Safeguarding Adults Review
Thematic Review on self-neglect

Hampshire Safeguarding Adults Board

Final version

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Date: March 2022

Contents

1. Introduction

1.1 This thematic Safeguarding Adults Review (SAR) is commissioned by the Hampshire Safeguarding Adults Board (HSAB) in order to learn from the circumstances around the deaths of six people in Hampshire between March 2020 and January 2021. There were concerns about their self-neglect at some point prior to their death. Five of the subjects died during the ongoing Covid Pandemic, between 2020 and 2021. One person died in March 2020, but had sustained injuries in December 2019, prior to the initial stages of the COVID pandemic.

1.2 Demographic details of the six people who are subjects of the SAR.

The six SAR subjects are three women and three men, all were of white UK ethnicity. One person identified as being part of the LGBT community. Three people lived in rented social housing, two were leaseholders and one was an owner-occupier. All lived alone, apart from Barbara who lived with her husband, he was in hospital at the time she died.

1.3 This Review is conducted in accordance with section 44 of the Care Act 2014 and the Hampshire Safeguarding Adults Board Procedures.

SAR Referrals were made to HSAB by various organisations between August 2020 and January 2021. The decision to commission a thematic review was made in early 2021 with the lead reviewers commissioned in February 2021.

Under section 44 of the Care Act 2014 a Safeguarding Adults Board must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if there:

- is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult,
- and the adult has died,
- and the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to:

a) identifying the lessons to be learnt from the adult's case, and
b) applying those lessons to future cases.

2. Terms of Reference

2.1 Timeframe: The SAR examines the time from when concerns first emerged about each of the six people, up until the time of their death.

2.2 The Key Lines of Enquiry set out in the SAR terms of reference covered demographic and factual information, these are detailed in section 5, 'the people and

their stories' and in the analysis of themes in section 6. A full list of the Key Lines of Enquiry (KLOEs) can be found in *appendix 1*.

3. Methodology

3.1 The methodology used was a 'Rapid Methodology' designed by the HSAB. This methodology uses a systems perspective and is intended where possible to build on existing reports over a shortened timescale. However, in this case no existing reviews, investigations or case audits specific to the SAR subjects had been undertaken prior to the initiation of the SAR.

Each organisation complied a review report using a standardised template to critically analyse their own practice against the key lines of enquiry. The themes identified within the reports were developed during three short learning event workshops, a longer learning event was held to identify findings and potential recommendations. The learning events were consistently attended by 30-35 representatives of relevant agencies.

3.2 The following organisations contributed Reports to the Review:

Organisation	Referred to in report as
Hampshire County Council	The local authority (as decision makers of the s42 duty) or Adult Health and Care (AHC) or MASH (Multi Agency Safeguarding Hub) as relevant.
Southern Health Foundation Trust	Referred to as the mental health trust
Solent NHS Trust	Referred to as 'the PICU'
Housing associations: VIVID Homes	Referred to as 'the landlord' or 'housing association' dependent on the SAR subject's tenancy/ownership status
South Central Ambulance Service (SCAS)	Referred to as the ambulance trust
GP surgeries: Gratton Surgery Jenner Surgery Fryern Surgery Willow Group Practice New Horizons Medical Partnership Shakespeare Rd Medical Practice	Referred to as the GP or GP Practice
Eastleigh Borough Council	
Winchester City Council	
University Hospitals Southampton NHS Foundation Trust Frimley Health NHS Foundation Trust Queen Alexandra Hospital Portsmouth Hospital University Trust Hampshire Hospitals NHS Trust	Referred to as 'the acute trust'

Hampshire Constabulary	Referred to as the police
Hampshire and Isle of Wight Fire and Rescue Service	Referred to as the Fire and Rescue service

4. Family Involvement

4.1 The families of three of the SAR subjects have individually met with the lead reviewer to talk about their family member and provide context to the reports given by organisations. Conversations with the families have provided useful background and context to the analysis and identification of themes. The three families have also taken the opportunity to review the SAR Report and to comment on the findings and recommendations.

An advocate from VoiceAbility was commissioned by HSAB to represent the potential views and wishes of three of the SAR subjects who had no friends or family that could be identified. The advocate was able to meet with people who knew the subject in all but one case. This provided a more personalised and detailed picture of their circumstances, potential perspective and wishes, both at the learning events and via non-instructed advocacy reports. The advocate was able to identify distinct themes which have contributed to the learning events and report.

5. The six people

5.1 Amanda

Amanda died in a hospital in March 2020, she was 33 years old, and had been an inpatient since being badly injured in a housefire in December 2019.

Amanda had a traumatic childhood, a sibling died of sudden infant death and her parents divorced when she was six with her father retaining full custody, her mother was emotionally abusive, and Amanda had been subject to a child protection plan. Amanda went to university to study zoology before re-training and gaining employment as an accountant in 2013. She was able to work for about a year after qualifying before her mental health declined and she stopped working. Amanda told mental health practitioners that her father was an alcoholic and that she had cared for him for the last six months of his life. He died in 2015 which precipitated a decline in Amanda's mental health with impulsive self-harm and suicide attempts.

Following her father's death Amanda inherited a large sum of money which enabled her to pay off all her debts and move into the Hampshire area, buying 80% of a shared ownership property with a 20% rental from a housing association. She was responsible for the repairs and gas servicing at her property. Amanda lived alone and reported knowing no-one in the local area. She did attend some appointments with a boyfriend and mentioned a girlfriend, she worried that a neighbour was harassing her because of her sexuality. Amanda had cats which she had adopted as kittens, they were well cared for.

In 2019 her grandmother died which Amanda felt had exacerbated her mental health and substance misuse. Amanda had no contact with other members of her family, she said that their religious beliefs resulted in them disowning her for being bisexual and for trying to kill herself.

Amanda had previously had a diagnoses of emotionally unstable personality disorder (EUPD) and alcohol abuse. After a mental health crisis in October 2019 the EUPD diagnosis no longer appeared to be accurate. Her psychiatrist thought that she had had a psychotic episode and also experienced agoraphobia and post-traumatic stress disorder.

Amanda reported a neighbour's anti-social behaviour to the police on ten occasions between June 2018 and September 2019. On one occasion Amanda visited the neighbour to enquire about the welfare of a child and was as a result allegedly threatened and later allegedly assaulted. In the analysis report submitted to the SAR the Hampshire Constabulary author has commented that there were missed opportunities to identify an agency to take a lead role in assessing and addressing Amanda's needs. The historical reports made by Amanda to the police do not appear to have resulted in the identification of her as a person who needed a coordinated multi-agency response. She was not assessed as a potential High Intensity User with mental health issues. Whilst Amanda reported her fears about her neighbour she did not want police to take action or to visit her in her flat. Amanda alleged that she had been raped by police officers in different police area 20 years previously but declined to provide any details. This allegation, together with Amanda's behaviour, resulted in a Publication Protection Notification (PPN1) report to MASH in January 2019.

In response to the police report the local authority referred Amanda to her GP to review her mental health and consider referral to other agencies. Amanda rarely saw her GP who found it hard to contact her as she did not answer the telephone and did not attend the surgery, using the acute trust ED and NHS 111 rather than primary care. Amanda had also been referred to her GP by AHC in January 2018, following a suicide attempt. The GP tried texts, calls and two letters over a period of six days and later emailed AHC to advise that they were unable to contact Amanda.

In August 2019, following her grandmother's death, Amanda attended the acute trust emergency department having self-harmed whilst drinking alcohol. She was assessed by the psychiatric liaison team and referred back to her GP with a recommendation to restart prescribed medication and signposted to engage with debt services due to rent and council tax arrears. She was not claiming benefits and was advised to engage with CRUSE bereavement services.

Amanda made her landlord aware of her concerns about antisocial behaviour from her neighbour in January 2019 and the landlord attempted two home visits. Amanda did not answer the door.

Amanda appears to have fallen into debt by 2019 when she could no longer pay her rent to the landlord. Both the housing association in-house tenancy support team and homeless prevention officers tried to engage with Amanda. The landlord intended to offer support around claiming benefits and putting in place a payment plan to help clear the rent arrears. No meetings with Amanda were possible, she cancelled or did not respond to messages, although the team did use flexible working practices, arranging to meet Amanda at a coffee shop rather than her flat and only using female workers at her request. Without face to face contact the landlord felt unable to assess what support needs Amanda might have.

Because Amanda was responsible for her own repairs and gas servicing the landlord was not able to enter her property to undertake these functions. The landlord had no next of kin details for Amanda as she was a leaseholder, not a tenant. From 2019 they were made aware by Amanda of her mental health difficulties which she described as anxiety and agoraphobia. The housing report author notes that there were missed opportunities to engage partner organisations by referring her to the in-house wellbeing team who could link with the adult mental health team/GP to confirm what current support was in place or what support could be available, or to arrange a MARM meeting as they believe that Amanda met the criteria for this. Further reports of antisocial behaviour experienced by Amanda should have resulted in the landlord re-opening and investigating the original case. Amanda had told the housing landlord that she could not read or write well, but they continued to communicate via text and letters.

On the 25th October 2019 Amanda telephoned the police as she was distressed, local police visited her and persuaded her to allow them entry to her flat. Amanda was very mentally unwell, and police called an ambulance, staying with her until it arrived.

For the first time the conditions in Amanda's flat could be seen. The police submitted a PPNI form noting that her flat was '*in one of the worst states that I have seen …..* '*knee deep in rotting and new rubbish'.* There was no edible food, empty cider containers and two new deliveries of vodka, and officers were unsure whether the gas was connected.

The attending ambulance crew also submitted a safeguarding concern identifying that the flat was a fire risk with heavy fire loading and high ignition source, careless smoking and disconnected smoke detectors. The referral recorded that the flat smelt of rotting rodents and faeces, there were 'multiple' amazon boxes containing alcoholic spirits, surgical scalpels and a bolt cutter in Amanda's bed. There was no food apart from cat food on the premises. This referral was intended to inform a referral to Hampshire Fire and Rescue Service and AHC. Due to a human technical error, now addressed by a new automated system, the electronic referral did not 'send' to the ambulance trust central safeguarding team, so those onward referrals were not made. The housing landlord report they also made a safeguarding concern referral by telephone but do not know the outcome of this.

Amanda was taken to ED and assessed under the Mental Health Act 1983 and subsequently detained under section 2. The ambulance report was included in the electronic notes sent and received by the acute trust who have a record of the concerns. This information should have helped to inform Amanda's discharge but appears not to have been passed onto the PICU unit where she spent four days, or to the mental health trust where Amanda was an inpatient for approximately three weeks.

The PICU reports that they knew little about Amanda when she was admitted, their focus was on stabilising her mental health. The Care Programme Approach was initiated at the PICU on the 28th October 2019, but Amanda was transferred to the mental health trust the next day, and lived outside the PICU area, the information about her self-neglect also appears to be unknown to the mental health trust.

There was no documentation regarding the transfer of care between the trust providing PICU and the mental health trust. The level of information sharing or risk assessment handed over verbally at transfer is not known.

AHC were aware of the police PPN1, and the social care Out of Hours team contacted the acute trust emergency department to tell them about the concerns about Amanda's home and that she may need additional support due to her inability to self-care. The acute trust agreed to share discharge plans with AHC, but perhaps because Amanda was admitted to PICU did not do so.

