

Introduction

Barnsley Safeguarding Adult Board (BSAB) initiated this Safeguarding Adult Review (SAR) in 2020. It followed an incident when a couple died, the man (Ian) aged 86 in April 2019 and the woman (Valerie) aged 75 in December 2019. A Housing Officer from Safer Neighbourhood Services had made a safeguarding referral in 2018, citing concerns about “severe self-neglect”, no bathroom, “a big dog that could be vicious”, and fire risk. It was converted to a request for assessment by the team manager. The case was closed after liaison with the Housing Officer without assessment having taken place, citing no access and no engagement.

In April 2019 Ian went to the Emergency Department with abdominal pain: he was unkempt and confused, and died within 48 hours of intra-abdominal sepsis.

Later that same year, in December 2019, Valerie went to the Emergency Department ‘unable to cope’ and living in squalor. She died within 24 hours of admission of pneumonia.

The couple were not the first to die of self-neglect and/or hoarding as BSAB completed a SAR into the death of Clive in 2020 and Jack in 2018. Valerie’s case was referred to BSAB by the coroner for a possible SAR. A decision was taken not restrict this Review to the usual SAR process, but instead to put Valerie’s death into a broader context: since it appeared that lessons learned in previous SARs were not translating into changing practice and that learning needs to address what had prevented the learning from the cases of Clive and Jack from making a difference in practice.

This Report therefore is organised as six main parts:

- Part 1 gives an overview of the process followed in this review
- Part 2 reviews the death of Valerie
- Part 3 draws the learning from Valerie’s death together with learning from two previous SARs, which used the pseudonyms Jack and Clive
- Part 4 describes consultations with groups within local systems and the learning drawn from them.
- Part 5 sets out learning from this SAR and good practice identified during the process of the SAR.
- Part 6 draws conclusions and recommendations

Part 1: Overview of the process followed in this Review

1.1 Introduction

The aim of a SAR is to promote learning and improvement action in order to prevent future incidents involving death or serious harm. The Care Act 2014¹ states the following:

(1) An SAB 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—

- (a) 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*
- (b) condition 1 or 2 is met.*

Condition 1 is met if—

- (a) the adult has died, and*
- (b) 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).*

(3) Condition 2 is met if—

- (a) the adult is still alive, and*
- (b) the SAB knows or suspects that the adult has experienced serious abuse or neglect.*

(4) An SAB may arrange for there to be a review of any other 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).

Part 2 of this Report provides an overview of deliberations, conclusions and recommendations from the information and analysis contained in Individual Management Reviews (IMRs) relating to Valerie and parts 3 and 4 broaden the context out by including learning from previous SARs in Barnsley and consultations with local communities of interest.

A family member kindly shared information about Valerie and Ian with the Independent Reviewer but did not want that information to be made public, so it has informed the consultations and this Report but details are not included.

1.2 Terms of reference

The learning lessons will examine

- Compliance with agreed Self Neglect and Hoarding Policy

¹ See <http://www.legislation.gov.uk/ukpga/2014/23/section/44>

(formerly known as VARMM) including risk assessments

- Examine the effectiveness of multi-agency information sharing and joint working
- Evaluate if the learning from previous SARs/ lessons learnt has been embedded in practice and how this has been evaluated
- Identify mechanisms, if needed, to embed learning from future SARs and lessons learnt

1.3 Process of this Safeguarding Adult Review

1.3.1 Independent Chair/ Author

The Author of this report is by professional background a psychiatrist and systemic psychotherapist specialising in work with older adults. She has broad clinical and multi-agency experience in the North West and West Midlands. She has acted as Chair and/or Author, and expert medical adviser/ consultant to Domestic Homicide Reviews, Serious Case Reviews, Safeguarding Adult Reviews, and Local Case Reviews in the past. She has no connections or ties of a personal or professional nature with the family, with Barnsley Council, or with any other agency participating in this review.

1.3.2 Timescale

The timescale for the Review was set as June 2018 to December 2019 (unless significant information exists prior to these dates).

1.3.3 Independent Management Reports in respect of Valerie

Individual Management Reports and chronologies were requested and provided by five agencies as set out in Table 1.

