Recognising all agencies as equals, particularly when it comes to the contribution of care providers, promoting mutual respect;

- Honest discussion of the pressures – what can and can't be achieved in the current context.

- Mechanisms to ensure that all relevant agencies are invited to multidisciplinary team meetings and learning huddles;

- A Mental Capacity Act checklist giving easy access to essential information about assessment;

- A centralised directory of agencies/services (Heron was quoted as helpful in this regard but concern was noted about its closure);

- Sharing of good provider practice across the network of providers, led by Commissioning;

- The development of standards of communication, and incorporation of these within a charter that can become a benchmark.

8.7. A poll was used to check with participants whether they recognised the challenges described in the learning from Adult R's situation, with respondents selecting one of four possible answers to indicate whether recognised all, many, only a few or none of the challenges described. Thirty five of the 37 participants who responded said that in their current practice they recognised all or many of those challenges, with only 2 participants recognising just a few.

8.8. A further poll asked participants to specify what improvement actions could be taken, choosing all that applied of the following options. With 37 participants responding:

- 60% said there were things they could do in their own practice to improve safe care at home.

- 78% said there were things that could be done better in safe care at home, but that these would require changes in their own agency to make them possible.

- 78% said there were things that could be done better in safe care at home, but that these would require changes in other agencies to make them possible.

These responses indicate the widespread recognition that service improvement requires systemic change. Yes, actions can be taken on an individual level, but much improvement relies on changes within and between agencies at organisational level.

9. CONCLUSIONS

9.1. This review has found some clear examples of good practice in how Adult R's needs were met.

9.1.1. Her care while in hospital, particularly during the first, long admission, was in line with expected high standards. There was strong multidisciplinary involvement to meet her evolving needs, including those relating to her mental health as she came to terms with her recent bereavement and with the impact of her stroke.

9.1.2. Her care package was timely on discharge and remained as an 'open case' with Adult Social Care.

9.1.3. Manorcourt Homecare staff established a strong and empathetic relationship with Adult R in which she felt cared for and well looked after.

9.2. Nonetheless, the review has found shortcomings in a number of aspects of Adult R's care.

9.2.1. Risk analysis and management

As Adult R's skin integrity deteriorated, there is no evidence that alternative interventions were pursued. The earlier decision not to provide overnight care could have been revisited as the length of time she spent overnight without repositioning is likely to have negatively impacted on her skin integrity. An option for respite care could have been proactively sought; the muddle about who might be arranging it is symptomatic of poor interagency coordination and a lack of leadership. Everyone thought she needed respite care, but no-one acted to secure it, despite mounting evidence of her deterioration.

The risks arising from the interaction between Adult R's incontinence, her pressure ulcers, and the positioning challenges she experienced were not sufficiently recognized and managed. There is limited evidence that the risks of continuing to receive care at home were fully discussed with her, or that in the light of her declining health her wish to remain at home was questioned or revisited with her. Questions remain about whether she really understood the seriousness of her condition.

Overall, it is hard to avoid the conclusion that although all agencies were concerned about Adult R's declining health, they were (except for Manorcourt Homecare) not sufficiently proactive in seeking out an alternative intervention strategy to match the level of risk that she faced as her skin integrity deteriorated. While, during acute episodes, hospital admission took place (or was offered and declined), what is missing is evidence that any agency held more considered and frank discussions with her about the risks of remaining at home without additional support. There was no review of her needs and no clear strategy to identify what alternatives might have been available, or which agency might lead on discussing these with her.

9.2.2. Impact of equipment delay on care provided and on Adult R's tissue viability

The supply of equipment to Adult R's home was not straightforward. Some of the equipment ordered was not suitable and had to be replaced. Other items were not used due to instructions not being available or Adult R declining their use. The tilt-in-space chair, which would have provided a safe space into which she could be lifted from her bed, was not delivered at all but once available remained at the depot due to delivery being placed on hold during Adult R's second, short hospital admission and not being reactivated - a failure of liaison between commissioner and supplier.

While one piece of alternative equipment was considered to address the risks arising from the problems with repositioning, it was deemed unsuitable, and it seems that no further consideration was given to how equipment might help solve this problem.

While it is not possible to isolate one single equipment failure that impacted on her tissue viability, it is likely that the cumulative effect of multiple shortcomings took its toll on how effectively her care could be provided.

9.2.3. Working together

There are three key elements to effective interagency working: good communication and information-sharing, a shared intervention strategy, and effective coordination of the efforts of all involved. In Adult R's case all of these could have been improved.

There were barriers to interagency communication. The community nursing service restructure was perceived by the GP practice as having made communication more difficult. The community nursing triage hub and Manorcourt Homecare experienced difficulties in reaching each other to exchange information on Adult R's condition. Technology got in the way here, making it impossible at times for full exchange of information to take place.

