Cumbria Safeguarding Adults Board

Thematic Safeguarding Adult Review

Self-Neglect

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Cumbria Safeguarding Adults Board

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1. Introduction

1.1. Cumbria Safeguarding Adults Board (CSAB) works in partnership with organisations across Cumbria to help protect adults with care and support needs from abuse or neglect. It is a statutory body established under the Care Act 2014 by the two unitary councils in Cumbria - Cumberland and Westmorland & Furness, which were created by local government restructuring in 2023.

1.2. During 2023, CSAB received notifications about a number of individuals who had died in circumstances of self-neglect. The Board had previously published reports from Safeguarding Adult Reviews (SARs) in earlier self-neglect cases, which had already led to action to strengthen safeguarding for people who self-neglect. In the light of the further six deaths, the Board was concerned to identify what systemic barriers to best practice in self-neglect remained and what features of safeguarding practice across agencies might need further adjustment to improve how people who self-neglect are supported and protected.

1.3. In Spring 2024, therefore, CSAB commissioned a thematic review, seeking common themes across the circumstances in the six cases. This was to include consideration of how the individuals involved had been supported, but also a broader scrutiny of how agencies across the partnership are working with self-neglect currently. This would enable the Board to identify the features that support best practice and those that might hinder it and to address these in its improvement priorities.

1.4. The individuals whose circumstances are included within this review are:

Name[1]	Local Authority	Age	Date Of Death[2]	Circumstances
Bill	Cumberland	53	7/4/2023	Died in hospital: cardiac arrest secondary to multi-organ failure.
Donald	Cumberland	78	6/2/2023	Died in hospital: urosepsis and diabetic ketoacidosis with cerebrovascular disease and self-neglect.
Diana	Cumberland	75	8/8/2023	Found deceased at home: cause of death unascertained.
Julie	Cumberland	52	1/11/2023	Found deceased at home: alcohol-related cause of death - acute ethanol toxicity.
Paul	Westmorland and Furness	53	21/6/2023	Found deceased at home: alcoholic cardiomyopathy with chronic obstructive pulmonary disease.
Tom	Cumberland	85	16/2/2023	Died in a fire at his home: accidental death.

[1] The families of Diana, Paul and Tom wished the individual's given first name to be used. Donald and Julie are pseudonyms selected at the family's request and Bill is a pseudonym selected by the Board in the absence of family involvement in the SAR.

[2] In some cases, this is the date on which the individual was found deceased rather than the date of death.

2. The Thematic Safeguarding Adult Review Process

2.1. The Care Act 2014 gives Safeguarding Adults Boards a statutory mandate to arrange a Safeguarding Adults Review in certain circumstances. Under section 44 (1-3), a review **must** take place where:

- An adult with care and support needs[3] has died and the Board knows or suspects that the death resulted from abuse or neglect[4], or an adult is still alive and the Board knows or suspects that they have experienced serious abuse or neglect, **and**
- There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

The Board has discretion (section 44 (4)) to undertake a review in any other case involving an adult with care and support needs.

2.2 The Care Act requires SAB partners to co-operate with and contribute to the review, with a view to identifying the lessons to be learnt and applying those lessons in the future[5]. The purpose is not to allocate responsibility or blame for the events but to identify ways of improving how agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

2.3. CSAB commissioned an independent reviewer[6] to lead the thematic review and established a SAR Panel of senior agency representatives, chaired by a senior officer from Cumberland Council who had no involvement with any of the cases, to work with the reviewer.

2.4. The key lines of enquiry for the review are as follows:

2.4.1. Are the six principles of safeguarding set out in the Care Act 2014 statutory guidance reflected in the approach taken to working with people who self-neglect?

- Prevention: Are we able to take preventive action before harm occurs?
- Protection: Do we protect and support those at greatest risk?
- Accountability: Do we deliver transparent and accountable safeguarding?
- Partnership: Do we deliver an effective multiagency response?
- Empowerment: Are people supported and encouraged to make their own decisions? Do their views inform agencies' interventions?
- Proportionality: Are we able to provide the least intrusive response appropriate to the risk presented?

2.4.2. What organisational or partnership factors aid or act as a barrier to effective practice?

2.4.3. Is there evidence that learning from previous SARs has impacted across the system?

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[3] Whether or not the local authority has been meeting any of those needs

[4] Abuse and neglect' includes self-neglect (Care Act 2014 Statutory Guidance)

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

[6] Suzy Braye (Emerita Professor of Social Work at the University of Sussex) is an independent adult safeguarding consultant with specialist expertise in self-neglect and in learning from safeguarding adult reviews.

2.4.4. Are there any relevant changes/improvements that have been implemented subsequent to the review scope period?

2.4.5. What further improvement priorities can be identified?

2.5. In each of these key lines of enquiry, focus is placed on both good practice and practice shortcomings, with a view to learning lessons that can be applied to future practice.

2.6. The time period under review for each individual was one year prior to their death.

2.7. The key steps for the thematic SAR are:

a. Review of initial scoping information gathered on each case by CSAB;

b. Review of chronologies of involvement and reflective/evaluative reports from agencies involved;

c. Initial analysis of emergent themes by the independent reviewer;

d. An event with front-line practitioners, operational managers and safeguarding specialists to explore the challenges and strengths of current self-neglect practice;

e. Meetings with family members[7];

f. Further analysis and consolidation of the emergent learning into a final report and recommendations to the CSAB.

2.8. The following agencies have submitted information to the thematic review, detailing and evaluating their involvement with the individuals concerned.

Accent Housing	Paul
Beacon Homecare	Tom
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW)	Donald, Julie, Tom
Cumberland Council Adult Social Care and Housing[8]	Bill, Donald, Diana, Julie, Tom
Cumbria Community Homes	Julie
Cumbria Fire and Rescue Service (FRS)	Bill, Donald, Tom
Cumbria Police	All six individuals
Home Group	Donald
Lancashire and South Cumbria Integrated Care Board (LSCICB) and relevant GP practice	Paul
Lancashire and South Cumbria Foundation Trust (LSCFT)	Paul
North East and North Cumbria NHS Integrated Care Board (NENC ICB) and relevant GP practices	Bill, Donald, Diana, Julie, Tom
North Cumbria Integrated Care NHS Foundation Trust (NCIC)	Bill, Donald, Julie, Tom

[7] Statutory guidance on SARs requires family members to be invited to contribute to reviews.

[8] Prior to disaggregation of Cumberland Council and Westmorland and Furness Council, services to the individuals concerned were provided by Cumbria County Council.

North West Ambulance Service (NWAS)	Bill, Donald, Diana, Julie, Tom
Recovery Steps Cumbria	Julie
University Hospitals of Morecambe Bay NHS Foundation Trust (UHMBFT)	Paul
Victim Support	Julie
Westmorland and Furness Council Adult Social Care[9]	Paul
Westmorland and Furness Council Public Health	Paul

3. Family Engagement

3.1. CSAB sought contact with known relatives of all six individuals included in the review to advise that the review was taking place and inviting their participation.

- Bill's aunt and brother were informed about the SAR and invited to contribute, but neither responded.
- Donald was known to have a son but no contact details were available. Donald's partner was informed about the SAR and participated in a telephone conversation with the independent reviewer in which she shared some information about Donald and learnt about the review findings and recommendations.
- Diana's sister-in-law and niece were informed about the SAR and chose to participate. The independent reviewer met with them at the sister-in-law's home and subsequently had follow-up contact to share the review's findings and recommendations.
- Julie's parents were informed about the SAR and her mother agreed to contribute. The independent reviewer had a telephone discussion with her to learn about her perspective on Julie's experiences and a follow-up conversation to share the review's findings and recommendations.
- Paul's two sisters were informed about the SAR and attended online meetings with the independent reviewer. They also attended the SAR panel to share their perspectives directly with senior agency representatives. At a follow-up online meeting the independent reviewer shared the review's findings and recommendations.
- Tom's two nieces were informed about the SAR and invited to contribute. One niece had a telephone conversation with the Board Manager and subsequently attended online meetings with the independent reviewer, including a follow-up meeting to learn about the review's findings and recommendations.

3.2. These conversations were very helpful in providing information that extends the review team's understanding of the individuals themselves, and also in learning families' perspectives on the work of the agencies involved. With their permission, a full record of their views appears as a later section in this report. CSAB and the independent reviewer recognise that participating in a SAR is not an easy process for families and are very grateful for their willingness to contribute to the learning that can emerge from such tragic circumstances.

[9] Prior to disaggregation of Cumberland Council and Westmorland and Furness Council, services to the individuals concerned were provided by Cumbria County Council.

4. Parallel Processes

4.1. Individual agency reviews

4.1.1. There were no internal parallel reviews in respect of Bill, Donald or Diana.

4.1.2. In respect of Julie, North Cumbria Integrated Care NHS Foundation Trust undertook a Rapid Review and provided the investigation report (15th November 2023) to this SAR.

4.1.3. In respect of Paul, Lancashire and South Cumbria NHS Foundation Trust carried out a Concise Investigation and provided the report to this SAR. Paul's sisters were involved in the investigation, providing questions for the Trust to respond to. On its completion, they attended a meeting with the Trust for further discussions. This resulted in an addendum report, which his sisters themselves provided to this SAR.

4.1.4. In respect of Tom, Cumbria Fire and Rescue Service carried out a Fire Scene Investigation and provided the report, dated 2nd May 2023, to this SAR.

4.1.5. The learning outcomes derived from the above parallel review processes are listed in Appendix One of this report.

4.2. Coroner's office

4.2.1. The Coroner's office has no record of Bill.

4.2.2. The inquest relating to Donald, held on 12th October 2023, concluded that he died of neglect.

4.2.3. The inquest relating to Diana, held on 25th June 2024, reached a narrative conclusion: "Diana was 75 years old. She lived alone …. She lived an extremely isolated and reclusive life. On 9th August 2023 her body was discovered in the loft of her home. It is not possible to ascertain how she came by her death."

4.2.4. The inquest relating to Julie, held on 2nd May 2024, concluded with a Regulation 28 Report to Prevent Future Deaths[10] issued to to North Cumbria Integrated Care NHS Foundation Trust, to which the Trust has made a formal response. Both documents have been provided to this SAR.

4.2.5. In relation to Paul, the Coroner's Office found in May 2024 that the cause of his death was alcoholic cardiomyopathy in the context of chronic obstructive pulmonary disease. The Coroner therefore discontinued their investigation and no inquest took place.

4.2.6. The inquest relating to Tom, held on 23rd March 2023, found that he died of smoke inhalation in combination with chronic obstructive pulmonary disease and ischaemic heart disease, concluding that this was an accidental death. The Coroner issued a Regulation 28 Report to Prevent Future Deaths[11] to Cumberland Council Adult Social Care. The local authority subsequently responded to this report listing actions that it had taken, or was intending to take, to address the concerns raised. Both documents have been provided to this SAR.

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[10] Issued under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.

[11] Issued under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.

5. The Six Individuals

5.1. Bill died in his early 50s. He had chronic obstructive pulmonary disease (COPD) and was alcohol dependent. He lived in squalid conditions with a lodger/friend and visitors who drank with him and possibly exploited him financially. His mobility was severely impaired and he relied on his friends to assist him with shopping, medication collection and cooking. He received pressure ulcer care from community nurses who made multiple safeguarding referrals about the conditions in his home and risks to his health and safety. In April 2023 he was admitted to West Cumberland Hospital and his aunt, concerned about his living conditions, mobility and general welfare, made a safeguarding referral to Adult Social Care, which was linked to an open safeguarding enquiry that had not yet been started. Two days later Bill died in the hospital's Intensive Care Unit from cardiac arrest secondary to multi-organ failure.

Agency involvement:

- **North Cumbria Integrated Care:** Bill was open to the community nursing service for six months between August 2022 and February 2023, primarily for pressure ulcer and moisture lesion care. The community nursing team raised multiple safeguarding concerns about the conditions in his home and escalated his case to the health-led Complex Case MDT. Bill also had multiple hospital inpatient stays associated with his COPD.
- **Cumberland Council Adult Social Care:** Bill was referred to ASC five times between 2014 and 2022 for health and mobility-related concerns. Further referrals resulted in a Care Act assessment in October 2022, followed by onward referrals for practical support. Multiple safeguarding referrals about self-neglect, skin integrity, home conditions and potential exploitation were also received during 2022 and 2023. All but the last of these were triaged out as not meeting a safeguarding threshold, either because they were single agency issues or because agencies (including Adult Social Care) were already involved in attempts to meet his needs. The final referral proceeded to s.42 enquiry but action was not taken under the enquiry framework before he died 3 weeks later.
- **Cumbria Fire and Rescue Service:** the Fire and Rescue Service made a visit to Bill in September 2022 at the request of the community nursing service. They undertook a risk assessment and provided fire safety advice.
- **Primary care:** Bill had been registered with his GP surgery since 1973. During the period under review, the surgery had contacts with him relating to his COPD, alcohol use and smoking, skin infection and hyponatraemia. Social prescribers provided him with food. He was a high intensity user of NHS 111, often resulting in onward contact with Cumbria Health On Call. The surgery raised a safeguarding referral in August 2022 in respect of his living conditions and skin integrity
- **North West Ambulance Service:** The Ambulance Service had a number of contacts with Bill, mainly for breathing difficulties and exacerbation of COPD or prescription requests. He was sometimes taken to hospital but on occasions when he refused he was referred to his GP. Within the timeframe of the review, the Ambulance Service raised 4 concerns in respect of his home environment and care needs.
- **Recovery Steps Cumbria:** Recovery Steps were involved with Bill in late 2021 for support with his alcohol dependence. He was assessed as suitable for an inpatient alcohol detox

and was on a waiting list for admission. He disengaged with the service, however, missing numerous appointments and was discharged from the service in February 2022. In September he re-referred himself but did not attend any of the appointments offered and his referral was again closed.

- **Cumbria Police:** The Police had involvement with Bill back to 2010. In the 12 months before his death, they were involved twice: (i) investigation of potential exploitation by a friend and (ii) domestic incident between a man (not Bill) and a woman living at his address, resulting in a safeguarding report to Adult Social Care about risks to Bill. They had raised three previous safeguarding reports relating to Bill's vulnerability to fraud, malicious communications and domestic incidents.

5.2. Donald died in his late 70s. He lived with his partner in poor conditions with significant hoarding. He had diabetes and neglected his health, diet, personal care and property, frequently soiling himself and his surroundings. He had memory difficulties and presented sometimes with confusion but declined formal testing. He declined all care and support. One night he fell from the chair in which he slept, with his partner reporting this to emergency services the following morning. This resulted in his admission to hospital, where he was placed on end-of-life care and died 3 days later. An inquest concluded that he died as a result of neglect.

Agency involvement:

- **Cumberland Council Adult Social Care:** Donald was first referred in 2017 and received support from the Health and Wellbeing Coach service to secure his own accommodation. HAWC support continued until 2019. In November 2022, following referrals about the state of the property, Adult Social Care undertook assessments under the Care Act 2014 (which identified that he had eligible care and support needs) and the Mental Capacity Act 2005 (which identified that he lacked capacity in relation to his care and support). Donald declined support and his case was transferred to a longer-term team to take a relationship-building approach but attempts at contact in the days before he died were unsuccessful.
- **General Practice:** Donald had been registered with the same GP practice from birth. He received medication for blood pressure, blood thinning, diabetes, enlarged prostate and urinary urgency/incontinence. He did not consult a GP during the final year of his life, though he did attend diabetes screening and received Covid vaccine boosters during that period. In May 2022 he did not collect his repeat medication and made no further repeat prescription requests after that date.
- **Cumbria Fire & Rescue Service:** The Fire and Rescue Service carried out a safe and well visit in November 2022.
- **Cumbria, Northumberland, Tyne and Wear Foundation Trust:** Donald was referred for delirium screening during his final hospital admission but this did not proceed as he was on an end-of-life pathway.
- **Home Group:** Home Group were Donald's housing provider. He had been the sole tenant of his property, a general needs rented property, since 2017 following a period of homelessness. Alerted by an electrical contractor to its condition, they visited in November 2022 when Donald's partner was staying there with him. They found the flat clearly hoarded with risks on access, health and safety, and referred to Adult Social Care.

- **North Cumbria Integrated Care:** When he collapsed at home following the fall from his chair, Donald was admitted to West Cumberland Hospital. He was unresponsive and a DNACPR[12] was put in place. He was placed on palliative, end of life care and died 3 days later. The trust had had no prior involvement.
- **Cumbria Police:** The police had had historic involvement only, and in 2017 had raised a safeguarding report relating to squalid conditions and hoarding in the property. They had no contact during the period under review.
- **North West Ambulance Service:** NWAS attended following Donald's collapse at home. They found the home significantly cluttered and a fire risk. Donald was emaciated and his clothing was stuck to his skin. He was transported to hospital under emergency conditions and a safeguarding concern was raised with Adult Social Care.

5.3. Diana died in her mid 70s. She lived alone in a severely neglected and decaying property and in conditions of self-neglect. Although she sought engagement with services during crises such as utility problems at the property, she persistently refused any ongoing support/services and withdrew into her isolation. She was found deceased by the police in the loft of her property following an alert from a neighbour who had not seen her for a long time. An inquest concluded that the cause of her death was unascertained.

Agency involvement:

- **Cumbria Police:** were called on several occasions during the 2 years prior to her death to check Diana's welfare in response to concerns from others. They found her house extremely hazardous but she declined any support. They ensured her urgent safety and wellbeing and referred her to Adult Social Care. On the final visit they found her deceased. They submitted the SAR referral.
- **Cumberland Adult Social Care:** in September 2022 Adult Social Care attempted without success to contact Diana in response to a referral from the borough council, concerned about the state of her property. In December, a further referral from a tradesman prompted a police welfare visit and subsequently home visits by Adult Social Care. The safeguarding enquiry was closed in January 2023 following a Care Act assessment that resulted in short term action to support involvement of an electrician, with Diana declining all other services. There was no further contact.
- **General Practice:** Diana had been registered with her GP surgery since 2017. A GP saw her at home in December 2021 and had subsequent occasional phone contact. In March 2023 she cancelled a surgery appointment, saying she would re-book when she felt brighter, but no further contact took place prior to the discovery of her death.
- **North West Ambulance Service:** The Ambulance Service were called to Diana's home by the Police in December 2022. Following clinical assessment she declined all offers of support. The ambulance crew considered she had capacity to understand the risks she faced in the property. They referred concerns about her safety to Adult Social Care.

5.4. Julie died in her early 50s. She was alcohol dependent and had hepatitis, liver cirrhosis, fibromyalgia, pernicious anaemia, vertigo, seizures, tachycardia and hypertension. She was extremely vulnerable when intoxicated, with seizures, falls and injuries necessitating emergency services' attention and hospital attendance. After periods of homelessness, she

[12] A recorded decision that that cardiopulmonary resuscitation will not be attempted.

spent time in the home of a male friend and disclosed he had assaulted and raped her. She subsequently moved to sheltered accommodation and had a period free of alcohol but later returned to drinking. She was found deceased at home the day after treatment for a seizure in the hospital Emergency Department. She had been discharged the previous evening without informing her housing support workers, who had requested notification of her discharge. An inquest concluded that her death was alcohol-related and the Coroner issued a Regulation 28[13] notice to North Cumbria Integrated Care NHS Foundation Trust.