Table 1: Details of IMRs

Agency	Abbreviated as	Author	Quality Assured by
Barnsley Hospital NHS Foundation Trust	BHNFT	Named Nurse for Adult Safeguarding	Deputy Director of Nursing
Barnsley MBC – Adult Social Care	ASC	Team Manager ASC	Service Director, Adult Social Care
GP practice 1	GP	GP partner	Practice Manager
South Yorkshire Fire and Rescue	SYFR	Safeguarding Officer	Temp Area Manager Prevention & Protection/Group

			Manager Community Safety
South Yorkshire Police	SYP	Case Review and Policy Officer	Superintendent

Additional information was sought from:

GP practice 2 re lan – summary report

1.3.4 Valerie: Family Involvement

Family details were secured after Valerie's death, and the Independent Reviewer was given contact details for one family member. Due to restrictions related to the covid-19 pandemic the Independent Reviewer spoke with this family member over the phone to seek background information, and ask this person to invite other family perspectives. We were told that other family members did not wish to be involved. The family did not want information to be available publicly, so details have been withheld from the Report but informed the Review.

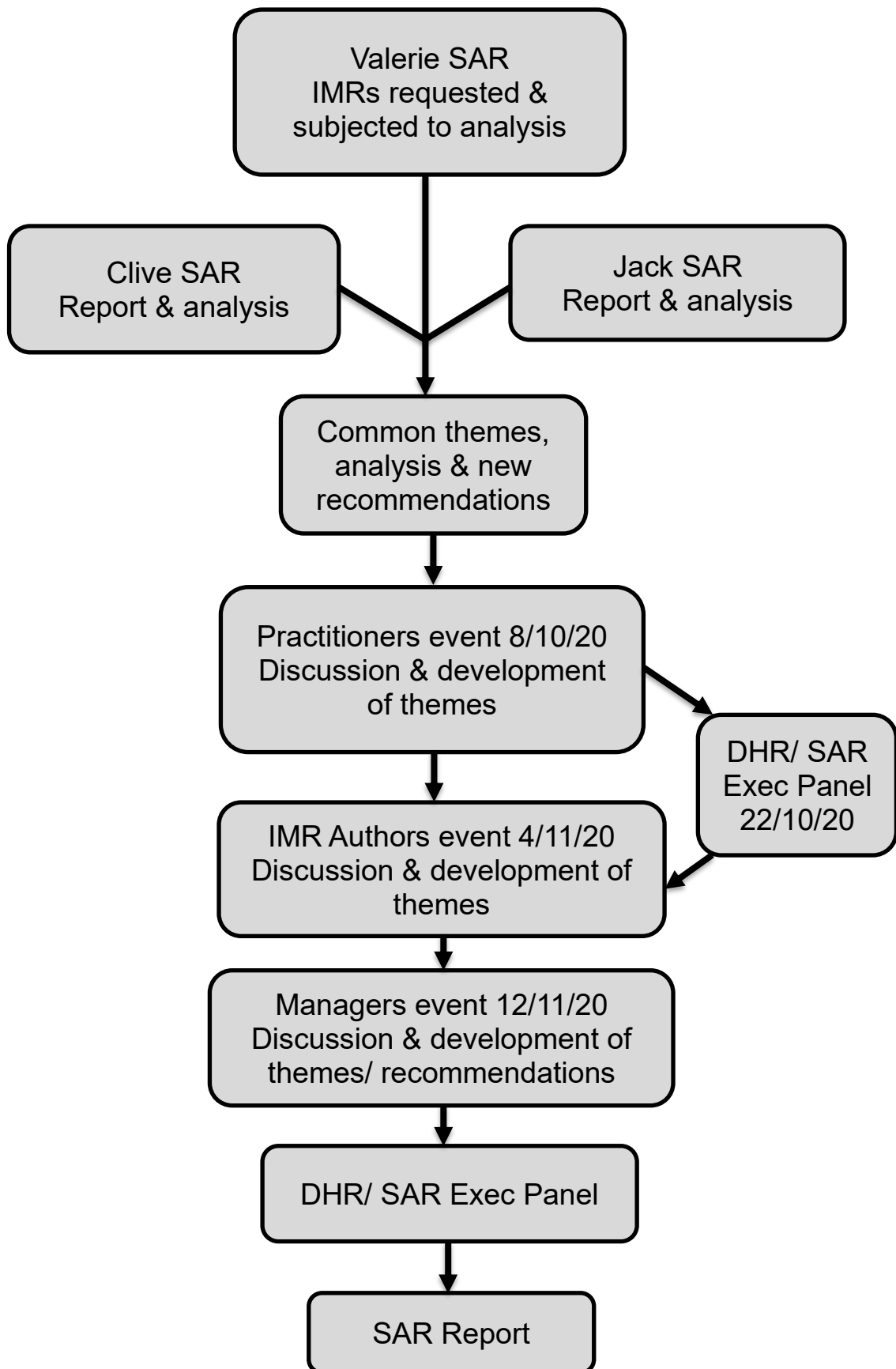
1.3.5 Meetings

The Review followed a recursive and developmental process where themes and recommendations were developed through a series of meetings with communities of interest. This is represented in Figure 1.

Dates of meetings were as follows:

8 October 2020	Practitioners' event
22 October 2020	Independent Author attended DHR/ SAR Executive Panel
4 November 2020	IMR Authors' event
12 November 2020	Managers' event
17 December 2020	Independent Author attended DHR/ SAR Executive Panel
28 January 2021	Independent Author attended DHR/ SAR Executive Panel
25 February 2021	Revised report to DHR/SAR Panel
25 March 2021	Final draft Report to BSAB for sign off

Figure 1: Showing the overall process of this Review



Part 2: Review of the deaths of Valerie and Ian

2.1 Circumstances of the deaths: Summary chronology

The Table below, Table 2, summarises the chronology of events in respect of Valerie and Ian over the timescale of the Review, ie June 2018 to December 2019.

Table 2: Summary chronology for Valerie and Ian

Date	Events
Early summer 2018	<p>A Housing Officer (HO) from Safer Neighbourhood Services made a safeguarding referral noting concerns about “severe self-neglect”, no bathroom and “a big dog that could be vicious”.