The concerns were also forwarded onto a AHC mental health team who emailed one of the police officers who had attended Amanda asking about his concerns. This AHC contact was 'completed' by the 31st October 2019 but no interaction with the mental health trust or further follow up was recorded. The Hampshire AHC mental health team were not aware that Amanda had been detained as she was assessed in a different local authority area.

One of Amanda's neighbours was feeding her cats and rang the local authority front door team on the 8th November 2019 to express concern about the state of the property and the cats. He said he knew Amanda had been detained under the MHA and said the police had told him the property was chaotic, there was nowhere to prepare food and there was a lot of clutter. This contact was sent to the AHC mental health team and 'completed' by them on the 11th November 2019 but there is no recording to indicate what actions were taken following this contact.

Amanda was offered advocacy from an Independent Mental Health Advocate during her four day stay on PICU, as is the right of a person detained under the Mental Health Act 1983. She is reported to have declined. It is unknown if she was offered advocacy during her stay on the mental health trust inpatient unit. During her time as an inpatient Amanda spoke about the recent death of her grandmother and her worries about eviction from her flat. She attended psychological inputs on anxiety and healthy eating on the ward.

After unescorted (MHA section 17) leave Amanda was discharged home on the 21st November 2019. She was supported by the mental health trust crisis and home treatment team who attempted to visit her at her flat. HCC AHC were not informed by the mental health inpatient unit when Amanda was discharged, and there was no consideration of the need for a care and support needs assessment at that time.

Amanda did not respond to the crisis and home treatment team requests or let the team in when they visited unannounced. Eventually the team were able to meet with Amanda but only by remaining outside of the flat. They looked through the flat windows and thought the environment dirty and uncared for, but Amanda said that she had let things slide when she was unwell and was cleaning up.

Amanda was referred to a Day Therapy Programme for a structured programme of intensive psychology support but reported that she could not afford the transport costs. She needed to make a benefit claim and was waiting for Universal Credit. She was thought to be able to manage this but later reported that she had lost the paperwork.

In mid-December 2019 Amanda's care was transferred from the crisis and home treatment team to the Community Mental Health Team (CMHT). At the point of transfer, it was noted that Amanda would still not allow access to her property but was reported to be tackling the mess in her flat gradually. Amanda reported that she had submitted an application for universal credit, and she was attending Job Centre on the 16th December regarding emergency payment as she had no money., she was also updating her CV with a view to return to work. Amanda was given an appointment to see a CMHT nurse within two weeks as her mental health appeared stable with no psychotic symptoms.

Amanda kept her appointment with the CMHT at an office on the 23rd December 2019. She attended with her new boyfriend. Amanda appeared mentally well with good insight into her illness and presentation when unwell. CMHT recorded '*No evidence of self-neglect noted, denied any substance use, explored why she has been reluctant to have people in her flat - she talked about needing to tidy up and didn't want others to see it - she does not want any help with this. Talked about risks - none identified and no risk to others noted'*. Amanda said she was engaging with MIND and the Recovery College.

CMHT began Amanda's care plan and made a further appointment with her for the 9th January 2020.

Neither the mental health trust nor local authority appear aware of the fire risk reported by the ambulance trust in October 2019. No referral was received by the Fire and Rescue service. The fire in Amanda's flat later that day appears to have started whilst she was cooking, igniting combustible items stored on the kitchen worktops next to the cooker. There were numerous camping gas cannisters and aerosol containers in the flat, many of which were empty. Amanda may have been using these to cook whilst she had no gas. The gas feed pipe in the kitchen had also failed due to the heat of the fire. Amanda was badly burned and did not recover from her injuries.

5.2 Terry

Terry died aged 76 at home, his body was found in September 2020, he had died some time previously. Terry described himself as a hermit, he did not trust people. He was proud of his two years of military service and often spoke about this. Terry was close to his housing support worker who described him as very independent and also a 'nice person'. She said that he used to like collecting thrown away items, such as bicycles, from skips, and then doing them up or making use of them for another purpose. If Terry thought that something was going to be put to good use he could 'let the item go'.

Terry was open with services about his long-term heavy drinking and tobacco use. He did not see his GP and neglected his physical health as well as the environment. He ate sandwiches and convenience food bought from local shops. During the pandemic he is reported to have 'stopped going out', he owed rent after December 2019 but explained that he could not pay arrears as he was self-isolating.

Terry was referred to AHC by the police in 2016. Concerns were expressed about the cluttered nature of the property and signs that Terry was neglecting himself. Terry was visited by an AHC social worker who undertook an assessment of his

mental capacity to '*identify and understand the risk he is exposing himself to by self-neglecting and neglecting his home environment'.* The mental capacity assessment is legally literate and within the conversation that informed the assessment Terry spoke about his worries about accepting support. The social worker appears to have used a respectfully challenging approach with Terry and negotiated how he might mitigate identified risk well. Although Terry was referred onto services for ex–service people on two occasions he did not use their support as he was worried he would have to pay for it.

Concerns were raised by the ambulance trust in July 2018 that Terry was living in squalor. He had not sought treatment for a broken ankle and was admitted to hospital. The concerns about his self – neglect and his inability to use his bed or kitchen /bathroom due to the cluttered nature of his accommodation led to a three-week admission whilst concerns could be addressed. Whilst in hospital Terry was sober and said that he was willing to consider support for alcohol misuse. No referral to the specialist alcohol nurse was made so losing a 'window of opportunity' to support him to resolve his addiction. The acute trust has learned from this and now ensures that referrals are made to specialist alcohol services within the hospital trust.

Health staff made contact with AHC requesting help to support Terry with a deep clean of his property in response to the concerns expressed by the ambulance crew, health staff thought that he could not be safely discharged until this had been completed. Hospital records indicate some reluctance from AHC in supporting Terry with this matter, stating that he had capacity and could organise this himself.

Terry was referred to the Fire and Rescue 'Safe and Well' service by his landlord in September 2018. Safe and Well is a person-centred prevention and early intervention service people who may have an increased vulnerability to fire within the home. Terry's smoking, alcohol use and impaired mobility would increase the risk of fire in the property. During the visit it was noted that the amount of clutter / hoarding within the bedroom of the property was at a rating of 7-9 (highest level) however, Terry said that he was in the process of clearing this. No other areas of the flat have been noted as a concern, apart from the amount of combustible material in the kitchen.
No onward referrals were made as, apart from his bedroom, Terry was managing his environment and did not appear during the visit to have care and support needs or capacity issues. Terry could not use his bedroom and instead slept on the sofa.

Terry referred himself to AHC in August 2019 for support to declutter and clean his home. AHC 'signposted him' with contact information for agencies via Connect to Support Hampshire. It is unclear whether Terry had access to the internet, and his fear of paying for services would have prohibited his independent use of agencies.

From 2018 to 2019 Terry worked with the landlord's older person's team to manage his possessions. This service was free, and the relationship worked well until October 2019 when Terry 'disengaged' with his support worker. Terry had agreed to two monthly support visits from the landlord, but these did not take place, he was not seen by housing association support staff or any other organisation again before his body was found in October 2020.

5.3 Case 088 - Janet

Janet died in October 2020, the day after she was discovered scalded and trapped in her own bath by a neighbour. She was 85 years old. Janet's family describe her as a sporty fun person, she made people laugh and had many friends; she could initially be shy but lively once she got to know people.

Janet's husband died in 2000 and she then moved into a sheltered housing bungalow. Janet loved to work with horses, she had been a groom and worked with the Olympic Riding team at one point. She bred and trained horses and owned a horse. After her husband died Janet worked part time on the night shift at Sainsbury's as a packer. She enjoyed the company. She had friends in the village and reliable neighbours.

Janet had three nieces who lived a distance away, they visited as often as they could and accompanied her to medical appointments etc. They had Lasting Power of Attorney for Janet's finances and her welfare. They found it difficult to support Janet to sort things out, she was proud and independent but also embarrassed and ashamed about the state of her home. She did not like her nieces to see her bungalow which was so cluttered it was impossible to cook or eat there. Janet drank wine regularly, sometimes drinking rather than eating which prompted concerns from her landlord, GP and latterly AHC.

Janet began to show the symptoms of dementia in 2019 and was diagnosed with Alzheimer's in October 2019. In May 2019 her neighbour had concerns about how she was coping and referred her to the landlord's tenancy support officer.

Janet initially declined support with the garden and property and her general wellbeing but engaged in October 2019 when fortnightly support visits began. These visits stopped in March 2020 during the national lockdown. The tenancy support officer continued to telephone Janet through this time. When visits recommenced in July 2020 the support officer identified that Janet's needs had increased, she was anxious and low, her cognition had deteriorated. Janet did not appear to be taking care of herself, she took her medication erratically, she was not eating regularly and had increased her alcohol use.

Janet's family referred her to AHC in July 2020. They raised concerns about her ability to maintain her personal hygiene, her environment was dirty and cluttered, and it was unclear how well she was eating. She was also reported as neglecting to care for herself and was hoarding items. The family also requested a shower as Janet could not get out of the bath and had been stuck in the past.

One of Janet's nieces also referred to the Fire and Rescue Service (HFRS) who conducted a Safe and Well check with her niece in attendance on 22nd July 2020. During this Safe and Well visit Janet's hoarding was assessed on the clutter rating scales as being between 7 and 9 (high), Concerns explored included Janet having dementia which might be affecting her capacity, and the levels of support she needed.

Concerns identified during the visit were discussed with Janet's niece who confirmed that she was in contact with AHC regarding help and support. Because of this the niece was encouraged to progress the concerns directly with AHC, and the Fire and Rescue service did not make their own referral.

Janet was well known at her local GP surgery and had been a patient there since 1991. She was recognised as vulnerable due to isolation, dementia and struggling to self-care by her GP who initiated eight welfare phone calls from practice social prescriber to check her wellbeing between April and July 2020, in July 2020 the funding for the social prescriber was withdrawn. The social prescriber handed over to a proactive care team who took over monitoring Janet's wellbeing. Janet was discharged from the older person's community mental health team in June 2020 as it was felt there was no longer a role for them. Janet was still driving a car despite being advised not to, it was unclear who was responsible for making sure she stopped driving. Her GP did inform the DVLA and advised Janet not to drive but this made little difference to Janet. In hindsight the GP doubts Janet had the capacity to make the decision not to drive. The proactive team undertook three home visits to Janet between July 2020 and her death in October 2020. These visits focussed on encouraging her to stop driving, help to declutter transit areas, checking her food was in date and plentiful, weighing her and trying to encourage her/her family to make arrangements for her to move out so that the kitchen and bathroom could be adapted for her.

On the 7th August 2020 an AHC Occupational Therapist (OT) visited Janet and reported that both the house and garden were cluttered, that the kitchen needed modernisation and that there was damp in house. Janet was advised to consider hiring a cleaner and to seek support from Winchester City Council in respect of a kitchen refurbishment, new shower and bath replacement. The OT followed up by making a referral to Winchester City Council on the 10th August 2020 regarding adaptations and replacements/repair of the kitchen and shower.

On the 25th August 2020, the case was allocated to an AHC social worker for a care and support needs assessment to be undertaken. The social worker spoke to Janet's niece who also confirmed that the GP surgery had also been contacted and that concerns about Janet had been shared with the proactive team. No further actions appear to have been taken, Janet was not assessed or seen by AHC before her death in October and events that would indicate an increased risk to Janet were not known.

