Thematic Review: Self-Neglect

NORTH SOMERSET SAFEGUARDING ADULTS BOARD

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Section One: Introduction

- 1.1. This thematic review considers three cases involving self-neglect. Stan¹ died on 11th June 2021 in hospital. He was 54 and White British. His case was referred to North Somerset Safeguarding Adults Board (NSSAB) by a hospital safeguarding team on 14th June. NSSAB concluded that the mandatory criteria² for a safeguarding adult review (SAR) were met. **Commentary:** the SAR referral was very timely.
- 1.2. Stan had been admitted to hospital on 9th June from his own home in a "terrible state of self-neglect." He was emaciated, with significant malnutrition and cachexia. Safeguarding concerns were raised by Paramedics. Stan's flat was noted as full of rat droppings, faecal matter, no indate food, mould and old urine bottles. He had called the ambulance and was difficult to understand on answering the door. Commentary: referral of safeguarding concerns by South West Ambulance Service (SWAST) was good practice.
- 1.3. He had previously had District Nurses for insulin administration but this had ceased. Stan had a medical history of mental health problems (paranoid schizophrenia). He was not in receipt of a package of care. He answered the door to the ambulance crew using a Zimmer frame and was independently mobile. The Paramedics found everything was covered in faecal matter, including his medication and bed³. He had extreme cachexia, was anaemic and was weak and lethargic. On admission he was seen by a hospital Tissue Viability Nurse for unstageable pressure ulcers, who was shocked at his skeletal condition. He was found to have abnormal bloods, unstable blood sugars and aspirate pneumonia. He was extremely unkempt and malnourished, and hypoglycaemic (low blood sugar). The Tissue Viability Nurse assessment recorded unkempt toe nails, left ischial tuberosity deep pressure ulcer, unstageable, and extreme cachexia with vulnerable prominent bony areas. A CT scan revealed aspiration with pulmonary emphysema, acute avulsion fracture of right femur and displacement, acute fracture of 11th rib and right uteric kidney stone.⁴
- 1.4. A Coroner's inquest hearing has been held into Stan's death. The conclusion was that Stan died of natural causes contributed to by self-neglect. Medical cause of death was recorded as aspiration pneumonitis, self-neglect and paranoid schizophrenia, accompanied by chronic obstructive pulmonary disease and type 2 diabetes mellitus. This thematic review has been completed in the knowledge that it will be shared with the Coroner.
- 1.5. Charlotte died on 2nd July 2021 in hospital. She was 71 and White British. Her case was referred to NSSAB by the hospital safeguarding department. NSSAB concluded that the discretionary criteria⁵ for a SAR were met. **Commentary:** once again, the SAR referral and subsequent recommendations to NSSAB from the SAR sub-group were timely.

¹ The names of the three individuals are pseudonyms.

² Section 44(1) (2) (3) Care Act 2014.

³ Paramedics provided photographs that show evidence of self-neglect.

⁴ Information in this and the previous paragraph obtained from the SAR referral from University Hospitals Bristol and Weston (UHBW).

⁵ Section 44(4).

- 1.6. Charlotte had been admitted from her own home in a "terrible state of self-neglect."

 Safeguarding concerns were raised by Paramedics. Charlotte had been living in her bedroom as she was unwell. One of her sons had called the GP who had then summoned an ambulance.

 When Paramedics arrived they found Charlotte to be covered in maggots, faeces and urine; she had been unable to get to the bathroom. On arrival to hospital she was found to be unwell with possible underlying malignancy and sepsis, chronic obstructive pulmonary disease and fluid filled legs (oedema). She was noted to be covered in faeces with multiple severe pressure ulcers⁶.

 Commentary: referral of safeguarding concerns by SWAST was good practice.
- 1.7. Shortly before her hospital admission, her son had raised concerns about his mother's health with a GP. He reported that her mental health had really deteriorated. She was spending nearly all of her time in bed smoking, rarely eating and only drinking approximately one cup of tea a day. He stated that she was really unsteady on her feet, had lost a lot of weight and all motivation, and was experiencing falls if she did get out of bed. He reported her having urinary incontinence and was worried about possible sores on her skin. He was trying to care for her and had tried to encourage her to seek help or to go into hospital but she was refusing. He felt she needed a review⁷. Commentary: the information was passed to her own GP. This was, perhaps, a missed opportunity to follow up with a home visit and to explore referrals for secondary health care and social care, and to the Fire and Rescue Service for a home fire safety visit. Of note, shortly before her son raised his concerns, Charlotte declined a second dose of the Covid vaccine and would not allow a Nurse upstairs.
- 1.8. A Post Mortem for Charlotte returned cause of death as 'metastatic small cell carcinoma of the lung'- a large tumour in her lung. According to the Pathologist's report this would account for her emaciation, fatigue and poor attention to personal care as well as eventually multi-organ failure and death.⁸ An inquest concluded that she died of natural causes. No criminal offences have been pursued. Charlotte's sons were not in receipt of any carer's allowance and no offences of neglect have been made out and no unlawful acts against Charlotte have been shown⁹.
- 1.9. Philip was admitted into hospital on 11th November 2021. He was found by a Social Worker and Paramedics on a bedroom floor, access to the property having been facilitated by the Fire and Rescue Service (FRS). It is unclear how long he had been lying there but he was surrounded by urine and faeces, and he was jaundiced. It is not clear why he could not get up. The SAR referral from University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) records the presence of fleas and maggots when he was admitted and observes that he was alcoholdependent, sometimes consuming 20 units daily. He had a grade 3 pressure sore to his sacrum and was described as an acopic vulnerable adult with increased alcohol intake. He had neurocyclic anaemia. By 14th November Consultants agreed that it was appropriate to place Philip on an end of life pathway. He died later that day. **Commentary:** it is not clear why FRS was the service contacted to gain entry to Philip's accommodation when it is the Police that have power of entry to save life and limb.¹⁰

⁶ This detail was reported in the SAR referral from UHBW. The NHS Trust also provided photographs showing the extent of the pressure damage.

⁷ Information received from the GP surgery chronology.

⁸ Information received from Avon and Somerset Police.

⁹ Information received from Avon and Somerset Police.

¹⁰ Police and Criminal Evidence Act 1984, section 17.

- 1.10. Paramedics and FRS completed referrals of adult safeguarding concerns. The SWAST chronology gives a clear account, as follows: "The house didn't have any electricity or heating and was in a significantly poor state. The electricity had been cut off back in May by the fire service following a fire. Has not been reconnected. Philip showed hoarding behaviour with lots of clothes/belongings blocking access to several rooms. Toilet was unusable. It was extremely dirty with cobwebs, faeces, flies, urine, old food etc. throughout property. He was unable to walk [a] dog due to mobility. He drank approximately 1ltr of sherry a day. He was an ex-smoker. Social Services had been involved for several months but he was reluctant to engage and often didn't answer the door ... He was lying supine on the floor in small gap between bed and wall. He had 1 x leg in his jeans which were extremely soiled with dried faeces and urine. He was also dressed [in] a shirt and 2 x jackets which were also extremely soiled. He [was] surrounded by papers and other belongings. The fire service had to dig a pathway down the hall to him. He was alert, no shortness of breath, jaundiced and pale. On examination he was alert, orientated and chatty with crew. His SATS were low so Oxygen was given ... Abdomen very swollen, very jaundiced appearance, both skin and eyes, abdomen non tender but hard on palpation. No headache, no dizziness, no confusion, no neuro deficit. No neck pain, no hip or other pain on palpation, gait not witnessed due to long lie. Crew cut his clothes off for assessment and used a bucket with soapy water and tissue roll / clean clothing to clean Philip. He was re-clothed in clean boxers and hospital gown."
- 1.11. The SAR referral was submitted by the local authority adult safeguarding team. His ethnicity is not recorded. He died aged 74. The referral records five referred adult safeguarding concerns, two in May 2021 from FRS and SWAST, one in July 2021 from the One Team (Police) and two in November 2021. One welfare concern is also recorded following the fire in May 2021 from the GP surgery. All concerns related to self-neglect, both self-care and the extreme disrepair of his property. The referral observes that between May and November 2021 a range of multi-agency actions took place with evidence of cross organisational information-sharing and appropriate referrals. However, concern was expressed that Philip's needs were not identified sooner and questions were raised about the responsiveness of mental health services and the absence of a mental health assessment. The referral gave the cause of death as 'natural causes' with underlying liver disease and pneumonia.
- 1.12. FRS had delivered fire safety literature in July 2019 but the concerns about Philip's self-neglect began with a kitchen fire on 15th May as a result of which gas and electricity were isolated. The fire was deemed to be an accidental ignition but access to the property had been restricted because of hoarding and the accommodation showed signs of extreme disrepair. In what was to become a pattern, Philip refused treatment at the scene and declined referral for support from the Red Cross. He was described as "very guarded" and, owing to concerns about self-neglect and risk of further fire and harm, his lack of consent to a safeguarding referral was overridden. **Commentary:** it is unclear whether fire safety literature was delivered as a result of a referral and whether any evidence of self-neglect was seen at that time. Submission of safeguarding referrals from FRS and SWAST was good practice; consent is not required for referring such concerns¹¹.

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¹¹ Department of Health & Social Care (2020) Care and Support Statutory Guidance. London: DHSC.

- 1.13. NSSAB has included self-neglect as a priority in its strategic plan and intended that the thematic review should move beyond familiar findings to focus on what lessons were still to be learned about working with people who self-neglect.
- 1.14. The SAR Panel agreed the scope for the thematic review with the Independent Author. It was agreed that reflective chronologies would be requested from the services involved, covering especially the final twelve months of their lives. A reflective learning event was held in which practitioners, operational managers and strategic managers were invited to discuss the evidence-base for working with people who self-neglect. The focus here was to consider alignment of policy and practice in North Somerset with the evidence-base, what enabled alignment and where the obstacles or barriers were to best practice.
- 1.15. Specifically, the thematic review's terms of reference were to consider, explore and address:
 - The level of consistency of staff in dealing with Stan's, Charlotte's and Philip's care and support.
 - What reasonable adjustments were made to support them?
 - Legal literacy with specific reference to the interpretation of relevant legislation and whether legal options to support Stan, Charlotte and Philip were considered.
 - Whether there was a positive and meaningful approach to information sharing.
 - Whether their wishes, feelings, views, experiences and desired outcomes were explored.
 - Whether use of policies and procedures for working with adults who self-neglect were referenced and applied in practice.
 - Was there suitable management oversight and case direction, and escalation where necessary?
 - Whether staff understood routes of escalation.
 - Use of multiagency meetings and lead professionals.
 - In relation to their care were joint partnership approaches considered?
 - How well the local safeguarding system responds to the needs of adults whose risk is increasing when self-neglect occurs.
 - Review the impact of the Covid pandemic on cases where self-neglect occurs.
- 1.16. In respect of mental capacity
 - A review of how mental capacity assessments are executed:
 - o Frontline staff understanding of executive functioning
 - O Who was best placed to undertake mental capacity assessments?
 - Whether assumptions were made about their capacity to be in control of their own care and support.
 - Whether the support of an advocate was offered.
 - How professionals in all relevant settings apply and understand the Mental Capacity Act.
 - Review of how the adult safeguarding and care management systems in North Somerset understand and support the application of the Mental Capacity Act.
- 1.17. In respect of practitioners' lived experience of work
 - How was making safeguarding personal applied in each case?
 - How the team around the individual worked in each case?
 - What support did the team involved receive from line managers and organisations?
 - Were there barriers in terms of practice?
 - Whether practitioners were supported by up to date self-neglect policy and procedures?