</p> <p>This was converted to a request for assessment by the team manager and joint visit was carried out by a social worker (SW) and the HO. The couple refused them entry as “the dog can be vicious” and were described as “very unkempt”. No capacity assessment was documented. Valerie/Ian refused to give either the housing or adult social care staff their family contact details and were thought to have capacity to refuse to share this information. They told the SW and HO that they had 4 children, two of whom visited at least monthly and brought provisions, and that one of their daughters would give support should it be needed. The couple were owner occupiers and their property was reported to be in a dilapidated state.</p> <p>The plan was for the HO to follow up with neighbours, and the HO later reported (from the neighbours) that Ian was unsteady on his feet and the toilet was believed not to be working: “using buckets”. Fire risk (smoking) was identified as an issue. The SW suggested using VARMM. The HO attempted further visits but did not gain entry. The SW tried to locate Valerie’s GP without success.</p> <p>The team manager decided to close the case on the basis of no access and non-engagement. The HO planned to continue with “welfare checks”.</p>
Summer 2018	<p>SYFR Fire Community Support Officers visited after receiving information from the HO: house windows stained yellow; open coal fires and Valerie smokes; self-neglect; not allowing entry. The Fire Community Support Officers failed to get entry and a home safety check was declined.</p>
Autumn 2018	<p>The HO requested SYFR make another attempt to see the couple. Officers visited and spoke with Valerie on the doorstep. She would not agree access and declined an offer of smoke</p>

	alarms. Advice was given regarding bedtime routine and escape plan. A letter was sent to the couple detailing the advice and the case was closed.
April 2019	Ian attended the Emergency Department with abdominal pain and increased confusion. He appeared unkempt. He died the following day of intra-abdominal sepsis related to diverticular disease. Medical records state that nursing staff raised safeguarding concerns but no referral was made.
	Ian died in April 2019 aged 86.
Dec 2019	Valerie attended the Emergency Department "unable to cope". Yorkshire Ambulance Service described her as "living in squalor", using a coal fire which she is unable to light, and with no functioning fridge, no hygienic surfaces for food preparation, a bucket in the kitchen used as toilet, sleeping on sofa, and no fresh food in house.
	Valerie died in Dec 2019 aged 75.

2.2 Analysis

2.2.1 Safeguarding referral and concerns

A Housing Officer (HO) from Safer Neighbourhood Services made a safeguarding referral in early summer 2018 noting concerns about "severe self-neglect", no bathroom and "a big dog that could be vicious". This was converted to a request for assessment by ASC, and a social worker attempted a joint visit with the HO but they were only able to talk on the doorstep. Further evidence of self-neglect was apparent: the property was described as dilapidated and the couple as "very unkempt".