On the 21st October 2020 Janet was found trapped in her bath by a neighbour. An ambulance was called, and she was conveyed to hospital. On the same day the ambulance trust raised a safeguarding concern to AHC regarding Janet's physical health and the state of the property. Janet died of organ failure the next day.

5.4 Barbara

Barbara 's body was found by police on 23rd November 2020, the coroner subsequently heard that she had died of natural causes related to aspirating the contents of her stomach having fallen from her chair. Conditions of self-neglect and hoarding in the house were extreme. She was 73 years old. Barbara and her husband were owner occupiers and described as 'very private people'. They lived on a remote farm.

Barbara had a trusting relationship with her GP and told him in December 2016 about how stressed she was by her husband's behaviour. She was seen five times

by the same GP in 2017 and admitted to binge drinking vodka to try to cope with the stress of being her husband's carer. Barbara attended the emergency department in July 2017 with gastritis related to her alcohol intake, she was advised to reduce her drinking and contact counselling services. Barbara told her GP in June 2019 that she had reduced her drinking and was able to have a glass of wine very occasionally. Barbara may have not had the time or motivation to engage with the specialist podiatry service, cancelling her appointment in May 2019 without making a new one.

The ambulance trust made three referrals regarding concerns Barbara and her husband's self- neglect, the first in August 2019. In this referral the ambulance trust reported that the house was '*very dirty with large piles of rubbish/accumulated clothes etc. very old and? unsafe wiring and electrical appliances. Walls are all covered in mould stairs are extremely steep with very narrow treads - unable to put a whole foot on each step, very difficult to extract patient or escape safely in a fire Incident'*

The referral was sent to Hampshire Fire and Rescue Service and Hampshire MASH on 14th August 2019 but neither organisation have identified that they received a referral in respect of the couple.

On 23rd October 2020 the ambulance trust submitted a second referral having attended the house and conveyed Barbara's husband to hospital. They again referenced self-neglect and hoarding issues noting that the couple did not want any support but that the toilet was not being used but was full of bags, and there was 'a large amount' of faeces around the house which was very cold. An AHC duty worker followed this concern up with a telephone call on the 2nd November 2020 to Barbara who said that she could cope with her husband's discharge from hospital and would be lighting the Rayburn to warm the house, a new mattress had been purchased and Barbara would be sleeping downstairs. Despite the information in the ambulance trust referral Barbara 's self-report was accepted at face value and her husband was discharged home.

On the 3rd November 2020 a friend of Barbara telephoned the GP surgery as she was concerned that Barbara was not coping with her husband's care. The GP rang Barbara who admitted that she was struggling with managing to look after her husband following his discharge from hospital the day before. She said that she had initially refused any additional help when asked prior to his discharge home as she thought she would cope but was now asking for someone to help with his washing/personal care at least once a day. She informed the GP that he was mobile and was able to get onto the commode but needed help with his toileting needs. She wanted to continue to help care for him at home but now acknowledged that she needed extra support.

The GP agreed that she would organise reablement care for Barbara's husband as soon as possible by involving the care navigator at the surgery. GP1 then spoke to the care navigator that day who contacted Barbara that afternoon and also made a same day referral via email to the re-ablement team at AHC. The care navigator also posted a copy of Wiltshire Farm Foods to Barbara. The care navigator contacted AHC the next day as the couple had not been contacted by reablement services. AHC had not received the referral and so the referral was made again on the phone.

What happened next is confusing, Barbara told the care navigator at the GP surgery that reablement services had been in touch and would start as soon as possible. AHC have recorded that reablement was declined but later on the 4th that *'carers would have to be sourced'*. Barbara appears to have followed this up with AHC herself on the 5th November 2020, she wanted support but was worried about payment.

She was told that it might take some time before someone was allocated to complete a care and support needs assessment. During this period the relevant team was absorbing an increased workload following the restructure of AHC services so waiting lists were longer than usual. Somehow the GP request for '*same day reablement*' services had been lost.

On the 10th November 2020 the care navigator contacted Barbara by phone again at to discuss attendance allowance and posted an application form to her. Barbara informed the care navigator that her husband was much brighter in himself and eating better.

The ambulance service attended Barbara's husband again on the 12th November 2020, he had been home for ten days. The crew submitted a safeguarding concern reporting that his commode had not been emptied and there were faeces all over his bedsheets. The house was cold and smelt of mould, there was mould in Barbara's hair, both appeared unclean and unkempt. Barbara's husband's bed could not be fitted into the bedroom and was half blocking the doorway. The couple had been hoarding and there were fire risks. Barbara consented for the crew to make a referral to get some support but said that issues seen were only recent. Her husband was admitted to the acute trust.

The hospital social worker reviewed Barbara's husband's case the next day and recorded that they had not picked up any concerns. At this point the first ambulance trust referral was known, the second was not added to the system until the 19th November 2020, six days after being received. The AHC report writer found the social workers conclusions surprising as the concerns about self-neglect raised by the initial ambulance trust referral had not yet been fully explored and Barbara's husband had been placed on the allocation list for assessment.

On 20th November 2020 the hospital staff became concerned that Barbara might have dementia. She telephoned the ward every hour and was repetitive in her speech. This was followed up the same day by an AHC OT who undertook a needs assessment over the phone with Barbara's husband who was still in hospital.
He said that his wife had mild dementia and that he lacked the motivation to do his own personal care. The OT's assessment also noted that the Discharge Officer at the hospital advised that his discharge would not be delayed as he had capacity and had declined care, however he was subsequently persuaded by the medical team to accept a package of care. Health staff made a note that a hospital social worker had described Barbara's husband's choices as 'lifestyle choices'. It seems that this comment was made as part of an understanding, which was shared across disciplines, that he retained mental capacity, but without sight of his actual circumstances at home.

On the 22nd November 2020 a hospital case worker spoke to Barbara's husband on the phone to discuss the concerns raised by the ambulance trust on the 12th

November 2020. He acknowledged that the house had become quite cold and damp over the past few months. He explained that his wife has lost motivation and he could not do it on his own. The case worker discussed care and support – Barbara's husband said that he had been told that he did not have much time left and that he wanted to spend this time at home. He was understood by the case worker to have capacity for discharge planning and to have declined care and support at that time.

The case worker then called Barbara who explained that they were aware that the house was damp, and that others think it is cold, however this is the way they prefer it and do not want to change. She went on to say that there was an electric heater in each room and when her husband is back home they would fire up the Rayburn which kept the property warm. The case worker discussed the paramedics concerns around faeces on the sheets. Barbara said that she hadn't really noticed it as her husband was a very private person. The case worker raised her husband's concerns around her lack of motivation, Barbara admitted that she had been feeling low for some time and had not wanted to do the housework. The case worker advised calling the GP and Barbara said that she had tried, but that it was difficult to get an appointment, especially now (during lockdown). She agreed for the case worker to call her GP on her behalf to see if they would make contact over the phone so that she can explain how things have become for her. The case worker also agreed to see if NHS Care Navigators covered the area and if so to make a referral for the couple. The case worker updated the ward as to these discussions. The case worker was unaware that Barbara had previously been in contact with the care navigators and had asked for support from AHC to care for her husband at home.

It appears that Barbara fell at home that night. She telephoned a neighbour for help but refused the offer of an ambulance. The acute trust alerted the police the next day as Barbara had not telephoned to see how her husband was.

Police found Barbara 's body. Officers reported that on entering the property there was an overwhelming smell of human excrement and every room was completely cluttered. The officer described it as the worst case of hoarding that they had seen. The bathroom, located at the rear of the property on the first floor was unusable with domestic items in the bath, and the toilet covered in dry faeces. There was no evidence of Barbara having anywhere to sleep or wash. The lighting inside the premises was also poor, with old style sockets and dim bulbs. There were boxes of items everywhere in every room. It did not appear that the first floor was being used as items including bottles of wine and cash were placed on the stairs, which were very steep and difficult for an able-bodied person to climb. There was no evidence of Barbara having anywhere to sleep or wash.

5.5 Ashley

Ashley's body was found in his flat in October 2020, he had died some time beforehand, the cause of his death was pneumonia, he was 48 years old.

Ashley's family reports that he was the youngest brother in a family of four children, the only child of this second marriage. Separated by some years from his siblings, Ashley grew up as an 'only child'. From the age of 14 or 15 he worked in the social club that his dad liked to drink in, collecting glasses etc. He developed a taste for alcohol there and is described by his family as a 'functioning alcoholic'. His family describe him as private and independent, he held down jobs, he did not like anyone

to see his struggles. He is reported to have had no girlfriends or other relationships for years.

He did not let his family, or anyone else, into his flat, he was perhaps ashamed of the state it was in. Ashley had purchased his flat in 2006 and owned it outright. The flat was located in a block of housing association flats. Ashley's family did intervene in his life around 20 years ago when he was not coping, his flat got into a state then as well. He was hoarding beer cans, neatly tied in black bags.

Ashley appears to have had contact with environmental health in 2013 and the housing association referred him to AHC in 2016 concerned about hoarding and self – neglect. Environmental Health are reported to have been able to work with Ashley to improve the condition of his flat. Ashley was in hospital with pneumonia in 2018 and spent some time in intensive care, his family tried to get involved in getting his flat ready for his discharge, but this time he resisted their involvement.
Because Ashley owned his property the Housing Association were limited in offering him support or intervening to prevent harm to himself and his property. They also had no details of emergency contacts or next of kin for him.

Ashley seemed to be doing well from 2018 onward. He worked as a warehouseman, with shifts from 2pm until the early hours. This suited his lifestyle. During the pandemic Ashley was furloughed from his job. Ashley's networks stopped; he went weeks without seeing anyone.

The AHC out of hours service received a call on the evening of the 3rd October 2020 from the police who reported that Ashley had been in a minor car accident. He was not injured, however he said he had driven his car as he did not feel strong enough to walk. The police also reported that he was actually in no fit state to drive either. The police took him back to his flat where they found that Ashley had been seriously neglecting himself. He appeared to be physically ill. The flat had rotting food in it, the lights did not work. Ashley had been hoarding and could not safely walk around the flat. The toilet was stuffed with toilet roll and was not being used. The police reported fire and environmental risks.

The attending police officer undertook a number of referrals whilst in Ashley's flat, she called 111 with the concerns about his physical health and established that a doctor would ring him back. She contacted 'Out of hours adult services (OOH) and told them about the concerns, sending a PPN1 directly to OOH, with a high-risk assessment. The PPN1 was also sent to the Fire and Rescue Service for a Safe and Well Visit, and in addition to this the officer made a Safe and Well referral to the Fire Service on their website. The officer also completed a DVLA medical concern form. The officer asked neighbourhood police to undertake a reassurance visit and to liaise with partner agencies to ensure this was actioned. The following day an officer sent an email to the housing association regarding the above concerns. Police used this 'window of opportunity' well to make referrals and alert relevant organisations to Ashley's physical state and the conditions he was living in.

In the PPN1 the police said that they thought it unlikely that Ashley would be willing to accept help and that assertive attempts to support and help him would be needed. They were concerned about the life-threatening nature of the situation caused by the level of self-neglect if there continued to be a deterioration in the state of the accommodation. Police advised that when making attempts to call at Ashley's flat, to

be aware that there was a note on the front door which states that he is not in because he is visiting his father in hospital. This appears to have been there for some time and is believed to be a way of keeping people from trying to speak to him at his address. The police advised that "*significant perseverance should be utilised to enable this contact*".