- Review of practitioner experiences of the impact of Covid, plus the clarity of practitioner guidance at time.
- Whether practitioners felt supported when working with individuals who were selfneglecting.
- Whether practitioners felt that there was a culture that encouraged and supported professional curiosity.
- If practitioners felt equipped to identify and respond to self-neglect.
- Whether self-neglect was viewed as a "lifestyle choice" thus inhibiting professional curiosity.
- 1.18. It has not proved possible to locate family members for Stan. However, contact was made with his friend/informal carer. Unfortunately, owing to prolonged serious illness, she was unable to contribute to the review.
- 1.19. No responses have been received from either of Charlotte's sons or from relatives of Philip. This has sadly meant that little information is available about their lived experiences, the backstory behind the events on which this review has focused. It underscores the importance of practitioners expressing concerned curiosity about people's lived experience. As was observed by those practitioners and managers who attended the learning event, we need to learn directly from people with lived experience of self-neglect, and from their relatives and friends. We must acknowledge that beneath presenting problems might well lie deep-rooted issues, including responses to trauma and adverse experiences. Short-term "fixes" that involve, for example, the use of statutory powers in relation to the environment surrounding an individual, such as Philip, are unlikely to prove effective if they are the only intervention.

Section Two: Evidence-Base

- 2.1. The evidence-base is drawn from research and findings from SARs¹² that enable a model of good practice to be constructed in relation to adults who self-neglect. This model enables a whole system exploration of what facilitates good practice and what act as barriers to good practice. It comprises four domains. In line with Making Safeguarding Personal, the first domain focuses on practice with the individual. The second domain then focuses on how practitioners worked together. The third domain considers best practice in terms of how practitioners were supported by their employing organisations. The final domain summarises the contribution that Safeguarding Adults Boards can make to the development of effective practice with adults who self-neglect.
- 2.2. It is recommended that direct practice with the adult is characterised by the following:
- 2.2.1. A person-centred approach that comprises proactive rather than reactive engagement, and a detailed exploration of the person's wishes, feelings, views, experiences, needs and desired outcomes; work to build motivation with a focus on a person's fluctuating and conflicting hopes, fears and beliefs, and the barriers to change¹³;
- 2.2.2. A combination of concerned and authoritative curiosity appears helpful, characterised by gentle persistence, skilled questioning, conveyed empathy and relationship-building skills; early and sustained intervention includes supporting people to engage with services, assertive outreach and maximising the opportunities that encounter brings¹⁴;
- 2.2.3. When faced with service refusal, there should be a full exploration of what may appear a lifestyle choice, with detailed discussion of what might lie behind a person's refusal to engage; failing to explore "choices" prevents deeper analysis; contact should be maintained rather than the case closed so that trust can be built up;
- 2.2.4. It is helpful to build up a picture of the person's history, and to address this "backstory" 15, which may include recognition of and work to address issues of loss and trauma in a person's life experience that can underlie refusals to engage or manifest themselves in repetitive patterns;
- 2.2.5. Comprehensive risk assessments are advised, especially in situations of service refusal and/or non-engagement, using recognised indicators to focus work on prevention and mitigation¹⁶;

¹² Preston-Shoot, M. (2019) 'Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice.' *Journal of Adult Protection*, 21 (4), 219-234.

¹³ Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern. NICE (2018) *People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services.* London: National Institute for Health and Clinical Excellence.

¹⁴ Alcohol Change UK (2019) *Learning from Tragedies: An Analysis of Alcohol-Related Safeguarding Adult Reviews Published in 2017.* London: Alcohol Change UK. Public Health England (2018) *Evidence Review: Adults with Complex Needs (with a particular focus on street begging and street sleeping).* London: PHE. Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern.

¹⁵ Alcohol Change UK (2019) *Learning from Tragedies: An Analysis of Alcohol-Related Safeguarding Adult Reviews Published in 2017.* London: Alcohol Change UK. NICE (2018) *People's Experience in Adult Social Care*

Reviews Published in 2017. London: Alcohol Change UK. NICE (2018) People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services. London: National Institute for Health and Clinical Excellence.

¹⁶ Parry, I. (2013) 'Adult safeguarding and the role of housing.' *Journal of Adult Protection*, 15 (1), 15-25. Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern.

- 2.2.6. Where possible involvement of family and friends in assessments and care planning¹⁷ but also, where appropriate, exploration of family dynamics, including the cared-for and care-giver relationship;
- 2.2.7. Thorough mental health and mental capacity assessments, which include consideration of executive capacity; assumptions should not be made about people's capacity to be in control of their own care and support¹⁸;
- 2.2.8. Careful preparation at the point of transition, for example hospital discharge, prison discharge, end of probation orders and placement commissioning;
- 2.2.9. Use of advocacy where this might assist a person to engage with assessments, service provision and treatment;
- 2.2.10. Thorough assessments, care plans and regular reviews, comprehensive enquiries into a person's rehabilitation, resettlement and support needs¹⁹; taking into account the negative effect of social isolation and housing status on wellbeing²⁰.
- 2.3. It is recommended that the work of the team around the adult should comprise:
- 2.3.1. Inter-agency communication and collaboration, working together²¹, coordinated by a lead agency and key worker in the community²² to act as the continuity and coordinator of contact, with named people to whom referrals can be made²³; the emphasis is on integrated, whole system working, linking services to meet people's complex needs²⁴;
- 2.3.2. A comprehensive approach to information-sharing, so that all agencies involved possess the full rather than a partial picture;
- 2.3.3. Detailed referrals where one agency is requesting the assistance of another in order to meet a person's needs;
- 2.3.4. Multi-agency meetings that pool information and assessments of risk, mental health and mental capacity, agree a risk management plan, consider legal options and subsequently implement planning and review outcomes²⁵;
- 2.3.5. Use of policies and procedures for working with adults who self-neglect and/or demonstrate complex needs associated with multiple exclusion homelessness, with specific pathways for

¹⁷ Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern.

¹⁸ NICE (2018) *People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services*. London: National Institute for Health and Clinical Excellence.

¹⁹ Ministry of Justice (2018) *Guidance: The Homelessness Reduction Act 2017 Duty to Refer*. London: MoJ.

²⁰ NICE (2018) *People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services.* London: National Institute for Health and Clinical Excellence.

²¹ Parry, I. (2014) 'Adult serious case reviews: lessons for housing providers.' *Journal of Social Welfare and Family Law*, 36 (2), 168-189. Ministry of Justice (2018) *Guidance: The Homelessness Reduction Act 2017 Duty to Refer*. London: MoJ.

²² Whiteford, M. and Simpson, G. (2015) 'Who is left standing when the tide retreats? Negotiating hospital discharge and pathways of care for homeless people.' *Housing, Care and Support*, 18 (3/4), 125-135. NICE (2018) *People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services*. London: National Institute for Health and Clinical Excellence.

²³ Parry, I (2013) 'Adult safeguarding and the role of housing.' *Journal of Adult Protection*, 15 (1), 15-25.

²⁴ Public Health England (2018) *Evidence Review: Adults with Complex Needs (with a particular focus on street begging and street sleeping).* London: PHE. Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern. The MEAM Approach (2019) *Making Every Adult Matter.* London: Homeless Link and Mind.

²⁵ Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern.

- coordinating services to address such risks and needs as suitable accommodation on discharge from prison or hospital²⁶;
- 2.3.6. Use of the duty to enquire (section 42, Care Act 2014) where this would assist in coordinating the multi-agency effort, sometimes referred to as safeguarding literacy;
- 2.3.7. Evaluation of the relevance of diverse legal options to assist with case management, sometimes referred to as legal literacy;
- 2.3.8. Clear, up-to-date²⁷ and thorough recording of assessments, reviews and decision-making; recording should include details of unmet needs²⁸.

2.4. It is recommended that the organisations around the team provide:

- 2.4.1. Supervision and support that promote reflection and critical analysis of the approach being taken to the case, especially when working with people who are hard to engage, resistant and sometimes hostile;
- 2.4.2. Access to specialist legal, mental capacity, mental health and safeguarding advice;
- 2.4.3. Case oversight, including comprehensive commissioning and contract monitoring of service providers;
- 2.4.4. Agree indicators of risk that are formulated into a risk assessment template that will guide assessments and planning;
- 2.4.5. Attention to workforce development²⁹ and workplace issues, such as staffing levels, organisational cultures and thresholds.

2.5. SABs are advised to:

- 2.5.1. Ensure that multi-agency agreements are concluded and then implemented with respect to working with high risk individuals; this will include the operation of complex case or multi-agency panel arrangements, responding to anti-social behaviour, domestic abuse, offending (community safety) and vulnerability³⁰; strategic agreements and leadership are necessary for the cultural and service changes required³¹;
- 2.5.2. Develop, disseminate and audit the impact of policies and procedures regarding self-neglect;
- 2.5.3. Include social housing providers in multi-agency policies and procedures³²;
- 2.5.4. Establish systems to review the deaths of homeless people and/or as a result of alcohol/drug misuse:
- 2.5.5. Work with Community Safety Partnerships, Health and Wellbeing Boards and partnership arrangements for safeguarding children and young people, to coordinate governance, namely oversight of the development and review of policies, procedures and practice;
- 2.5.6. Provide or arrange for the provision of workshops on practice and the management of practice with adults who self-neglect.

²⁶ Public Health England (2018) *Evidence Review: Adults with Complex Needs (with a particular focus on street begging and street sleeping).* London: PHE.

²⁷ Parry, I. (2013) 'Adult safeguarding and the role of housing.' *Journal of Adult Protection*, 15 (1), 15-25.

²⁸ Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern.

²⁹ Whiteford, M. and Simpson, G. (2015) 'Who is left standing when the tide retreats? Negotiating hospital discharge and pathways of care for homeless people.' *Housing, Care and Support*, 18 (3/4), 125-135. The MEAM Approach (2019) *Making Every Adult Matter*. London: Homeless Link and Mind.

³⁰ Parry, I. (2013) 'Adult safeguarding and the role of housing.' *Journal of Adult Protection*, 15 (1), 15-25.

³¹ Ward, M. and Holmes, M. (2014) *Working with Change Resistant Drinkers. The Project Manual.* London: Alcohol Concern.

³² Parry, I. (2013) 'Adult safeguarding and the role of housing.' *Journal of Adult Protection*, 15 (1), 15-25.

Section Three: Thematic Analysis – Direct Work with Individuals

- 3.1. Using the evidence-base as a framework for analysis, themes arising from the chronologies are analysed here. Reflections from the learning event have been added to this analysis.
- 3.2. <u>Person-centred approach and responses to repeating patterns</u>. Research has identified that staff can become inured to or normalise risk when what is being presented is repetitive³³.
- 3.2.1. One repeating pattern involves failed attempts to engage and service refusals. The UHBW chronology for Stan records 9 missed dietetic, endoscopy and diabetic outpatient appointments between March 2019 and March 2020. He was eventually discharged back to his GP. The GP chronology records numerous failed attempts to contact Stan by Diabetic Specialist Nurses in January 2020, with planned discharge if he did not make contact. It also records missed appointments for blood tests, and mental health and medication reviews, and failed attempts to make contact regarding the necessity and outcome of blood test results, and adjustments to his insulin, during 2020 and early 2021. His response to text, letters and voice mail messages was erratic. **Commentary:** what is unclear from the written documentation is whether this was seen as Stan being unwilling or unable to engage to attend appointments³⁴. His physical disabilities and mental ill-health might have contributed to this repeating pattern. This highlights the importance of professional concerned curiosity, follow-up and outreach.
- 3.2.2. Primary care records for June 2019 note that Stan had declined a package of care and a home visit by practitioners from community mental health. He had also declined a medication review. It appears to have been agreed that no further appointments would be booked by Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) until Stan had agreed a plan about moving forward. On one occasion when a missed appointment is recorded as having been raised with him, he appeared confused and the appointment was rearranged. **Commentary:** the AWP plan does not appear to have been followed up. In the main the chronologies of involvement do not record any discussion with Stan or between the services involved about missed appointments and refusals of care, support and/or treatment. On one occasion a Nurse observed that he had not collected his prescriptions for six months and yet was adamant that he was taking his medication. Again, it is unclear whether this apparent discrepancy was explored, especially in the context that he had, on at least one occasion, expressed a wish to focus on his physical health (rather than his mental health). It does appear that, when Stan did not attend GP surgery appointments, new offers were made. Repeating patterns are information, indicating that a different approach might be needed.
- 3.2.3. Yet Stan did not remain totally out of contact. For example, he twice telephoned the GP surgery in June 2020 for replacement medication. In December 2020 he telephoned a Nurse for a new monitor, which was left in reception for him. This contact resulted in a very overdue

³³ Braye, S., Orr, D. and Preston-Shoot, M. (2014) *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. London: Social Care Institute for Excellence. Preston-Shoot, M. (2019) 'Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice.' *Journal of Adult Protection*, 21 (4), 219-234.