Agency involvement:

- **North Cumbria Integrated Care:** Julie had a significant number of contacts with the Trust's services dating back to 2012 with ad hoc attendances at emergency departments presenting various health concerns. She came to the notice of the safeguarding team when she disclosed domestic abuse in January 2023, resulting in DASH, MARAC and safeguarding referrals. In May 2023 she spent 4 weeks as an in-patient, undergoing detoxification, and a further 5 days in October. Following this, she was discharged from a final emergency department attendance and was found deceased the following day.
- **Cumberland Adult Social Care:** Adult Social Care provided a health and wellbeing coach, received safeguarding referrals relating to Julie's self-neglect and domestic abuse, and carried out a safeguarding enquiry, including risk assessments. In early 2023 multiagency safeguarding meetings took place on a monthly basis. During June 2023 reablement were involved in assessing her needs following a period of hospitalisation.
- **Cumbria, Northumberland, Tyne and Wear Foundation Trust:** Julie had sporadic involvement with mental health services (2020 and 2021) but had no formal mental health diagnosis. She was recognised as being at risk due to her alcohol dependency and homelessness. During an emergency department attendance in November 2021 she was referred to the Psychiatric Liaison Team and in early December disclosed to them that she had been raped by the friend with whom she was staying. The mental health practitioner raised a safeguarding concern, advised her to contact the Police and referred her for safe accommodation (which she declined). After this period of involvement mental health services had no further contact with her.
- **Cumbria Community Homes:** Cumbria Community Homes were Julie's housing provider (sheltered housing) from February 2023. They provided 3-5 hours per week tenancy-related support: this involved supporting her with bill and budgeting, reporting and recognising repairs, attending appointments and ensuring her benefits were correct.
- **General Practice:** Julie's GP was in regular contact with her, monitoring her health and prescribing medication, and had extensive involvement in the 12 months prior to her death. The surgery made referrals to social prescribing and Recovery Steps Cumbria.
- **North West Ambulance Service:** the Ambulance Service's contacts with Julie primarily related to her need for care during alcohol-related seizures. They shared 15 safeguarding concerns with adult social care between 2018 and 2023 and provided pre-hospital emergency treatment and transport to her on 6 occasions in the year before she died.

[13] The Coroners and Justice Act 2009 allows a coroner to issue a Regulation 28 Report (known as a Report to Prevent Future Deaths) to any individual or agency where the coroner believes, following an inquest, that action should be taken to prevent further deaths.

- **Cumbria Police:** Between April 2020 and November 2022 there were 23 risk reports for Julie concerning rape, domestic abuse and coercive and controlling behaviour on the part of her friend. In December 2021 no further Police action was taken on her report of rape as she was herself not supportive of this. Following consideration of the domestic abuse/coercion at MARAC in February 2023, officers carried out safety planning with her.
- **Victim Support:** Victim Support supported Julie at various points between April 2020 and April 2023.
- **Recovery Steps Cumbria:** Julie referred herself to Recovery Steps in November 2022 and received support towards achieving alcohol detox and abstinence. The plan was to work towards a medically assisted alcohol detox in an inpatient facility, a setting preferred due to her presenting physical health needs, unstable housing situation, limited suitable support and history of alcohol related seizures. She became alcohol-free following an in-patient hospital stay and from July 2023 felt she no longer needed support.

5.5. **Paul** died in his early 50s. He lived alone. He was alcohol dependent and experienced increasingly poor physical health. His heavy alcohol intake had resulted in abnormal liver function and he suffered from asthma, cellulitis, leg ulcers, insomnia, peripheral neuropathy and an ischemic toe requiring an arterial stent. He also had a colovesical fistula for which he required colorectal surgery. He had been diagnosed with bipolar disorder, emotionally unstable personality disorder, low mood and possibly autism. His father's death in 2022 triggered a significant decline in his mental health. He had become alcohol-free but began to drink again and his living conditions became very squalid. In fear and distress about his condition, he requested help with moving accumulated soiled rubbish. His sisters also raised concerns and requested help for him. Following triage by the Initial Response Service he was allocated to the mental health social work team for assessment, but no assessment had taken place by the time he died. The Coroner's office concluded that he died of natural causes.

Agency involvement:

- **Lancashire and South Cumbria Foundation Trust:** Paul had been assessed by secondary mental health services in December 2020 following episodes of suicidal ideation, poor sleep, low appetite, feelings of hopelessness, financial stresses/unemployment and panic attacks. Following short-term follow-up he was discharged back to the care of his GP a month later. In March 2023 he had contact with the mental health Initial Response Service, where triage assessment indicated that he was struggling with multiple stressors. IRS advised him to contact Cruse for bereavement counselling and requested support from ASC to clear and clean his flat. They had no further contact with Paul.
- **Accent Housing:** Accent Housing were Paul's landlord between 2015 and 2023. Their interaction with him was mainly by phone, with occasional tenancy visits. In April 2023 a postal delivery worker reported a smell from the property, resulting in Accent visiting and subsequently raising a safeguarding referral. They were advised by Adult Social Care that the Council would not assist with arranging clearance of Paul's rubbish and would not provide support until the rubbish was cleared. In May 2023 Accent secured a quote from a cleaning company and agreed to support the cost. However the work did not take place prior to Paul's death, for reasons that remain unclear.
- **General Practice:** Paul was registered with his GP surgery for most of his life, apart from one brief period spent elsewhere. He accessed the surgery for consultations on a range of

physical and mental health symptoms that often-required treatment and/or onward referral to specialist services. He had frequent contact with his GP following his father's death, for discussion of both his physical and mental health. During 2022 the GP referred him to Recovery Steps (although he did not engage with this service), liaised with UHMBT about treatment for his colovesical fistula and referred him to Adult Social Care to secure Health and Wellbeing Coach support. In March 2023 a GP also spoke to Paul after Adult Social Care reported a serious deterioration in Paul's wellbeing.

- **Cumbria Police:** the Police had historical involvement when Paul was cautioned for an assault. During the period under review their only involvement was when they were called to attend Paul's home and found him deceased.
- **University Hospitals of Morecambe Bay Trust:** the acute hospital had ad hoc involvement with Paul over a number of years. Podiatry and district nursing also had some contact with him in 2021. In March 2022 he was referred for colorectal surgery but did not attend appointments; his GP re-referred him in March 2023 and he was added to the wait list.
- **Westmorland and Furness Council:** Paul had historically received health and wellbeing coach services (HAWC), provided by Public Health. He was offered the service again in December 2022 following a request from his GP but declined support. In March 2023 he self-referred to Adult Social Care, with his sister making a follow up referral. The Short-term Assessment Team liaised with the mental health Initial Response Service and passed the request for support to the mental health social work team. They also referred him to the HAWC service, although his sister expressed concerns that he was unlikely to allow them access. HAWC had phone conversations with Paul to offer support and also referred him to Adult Social Care for Care Act assessment. While this referral awaited allocation HAWC continued their contact with him, although Paul refused them access to his home, and they liaised with his landlord about the rubbish clearance. The mental health duty team also asked the Council's waste service to assist with removing it but this was declined[14]. Despite HAWC's repeated contacts, Paul remained reluctant to engage with the service and at the end of May his case was closed. No resolution of the waste removal was achieved and no Care Act assessment took place prior to his death.
- **North West Ambulance Service:** the Ambulance Service attended Paul on two occasions: in December 2021 to convey him to hospital following assessment from a GP and in June 2023 when the Police forced entry and found him deceased. Ambulance clinicians attended and confirmed his death.

5.6. Tom died in his mid 80s. He had lived alone since his wife's death in 2019 and was supported by his two nieces. He lived in squalid and unhygienic conditions due to his refusal to use the toilet and bathroom, which resulted in him and his surroundings being soiled. He had venous insufficiency causing skin breakdown and leg ulcers, which were attended by district nurses. Since 2020 he had received daily care visits to wash and cream his legs but he refused personal care. He smoked and fire risks had been identified due to his method of cigarette disposal. He died in a house fire and an inquest concluded that his death was accidental.

Agency involvement:

- **Cumberland Adult Social Care:** Adult Social Care had provided support for Tom since 2020,

[14] Westmorland and Furness Council waste services were approached for further information but found no record of this contact.

following referral from the Integrated Care Community for general domiciliary care to treat the oedema in his legs. Following further concerns about his personal care a social care package was arranged from June 2022. In January 2023 Adult Social Care received four safeguarding referrals about fire risk from the care provider and district nurses, the last of which was escalated to s.42 enquiry, but this did not proceed before Tom died.

- **Beacon Homecare:** Beacon Homecare were commissioned by Adult Social Care to provide daily care visits to support Tom with his skin integrity. Aware of his fire risks and concerned about his personal care, they maintained regular contact with Adult Social Care, district nurses and Tom's nieces, and raised a safeguarding concern about his safety.
- **Cumbria Police:** The Police had historical involvement when Tom was a victim of criminal damage to his property in 2010. They had no further involvement other than when called to the house at the time of his death in the fire.
- **General Practice:** Tom's GP responded to physical health concerns as required and Tom was also visited by the frailty team, with follow up monitoring as required. Ongoing leg swelling was investigated.
- **North West Ambulance Service:** The Ambulance Service attended Tom once, following a report of leg swelling and lethargy. On this occasion he refused hospital treatment and was given worsening advice. They were also called to the fire in which he died.
- **Fire and Rescue Service:** The Fire and Rescue Service had carried out a home fire safety visit to Tom's property in May 2020 and were called to the fire on 16/2/23.
- **NCIC:** Tom was known to the district nursing service from February 2022 following referral for Doppler assessments. He was seen on a regular basis by the community nursing team throughout the year depending on the condition of his legs but was often non-compliant with treatment. Nurses raise safeguarding concerns about fire risks in January 2023.
- **Cumbria Health On Call**: There was one On Call contact with Tom regarding a swollen leg.

6. Thematic Analysis

6.1. A systemic learning focus

Evidence from SARs on self-neglect nationally shows that in cases that have had tragic outcomes the answers to questions about why events unfolded as they did are often to be found within wider domains of the safeguarding system, which influence how practice takes place. This points to the need for the SAR to focus on the safeguarding system as a whole.

Domain 1: Direct practice: how practitioners engage with the individual

Domain 2: Interagency working: how practitioners from different agencies work together

Domain 3: Organisational features: how organisational features influence the work done

Domain 4: Governance: the leadership exercised by the Safeguarding Adults Board

Domain 5: National context: the influence of national factors (law/policy/economics)

Thus this thematic SAR seeks broader answers to the question of why direct practice unfolded as it did in the cases under review and makes recommendations for improvement priorities to strengthen all levels of the safeguarding system. Learning themes in each domain are explored in turn.

Domain 1: Direct practice

6.2. Meeting needs

6.2.1. The six individuals all had complex and multiple needs relating to physical and mental health as well as in relation to their daily living and personal care. A key question for the SAR is how well those needs were recognised by agencies, to what extent they were met and what system barriers might have been present.

6.2.2. It is clear that physical health needs presenting acutely were generally met, often through Emergency Department attendance and/or hospital admission during which necessary medical care was provided. In Julie's case, for example, her housing provider was proactive in summoning help when medical attention was clearly necessary. In some cases such episodes acted as gateways for other needs to be addressed, as when she underwent detoxification in hospital following admission for abdominal pain.

6.2.3. The individuals' primary care needs also were met, with their respective GPs often attentive in undertaking annual reviews, assessments, interventions and preventative measures including advice on smoking cessation, exercise, alcohol use and diet as well as blood investigations, blood pressure, pulse, weight, height and BMI monitoring. Onward referrals to other primary care services such as district nursing took place, as well as to specialist services, as for example when Donald was referred to memory services, and Tom to the Frailty Team.

6.2.4. However, GPs were not always aware of deterioration in health. In some cases individuals were hidden from view due to their own reluctance; in others, where contact did take place it was often by phone, so without the opportunity for the GP to match what the individual told them with their own professional observations.

6.2.5. There was evidence too that some individuals found contacting their GP difficult. Bill, for example, presented his health needs in an immediate and unplanned way rather than through his GP surgery, frequently calling on the ambulance service, NHS 111 and Cumbria Health on Call. Paul's family say he found the GP call triage system, which he believed required calls to be made at specific times, frustrating (although the surgery's own perspective is that, despite high volumes of incoming contacts, patients can call at any time during weekday opening hours. There is evidence that when Paul did contact the surgery they were responsive, but there may have been times when he felt discouraged and did not call. This does indicate a need for further exploration of patient views on surgery front door processes, particularly seeking out the views of those who may experience challenges in following the regular pathways.

6.2.6. There were in fact multiple barriers to needs being recognised and met. Individuals' reluctance to engage, with contact often confined to crisis episodes followed by withdrawal, made it difficult to gain a full picture. Such was the case with Bill, Donald, Julie, Diana and Paul. While the Cumbria, Northumberland, Tyne and Wear Foundation Trust undertook active outreach through cold calls to Julie, they reflect that the sporadic nature of their involvement militated against comprehensive needs fulfilment.

6.2.7. Health providers, becoming aware of individuals' wider needs, would sometimes signpost them to other services. In some cases, however, the individual's needs made them unable to be proactive in following these signposts. More direct referral practice was necessary in many

cases, as for example when the Ambulance Service referred Bill for early help or alerted the hospital to the conditions in Donald's home when conveying him for immediate clinical support.

6.2.8. In some cases services did recognise needs and were proactive in calling in other agencies. One example is an electrical contractor who, having visited Donald's property, alerted his housing provider to its condition, triggering a housing provider visit during which the hoarding in his property was recognised and referred to Adult Social Care. Others failed to recognise needs beyond those to which their own involvement related. Cumbria Fire and Rescue Service, for example, in carrying out home fire safety visits to Bill, Donald and Tom, made no observations about conditions in the home and did not note the evident indicators of self-neglect. Paul's GP surgery, reviewing possible missed opportunities in their contact with him, reflects that the home visit undertaken in December 2022 focused primarily on his physical ill-health. While this was appropriate in the context of his clinical presentation at the time, the surgery recognise that it could also have been an opportunity to recognise his self-neglect and need for support.

6.2.9. For some individuals, there was no Care Act 2014 assessment. In Diana's case, her reluctance was certainly a barrier, but so too was an absence of curiosity on the part of Adult Social Care practitioners who took at face value her reassurance about the state of her property without checks on the accuracy of what they were told. This was despite being aware of the level of decay noted by the Police on a previous visit. For Julie, the focus of Adult Social Care involvement was limited to a Discharge to Assess assessment and onward signposting to Age UK. Her self-neglectful behaviour was seen as indelibly linked with her alcohol dependency, and it was recovery from the alcohol dependency that was seen as the priority. For Paul, despite the need for Care Act assessment being recognised, no assessment was offered for 4 months, by which time he was deceased. In Donald's case, despite awareness this his partner was actively undertaking care duties for him, no carer's assessment was offered.

6.2.10. When assessments of need did take place, they did not always convey an accurate picture. In Bill's case, a social worker found conditions in his home less concerning than other agencies had reported and concluded that although he had eligible needs his friend was meeting them. Those that remained unmet – primarily his need for a move to a ground-floor flat – became the focus of concern rather than his daily living needs, despite the social worker being aware that reablement had declined to provide a service to him due to the conditions in his home. Adult Social Care reflect that use of a clutter-rating tool could have given a clearer picture of his needs. In Tom's case, the services that were provided following Care Act assessment were not successful in fully meeting his needs, despite the best efforts of the care workers, due to his refusal of personal care and difficulty in adapting his risky behaviour. Yet this does not seem to have resulted in a review of the arrangements, the provision of additional support such as OT aids, or escalation to intervention that could have managed risk more effectively.

6.2.11. In terms of specialist services, some good practice in meeting needs is evident. In Julie's case, Recovery Steps Cumbria carried out a comprehensive assessment in November 2022, followed by repeated risk assessments and recovery plans. Their intervention, focusing on alcohol use and practical concerns such as housing, lasted until July 2023, when it was closed through mutual agreement. Victim Support also worked with her to an Individualised Safety &

Support Plan at various points through this period.

6.2.12. One striking example of inadequate response to needs, however, is seen in agencies' responses to Paul's request for help to clear his flat of the bin bags full of rubbish and waste that had accumulated, which prevented him from using the facilities in his flat and added immeasurably to his distress. This was only one in a set of wide-ranging needs that he experienced as a result of his mental distress, but it was the one with which he asked for help, referring himself in March 2023 to the Westmorland and Furness Council Single Point of Access for support. This resulted in a roundabout of referrals between the Single Point of Access, the Mental Health Social Work Team and the Health and Wellbeing Coach, as well as discussions with Paul's sister. The referral was finally triaged to the Mental Health Social Work Team with the local authority asking the mental health Initial Response Service (IRS) to support him in the meantime.

6.2.13. The IRS carried out a phone triage, which the Lancashire and South Cumbria Foundation Trust internal investigation found to be inadequate in identifying both his needs and the risks he faced. None of his reported symptoms of acute distress were explored in any depth in the call, which focused primarily on his wish for help with clearing the accumulated rubbish. IRS merely signposted him to bereavement services and referred back to the local authority for support with the rubbish. An absence of professional curiosity about his underlying needs resulted in poor understanding of the complex challenges of mental, physical and social wellbeing he faced and how these were impacting on self-care. The Trust's own Concise Investigation acknowledges that, given what was known at the outset about his circumstances, a face-to-face assessment should have taken place and safeguarding advice about his self-neglect sought. A focus on presenting need at the cost of engaging with more deep-seated features is a common shortcoming in self-neglect practice, resulting in an absence of holistic understanding.

6.2.14. For Paul, even the rubbish removal remained elusive. The borough council was asked to remove it but declined. Paul was then put in contact with a private contractor, with Accent Housing offering support with the cost, yet still no arrangements were made for reasons that remain unclear. Westmorland and Furness Council have reflected that they were not effective in preventing deterioration in Paul's circumstances during this period. There were multiple transfers of responsibility between the various teams involved and no consideration was given to the need for safeguarding action. The Health and Wellbeing Coach service did for some weeks offer ongoing support through phone calls and a visit (at which Paul declined access to his home), but beyond the knowledge that he needed help clearing waste they had no information on the extent of his self-neglect. They knew of his physical health challenges but without the opportunity to meet him could not assess how mental health needs and alcohol use might be preventing him from taking action. The mental health social work team allocated his case for assessment on 21st July, four months after referral and a month after he was discovered deceased.

6.3. Managing risk

6.3.1. Some risks in the lives of the six individuals were very evident.

- Primary care clearly articulated the risks posed to Bill from the impact of his self-neglect on his health. The impact of alcohol on his decision making was noted, along with his poor home conditions, fire risk, lack of basic amenities and access to food.

- When police officers attended Diana's home, they were very concerned at the conditions in which she was living and were persistent in attempting to persuade her to leave the property and stay elsewhere while it was made safe. Unable to persuade her, they demonstrated further good practice in calling the Ambulance Service to assess her health and presenting capacity and submitted a detailed report for referral on to other support agencies.
- Recovery Steps, working with Julie between December 2022 and July 2023, were proactive in assessing risk to inform their intervention and recovery planning.

6.3.2. Sometimes, however, recognition of risk did not result in appropriate risk management action. The Fire and Rescue Service identified fire risks in respect of three individuals but did not take all necessary action. In Bill's case, safety issues should have been raised directly with his landlord, who was non-compliant with the Smoke and CO Alarm Regulations 2015. In Donald's case, the Service acknowledges that a safeguarding referral should have been made. For Tom, the "hazards remain" outcome from the fire safety advice provided should have been escalated to safeguarding action.

6.3.3. The Police note that an assault on Julie by her friend was time-barred as it had taken place almost six months previously. In fact, the Domestic Abuse Act 2021 allows for offences to be reported up to 2 years after being committed, so the 6-month lapse was not a barrier and although no direct evidence was available a supporting statement from the Independent Domestic Abuse Advocate could have provided hearsay evidence.

6.3.4. Adult Social Care too reflect that indications of risk were sometimes not appropriately explored. In Bill's case, for example, information about potential cuckooing and exploitation/ financial abuse of Bill by his friend were not explored in safeguarding.

6.3.5. Paul's GP surgery considers that there were missed opportunities to identify and respond to his self-neglect, for example at a home visit in December 2022 and three months later on receipt of a request from the social worker to assess his physical and mental health. Although his self-neglect was not obvious, the surgery recognises that a greater level of professional curiosity could have been demonstrated and that in the necessary prioritization of physical health concerns other matters were less foregrounded. The surgery has identified a need to improve safeguarding awareness in terms of identifying and responding to self-neglect.