The next day an AHC duty social worker officer tried to call Ashley, but all calls went to voicemail. The duty social worker rang Ashley's GP but was advised to email the concerns, which was done to alert them to the situation and ask if they had any knowledge in relation to his current health issues and needs. Ashley had not seen a GP for many years. The social worker was aware that at that point there was insufficient information to determine which AHC care group would be best placed to respond to Ashley's social care needs. There is no record of any response to AHC from the surgery.

The duty social worker agreed in discussion with her manager to undertake a home visit the following day and arranged to meet a colleague social worker at Ashley's address. The social worker contacted the Housing Association and sent them the photographs the police had taken of the inside of the house, advising of the home visit the following day.

When the social workers visited the next day there was no answer at the door and no sign of movement inside the property. Conscious that they had no powers to enter the property, the social workers were unsure what to do and thought it possible that Ashley was not at home. The social workers left and discussed the dilemma with their manager, later emailing the housing association to advise that they had not been able to make contact with Ashley and would write to him but were unsure what else to do. The police officer or neighbourhood team was not contacted to inform this discussion or to engage in multi-agency problem solving as to how to gain access to Ashley.

The following day (7th October 2020) Adult Health and Care decided to close Ashley's case stating that there were no indications that Ashley lacked capacity and he had not consented to the referral. Ashley was thought to be either not present or was choosing not to answer the door, he also did not answer the phone.

Ashley's GP reports that he was last seen in 2005 when he had a large swelling on the face but declined to go to hospital. He was seen in hospital for a fractured humerus in 2006 and a seizure in 2018 but was not seen for any other reason. He had been invited for a review appointment with the GP following his seizure but did not respond to this.

Ashley's flat post-mortem was full of his hoard – black bags of beer cans, letters, bills, receipts. The oldest materials (ten years old) appear to be in his bedroom which was waist high, he could not access his bed and slept in a chair. All other rooms were full of black bags with beer cans in – to waist height. He would not have been able to access kitchen or bathroom. He had no water, on investigation Ashley's family found that the stopcock that supplied water to the flat had been turned off, probably when new stopcocks were fitted, and the supplier could not get access to Ashley's flat. Ashley appears to have tried to 'contain' his addiction by packing beer cans into black bags and keeping them. His desire to keep people away from his environment extended to having no water and denying himself treatment for illness.

5.6 Kieran

Kieran died in hospital from liver disease. He was 38 years old. Kieran's family report that he was a lively and fun-loving man who had travelled the world as a chef. He enjoyed parties, people and liked to drink alcohol. He had plans to settle back in England and open his own restaurant but lacked the immediate funds. Kieran had moved in with his parents in 2017. He was diagnosed with cerebellar ataxia in 2017 which impacted on swallowing, speech, mobility and balance. Kieran also had epilepsy. He was proud and independent, he hated becoming disabled.

Kieran reported addressing his alcohol issues, he said that he had drunk half a bottle of vodka a day in 2017 but stopped all alcohol use from June 2018.

Kieran applied for a housing association flat in May 2018, he wanted to secure housing to regain independence from his parents. A report provided by Hampshire Occupational Therapist recommended a ground floor, level access property with level access shower to meet Kieran's physical needs now and in the future. Kieran was matched to a housing association ground floor, new build, adapted property in December 2019. By this time Kieran was occasionally using a wheelchair as his mobility was declining.

After March 2020 Kieran would not let his family into the flat. He said that he was afraid of COVID infection. They left shopping and meals at his door and spoke with him over the phone. He is reported to have been very depressed.

In May 2020 Kieran's father telephoned the AHC front door (Contact, Resolution and Assessment Team or CART) to request help for Kieran whose illness had progressed, he was now dependent on using a wheelchair and needed help with shopping as well as other support. CART sent Kieran's father details of the British Red Cross wheelchair service, how to register as vulnerable on Government website, and also signposted him to his GP for health-related concerns. They provided the contact number for AHC social care and OT services if further assessment was wanted, together with details of NHS check and chat service and the Connect to Support Hampshire web pages. Kieran's family contacted several of these agencies but found that there were delays in support due to COVID demand and restriction, they report feeling as if they were going round in circles trying to get help for Kieran.

Kieran's father telephoned CART again in September 2020, reporting that Kieran had begun to self-neglect, he was not eating or washing, had lost weight and become reclusive, and may be having suicidal thoughts. His GP had advised the family to contact AHC for a care package. The CART worker advised Kieran's father to re-contact GP in relation to any mental health concerns. The family concerns about self-neglect were sent onto the MASH who sent a referral to the AHC mental health team asking for a home visit or to consider arranging a MARM as Kieran was unlikely to respond to a telephone call.

A referral was sent to the AHC Mental Health team, this coincided with a re-structure within the service which included the electronic case workflow, and the referral did not reach the team. Kieran's case was never allocated.

Kieran's parents found him on New Year's Day 2021. They called an ambulance. The crew took him to hospital and also completed a safeguarding referral highlighting the following:

'Called to address as patient found on floor by family, patient had refused to allow family to help yesterday. Ambulance called today as patient on floor, confused. Lots of empty spirit bottles in flat, family state Kieran has been alcohol dependent since start of first lockdown (end of March 2020), has previously attended rehab two years ago. Family have tried of several occasions to get help and support for Kieran, still waiting for assessment currently.

Soiled clothing and bedding, faeces on floor in multiple rooms of property. Kieran found to have low blood sugar, family report he has not been eating properly. Family report Kieran has not attempted self- harm or overdose recently, but he has a large ornamental knife on bed. Family report Kieran unable to use bed, has had declining mobility and muscle wastage, family feel Kieran would benefit from physiotherapy and support'.

Kieran sadly died two days later.

6. Themes

A number of themes emerged within the analysis reports submitted by organisations in respect of each individual. These themes were explored further in three multi-agency workshops.

6.1 The impact of the COVID pandemic on people and services

Five of our subjects died during the COVID pandemic, the first lock down began on the 23rd March 2020, with subsequent lockdowns on the 5th November 2020 and 6th January 2021. Services were restricted in their responses from March 2020 onward, for a number of reasons including pressures of demand, staff sickness or self-isolation, risk management policies and the legal requirements of the Coronavirus Act 2020.

Workshop participants commented that nationally and locally people living in their own homes were thought to be safer than those in hospitals and care homes. This may have been true in terms of risk from the virus, but not in terms of the exacerbation of pre-existing risk issues. All organisations retained adult safeguarding as 'core business' but it was acknowledged that it is hard to create a multi-agency safeguarding response when organisations were under such severe pressure. As the pandemic progressed organisations and their staff became more experienced in both risk mitigation and awareness of risk in the community. We noted that we need to continue to be aware and creative in addressing risk, when 'business as usual' will return for many organisations is uncertain as the pandemic is ongoing.

The high-pressure conditions people were working in within acute trusts and other organisations supporting hospital discharge in November 2020 may have contributed to the misunderstanding and lack of communication between GP, AHC, and acute trust when negotiating Barbara's husband's care and support.

The people considered by this SAR were already isolated or at risk of isolation. During the pandemic lockdowns they lost the support they had or were isolated from friends and family or furloughed from work.

Pre and during the pandemic the SAR subjects who lived in social housing had access to more support and observation than those in owner occupied housing.

The SAR subjects who had pre-existing alcohol issues escalated in their use of alcohol or may have returned to a pattern of drinking to cope with challenging times.

Two of the subjects had not seen their GP for years, but two of the women in the cohort did continue to see and communicate with their GPs who used a number of strategies to offer support including use of social prescribing resources to provide telephone support, arranged visits from a proactive nursing team and support from the care navigation team to arrange post discharge care.

Workshop participants noted that whilst the reliance on technology to communicate was effective for day-to-day issues, people who were self-neglecting and/or experiencing a decline in mental or physical health needed face to face encounters to appreciate and empathise with their situation. It was hard to use a person-centred approach without seeing the person. AHC maintained visits at home where there were safeguarding concerns and a visit was required to ensure the person's safety whilst factoring in clinical risk. Research[1] has begun to emerge about social work responses to self -neglect during the pandemic, emphasising the importance of using 'professional judgement' when working remotely and the importance of face-to-face visits to people who are self-neglecting, the need to rely on reports from trusted organisations and the increased ease of multi-agency meetings on virtual platforms.

After a low level of referral, an increase in referrals of safeguarding concerns was noted nationally[2] as restrictions eased during May – July 2020, together with an increase in referrals from emergency services and an increase in self-neglect, as well as domestic abuse, referrals. Due to the unprecedented nature of the pandemic the interpretation of data is tentative, but similar trends were recounted in the Hampshire workshops. Within the national surveys referrals about self-neglect were often made about people who were visited by volunteers and identified as 'clinically vulnerable'[3]. The five people we considered who died during the pandemic where not deemed 'clinically vulnerable'.

Workshop participants considered how we might identify people who may be at risk of life endangering self -neglect, a difficult task given the disparate nature of our group and their networks. Suggestions included a GP held 'white board' list of people with dementia living alone, identification on a person's health notes, for example 'dementia: self-caring;' housing association landlord central list of people known to self-neglect and /or misuse alcohol. Services for adults do not have the same

[1] Manthorpe, J; Harris, J; Burridge, S; Fuller, J; Martineau S; Ornelas, B; Tinelli, M and Cornes, M (July 2021) *Social Work Practice with Adults under the Rising Second Wave of COVID-19 in England: Frontline Experiences and the use of Professional Judgement*. BJSW Vol 51 no 5 pps 1879-1896.

[2] https://www.local.gov.uk/publications/covid-19-adult-safeguarding-insight-project-second-report-july-2021#part-8-themes-around-safeguarding-in-a-pandemic

[3] https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19

opportunities as children's organisations to identify the majority of children through school attendance, our approaches will need to be multi-factorial and underpinned by commonly agreed 'red flag' or risk indicators. For some groups of people, particularly owner occupiers or those in the private rented sector who do not see primary care services we will be reliant on emergency services to raise concerns.

A useful suggestion as to how to create a 'high risk' register in teams can be found with the Hampshire guidance[4] on multi-agency risk management framework or 'MARM'.

6.2 Engagement

Organisations had difficulty in engaging five of the people in the SAR group, although she did not like people in her home Janet was easily seen face to face and at home. Through examining the potential for organisations to engage with each of the five people numerous opportunities could be identified. Positive working relationships could be made with Amanda, as long as they were outside her flat, Terry was ambivalent about losing control of the things that were important to him, but wept when he was first offered support, the first time someone had 'taken an interest' in him. Terry engaged well with his housing support officer who appreciated his perspective and his need to be in control of how items in his flat were disposed of. Kieran had an engaged and concerned family, Ashley also had a family although their contact details were not known to his landlord or any other agency. Ashley also appears to have been very ill and may have been willing to accept support as he had in the past when very physically unwell. Barbara was ambivalent about support but prepared to ask for help with the support of her GP and care navigator.