³⁴ SAR Andy, published by Salford SAB (2019), is another case that highlights the impact of ill-health and disability on engagement.

appointment for blood tests. **Commentary:** these contacts were opportunities to explore barriers to engagement.

- 3.2.4. In June 2020 a Care Coordinator made telephone contact with Stan who reported that everything was okay. In August he was discharged by the Care Coordinator following a telephone consultation, the rationale being that he had reported that his mental health was stable and massively improved. He had said that he was getting to the shops and eating well, and that he was building up his confidence and strength³⁵. The AWP report records that he had declined a package of care. His GP was informed. **Commentary:** it is not good practice to rely on self-reporting alone. As AWP's own analysis highlights, there was "no active social care package in place (there is no evidence that a Care Act assessment was completed or referral for this) -He was paying for a private care package and cancelled this because of cost. [The Care Coordinator] did not liaise with District Nurses to check if they were still visiting. The case was not care coordinated by a social care staff member case would not have passed to the reviewing team on closure because of this and mental health team involvement will have ceased. This review was done over the phone, due to current Covid-19 restrictions."
- 3.2.5. In September 2019 a treatment escalation plan was signed by Stan's GP. This recorded that he had advanced chronic pancreatitis and a poor quality of life. The plan stated that CPR success would be very unlikely and that he was not for resuscitation. **Commentary:** it is not clear from primary care records whether this plan was discussed with Stan. The AWP report records that during the period February 2019 to May 2019 Stan completed a do not resuscitate notice with his GP. There are clear requirements in law (Mental Capacity Act 2005) with respect to advance decisions, if indeed the treatment escalation plan was envisaged, and endorsed by Stan, as an advance decision. AWP was not involved in the formulation of the treatment escalation plan.
- 3.2.6. Primary care records for Stan fall silent after the end of January/beginning of February 2021 when a text and letter were sent to Stan. **Commentary:** this is surprising given his well-documented physical ill-health. The response to the pandemic may provide one explanation.
- 3.2.7. The local authority chronology for Charlotte records that Occupational Therapists sometimes experienced difficulty in contacting her. Her case was closed in February 2017 because of a lack of contact. **Commentary:** however, Charlotte was not out of reach. Home visits when difficulties were experienced in making contact with her could have been attempted. Charlotte also initiated contact by email, which did result in onward referrals and assessments.
- 3.2.8. Primary care practitioners also experienced some difficulty in engaging with Charlotte. In the final year of her life, there were instances where she refused entry to Community Nurses who wanted to administer blood tests, failed encounters with messages being left³⁶, refusing pulmonary rehabilitation in response to her COPD, and declining a second dose of a vaccine against Covid-19 when she would not allow a Nurse upstairs. However, there was an occasion when she did respond to a GP letter that led to an arrangement for practitioners to visit at her preferred time. She also engaged with an Occupational Therapy with respect to aids and adaptations to assist her with activities of daily living. **Commentary:** it is not clear from the

³⁵ Detail from AWP case records.

³⁶ She refused blood tests on one occasion because of the pandemic.

primary care records if all refusals were followed-up. Importantly, as emphasised at the learning event, when an individual does engage with a practitioner and service, this might provide an important opening for other practitioners and services to become involved. This requires practitioners to think of the whole system, to think beyond their specific roles and tasks.

- 3.2.9. The Adult Social Care (ASC) chronology for Philip records that staff recognised the need to give him "the opportunity to build positive rapport with professionals as he had declined support in the past." However, engaging Philip proved challenging. A Paramedic was not allowed into the property when they visited for follow-up after the May fire. The Public Health chronology records that Philip had to be persuaded to allow officers to inspect the property beyond the kitchen. There were many occasions when Social Workers, Environmental Health Officers and other practitioners did not obtain an answer when they visited³⁷; on other occasions Philip refused to allow them into his accommodation. He consistently declined support that was offered by statutory services and third sector agencies, or to which he was signposted. The ASC chronology also records that he did not respond well to being questioned about his circumstances. The Public Health chronology records that he did not want to engage with the Social Worker and on one occasion made a racist comment about them. He was unhappy about plans for a cleaning service to visit, even when it was explained that this was a necessary precursor to reconnection of the gas and electricity. He subsequently declined to allow the cleaning service into his property at the end of September. Commentary: there were persistent efforts to engage with Philip and to ascertain his wishes in line with the principle of making safeguarding personal³⁸. What is less clear from the records is whether there were attempts to engage with Philip about his response to offers of support and the agitation that he showed when support was offered. Concerned curiosity is a core component of best practice but the chronologies do not record his reasoning for declining care packages so his voice regarding his lived experience is silent.
- 3.2.10. The AWP chronology records that Philip had declined to give consent to referral to mental health services in November 2021. This followed a referral from a Social Worker and discussion of concerns about his self-neglect and the disrepair of his accommodation at a meeting of professionals. The Social Worker was advised to contact Philip's GP regarding referral. **Commentary:** as discussed further below, there was disagreement between services as to whether consent or referral from a GP was necessary or whether there was a pathway to mental health support from a decision-making forum of professionals. At the learning event it was confirmed that the Primary Care Liaison Service (PCLS) will accept referrals from any practitioner, not just a person's GP. This pathway, however, might not be widely known across services.
- 3.2.11. The FRS chronology records that Philip declined services when they attended to extinguish the kitchen fire. Nor did he engage and respond to a further fire safety visit in September. The chronology refers to planned further attempts to engage Philip but no follow-up visits are recorded.

³⁸ The ASC chronology records 13 occasions when Philip was not at home and/or did not answer. It records one occasion when he refused entry to a Social Worker and 7 occasions when he declined care and support assessments and help. The GP chronology records 4 occasions between May and November when he did not attend appointments or was not at home, and two occasions when he declined treatment.

³⁷ The Public Health chronology records at least six occasions when Philip appeared not to be at home when they visited.

- 3.2.12. Those attending the learning event focused on the issue of engagement, highlighting that it was important for practitioners to question whether a person was unwilling or, in fact, unable to engage, perhaps because of mental distress (voices in the case of Stan, agoraphobia in Charlotte's case). It was also important for practitioners and managers to question whether services were making it difficult for people to engage because of the way they organise the work.
- 3.2.13. Those attending the learning event also recognised that practitioners should follow-up referrals and requests for assistance from colleagues in other services, when nothing had been heard back. Moreover, in cases where there were significant risks arising from physical and/or mental ill-health, practitioners should not just rely on expecting responses from telephone or text messages, or letters.
- 3.3. <u>Risk assessment</u>. Risk assessment and risk management are crucial, with plans preferably codesigned with service users/patients and shared across partners. A risk assessment was completed for Stan as part of the case closure process. Risk was rated as medium. **Commentary:** the AWP report does not refer to any risk mitigation planning that was put in place as part of the case closure decision.
- 3.3.1. Philip remained without gas and electricity between the fire in May 2021 and his death in November. Initially he declined assistance with reconnection on the basis that a friend could help him achieve this. When that did not materialise, it is not clear that the impact of disconnection was actively considered as a risk to mitigate.
- 3.3.2. There were also risks to others from dog faeces in the garden and from water overflow causing damage to a neighbour's house.
- 3.4. <u>Mental capacity assessment</u>. Paramedics were unable to complete a mental capacity assessment for Stan when they attended prior to his final hospital admission as he was muttering and difficult to understand.
- 3.4.1. Mental capacity assessments are referred to in chronologies. On several occasions Paramedics assessed that Stan had mental capacity regarding whether to accept transfer to hospital. In January 2020 UHBW records note that he self-discharged with capacity against medical advice. In July 2019 an assessment was completed by a Community Matron following his refusal to see a GP or attend hospital when he was not eating. In September 2019 he again self-discharged against medical advice. **Commentary:** UHBW records observe that he stated that he had capacity. It is unclear whether a formal assessment was completed.
- 3.4.2. There is no reference in the chronologies to the impact of Stan's substance misuse or mental ill-health on his mental capacity. **Commentary:** prolonged substance misuse and repeated detoxification can impact on the frontal lobe of the brain. For this reason, mental capacity assessments must include consideration of executive functioning. Especially where there are repetitive patterns, it is essential to assess executive capacity as part of mental capacity assessment. Guidance has commented that it can be difficult to assess capacity in people with executive dysfunction. It recommends that assessment should include real world

observation of a person's functioning and decision-making ability³⁹, with subsequent discussion to assess whether someone can use and/or weigh information.

- 3.4.3. In the AWP report there is reference to a practitioner believing that Stan had "a right to make unwise decision regarding eating little." **Commentary:** this is an incorrect reading of one of the five principles in the Mental Capacity Act 2005. A correct reading would be that practitioners should not assume that a decision that they regard as unwise is automatically indicative of a lack of mental capacity. Put another way, assessment of capacity is indicated.
- 3.4.4. Avon and Somerset Constabulary's initial information for the thematic review, reporting on Charlotte's hospital admission and death, observes that she had had mental capacity but had refused help. Her sons had apparently confirmed to Police Officers that she had refused medical care. **Commentary:** it does not appear that her mental capacity was ever formally assessed.
- 3.4.5. The ASC chronology records that there was no evidence to query Philip's mental capacity in late May 2021, following a fire at his property, when he was refusing to allow entry into his home and was declining care and support, assistance to secure reconnection of his power supply, and onward referrals regarding his physical ill-health. This despite clear evidence of self-neglect. The Public Health/Environmental Health chronology observes that Philip would state that he would clear and clean his house but did not do so. **Commentary:** assessment should distinguish between whether a person is unable or unwilling to address the manifestations of self-neglect. A repetitive pattern, such as here with utility reconnection and with house clearing and cleaning, should trigger consideration of executive functioning.
- 3.4.6. A Social Worker requested Philip's GP to refer him to PCLS for a mental capacity assessment. **Commentary:** the ASC chronology does not record for what decision this referral was made. If it was in response to his consistent declining of care and support, then the Social Worker could have completed that assessment, especially as they had knowledge of Philip over several months. If the referral was for assessment of his decision-making with respect to treatment, this was not completed by PCLS prior to his death.
- 3.4.7. The ASC chronology records a completed mental capacity assessment with respect to Philip's care and support needs on 23rd September. The conclusion was that he could understand and retain information, and use or weigh expressed concern about his living situation. He presented his way of living as longstanding and non-problematic. **Commentary:** It is unclear whether the assessment included discussion of the impact of his self-neglect on neighbours.
- 3.4.8. The AWP chronology for contact with a Social Worker in early November 2021 records that the Social Worker did not consider that Philip lacked mental capacity. The chronology does not record how capacity had been assessed, for what decision or when. The UHBW chronology repeats this opinion.
- 3.4.9. Those attending the learning event questioned whether practitioners "wondered enough" about mental capacity, for instance in cases where there was a history of prolonged and significant substance misuse. They noted that the assumption of lifestyle choice, and the

³⁹ NICE (2018) *Decision Making and Mental Capacity*. London: National Institute for Health and Clinical Excellence.

misreading of the third principle in the Mental Capacity Act 2005, namely that individuals have a right to make unwise decisions, were too often used as a justification for walking away and closing down involvement. They agreed that it was a priority to reinforce a correct interpretation of the third principle in practice. They also referred to NSSAB's self-neglect procedures to highlight the importance of including executive functioning in mental capacity assessments, to observe how people respond to their circumstances and whether they can use or weigh the feedback received, for instance about repeating patterns.