6.3.6. When Paul was contacted by the Initial Response Service in March 2023 and gave an account of his distress, including suicidal thoughts, the triage tool applied during the conversation recorded minimal risks and no risk management plan was identified. Beyond his need for support clearing his flat, other issues were missed: suicidal thoughts, dual diagnosis, poor physical and mental health, isolation from family through embarrassment, tearfulness, devoid of feeling, poor physical wellbeing through neglect of daily living needs. All were factors that would raise risk levels in his situation, yet they were not explored, and safeguarding action was not considered. Westmorland and Furness Council too recognise that risk in Paul's case was not recognised or managed. The HAWC service did attempt to visit him on one occasion, but he did not allow access and their prior knowledge of him from 3-years previously did not indicate any concerns about self-neglect. Given his reluctance to engage, however, and in the context of his sister's expressed concerns, a safeguarding referral would have been an opportunity for risk to be appraised. Yet even a safeguarding referral from his housing provider in April 2023, triggered by reports of a bad smell from his

property, was not logged by Adult Social Care as a safeguarding concern and did not result in any risk assessment or action.

6.3.7. Use of formal safeguarding processes was inconsistent across all six cases, with evidence that self-neglect is not being recognized as a safeguarding issue and weaknesses at decision-making points within the safeguarding pathway. The Ambulance Service did report safeguarding concerns, for example in relation to Bill's alcohol use, self-neglect and medication compliance. The Service notes, however, that in self-neglect cases early help is often used to request assessment of need as opposed to safeguarding action, when in fact safeguarding would be warranted. They question whether the pathways are sufficiently well differentiated, and whether the threshold for safeguarding in self-neglect is sufficiently well understood.

6.3.8. Any agency can lead a multidisciplinary team meeting in relation to a case of self-neglect, initiating a parallel or alternative process in which presenting concerns can be discussed through a collaborative approach. With multiple avenues for risk-management, however, it is vital that parallel pathways are sufficiently differentiated, and that an escalation pathway is evident and understood.

6.3.9. A related issue arises in relation to Police referrals. Officers recognised multiple risks in relation to some individuals and completed vulnerable adult forms to report their concerns. The MASH reviewed these and passed safeguarding referrals on if the adult had care and support needs. This seems to involve a judgement being made at an early stage as to whether an individual has care and support needs, and that judgement being made by the Police rather than by Adult Social Care. This raises the question of whether self-neglect is triaged out of safeguarding prematurely.

6.3.10. In Donald's case, the Police were deeply shocked at the state of his property during a visit in 2017. Officers submitted a vulnerable adult form to the Public Protection Unit (at the time responsible for screening forms). The Unit did not pass the concern on to safeguarding because Donald and his partner had declined the offer of referral for support and were assumed to have capacity (although this had not been assessed). This seems a serious missed opportunity; given the state of the premises and evident risks to health and from fire, this was very much a safeguarding situation. The Police have stated that in these circumstances now, the information would be shared without consent.

6.3.11. The Police also reflect that sometimes a vulnerable adult form is not submitted because another agency is involved and is assumed to take responsibility for raising the alert. They point out that multiple alerts can and should be raised, as this gives a fuller picture of an individual's circumstances.

6.3.12. Cumbria, Northumberland, Tyne and Wear Foundation Trust note two instances in which Julie was observed by clinicians to have bruising or reported abuse by a friend with whom she was staying. On neither occasion was safeguarding advice taken, indicating that the role of safeguarding advisors may need a higher profile within the Trust. In 2021, when Julie disclosed sexual assault, Trust practitioners did undertake appropriate risk assessment and raised a safeguarding referral, also notifying the Police (although they did not raise an internal incident report to the Trust's safeguarding and public protection team). Safeguarding strategy meetings took place, attended by a range of agencies, resulting in a safeguarding plan that was effective, at least in the short-term while Julie remained sober.

6.3.13. Her return to using alcohol resulted in a sequence of North Cumbria Integrated Care hospital attendances and admissions during October 2023. While her physical injuries and medical condition were attended to, her self-neglect and alcohol misuse were not. No referrals were made for either care and support needs assessment or safeguarding action, despite the risks from her self-neglect persisting. Re-referral to alcohol support services was apparently not considered and no notification of her hospital attendance was shared with either the Trust's safeguarding team or Recovery Steps, despite their previous involvement. Thus, safety planning and effective communication to promote her safety and welfare were lacking. Her discharge from treatment for seizures and confusion with no care or support in place was a serious failure of risk management that contributed to the coroner's decision to issue a regulation 28 notice to the Trust.

6.3.14. In some cases, self-neglect was recognised and referred into safeguarding. Donald's housing provider, concerned at the hoarding in his property, made a safeguarding referral to Adult Social Care in November 2022. This did result in a Care Act assessment and determination that he had eligible needs.

6.3.15. North East and North Cumbria ICB, however, comment on mismatched perceptions of whether a safeguarding pathway is required, as when a referring GP's judgement that the safeguarding criteria were met was followed by a safeguarding decision not to progress the referral to a s.42 enquiry. The ICB found other examples of the CSAB threshold tool used as a rationale not to progress into safeguarding.

6.3.16. In Bill's case, his GP observed the urine-soaked and malodorous condition of his flat and made onward referrals to community nursing and to safeguarding. Community nurses subsequently raised a total of six safeguarding referrals for self-neglect and vulnerability to exploitation between August 2022 and February 2023. All were declined on the basis his needs did not meet the threshold for safeguarding, but the Trust did not use the CSAB escalation process to challenge this.

6.3.17. Adult Social Care reflect that each safeguarding referral was considered and triaged in a timely way but that each was looked at in isolation, ignoring the cumulative evidence from the repeated nature of the concerns. Decisions to not progress to s.42 enquiry were based on the belief that Bill was engaging in support and had current professional oversight, or universal services were sufficient to manage his care and risks. However, it was clear that his engagement was not consistent and that risks were not being managed. In addition, the triage decisions were made in isolation, without consultation with operational teams or other professionals who knew him.

6.3.18. In general terms, Adult Social Care acknowledge that there are tensions in managing self-neglect through a case management route and there is evidence that case management sometimes does not engage sufficiently with risk factors in an individual's situation. Tom's care and support needs, for example, were assessed under the Care Act in 2021, but fire risk was not identified, despite clear risk factors being evident at that point, and no referral for home fire safety visit was made. A further Care Act assessment a year later did not risk-assess ongoing fire risks arising from his smoking, cooking habits, poor hearing and cognitive decline. Again in 2023, when four safeguarding referrals were received about his self-neglect and risk to health, no risk assessment took place. Only the last of these referrals progressed to a s.42 enquiry but no action had been taken by the time he died. That he was allocated to a social worker appeared to be the driving force behind decisions not to act under safeguarding, and it is clear

that the lack of urgency and escalation impeded risk management.

6.3.19. Adult Social Care have reflected that a non-safeguarding route for managing self-neglect could be feasible in circumstances where certain features are present: no barriers to multi-agency involvement, a clear sense of a common risk management goal, understanding of the individual's wishes and views and strong legal literacy guiding the intervention. There is, they claim, an argument for adopting a parallel risk management process that sits between safeguarding and case management: a vulnerable adult risk management process that can proceed alongside and mutually support other pathways.

6.3.20. Concerns were also expressed about the mode of referral into safeguarding. In Bill's case the concerns and risks were clearly articulated in the primary care records; however, it wasn't clear what information was documented on the single safeguarding system in social care. The fact that all adult safeguarding concerns must be telephoned into the local authority is thought to act as a barrier to sharing an accurate picture of the situation. This is seen as being in contrast to children's social care, where all concerns are recorded on an online single contact form, of which both referrer and receiver hold a copy. In addition, the safeguarding decision and response is not made by the social worker who attends surgeries' multidisciplinary team meetings, who are those best informed about the individual's situation.

6.3.21. Where more multifaceted risks required a multiagency response, North East and North Cumbria ICB reported that GPs were sometimes not informed of this, or struggled as an individual agency to provide the level of coordination and oversight the case required. In these circumstances onward referrals for support were initiated but the output and outcomes were rarely known to general practice.

6.3.22. A further striking feature is the absence of shared risk assessment and safety plan. This was the case for Donald, Paul and Tom. It was only after Tom's death in the house fire, for example, that the creams used to treat his legs were found to be paraffin-based emollients, which can soak into clothes, skin, bedding and furniture and, in the presence of an ignition source such as a cigarette, catch fire quickly and burn hotter than clean fabric. No risk analysis had been carried out during his treatment by community nursing.

6.3.23. There are some pivotal moments in the stories that have unfolded in this SAR – moments at which a different course could have been taken and a different outcome gained. Sometimes these are apparently routine events, the significance of which are only apparent when seen in a more risk-aware context. Diana's GP, for example, has reflected that when she cancelled a surgery appointment in March 2023, saying she would "rebook when feeling brighter", had the surgery linked this remark to the broader concerns about her health and wellbeing a more proactive response could have been made, reaching out to her with further phone communication or a home visit.

6.3.24. Overall it seems that in these cases that have had tragic outcomes, agencies have not worried enough about the risks arising from their self-neglect. Research tells us that assumptions of lifestyle choice, assumptions of capacity, respect for privacy and lack of professional curiosity all militate against gaining a true risk picture.

6.4. Making safeguarding personal

6.4.1. The principle of respect for individuals' views and wishes was seen by all agencies as central to the work they undertook. Northeast and North Cumbria Integrated Care Board,

in reviewing primary care provision to those involved, have found no barriers to engaging individuals in their primary care and other medical treatment. There are good examples of GPs reaching out to both Julie and Tom following non-attendances. Recovery Steps Cumbria, in working with Julie, have confirmed that her views and wishes were discussed and used to inform their recovery planning and interventions. This included her views on the support she required. During her contacts with the service her needs changed and although she had initially wanted to undertake a self-reduction of her alcohol use, this plan was changed on consultation with her to a referral for inpatient detox due to ongoing review of her needs.

6.4.2. The Fire and Rescue Service have confirmed that in all cases where a safe and well visit took place, it was with the individual's consent and that they had input during the visit. Similarly, the Ambulance Service reports that views and wishes were considered at every contact and that where onward referrals were made it was with the individual's consent.

6.4.3. Paul was himself proactive in seeking out regular consultations in relation to his physical and mental health and there is evidence that his GP surgery were responsive to those needs and requests. They also took steps to reach out to him when he missed an appointment or did not respond, demonstrating good practice. Lancashire and South Cumbria Integrated Care Board consider there is a need to clarify responsibility for following up missed appointments where a GP surgery has referred a patient to specialist services and the patient does not attend. This will be addressed in a new Sample Policy for Adult Not Brought to Health Appointments for Primary Care, GPs, Pharmacy, Optometry and Dental Practice, which is currently in the process of being ratified.

6.4.4. The Westmorland and Furness HAWC service also were persistent in attempts to contact him, despite his reluctance to engage. They reflect, however, that while mindful of the need not to harass him they could have been more persistent by repeating attempts to visit him at home and bringing in a practitioner with whom he had had a good relationship three years previously.

6.4.5. The need to make onward referrals is an example of where known views and wishes can be appropriately overridden in certain circumstances. In Julie's case, for example, while her wishes and feelings were respected by medical and nursing staff while treating her, staff did pass information about her reported sexual assault to safeguarding and the police. Similarly, the Police have stated that while consent would generally be sought before an individual's personal information was shared elsewhere, it would nonetheless be shared without consent where believed necessary for safeguarding purposes.

6.4.6. In general terms, then, there is evidence that views and wishes are recognised and respected, while in certain circumstances information can be shared without consent. That is far from being the whole story, however. Respecting views and wishes is dependent on those views and wishes being known, and it is clear that there were challenges here. Four of the individuals were very reluctant to engage with services. When they did engage, it was often through a crisis during which their underlying perspectives remained largely hidden from view. Bill, even when initially accepting support, would subsequently decline. At one point he contacted primary care saying that he would like support to stop drinking and smoking but did not following the signposting he was given to Recovery Steps and smoking cessation. Donald's needs were recognised but he remained opposed to receiving any help, with the reasons for this not explored. When Diana was referred to Adult Social Care by the Council's waste service but did not respond to contact, the referral was closed without any other action.

6.4.7. A GP contacted Paul by phone in March 2023, the surgery having received a request from Adult Social Care for a GP home visit to review his physical and mental health. The call resulted in re-referral to colorectal surgery and prescription of medication to assist him in attending an appointment. The call was made by a GP who knew Paul less well and the surgery reflects that had the call been made by the medical practitioner who had seen Paul three months previously his deterioration would have been more evident. They also consider that a face-to-face appointment, or a phone call followed by a visit, would have been beneficial and that his presentation as an articulate patient potentially masked his vulnerabilities. This, they feel, may have been a barrier to the surgery taking a more proactive approach or preventive action. Had his vulnerabilities been coded on his medical record, the deterioration in his circumstances would have been more evident and have led to closer monitoring. Equally they consider assumptions may have been made by all agencies, including by the GP, about who was taking responsibility for responding to Paul's needs at this point.

6.4.8. Similar assumptions about Paul's ability for agency during this period may have been made by the Initial Response Service. When Paul talked about the impact of his bereavement the IRS practitioner gave him details of bereavement services. But given the number of challenges it was known he was experiencing, his ability to self-refer on to any service could be questioned. Given the complex challenges he faced it would have been more beneficial to support him proactively. The same applied to his use of alcohol. Taking at face value his preference to address this once the rubbish was cleared did not allow for how alcohol would be impacting on all areas of his life, including his motivation and ability to act. This superficial interpretation of what making safeguarding personal means leaves important issues unaddressed and does not serve the individual well.

6.4.9. These were not the only views and wishes taken at face value. On a home visit to Diana in 2021, the GP had observed the neglected state of her property and recognized her social isolation. But they did not find any medical concerns and considered that she had capacity to choose to live in this way. After further attempts to support her with practicalities, with which she did not engage, no further active attempts to contact her were made. A year later, the Police were alerted by a plumber, whom Diana had called to attend to a burst pipe. With no response, officers gained entry via a broken window and found the house in disarray with ceilings and the main staircase mostly collapsed, damp throughout, no heating, no running water, electricity only in the kitchen via an extension cable and Diana herself not attending to her personal care. The Ambulance Service, called by the Police to provide medical checks, described the house as uninhabitable, but Diana declined offers to go elsewhere. Adult Social Care, later visiting following Police referral, accepted her assurances about the physical state of her home despite having access only to the porch and being unable to verify all that she told them, which was in acute contrast to the Police and Ambulance Service observations.

6.4.10. Both Adult Social Care and North Cumbria Integrated Care Trust have noted the challenges facing staff in identifying Julie's wishes during the periods when she was acutely unwell and indeed there is little in hospital records about what her views were. The Trust notes that she was often confused or intoxicated during admissions, which prevented staff ascertaining her views.

6.4.11. In other circumstances, challenges came from the individual's own way of relating to practitioners. North Cumbria Integrated Care Trust note that Bill, although never violent, could sometimes be abrupt and rude. He often disagreed with the community nurses about the need for leg dressings and the environmental conditions he was living in. He sometimes had 'friends' present during the nurses' visits, who were often intoxicated and intimidating, and he himself was also at times intoxicated, making communication difficult. Nonetheless the nursing records demonstrate involvement and shared decision-making in his care. Adult Social Care comment, however, that as the safeguarding concerns escalated and it became harder to engage with him, the more it became challenging to find any avenue to establish his views and wishes.

6.4.12. For Tom, barriers to ascertaining his views and wishes arose from Adult Social Care practitioners' poor adaptation to his specific communication needs. He was very hard of hearing yet he would not wear hearing aids. He communicated best through written notes but there is no evidence that the practitioners spent the time to do this with him. He was visited on 5 occasions, with two Care Act assessments and two reviews being completed. Described by a niece as "a very private man who does not take well to strangers" his wishes were mostly communicated through his nieces. It was known he had lost his wife in 2019 and had stopped leaving the house or looking after himself, but this was not explored with him. There is no evidence that he was asked his opinion or wishes in relation to any of the safeguarding issues that were raised by community nurses in months before he died.

6.4.13. There was no apparent consideration of whether advocacy would assist any of the individuals in engaging with services and expressing their views.

6.5. Protected characteristics

6.5.1. Closely linked to the principle of making safeguarding personal, and indeed central to any intervention by any public body in an individual's life, is the requirement to ensure compliance with Equality Act 2010, which protects people with protected characteristics from unlawful discrimination[15]. This review has explored two key questions: (a) did agencies recognise individuals' protected characteristics and (b) if so, how were those characteristics taken account of in assessment and intervention?

6.5.2. The questions, however, are hard to answer as few protected characteristics were identified and it remains unclear to what extent agencies record such information. North East and North Cumbria Integrated Care Board find that age and disability (including mental ill-health) were those most commonly identified in GP records. But GPs for Donald, Julie and Tom had none recorded, nor did Cumbria, Northumberland, Tyne and Wear Foundation Trust, the Ambulance Service, the Fire and Rescue Service, North Cumbria Integrated Care Foundation Trust, Cumbria Community Homes, Home Group, Victim Support and Recovery Steps Cumbria. The Fire and Rescue Service state that they do not routinely record protected characteristics, though age and disability would be noted where relevant to fire safety. Cumberland Adult Social Care noted disability only in relation to Bill but found no evidence that this explicitly influenced the approach that was taken. There was some evidence of adjustment by some GPs, for example in home visits being made when people were unable to attend the practice.

[15] Characteristics protected under the Equality Act 2010 are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation. The Act also requires services to make reasonable adjustments to their policy, practice and provision to ensure disabled people are not disadvantaged.

6.5.3. Paul's GP record, in contrast, indicates that he was single, white British, male, in his early fifties, with mental and physical health conditions. The records indicate that as a result of his difficulty attending the surgery he had phone consultations and home visits when clinically necessary. Lancashire and South Cumbria Foundation Trust records note his diagnosis of bipolar affective disorder, and indeed his mental health was the focus of the intervention offered. Westmorland and Furness Adult Social Care records note that he had a disability but have stated that this was not seen as a protected characteristic and it does not appear to have informed the Council's actions.

6.5.4. The Police had age and gender identified in records relating to Diana, gender and disability for Julie and disability for Bill. These characteristics informed officers' decisions during their contact with them, including on whether to raise notifications about vulnerability. In Diana's case it influenced officers' decision to remain with her for some time and to call the ambulance service to assist.

6.5.5. No agency found evidence of discrimination by their services. It is clear, however, that agencies foregrounded certain protected characteristics (most often age or disability/ mental ill-health) while others such as race, religion or sexual orientation remained below the radar. Evidence is also mixed on whether and how protected characteristics that were noted were taken into account by practitioners working with the individual.

6.6. Mental capacity

6.6.1. One important aspect of making safeguarding personal is determining whether the individual has the mental capacity to make the decisions that are being expressed in their views and wishes. There seems, in these six cases, to have been a reliance on an assumption of capacity rather than explicit testing under the Mental Capacity Act, even in situations where an individual's apparent decisions placed them at extreme risk.

6.6.2. Cumberland Adult Social Care have reflected that no formal capacity assessment was completed during the safeguarding enquiry relating to Julie and it appears their safeguarding practitioners assumed she had capacity with respect to the concerns. Neither her GP nor Recovery Steps Cumbria assessed her capacity, despite knowledge of her alcohol dependency and evidence that her decision-making placed her at extreme risk. Little attention appears to have been given to the impact of heavy alcohol consumption on her executive brain function. If frontal lobe damage was present this could have compromised her decision-making about risk and safety. Her capacity was assessed on one occasion by North Cumbria Integrated Care, when the Deprivation of Liberty Safeguards were applied to prevent her from leaving the ward when she was hallucinating and at risk of falling.

6.6.3. Attention to executive brain function was a significant omission also for Bill, for whom no agency undertook capacity assessment, despite knowledge of his alcohol dependency, his worsening self-neglect and his difficulty carrying out stated decisions.

6.6.4. There are no documented capacity assessments relating to Paul – it appears to have been assumed by both Westmorland and Furness Council and Lancashire and South Cumbria Foundation Trust that he had capacity to make the decisions he expressed to them. The Trust have indicated that the Initial Response Service triage tool, which was used during the telephone triage conversation with him in March 2023, includes a prompt on capacity, and that any capacity assessment thought necessary would have been done. His GP surgery also has indicated that when visiting Paul at home in December 2022 the GP did explain to him

the severity of his condition and the risk to his life should he not take action to address his alcohol consumption and engage in treatment for his colovesical fistula. When he declined hospital admission they did consider his capacity to make that decision but did not document this in his records. The GP instead planned to review the risks again in 48 hours, but this did not happen, most likely due to oversight in the context of heavy workload (indicating the need for a stronger follow-up system that can mitigate the impact of human error). In the context of Paul's long-term alcohol use and his return to alcohol, however, and evidence of his struggles to make arrangements to improve his living conditions, the failure of all agencies to carry out a capacity assessment, including consideration of executive brain function, was a significant omission.