Good information gathering will help to identify what type of engagement a person can tolerate initially, who is in their network who may be able to help, whether their current circumstances mean that they may be more open to support than in the past. Workshops participants emphasised the importance of a creative approach to engagement, for example letters may be hard to read, frightening or added to a pile of unread mail. We may need to make joint approaches with the referrer, many referrers who adopt an 'outreach approach' spoke of the frustrations of being 'stuck' between a person who has consented to referral but is ambivalent and an agency who does not visit in person or jointly. Referrers will need to remain involved in order to facilitate engagement. Practitioners may well need to meet outside the home initially. Systems and workflows are needed that can 'flex' to help services to engage with the person, for example visiting a person rather than sending appointments, working outside of usual hours to secure engagement, extending the expected time taken to work with a person. These adaptations are consistent with a personalised 'making safeguarding personal' approach.

Workshop participants noted that organisations sometimes disengage on the basis of assumption about a person's situation. This can be about a belief that a person is making a 'capacitated choice' and not considering the impact of addiction, mental health or trauma on how the person is living their life. If organisations are reporting that a situation of self-neglect is high risk services cannot disengage on

[4] 4LSAB (2020) *Multi-Agency Risk Management Framework* 2020 pages 20-21

the assumption that the person is making a capacitated choice to refuse support. AHC responded quickly to police reports about the life-threatening nature of Ashley's environment and health needs. But when visited Ashley did not answer the door.

His GP was contacted as was the social landlord, but not the police officer who made the referral and witnessed Ashley's situation first-hand. A management decision was made to write to Ashley and close the case on the basis that Ashley did not consent to the referral, was thought to have mental capacity and may not wish to see a social worker. People have a right to privacy (HRA article 8) but also a human right to life (HRA article 2) and freedom from degradation (HRA article 3), including degradation caused by their own behaviour. Given the severe nature of risk reported by the police the inability to access Ashley could have been considered with the police and social landlord further. Practitioners need clear guidance on risk and rights in order to resolve the ethical challenges of balancing a person's rights to privacy with the duty of care to uphold all human rights including the right to life.

Bray et al (2017)[5] remind us that practitioners who work with people who self-neglect may struggle to manage the tensions between respect for autonomy, self-determination and the legal duties to safeguard and protect, which can then result in practitioners failing to employ respectful challenge and concerned curiosity.

It is important to establish who is part of a person's network. We need to be aware of the relationships between the person and family members, or practitioners from other organisations. Janet's family had a lasting power of attorney for both her finances and her welfare, expectations were made that they could influence Janet's behaviour but they were as unable to as were other organisations. Amanda was afraid of the police although she frequently reached out to them. Whilst Terry and Ashley had not seen a GP for years, Barbara did and had a trusting relationship with her GP at the time. It is important to understand what their network means to the person.

The review explored resources that can support engagement with people who are at risk of the consequences of self- neglect. Advocacy can be a key support to efforts made to engage with the person by introducing a neutral person whose purpose is to understand and promote the perspective and voice of the person who organisations might find hard to engage.

Lastly the review explored potential 'windows of opportunity' for engagement in the six SAR case studies. Good information gathering at the point of referral can help to identify windows of opportunity as can the recognition of a window by all services encountering the person. Valuable opportunities can be presented when a person is out of their usual environment and in hospital, or is very ill and recognising the need for help, or when the fire officer or emergency service has managed to get inside the door. The person may also make their own approach for support. The window of opportunity was recognised by police officers attending Ashley who responded proactively, alerting the relevant organisations and trying to get help to him at that same time.

[5] Braye, S., Orr, D. and Preston-Shoot, M. (2017), "*Autonomy and protection in self-neglect work: the ethical complexity of decision-making*", Ethics and Social Welfare, Vol. 11 No. 4, pp. 320-35

We need to be prepared to use these opportunities, workshop participants thought it would be useful to develop training and mentoring to promote confidence in recognising and responding to 'windows of opportunity'.

6.3 Professional curiosity and legal literacy

Professional curiosity protects practitioners from making assumptions about what is happening in a person's everyday life, how and why they make decisions, what is important to them[6]. In the cases of all six people an assumption was made that they were capacitated and making a choice about how they lived their lives. The powerful influences that may have affected their behaviour, childhood or adult trauma, addiction, shame about environment and circumstances, grief about increasing disability, fear of loss of control, were not recorded and do not appear to have been considered. We were reminded by a participant in one of the workshops of the powerful consequences of shame, and how these emotions can ultimately lead to self-harm (in women) and suicide (for men).

The assumption was made that the six people considered by the SAR had the mental capacity to make decisions about their own safety or support. Only Terry had a formal assessment of capacity recorded in 2016 which then appears to have informed decisions about his capacity in 2019. Janet's capacity to make a decision about stopping driving was not assessed, a potential risk to herself and to others.

If we focus on a person having decisional capacity, we will not understand the person's ability to carry out their decision (executive capacity) and what prevents them from doing this. We will not understand why the person will continue to neglect themselves and will limit practitioner's confidence in using professional curiosity and respectful challenge. Practitioners can be fearful of limiting a capacitated person's 'right to make unwise choices' and this common misconception of the Mental Capacity Act legislation[7] is quoted in some of the guidance adopted by HSAB[8] although explained more clearly in other HSAB guidance.[9] The idea that adults have 'a right to make an unwise choice' has gained currency nationally in practitioner thinking and training, we must remember that the actual Mental Capacity Act legislation says that '*A person is not to be treated as unable to make a decision merely because he makes an unwise decision*[10]*'.* It does not afford such a right to a capacitated person; indeed, a local authority has a duty to assess the care and support needs of a person (Care Act s11) if it believes the person is experiencing, or at risk of, abuse or neglect. Barbara's husband was thought to have capacity to make a decision about his care and support needs whilst in hospital, referrals had already been received at that point indicating a high-risk neglect/self-neglect in the household, and a belief that Barbara had 'mild dementia'. The section 11 duties would apply in this case but were not considered pre-discharge as the risks referred were not included in any assessment.

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[6] Thacker, H; Anka, A; Penhale, B (2019) *Could curiosity save lives? An exploration into the value of employing professional curiosity and partnership work in safeguarding adults under the Care Act 2014* The Journal of Adult Protection Vol. 21 No. 5 2019, pp. 252-267

[7] https://www.communitycare.co.uk/2019/06/28/misinterpretation-unwise-decisions-principle-illustrates-value-legal-literacy-social-workers/

[8] 4LSAB (2020) *Multi-Agency Risk Management Framework* 2020 pages 6 and 8

[9] 4LSAB (2020) *A multi-agency framework to support decision making in relation to adult safeguarding concerns*).

[10] Mental Capacity Act

Health staff reported to AHC that hospital social workers said that Barbara's husband was making a capacitated 'lifestyle choice'. Such a phrase, commonly used, implies a freedom of choice, but without professional curiosity we cannot know whether people are truly choosing to live in circumstances that damage their wellbeing or whether they are restricted by the duress of others, addiction or powerful feelings of shame or fear.

Legal literacy, as well as good training opportunities, managerial supervision and manageable workflows, will support practitioners in being curious and empathetic to what may lie behind a person's decisions. The principles of proportionality and duty of care together with the confidence to understand and balance the person's Human Rights can usefully inform thinking about our responses to the person's decisions.

6.4 Alcohol misuse

Government surveys have indicated that people who were already heavy drinkers accounted for much of the increase in alcohol consumption during the pandemic. In 2020, there was a 20.0% increase in total alcohol specific deaths compared to 2019[11]. All six of the SAR subjects misused alcohol. Ashley and Kieran appear to have misused alcohol whilst isolated, as a long-term heavy drinker Terry may have also done so. Barbara, who previously used support to reduce her binge drinking, was drinking alcohol whilst her husband was in hospital and potentially to cope with his care. Her forgetfulness and the repetitive nature of her speech was thought to be a sign of dementia, reinforced by her husband's comments about her. However, she had no known cognitive impairments. Janet appears to have been drinking alcohol rather than eating, it is not known whether alcohol contributed to the incident in which she died. Amanda used alcohol potentially to cope with trauma and mental ill-health.

The Inclusion[12] representative at the workshops reminded us that alcohol misuse occurs at any age and in any circumstance. Older people may have addictions with consequent increased risk to their health and safety by using a toxin whilst already cognitively impaired or frail.

We asked workshop participants to consider how confident they felt about talking with people about their alcohol use, the impact it has on their lives and what they may need to support them to reduce/stop drinking. We recognised that in some cases there were windows of opportunity when for example a change in circumstances might make it more possible for an adult to contemplate using support to address their addiction, and that we need to be ready to use those opportunities when they arise. Terry's admission to hospital for three weeks in July 2018 is one example of a significant 'window'. He told hospital staff about 'high alcohol use' on admission and did not drink alcohol during his time in hospital. No referral was made to the hospital specialist alcohol nurse to initiate a discussion about further support, the acute trust has learned from this and now highlights the importance of referral to the specialist nurse whilst the person is sober and an in-patient.

[11] Public health England (July 2021) https://www.gov.uk/government/publications/alcohol-consumption-and-harm-during-the-covid-19-pandemic/monitoring-alcohol-consumption-and-harm-during-the-covid-19-pandemic-summary

[12] NHS Inclusion Recovery Hampshire, find out more at https://www.inclusionhants.org/

Health staff generally felt confident about asking questions about alcohol use, it is often part of a general health needs screening process. But they did not feel confident about following up disclosures or how to find support that would engage and motivate the person. Outreach workers in housing organisations did feel confident, but other housing colleagues less so. If an opportunity was identified some organisations did not feel prepared to initiate a discussion about alcohol use and would welcome further training to enable them to do so, including training to understand the impact of alcohol use on the person's specific circumstances and how to understand this in the context of risk.

Following Dame Janet Black's reports on substance misuse[13] organisations like Inclusion have been given a financial uplift, welcome after years of restriction. Inclusion offers free training and advice and have also been able to re-establish an outreach service.

Workshop participants identified that they struggled to assess mental capacity when people misused substances. We identified good practice, to assess when the person is not intoxicated, and also discussed the importance of understanding executive capacity and the impact of addiction in this context. Good practices in the proportionate and confident use of legal powers to safeguard 'highly vulnerable' and dependent drinks are detailed in recent guidance[14] and include many of the themes explored within this SAR.

6.5 Making Safeguarding Personal

Health and safety requirements during the pandemic meant that many people were not seen face to face and /or their living situation was not known until emergency services entered their household. This happened on two occasions regarding Barbara's husband. Although referrals had been received from the ambulance trust by November 2020 which indicated high risk neglect/self-neglect within the household these were not responded to as 'safeguarding concerns 'necessitating a home visit. Barbara and her husband were spoken with over the telephone and he was thought to have capacity to make a decision about his own needs, but this assumption was uncertain without a face-to-face assessment or engagement with him or his wife, or exploration of his ability to discuss and plan for the risks both were facing.

In the months before they died reports about the circumstances some of the people were living in were reported by emergency services, however Amanda and Barbara 's self-reports were relied upon to determine the condition of their environment and the reports from emergency services were either lost (Amanda) or discounted in terms of the severity of risk (Barbara). Even outside of the pandemic restrictions it can be hard to gain access to a person's property, especially if they feel shame or are afraid that matters will be taken out of their control. In these situations, we must rely on the reports of other organisations about the level of concern. Whilst Making Safeguarding Personal approaches say that good practice is to see the person and use a person-centred approach, we must acknowledge that there can be

[13] Dame Janet Black 2020 at https://www.gov.uk/government/publications/review-of-drugs-phase-two-report
[14] Professor Michael Preston -Shoot and Mike Ward (2021) *How to use legal power to safeguarding highly vulnerable dependent drinkers* Alcohol Change find at https://alcoholchange.org.uk/publication/how-to-use-legal-powers-to-safeguard-highly-vulnerable-dependent-drinkers

circumstances in which we need to press forward with an enquiry which supports engagement whilst beginning to plan for risk mitigation.