- 3.5. <u>Care and support assessment</u>. Adult Social Care assessment is an essential part of any plan that seeks to address a person's accommodation, and mental and physical health needs, as part of wrap-around support. Outreach social work is a possible helpful development⁴⁰, alongside other practitioners reaching out and assessing the person in their locations. Research elsewhere⁴¹ has found that agencies can be deterred from making referrals to Adult Social Care because of potential volumes and/or that Adult Social Care is operating a higher threshold for care and support assessments than Section 9 (Care Act 2014) permits.
- 3.5.1. A care and support assessment for Charlotte in August 2017 provides details about her physical ill-health and concluded that she had eligible needs that were impacting on her physical and emotional wellbeing. The response included occupational therapy assessment and the provision of aids and adaptations, both before and after her move in March 2018, and onward referrals. Charlotte is recorded as having declined other services from Adult Social Care in August 2017. **Commentary:** this refusal does not appear to have been revisited subsequently. This represents a missed opportunity, not least because the local authority chronology records that a GP had undertaken a home visit around August 2017 and reported that Charlotte was unkempt and her accommodation filthy, evidence of possible self-neglect and/or neglect.
- 3.5.2. Following case closure by an Occupational Therapist in July 2018, the local authority had no further contact with Charlotte before her death. When notified by the hospital of her death, an adult safeguarding enquiry (Section 42 Care Act 2014) was initially considered on grounds of serious self-neglect and neglect. This was not pursued as Charlotte had died. A SAR referral was sent to NSSAB instead. **Commentary:** the decision to make a SAR referral as opposed to continuing with a Section 42 enquiry was appropriate in this instance as there was no evidence of any other adult being at risk of abuse or neglect.
- 3.5.3. The AWP report for Stan records that a Care Act 2014 assessment was recommended sometime after February 2019 and that screening was completed. The report does not indicate Stan's response, although it is stated that sometimes he declined support from services, such as from District Nurses. Between May and August 2019 the AWP report references that he declined a care package following concerns expressed by a Community Matron that his health and wellbeing were deteriorating. Another assessment was undertaken around August 2020 and he declined a care package. Commentary: Stan's consent was required for provision of a care package. However, it is not clear whether practitioners explored his reluctance to accept support with him, and how any consequent risks were to be managed. At the onset of the pandemic a

⁴¹ Mason, K., Cornes, M., Dobson, R., Meakin, A., Ornelas, B. and Whiteford, M. (2017/18) 'Multiple exclusion homelessness and adult social care in England: exploring the challenges through a researcher-practitioner partnership.' *Research, Policy and Planning*, 33 (1), 3-14.

⁴⁰ Preston-Shoot, M. (2020) Adult Safeguarding and Homelessness. A Briefing on Positive Practice. London: LGA and ADASS.

Care Coordinator set up food delivery from a local food bank, which suggests concern about how he would manage with activities of daily living. However, it does not appear that the question of care and support more generally was revisited.

- 3.5.4. The AWP report also references consideration of possible alternative accommodation at the end of 2018 but this focus was discontinued at Stan's request. In 2019 a Community Matron requested a respite care placement for Stan but the Care Coordinator did not regard this as appropriate. **Commentary:** this seems to indicate a search for a plan that would mitigate risks. It suggests that practitioners disagreed on the best way forward. A multi-agency meeting to share information and to agree a risk management plan would have been appropriate.
- 3.5.5. Philip was not known to Adult Social Care before the fire at his home in May 2021. Philip was consistent in declining care and support, stating that he could manage activities of daily living. The ASC chronology, however, records that he appeared unable to maintain a habitable environment and notes that the local authority had once deep cleaned his accommodation. Indeed, in an entry in August 2021, when Philip again declined assessment and stated that he was managing, the chronology records that evidence in terms of his appearance and home environment clearly contradicted this. This does not appear to have triggered a review by a Social Worker of his mental capacity, especially his executive functioning. A similar picture emerges in early September when, on a home visit, a Social Worker witnessed that Philip had soiled himself but was declining all support, and referrals to his GP and a substance misuse service, other than with reconnection (something that he had previously declined).
- 3.5.6. Although visits by a plumber and a cleaning service were arranged, Philip declined to accept their support. His gas and electricity were not reconnected before he died. The Public Health chronology records that when officers accessed his property in late August, it was verminous and filthy, with dog faeces and flies. **Commentary:** this appears to be clear evidence that he was unable to maintain a habitable environment. It is not clear from the chronologies whether the provision in Section 11 of the Care Act 2014 was considered⁴².
- 3.6. <u>Responses to substance misuse and mental distress</u>. Individuals in the grip of substance misuse do not find change easy to achieve and this realisation should be factored into how services are set up to provide support. This reinforces the commentary on executive decision-making and mental capacity assessment above. This links also to later sections on commissioning and on workforce development.
- 3.6.1. The chronology provided by the local authority records that Charlotte had a history of depression, anxiety and a phobia of going outdoors. In August 2016 she is recorded as not having been outside her home for 18 months. This pattern had not changed by August 2017 and she was hopeful that a move back to an area with which she was more familiar and where she had social contacts would encourage her to go out. **Commentary:** she was signposted to services that could help her with her anxiety. A referral to Positive Steps was made in August 2017 but the outcome has not been recorded in the chronologies. After she moved in March 2018 there does not appear to have been any focus on whether she was going out and whether she needed further assistance to do so. Prior to the move, she had described herself as very lonely and

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⁴² Section 11 (2) (b) Care Act 2014 and paragraph 14.69 of the Care Act Statutory Guidance are clearly relevant.

unhappy. There is no reference to her mental wellbeing after she moved. Signposting to services alone is frequently ineffective.

- 3.6.2. Stan had been known to mental health services since at least 2007 for paranoid psychosis and heavy alcohol use⁴³. He had a long history of paranoid thoughts that people were against him due to thinking that was a paedophile. He had a history of self-neglect and in 2018 was admitted under Section 2 of the Mental Health Act with severe malnutrition and a deteriorating mental state. He self-discharged against medical advice, and was subsequently re-admitted on 2 further occasions following this due to vomiting and low blood sugar, again discharging himself against medical advice. He also refused admission to hospital on another occasion, when District Nurses had called an ambulance due to high blood sugar levels. He was assessed by the Paramedics as having capacity to make an informed decision and remained at home.
- 3.6.3. GP notes advise he had been a heavy drinker (1 litre of vodka and 9/10 pints a day) since 1989; however Stan reported he had been drinking since 14 years old. There is also reference to cannabis use in the past. He smoked 20 cigarettes a day but had reportedly been abstinent from alcohol and drugs for several years.
- 3.6.4. When asked about his use of alcohol in January 2019 whilst an inpatient, he stated that he had not been drinking for months. In the same year, however, he also reported drinking occasionally. When asked about alcohol consumption in December 2020, he denied misuse. **Commentary:** self-reporting appears to have been accepted at face value. There is little detailed information about his alcohol use in the combined chronology.
- 3.6.5. The AWP report records that during the months of February to April 2019 Stan experienced increasing anxiety and agitation, and was diagnosed with moderate depression "on the back of" social stressors. He had stopped taking anti-psychotic medication several months previously. Medication was recommenced for anxiety, paranoid ideas and hearing voices. Following a meeting of professionals at the end of April 2019, a Care Coordinator did liaise with the Approved Mental Health Professional (AMHP) service. The AWP report records that use of the Mental Health Act 1983 was not appropriate as Stan was not actively psychotic and had mental capacity regarding decisions concerning accommodation and health and welfare. By August 2019 discharge from the recovery team was being considered, it seems because Stan saw his physical health as a priority and because he had been reporting improvement in his mental health, denying low mood, suicidal ideation and delusional thoughts.
- 3.6.7. In September 2019 the UHBW chronology records that Stan was seen by the mental health liaison team. The plan was for a joint review with the community team but the UHBW chronology does not record if this took place. The AWP report references that his problems were seen as largely physical at this time. From February 2020 Stan was reporting that his mood was stable. **Commentary:** the planned joint review did not take place because Stan self-discharged from hospital.

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⁴³ The information about Stan's mental health and alcohol use is drawn from AWP's 72 hour report for potential serious incidents. Diagnosis is given as mental and behavioural disorders due to use of alcohol; residual and late onset psychotic disorder.

- 3.6.8. **Commentary:** case closure by the recovery team in August 2020 meant that, thereafter, Stan's mental wellbeing was not actively tracked. It is not clear whether a plan recorded in the AWP report around October 2019 for a Care Coordinator to work through a psychoeducational booklet with Stan on hearing voices was implemented.
- 3.6.9. Philip was not known to the provider of substance misuse services when a Social Worker checked in July 2021. A referral was suggested and appears to have been sent by a Social Worker as the service provider wrote to Philip offering assessment and support in mid-October 2021. **Commentary:** it does not appear that Philip responded to the letter and there was no outreach before he died. Outreach is more likely to be effective than signposting when there is a history of non-engagement. It does not appear that he was known to substance misuse services prior to October 2021.
- 3.6.10. The UHBW chronology records that, during his final hospital admission, a CT scan revealed advanced cirrhosis and other liver complications, likely due to alcohol abuse.
- 3.6.11. Consideration of referral to the Primary Care Liaison Service (PCLS) was raised at a meeting of professionals in mid-September and at a follow-up meeting at the beginning of November. A referral was finally made on 4th November. **Commentary:** the delay might have been because Philip's consent was felt to be necessary despite a multi-agency meeting having concluded that a referral was necessary. Different services clearly had different expectations with respect to pathways and flexible working, and no practitioner escalated concerns about the consequent delay.
- 3.6.12. From mid-September onwards focus turned to changing his GP surgery registration in order that he could access mental health support from a location that was more convenient for him. Philip appears to have finally agreed to this at the beginning of November. The mental health support that it was hoped he would access did not materialise before he died.
- 3.6.13. A few days before Philip died a Social Worker sought advice from an Approved Mental Health Professional (AMHP). The AWP chronology records that it was concluded that an assessment under the Mental Health Act 1983 was not appropriate at that point. It was noted that mental health support from Horizon might be sought. **Commentary:** whilst an assessment under the 1983 Act might not have been warranted, a mental health assessment was arguably indicated given longstanding concerns about self-neglect. One was not completed before Philip died, arguably a missed opportunity. There is no record of mental health services being involved with Philip prior to the period under review.
- 3.6.14. At the learning event an observation was shared that it could prove difficult to align, or dovetail, substance misuse, mental health and physical health services. It was also shared that in hospitals, particularly, high impact frequent attenders are seen, often with social complexities such as substance misuse, who often do not meet the criteria for referral of an adult safeguarding concern (Section 42(1) Care Act 2014). In this situation, staff feel challenged when attempting to connect individuals with services. In that context, it was noted that substance misuse services work on consent and will not take referrals in the absence of consent.
- 3.6.15. Also at the learning event, there was discussion of the interface between GP services, PCLS and secondary care mental health services. Views were expressed that services could work

more effectively to "close the loop", to ensure that the inter-connections between these services were firmly in place, especially for those with long-term and fluctuating forms of mental distress. When referrals are made, such as when Charlotte was referred to Positive Steps, it was important to follow-up in order to seek assurance about outcomes.