6.6.5. In respect of Tom, the local authority did not assess his capacity to understand his care and support needs or his ability to keep himself safe, despite the deterioration in his cognitive abilities and despite the fact that on occasion during their visits community nurses had found him to lack capacity in relation to treatment. There was thus no discussion of initiating a best interests decision-making process that could have considered options for management of the known risks in his situation. The council's finance section also asked the social worker to confirm that Tom had capacity regarding management of his finances, but this does not appear to have been actioned.

6.6.6. In a few cases, mental capacity was explicitly tested. Diana's capacity was assessed by a GP who visited her eighteen months before she was found deceased. The GP had a detailed conversation with her, and the capacity assessment was well recorded. She was found to have full capacity and understanding around her living choices. In November 2022 Cumberland Adult Social Care assessed Donald's capacity to understand his care and support needs, finding that he lacked capacity in this regard. There was, however, a two-month delay in this being entered into records, and there is no evidence that a best interests decision was ever made in relation to the provision of services for care and support. This was a serious omission.

6.6.7. The Ambulance Service refer to best interests decisions being made on behalf of both Donald and Julie at times when they were unable to express their views about hospital conveyance, although it is not clear whether action here was taken because they were found to lack capacity or whether ambulance crew acted under the concept of necessity.

6.6.8. There was recognition that mental capacity can fluctuate. Julie's capacity was assessed on every contact she had with Cumbria, Northumberland, Tyne and Wear Foundation Trust services, with practitioners finding that her capacity fluctuated depending on her alcohol use. Community nurses undertook capacity assessments in relation to Tom's ability to consent to treatment during their visits, with some nurses finding he had capacity and others finding he did not. This fluctuation was not, however, explored or escalated. North Cumbria Integrated Care reflect that, given his self-neglect, his capacity to self-care should have been assessed.

6.6.9. It seems there may be potential uncertainties about which agency takes responsibility for a capacity assessment. In Julie's case, Adult Social Care have stated that had they carried out an assessment it would have related to her decision-making about care and support and/or safeguarding. Given there was a wider question about her capacity for decisions about her alcohol consumption, on which drug and alcohol services were acting as the lead agency, they do not consider this would have been their responsibility. This is despite the fact that the risks she faced were directly related to her use of alcohol.

6.6.10. North Cumbria Integrated Care reflect that across all the cases in which they were involved there appears to be confusion regarding assessment of mental capacity for particular decisions and that assessments were either not completed at all or were poorly completed, not in a timely manner and often containing conflicting information. They also find there was confusion about whether self-neglect was a "lifestyle choice", which they believe may have resulted in referrals either not being made or being made too late to alter the outcome.

6.6.11. Two services have indicated that they do not carry out capacity assessments. The Fire and Rescue Service state they do not have the ability or training to assess capacity. They do recognise, however, that in Donald's case they should have made a referral for his capacity to be assessed. The Police have stated their officers do not carry out capacity assessments, although in circumstances where they find capacity in doubt they would call in another service, as here in Diana's case, where they requested Ambulance Service attendance.

6.7. Family networks

6.7.1. One key value for practitioners of engaging with family members is that they will sometimes be able to cast light on an individual's history and life experience, and thus aid understanding of the individual's present circumstances. In most cases here, however, it was generally only when family members took the initiative that contact was made. This was apparent for Tom, whose niece was usually present during nursing and social care practitioners' visits, and who played a key role in liaising on his behalf with the agencies involved. She was in consequence a key informant and decision-maker about his situation, which was helpful to practitioners' understanding of the risks that he faced but also reduced the amount of direct communication with Tom himself.

6.7.2. Paul's sisters also had direct contact with agencies. One sister was instrumental in alerting services to his situation, providing extensive background information as well as detailed information about his present needs. Lancashire and South Cumbria Foundation Trust have reflected that the information his sister shared could have given rise to a greater level of professional curiosity in seeking to understand the decline in Paul's home environment and in exploring the extent of his suicidal intent. It could have prompted further discussion with him about his use of alcohol, and about the decline in his memory. In the event, it did not result in any changes to their plans.

6.7.3. Cumberland Adult Social Care, in considering Donald's needs, did not use information that was available to them about his partner, who was known to them independently due to her history of hoarding. Previous information in their records indicated that she had had to vacate a previous property due to its condition, but this was not connected at the time to their understanding of Donald's situation. In contrast, the Ambulance Service did show vigilance in relation to her needs, raising safeguarding concerns about her situation when they conveyed Donald to hospital. Donald's landlord, Home Group, had no contact with his son until after his death, as Donald had given no details during his pre tenancy assessment. They did, however, liaise with his son after his death.

6.7.4. In two cases, agencies took the initiative in reaching out to family members. In Diana's case, the Police tried to trace her relatives, although this did not result in contact being made while she was alive. With Julie's permission, Cumbria, Northumberland, Tyne and Wear Foundation Trust contacted her parents as part of their mental health assessment, to assist in understanding her presentation, although other agencies have stated that they respected

her wishes for her family not to be contacted. There was some contact with her partner, particularly as a means of reaching Julie when she herself was reluctant to engage, although caution was exercised due to concerns about his abusive behaviour.

6.7.5. Julie's mother has expressed concern that agencies did not inform her of events such as Julie's hospital admissions or experience of domestic abuse. While recognizing the constraints of confidentiality, and the possibility that Julie withheld permission, she feels that through not knowing she missed opportunities to support her daughter.

Domain 2: Interagency practice

6.8. Self-neglect, like all good safeguarding practice, requires strong interagency collaboration. Single agencies working alone are unlikely to fully meet an individual's needs and managing the risks in their situation. Interagency collaboration is at a premium here and requires consistent information-sharing, shared strategy, case coordination and sequencing of input.

6.9. Overall, in these six cases, it seems agencies had good understanding of each other's role and function, although it this did not prevent some matters and decisions being contested. In respect of Bill, for example, healthcare practitioners could not understand why their concerns repeatedly did not meet the threshold for safeguarding and they consequently found it difficult to challenge or escalate these decisions. Even where a shared intervention strategy was nominally in place, there was a lack of communication between community nursing and adult social care, and poor understanding of each other's roles.

6.10. Lack of feedback on safeguarding referrals was raised by others also as being a key barrier to the development of a shared understanding of risk and a shared strategy for managing it. Equally, however, it seems that where safeguarding referrals were not accepted, agencies did not turn to the CSAB escalation policy to attempt to resolve the differences.

6.11. There is evidence of some effective information-sharing. In Paul's case, for example, the HAWC service was proactive in liaising with his landlord to follow up on the question of rubbish clearance. Ambulance Service clinicians used clutter scoring scales to assist in depicting to other agencies the level of environmental impact and risk they have observed in an individual's home, along with descriptions of personal impact on the patient. Information is shared both verbally during handover to hospital or GP and digitally to social care partners. This was the case in respect of Bill, about whom frontline ambulance clinicians shared information appropriately. In Donald's case, because he was in critical condition immediate clinical support was a priority, but information about his home circumstances was shared during verbal handover at the hospital and with adult social care via a safeguarding referral. In Diana's case, ambulance clinicians liaised with Adult Social Care to ensure safety-netting. For Julie, both verbal and electronic pathways were used to share information about her environment and presentation when she was taken to hospital, as well as discussion taking place with her housing support officers. When Tom declined hospitalization for his leg condition, Ambulance personnel liaised directly with his GP.

6.12. The Police see Adult Social Care as their main partner for information-sharing in relation to adults who are vulnerable. Staff undertaking triage of vulnerability alerts have good understanding of thresholds and it is predominantly they who work across agency boundaries. They have some limited access to Adult Social Care systems so can see if someone is open to a social worker and can therefore pass information on directly. GP details are usually not available. In Westmorland and Furness, morning triage meetings relating to vulnerable adults

see Police and Adult Social Care working closely together, with safeguarding team members in attendance.

6.13. There are concerns from others, however, that information-sharing across the partnership was not robust and consistent. North East and North Cumbria ICB consider that a key barrier across all five cases in their area was a failure to share information with GP surgeries in relation to escalation of concerns, risk or involvement/discharge from other services. General practice was either not informed or struggled as an individual agency to provide the level of coordination and oversight the case required. Onward referrals for support were initiated but the outcomes were rarely known to GPs. In Bill's case, although primary care attempted to review, engage and offer services/support to him, the information needed to enable them to lead and coordinate discussions wasn't always accessible; the whole picture was not known. Primary care for example does not always receive notification of ambulance calls/visits unless a person is transferred to hospital. This gap in information sharing may have been a barrier to the identification of behaviour patterns that could have led to more timely interventions and oversight from primary care services. In Paul's case, the GP surgery made referrals to Recovery Steps and to the Health and Wellbeing Coaches, but received no feedback, making it difficult to see how services were responding to his needs.

6.14. In Paul's case also, although the HAWC service had information about his situation from within Council records and proactively pursued contact with him, his reluctance to engage prevented direct attention to his mental health, bereavement and alcohol use, and his decline of all offers of support ultimately resulted in his case being closed.

6.15. A further shortcoming in information-sharing was acknowledge by the Fire and Rescue Service, who did not take action to escalate concerns about fire risk in Bill's property, arising from his landlord's failure to comply with fire safety regulations. The lack of direct escalation here meant that effective fire safety measures were not in place. In Donald's case, it seems that information about observed risks was not shared by the Fire and Rescue Service because of misinterpretation of the data protection rules on information-sharing without consent. The Fire and Rescue Service have also echoed GPs' concerns about lack of information on other agencies' involvement with the individuals they visit, stating "*the service would benefit from further information and clarity around sharing information with other organisations, alongside being more involved in the broader safeguarding apparatus.*"

6.16. One key mechanism for promoting shared perspectives and good interagency coordination is the use of interagency risk management meetings. In Julie's case, multiagency meetings did take place under safeguarding procedures and were attended by relevant agencies attempting to support her. These resulted in a safeguarding plan to support her in remaining safe and accessing support around her alcohol dependency. She was provided with supported living and continued to be assisted in terms of goal setting and safety netting.

6.17. In other cases there is evidence that health-led multidisciplinary team meetings took place but these were largely limited to a core group of agencies that didn't have any impact on the wider system. In Bill's case, given he made extensive use of NHS 111, CHOC and the Ambulance Service, these agencies should have been invited but were not. The Ambulance Service has commented that it has a limited role in strategy and planning meetings and that supporting strategies put in place is difficult due to the sporadic nature of their service.

6.18. But beyond this, there sometimes remained a disconnect between health and social care

agencies. The North East and North Cumbria Integrated Care Board has commented on a disconnect between understandings achieved in meetings and what then happened in practice. Primary care noted that Bill's case was moved between three social care teams for decisions, assessments and case management; they were unable to converse with one person. Identification and communication around his worsening situation were made more difficult without a multiagency agreed risk assessment and safety plan outlining specific triggers to escalation. Although adult social care practitioners and community nurses undertook joint visits, it is not evident that this approach was effective in managing the risks in his situation. Adult Social Care have reflected that it was unclear which agency was leading, how often the meetings needed to be, and how regularly the risk management plan was reviewed. An overall plan or shared goal seemed to be lacking, and it seemed that the multiple referrals to safeguarding resulted from a search for direction.

6.19. The Fire and Rescue Service have observed that they were not invited to be present at any multiagency meetings for the individuals with whom they had been involved.

6.20. In Tom's case, North Cumbria Integrated Care have reflected on the lack of formal conversation between community nursing, Adult Social Care and the care workers providing his care, noting that there was scope for greater integration between the efforts of those trying to keep him safe, particularly in the context of evidence that there were unmitigated risks in his situation. Adult Social Care are of the same view, finding that poor communication and absence of multiagency meetings resulted in no shared strategy for managing the risks.

6.21. Paul's GP has commented that there appeared to be some duplication in a request from Adult Social Care to review Paul's mental health, when the Initial Response Service were also involved. They consider that a multiagency meeting would have clarified actions assigned to each agency and ensured that the outcomes of assessments were pieced together to give a holistic picture. Instead, communication broke down, with neither the GP nor Adult Social Care exchanging further information as events unfolded. It seems assumptions were made by all agencies in relation to who was leading on what actions, resulting in silo working. There is no evidence to suggest that any agency considered utilising CSAB's self-neglect guidance. This would have prompted a multi-agency discussion or meeting to clarify roles, responsibilities and actions. In the absence of this structure, the pressures of workload, capacity and competing priorities may also have influenced the ability of agencies to effectively work together.

6.22. Lancashire and South Cumbria Foundation Trust and the HAWC service are similarly both of the view that multiagency risk management meetings could have resulted in a more strongly coordinated approach to supporting Paul and provided a pathway for recovery. Instead, there were multiple barriers between agencies. Accent Housing have commented that Adult Social Care's refusal to visit for assessment of needs before the accumulated rubbish in Paul's flat had been removed was a major barrier to moving forward. Relevant information did not inform agencies' decisions on matters such as responding to his refusal to engage, or the degree of urgency assigned to his assessment. The difficulties experienced in securing help with the practical clearance task were a classic example of responsibility being shifted around an interagency system with no one taking responsibility.

6.23. In the absence of effective information-sharing and shared multiagency risk management strategy, agencies remain solely on their own track. As one respondent puts it: "*I believe that a recurring theme within this review is a failure to communicate between agencies, with*

information around capacity and individual risks not necessarily being shared. This contributed to a degree of siloing within agencies, with a negative impact on the individuals concerned." Another referred to an absence of professional curiosity in failing to consider who else might be involved and might need to know what action has been taken.

6.24. There was occasional evidence of some good joint working between agencies. When the Police found Diana in such neglected and risky home circumstances, they secured the timely attendance of the Ambulance Service, who were able to undertake physical checks and also assess Diana's mental capacity, with both services remaining on site together. Further to this, concerns were escalated and discussed with Adult Social Care. Nonetheless, no multiagency meetings took place to discuss the ongoing concerns about her situation, or to discuss the different perceptions held by the Police, Ambulance Service and Adult Social Care about the state of her home.

6.25. In Donald's case too, although there was a line of communication between the GP practice, Adult Social Care, the memory team and others, there were significant omissions in terms of shared information. Two multidisciplinary team meetings took place but no information is recorded about the content or outcomes of any discussions. His housing provider, who had raised concerns about the hoarding in his property, was not invited. Nor were they given information known by Adult Social Care about Donald's partner's history of hoarding. Family information that was held by his GP was not known to Adult Social Care. Nor did Adult Social Care know, until it was revealed at his inquest, that his medication had not been being collected for some time. Had this been known, it would have altered Adult Social Care's perception of his partner's ability to cope. Conversely, however, the later concerns held by Adult Social Care about Donald's ability to manage his own care and support were not shared with the GP.

6.26. Despite the effective safeguarding process that took place in relation to Julie, there were subsequent significant failures of communication and coordination. Recovery Steps Cumbria note that after they ceased their service in July 2023, by mutual agreement with Julie who was stable and alcohol-free, they received no further communication from agencies who later were aware that she had returned to using alcohol and could have benefitted from their support. A further failure of multiagency collaboration was found in the hospital discharge process on what became her final visit to the Emergency Department during a sequence of crises in October 2023. The hospital was asked not to discharge her without informing her housing support team, so that staff could immediately visit and ensure she was safe at home. In the event, she was sent home in a taxi without any such notification and was found deceased the following day. This significant omission was included within the Coroner's Prevention of Future Deaths report issued to North Cumbria Integrated Care NHS Foundation Trust.

6.27. Given the difficulties of securing multiagency coordination under current structures, there have been calls for a new framework for responding to concerns that do not meet the safeguarding threshold but that can provide a shared understanding of risk assessment, safety planning and engagement. It could be said that escalation to the complex care process serves this purpose, but as an essentially health-led process it does not fulfil a truly interagency function. Creating a further pathway, however, runs the risk of creating yet further processes that are either not used or are not effective in securing case coordination.

Domain 3: Organisational factors

6.28. A key element in seeking to strengthen safeguarding systems is the organisational context within which safeguarding practice takes place. The actions of practitioners engaged in direct practice are directly impacted by organisational structures, culture, systems, resources, staffing, management, workflow, training and support. Exploration of these features can cast light on why things happened in the way that they did. This review therefore invited information on organisational features that would have impacted on practice during involvement with the six individuals.

6.29. Practitioners need to draw upon a wide range of support to inform their direct work. Key here are resources such as training to enhance knowledge, skills and confidence in working with self-neglect, along with guidelines, policies, pathways and sources of consultation to support decision-making. Case supervision and management scrutiny are vital, as is access to legal advice when needed. The measures in place in the organisations involved in this review are set out below.

6.30. GPs in the North East and North Cumbria ICB area have access to a wide range of support and advice and can commission their own legal advice as well as seek advice and support from the Medical Defence Union, the General Medical Council and the British Medical Association. Surgeries have safeguarding policies and procedures and must provide safeguarding training as part of their NHS contract. All staff must be trained to either safeguarding level 1, 2 or 3, with training (in North Cumbria) commissioned via North Cumbria Primary Care Alliance and accessed via Teamnet. GP practice teams also have access to the CSAB learning offer as well as the Integrated Care Board's programme of learning via the safeguarding leads forum, North Cumbria safeguarding health professionals' network and the Protected Learning Time offer. Lancashire and South Cumbria ICB host an annual safeguarding learning event, in which self-neglect and professional curiosity have been topics. For all GPs there is access to multiple online resources and safeguarding lead GPs within surgeries are available for consultation.

6.31. Support can also be sought from the Integrated Care Boards' safeguarding teams. Health Pathways is an online clinical tool/pathway for all primary care staff and the CSAB threshold tool is available to assist professional judgement on what safeguarding action may be necessary. EMIS healthcare software offers a collection of standardised clinical templates to promote best practice during consultations, including prompts on mental capacity. Some practices hold regular safeguarding meetings at which information can be shared, concerns identified and management plans agreed for complex safeguarding cases.

6.32. In Cumbria, Northumberland, Tyne and Wear Foundation Trust all staff complete level 3 safeguarding training. Staff within Cumbria Fire and Rescue Services complete safeguarding awareness training, with additional training for certain members. Beacon Care receive annual training updates. Spot checks are carried out and staff are involved in quarterly staff meetings, two supervision sessions per year and annual appraisal.

6.33. The Ambulance Service has a clear safeguarding pathway within the organisation. All frontline clinicians receive safeguarding training to level 3 as part of the mandatory annual offer. This includes coverage of self-neglect, and clinicians use clutter scoring to emphasise environmental issues to partner organisations. Clinicians have access 24-hour access to the Trust's intranet where all policy/procedures can be viewed and there is 24-hour access to a complex incident hub staffed by senior paramedics, nurses and mental health practitioners, where clinicians can seek senior advice. The hub also provides access to legal advice if needed.

6.34. North Cumbria Integrated Care Foundation Trust provides a threshold tool for all types of abuse including self-neglect. There is also a clutter scale to objectively assess environmental conditions. The Trust has an overarching safeguarding policy as well as a separate policy for action under the Mental Capacity Act and Deprivation of Liberty Safeguards. There is a safeguarding section on the Trust's intranet, which covers all aspects of safeguarding, giving advice and guidance. There is also a safeguarding advice and support line for staff to contact the safeguarding team for support and staff are able to contact the Trust's legal team for support and advice, with potential to escalate to the Trust's solicitors. Self-neglect is covered in safeguarding training and as a standalone training session.

6.35. Officers within Cumbria Police have access to the Police National Legal Database to check legislation, and a legal department can be accessed if advice is needed on powers and duties. The Cumbria Safeguarding Adults Board self-neglect guidance is made available to officers, as are lunch and learn sessions run by the Board and learning briefings on SARs.