The housing officer followed up with the neighbours and elicited additional concerns including the use of buckets (as the toilet was believed not to be working), and about fire risk since Valerie was a heavy smoker.

The social worker suggested a vulnerable adult risk management meeting (VARMM) and it is noted that the HO thought this was a good idea but it was not pursued. This was a missed opportunity.

Subsequently a decision was made by the team manager and "communicated to the social worker" that, in view of no access and non-engagement, there was little that social care could do and the case was to be closed. Involvement ceased at that point. It is worth noting that the view taken here is not uncommon and Braye and colleagues, reviewing a number of SARs involving self-neglect, write that:

failing to co-operate should not be reason to close a case or reject re-referrals. Certainly, a risk assessment should be conducted prior to any

termination of involvement, coupled with investigation of what might lie behind refusal to accept care. (Braye, Orr et al. 2015)

This raises questions about how cases are closed in view of the description of severe self-neglect, about professional curiosity and persistence in relation to non-engagement, and how to facilitate relationship-building.

There was a missed opportunity for a safeguarding referral when Ian was admitted to hospital and later died. He was noted to be unkempt and that his lower legs were dry and scabbed. The medical record noted that nursing staff raised safeguarding concerns but these were not followed up with the family or in any other way. This may have happened because the focus was on Ian's acute illness but the BHNFT IMR notes that this "may have been a missed opportunity to establish if Valerie may require further support following the loss of her husband."

Not sure if it is worth noting here that we know bereavement is a major factor – or this may be included in the learning. They had been married a long time!

2.2.2 Capacity

No capacity assessments were documented during the contact with ASC and the stance taken by the social worker was deemed to be that of assuming capacity and that Ian and Valerie could therefore take unwise decisions.

The presumption of capacity is not at any point rebutted. Barnsley Multi-Agency Self-Neglect and Hoarding Policy and Procedure was approved on 15/3/2018 and issued on 1/6/2018. It contains information and advice about mental capacity, saying:

in extreme cases of self-neglect and/or hoarding behaviour, the very nature of the environment should lead professionals to question whether the adult has capacity to consent to the proposed action or intervention and trigger an assessment of that person's mental capacity. This is confirmed by the MCA² Code of Practice which states that one of the reasons why people may question a person's capacity to make a specific decision is 'the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision' (4.35 MCA Code of Practice, p52 (Department for Constitutional Affairs 2007)). (p.10 of Policy)

The Policy goes on to make reference to executive dysfunction, an area of particular concern in relation to self-neglect and hoarding. Individuals may have decisional capacity but lack the ability to act on/ execute the decision (Braye, Orr et al. 2011).

Mental capacity was a theme in 50% of serious case reviews involving self-neglect that were analysed by Bray, Orr and Preston-Shoot (2015), and the authors note that:

² Mental Capacity Act 2005, see <https://www.legislation.gov.uk/ukpga/2005/9/contents>

practitioners (may be required) to challenge their own assumptions about lifestyle choice and capacity (Braye et al., 2014), and the impact of the powerful ethical force of the statutory Mental Capacity Act 2005 assumption of capacity and associated notions of autonomy (p.14) (Braye, Orr et al. 2015).

People are not making a life-style choice and free choice is not a helpful concept, if people cannot conceive of anything being different or see a way out of their circumstances. Professional curiosity is important here in questioning and trying to understand a self-neglecting adult's perspective.

2.2.3 Self-neglect & hoarding policy and related issues

The Housing Officer raised concerns including severe self-neglect and poor hygiene, noting that Valerie presented as unkempt and a fire risk, including to the neighbours, this latter being potentially a public interest concern. The social worker, according to the IMR, noted that both Ian and Valerie indicated that they were able to manage their own personal care but added that *"it was very difficult to believe that they have washed or changed their clothing ... for a very long-time. Valerie's hair was long and knotted at the back."* It appears that, in the absence of consent to an assessment and, since she considered that the couple (probably) had capacity to make decisions about their circumstances and self-care, the social worker felt that few options were available, although she referred to possible use of the VARMM.