- 3.7. Responses to physical ill-health. Stan had diagnoses of Type 2 diabetes (insulin dependent), Barrett's Oesophagus, chronic pancreatitis, hypothyroidism and hiatus hernia. Stan experienced chronic fatigue, pain and mobility issues. In 2014, he fell down a hole and sustained a broken knee, which later became infected due to e-coli and self-neglect. He required a Zimmer to mobilise and did not leave his flat often, only to go shopping, using a taxi. UHBW records for January 2019 note a referral to Dietetics during two hospital admissions and refer to "previous dietetic involvement for malnutrition prior to 2019, sectioned in hospital 2018 for self-neglect and malnutrition. Paranoid Schizophrenic. Endoscopy diagnosed Barrett's oesophagus (severe acid reflux causing lesion) has oesophageal stricture." Also recorded is "known chronic pancreatitis and alcoholic, says no alcohol for months. Admitted with vomiting. Seen by Dietitian (well known to team) seen by staff to tip his nutritional drinks into his vomit bowl and report vomiting."
- 3.7.1. There was ongoing concern about Stan's physical health. In June 2019 primary care records observe a high risk of malnutrition and times when he had been off insulin before accepting daily injections. The following month a Community Matron recorded that Stan was not eating and was refusing a GP review and hospital admission. He was struggling with swallowing as a result of the return of gastro-oesophageal reflux disease. A referral to gastroenterology was sent.
- 3.7.2. Concerns continued to be expressed by a Community Matron, triggered by chest infections and considerable weight loss. He had one hospital admission in September 2019 but concerns continued thereafter, with high glucose levels, abnormal haemoglobin, insomnia, and passivity and lack of energy. In April 2020 primary care records contain concerns about nutritional loss due to loose bowels and vomiting. In July 2020 a Community Dietician wrote of a medium risk of malnutrition. In December 2020 a Community Dietician wrote an urgent prescription letter for nutritional supplements. Stan was recorded as no longer having snacks or taking prescription medication with meals to assist with digestion when his pancreas was not producing sufficient enzymes.
- 3.7.3. The AWP report covering the period from November 2018 to case closure in August 2020 also references periodic concerns from a Community Matron and seen by a Care Coordinator regarding Stan's weight loss, not eating and drinking, blood sugar levels and non-compliance with medication. Feelings of sickness are referenced occasionally when Stan was not eating and drinking regularly. Occasionally he reported that he was gaining weight and it does appear that his diabetes fluctuated. **Commentary:** the AWP report records that around August/September 2019 Stan was expressing frustration that plans for physical investigations kept being changed and that practitioners were attributing his difficulties to his mental health. He was also clear around this time that he saw his physical health as the priority. There does appear to have been a missed opportunity for practitioners to meet together and with Stan to combine consideration of the approach to his mental and physical wellbeing.

- 3.7.4. Concerns continued to be expressed by Community Dieticians and Nurses regarding very high blood glucose levels and loss of weight. In June 2021 a Community Dietician was expressing concern "about his appearance and his possible self-neglect. He has diabetes and is on Creon tablets for insufficient levels of the pancreatic enzyme. He has lost a lot of weight dropping form 49kg down to his current 38kg. District Nurses were going in to administer his insulin but no longer appear to be doing this he may have said he will self-administer but he does not seem to be doing that. He is also supposed to have meal supplements but is not getting these. ... His flat is in a filthy state and he is hopping round on one foot." Commentary: primary care records for December 2020 observe that foot examination had found long nails and dry skin. He was experiencing knee pain, for which his GP referred him to the musculoskeletal clinic. There is growing evidence of self-neglect but a missed opportunity to coordinate a multi-agency, multi-disciplinary response.
- 3.7.5. Records for Charlotte, dating back to 2011, record that she had a sensory impairment, haemophilia and COPD, which had progressed to stage 4 by August 2016. Also recorded are arthritis, bronchial asthma, hiatus hernia, depression, and panic and anxiety attacks. In August 2017 local authority records noted a history that included mental health and behaviour related to alcohol misuse, previous drug overdose and self-harm.
- 3.7.6. Charlotte's ill-health clearly had an impact on her mobility and activities of daily living. She was prone to falls and had difficulty getting on/off the toilet and in/out of bed. Grab rails, a stair lift (when she moved from a one bedroom to a two bedroom property) and other equipment were provided following occupational therapy assessments. Following a review of the equipment that had been provided by an Occupational Therapist in July 2018, Charlotte's case was closed. **Commentary:** the local authority's intervention was focused exclusively on occupational therapy assessment and the provision of equipment, including through a disabled facilities grant. Referrals were made for community physiotherapy and for more suitable housing in August 2017, and referral was offered with respect to her anxiety.
- 3.7.7. The primary care chronology for the final year of her life records four medication reviews and routine blood tests. These sometimes revealed worsening hypochromic anaemia but occasionally her blood count was satisfactory. She accepted a first dose of a Covid-19 vaccine in March 2021 and several months previously she had accepted the seasonal influenza vaccine. In May 2020 there was a detailed review of her COPD, performed remotely due to the pandemic, where she reported increasing breathing difficulties. She was not eligible for oxygen therapy on account of her smoking and was receiving all available treatment otherwise. She received a new nebuliser in August 2020.
- 3.7.8. At the end of June 2021 the son living with her raised concerns with a GP. The chronology observes that he reported that her mental health had really deteriorated recently. She was spending nearly all of her time in bed smoking, rarely eating and only drinking approximately 1 cup of tea a day. The son reported that she was really unsteady on her feet and had lost a lot of weight, had lost all motivation and was falling if she did get out of bed. He reported that Charlotte was incontinent of urine and he was worried about possible sores on her skin. He was trying to care for her and had tried unsuccessfully to encourage her to seek help or to go into hospital. He felt that she needed a review, especially of her medications. The son reported that she only trusted her own GP and would not readily see anyone else. The information was passed to her GP. **Commentary:** no home visit was completed before Charlotte died. The son had

provided significant information about self-neglect and ill-health. There does not appear to have been consideration of referral to FRS for a home fire safety visit. An opportunity appears to have been missed for immediate intervention.

- 3.7.9. The ASC chronology for Philip records that following the fire at his property he declined to give consent for a referral with respect to his arthritis. The GP chronology records that Philip accepted the first vaccine dose against Covid-19 in February 2021 but declined the second dose in August. A Social Worker subsequently informed the GP that he would accept the second vaccine dose but this does not appear to have been administered before Philip died.
- 3.7.10. Philip had no contact with GPs during 2020 and most of 2019. Contact was also limited in 2021. A GP made a home visit welfare call in May 2021 following the fire but was unable to see Philip. The GP chronology refers to observed clutter and to concerns expressed by a neighbour. A GP declined a Social Worker's request for a welfare visit in early September on the basis that Philip had capacity concerning whether or not to accept treatment for an infected left eye and arthritis. **Commentary:** it appears that this decision was made on the assumption of mental capacity.
- 3.7.11. A further request was made by a Social Worker at the beginning of November. Letters were sent to Philip offering appointments. **Commentary:** since Philip had a history of nonengagement, more assertive outreach was indicated. There is also some doubt as to Philip's reading ability.
- 3.7.12. The UHBW chronology records the range of tests administered when Philip was admitted to hospital, the plans made to address his multiple medical conditions, and the treatment escalation plan that was agreed with him. There were, for example, clear plans to address the risk of refeeding syndrome and vitamin deficiency. He was placed under an alcohol withdrawal pathway. **Commentary:** hospital treatment at this time was coordinated and thorough.
- 3.8. An additional feature of the evidence-base is "think family." The chronology for Charlotte from the local authority records from August 2016 onwards that one of her sons was living with her and helping with shopping and domestic duties. In August 2016 there is no reference to a carer assessment being considered or offered. In August 2017, when they were living in a onebedroomed bungalow, it was recorded that he was sleeping on the floor and that referral for a carer assessment would be made. The chronology does not record the outcome of any referral nor does it indicate whether practitioners spoke to the son about the care and support he was providing and his mother's response to services. By April 2018 the son is recorded as requesting a carer assessment but again the outcome of any referral is not recorded. It is also noted that he could be eligible for a carer's allowance but it is unclear if he was supported to apply to the Department for Work and Pensions. He had clearly been supporting his mother, for example cooking and shopping, and assisting her with transfers. Commentary: it appears that the son was not in receipt of a carer's allowance⁴⁴. There appear to have been missed opportunities to complete a carer assessment. Three referrals for a carer's assessment have now been identified across 2017 and 2018, with contact attempted by telephone and letter. The referrals were closed when attempts to make contact failed. A home visit would have been appropriate on each occasion before these closure decisions.

 $^{^{\}rm 44}$ Information provided by Avon and Somerset Constabulary.

- 3.8.1. The AWP report following Stan's death records that he had not had contact with his family since 2010 as a result of arguments. The same report records the involvement of a private carer/friend from early 2019 onwards. She was present at a meeting involving Stan, a Psychiatrist and a Care Coordinator, and subsequently raised concerns about malnutrition. In September 2019 she phoned the psychiatric liaison team concerned that a hospital was attributing his physical health symptoms to mental health and observed that his mental health had improved considerably. The AWP report records that Stan sometimes declined her support. Commentary: it does not appear that the friend was offered a carer's assessment. Around May 2019 it appears that she was visiting daily and sometimes was present when Stan met with a Care Coordinator. After September 2019 there is no further reference to the private carer/friend, including the impact that the pandemic might have had on the support she had been offering. A CPA review in August 2020 recorded that there had been no contact between Stan and his carer/friend for several months.
- 3.8.2. The ASC chronology records engagement with neighbours during failed attempts to find Philip at home. This provided a picture of his movements and also some historical information. He had lived in the property as a home owner for a long time and his environment "had been like that for years." Practitioners were informed that a brother-in-law and nephew had helped Philip in the past. Neighbours reported that he did not trust anyone and that his longstanding use of alcohol was because he had "lost everyone." One neighbour was concerned that mould was coming through into their property and that Philip had done nothing about the fire.

 Commentary: there is no reference to attempts to contact family members until November 2021, shortly before Philip died, when a meeting of professionals agreed that a Social Worker should contact his brother. Contact details for his brother and a nephew were obtained but only shortly before Philip died. Opportunities were therefore missed to obtain background information from his extended family. Not all agencies held records of Philip's next of kin or extended family. However, engaging with neighbours to obtain a picture of Philip was good practice.
- 3.8.3. In August and September 2021 neighbours continued to report concerns about Philip's behaviour, sometimes through local councillors.
- 3.8.4. The UHBW chronology records that the hospital contacted Philip's niece who visited shortly before he died and was understandably very upset.
- 3.8.5. Those attending the learning event acknowledged the impact on carers, on family members and also on neighbours and communities. They reinforced the importance of exploring not just the needs of carers as carers but also their own care and support needs. They questioned, for example, whether sufficient focus was given to any care and support needs of Charlotte's sons.
- 3.8.6. What also comes through strongly is the absence of involvement of family and friends. Perhaps this was curtailed by fears around information-sharing and confidentially, discussed in the next section of the report under information-sharing. At the learning event it was reported that, in cases where services had involved family and friends early, this facilitated the adoption of a trauma informed and social history informed approach.