6.36. Home Group staff receive adult safeguarding training with a separate digital training provision on hoarding. The housing provider also has a hoarding policy with a clear guide on how to categorise levels of hoarding and actions to be taken. Regional operations managers and safeguarding leads support decisions, as does a legal team.

6.37. Cumbria Community Homes provide regular supervision, team meetings and management support to their staff, who also receive awareness training on self-neglect, self-harm, mental health and drug/alcohol use. Victim Support receive regular case management from designated safeguarding officers. The organisation has a safeguarding policy and provides guidance on working in the context of self-harm. National independent domestic violence adviser guidance is available also.

6.38. Recovery Steps Cumbria staff receive regular individual supervision, complex case supervision and safeguarding supervision, which provide oversight, guidance and support with case management. Staff are required to undertake safeguarding training from a central training team; this covers learning around self-neglect. There is an organisational safeguarding adult policy, which covers concerns relating to self-neglect, along with a local self-neglect guidance document for staff across the service in response to learning from safeguarding cases. The service operates a RAG rating system for all individuals within the care of the service, dependent upon their presenting needs and risks. This system also provides guidance on the interventions required and minimum timescale of contact with the service.

6.39. Cumberland Adult Social Care has a self-neglect policy in place and specific training sessions have been delivered to broaden professional knowledge in this area. Their practitioners use the CSAB threshold tool to aid decisions and can access advanced practitioner advice. Supervision is routine and legal advice is available and encouraged.

6.40. Westmorland and Furness Adult Social Care provide specialist training on self-neglect, available to all staff. The HAWC service have raised concerns that although self-neglect training in general covers signs and symptoms it does not address their particular needs in terms of skills for building rapport and relationship. Threshold tools are available to support social care practitioners' decision-making and since Paul's death guidance has been developed to support staff in engaging with people in circumstances such as those he was experiencing. The Council employs specialist legal officers who can provide advice on legal rules.

6.41. Lancashire and South Cumbria Foundation Trust staff have access to a specialist safeguarding team for guidance and direction if concerned about self-neglect. The local authority's safeguarding hub can also be accessed for advice or referral. The Trust's intranet site has a safeguarding section that offers access to a range of resources and learning, including on self-neglect. Safeguarding supervision was due to be introduced in the Initial Response Service in September 2024. Staff also have access to a legal team to which they can direct legal queries and the safeguarding team can also support in relation to legal frameworks. All staff are trained in safeguarding levels 1, 2 or 3, which includes coverage of self-neglect, and in application of the Mental Capacity Act. Outside of mandatory training there has also been continuing professional development training within the Initial Response Service in relation to the self-neglect framework.

6.42. The University Hospitals of Morecambe Bay Foundation Trust provides specific support to its staff on self-neglect via its intranet. The Trust has a specific incident category for self-neglect, which if used results in the safeguarding team having oversight of the incident and being able to offer support/guidance as well as initiating a high-profile case tracker to ensure regular oversight. Staff have 24/7 access to a legal team within the hospital. Self-neglect forms part of the Trust's safeguarding adults policy and also features within its Management of Patient Care Choices policy. This highlights threshold guidance, when to submit a patient safety incident, how to contact the Trust's safeguarding team and how to make referrals into Adult Social Care. Learning from SARs can give rise to specific training sessions and ad-hoc sessions are also provided for staff in specific teams. The safeguarding team run monthly safeguarding supervision sessions focusing on self-neglect, which are well attended and can also be used as training sessions. Patient safety incident data is able to identify clusters of concerns in relation to self-neglect, which can then be targeted.

6.43. Accent Housing have a safeguarding lead, a deputy lead and area leads for all housing service areas, plus representation from Asset and Planned as well as People Services. All staff are required to complete annual eLearning on safeguarding and all leads complete level 3 safeguarding training. A new reporting module on the housing case management system enables a more thorough recording and reporting process. Leads attend monthly meetings to discuss the development of the reporting tool and to support colleagues with case concerns. The leads also provide events related to safeguarding. Clinical supervision promotes reflective practice on any cases that may require professional challenge.

6.44. In much of the work carried out across the six cases, supervision and management scrutiny were evident. Within Cumberland Adult Social Care team managers endorsed decisions on whether to pursue section 42 enquiries, in Bill's case agreeing not to proceed and in Julie's case supporting decisions to progress enquiries around domestic abuse and self-neglect. North Cumbria Integrated Care have found appropriate management oversight of decisions made during the care Bill received. When the planned care couldn't be carried out because he either refused or wasn't home, this was always escalated in a timely and appropriate manner. The Police have confirmed there is oversight of safeguarding concerns raised by officers. Westmorland and Furness Adult Social Care have identified there was management oversight of the mental health social work team's involvement with Paul.

6.45. Agency policy and procedure had a direct influence on organizational responses. In Bill's GP surgery there were changes in systems and processes to ensure best use of limited clinical resource. The practice has acknowledged that contacting them for an appointment during this

period was a challenge, potentially explaining why Bill preferred to use alternative services such as NHS 111, NWAS and CHOC. While now rectified, it is clear that for some patients the pre-planned appointment system brings challenges.

6.46. Cumbria Police now adopts the Right Care Right Person approach to responding to concerns for safety. The approach aims to ensure vulnerable people get the right support from the right people and applies to calls about concerns for welfare, self-discharges from healthcare settings, absence without leave from mental health settings and medical incidents. A College of Policing toolkit supports forces to decide the appropriateness of a police response to these calls and to work closely with health and social care agencies to implement the approach. It seems possible that the change in Police response to concerns for Diana's safety, resulting in a welfare visit being declined, was affected by this policy.

6.47. Cumberland Adult Social Care have a standard operating procedure in place with regards to triaging of referrals. This provides guidance on which team is most appropriate to support at the point of contact. Referrals are prioritised and assigned to the most appropriate team. The Council has introduced a new self-neglect strategy, which is used in conjunction with the Council's Self Neglect Guidance Policy and aims to strengthen practice in responding to people who are presenting with self-neglect. The new procedure raises the importance of multiagency working as a positive means of addressing issues of self-neglect and is working to embed the principles of this approach into practice. Implementation has been supported by the advanced practice leads team, who led sessions that were mandatory for all staff.

6.48. Despite the systems and processes in place to give organisational support to self-neglect practice, shortcomings in the organisational domain are evident across the six cases.

6.49. There is evidence of staffing pressures within teams. Such pressures were found responsible, for example, for the absence of a best interests intervention in relation to Donald following the finding that he lacked capacity for care and support needs decisions. Limited clinical resource in Bill's surgery impacted on patients' access to GP appointments. Time constraints and high service demands, limited resources and staff shortages are seen as barriers to effective multiagency working also.

6.50. Cumberland Adult Social Care notes that teams run with vacancies due to fluctuations in availability of a trained workforce and changes in the labour market in the period following the Covid pandemic. The Council has identified that both short-term and long-term teams, as well as safeguarding teams, are under-resourced and that this limits their capacity to respond to the volume of work and apply the appropriate policies/procedures and guidance. This also affects the teams' ability to apply a longer-term approach to self-neglect. Thus the difficulties of balancing resource and demand present a significant challenge. There is reliance on an externally provided work force, some of whom are remote working. Consideration of investment in permanent staffing and balancing resource/demand requirements is a crucial consideration moving forward.

6.51. Paul's GP surgery consider that the overall demand on general practice may have been a barrier to his care at times. The sheer volume of referrals made to other agencies militates against following up those on which feedback is not received. Limitations on capacity in the face of heavy demand also had an impact on the ability of general practice to offer continuity of patient care or oversight with the same GP. The volume of demand outweighing capacity requires some responses to be prioritized over others. This may have had some impact on

the surgery's ability to be professionally curious, to consider all factors during appointments, to triangulate with previous contacts, to follow up on outcomes of referrals and to ensure that review appointments were booked.

6.52. Westmorland and Furness Adult Social Care attribute the delay in allocation of a social worker to complete a Care Act needs assessment with Paul to a lack of available staffing. It may also be the case that the involvement of the HAWC service can at times be perceived as meeting an individual's needs in the interim, although this was not the case here.

6.53. Cumberland Council reflect that a better understanding of self-neglect among social care practitioners and managers during involvement with Tom would have provided a more effective framework for responding to the risks arising from his self-neglect. At this time the Council did not provide any specific training for staff on working with people who self-neglect. Subsequently the Advanced Practice Leads team have delivered self-neglect strategy briefing sessions and practice workshops.

6.54. The social care practitioner who undertook Donald's capacity assessment had not had any training in working under the Mental Capacity Act. Although management oversight and advice were provided, this did not identify that no best interests process had followed the mental capacity assessment in which he was found to lack capacity.

6.55. The Fire and Rescue Service's safeguarding training does not include coverage of self-neglect and the safeguarding training offered by Cumbria Police has a limited focus on self-neglect. Victim Support do not have a specific training offer on self-neglect.

6.56. The use of supervision within Adult Social Care is not always recorded and it is not clear, therefore, whether there was regular manager oversight. While this does not mean that case discussion did not take place in personal supervision, the lack of recording means that the rationale for decisions is lost. In Tom's case a supervision session is entered on the record but the record makes no mention of the safeguarding concerns, which were being dealt with by the safeguarding team, showing a disconnect between the focus of attention given to the same person by practitioners from the different teams.

6.57. Some GP surgeries (in both ICB areas) have stated that management scrutiny of senior clinicians' decisions would not be expected practice. Concerns of a safeguarding nature could, however, have been discussed with the nominated safeguarding lead GP, raised at internal safeguarding meetings or escalated to the ICB's safeguarding team for advice and this did not happen in relation to the individuals concerned.

6.58. Paul's surgery have reflected that although staff had access to CSAB's safeguarding adults threshold tool and CSAB's self-neglect guidance, knowledge and experience of applying these in practice could have been stronger, particularly in terms of the use of professional curiosity and the importance of multiagency co-ordination. Similarly, Westmorland and Furness Adult Social Care reflect that the tools available to social care practitioners to assist decision-making do not appear to have been used or to have informed decisions around face-to-face contact with Paul.

6.59. Some patients may experience particular challenges in accessing services, in part due to their own difficulties in overcoming their own reluctance, in part because the service model may be difficult for them to negotiate. For example, although Bill's surgery had a specialist substance misuse GP lead, with whom his case was discussed, Bill was not able to engage consistently with substance misuse provision.

6.60. Organisational and service change was also apparent and potentially impacted on case management. In Paul's case, the Lancashire and South Cumbria Foundation Trust's Initial Response Service had gone live in his locality only the day before they undertook a phone triage with Paul. This was a huge organisational change with the introduction of a new service, new assessment documentation and new team (albeit experienced practitioners) who were working towards new processes and pathways for service users. All processes were new to all staff and those that are now in place, such as daily handovers and daily multidisciplinary huddles, were not embedded in practice.

6.61. In Bill's case, his GP practice had in 2021 been through a merger with four other primary care services, resulting in a lengthy process of aligning multiple systems and processes. The start of Cumberland Council's involvement with Tom coincided with the implementation of a new structure for the older adults' service area, although the impact of this on the care Tom received is thought to have been minimal.

Domain 4: SAB governance

6.62. During this review the Board's governance role has been referred to in relation to the threshold tool, released in 2021 and designed to support decision-making on whether the circumstances witnessed in an individual's life warrant safeguarding action. This tool was in place during the period of work with the individuals included in this review and is clearly seen by agencies as a resource to assist decision-making. In some cases, however, concerns have been expressed that the tool could be acting as a barrier to safeguarding action. In one case it became the source of confusion, professional disagreement, and delay in response.

Domain 5: Features of the national context

6.63. Looking beyond organisations to the wider national context, the aftermath of the Covid pandemic was one key feature during the period under review. Services to all the individuals were potentially affected, either by the initial lockdowns of 2020 and 2021, or by the transition in 2021. Perhaps surprisingly, relatively little direct impact was noted.

6.64. Policing carried on as normal. The only change was that officers wore protective equipment including masks, which may have impacted upon communication with some people. Even here, however, individuals in this review were not affected. Officers engaging with Diana, for example, did not wear masks and communication was not impeded. Although Tom's requirement for care coincided with the Covid pandemic, his interventions do not appear to have been affected and face-to-face visits took place when required. Similarly, Paul's surgery does not believe there to have been any legacy impact of Covid on their service delivery during their engagement with him in the months before he died.

6.65. More generally, however, the intense and in some cases ongoing pressures experienced as a result of the demands that Covid placed upon agencies have endured. One agency has described the impact of the Covid pandemic as taking years to recover from.

7. Family Perspectives

The perspectives of family members who participated in this thematic review have informed the analysis throughout. They also provide powerful testimony to the impact of self-neglect on the individuals concerned and, in some cases, their own experience of interactions with agencies. For these reasons this section reports the views they expressed during conversations with the independent reviewer. In all cases they have given permission for inclusion.

7.1. Donald

Donald's partner participated in a telephone conversation with the independent reviewer during which she shared some information about the challenges Donald faced. She described him as a very poorly man, whose ability to undertake domestic tasks had been impeded by an episode of work-related blood poisoning, which had caused him to lose the use of one hand, which frequently entered spasm and gave him great pain. He was often very sad. She did her best to help him but was herself in poor health. She recognised they needed help but her attempts to persuade him to accept care and support were unsuccessful. She felt his reluctance arose from embarrassment about the conditions in the home, which he didn't want others to witness.

She was glad to hear about the review findings and recommendations and expressed the hope that others should be able to learn from the experiences of the six individuals in this review.

7.2. Diana

The independent reviewer met with Diana's sister-in-law P and P's daughter C, together in-person at P's home. Both were keen to see what can be learnt from the tragic circumstances of Diana's death and to contribute to improving how others in similar situations are safeguarded in future. In follow-up contact, they learnt about the review findings and recommendations.

The house in which Diana lived had been her family home for most of her life, a property in which her parents had located their Bed & Breakfast business. Diana herself worked as an administrator but left her job when she married P's brother in the late 1980s. He joined her in her family home, where her father was also resident. Diana and her husband did not have children of their own but Diana became step-mother to her husband's son from a previous marriage, who later left home.

P and C described how, after the couple's marriage, they withdrew into the house and rarely went out. C, as a child, would stay with them during the summer holidays. They described Diana's daily routine as being awake during the night and sleeping during the day. The house showed signs of neglect. Diana's husband died in 2004, aged 57. After his death, P and her family would occasionally visit but never stayed in the house. It seemed its upkeep became too much for the funds available. Diana would not consider moving, however, and P believes she convinced herself its deteriorating condition did not matter. Diana would sometimes ring P for conversation, often at odd hours during the night, with the strangeness of her behaviour increasing as she got older. Her personal care was poor and it seemed she didn't care how she looked. The last visit the family made was by C in 2019. She found the garden/grounds very overgrown and there was no reply from Diana. Through the kitchen window she could see things piled on the table but could not tell whether the room was clean. C left a note with her telephone number but heard nothing further.

The first the family knew of Diana's death was a call from Cumbria Police, who rang C as a means of contacting P. The coroner viewed P as Diana's next-of-kin and advised her to make funeral arrangements. Later, however, P was informed by Cumbria Council's Estates Research Department that they had found two cousins and that she was no longer Diana's next-of-kin. She

ceased the funeral arrangements and later received a solicitor's letter informing her that Diana had been cremated, her ashes to be placed with her husband's grave when that was located.

Since then, P and C have heard nothing more and have been concerned that they don't know where Diana's ashes are. They do not know who the cousins are. They do know that Diana's father had a brother who had two children but have no contact details.

Both P and C remain very concerned at the lack of communication with them about (a) the circumstances in which Diana died and (b) the whereabouts of her ashes. They were unaware of when she had last been seen, what efforts might have been made by local agencies to support her before her death, and when she was thought to have died. This caused them distress. C in particular was concerned that at the time of her attempted visit five years previously Diana might have already been deceased. They were reassured to hear that since then a neighbour, a plumber and agencies had made efforts to check on Diana's welfare and that she had been seen.

In light of this information, they were reassured that she had been offered support. They do, however, feel that communication with them was poor, particularly following the decision that P was no longer seen as next-of-kin. This left them not knowing about the funeral arrangements and without knowing where Diana's ashes are they cannot visit to pay their final respects.

7.3. Julie

The independent reviewer had two phone conversation with Julie's mother, who shared background information about Julie's earlier life and expressed views on the support she had received during the period leading up to her death.

Julie was the second of three children in a close-knit family, with Julie herself being very family-oriented. Growing up she was 'a good girl, no trouble'. She was successful at school, worked in x-ray and microfilm and later achieved a care work diploma. She got married and had two sons, the elder of whom has recently become a father himself. Julie would have been 'over the moon' had she known. Julie's husband worked away, however, and the marriage ended when he had an affair. This period in her mid-40s was one of extreme stress for Julie. She got divorced and lost her house. She entered the menopause but found it difficult to talk to male doctors. Her father was diagnosed with dementia and her mother had multiple serious health issues. Julie herself had extreme fatigue and many physical ailments – too much to cope with. She became very anxious and drank to self-medicate. Her sons went to stay with her mother and later moved away. During Covid, Julie's mother had to self-isolate as she was receiving chemotherapy. She and Julie still spoke on the phone but the physical and emotional support Julie needed wasn't available.

Her mother's strongest concern about the services involved is that they seemed to see Julie merely as a 'down and out' who had drunk alcohol all her life, when this was far from being the truth. Her mother feels no-one read between the lines or asked what was behind it all or enquired into the pain that Julie was struggling to manage. She also expressed concern that agencies did not inform her of events such as Julie's hospital admissions or experience of domestic abuse. While recognizing the constraints of confidentiality, she feels that through not knowing she missed opportunities to support her daughter.

Julie's mother remains in distress at the loss of her daughter and does not see the review as resolving this for her. "What does lessons learnt mean? It's just a cliché – it doesn't cover up your ordeal". But she was glad to hear about the review's findings and recommendations, and expressed strong hopes that others learn from the experiences of her daughter and others.

7.4. Paul

The independent reviewer held a MS Teams call with Paul's sisters, referred to here as L and J, and had a number of email exchanges with them also. Both are familiar with safeguarding processes due to their professional roles. Both were keen to participate in the SAR in order to ensure that we have as full an understanding as possible of the challenges that Paul faced in his life as well as the frustration and distress he experienced in the months before he died. In a follow-up call they heard about the review findings and recommendations.

As a child Paul's behaviour had been identified as unusual; he could become very cross, became fixated on certain things and was preoccupied with cleanliness; this persisted through his life. He had had long involvement with mental health services, being diagnosed at various points as having a personality disorder, bi-polar disorder and a possible autistic spectrum disorder. He had experienced alcohol dependency, although also spent many years sober. In the year before he died he had become agoraphobic and never left his flat.

As a punk rocker, his pride and joy was a unique collection of music meticulously arranged in his flat. He was highly articulate and would post stories on Facebook. He also had a wicked sense of humour. While he could sometimes be challenging, he was essentially kind-hearted and he very much loved his family; he would always end messages with 'love you'.

During the Covid pandemic, the isolation he experienced caused a decline in his mental health. L and J believe that he began to drink again at this point. He also experienced physical health challenges, with an ankle injury and a hole in his bowel that resulted in faeces transferring into his urinary tract. He found it difficult to contact his GP surgery due to what he understood to be their rules about when calls could be made. His father, for whom he had been a carer, died in October 2022 and the bereavement brought Paul additional distress. His self-care declined dramatically and he hoarded rubbish in his property to the point that he could no longer sleep in his bed or use his bathroom. His sitting room became his toilet. He was acutely aware of his circumstances and too embarrassed to allow his sisters access to his flat. He would have known also that his tenancy was at risk. He recogised that he needed support and actively sought help to clean his flat. At one point, he stated: "If I don't get support, I'm going to die".

In March 2023, alerted by a friend to the state of Paul's flat, J made a referral to Adult Social Care for support for him. Adult Social Care referred him on to the mental health Initial Response Service (IRS), who spoke to him by phone and advised him to contact Cruse for bereavement counselling and to contact them again if his mental health deteriorated further. He did contact them further, but this did not result in any different outcome. His case was closed to mental health services. J received no feedback on the outcome of her referral, nor was there any ongoing contact by IRS with either J or L to follow up on the actions they had advised Paul to take.