The appointment of an advocate for the person can increase the potential to engage the person and make sure their voice and perspective is heard. The barriers that the six SAR subjects experienced in accessing care and support are now appreciated in hindsight, but we need to understand these in the moment when risks to the person's wellbeing and life itself is high. Local authorities have a duty[15] to commission an advocate if the person appears to have 'substantial difficulty' in being involved in their own safeguarding. The barriers to engagement experienced by the six people within the SAR may have been mitigated by the appointment of an advocate were these people to have been considered under the s42 duty.

6.6 How is self-neglect and hoarding understood?

Workshop participants noted that they felt more confident in identifying hoarding behaviour than behaviour that may indicate self-neglect. This lack of confidence extended to feeling unsure about the early indicators of self-neglect which may initiate a preventative approach, to the signs of risky self-neglect which would require a multi-agency response. Participants would welcome clear guidance and a toolkit. Participants felt that the topic of assessing risk in situations of identified self-neglect was also lacking '*I do not know what the risks are in self neglect*' and '*I do not know when the risk is high enough to refer to adult safeguarding'*. The referrals made about the self-neglect of Barbara and her husband, Amanda and Ashley indicated high risk self-neglect, factoring in the health status of those concerned and the descriptions of their environment, high levels of fire risk and physical health deterioration with no evidence of a current ability to self-care. The referral made about Kieran by his family indicated that he was no longer eating or self-caring and depressed. These referrals described likely imminence and high impact. They were about the inability to meet basic needs, eating, keeping warm, having a place to wash or sleep. Whilst Ashley's referral was understood and an immediate response attempted, Barbara and Amanda's referrals were not directed down an assured route for high-risk situations related to people with care and support needs, that of the s42 adult safeguarding duty.

6.7 Making referrals

As indicated above workshop participants were not always sure that the indicators and risk they observed were appropriate to refer to the local authority to decide whether the section 42 duty applied to a person who is self-neglecting. Report authors from organisations who had longer term connections with the person, GP surgeries and social landlords, thought that they should have convened a MARM meeting. Although aware of MARM none had taken this step. Some participants were also confused about whether they could refer without the person's consent and in what situations they should do so.

Decision makers in AHC and MASH talked about the pressure of workflow and high volume of concern referrals which do not contain enough information to enable the initiation of information gathering or identify the potential for the need for the s42 duty. In terms of self-neglect further work is needed to enable referrers to clearly and

[15] Care Act 2014 section 68

confidently identify and detail concerns. Referrals sent by emergency services did contain good detail to indicate the level of potential risk, and the recording of Kieran's parent's referral also appears thorough. Absence of detail within the referral was not the reason for non-consideration of the s42 in these cases.

A recurrent theme is that of transition, either inter- organisational, between organisations or as part of organisational restructuring. Kieran is perhaps the starkest example, at the end of September 2020 his parents referred him to AHC asking for urgent help. The referral stated that Kieran had begun to self-neglect, he was not eating or washing, had lost weight and become reclusive. The referral was triaged by MASH and the decision made that s42 did not apply but that Kieran needed a visit by the mental health community team or a MARM needed to be arranged should Kieran not engage with efforts to support him. This referral was lost during the transition work between new AHC mental health teams, as a not yet opened referral it sat in the old electronic workflow and was not picked up by the new mental health team. Kieran's parents continued to wait, mindful that services were busy during COVID.

Information lost during transition is also a theme in Amanda's case, it was assumed that the police information about Amanda's living conditions would be taken account of in her discharge from the acute trust. Whilst the referral from paramedics did not arrive at the ambulance trust safeguarding team the safeguarding information was contained in Amanda's acute trust hospital notes. This information appears to have been lost in the two transitions between acute trust, PICU and mental health trust. A vital opportunity to understand Amanda's poor living conditions and fire risk and the impact of these on her safety and wellbeing was lost.

The team Barbara and her husband were referred to once they had agreed to support was experiencing difficulty in allocating cases due to waiting lists created during a transition. Given the risks indicated in the two SCAS referrals made in October and November 2020 it might be expected that Barbara and her husband would be seen as in urgent need of allocation.

Transition, either of people or services, creates risk of loss of information and continuity of support, these risks must be addressed in any transition, whether it is of an individual or of a service.

Technological errors also affected Barbara 's referral by her GP to AHC, although these were quickly rectified, but only because the GP surgery followed up the referral.

The human error in Janet's case resulted in her not being seen by AHC for an assessment of her care and support needs for three months before her death. It is unknown what pressures were on this team, managerial oversight may have been able to identify the absence of support.

6.8 Who does the s42 duty apply to?

How the s42 duty is used with regard to self–neglect and how, self-neglect and its associated risks are understood, are areas which are problematic nationally.

A recent analysis of SARs[16] in England between 2017 - 2019 found that 45% of SAR commissioned in England during that period related to self-neglect. Despite this learning, how best to work with people who self-neglect continues to challenge adult safeguarding partnerships. The themes that we have identified within this cohort of people are repeated in research drawing on other SARs in England[17], including the importance of professional curiosity, of understanding and using legislation correctly, the risks around transition and need for flexible and creative partnership working.

An interesting feature of these six cases has been the absence of use of the local authority s42 duty in relation to referrals where risks are reported to be high, i.e., the person is not eating, is cold, is unwell or frail, there are fire or other life-threatening risks in the environment.

We explored this aspect of the cases within the workshops by thinking through whether the section 42 duty applied to the people within the SAR and if so what processes were then used. Current statutory guidance[18] advises us that '*it should be noted that self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case-by-case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support'.* (DHSC Chapter 14.17)

To apply the criteria used to determine the s42 duty: Was there are reasonable suspicion that the people in the SAR had care and support needs? Were they at risk of or experiencing actual abuse?[19] The lead reviewer would argue that the six people considered within this SAR met the criteria for the s42 duty. In addition to the range of care and support needs these people had (physical disability, mental health issues, addiction and cognitive impairment) their hoarding behaviours and self-neglecting behaviours demonstrated a risk of or actual abuse. Participants in the workshops reported a risk of decision makers thinking that self-neglect is not as 'serious' as or different from other forms of abuse because it is self-inflicted, there is no third party involved.

The third criteria for use of the section 42 criteria is about the person's ability to protect themselves, and in the case of self-neglect this is termed in statutory guidance as '*the ability to protect themselves by controlling their own behaviour*'. In the cases seen an emphasis was put upon whether the person had capacity to make decisions, and in all cases it appears to have been presumed that they did. Having the mental capacity to make decisions about behaviour is not the same as having the ability to protect oneself or control one's own behaviour. The concept of executive capacity or put simply, the degree to which addiction, mental or physical

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[16] Preston-Shoot, M; Braye, S; Preston, O; Allen, K; Spreadbury, K (2020) *Analysis of Safeguarding Adult Reviews April 2017 – March 2019*. Local Government Association. at https://www.local.gov.uk/sites/default/files/documents/National%20SAR%20Analysis%20Final%20Report%20WEB.pdf

[17] PRESTON-SHOOT, M., 2017. *On self-neglect and safeguarding adult reviews: diminishing returns or adding value*? The Journal of Adult Protection, **19**(2), pp. 53-66.
Preston-Shoot, M. (2016) '*Towards explanations for the findings of serious case reviews: understanding what happens in self-neglect work*,' Journal of Adult Protection, 18(3), 131- 148.
Braye, S., Orr, D. and Preston-Shoot, M. (2015) '*Serious case review findings on the challenges of self-neglect: indicators for good practice'*, Journal of Adult Protection (17, 2, 75-87).

[18] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1

[19] Care Act 2014 section 42

health, trauma etc. stops the person acting on their decision, must be understood in each circumstance.

The statutory guidance says that '*An assessment should be made on a case-by-case basis',* it does not say that other routes should be attempted before the decision that the s42 duty applies is made. Had the decision been made that the s42 duty applied to any of the six cases within this SAR the loss of referrals, absence of multi-agency working, lack of urgency or escalation may have been avoided or minimised. When a person appears to be frail or physically/mentally unwell and is presenting with risks that are life endangering that they struggle to overcome the s42 duty will apply.

In Hampshire two other routes are used to support people who are self-neglecting. In situations where there are likely to be low impact outcomes allocation to a community team for a care and support needs assessment is useful. It should be borne in mind however that there may be, as with Barbara and Janet, a wait for the assessment. If a person appears to be at great risk the section 11 'refusal of assessment' duty[20] must be considered, but high-risk situations as described in referral need to be considered under the s42 duty. Discovering whether the situation is as risky as described initially will be ascertained via information gathering under s42(1) and/or enquiry under s42(2).

The second route promoted in Hampshire is to convene a Multi-Agency Risk Management (MARM) meeting. These meetings are underpinned by rigorous guidance[21] which supports the person's involvement and multiagency co-operation in problem solving or risk mitigating with the person and utilises the HSAB resolving professional differences escalation pathway. The MARM guidance[22] used in Hampshire does say that it is useful:

'*to any professional who is working with adults experiencing an unmanageable level of risk as a result of circumstances which create the risk of harm but not relating to abuse or neglect by a third party such as …b) Self-neglect including hoarding and fire safety' …… e) On-going needs or behaviour leading to lifestyle choices placing the adult and/or others at significant risk f) Complex needs and behaviours leading the adult to cause harm to others. (p.3)*

The guidance explains that '*MARM, differentiates itself from the statutory s42 enquiry process which is intended to respond to a specific incident sometimes at a point of crisis, when specific statutory criteria are engaged. However, there are common themes across the two processes for example, both processes are responding to risk and each is built on the same principles and value-based themes promoting prevention, person-centred working, developing personal resilience, effective partnership working, strength based and a whole family approach and Making Safeguarding Personal'.*

[20] Care Act 2014 s11 Section 11 – **Refusal of assessment**
(1) Where an adult refuses a needs assessment, the local authority concerned is not required to carry out the assessment (and section 9(1) does not apply in the adult's case). (b) the adult is experiencing, or is at risk of, abuse or neglect.
[21] 4LSAB (2020) *Multi-Agency Risk Management Framework* 2020
[22] Ibid.

Although the MARM process is aligned to the Care Act it is not underpinned by statutory duties including the duty to cooperate or indeed the s68 duty to commission advocacy when a person has no representative and would experience substantial difficulty in being involved in their own safeguarding.

The guidance has perhaps contributed to a culture where self-neglect is not thought of as something which sits under the s42 duty but is dealt with using other arrangements for multi-agency or single agency working. MARM may well be useful for preventing harm, but it appears unclear both in practice and guidance when harm constitutes a crisis and has reached a point of imminent and high impact.

We must reiterate that an adult who meets the criteria for use of the s42 should be considered under the s42 duty. That does not necessarily mean that other steps cannot be taken, but that there is a clear and robust process for information gathering, decision-making and communication.

6.9 Making decisions

'Front-door' decision making teams must gather information and make decisions quickly in environments that are pressured. The demands made on such teams existed prior to the COVID pandemic, however we noted that in July 2021 CART had 18,000 contacts and the Multi-Agency Safeguarding Hub (MASH) 1,600 decisions to make about the s42 duty. It is difficult to make good decisions in environments that are overwhelming. Detailed referrals are vital, together with external referrers who make themselves available for follow up discussions and can provide further detail, facilitate joint visits or undertake follow up actions.