Section Four: Thematic Analysis – Team around the Person

- 4.1. From a reading of the combined chronologies, and mindful of the evidence-base, the following themes were identified for exploration at the learning event and are analysed here.
- 4.2. Working together. The chronologies disclose many examples of practitioners working together. A GP surgery liaised with a Pharmacist regarding Charlotte's COPD treatment (June 2020). A Community Matron and GP worked together in August 2019 regarding Stan's weight loss and hospital admission. A Diabetic Specialist Nurse visited Stan at the request of Community Nurses (October 2019). The recovery team asked a GP/primary care if they had any contact with Stan as they had been unable to get hold of him. AWP advised the GP surgery of DNAs. Around May 2019 a Care Coordinator liaised with the AMHP service. A GP requested a Care Coordinator to complete a capacity assessment regarding his health and welfare and his decision not to attend A&E (circa February 2019). A Social Worker liaised with FRS and invited the service to a multi-agency meeting in November. UHBW staff liaised with a Social Worker.
- 4.2.1. **Commentary:** There is little sense that practitioners were working to a support and risk management plan with and for Stan. Rather, requests for support and information-sharing was episodic. There were also missed opportunities. A Community Matron intended to assess Stan's mood with a colleague but it is not clear from chronologies that this was done. There were missed opportunities in Charlotte's case for closer liaison between primary care and the local authority, for example regarding the care and support being provided by the son. Her smoking in bed was a fire risk that does not seem to have been considered.
- 4.2.2. In Philip's case there were joint visits involving a Social Worker and Police, Social Worker and Environmental Health Officers, and Social Worker and FRS personnel. Records held by the local authority demonstrate liaison between Adult Social Care and Environmental Health with respect to whether a Community Protection Warning should be served on Philip prior to a Community Protection Notice if there was no progress in reducing the impact of self-neglect on neighbours. ASC also liaised with FRS in early September 2021 when FRS offered a home fire safety visit. Commentary: there is clear evidence of practitioners across different services working together to attempt to engage Philip and to mitigate the risks to Philip and his neighbours of his self-neglect. At the learning event it was observed that internal communication within the local authority, between housing, environmental health and social work practitioners had worked well but that working with external partners could prove more problematic.
- 4.2.3. A Social Worker informed a GP in September of Philip's request for a second vaccine as protection from Covid-19. A GP asked a Social Worker to complete a capacity assessment in early October 2021. In September a Social Worker requested a GP to refer Philip to PCLS but this was not done until early November.
- 4.2.4. At the learning event, those attending observed that services were compartmentalised, too often working in silos. Particularly in complex and challenging cases, it was important that multi-agency working was coordinated through the appointment of a lead agency and key worker. A view was also expressed that the potential of different methods of working together,

such as family group conferencing, could be explored and that more could be done to embed firmly in practice the approach of convening the team around the person.

- 4.3. <u>Information-sharing</u>. In both Stan's case and Philip's case there is evidence of information-sharing, for example between a Community Matron and GP (for Stan), and an ongoing exchange of information between Adult Social Care and Environmental Health (concerning Philip) to ensure that everyone was clear about how the different services were responding and viewing the situation.
- 4.3.1. At the learning event some uncertainty was expressed regarding the law on confidentiality and information-sharing. Not everyone was clear that there is discretion in the Data Protection Act 2018 to share information (including without consent) in order to safeguard an adult at risk. Similarly, there was uncertainty regarding whether it was permissible (and not an infringement of an individual's right to private and family life) to contact family members to enlist their support and to obtain information about a person's history and the backstory behind self-neglect. Again, discretion exists to request information. It is important when there is discretion to record decision-making, including what was considered when determining whether or not to exercise discretion to request or to share information.
- 4.4. <u>Referrals</u>. As itemised above, there are examples of referrals, especially in the cases of Stan and Philip. As itemised also, there were occasions when referrals might have been sent.
- 4.4.1. At the learning event there was acknowledgement that, because of resource constraint and workloads, referrals were not always followed up to ascertain an outcome.
- 4.4.2. At the learning event it was clarified that PCLS policy was to accept referrals from any service. However, there was concern that actual practice might not consistently match policy. Some of those attending the learning event had found PCLS to be reluctant to accept referrals from any other source than the GP.
- 4.5. <u>Multi-agency meetings</u>. The AWP report records that one professionals meeting was held on 30th April 2019 where concerns were expressed about Stan's low weight, lack of compliance with medication and the impact of his low mood. Those at the meeting agreed to consider respite care and contact with the AMHP service. **Commentary:** no further multi-agency meetings were held so there was no whole system oversight of how the recommendations were taken forward from the one meeting that was held.
- 4.5.1. When an adult safeguarding enquiry was opened in late May 2021 concerning Philip, it was clearly recognised that a joint approach, including the use of multi-agency meetings, would be required to address the safeguarding concerns. A multi-professional meeting was held on 18th June and an action plan was developed. This involved weekly social work visits to offer assessment for care and support, contacting his GP, and checking whether he was known to substance misuse services. Contact was also to be made with Citizens Advice Bureau. These actions were completed. **Commentary:** this was good practice. However, there was no GP or legal input into the meeting. The ASC chronology observes that this meeting should have been a formal Section 42 safeguarding meeting.

- 4.5.2. A further multi-agency meeting concerning Philip was held on 19th July. All services involved were present with the exception of the GP and FRS. A Social Worker provided an update and it was recorded that enforcement action had been deferred so as not to jeopardise future engagement with Philip. **Commentary:** the routine use of multi-agency meetings was good practice. Attempting to negotiate rather than impose a way forward with Philip was also good practice. However, the ASC chronology observes again that the meeting should have been constituted as a formal safeguarding response and that it was unclear whether Philip had been informed about the safeguarding enquiry and, if so, what his response to this was. It is unclear whether advocacy had been considered and offered in order to assist Philip to engage and how the local authority would have responded if Philip declined to consent to or participate in interventions to reduce the self-neglect risk. Finally, the concerns expressed by neighbours in terms of the impact of his self-neglect on their lives and environment do not appear to have been picked up.
- 4.5.3. A review multi-agency meeting was convened in mid-August. It was agreed that a Social Worker would continue home visits alongside practitioners from Environmental Health/Public Health, that a mental health support service (Horizon) would be approached to assess his capacity, and that a referral to PCLS would be sent. **Commentary:** it is unclear what decision would be the focus of a mental capacity assessment by the mental health support service.
- 4.5.4. A decision was taken in August 2021 to present the case to a professional decision-making forum. This was delayed by a Social Worker's annual leave. The first meeting of this forum took place on 15th September. **Commentary:** good use was being made of seeking specialist advice. As recorded in the ASC chronology, however, there are several statements that are puzzling. The chronology records that the meeting was told that there were no obvious mental disorder or physical health issues, that there was no evidence of an impairment or disturbance in the functioning of Philip's mind or brain (the diagnostic test) and that he appeared able to understand information, and that use of the Mental Capacity Act 2005 and Mental Health Act 1983 was not appropriate. It is hard to discern how these conclusions were reached, for example whether he could use or weigh concerns about the risks to himself and others. It was acknowledged, correctly, that ASC had no legal power to enforce care or engagement but that Environmental Health could use enforcement powers. The meeting considered closure of the safeguarding enquiry because as recorded Philip had no obvious care and support needs and it was not clear that he was unable to care for himself. Again, this conclusion is puzzling given what had been witnessed regarding his presentation and his home environment. Agreement was reached that practitioners would continue to attempt to engage with Philip, that agencies would work together, and that PCLS would be approached with a view to conducting a "more formal" mental capacity assessment.
- 4.5.5. A follow-up meeting of the professionals' decision-making forum was held on 1st November. Not all of the services or practitioners who were involved or who might have had a contribution to make were present. A referral to PCLS was once again agreed, with a request for an "assertive home visit." It was agreed that a mental health assessment would be helpful. It was also agreed to reopen the Section 42 adult safeguarding enquiry as he appeared to have eligible care and support needs. **Commentary:** the review of options in mental health law was good practice. The decision to reopen the enquiry was good practice but, arguably, Philip had always presented with care and support needs even when declining assessment. Section 42(1) only requires the appearance of care and support needs, not whether such needs are eligible.

- 4.5.6. Participants at the learning event returned to the issue of multi-agency meetings at several points. Although a multi-agency risk management process had been establish, not everyone appeared aware of it and doubts were raised about how well known and/or embedded self-neglect and multi-agency meeting procedures were amongst partner agencies, such as Housing and Environmental Health, especially when cases were sitting outside an adult safeguarding enquiry (Section 42, Care Act 2014). More work appeared necessary to embed policies and procedures on convening multi-agency risk management meetings and ensuring that risk assessments were completed and shared.
- 4.5.7. There was agreement that multi-agency risk management meetings needed to be convened to focus on prevention alongside plans to mitigate known risks. Some services did not appear familiar with available pathways to convene a team around the person, with the result that they felt that they were left "holding the case and risk." There did not appear to be a step-up from a multi-agency risk management meeting, when mitigation and contingency plans had failed to reduce risk. Reference was made to the successful adoption in some areas of a Creative Solutions Panel, where senior leaders across partner agencies attempt to resource bespoke solutions for cases that have not been resolved through earlier multi-agency risk management meetings.
- 4.5.8. Some attendees at the learning event expressed the need for a regular multi-agency forum at which complex and challenging cases could be presented. It emerged that an anti-social behaviour steering group met regularly. Also in existence in ASC were a peer support group and good practice forums. These provide opportunities for confidential case discussions and are being amalgamated. They are multi-agency and part of a training offer, meeting quarterly. The professional decision making forum (as referred to in the Philip case) is a support mechanism within ASC for social workers, led by the Principal Social Worker.
- 4.5.9. A review seems appropriate of the different meetings to ensure that they dovetail and of the pathways through which practitioners across partner agencies can access these opportunities to share concerns and agree ways forward with respect to complex and challenging cases.
- 4.6. <u>Use of policies and procedures</u>. The ASC chronology for Philip records that the hoarding protocol was to be followed but it is unclear what exactly this meant in practice.
- 4.6.1. NSSAB has published self-neglect procedures but not everyone at the learning event was convinced that these procedures were referred to in practice.
- 4.7. <u>Safeguarding literacy</u>. The AWP report on involvement with Stan records that a safeguarding referral was raised in first half of 2019. This did not progress to an enquiry because Stan had capacity and understood the concerns. **Commentary:** decision-making regarding this referral should have stated clearly whether or not Stan appeared to have needs for care and support, was at risk of abuse or neglect, including self-neglect, and whether he was able to protect himself from that abuse/neglect.
- 4.7.1. Stan was seen by the mental health recovery team in April 2020. He was described as unkempt, although his mood was observed to be stable. He reported that he was struggling with

his sleep pattern. **Commentary:** since self-neglect was observed, this was a missed opportunity to consider referral for an adult safeguarding enquiry.