L and J are concerned that although a range of agencies had contacts with Paul between that time and his death, none responded to his needs or accurately identified the risks in his situation. They believe there was a marked lack of professional curiosity about his circumstances and no home visit took place to witness the conditions in which he was living. Despite his repeated requests for practical support to remove accumulated rubbish, he received none.

L and J's further concerns are:

- As a tenant in supported accommodation, Paul's housing provider had a duty of care towards him, which was not fulfilled. Contact them as his family came too late.

- Paul was ordering alcohol online and deliveries of food were being made but not used. Yet no suppliers or delivery companies reported concerns.
- Adult Social Care, mental health services and the GP surgery knew that Paul had started to drink again yet to their knowledge did not receive support to address this.
- It is not clear how much of the extensive information that J gave Adult Social Care was shared with other agencies such as mental health services and the housing provider.
- When IRS spoke with Paul by phone and heard the level of his distress, it was not appropriate to take his reassurance that he could keep himself safe and to close his case.
- No question was raised about his mental capacity and in particular whether his executive function was impaired.
- Paul had been a very frequent caller to his GP surgery. It is unclear at what point he reduced contact and whether his medication was still being ordered and delivered.

They feel all agencies 'passed the buck'. Paul's needs were not 'owned' by anyone and no one was accountable for decisions. He was lost in the legal framework and received no humane response.

On 21st June 2024, L received a call from Paul's housing provider who had been unable to contact him. L tried without success to contact Paul by phone. The housing provider then told her that the Police would be going to his flat. When L later rang the Police, they would not tell her what they had found, saying they would be visiting J (who lived locally) and telling her not to ring her sister.

After Paul had been found deceased that day, L and J were initially told not to go to the flat. Five days later the housing provider asked them to clean and clear the property. The state in which they found it deeply shocked and distressed them both. They were unprepared, ill-equipped and, they feel, totally unsupported in what they had to do, with no protective clothing, no advice about contractors who might take on the task, and no emotional support for themselves. They point out that when someone dies by suicide, an active protocol for family support is followed; yet here, for Paul's death in similarly distressing circumstances, there was nothing.

In summary, L and J are very concerned about the level of self-neglect that can remain 'hidden in plain sight'. In taking part in the SAR, they have two key objectives: They want answers to their questions so that they can understand what happened to Paul – this is essential if they are to be able to lay him to rest. They want the learning from Paul's circumstances to benefit others in similar circumstances by preventing what happened to Paul from happening to others.

They would like to see SAR recommendations about pathways/protocols for communication with families and the provision of support, professional curiosity, thresholds for action, mental capacity, alcohol dependency, GP policies on non-attendance, accessibility of services.

7.5. Tom

The independent reviewer held two online meetings call with Tom's niece, referred to here as K, who was committed to seeing what can be learnt from the tragic circumstances of her uncle's death and improve how others in similar situations are safeguarded in future. In the follow-up meeting she learnt about the review findings and recommendations.

Her Uncle Tom was her mother's older brother; he and his wife had been almost like a second set of parents to her. They had one child of their own, who had left home at 16 and had little contact

with them. As a young man Tom had served in the RAF for 12 years and later had been a factory cleaner. K described him as a lovely man who enjoyed socialising in his local pub. He was happy go lucky with a love of children, whom he would entertain by dressing up. He liked to draw and make things that he would paint and place in his garden. He was always smart, with never a hair out of place. He became quite deaf but could understand what was being said if articulated clearly; he had a microphone that he placed in front of him.

Tom's wife became ill and from 2015 onwards K supported the couple. His wife died in 2019 and Tom did not deal well with this loss. He withdrew into himself and stopped going out. Other family bereavements hit him hard too. In mid-2020 he stopped washing and his hygiene deteriorated. He stopped going upstairs to use the bathroom and would urinate and defecate in his clothes. He had oedema in his legs, with skin breakdown causing leg ulcers. He was a smoker and often discarded cigarettes carelessly. He would cut up pieces of paper into thin strips, creating an additional fire hazard. The fire in which he died was the thirteenth that had taken place.

In addition to the care visits arranged by Adult Social Care, K visited Tom every day, sharing the task of supporting him with her cousin V. He declined offers of washing and was reluctant to change his clothes. She would discuss the risks with him, but his response was 'if I die, I die'. She describes it as being as if he had just given up on life.

K and V attended the inquest, along with two members of staff from the care agency supporting Tom. The coroner found that Tom had died an accidental death but raised a Prevention of Future Deaths report.

K has the following concerns about how agencies supported her uncle.

- **Communication:** The social workers did not seem to understand how best to communicate with Tom, given his deafness.
- **Mental capacity:** K questions how Tom could have been found to have capacity when he was behaving as he did. She accepts that he knew what day of the week it was, but his self-neglectful behaviour seemed to demonstrate that there was a gap somewhere in terms of his ability to self-care. She also was aware that his capacity could fluctuate and she questions whether this was taken into account when his capacity was assessed.
- **Leg care:** Tom was not referred for physio to assist his movement, which K feels would have helped his oedema.
- **Risk assessment:** K is concerned at the absence of a risk assessment relating to the use of emollient creams.
- **Fire report:** K questions the events as described in the Fire and Rescue Service's Fire Scene Investigation Report. She believes the fire started through a cigarette dropped into a bin.
- **Safeguarding:** none of the safeguarding referrals that were made resulted in safeguarding action being taken. She believes the risks were judged to be low level. They were not escalated and no risk management action was taken. She is concerned that practitioners have insufficient training in recognising and managing risk from fire and emollients.

In terms of what could have been done differently, K wanted some intervention that could have made Tom safer than they, as a family, could. She feels that residential care should have been pursued. It was raised with Tom, but he kept changing his mind. The student social worker who visited him was due to discuss it with her practice educator, but K has no evidence this discussion took place and the question of residential care was never taken forward.

8. The Learning Event: A 'Temperature Check' On Current Practice

8.1. Nature of the event

8.1.1. The event took place online and was attended by 120 people representing over 20 agencies from across the safeguarding partnership. It brought together professionals from many disciplines who encounter self-neglect in their work, operational managers, supervisors and those in safeguarding advisory roles, and those responsible for strategy and leadership. In this way, it 'took the temperature' of self-neglect work from the perspective of all the organisational layers on which positive change will depend.

8.1.2. The independent reviewer first shared some of the learning themes emerging from review of the six cases under review. The main purpose of the event, however, was to explore two broader questions:

- What is working well now across Cumbria in work with people who self-neglect: what are we getting right and what enables that to happen?
- What are the challenges now of working with self-neglect in Cumbria: what could we improve and what barriers exist?

8.1.3. Participants were not expected to comment directly or answer questions specifically on their own involvement with any individual. The discussion sought perspectives at a more general level, with a focus on the position now and going forward. Much of the discussion took place in breakout rooms, facilitated by members of the SAR panel.

8.2. What works well in current practice with self-neglect?

The discussions revealed much that staff believe is positive in current practice, providing evidence that some things have changed for the better since the circumstances under review.

8.2.1. Organisations have better recognition of what constitutes self-neglect and there is a collective desire for positive change.

8.2.2. At the level of individual practice:

- Greater levels of persistence and professional curiosity are in evidence.
- Identifying a trusted person and developing relationship-based practice are recognized as important approaches.
- There are better understandings of the need for trauma-informed responses.
- There is more creativity in how practitioners interact with people, with recognition that reluctance to engage does not mean responsibility ends.

8.2.3. Improved structures are in place, with escalation mechanisms that are available and utilised.

- The safeguarding triage function in Adult Social Care promotes consistency of decision making and discussion with referrers provides information on how current risks are being managed. Police hub triage promotes joined-up thinking on the criteria for action and expected responses.

- Adult Social Care now have a Safeguarding Operational Support Group, attended by service and team managers and practitioners, to which complex cases involving self-neglect can be escalated for support and guidance. This group feeds into the Oversight and Performance Group.

8.2.4. Interagency working is improving:

- Communication and collaboration are often evident from the beginning – getting the right people round the table, including family and informal support networks.
- A person's history is shared with relevant agencies.
- There is a better shared understanding of roles and responsibilities and stronger transitions between teams.
- Liaison between agencies can identify which might be best able to forge a relationship
- Multidisciplinary meetings are happening more frequently.
- There are good links between Adult Social Care and Environmental Health and between the Fire and Rescue Service and neighbourhood policing teams.
- Links between the Police and Adult Social Care are strong. The Police commended the safeguarding team at Westmorland and Furness Council who were an excellent point of contact; the collaborative work that occurs prevents people falling through gaps.

8.3. What challenges remain?

Nonetheless, participants were clear in their discussions that multiple challenges remain for those working with self-neglect.

8.3.1. Challenges in daily practice:

- Most consistently mentioned here were difficulties surrounding mental capacity, with better understanding of the Mental Capacity Act thought to be necessary. The presumption of capacity principle was thought to pose a barrier to assessment being carried out, and records do not always evidence a rationale for relying upon it. Practitioners are sometimes unclear who can assess capacity, how assessments should be done and who the decision-maker is. It is not always recognised that capacity assessment may need more than a one-off conversation with the individual. Finding that an individual has capacity, whether or not through formal assessment, can be a barrier to then ensuring their safety when this would require longer-term involvement beyond the safeguarding enquiry process. There still seems to be an assumption that if the individual has capacity and declines support, then this is an 'unwise decision' and nothing more can be done.
- Virtual contact was thought to hinder clarity and a true understanding of the person's self-neglect. Without face-to-face contact, witnessing the home conditions was impossible, as was observing executive function when judging mental capacity.
- It can be challenging to distinguish between self-neglect vs neglect by others.
- Better understanding is needed of when refusal of consent to make a referral can be overridden. There is still a belief that the self-neglect is a lifestyle choice.
- The focus of assessment and intervention tends to be on immediate symptoms rather than on the underlying drivers for the self-neglect.

- While immediate risks are addressed, ongoing oversight/contact/support then drifts
- Gaining access to the individual's home can be difficult when safeguarding practitioners have no statutory power to gain access.
- A decision that an individual is 'not ready to engage' can result in their case being closed, leading to serious incidents later.

8.3.2. Challenges of interagency working

- Not all Integrated Care Communities are thought to be as effective as each other; there is something of a postcode lottery.
- When the criteria for following a safeguarding pathway are not met, it is hard to navigate between organisations to find the appropriate process to secure support.
- Not all organisations are thought to see themselves as able to take the lead in convening a multiagency strategy discussion.
- It is a challenge to get agencies round the table to formulate a plan for case coordination. Even when agencies do convene, there can be discussion but no action.
- True multidisciplinary working is hard to achieve when there is a risk that agencies are positioned against each other in terms of who takes responsibility, risking a continuation of silo-working. It seems that agencies feel responsibility is transferred when a safeguarding referral has been made.
- There can be a lack of feedback between services and those involved are often not aware when no further action is being taken.
- Not having access to other services' notes limits understanding of how interventions fit together.
- Better contacts are needed with specialist services who are perhaps less involved routinely in safeguarding processes.
- Homeless individuals can end up in a revolving door process in hospital – the hospital is not able to refer them to social care as they have no address. Discharge occurs without an adequate network of support.

8.3.3. Challenges relating to resources

- Workloads impact on the time that can be dedicated to individual cases.
- Time constraints limit how long can be spent with an individual and how much professional curiosity we can show. This means missed opportunities.
- The intensity and duration of time required to engage people who are reluctant to engage and intervene at a pace acceptable to them are not available.
- There are gaps in the breadth of knowledge, skills and resources required to determine the best course of action, e.g. resources for trauma-informed working.
- The voluntary agencies on which statutory services often rely for support to the individual are fragile due to uncertainty about their funding.

- Preventive services are lacking. Thresholds have to be reached before anything can be done. Thresholds vary between agencies, resulting in individuals falling into the gap between services when concerns are deemed to not meet the threshold. Situations get left until it is too late.

8.4. What did participants believe should happen going forward?

Participants discussed what they and others, including Cumbria Safeguarding Adults Board, could do to further improve work with self-neglect.

8.4.1. What action can you take yourself in your own practice? At a personal level, practitioners felt they needed to:

- Embed a more trauma-informed holistic approach rather than seek a quick fix to the main presenting issues. Not addressing the root cause contributes to repeat referrals;
- Challenge misunderstandings about the assumption of capacity and misleading language about capacity in records/reports (e.g. 'deemed to have capacity' or 'has capacity' where no capacity assessment has taken place);
- Ensure a collaborative, longitudinal approach to capacity assessments including the triangulation of observations & evidence;
- Ensure consent and capacity assessments are robust and recorded adequately (including best interest decisions);
- Ensure face-to-face visits are prioritised for self-neglect referrals;
- Commit to a holistic, 'whole person whole family' lens and approach;
- Seek a balance between perseverance and being pushy;
- Gain more understanding of safeguarding roles and thresholds;
- Invite people with specialist knowledge to team meetings;
- Engage with CPD to access more specialist knowledge;
- Seek support to develop better knowledge of legal frameworks;
- Reach out more and seek advice/support with difficult situations, ensure supervision is available and used;
- Give clear communications to other agencies;
- Seek and give feedback from and to other agencies after referrals have been made;
- Work to establish multidisciplinary risk management plans;
- Slow down.

8.4.2. What actions would you like to see other practitioners take? As well as changes in their own practice, participants discussed changes they would like to see others make.

- Those referring to safeguarding should gather as much information as possible on the presenting situation (including sharing their own risk assessments) to support decisions on safeguarding triage.

- Referrers should have open and frank discussions with the individual before raising a concern. There should be a shared sense of responsibility for this.
- Participation in multidisciplinary working should be the expectation from the offset.
- There needs to be improved understanding of information governance and data protection so that it does not pose a barrier to working together.
- Regular liaison between GPs and Adult Social Care about patients whose self-neglect is causing concern would be helpful.
- We need proactive sharing of knowledge and learning through multi-agency forums.
- We should stop using the "threshold" tool and be clear whether the concern meets the Care Act eligibility criteria and what the proposed/agreed action is from this contact. If the concern does not meet section 42 criteria, there should be discussion of what else can/should happen and further discussion with the referrer.

8.4.3. Organisationally, practitioners called a range of measures – some for attention by their own or others' agencies, others for leadership by the Safeguarding Adults Board:

- We need agencies in the safeguarding partnership to embrace the multidisciplinary model of working around risk management. Existing frameworks and models should be reviewed to provide pathways for risk assessment and risk management.
- We need designated pathways for information-gathering and sharing; shared assessment and responsibility; establishing agreed understandings of risk; the ability to arrange urgent strategy meetings (as can happen in children's safeguarding).
- We need clear and agreed understandings of agency roles and responsibilities in self-neglect work, as well as guidance on establishing a lead professional in multiagency intervention strategies and on strategies for resolution of conflicts between agencies.
- We should be able to make written referrals to safeguarding, so that information is not lost in translation through verbal referral discussions.
- Engaging social housing associations is key, as they often see people at earlier stages of self-neglect and could take the lead on preventative options.
- Consideration should be given to establishing an adult safeguarding hub.
- Appropriate training on self-neglect should be commissioned and delivered:
  - o Awareness and recognition of signs and symptoms;
  - o Techniques for engaging people who are reluctant to engage;
  - o Approaches to intervention ;
  - o Mental capacity training with a focus on self-neglect.
- Lead professionals in self-neglect cases need support: e.g. trauma-informed and professionally curious supervision, time for reflection, mentoring by experienced staff, a self-neglect forum to which cases can be brought for discussion.
- Agencies should account for their implementation of trauma-informed practice.

- Investment is needed in a preventative model, which should include visiting support and an 'Early Help' ethos.
- We need to have a more flexible approach to people who need help but not necessarily the help that is being offered or how it is being offered. We seem to discharge people who don't engage, whereas an assertive outreach approach could give better outcomes.
- There needs to be a robust system for learning, where learning from positive outcomes is given the same weight as that emerging from safeguarding adult reviews.

8.5. 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.

8.6. At the end of the event, participants were invited to share their experience of participating. Almost all (94%) had found the session interesting, with 92% finding the content relevant to their work. Eighty one percent had been able to participate in discussions as much as they had wanted to, with a further 14% saying that they had partly been able to participate at the level they wished. Almost three-quarters (72%) had some learning or reflection to take away, this being one example: 'I've found that this session has really made me consider what I could be doing differently in my day-to-day practice. It has made me think about how I will better work with partner agencies in the future to build good working relationships and improve communication between involved professionals".

9. Changes Within Agencies

Understandably, agencies do not wait for the outcome of a SAR before making changes they feel are necessary in how they work. In addition, some agencies have already carried out their own internal reviews, resulting in priorities for change. The SAR has therefore sought to capture what has been done in the intervening period since the individuals here died. Agencies were asked to provide information about changes implemented in response to their own reflection and learning.

9.1. Changes already implemented within agencies

9.1.1. Accent Housing

- Accent has implemented an action plan to improve reporting to their Board and to improve the ability of staff to identify safeguarding concerns.
- Wider teams are supported by safeguarding leads who have delivered campaigns about safeguarding and attended team meetings.
- All safeguarding leads complete Level 3 Safeguarding Adults training.
- Supervision is in place and includes training on professional challenge and greater understanding on pressing social need.
- A drive on making safeguarding personal has been instigated, which includes both customer-facing and back-office colleagues.
- A review of the training framework has recommended face-to-face training for customer facing colleagues.
- Contractors are supported their contractors to become more aware of self-neglect risks and to meet clear expectations on the reporting of concerns when carrying out work on properties.

9.1.2. Cumberland Council Adult Social Care

- The Council has developed a self-neglect and housing strategy which raises the importance of multidisciplinary working from the first point of contact. Debriefing sessions have been rolled out to all staff.
- A practice guidance principles document has been produced.
- Safeguarding Service Manager Meeting terms of reference have been agreed. This forum allows for social care practitioner support around complex cases.
- The Screening and Assessment Team have been made aware of the importance of contacting the referrer to gather information and other professionals at the point of contact. Multidisciplinary discussions with internal and external partners are happening more regularly on duty.
- Significant changes have taken place to the way people who use emollient cream are supported and protected. Communications are circulated repeatedly on the use of emollients and risk assessments are routinely carried out. This is included in the new self-neglect strategy and training has taken place.
- A guidance and briefing note has been developed and shared with all care providers on how to raise concerns around potential changes in a person's mental capacity, or any other issues where Adult Social Care are the responding agency.
- The Council has a Mental Capacity Act forum in place, which is a recurring event providing a reflective space for learning to be shared. It is open to social care and health practitioners across Adults' and Children's services. Discussions have included fluctuating capacity and executive function.
- The Adult Social Care Advanced Practice Lead Team have produced a 7-minute briefing on fluctuating capacity for managers to deliver in team meetings and individual staff supervisions. It will remain available for continuous professional development.
- Adult Social Care practitioners have planned legal briefings every 6 weeks, with the Mental Capacity Act regularly being a focus of the session.
- All safeguarding contacts, with the exception of Learning Disability and Mental Health services, are triaged by the Safeguarding Team. A further multidisciplinary decision function has been introduced, which includes any allocated worker from within the directorate, to support progression of the enquiry and key risk- management action to be taken and by whom.
- A Service Manager-led oversight meeting has been established.

9.1.3. Cumbria Community Homes have increased the amount of weekly support when a tenant's needs warrant it.

9.1.4. Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

- Has moved away from using FACE risk assessment tool in favour of the nationally recommended biopsychosocial approach to clinical risk assessment in mental health services.
- Has a Safeguarding Adults at Risk policy that includes staff's duties and responsibilities, what to do if abuse or self-neglect is suspected or disclosed, principles of confidentiality, good

practice for victims and perpetrator disclosures, and support for staff. Appendices include What to Do If You Are Worried an Adult at Risk Is Being Abused? Local Safeguarding Adult Partnership Referral Links and Threshold Tools.