The Self-Neglect Policy is dated April 2018 and prior to that a VARMM policy was available to staff. Thus, the Self-Neglect Policy was available at the time that the Housing Officer made the safeguarding referral and a social worker became involved. The Adult Social Care IMR acknowledges that the VARMM policy was still "heavily referred to" at that time but neither the Self-Neglect Policy nor the VARMM policy was implemented and an opportunity to involve multi-agency partners was missed. It appears from this information that the Self-Neglect Policy was not fully embedded in practice at that time.

There are several areas that are relevant here:

- Use of the policy in ASC on self-neglect cases: is the use of the Self-Neglect Policy now more firmly embedded in practice?
- Decision-making in ASC on self-neglect cases: is decision-making related to self-neglect cases taking place at the appropriate level? This applies to both taking cases on and closing cases, especially when risks remain.
- Training: the social worker involved in Valerie's case did not recall undertaking any training in self-neglect and the IMR author regarded training as an important issue.
- Role of supervision: it appears that practice in relation to self-neglect was not picked up and addressed in supervision in this case.
- Professional curiosity: the social worker identified a mis-match between the couple's assertions that they could care for themselves and how they and their house presented but did not enquire further into this.

2.2.4 Family contact and roles

The couple did not share contact details of family members with the social worker and Housing Officer. It was said that family members were taking food to the couple. The social worker tried to establish whether the couple was registered with a GP but was unable to identify a GP. It is interesting that a PCSO managed to obtain dates of birth from the couple. With persistence and a sensitive person-centred approach that strives to understand the individual's unique perspective on their situation, would it have been possible to obtain family contact information? It is impossible to know for sure with hindsight. However, support for practitioners in this area may be beneficial.

2.2.5 Invisibility

Valerie registered with a GP practice in 2003 and was only ever seen once (in 2005). She was invited repeatedly to appropriate checks etc but did not respond and was described in the GP IMR as "invisible" to the practice. The GP IMR proposes an audit of patients over the age of 75 who are not on repeated prescriptions, have not been seen for 2 years, and with no known chronic diseases. The IMR also raises the issue of the role of the accountable GP in respect of invisible or silent patients. It appears that the aim of the named accountable GP was:

to provide personalised, proactive care to keep older people healthy, independent and out of hospital. (Tammes, Payne et al. 2019)

It would also seem likely that invisibility increases risk.

2.2.6 Relationship- building

The Safer Neighbourhood Services Housing Officer who was involved in this case showed persistence in following up the case after the case was closed by ASC and in trying to involve other agencies, although with limited success.

SCIE (Social Care Institute for Excellence 2018) identifies the importance of long-term approaches and relationship-building in working with people who self-neglect:

the importance of taking time, being genuine and human, demonstrating empathy and care, judging pace and when to be hands-on and when hands-off, and finding out about the individual. Trust needed to be established ... concerned curiosity and, when necessary, honesty-based authority and direction; non-judgementalism did not mean silence on risks and concerns. (Social Care Institute for Excellence 2014) (p.192)

2.2.7 Opening up alternative approaches

When Ian died, bereavement could have been identified as an opportunity to attempt to engage with Valerie and offer her support/ intervention.

Multi-agency involvement is also a way of opening work up to a range of different ideas and approaches, but, in the absence of a safe-guarding response and failure to follow the route of a VARMM, this did not take happen. Although enforcement is likely to be a last resort, involving other agencies would have been likely to highlight new possibilities; for example, had there been a dog in the property (which now seems unlikely) that dog may well have been neglected and this could have led to further action.

Part 3: Learning from Valerie's death together with learning from two previous SARs, which used the pseudonyms Jack and Clive

3.1 Summaries of previous SARs

3.1.1 Jack

Jack died at his home aged 68 in early 2018. He went to university and became a teacher, then worked as a teacher until early adulthood. He married and had one child but divorced after approximately 3 years. Around this time Jack's father gave him the property he lived in until his death, and, from around this point on, Jack did not have any paid work but was intelligent and creative, taught himself the guitar/ piano, and made furniture etc. He was self-sufficient and lived a frugal life "more like that of the 1920s" – not using electricity, making potions to heal local animals owned by neighbours. He was supported for several years by both parents: his mother ensured that basic living tasks were completed, eg eating, washing etc. His mother continued to support him, after the death of his father, until she went into a Care Home and died in 2015. After this he was supported by his younger brother, who was often excluded from Jack's home and therefore had limited influence on Jack's living circumstances. In 2003-2007 Jack was seen by mental health services with a psychotic illness, but this mental health information was not known to social care. He kept to himself and did not engage with services without a clear reason. He was reluctant to allow people into his home for some years and neglected himself. Alcohol was an issue.