Workshop participants made a number of observations about how processes used that might influence which route is taken regarding referrals about self-neglect. Use of the s42 duty means initiating a module on the electronic recording system, which is cumbersome, referring for a s9 assessment or a MARM is quicker to do, and practitioners will still believe they are using the best approach to supporting a person who is self-neglecting.

If the s42 duty is accepted a process of information gathering will be initiated which will not only explore who is involved with person and begin to understand their relationships with formal and informal supporters but will also look at historical information including referrals and historical risk. This activity under s42(1) will inform the next steps, from a considered perspective which includes a risk assessment rather than a reaction to the label 'self-neglect. It is sometimes only when we begin the process of enquiry or ask another agency to enquire under s42(2) that we can understand what is happening and how the person struggles to act on decision making.

Decisions in the six cases to signpost or refer on to other organisations were not always underpinned by good information gathering. Families (Kieran) or individuals (Terry) who referred either themselves or their relative were signposted to other services by the AHC front door (CART). Janet was signposted by the OT who undertook an assessment of her needs. Signposting is often a useful response which enables people to remain in control of their situation. However, from looking at the case studies workshop participants suggest there are a number of considerations that need to be made before the person is directed onward:

Make sure that the person is able to use the pathway they are directed to – do they have the cognitive and physical ability to make connections with other organisations, to self-refer? (Janet)

Make sure that the person is able to access the internet and/or has a working telephone in their home. (Terry)
Look for historical records which might indicate previous concerns and highlight the 'window of opportunity' that has opened via a self-referral? (Terry)

Look for factors which may impede the person or their family in accessing support from other agencies? Concerns about money? (Terry) Diminishing influence between family and person? (Kieran/Janet)

Similarly, when a person with concerning presentations is directed to their GP for support it is important to understand whether the person sees their GP. Terry and Ashley had not seen their GP for years, Amanda could not be contacted by her GP. Janet and Barbara had positive relationships with the GP and primary care services. Referring on to primary care may make sense in terms of presenting need but will not be effective in situations where risk is known and the person does not go to the GP surgery.

6.10 Multi-agency working

There were no multi-agency arrangements in respect of the six people. There may have been a Care Programme Approach (CPA) in place for Amanda which can also support multi-agency working.

We discussed how multi-agency working could have been facilitated with our SAR subjects. We reflected on how multi-agency working must be supported by a framework to provide leadership and coordination, enabling organisations to move beyond eligibility criteria and silo working to a position of shared responsibility. Whilst shared responsibility is productive, shared ownership can lead to chaotic responses.

Use of either the s42 duty, MARM or in Amanda's case CPA, could have provided a framework for partnership working and shared responsibility. Participants at the workshops found it easier to formulate a response based on a common understanding of legislation and procedure enabled by multiagency discussion.
As well as a framework around multi-agency working participants thought that having a common language with which to describe risk was important, they welcome clarity on what the indicators might be for high risk in different circumstances and when a safeguarding concern referral should be considered. This clarity is consistent with recent suggested guidance on supporting effective outcomes in adult safeguarding[23].
Access to each other's expertise was valuable at all stages, from local authority

[23] LGA (2020) *Understanding what constitutes a safeguarding concern and how to support effective outcomes page 30* at https://local.gov.uk/sites/default/files/documents/25.168_Understanding_what_constitutes_a_safeguarding_07.1.pdf

decision makers trying to understand health terms, to all organisations having access to specialist advice about addiction or fire risk.

We spent some time looking at 'feedback loops' in the light of how agencies communicated with each other in the six SAR cases. Fire and Rescue services were most often asked to visit, assess and advise the people and did so in two cases. The Fire and Rescue Service continue to review the closure of its feedback loops, to ensure that feedback is provided to the most appropriate agency. i.e., the police may refer but the feedback goes to AHC who will need to be aware of care and support needs or safeguarding risks.

Amanda's GP told AHC that Amanda could not be contacted with regard to her deteriorating mental health. No actions appear to have been taken regarding this, but it is assumed that the information would be kept on Amanda's records should a referral to the GP be considered.

When referrals were made to other organisations there was no follow up form CART or MASH as to what the outcome of the referral was. Participants noted that we should not assume that another organisation can engage someone that we or the referrer is finding hard to engage and in situations of specific imminent risk (e.g., fire) we should ask what happened as a result of our referral.

The concept of a caused enquiry may be helpful, if someone meets the s42 duty the local authority can cause any organisation with the appropriate role to enquire and will require a report on the outcome of that enquiry. Hampshire tend to use caused enquiries with provider services but can ask a range of services to enquire including Fire and Rescue and housing colleagues.

On several occasions within the case studies organisations made safeguarding referrals but did not know the outcome (Amanda/Terry/Ashley). The attending police officer asked to be made aware of the outcome of the referral about Ashley, but this did not happen. We discussed a proportionate approach to feedback as some agencies, including the police and ambulance services risk being overwhelmed by feedback on people that they may not see again. Emergency services would favour an approach were they could indicate that they wanted to know the outcome of the referral for a specific case. This would assist local policing teams who may encounter the person frequently (Amanda) or are extremely concerned about the person and may need to escalate (Ashley). It was noted that police neighbourhood teams can feel discouraged by the absence of follow up and dialogue with the local authority. GP participants wanted to know the outcome and rationale for decision making so that they could continue to be the lynchpin for a person's health and wellbeing. Landlord colleagues felt the same, they are usually very aware of risk to the person and risk to others in the same property and will continue to monitor and try to engage the person. If an organisation does not know the outcome of a referral it cannot provide further information or escalate if it believes that the decision is wrong.

To work together successfully as a multi-agency partnership, we need to be aware of each other's skills, role and responsibility. Fire and Rescue participants noted that the 'Safe and Well 'service had existed for fifteen years but there were still organisations unaware of their work. Participants were not all aware of the potential

for advice and support for practitioners from Inclusion. With high pressures it is tempting for organisations to be siloed and keep to their eligibility criteria. Flexible and creative responses will involve organisations being clear about what they can offer to each other, and to be prepared to offer advice and support.

Workshop participants considered whether there were gaps in existing resources which could be addressed through commissioning a specific service. We were reminded that a service to support the engagement and involvement of people is already commissioned – that of advocacy.

As we have seen in this SAR landlord support services do provide effective and welcome support to tenants who are hoarding and as a result self-neglecting. A specific support service to work long term with people who need on-going support with motivation and confidence to de-clutter and self-care would be welcomed. It will be useful to ask people who self-neglect and/or hoard in Hampshire what they would find useful, for example we understand that peer support groups have been set up elsewhere and are a powerful way of overcoming feelings of shame.

7. Findings and learning points

7.1 Organisations have not returned to post pandemic 'business as usual' and it is very uncertain when they may be in a position to do so. On-going risks generated by the COVID pandemic in addition to high demand and pressures on resources and staffing may continue for the foreseeable future. It is important to create a way of identifying the individuals who we know may be vulnerable, not because of their clinical risk of COVID but because of the risks of self-neglect exacerbated by isolation, addiction or other circumstances. We can be aware and seek to prevent harm through our own organisational practice or by reaching out to volunteer or faith groups as is appropriate for the person.

Learning Point 1.
Organisations must strive to find ways to identify people who are vulnerable to self-neglect and think about how harm can be prevented during the on-going pandemic.

7.2 We must change the perception of self-neglect including hoarding in Hampshire. Through good information gathering we can identify ways to 'flex' our response to find the most positive way to engage the person. We need to understand what can motivate a person, how to confidently use 'windows of opportunity' to enable the person to begin change. We should not believe that people who self- neglect are always going to be difficult to engage. A supportive relationship which motivates and encourages the person is valuable, but the right initial approach is needed to start this work. Advocacy may support these efforts but might only be commissioned if a statutory duty or use of a multiagency forum is utilised. Consideration should be given to commissioning a specific support service to work long term with people who need on-going support with motivation and confidence to de-clutter and self-care. Lastly, people who self-neglect can be asked what they would find most helpful.

Learning Point 2.
We need to develop positive, flexible and creative approaches to engage people who are self-neglecting. We need to understand the barriers we as organisations erect to engagement rather than decide that the person has disengaged with us. We can commission advocates to support us to engage with people who are self-neglecting and commission specific support services to work alongside people to achieve longer term change. Organisations may require training and mentoring to recognise and confidently use a 'window of opportunity'.

7.3 We need to be legally literate. Understanding what the legislation and guidance we are using when working with people who self-neglect is part of changing the culture around the perception of self-neglect. There must be an understanding and an agreement about what a care and support need is, and in what circumstances we should apply the principles of the Mental Capacity Act and when we should apply the six principles of adult safeguarding, Human Rights and the duty of care. We need to clearly understand what the statutory guidance is saying about self-neglect.

Learning Point 3.
Legal literacy will improve the guidance used in Hampshire to support work with people who self-neglect and to make the statutory duties of local authorities and partner organisations clear. It will also improve the preventative and reactive responses made to people who self-neglect including hoarding.

7.4 Alcohol misuse featured in all six of the cases considered by this SAR. Practitioners across the safeguarding partnership are not consistent in their recognition of alcohol misuse and the impact of this on wellbeing, or in their understanding and confidence in approaching addiction issues or in working out plans to mitigate the risks that arise when people who have care and support needs misuse alcohol. It is uncertain whether all organisations in Hampshire recognise that an addiction that prevents the person meeting their own basic needs is in itself a care and support need.

Learning Point 4.
We must ensure that guidance on self-neglect includes guidance on working with people who misuse alcohol. Knowledge and confidence can be promoted through accessing training and advice provided by specialist alcohol services. All organisations work with people who misuse alcohol, we all need an awareness of useful approaches to supporting a person to access help, discuss and where possible mitigate risks and promote wellbeing.

7.5 Whilst we must strive to talk with a person face-to face, there are circumstances when it is not possible to either see them or their environment. We must be able to rely on referrals from organisations who have seen the person and their environment. Improved guidance on self-neglect will improve referrals. Referring organisations must leave contact details and be prepared for further discussions. In these six cases studies the urgent nature of the risks documented in

referrals from emergency services do not appear to have resulted in urgent action, with one exception, or use of the s42 duty.

Learning Point 5.
Referrals from emergency services or other organisations may be the only insight we have into a situation where a person is at high risk of harm through self-neglect. The inability to use a person-centred approach must not prevent considering and acting on the risk information contained in the referral.

7.6 The six SAR cases were used as a window through which to reflect on self -neglect in Hampshire during the learning events. Participants in these events indicated a lack of clarity about risk and self-neglect. Guidance about working with people who hoard has a clutter rating scale which supports decision making about risk. Guidance in Hampshire[24] about self -neglect contains a list of aspects to be considered in risk assessment, including 'Observation of the home situation and environmental factors' and 'Engagement in activities of daily living'. The list needs to be expanded upon, high risk behaviour in self-neglect must be explicit, for example the 'activities of daily living' in high-risk situations include not eating and being cold. If a person has a life endangering medical condition that needs medication then a high-risk behaviour might be not taking prescribed medication. Ignoring a developing pressure ulcer can be life threatening. Organisations need better tools and guidance with which to work with people who are self-neglecting.