- The Domestic Abuse Policy and the Safeguarding Children Policy provide advice on how to respond to incidents/disclosures of abuse and neglect.
- Since 2022, all registered professionals undertake level 3 safeguarding training. Safeguarding and Public Protection practitioners work collaboratively with the Multiagency Safeguarding Hub to share information between partners so that safeguarding concerns can be identified earlier and managed more efficiently.

9.1.5. Cumbria Police

- Many more vulnerable adult reports are being shared with Adult Social Care.
- Morning triage between the police and Adult Social Care is being used on daily basis and is proving to be effective at information sharing.

9.1.6. Donald's GP practice now has a planned care team to follow up patients who do not attend for their annual review appointments. All staff must undertake self-neglect training that includes expected responses to concerns.

9.1.7. Home group

- A clear expectation of Housing Manager follow-up on cases is established; on any properties to which we cannot gain access, Housing Managers follow up with other agencies to ensure they are invited to relevant meetings and kept updated. A training session is provided for all Housing Managers as a reminder on concerns to look out for when visiting a tenant's home.
- The agency is seeking to establish a budget for skips to assist with intervention.

9.1.8. Lancashire and South Cumbria NHS Foundation Trust

- **Dual diagnosis:**
  - The Trust has developed and ratified a Dual Diagnosis and Addiction Policy concerning clinical approaches to supporting patients who use substances.
  - There are now Dual Diagnosis groups in each locality undertaking monthly Co-occurring Diagnosis meetings to which all clinical services, internal and external are invited. A review of these meetings showed that each locality had differing approaches, so further work has taken place to standardise the forums and ensure they are efficient and effective.
  - There is a reporting structure into the Dual Diagnosis Best Practice Group (which reports into the Clinical Standards Group). This will enable the Best Practice Group to undertake regular associated clinical and operational audits of the meetings.
  - The Trust has developed a standardised dual diagnosis training package to further support all staff in adopting a uniform approach to dual diagnosis.
- **Professional curiosity:** A monthly discussion around professional curiosity has been introduced with professionals in the team. This allows for focused reflective discussions on questioning styles and supporting the practitioners to reflect on learning, develop their skills further and offer shared learning.

- **Multiagency working:** The Trust has introduced Enhanced Multidisciplinary Teams, bringing together mental health practitioners from primary care and community teams, voluntary organisations, peer support services, psychologists and consultants, who meet weekly to discuss complex cases.
- **Safeguarding:** Specialist safeguarding supervision has been introduced.

9.1.9. Lancashire and South Cumbria Integrated Care Board

- The Safeguarding Team have carried out a series of supportive safeguarding visits to Paul's GP surgery, who have proactively further strengthened their safeguarding arrangements. One example of this is that the surgery are now recording on a patient's GP medical record, with consideration to online visibility, when they are discussed at the internal safeguarding meeting along with adding a relevant code. This clearly highlights any active safeguarding or vulnerability considerations and associated actions to any Clinician reviewing a particular patient.
- The Safeguarding Team are in the process of ratifying a Sample Policy for Adult Not Brought to Health Appointments for Primary Care, GPs, Pharmacy, Optometry and Dental Practice, which will be launched to GP Surgeries across the ICB's area.
- During the process of this SAR, the Safeguarding Team have re-shared CSAB's self-neglect guidance and threshold toolkit with Paul's GP surgery and reminded them of escalation routes into the ICB Safeguarding Team for support and supervision with complex safeguarding cases. The Safeguarding Team have noted that self-neglect may be a topic to revisit at a future protected learning time event for GP Surgeries across the Lancashire and South Cumbria footprint.

9.1.10. North Cumbria Integrated Care NHS Foundation Trust has a review of Symphony ongoing to ensure routine enquiry questions are asked at the appropriate time within Emergency Departments.

9.1.11. North East and North Cumbria NHS Integrated Care Board launched an "adult was not brought" initiative in North Cumbria in 2023.

9.1.12. North West Ambulance Service in 2022 introduced an early help option within the safeguarding system across the North West of England. This was in response to review of safeguarding referrals, which identified that a number of patients required Care Act assessments and did not meet safeguarding threshold. This was in consultation with local authority social care teams across the North West geographical footprint.

9.1.13. Recovery Services Cumbria

- The service has developed a Self-Neglect Guidance document, introduced an alcohol multidisciplinary team, aimed at coordinating all inpatient detox referrals, action planning and complex discharge review), introduced a comprehensive safeguarding recording template within the clinical recording system, added a safety screening question to assessment and embedded links to a Risk Identification Checklist and MARAC referral form embedded within the clinical recording system.
- Across the organisation there has been a review of the safeguarding and domestic abuse training offer for all staff.

9.1.14. University Hospitals of Morecambe Bay Trust

- The Trust has introduced a monthly supervision and learning session for staff specifically aimed around self-neglect, launched 7-minute briefings for staff regarding self-neglect and factors that make patients more vulnerable, a 'who to tell' guide to enable staff to know what to do when a patient appears to be self-neglecting.
- Self-neglect has been added as a case group within the Trust's patient safety incident recording system to enable oversight of the volume of cases we are seeing.
- The patient care choices policy has been updated to include indicators of self-neglect.

9.1.15. Westmorland and Furness Council

- The Council has implemented guidance on in-person visits.
- A member of the Safeguarding Team attends the Police Triage meeting every weekday morning to consider all submitted SAFs from the Police.
- Self-neglect workshops for social work and OT teams have been held in all geographical areas of the Council.
- Guidance on working with risk has been issued to all social workers and occupational therapists.
- Safeguarding workshops that include content on self-neglect have been delivered to all newly qualified social work practitioners, apprentices and students on placement.
- Peer reflection sessions on self-neglect have been held across all geographical areas.
- The Safeguarding Adults Team and the Council's Advanced Practice Leads are involved in the delivery of CSAB facilitator lunch and learn events.
- Self-neglect updates are shared in monthly Principle Social Work updates.
- Safeguarding is a standing item at monthly Practice Learning Group meetings.
- The Council has introduced a Risk Enablement Panel to provide effective, transparent and safe ways to reach the best decision based on the information available. The Panel guides, advises and supports staff to ensure risks are explored, minimised and managed wherever possible. It is a safe and supportive environment for staff, demonstrating that no-one should be left alone to make a difficult decision and fulfilling our duty of care. It does not replace any existing processes or roles in respect of risk, for example, safeguarding referrals or enquiries, MAPPA or MARAC.
- The Council has developed a Self-Neglect Strategy that has been issued to all operational staff as a practice guide.
- MDD Guidance is in place with a daily meeting for any potential case escalations.
- An internal post-incident review process has been introduced to explore lessons learnt where critical incidents occur.
- The HAWC service has fortnightly risk meetings in place, chaired by a manager, providing staff with an opportunity to discuss concerns about risk, seek support with risk management, safeguarding or engagement and agree any escalation required.

- When both HAWC and social work teams are involved, updates are provided through conversations and meetings rather than merely through records. When concerns and risks are not being managed an escalation can also take place.

9.2. Changes within agencies remaining to be made

9.2.1. Cumberland Council Adult Social Care

- The risk assessment process is a priority review action held at the Practice Improvement Sub-Group, chaired by the Principal Social Worker. The intention is to review the existing process as engagement with staff and managers indicates the process is not optimal.
- A rolling programme of mandatory training on the Mental Capacity Act is high priority on the Training Plan. This will incorporate a specific focus on carers noting changes in presentation and how these are to be responded to, and a focus on executive capacity, fluctuating capacity and interpersonal influence on capacity. Using this training as a foundation, the Advanced Practice Lead Team will build Mental Capacity Act forums, communities of practice, practice workshops and briefings. Having a rolling training program will ensure that mental capacity is maintained at the forefront of practice and all staff – new and experienced – are continuously developing through a refresher and reflective approach.
- There is an active discussion within the Council regarding the future shape and function of the safeguarding offer and an appetite for sustained change, as well as a necessity for improvement arising from a recent Local Government Association peer challenge. There is a clear tension around how a case with a self-neglect narrative can be progressed through a case management route. This might be feasible if there was no barrier to multi-agency involvement, a clear sense of what the common goal was, a sense of what the individual's wishes and views were and legal literacy to guide the intervention. However, it seems there can be barriers to taking a non-safeguarding route. We need to fashion a way of working where multidisciplinary working and safeguarding processes can mutually support each other. It might be that a case moves between such routes and does not exclusively rest in one domain. This is why Vulnerable Adult Risk Management is attractive as a way of working.

9.2.2. Cumbria Community Homes will ensure new staff receive self-neglect training.

9.2.3. Cumbria Fire and Rescue Service personnel and crews will receive training on recognising and responding to self-neglect.

9.2.4. Cumbria Police will consider ways of raising the profile of self-neglect for officers, either by adding it to student officer training or through continuing professional development.

9.2.5. GP surgeries

- Bill's GP surgery will:
  - Consider review of the records of high intensity patients of NHS 111, the Ambulance Service and Cumbria Health on Call and agenda them for discussion at the Integrated Care Community multidisciplinary team to follow up any unmet needs
  - Consider how to improve the flow of information from the Ambulance Service to primary care when a patient is not transferred to hospital
  - Review the support available for adults who want to address alcohol use but struggle to engage with current provision.

- Paul's GP surgery have identified the need to
  - Strengthen their practice in relation to mental capacity, to ensure that executive function is consistently considered and is robustly documented
  - Improve their consideration of adults at their internal safeguarding meetings, which tend to be quite child focused
  - Focus further safeguarding awareness and learning towards professional curiosity and identifying and responding to self-neglect.

9.2.6. Lancashire and South Cumbria NHS Foundation Trust: The Initial Response Service has an action plan listing all improvement requirements arising from its Post Implementation Review, findings from Serious Incidents and subsequent quality reviews. This single plan aims to ensure that during this period of standardising and embedding the service all improvement requirements are visible and are prioritised according to risk and impact. All actions will be monitored, and progress reported through the IRS Delivery Group.

9.2.7. North Cumbria Integrated Care NHS Foundation Trust will support staff to achieve:

- Greater understanding of the responsibilities of key agencies for self-neglect
- Understanding of self-neglect and trauma-informed approaches
- Modified practice on early discharge of patients who do not engage with support
- Better understanding and engagement with the escalation processes

9.2.8. North East and North Cumbria NHS Integrated Care Board will promote increased awareness of the CSAB website and escalation policy.

9.2.9. Westmorland and Furness Council Adult Social Care

- The Council will clarify areas of responsibility in order to ensure that appropriate teams receive and act on case allocations without unreasonable delay.
- The Adult Social Care reshape that goes live in April 2025 will maintain the separate Safeguarding Adults Social Work Team. It will triage all safeguarding contacts (inclusive of mental health and learning disabilities), set a priority status and provide feedback to the referrer on next steps. The aim is to provide a consistent response to all areas of reported safeguarding.

10. Summary And Conclusions

This section summarises the learning from this thematic SAR, providing the context for the service improvement priorities identified in the recommendations that follow in section 10. The learning encompasses the multiple domains of the safeguarding systems: direct practice, interagency working, organizational features, SAB governance and national context.

10.1. Meeting needs

10.1.1. The six individuals all had complex and multiple needs relating to physical and mental health as well as in relation to their daily living and personal care. Many had faced challenges in their lives and had personal histories in which trauma and loss were notable features. There were examples of good practice, notably by specialist services with a clear and focused remit

on one aspect of need, such as alcohol dependency. Yet there were multiple barriers to needs being recognised and met.

- Physical health needs presenting acutely were generally met, but crisis events could obscure underlying needs that were preventing self-care. Acute episodes followed by withdrawal – either by the individual or by the service – meant that agencies rarely gained a full needs picture and root causes were not addressed.
- While general practice was often attentive, the habit of signposting individuals to other services was unrealistic for individuals who lacked the ability to self- motivate.
- The practicalities of GP contact were difficult for some and others were reluctant to seek help, remaining hidden from view.
- While there were some good examples of contractors visiting a person's home being proactive in raising concerns, other services sometimes did not see beyond the function of their own agency, missing opportunities to recognise the fuller extent of an individual's needs and seek help from other agencies.

10.1.2. Yet even when needs were evident, they were in some cases not met. Practitioners took at face value an individual's reassurance that they did not need any support. In some cases no Care Act assessment took place, and no carer's assessment was offered to a partner. In one case an assessment resulted in eligible needs being identified but reliance was placed on them being met by a friend, despite contrary evidence. In another, where a support package was not fully meeting needs due to the individual's reluctance, no review or escalation took place. Another individual presented a very clear need and request for practical support to clear accumulated rubbish and waste, yet no agency took responsibility for assisting him with this task and an absence of professional curiosity about his mental, physical and social wellbeing resulted in the level of his self-neglect not being recognised.

10.1.3. A focus on presenting need at the cost of engaging with more deep-seated features is a common shortcoming in self-neglect practice, resulting in an absence of holistic understanding and needs remaining unmet. While at times such a focus may be appropriate in the immediate context, more persistent approaches to identifying needs are also needed: greater levels of professional curiosity, better understanding of the individual's lived experience and assertive outreach in the provision of support. At the same time, self-neglect can sometimes present needs that it is no agency's sole responsibility to meet, requiring discussion and shared decision-making to ensure that they are recognised and met.

10.2. Risk management

10.2.1. Some risks in the lives of the six individuals were very evident and in some cases were proactively assessed and managed. In many cases, however, there were shortcomings in both the identification and management of risk.

- Known risks were not managed: for example in three of the cases fire hazards were identified but not all necessary action was taken. Potential cuckooing and exploitation/financial abuse were not explored as safeguarding issues.
- Risks were not identified: during a medical home visit, risk to physical health was prioritised over awareness of risk from conditions in the home. During a mental health triage, despite knowledge that a range of risk factors was present, the triage record identified minimal risk

and no risk management plan was made. Insufficient concern was attached to reports that indicated probable high levels of self-neglect.

- In some cases where multiple agencies were involved, there was no shared risk assessment and no shared risk management plan, resulting in individual agencies having a limited perspective and understanding of the risks facing the individual.

10.2.2. Use of formal safeguarding processes was inconsistent across all six cases, with evidence of self-neglect not being recognized as a safeguarding issue and weaknesses at decision-making points within the safeguarding pathway.

- **Referrals not made:** It may be the case that the threshold for safeguarding in self-neglect is not sufficiently well-understood and that referral pathways for raising concerns are not sufficiently well-differentiated. Referrals may not be made on the assumption that other agencies are involved and aware of risk. Healthcare staff may not take appropriate advice from safeguarding specialists in their agency. Attention in hospital may be given solely to physical injuries and medical condition, overlooking self-neglect and alcohol misuse. Some concerns have been raised about the use of the CSAB threshold tool in determining whether safeguarding referrals are made and how they are responded to.

- **Referrals triaged out of safeguarding:** Some referrals are triaged out through actions in the MASH. Within Adult Social Care, repeated referrals may be considered in isolation, ignoring the cumulative evidence and without consultation with operational teams involved. The requirement to refer into safeguarding by phone is thought to risk information detail being lost in translation.

- **Risk managed within case management:** There is evidence that managing self-neglect through a case management pathway, with a focus on care and support needs, may result in insufficient engagement with risk elements in the individual's situation. Equally, care and support needs involvement can influence decisions not to act under safeguarding. Adult Social Care suggest a risk management process is needed that sits between safeguarding and case management and operates in parallel to them.

10.2.3. Overall it seems that agencies sometimes have not worried enough about the risks arising from the individuals' self-neglect. To some degree, this is down to approaches taken in individual practice. Assumptions of lifestyle choice, assumptions of capacity, respect for privacy and lack of professional curiosity all militate against gaining a true risk picture. But interagency processes impact too on whether a robust risk management strategy is put in place. Action in both domains is therefore necessary.

10.3. Making safeguarding personal

10.3.1. The principle of respect for individuals' views and wishes was seen by all agencies as central to the work they undertook and there is evidence across the six cases that individuals' perspectives were sought, recognised and respected. In certain circumstances it was also understood that information could be shared without consent where believed necessary for safeguarding purposes.

10.3.2. However, identifying views and wishes was complicated by individuals' reluctance to engage. It was sometimes easier to identify what they did not want than it was to find out what they did, particularly when working under time constraints. This was sometimes complicated by intoxication and intimidation, or the presence of others. In one case, the individual's views

on his situation appear not to have been sought, with communication mediated by a family member through failure to adapt communication methods to suit his needs and preferences.

10.3.3. Even initial acceptance of support was sometimes later declined. In some cases, refusal was taken at face value, showing a simplistic interpretation of what it means to make safeguarding personal. In other cases, an individual's ability to exercise agency was overestimated and failed to allow for how features such as alcohol dependency would be impacting on their motivation and ability to act.

10.4. Protected characteristics

10.4.1. Closely linked to the principle of making safeguarding personal, and indeed central to any intervention by any public body in an individual's life, is the requirement to ensure compliance with Equality Act 2010, which protects people with protected characteristics from unlawful discrimination. In fact very few protected characteristics were explicitly identified in the six cases under review and it is unclear to what extent agencies record this information. Age and disability were sometimes noted but the majority of agencies had no characteristics evident in records.

10.4.2. There was evidence of some adjustment of practice in response to disability, for example in GPs carrying out home visits rather than surgery consultations, and recognition of age with disability and gender appears to have informed Police decisions during their contacts. But elsewhere there was no evidence that protected characteristics informed practice, and some (such as race, religion or sexual orientation) appeared completely off the radar.

10.5. Mental capacity

10.5.1. The absence of capacity assessment in situations where the circumstances warranted assessment is striking. There seems to have been a widespread reliance on an assumption of capacity rather than explicit testing under the Mental Capacity Act.

- In most of the cases under review, the individual's behaviour continuously placed them at serious risk, yet their capacity to make those decisions was not assessed.
- In some cases, the individual's alcohol dependency was well known and could have given rise to impairment that would affect their decision-making. The impact of persistent, heavy alcohol consumption on executive brain function is increasingly being recognised as a key consideration in mental capacity and for those individuals the lack of attention to it was a serious omission.
- There was some recognition that capacity could fluctuate but beyond recognising the impact of intoxication, the reasons for fluctuations were not explored.
- There was some uncertainty about which agency should take responsibility for capacity assessment.
- Where capacity assessments were undertaken they were found in some cases to have been poorly completed.
- A further omission, where assessment had found the individual lacked capacity to understand their care and support needs, was the absence of any subsequent best interests decision about how to keep them safe through the provision of support.
- Two services have stated that they do not carry out assessments of mental capacity but rely on calling in other services where they find capacity in doubt.

10.6. Family networks

10.6.1. In most of the cases under review, agencies had contact with families only when family members themselves sought it and even there the weight placed on their involvement varied.

- In one case, a relative was a key informant and decision-maker, with reliance placed on their views (to a degree that reduced the amount of direct discussion with the individual).
- In another, information provided by the family was not pursued in triaging the individual's needs and risks and appeared to make no difference to the outcome of that triage.
- Information arising from an agency's previous involvement with the partner of one individual was not taken into account when attempting to intervene with the individual's self-neglect.
- In two cases, agencies did take initiative in relation to family contact, seeking (albeit unsuccessfully) to trace family members to share concerns and seeking background information that would assist in understanding an individual's presentation.

10.7. Interagency working

10.7.1. Interagency collaboration requires consistent information-sharing, shared strategy, case coordination and sequencing of input. The picture across these six cases is mixed.

- Agencies appear to have had good understandings of each other's role and function, although differences of opinion, particularly about safeguarding thresholds, were common. No recourse appears to have been taken here to the CSAB escalation policy.
- Some good joint working was evidenced, for example between the Police and the Ambulance Service.
- In relation to information sharing, some good practice is in evidence, for example by the Ambulance Service in sharing detail of home environments. But it seems that GP surgeries can be left out of the information loop, as can the Fire and Rescue Service.
- Data protection rules on information-sharing without consent appear sometimes to be misinterpreted, resulting in information not being shared when it should be.
- Of concern was the lack of feedback on the outcome of safeguarding referrals.
- In other instances, failure to share information was a significant omission that impacted upon the outcome, for example that an individual's prescriptions had not been collected. In another case, hospital discharge took place without communication with the individual's support network.