At no point did the whole network convene together to share perceptions of risk and to plan for shared risk-management strategy. While each agency did what it might expect to do within its own role and function, each of Adult R's needs - pain management, pressure ulcer care, continence, positioning, personal care - was addressed separately. What was missing was holistic care management.

The impact of this was compounded by an absence of coordination and leadership. There was no one agency who could see the whole picture or act as a conduit of communication between those involved. In the absence of an overall risk management strategy, those closest to Adult R – the Manorcourt care workers – sought the attention of others when they considered Adult R's condition warranted it, coming closest to acting as a coordinator but without recognition or a clear mandate, other than that of necessity.

9.2.4. Escalation

The timely escalation of concerns is fundamental to securing appropriate review of an individual's safety. Escalation to those more distanced from the day-to-day situation, whether within a single agency's management structure or across agency boundaries, can lead to shared problem-solving that brings positive outcomes. Whether it results in an alternative strategy for managing risk, the release of resource not hitherto available, or simply an assurance that best practice is already established, it is an important component of professional and organisational accountability.

In Adult R's, a lack of awareness of suitable escalation routes was apparent, and even where awareness was in place, staff appeared not to be confident in using the pathways for escalating their concerns. The absence of safeguarding referrals, other than from Manorcourt Homecare on 17th August, is one example, compounded by missing knowledge in some agencies of the relevant guidance on escalation of concerns about pressure ulcers.

Escalation of concerns could have triggered important processes – review of Adult R's care and support provision, review of her turning plan, discussion of alternative ways of providing the care she needed or ways of increasing its frequency, respite care, and review of her eligibility for continuing care to enable care to be provided overnight.

10. RECOMMENDATIONS

In completing their IMRs, agencies were asked to identify what actions should be taken as a result of the learning from Adult R's case. In addition, participants at the learning event contributed their thoughts on improvement priorities. This section draws on both sources, as well as on the foregoing analysis of learning from Adult R's case, to set out recommendations to the SAB. The following priorities can be identified:

10.1. **Hospital discharge**: Learning from this SAR relating to Adult R, as well as learning on hospital discharge arising from 4 other cases under review by the Norfolk SAB, provides evidence of the need for action in relation to specific aspects of hospital discharge[23]. In addition, updated DHSC guidance on hospital discharge and community support, issued in January 2024[24], will require both strategic and operational arrangements for hospital discharge to be reviewed more broadly. Regardless of timescales for any developments arising specifically from the new DHSC guidance, actions arising from SAR learning should be pursued as a priority:

10.1.1. The SAB Quality Assurance sub-group should lead an audit of arrangements for discharge of people with complex needs, including (but not exclusively) those returning home to bed-based or fully hoisted care. Particular attention should be paid to:

- how night-time needs are considered and whether care arrangements (including overnight provision) are adequate,
- whether equipment is ordered and installed in a timely way, and
- how decisions on eligibility for continuing care funding are made, recorded, and reviewed in the light of any subsequent changes in the person's condition.

[23] Short case vignettes are provided in Appendix 1.

[24] https://www.gov.uk/government/publications/hospital-discharge-and-community-support- guidance/hospital-discharge-and-community-support-guidance

10.1.2. Based on the findings of that audit, the SAB Quality Assurance sub-group should lead a review of hospital discharge arrangements for people with complex needs, with a particular focus on multiagency planning and coordination. This might involve consideration of the need for a 'complex discharge forum' at which all agencies involved in any individual case can set out shared understandings of goals, intervention strategies for meeting them, expected milestone markers and pathways for escalation should they not be met. The resulting 'care map', specific to the individual, should also contain:

- key contact details for avenues of communication about aspects of their care;
- arrangements for proactive, ongoing multiagency review of their situation;
- a key agency named as case coordinator (for example, one of the agencies most closely responsible for their care) to ensure leadership and coordination of the arrangements going forward.

10.2. **Escalation:** The SAB Quality Assurance sub-group should review the different pathways available for escalation of concerns when the condition of an individual being cared for at home deteriorates. Relaunched guidance should include clarity on the choice of appropriate escalation pathways and triggers/thresholds for their use, as well as the importance of proactive review of whether the care and support in place is meeting changing needs. It should also emphasise the importance of attendance at multidisciplinary meetings, including the participation of care workers and others with direct knowledge and experience of the individual's condition.