Learning Point 6.
Single and multi-agency responses to self-neglect will benefit from a shared and commonly understood definition of self-neglect and what is considered 'high-risk' self-neglect.

7.7 Communication of information about risk broke down when either people or organisations were in transition. We need to recognise and identify the risk of vital information being lost. It may be that a practitioner is identified to coordinate the transmission of information in such scenarios.

When re-organisations are planned there must be careful and knowledgeable assessment and mitigation plans in place to prevent the loss of electronic referrals or the inability to react to urgent need. Some of the learning from this SAR should be shared with project leads across the HSAB partnership in order to help to prevent the lack of support experienced by Kieran and his family.

Learning Point 7.
Transitions can create the risk of loss of continuity and information, putting individuals at risk. Project planning must always factor in and mitigate risk to the people using services. Individual transitions are also risky, as a person moves through different services whilst in crisis efforts must be made to ensure their risk information goes with them. This may be better ensured under the s42 duty.

7.8 The s42 duty applies to people who are self-neglecting. The six cases were not thought to meet the criteria for the s42 at the time, and some were sent on to community teams for care and support needs assessment, which can be a useful

[24] 4LSAB (2020) *Multi-Agency Risk Management Framework* 2020 page 11

decision if matters are not urgent or high risk. The practice seen in these six cases,, indicated that responses from community teams do not engage multiagency partners and are not always timely or sustained. It may be that pressure or workflow demands led to cases (Amanda and Ashley) being closed so quickly.

It is unclear whether Hampshire is using an alternative pathway (MARM) for people who self-neglect and do meet the criteria for use of the s42 duty. MARM guidance would indicate that it should be used in some cases of self-neglect, but organisations who participated in the learning events and who contributed to this SAR do not appear to be confident in either a) using MARM or b) knowing when to use MARM or when the s42 duty applies.

Using a MARM instead of section 42 means that statutory duties are not engaged, neither the duty to cooperate including information sharing, nor to enquire, nor the duty to commission advocacy in specified circumstances.

The use of a multi-agency forum outside of s42 for people who meet the s42 criteria is contrary to legislation and will contribute to a culture that thinks of self-neglect as 'less serious' than abuse by a third party. The MARM should not be used regarding self-neglect that carries a high risk to a person with care and support needs. The s42 duty enables the local authority to undertake multi-agency information gathering (s42.1) and make enquiries or cause other organisations to do so (s42.2). Activities undertaken under the s42 duty should ensure that information is not lost, that people work according to the six principles of adult safeguarding, and that activities are well led and coordinated.

Learning Point 8.
If it is unclear to decision makers whether a person meets the criteria for the s42 duty information gathering under s42(1) should be initiated. This will enable a decision based on 'reasonable cause to suspect' that the person either meets the criteria for use of the s42 duty or does not. If there is still uncertainty an enquiry under s42(2) will be necessary. It may then be decided that alternative pathways or multi-agency meetings are appropriate, but only after consideration based on information gathering, not solely on the basis that the person is self-neglecting or hoarding.

7.9 Both discussion at the learning events and practice examined within the SAR highlight that the AHC front door (CART) and the MASH experience a high volume of referrals and must make decisions effectively but quickly. Referrers must appreciate the importance of detailed referrals and also maintain involvement to assist with information gathering and engagement. Adult Safeguarding is 'everybody's business.'

We have to accept that individual mistakes will be made under pressure, but we can build in supports to good practice whilst engaging with referrers to meet demand effectively together.

Learning Point 9.

Managers will need to be alert to the need for continual support to practitioners under pressure, both in the front door and MASH, and in the AHC community teams as well as partner organisations. Practitioners need tools

that support decision making and detailed referrals, the challenge to use professional curiosity and flexibility to change working practices and expectations to accommodate the need for extra information gathering or multi-agency working.

7.10 Multi-agency working was not apparent within the six cases considered by the SAR.. Organisations worked hard to provide support, but often did so as single agencies, and did not work coherently together. Multi-agency working with people who self-neglect is supported by a number of factors:

a) a framework which provides leadership and coordination and enables organisations to move beyond eligibility criteria and silo working to a position of shared responsibility.
b) a common language and understanding, in these cases about self-neglect, risk and legislation.
c) proportionately updating each other as to decisions and outcomes. Referrers cannot assist or escalate their duty of care if they are not told about the outcome of their referral, they can be given the option of being given feedback about specific cases.
d) causing organisations to undertake enquiries, so enabling the local authority to quality assure the outcomes of crucial interventions.
e) knowing and appreciating each other's skills, role and responsibility. Being prepared to advise and support each other, even if the person does not meet our organisations' eligibility criteria.

Learning point 10
Multi-agency partnerships are the powerful vehicles which underpin adult safeguarding. Partnerships will be most effective when there is a framework to support cooperation, mutual respect and a common understanding about the basic elements of good safeguarding practice.

8. Conclusion

There is so much learning in each of the six cases considered by the SAR, this thematic review has only been able to reflect and learn from the over-arching themes in the cases.

The SAR has provided an opportunity to reflect on practice, policy and procedures around self-neglect. The majority of practice occurred during a pandemic which was unprecedented in the experience of the organisations who took part in the SAR.

The SAR has given us an opportunity to stop and reflect on what we have learned so far, what happened to some of the six people reflects national trends about people who have pre-existing vulnerabilities, are isolated and/or have used alcohol and have a history of neglecting themselves.

The SAR has also questioned some practices more locally, in particular the understanding of and responses to self-neglect in Hampshire. We have reflected on the way legislation and guidance is used and how we can strengthen multi-agency practice, through the lens of tragic circumstances. Organisations in Hampshire have demonstrated commitment and creativity in consistently attending workshops and

providing reports and information to the SAR, the need to develop the way in which we work with people who self-neglect has been recognised.

9. Recommendations for SAB

9.1 Hampshire Safeguarding Adults Board (HSAB) is recommended to clarify the guidance on self-neglect and hoarding, to include;

1) What is a care and support need?
2) What constitutes an inability to protect oneself in the context of self-neglect including hoarding.
3) Circumstances in which an advocate should be commissioned.
4) Detailed guidance on risk assessment.
5) Guidance on working with people who self-neglect and misuse alcohol, including trauma informed approaches and consideration of decisional and executive capacity.
6) Professionally curious approaches.
7) Guidance on mitigating risk to individuals who are transitioning between services.
8) Once guidance is clarified HSAB is recommended to hold a learning event, and to consider other approaches, to disseminate the guidance with the purpose of changing the culture around self-neglect in Hampshire.

(LP2, 3, 4, 6, 7, 8 and 9)

9.2 HSAB is recommended to audit a sample of MARM cases to determine whether MARM is being used to address safeguarding concerns which meet the criteria for the s42 duty.
(LP 8)

9.3 HSAB is recommended to receive assurances from organisations undertaking restructuring of services that the risks to service users have been assessed and mitigated with detailed project planning and well understood approaches.
(LP 7)

9.4 HSAB is recommended to establish how partners will engage in improving partnership work with people who self-neglect including:

1) Arrangements which promote a commitment to shared responsibility.
2) Proportionate feedback and use of escalation pathways.
3) Making known and sharing skills and knowledge.
4) Implementing the core messages about partnership in the recent LGA guidance on 'understanding what constitutes a safeguarding concern?[25] will support this recommendation.

(LP 9, LP10)

9.5 HSAB partners are recommended to promote training and other learning opportunities open to all organisations on:

[25] https://www.local.gov.uk/sites/default/files/documents/25.168_Understanding_what_constitutes_a_safeguarding_07.1.pdf

1) Alcohol awareness.
2) Using windows of opportunity to engage. Making every contact count training[26] could be adapted for this purpose.
3) Professionally curious approaches, building confidence in having difficult conversations and using respectful challenge.
4) Trauma informed approaches.

(LP2)

9.6 HSAB partners are recommended to promote methods that can be used to identify people who are vulnerable to self-neglect and encourage organisations to use preventative approaches, including community resources (volunteers, faith groups) as appropriate to reduce isolation and potential harm.
(LP1)

10. Recommendations to single agencies

10.1 Inclusion is recommended to publicise training and advice arrangements for organisations in Hampshire and use the learning from this SAR to consider training and support for organisations working with people who self-neglect and/or hoard.
(LP 4)

10.2 Hampshire County Council AHC and MASH are recommended to use the s42 duty consistently to gather information under s42(1) when receiving concerns about self-neglect including hoarding. If necessary to undertake an enquiry under s42(2) to ascertain the nature and degree of risk. Only then should the most useful pathway be determined.
(LP8)

10.3 Hampshire County Council AHC and all MASH partners are recommended to review referral templates to include an indication of when feedback on decisions or outcomes is required. To also consider whether any changes are needed to encourage detailed referrals which may be the only insight possible on a person's views and circumstances.
(LP 5 and 10)

10.4 Hampshire County Council AHC and all MASH partners are recommended to identify and monitor the impact of workload pressures on responses to people who self-neglect, escalating as necessary. Managers must be confident in encouraging professional curiosity through supervision and have access to tools and approaches which will ensure robust decision making and responses.
(LP9)

10.5 Hampshire County Council Commissioners are recommended to identify a resource to provide long term support to people who need on-going support with motivation and confidence to de-clutter and self-care.
(LP 2)

[26] http://makingeverycontactcount.co.uk/

11. Glossary of terms used

AHC	Adult Health and Care (Hampshire County council, the local authority).
CART	Contact, Assessment and Resolution Centre (CART). The first point of contact for someone requiring advice from Adults' Health and Care.
COVID	Coronavirus disease.
CPA	Care Programme Approach.
CMHT	Community Mental Health Team.
DVLA	Government Driver and Vehicle Licensing Agency.
ED	Hospital Emergency Department
GP	General Practitioner (primary care doctor)
HSAB	Hampshire Safeguarding Adults Board.
MARM	Multi-agency Risk Management meeting.
MASH	Multi-agency Safeguarding Hub.
OT	Occupational Therapist.
PPN1	Public Protection Notification.
SAB	Safeguarding Adults Board.
SAR	Safeguarding Adults Review.

Appendix 1 Key Lines of Enquiry and themes (from terms of reference)

1) Demographics – age, gender, location, living situation.
2) Timeline of when concerns materialised to death.
3) Would the adult's circumstances have met s42 criteria?
4) Point at which things begin to deteriorate - duties around wellbeing, prevention deterioration of needs before crisis point.
5) Underlying physical/mental health/conditions.
6) Primary form of self-neglect and compounding factors.
7) Informal support network available, isolation.
8) Family involvement.
9) Care and support services in place/offered.
10) Involvement with primary care.
11) Which front door used.
12) Decision making capacity re wellbeing/safety.
13) How refusal or disengagement was managed.
14) Strategies used and evidence of a trauma informed approach.
15) Opportunities to detect/respond to deteriorating health and risks - missed or not available?
16) How did COVID impact on care and support provided, business continuity arrangements, effect of lockdown, service disruption, etc?
17) Multi-agency working - risk assessments and plans.
18) Evidence of MARM.
19) Risk management – timely referral to the appropriate risk pathway.
20) Escalation.
21) Reaching out for help.
22) Knowledge of how to seek help.
23) Strategies, for example, Making Every Contact Count.
24) Whether there would have been services available to meet the need of this group of people if not is this a consideration for future specialist commissioning.
25) Specialist services, practitioners to build expertise across the system.