10.7.2. One key mechanism for promoting shared perspectives and good interagency coordination is the use of interagency risk management meetings. In one case a sequence of safeguarding meetings resulted in an effective outcome for the individual. In other cases, health-led multidisciplinary meetings took place but were not broad enough in membership to impact on the overall strategy. Few system-wide meetings took place.

10.7.3. There remained a disconnect between health and social care agencies and silo-working was common. In one case where both were involved, there was little contact or liaison between them. In another, where health and social care practitioners did work together, no overall unifying goal and plan were in place. The involvement of multiple teams could lead to a lack of clarity on who was responsible for what aspect of intervention, and which agency,

if any, was in an overall coordinating role. With no agency convening any multiagency discussion, piecemeal communication between agencies failed to achieve any constructive progress. Equally, the potential value of agencies' contribution could be overlooked and opportunities for engagement lost.

10.7.4. It is hard to avoid the conclusion that in these six cases interagency working was neither consistent nor effective. Given the difficulties in securing multiagency coordination under current structures, there have been calls for a new framework for responding to concerns that do not meet the safeguarding threshold in order to provide a shared understanding of risk assessment, safety planning and engagement.

10.8. Organisational factors

10.8.1. Practitioners engaged in direct practice are directly impacted by features such as organisational structures, culture, systems, resources, staffing, management, workflow, training and support. This review therefore invited information on organisational features that impacted on practice during involvement with the six individuals.

10.8.2. It is clear that a wide range of guidance and support on safeguarding in general and self-neglect in particular is available. No agency fails to provide both training and guidance, although some agencies' training offer has limited or no coverage of self-neglect specifically. Some have sophisticated support structures that involve decision-making tools, routine supervision, specialist safeguarding advice, management scrutiny, legal advice and learning from SARs. The CSAB policies and tools are routinely available to all. Some agencies have gone further and implemented guidance on specific aspects of safeguarding, for example working with reluctance to engage.

10.8.3. Organisational structures too are sometimes adapted to facilitate vigilance about self-neglect, as for example in the introduction of a hospital incident category for self-neglect that, if used, triggers safeguarding team oversight. In similar vein, a housing provider has implemented a new reporting module on its case management system to enable a more thorough recording and reporting process.

10.8.4. Despite the systems and processes in place to give organizational support to practice, it is clear that some impacts were experienced.

- Some services were in a state of change or flux during their involvement with individuals in this review or were in the process of introducing new policies or structures. In one case, this may have impacted upon the ease of contact for an individual to their GP surgery. In another, it would have influenced Police decision-making on a welfare visit request. In another, the team responding to an individual's distress was at the very beginning of its operating procedures.
- Some teams were under staffing pressures, which in one case resulted in the serious omission of a best interests decision. In others, it made continuity of personnel difficult to achieve. Staff shortages also limited teams' capacity to respond to the volume of work, to undertake timely assessments, and to allocate the time recognized as necessary to work effectively. Balancing resource/demand requirements and reducing reliance on an external workforce is seen as a priority.
- Management scrutiny and supervision are not always evident. This may be because supervision decisions are not recorded and the rationale for decisions becomes lost. In other cases, the decisions of senior clinicians may not be routinely scrutinized.

- Decision-making tools and guidance available were in some cases not used to inform practice decisions.

10.9. SAB governance

In this review, the only mention of CSAB's governance role has been in relation to the safeguarding threshold tool. While seen by agencies as a resource to assist decision-making there are concerns that it can act as a barrier to safeguarding action and in one case it became the source of confusion, professional disagreement, and delay in response.

10.10. National context

The interventions during the last year in the life of each of the individuals featured in this review took place in the immediate aftermath of the Covid pandemic. All services had experienced the extreme pressures that the pandemic had placed on them and which at that point for some were still ongoing. In fact, however, relatively little impact on practice with these six individuals was noted. Nonetheless, there are enduring pressures on agencies as a result of the demands that Covid entailed, with one agency describing recovery as taking years to achieve.

10.11. Current practice

10.11.1. The temperature check event, which was attended by 120 people representing over 20 agencies, explored participants' perspective on what is working well now in self-neglect practice across Cumbria and what challenges remain. It is clear that there is much that is improving across the domains of individual practice and interagency working. Multiple challenges remain, however.

- At the level of direct practice, most consistently mentioned were difficulties relating to mental capacity. Other issues included a continued assumption that self-neglect is somehow a lifestyle choice, lack of clarity on certain legal rules, and focus on immediate symptoms rather than underlying causes and premature case closure.
- At the level of interagency working, there are ongoing challenges bringing agencies together, particularly outside of safeguarding pathways, establishing responsibilities, ensuring leadership and case coordination and keeping communication channels open.
- Resource challenges are common too with workloads and time constraints continuing to impact on practice, gaps in implementing trauma-informed practice, fragility in the voluntary sector and a lack of preventive services.

10.11.2. In terms of moving forward, the priorities identified by participants indicate a 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 in order to create the context in which best practice can flourish.

10.12. Concluding points

10.12.1. One challenge of self-neglect is its diversity of presentation. The six individuals whose circumstances are featured in this thematic SAR show a wide range of negative impacts relating to physical, mental and emotional health, hygiene and personal care, substance dependency, home conditions of squalor and decay, hoarding and withdrawal from social contacts. The life experiences that contributed to their self-neglect are equally diverse. This diversity poses challenges of recognition and understanding. Nonetheless there are key

markers of practice that are applicable in every case - professional curiosity, perseverance and trust, consideration of mental capacity, holistic appraisal of need, robust evaluation of risk, strong interagency collaboration, flexible organisational systems. Such approaches are applicable regardless of the specific presentation of self-neglect in each individual's situation. The challenge for agencies is to ensure that practitioners are skilled in these approaches and to create the organisational and interagency environments in which they are able to use them.

10.12.2. Like many Safeguarding Adults Boards, CSAB has a back catalogue of SARs featuring self-neglect. They identify similar learning themes to those found in the present thematic review: the importance of relationships, professional curiosity, adequate time, skills of engagement to work with resistance, preventive support, risk management, decision-making capability, making safeguarding personal, multiagency working and strategic infrastructures to ensure accountability. This picture is repeated at national level in the SARs included in the second national analysis published in 2024[16], where self-neglect featured in 60% of the 652 SARs completed by Boards in England between 2019 and 2023. This is in contrast to self-neglect accounting for only 11% of completed section 42 enquiries nationally (2023-24 figures)[17].

10.12.3. Such figures clearly bear witness to the challenges to practice that are posed by self-neglect. When those challenges are juxtaposed with the acute and ongoing resource constraints experienced within health and social care, the result can be described as a perfect storm. Resources of all kinds can be in short supply and the constraints of workload, capacity and competing priorities clearly influence agencies' ability to implement best self-neglect practice. In particular, the widespread norm of involvement being short-term and focused on solving immediate problems limited the ability to take a longer-term, relationship-based approach. The one exception could be the HAWC service, with its optimal involvement period of 6-9 months, clearly offering potential to take the time to establish rapport and build relationships of trust. This would, however, require the service's involvement to be a more integral part of a multi-team intervention strategy than was evident here.

10.12.4. The testimony of practitioners at the temperature check event shows that some progress has clearly been made in relation to these challenges, even though more remains to be done.

10.12.5. Part of the terms of reference for this thematic SAR was for the review to determine the degree to which evidence of the six principles of safeguarding are observable across the six cases. There are both strengths and shortcomings in how each is demonstrated.

- **Prevention:** Are we able to take preventive action before harm occurs? While there are examples of preventive risk-management, safeguarding thresholds can remain a barrier to taking action to prevent harm, with uncertainty about pathways for interagency collaboration and risk management below the safeguarding threshold.
- **Protection:** Do we protect and support those at greatest risk? While some risks were managed well, in some circumstances there were serious omissions and errors that resulted in risk going unchecked.
- **Accountability:** Do we deliver transparent and accountable safeguarding? While there are systems and structures in place to support practitioners working with self-neglect, it seems these do not always inform or support decision-making in practice.

[16] https://www.local.gov.uk/publications/second-national-analysis-safeguarding-adult-reviews-april-2019-march-2023

[17] https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults/2023-24

- Partnership: Do we deliver an effective multiagency response? While there are examples of good interagency collaboration, silo-working remained in evidence, with inconsistent information-sharing and an absence of shared risk management and decision-making. Lack of case coordination and leadership leaves gaps through which individuals fall.
- Empowerment: Are people supported and encouraged to make their own decisions? Do their views inform agencies' interventions? Attempts to ascertain individuals' views and wishes were well-evidenced but there were occasions on which individuals' high-risk wishes were taken at face value without further exploration or assessing their mental capacity. This left risk unmanaged and signals perhaps an over-simplified interpretation of what making safeguarding personal means.
- Proportionality: Are we able to provide the least intrusive response appropriate to the risk presented? Proportionality here is about judging the level of intervention that will address the level of risk present. In the cases under review here, an absence of action is more evident than over-zealous intervention. Whether through respect for autonomy or an absence of risk awareness, intervention was often insufficient to safeguard the individual and was therefore not proportionate.

10.12.6. Some of the recommendations from this thematic SAR will be similar to those from Cumbria SARs carried out in 2022. Implementing change clearly takes time, particularly so in the context of financial constraint, resource shortage and workload pressures that face agencies across the partnership. Yet the human stories of our six individuals and the learning that arises from the tragic outcomes they experienced cannot fail to support the motivation and commitment of CSAB and its partner agencies to implement actions that increase the possibility of better outcomes being achieved in future work.

11. Recommendations

In the light of the learning from this thematic SAR, it is recommended that the CSAB exercises leadership on the following improvement priorities. These arise from the analysis of the documentary evidence reviewed, from the discussions at the temperature check event, and from submissions by agencies themselves. They are designed to lead to specific actions with measurable impact.

Assessment

11.1. Review (and where necessary revise) assessment tools, templates and guidance used by agencies to guide their initial assessment processes, to ensure they incorporate prompts for practitioners to

a) Be alert to signs of self-neglect

b) Assess the level of that self-neglect, the risks that it poses and whether any forward action is necessary (this to include explicit focus on fire risk)

c) Consider the nature of any involvement by a third party

d) Consider whether decisions relating to self-care and care of the domestic environment are being made with mental capacity and

e) Consider whether needs that fall outside the assessor's own agency's remit should be referred elsewhere.

11.2. Development of training and guidance for practitioners on engaging individuals who may be reluctant to make and maintain contact with services, with particular focus on the use of professional curiosity in seeking to understand their circumstances, including life history and possible trauma that impacts on their self-neglect and their openness to support.

11.3. Undertake an audit of how advocacy services are being used and a review of guidance on when and how advocacy services should be considered.

11.4. Seek assurance from agencies that protected characteristics under the Equality Act 2010 are routinely recorded in agency records and any necessary resulting measures are being implemented in practice.

11.5. Seek assurance from Cumberland Council and Westmorland and Furness Council that:

a) Care Act assessments are being undertaken in a timely way and that where delays are unavoidable regular reviews of waiting list circumstances are undertaken to ensure that urgent cases are prioritised;

b) Carers' assessments are being undertaken in circumstances where an individual who appears to be self-neglecting has a companion or co-resident.

Mental capacity

11.6. An agencies-wide audit of self-neglect cases with a view to determining whether capacity is being routinely and appropriately considered in self-neglect cases:

a) To include cases in which capacity assessment has been carried out and those in which it has not,

b) In self-neglect cases where capacity has been assessed as lacking, to review how best interests decisions have been implemented.

11.7. Review of both CSAB's and agencies' own resources and guidance on mental capacity to ensure that these place an appropriate focus on:

a) The need to undertake formal capacity assessment when an individual's apparent decisions place them at extreme risk

b) Identifying the decision-maker (and therefore who should conduct the assessment)

c) Determining whether executive dysfunction may be a factor and if so, how and where to seek expert advice for this to be assessed

d) Making a clear record of how mental capacity has been assessed and the grounds on which the outcome of the assessment is based

11.8. Following the audit and the review of guidance, implement measures to boost awareness and practice in relation to mental capacity across the partnership. These may include training, mentoring and other forms of practice development, monitoring and audit to ensure that mental capacity in cases where risks arise from self-neglect is given routine and skilled attention by practitioners from all agencies.

Risk and safeguarding

11.9. Review use of the CSAB threshold tool to

11.9.1.1. Determine to what extent it is understood and used by agencies as a tool for selecting an appropriate pathway for concerns about self-neglect

11.9.1.2. Ensure that it is used only to assist referrers rather than as a triage tool to screen referrals received. And, following review, to make any necessary adjustments to the tool or guidance on its application.

11.10. Consider the wider use of notifications in cases where frontline practitioners note self-neglect, to trigger an automatic alert to the agency's safeguarding lead/advisor for advice/ discussion of what action may be necessary (as per the system already in place in University Hospitals of Morecambe Bay Trust).

11.11. Consider the introduction of electronic referral pathways for safeguarding referrals.

11.12. Audit how safeguarding triage is operating in relation to safeguarding referrals relating to self-neglect, to include:

a) Self-neglect cases that have proceeded into a s.42 safeguarding pathway

b) Self-neglect cases that have been triaged out of safeguarding at referral, to include consideration of what subsequent risk management pathway (if any) was pursued.

The purposes here are to identify the level of consistency in how thresholds are being applied and to determine to what extent safeguarding and other pathways are able to secure effective risk management in terms of outcomes.

Interagency working

11.13. In the light of the above audit, to consider introducing a parallel interagency risk management pathway, similar to MARM or VARM processes used elsewhere, for cases that do not meet the safeguarding threshold but nonetheless need multiagency risk management, shared goals and strategies, clear channels of communication, case coordination and leadership. It will be vital, in this event, to ensure that pathways are clearly differentiated but have clear connecting routes to ensure escalation where risk remains unmanaged.

11.14. Review the availability across agencies and across sectors of services that can provide longer-term support for people on a self-neglect pathway. This should include review of the contribution that existing resources, such as HAWC services, can make if fully integrated within self-neglect service pathways. It should also include consideration of what commissioning strategies are necessary to meet the long-term support need.

Guidance and training

11.15. Review of the self-neglect content within the safeguarding training used by agencies, and subsequent development of this content where required.

11.16. Commission interagency training on self-neglect to raise shared awareness and understanding of self-neglect and of service-specific approaches to intervention, with the aim of supporting shared understandings and shared responsibility for intervention.

11.17. Review CSAB guidance on self-neglect and consider the development of additional 'bitesize' learning tools, accessible to all agencies, covering specific topics to support continuing professional development (e.g. responding reluctance to engage, exercising professional curiosity, understanding trauma, using advocacy)

11.18. Undertake with agencies an audit of their use of guidance, training and learning tools.

Organisational context

11.19. Review with agencies where operational procedures may create barriers to use of services by people who self-neglect because they are reluctant to engage or have difficulty attending appointments, to consider how flexibility for greater outreach can be introduced.

11.20. Consider development of an interagency protocol to determine how practical tasks of support to people who are unable to organize these for themselves can be provided. Include in this, robust mechanisms for ensuring support is given to family members who lose someone through self-neglect, in terms of both emotional support and practical support with the task of returning properties to a fit state when tenancies come to an end.

11.21. Seek assurance from Lancashire and South Cumbria NHS Foundation Trust that the Initial Response Service has embedded learning from its Concise Investigation into the death of one individual featured in this SAR. Request that the Trust report to the SAB on an audit of the team's use of its triage tool and any further development work required as a result.

11.22. Seek assurance from (i) North Cumbria Integrated Care NHS Trust and (ii) Cumberland Council that intended actions set out in their responses to Coroners' Prevention of Future Deaths processes have been carried out.

11.23. Seek assurance from all agencies that organisational changes identified during their internal reviews and in their SAR responses (listed in section 8) have been implemented.

Dissemination

11.24. Hold a learning event to disseminate (a) the findings of the thematic review and (b) the action plan for addressing its recommendations. This to be followed after 12 months by a further event to evaluate progress, outcomes and further forward changes needed.

Appendix One: Parallel Processes

1. Julie

The Rapid Review undertaken by North Cumbria Integrated Care NHS Foundation Trust was unable to finds any written documentation in Trust records about the housing officer's request to be advised of Julie's discharge and is therefore inconclusive on whether the hospital could have known that this had been requested.

The review did find shortcomings in how routine safeguarding questions had been addressed. The hospital documentation relating to Julie's visit to the Emergency Department indicates that there were no safeguarding concerns when in fact the clinician knew from the ambulance log that the housing officer had raised a safeguarding concern and did explore safeguarding matters with Julie. The review made recommendations about:

(i) The need for staff to complete the routine safeguarding questions at the bedside rather than away from the patient;

(ii) Emergency Department staff attendance at safeguarding training;

(iii) Consideration of the need for training on trauma-informed practice to be provided;

(iv) Safeguarding alerts on Symphony to be made clearer and the course of action to be recorded.

The Coroner issued a Regulation 28 Report to Prevent Future Deaths[18] to North Cumbria Integrated Care NHS Trust, setting out matters that could give rise to risk of future deaths:

(i) There were errors in the completion of the hospital's safeguarding questions, raising concerns that the form is regarded as a 'tick box' exercise rather than a vital safeguarding tool.

(ii) There was evidence that Cumbria Housing staff had asked to be notified of the discharge of Julie, a vulnerable patient, so that they could provide support to her but that they received no communications, raising concerns that other patients may be discharged without appropriate support being alerted.

(iii) The evidence received emphasised that Julie had capacity and indicated that she felt safe as part of the reason for not logging a safeguarding concern. The Coroner stated that this did not mean that obvious vulnerability or safeguarding concerns could not be addressed; her vulnerability was obvious. This raised concerns that the concepts of 'having capacity' and 'not being vulnerable' are being elided.

The Trust subsequently responded to these findings, providing assurance on certain matters and listing actions that it intended to take.

2. Paul

The Concise Investigation undertaken by Lancashire and South Cumbria NHS Foundation Trust found no root cause but identified learning:

(i) The phone triage by the IRS practitioner should, in the light of the known circumstances at the time, have been a face-to-face assessment. He had been referred by social services, his presentation was complex, he was on antipsychotic medication, and had an established mental health diagnosis, physical health needs and social needs.

[18] Issued under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.

(ii) IRS did not forward any information to Paul's GP by IRS.

(iii) A referral to drug and alcohol services should have been explored.

(iv) A referral on Paul's behalf should have been made to Cruse (rather than advising self-referral).

(v) Safeguarding advice about his self-neglect should have been requested.

The investigation made the following recommendations:

(i) Patients who are drinking over the NICE recommended limits should be offered a referral to drug and alcohol services.

(ii) Further training is to be provided around questioning style to ensure that appropriate information is gained to support informed clinical decision making.

(iii) Staff are to be reminded about accessing safeguarding support.

3. Tom

The Fire Scene Investigation undertaken by Cumbria Fire and Rescue Service found that the most probable cause of the fire was careless handling and discarding of lit cigarettes and the habit of cutting up paper into small strips, creating easily ignitable fuels. The fire spread to the duvet, which Tom attempted to remove from his house via the front door. Unable to exit, he remained trapped in the stairwell where the fire took hold with additional fire loading from his bandaging and adjacent coat rack, thus contributing to its rapid development and resulting in Tom's loss of life.

Samples of the compression bandaging system used for his lower legs, when tested were found to shrink, char, then ignite producing flaming combustion with high volumes of heavy black carbon string like particulate smoke. The emollient cream used was Dermol 500 which contains 2.5%

Paraffin (although on the last treatment he had received the emollient was only used to clean and was not applied as a topical cream).

The Coroner issued a Regulation 28 Report to Prevent Future Deaths[19] to Cumberland Council Adult Social Care, setting out matters that could give rise to risk of future deaths:

(i) The absence of a reliable and routine liaison between Adult Social Care and care providers through which care workers can raise concerns about an individual's mental capacity. If care workers perspectives are not considered, opportunities to safeguard vulnerable may be missed;

(ii) Concerns that in considering an individual's mental capacity, insufficient attention may be being given to the possibility that their capacity may be variable and fluctuating and that what is found on a 'good day' is not the whole picture.

The local authority subsequently responded to this report listing actions that it had taken, or was intending to take, to address the concerns raised.

[19] Issued under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.