10.3. **Pressure ulcer care**: NCHC should lead and report to the SAB on development of the following:

10.3.1. Guidance and checklists on the interaction between factors such as pain and continence with pressure ulcer condition;

10.3.2. Protocol and guidance on the expected use of photography for skin integrity monitoring;

10.3.3. Strengthened guidance on thresholds for tissue viability nursing involvement;

10.3.4. Discussion of a protocol for care providers to be able to contribute photographs as a means of exchanging information with community nursing staff;

10.3.5. Review of community nursing's ease of communication with care providers to identify any ongoing difficulties with call back to those referring concerns, and action to seek any necessary improvement;

10.3.6. Audit of care logs in individuals' homes and, based on the outcome of the audit, any action necessary to ensure they are consistently completed by all agencies;

10.3.7. Ensure awareness of best practice guidance on pressure ulcers diagnosis and management https://cks.nice.org.uk/topics/pressure-ulcers/;

10.3.8. Review and relaunch of local guidance on pressure ulcer care and safeguarding (in the context of the national guidance being suspended).

10.4. **GP safeguarding policies**: The ICB should undertake (and report to the SAB) an audit to identify whether all GP practices have access to a safeguarding adult policy (a template for which was produced and shared by the ICB in May 2022), who has access to the policy and how, and who is responsible for reviewing and updating it.

10.5. **Significant event analysis**: The ICB should ensure (and assure the SAB) that all GP practices in Norfolk and Waveney understand Care Quality Commission expectations for completion of significant event analysis[25].

10.6. **Mental capacity:** The SAB should review its resources on mental capacity to ensure that they provide sufficient guidance to practitioners on:

10.6.1. The need for mental capacity assessment in situations where an individual's decision- making places them at extreme risk;

10.6.2. The importance of a clear record to demonstrate that an individual's choice for discharge home has taken account of clear explanation of the risks involved and strategies to mitigate them.

The SAB should then re-launch the guidance, along with measures to embed its principles in practice and to monitor its effectiveness.

10.7. **Shared care records**: The ICB should undertake (and report to the SAB) an audit of GP patient records to identify whether they record consent (implied or explicit) to sharing of records with other SystmOne services. This should be followed by audit of NCHC patient records to identify whether patients' consent to accessing their GP data and sharing NCHC data with GPs is routinely sought and recorded.

10.8. **Transcription of medication**: The Integrated Quality Assurance Service should provide assurance to the SAB that where manual transcription of medication records remains in place, agencies have mechanisms for ensuring that the accuracy of transcription is cross- checked.

10.9. **Equipment**:

10.9.1. The Integrated Community Equipment Service should share the findings of this SAR relating to Adult R's equipment with NRS (who were responsible for equipment supply at the time) and Medequip (who now hold the contract for equipment supply), and with prescribers and commissioners of equipment.

10.9.2. The Integrated Community Equipment Service should escalate the learning from this SAR on equipment to the National Association of Equipment Providers at both regional and national levels.

[25] Care Quality Commission guidance on Significant Event Analysis

10.9.3. The Integrated Community Equipment Service should carry out an audit of equipment supply to people being receiving bed-based or fully hoisted care at home, to identify whether key performance indicators, particularly relating to suitability, timely delivery, and review, are being met. This will require the participation of Discharge Hubs across Norfolk to identify cases for audit, as well as of prescribers and of the supplier Medequip.

10.9.4. Based on the outcomes of the audit, the Integrated Community Equipment Service should address any shortcomings, if necessary, through revised contractual arrangements.

10.10. **Interagency communication**: The SAB should consider producing a 'communication charter' setting out standards for interagency communications to assist agencies in benchmarking their own communication practices and in resolving interagency communication difficulties.

10.11. **Safeguarding triage**: The SAB should seek assurance from the local authority on the outcomes of local authority audits of new arrangements for closure of section 42 referrals that do not become safeguarding enquiries.

10.12. **Safeguarding mandate**: The SAB should seek assurance from the local authority on its understanding that the legal mandate to conduct a section 42 enquiry ceases when an individual has died.

10.13. **Learning events**: The SAB should convene two learning events:

10.13.1. The first to disseminate and discuss this SAR's findings with agencies across the partnership;

10.13.2. The second, one year on, to report on the outcomes of actions taken in response to the improvement priorities identified in this SAR.

Appendix 1 – Case vignettes for Recommendation 10.1 on Hospital Discharge

Adults W1 and W2

Adults W1 & W2 lived together in a small market town in Norfolk. In the summer of 2022 concerns were raised by their doctors surgery that both Adults W1 & W2 were missing medical appointments. At this time Adult W2 was Adult W1's main carer. However, the surgery was concerned that Adult W2 was struggling to meet her own, as well as Adult W1's, activities of daily living.

A social care assessment was actioned for both Adults W1 & W2 and attempts were made to contact each party separately. During telephone contacts Adult W2 said her husband had taken himself to hospital for an appointment and she stated the couple did not need any support. The case was closed the same day, as it was recorded neither party needed any support.