- 4.7.2. On 3rd June 2021 a referred safeguarding concern regarding Stan was received by the Recovery Team following contact with a Dietician. This thematic review has been provided with the following context for this day: there was a total of 7 concerns received for different service users; Recovery operate a 'safeguarding rota' each day for social care staff - this rota is not staffed by AWP colleagues. This rota is separate from the care coordination role' and involves the use of both Rio and LAS for recording. The recording in this case was not completed at the time." A Social Worker's statement continues: "I looked at the information which stated possible self-neglect, weight loss, and Stan's flat being in a poor state. I saw that this was the only safeguarding concern recorded on LAS for Stan. There had been no others in the last year. I therefore concluded that there was not an immediate risk of severe harm so no immediate action was needed. There was a lot of other safeguarding work that day so I was not able to follow this up the same day and planned to do so the following Tuesday when I would next be on safeguarding duty. I do safeguarding duty once a week and had 5 safeguarding enquiries open at the time of receiving this concern. In addition to this I have a caseload of 33 people, 28 on the recovery caseload and 5 on the reviewing team caseload. Additionally, on the 7th of June, the day before my next safequarding duty, I was informed a service user on my recovery caseload whom I had worked with for 3 years had died as a result of suicide the day before. This increased my workload for the week and the distress I felt made it difficult to prioritise other work. As a result I was unable to work on this safeguarding concern. The rationale was not recorded to RIo /LAS at the time." Commentary: there is a clear link here to safe workloads, to be addressed further in the next section of this report.
- 4.7.3. A second referral was received post mortem from UHBW, as follows: "Patient admitted in terrible state of self-neglect. Emaciated. Background of Mental Health and addiction. Significant malnutrition and cachexia; safeguarding concerns raised by ambulance crew. Patient's flat noted as full of rat droppings, faecal matter, no in date food, mould and old urine bottles. He called the ambulance and was difficult to understand on answering the door. Had previously had District Nurses for insulin administration, but this had ceased. Has there been a gap in services that has enabled this man to deteriorate and decease at such a young age? Very abnormal bloods, unstable blood sugars and aspirate pneumonia now deceased."

 Commentary: as Stan had died, referral for a SAR was the more appropriate pathway.
- 4.7.4. An adult safeguarding concern was referred by FRS with respect to Philip following the fire in his home and an enquiry was begun. This was a concern for potential self-neglect. Fire crews were not given consent to make an onward referral but after discussion with FRS management, it was felt this could be overridden given the circumstances. **Commentary:** this was an appropriate decision. Philip's consent for referral of an adult safeguarding concern under Section 42 Care Act 2014 was not required.
- 4.7.5. The Officer in Charge of the incident reported the following in their safeguarding/alert of concern form following the call to Philip's property: "The property is in a state of extreme disrepair from the moment you walk through the front drive way and into the house. A lot of personal belongings that most would consider "rubbish". Access in the property was very limited with narrow corridors among the large volume of belongings to get to his bed. The kitchen has had a considerable fire in it rendering it now unusable. Electrics are not safe to use, we isolated

gas and electrics. Personal hygiene was poor. Mobility was ok. Philip's behaviour was friendly towards us once he realised we wanted to help, however he was very guarded in the initial approach and neighbours have reported violent and angry interactions with him in the past. Ambulance crews managed to confirm that Philip is also an alcoholic. Philip lives in a property that I believe is unsafe. His living style is also unsafe and I strongly believe that he is at very high risk of causing harm to himself in his property, and the likelihood of a further fire at this property is almost certain. Access to areas he uses were in place. We also created space to get to the utilities in the property so we could isolate them and make them safe. SWAST crews discussed his living conditions with him and have advised that they will also be safeguarding Philip, as well as ensuring a GP carries out a home visit over the next week."

- 4.7.6. ASC also received a safeguarding concern from Paramedics, highlighting self-neglect including considerable amounts of rubbish in the property. **Commentary:** the referrals from FRS and SWAST were thorough and good practice. Consent is not required for referral of an adult safeguarding concern. A plan was developed.
- 4.7.7. An enquiry commenced because of evidence of self-neglect. The decision also recognised the need to have contributions from other professionals to promote his safety and wellbeing. A further adult safeguarding concern was referred in July 2021 from the One Team (Police), observing that Philip lacked understanding of his basic welfare and also social awareness. Concern was expressed about the welfare of his dog also. **Commentary:** this was seen as a duplicate referral when it might have been more helpful to regard this as an additional referral, reinforcing concern about risk and about mental capacity. A referral to the RSPCA might have been appropriate at this point also.
- 4.7.8. The safeguarding enquiry was closed on 15th September as the case was open to case management (see the discussion above regarding multi-agency meetings and the apparent belief that Philip did not have care and support needs at this time). **Commentary:** at this point the risks to Philip and others arising from his self-neglect had not been mitigated. The enquiry was reopened at the beginning of November.
- 4.7.9. Paramedics and FRS referred an adult safeguarding concern when Philip was taken to hospital for the final time. **Commentary:** the referrals represent good practice.
- 4.7.10. At the learning event the value of emergency services referring adult safeguarding concerns was emphasised, not least because such referrals could counteract the risk of normalisation of risk by practitioners and services more regularly in contact with an individual. However, referrals also needed to be clear whether what was being referred was a general concern about a person's welfare, which might indicate the need for a care and support assessment (Section 9 Care Act 2014) or whether the referring service believed that the three criteria for an adult safeguarding enquiry had been met (Section 42(1)).
- 4.7.11. Some concern was expressed in relation to decision-making about referred adult safeguarding concerns in cases involving substance misuse and self-neglect. This concern focused particularly on how the criteria in self-neglect cases, "unable to protect themselves" and "unable to control their behaviour" were interpreted.

- 4.7.12. A new operational model for adult safeguarding in North Somerset has been introduced, namely a specialist central safeguarding team. A view was expressed at the learning event that this team would need to be adequately resourced and that its establishment should not result in locality teams handing over all responsibility for safeguarding.
- 4.8. <u>Legal literacy</u>. Awareness in Philip's case is clearly demonstrated of the enforcement powers available to Environmental Health. A Community Protection Warning was served on Philip on 15th September giving him 30 days to address concerns about the environment in which he was living. Obtaining a warrant to access the property to complete necessary works was discussed mid-October but it was considered better to continue to attempt to persuade and negotiate. **Commentary:** it is good practice to negotiate where possible but imposed interventions are sometimes necessary.
- 4.8.1. Options in the Mental Health Act 1983 were considered at the decision-making forum meeting at the beginning of November and agreement was reached to consider a Mental Health Act 1983 assessment if he declined to engage with PCLS. Public Health referred their concerns about Philip's dog to the RSPCA on 1st November and the dog was taken to the vets on 11th November. Records also indicate awareness of the limited powers available to ASC.

 Commentary: in complex and challenging cases it is helpful to involve legal practitioners in decision-making and multi-agency meetings. There is no explicit mention of provision in Section 11 (2) (b) Care Act 2014 in relation to continuing with care and support assessments, despite absence of consent, where there is evidence of abuse or neglect, including self-neglect.
- 4.8.2. **Commentary:** this aforementioned provision might have proved helpful in Stan's case also. Depending on the outcome of completed mental capacity assessments, in the context of being frustrated in attempting to implement best interest decisions, referral to the Court of Protection would have been an option, for both Stan and Philip. Legal provisions with respect to advocacy might have been helpful in Philip's case but do not appear to have been considered. Completion of carer assessments (Section 10 Care Act 2014) would have been appropriate in the case of Charlotte and possibly also Stan.
- 4.8.3. Reference from the learning event has already been made to legal literacy in respect of accurate interpretations of the principles with the Mental Capacity Act 2005 and accurate understanding of when the law (Data Protection Act 2018) permits information-sharing without consent. Concern was also expressed, in the context of engagement and consent to assessment of care and support needs, that the provisions in Section 11 Care Act 2014 were not embedded in practice.
- 4.8.4. One barrier to effective multi-agency working, expressed at the learning event, was the lack of clarity across partner agencies regarding the legal powers and duties available to different services.
- 4.9. <u>Recording</u>. All three cases highlight the importance of recording follow-up to refusals of care and support, and of treatment. In Charlotte's case there is no reference in chronologies as to what Nurses saw at home. Her son was known as her carer but there is no reference to any support for him or to how he presented when he was seen with Charlotte. The outcomes of referrals for carer assessments were not recorded on ASC systems so there was no opportunity for review of the approach being taken to the case. Similarly, records reveal that in May 2016 a

Tenancy Officer referred Charlotte for assistance with claiming and understanding welfare benefits, managing health and wellbeing and accessing health and social care services. However, there is no record of an assessment occurring or support being provided.

- 4.9.1. In Stan's case records refer to a lack of clarity about the type of health review necessary, whether he attended some reviews and whether reviews were rearranged when he did not attend. Nor do records consistently make it clear if planned telephone calls were made after messages had been left advising him to make appointments concerning his diabetes to make sure he was taking insulin. There is no evidence of follow-up when letters were sent advising him to make appointments regarding his physical health. It is not documented what discussions took place between primary and secondary care services, if any, when he missed appointments.
- 4.9.2. More positively, UHBW recorded a full history regarding self-neglect on Philip's admission in November 2021.

Section Five: Thematic Analysis – Organisations around the Team

- 5.1. <u>Supervision</u> and <u>management oversight</u> are core components of the evidence-base for best practice. The ASC chronology for Philip records that a line manager was consulted in supervision about the safeguarding concerns referred by FRS and SWAST. **Commentary:** this represents good use of supervision.
- 5.1.1. At the learning event there was recognition that supervision was essential both to prevent practitioners normalising a situation through over-familiarity with what they were seeing, and to reflect on whether engagement was proving challenging because of how services expected or required individuals to respond.
- 5.2. The evidence-base also refers to <u>commissioning</u>. NSSAB has a statutory mandate to seek assurance that, in order to prevent and to safeguard people from abuse and neglect, commissioners are responding effectively to people who present with complex needs. Research⁴⁵ strongly recommends new commissioning approaches that deliver integrated provision and a greater number of specialist multi-disciplinary services.
- 5.2.1. When Philip arrived at the Emergency Department by ambulance on 11th November, no beds were initially available. He was admitted onto a ward the following day.
- 5.2.2. One gap in provision that was noted at the learning event was the absence of a precontemplative service for people with a history of dependence on alcohol and other drugs. Another gap, it was suggested, was the lack of specialist practitioners in self-neglect work at a time when services were seeing an increasing number of self-neglect and hoarding cases, described as a "Covid surge."
- 5.3. <u>Workforce and workplace development</u> are other components of this part of the evidence-base. Workloads clearly impacted on how a safeguarding concern regarding Stan was triaged in early June 2021, as itemised in the section of this report on safeguarding literacy. **Commentary:** the lack of time might have prevented the social worker from triangulating the information in the referred concern with what was known by other services. The referral was seen as an isolated episode rather than part of a pattern. Reliance on a single practitioner raises the question of whether the safeguarding system itself is safe.
- 5.3.1. Workloads featured in discussions at the learning event. One barrier to working effectively with individuals who self-neglect was seen in the focus on assessment and short-term work as opposed to building long-term relationships. When resources were stretched, this barrier became even more noticeable.
- 5.3.2. Workloads and staffing within primary care teams and GP practices meant that it was difficult to identify and follow-up patients who were repeatedly missing appointments and reviews, and were at risk. The result was a reliance on other services, equally under pressure, to

⁴⁵ Cream, J., Fenney, D., Williams, E., Baylis, A., Dahir, S. and Wyatt, H. (2020) *Delivering Health and Care for People who Sleep Rough: Going Above and Beyond*. London: King's Fund. Weal, R. (2020) *Knocked Back: How a Failure to Support people Sleeping Rough with Drug and Alcohol Problems is Costing Lives*. London: St Mungo's.

share information and to alert GPs to escalating risk. Some services, for example hospitals, were experiencing challenges in recruiting staff to work in adult safeguarding. Recognised as a national and not just a local issue, a greater emphasis on succession planning was needed to minimise the risks associated with taking expert clinicians away from direct practice.

- 5.3.3. With increasing demands on services, the danger was recognised that competing priorities within workloads could lead to an assumption that another service would respond to a particular risk or concern. To counteract this, at least in part, practitioners and services had to be clear about each other's roles and responsibilities. The ongoing Covid pandemic, coupled with winter pressures and the cost of living crisis, suggested the need for a whole system review of how services interlink. **Commentary:** the Independent Reviewer understands that NSSAB partners have already discussed the current crisis and that further work is being undertaken.
- 5.4. <u>Availability of specialists</u>. The evidence-base recognises the importance of practitioners being able to access specialist practitioners in law, mental capacity, mental health, substance misuse and safeguarding. At the learning event the importance of being able to access specialists, for example in the local authority and/or the Integrated Care Partnership, was stressed. Joint visits were suggested as a helpful way forward in complex and challenging situations.