Three days later Adult W1 was contacted by telephone, this call was answered by Adult W2, who told the caller that her husband was in hospital (no reason given/recorded for his admission). Adult W1's case was closed at that stage also, as it was seemingly considered that if he needed support, this would be recognised during his time in hospital and arranged on discharge.

During this time Adult W2 attended the surgery in a confused state and a referral was made to the Network Escalation Avoidance Team (NEAT).

Adult Services received a call from a worried neighbour of Adults W1 & W2 in early February 2023, raising concerns that both adults were self-neglecting, having noted during a visit to the couple, that there was moldy/out-of-date food, they were in bed a great deal, walking around with minimal clothing on/not dressed properly, both parties in a confused state and not locking the door.

The neighbour called Adult Services again two days later following up on their earlier call. The neighbour said they could no longer get into the home and that the house was in darkness. A visit was planned for the following morning, on Saturday. However, the neighbour called back on Friday evening, stating they had shone a torch through the letter box and saw Adult W1's legs lying on the ground. On calling the Police, they discovered Adult W1 deceased, with it being recorded that he had been deceased for a few days. Adult W2 was in the home with Adult W1, seemingly not realising Adult W1 had passed away and had placed a blanket over him. Adult W2 was reported to be very confused and could not explain what had occurred over the last few days. Further evidence of self-neglect was discovered as professionals accessed the home.

Adult W3
Adult W3 lived in supported living accommodation. He had a diagnosis of Prada-Willi syndrome, learning disabilities, and a number of physical health problems including heart failure.

In November 2021 he was admitted to hospital with shortness of breath and oedema. Soon after Adult W3 was admitted to hospital, the supported living provider gave notice of termination of his contract as they couldn't meet his increased needs. After an extensive search, an out of county residential care placement was identified. and discharge planning started at the end of January 2022. The early February discharge was delayed due to equipment delivery issues. Adult W3 was discharged to the new care placement on mid-February 2022, he arrived wearing socks, shorts and a hoody. The items were soiled and the hoody ill-fitting. Adult W3 had no other clothing or belongings with him. The necessary equipment for his diabetes management was not working.

Staff urgently needed to request a new prescription at the same time that he was registered with the new surgery the next day. Medical advice was sought but in the late afternoon his blood glucose levels were still low and he was admitted to hospital. Adult W3 passed away in hospital two days later on 12 February 2022. The acute hospital held a debrief meeting in mid-March 2022.

Adult W4
Adult W4 lived in a care home; she had cerebral palsy, moderate learning disabilities, epilepsy, dementia and dysphagia and required assistance with all aspects of daily living. Her mobility had decreased and within the last couple of years of her life, she required a hoist and use of a wheelchair. She lacked capacity for any decision and therefore all care was provided in her best interest. She was under a DoLS.

Adult W4 was admitted to an acute hospital in late May 2022 for being unwell and having increased seizure activity. She was diagnosed with aspiration pneumonia and remained in hospital until June 2022. During her hospitalisation, Adult W was found to have significant dysphagia and therefore advised nil by mouth, she lost 4.7kg in weight.

There was no discharge planning meeting to discuss how Adult W4's needs would be met in the community and the dietician's recommendations were not included on the discharge letter. No support for Adult W4's needs was offered to the care home and there was no handover to a community dietetic team for ongoing support.

Due to increased seizure activity Adult W4 was taken to A/E in late June 2022, admitted and stayed overnight. The care home understood that Adult W4 was being discharged for end of life however there was no referral to palliative care or any support to arrange medication if the patient was continuing to have seizures. The home was told that these were very likely due to brain shrinkage. Over the following 24 hours, the Adult W4 had 130 noted seizures. Paramedics were called three times and on the third visit they took her to hospital.

When Adult W4's seizures settled, a conversation took place between the care home

and medical team to decide if the patient could be discharged to a care home (her preferred place of death according to an advance care plan), but she was too frail to be transferred. Adult W4 remained in hospital for end-of-life palliative care.

Adult W5

Adult W5 was very well known to health and social care services in Norfolk and Suffolk. The local authority had 38 contacts recorded over 17 month period and 12 were marked 'Request for self-neglect enquiry'. Whilst he would agree to provision of care, there were occasions where he acted aggressively towards care staff and health professionals and declined care. The condition of his home and non-compliance with medication appears to be an ongoing theme with references to self-neglect.

Police visited Adult W5 at the end of December 2022, raising concerns about risk due to self-neglect and mental health, noting he had large bags of unused medication. Adult W5 was admitted to hospital on the 1st January 2023, having previously been discharged on or just prior to the 24th December, a discharge which was referred to as inappropriate by a Senior Community Nurse due to self-neglect, his home environment and lack of follow up in relation to diabetes, noting the lack of a discharge letter. A multi-disciplinary team (MDT) meeting was held on the 4th January, but he died on the 6th January 2023.