Section Six: SAB Governance

- 6.1. There were some delays in progressing this thematic review once it had been commissioned, mainly owing to changes of SAR sub-group chair and departure and appointment of a SAB business manager.
- 6.2. At the learning event it emerged that not all practitioners and managers across services are familiar with the roles and responsibilities of the SAB and its sub-groups. The Board might benefit from reviewing how services such as Housing and Environmental Health are included in the work of the SAB and its sub-groups.
- 6.3. Also expressed at the learning event was a recognition of the complexity of working with cases of self-neglect, not least difficult decision-making about when and how to intervene. Joint training, it was suggested, might help to break down silo working and to facilitate diverse services to familiarise themselves with each other's area of work. A review of pathways into services and into multi-agency meetings would also be helpful in facilitating how services work together.

Section Seven: Revisiting the Terms of Reference

- 7.1. The terms of reference set for this thematic review have been reordered to correspond to the four domains used in the previous sections of this report, beginning with direct practice. The summary analysis that follows, and the recommendations that are offered, are informed by an understanding shared at the learning event that self-neglect cases, of the types described in this review, are typical and increasing in North Somerset.
- 7.2. Making Safeguarding Personal is a central principle within adult safeguarding practice. In Stan's case and Charlotte's case, in particular, due regard was paid to their wishes, feelings and desired outcomes but less evident is the degree to which different practitioners shared their concerns during conversations about what was being observed. Also much less evident is recorded understanding of each individual's backstory that might have cast light on their mental health and substance misuse, refusals of assessments and support, and responses to their physical ill-health and treatment recommendations. Concerned curiosity should be a core component of practice. Put another way, and emphasised at the learning event, practitioners and services must be trauma aware.

 Recommendation One: NSSAB should consider revisiting how Making Safeguarding Personal is embedded in practice and how conversations in a context of adult safeguarding are recorded about the outcomes to be prioritised.
- 7.3. Engagement has emerged as a key theme in this thematic review. When individuals for whatever reason are reluctant to engage, or experience difficulties with engagement, continuity of relationships with practitioners helps to build trust over time. In Philip's case especially, that continuity was evident; to a lesser extent it was present in Stan's case also. However, it was less evident in Charlotte's case and in Stan's case continuity was lost when practitioners ended their involvement. Moreover, whilst recognising the increasing demands on all services, practitioners and managers must reflect in a context of missed appointments whether an individual is unwilling or unable to engage, and whether services are creating barriers to engagement by the way their work is organised. Attitudes and assumptions should be questioned, such as lifestyle choice. Charlotte, for example, was once described as "demanding and aggressive." Practice must guard against failure to consider risk as a result of either reliance on self-report or becoming over-familiar with an individual's presentation. Recommendation Two (A): NSSAB should consider seeking assurance that supervision and multi-agency and multi-disciplinary discussions routinely explore how presentations of self-neglect are understood, and which practitioners have the strongest relationship with an individual that might open up the possibility of effective work. Recommendation Two (B): NSSAB should consider raising with other SABs, initially in the South West region and subsequently nationally, the challenge of identifying in a context of automated systems individuals at risk who miss or are not brought to appointments. NSSAB should through this process consider escalating this system issue to NHS England via the Safeguarding Adults National Network, NHS Digital, and the Department of Health and Social Care via the National Network for SAB Chairs.
- 7.4. Concerns have emerged about mental capacity assessments, most especially a misunderstanding of the principles within the Mental Capacity Act 2005 and uncertainty about how to embed consideration of executive functioning within assessments. The use of Independent Mental Capacity Advocates does not appear to have been considered. When treatment escalation

plans are agreed, it must be clear whether what is being discussed is, in fact, an advance decision⁴⁶. **Recommendation Three:** NSSAB should consider commissioning a multi-agency case audit of mental capacity assessments, focusing particularly on self-neglect, on executive functioning and on understanding of the five principles within the Mental Capacity Act 2005, and agreeing an action plan once the findings are known.

7.5. Although mental distress was evident in all three cases, only in Stan's case was there sustained mental health service input for a period of time. In his case, and quite possibly in the other two, mental health fluctuated. Whilst not in acute (psychotic) crisis, there does appear to have been a gap in the offer of support for mental health wellbeing. Stan, for example, was assessed to have been severely depressed when a test was administered in September 2019. None of the three individuals appears to have had involvement with substance misuse services and the backstory to alcohol-dependence or misuse is unknown. Where both mental health and substance misuse services are involved, joint working is best practice. The impact of prolonged substance misuse on mental capacity also needs to be factored into assessments, focusing especially on executive functioning. **Recommendation Four:** NSSAB should consider reviewing how mental health and substance misuse services work together. **Recommendation Five:** NSSAB should seek assurance from health and social care commissioners that there is appropriate provision for individuals experiencing longstanding, fluctuating and ongoing mental health issues.

7.6. In all three cases self-neglect and the risks of self-neglect were apparent. None of the individuals were out of sight but in two cases (Stan and Charlotte) there had been an acceptance of self-reporting and an assumption that they would make contact with services if they needed help. In Philip's case the focus on attempting to negotiate an intervention that he would regard as acceptable did not mitigate the risks to himself or to others. There is a danger of over-optimism, that a situation has improved sufficiently to withdraw and/or that individuals will re-establish contact when needed. When there are life-long conditions, such as diabetes, and a pattern of erratic compliance with treatment advice, and when there are longstanding and fluctuating mental health concerns, shared risk assessments are indicated alongside identification of cases where oversight is necessary to prevent the kind of deterioration that became evident in the final days for Stan, Charlotte and Philip. **Recommendation Six:** NSSAB should consider auditing the quality of risk assessments and taking action in response to the findings.

7.7. Turning to a focus on the team around the person, whilst some partnership working was evident, especially in Philip's case, and information was shared, for instance in Stan's case, no lead agency or key worker was appointed in any of the three cases. There were occasions when practitioners from different services met together, again especially in Philip's case, but much practice was undertaken in silos. Pathways to convene multi-agency risk management meetings were perceived by some agencies to be unclear and there was general concern that further work was necessary to embed "case conferencing" in practice. **Recommendation Seven:** NSSAB should consider reviewing and revising existing guidance on pathways into and procedures for multi-agency risk management meetings, disseminating expectations about multi-agency and multi-disciplinary working, and auditing outcomes.

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⁴⁶ See Salford SAB (2022) SAR Kannu for a detailed discussion of the distinction between care and treatment planning, and advance decisions.

- 7.8. There is some evidence of uncertainty about legal powers and duties with respect to information-sharing and mental capacity. **Recommendation Eight:** NSSAB should consider commissioning multi-agency training on legal literacy.
- 7.9. One component of legal literacy is understanding and decision-making with respect to the duty to enquire into referred adult safeguarding concerns. The three criteria within Section 42(1) Care Act 2014 clearly apply to cases of self-neglect and the statutory guidance also focuses on how the criteria are to be applied in such instances. There were referred adult safeguarding concerns in Stan's case and Philip's case. There were missed opportunities to refer concerns in all three cases and no enquiry was completed with clear outcomes about what action the local authority, with its partners, would take to mitigate the risks. **Recommendation Nine:** NSSAB should consider commissioning an audit of decision-making with respect to referred adult safeguarding concerns.
- 7.10. Turning to organisational support for practitioners, NSSAB has published various protocols, including for information-sharing, multi-agency safeguarding, and self-neglect. Concern has been expressed during this review that these protocols are insufficiently embedded in practice. There might also be some gaps, for example in relation to routes for escalation of concern, or decision-making about the appointment of a lead agency and key worker. **Recommendation Ten:** NSSAB should consider reviewing published protocols, revising where this is indicated following consideration of the learning from this thematic review. A programme of dissemination and auditing should follow publication of revised procedures. NSSAB should also consider where new protocols are needed, for example so that practitioners and managers know the procedure for escalating concerns and raising professional differences.
- 7.11. Little information emerges from the combined chronologies regarding management oversight and direction in response to complex and challenging cases. Recommendation two above focuses on the importance of supervision to enable practitioners to review their approach to a situation. Case closure decisions should routinely be discussed in supervision, with case records clearly indicating how risks had been assessed, for example of mental health relapse.
- 7.12. Earlier sections of this report have highlighted how the pandemic impacted on the work being undertaken. For example, in Stan's case there is evidence that practitioners considered how to mitigate the risks that enforced isolation would pose for him. In Philip's case home visits were conducted with clear recognition of the importance of complying with Covid guidance.

 Operationally, working with self-neglect cases can often be experienced by practitioners as lonely, exhausting and stressful, and the ongoing pandemic highlights further the importance of operational managers and senior leaders paying close attention to the lived experience of their staff. Workloads are just one element of this, the degree to which practitioners across health, social care and housing services, for instance, feel that they are working within a safe environment. **Recommendation**Eleven: NSSAB should consider seeking assurance from all partner agencies about how operational and strategic managers ensure that workloads are experienced as manageable.
- 7.13. Turning finally to governance, it is important to introduce learning from SARs in as timely a way as possible. There were some delays in completing this review. **Recommendation Twelve:** NSSAB should review its current arrangements for commissioning and undertaking SARs.

Recommendations

Recommendation One: NSSAB should consider revisiting how Making Safeguarding Personal is embedded in practice and how conversations in a context of adult safeguarding are recorded about the outcomes to be prioritised.

Recommendation Two (A): NSSAB should consider seeking assurance that supervision and multiagency and multi-disciplinary discussions routinely explore how presentations of self-neglect are understood, and which practitioners have the strongest relationship with an individual that might open up the possibility of effective work.

Recommendation Two (B): NSSAB should consider raising with other SABs, initially in the South West region and subsequently nationally, the challenge of identifying in a context of automated systems individuals at risk who miss or are not brought to appointments. NSSAB should through this process consider escalating this system issue to NHS England via the Safeguarding Adults National Network, NHS Digital, and the Department of Health and Social Care via the National Network for SAB Chairs.

Recommendation Three: NSSAB should consider commissioning a multi-agency case audit of mental capacity assessments, focusing particularly on self-neglect, on executive functioning and on understanding of the five principles within the Mental Capacity Act 2005, and agreeing an action plan once the findings are known.

Recommendation Four: NSSAB should consider reviewing how mental health and substance misuse services work together.

Recommendation Five: NSSAB should seek assurance from health and social care commissioners that there is appropriate provision for individuals experiencing longstanding, fluctuating and ongoing mental health issues.

Recommendation Six: NSSAB should consider auditing the quality of risk assessments and taking action in response to the findings.

Recommendation Seven: NSSAB should consider reviewing and revising existing guidance on pathways into and procedures for multi-agency risk management meetings, disseminating expectations about multi-agency and multi-disciplinary working, and auditing outcomes.

Recommendation Eight: NSSAB should consider commissioning multi-agency training on legal literacy.

Recommendation Nine: NSSAB should consider commissioning an audit of decision-making with respect to referred adult safeguarding concerns.

Recommendation Ten: NSSAB should consider reviewing published protocols, revising where this is indicated following consideration of the learning from this thematic review. A programme of dissemination and auditing should follow publication of revised procedures. NSSAB should also

consider where new protocols are needed, for example so that practitioners and managers know the procedure for escalating concerns and raising professional differences.

Recommendation Eleven: NSSAB should consider seeking assurance from all partner agencies about how operational and strategic managers ensure that workloads are experienced as manageable.

Recommendation Twelve: NSSAB should review its current arrangements for commissioning and undertaking SARs.