Safeguarding concerns were raised twice in 2017: issues of self-neglect and poor living conditions. He died in a house fire in early 2018, when fire crews were called to his property and found him deceased in a bedroom. There were various dead animals throughout the property and "thousands" of empty alcohol bottles. After Jack's death it took three 10 tonne skips, protective clothing, and gallons of cleaning fluid to clean the house. There were barrels of salted pork and hung gammons in the cellar, which family members understood as a throwback to Jack's childhood, growing up with a father who was a butcher.

Learning from Jack's SAR included:

- Missed opportunities to involve other relevant agencies
- Challenges of working with complex cases of self-neglect
- Agencies' over-reliance on Jack's brother and his account
- Failure to use available powers eg environmental health
- Lack of relevant historical information from mental health and primary care
- A need for varied responses when people fail to keep appointments
- A need to "close the loop" and feedback to referrers
- Training issues in relation to self-neglect in particular

3.1.2

Clive

Clive was found dead in his home by care agency staff aged 59 in 2019. He had lived with his parents most of his life and had longstanding issues with anxiety (from the age of 16). His parents looked after him, cooking meals, washing his clothes, organising appointments etc. Clive only lived away from his parents for a few months, and during that time visited them every day and often stayed over. After his mother died in 2012, he lived alone in a Berneslai Homes tenancy, but obsessive-compulsive behaviour limited his ability to leave the house.

Clive's two sisters tried to support him, but without success. He went long periods without income and developed rent arrears: he struggled to attend DWP appointments and was unaware that he could request a home visit. Apart from family he had no relationships and told professionals that he was "very lonely", but he was unable to access any support to address this. He was an avid reader, and loved football and music, but was very sensitive to noise and "germs", with repeated handwashing, reluctance to touch door handles, and reluctance to travel on buses etc. After a fire in 2014 (believed to have been set by him) he slept on the floor in the living room, even though the family had decorated and replaced furnishings after the fire, and the fact that the property had two bedrooms.

In 2019 Clive was found dead at home by carers commissioned by Adult Social Care. At the time of his death, he was in receipt of:

- mental health tenancy support
- a housing management worker employed by Berneslai homes
- a domiciliary care package to assist with meals and personal hygiene for the six weeks prior to his death

When he died, Clive only weighed 6 stones, as a consequence of self-neglect.

Learning from Clive's SAR included:

- Bereavement services were not easily accessible to Clive
- Very few workers were aware of the DWP home visiting service
- Clive failed to attend GP and other appointments, but this did not raise questions
- Organisations were aware of self-neglect.
- Towards the end of his life, Clive did form relationships with people and did not prevent workers coming into his home, but denied access to family members
- No effective risk assessment was completed under the self-neglect and hoarding policy
- Three referrals raised concerns about self-neglect
- Family members' attempts to seek help for Clive were not taken "seriously" as Clive had not given permission.

- Policies agreed by Barnsley Safeguarding Adults Board were not well embedded (lack of robust training offer).

3.2 Parallels between the three SARs

Important characteristics of these three SARs include the following:

- Men and women were involved
- Ages of those involved ranged from 59 to 86
- Living arrangements varied and included owner occupier; private rented; Berneslai Homes
- Self-neglect was a feature in all three SARs
- Hoarding was a feature in all three SARs
- Open fires were present in two of the three SARs
- Family members were involved in all cases but their input was restricted by the individuals involved
- All were deemed to have capacity
- Alcohol featured in one case
- All received some form of external support: in two cases this came from family members and in one from ASC
- Bereavement played a role in all cases
- Professionals supported family and/ or friends to have a major influence on their contact with the adult and/ or allowed them to make decisions about whether services became involved or not

Table 3 gives more details of parallels between the three SARs.

Table 3: Parallels between the three SARs

	Valerie and Ian	Jack	Clive
Death	Valerie died Dec 2019 aged 75 Ian died April 2019 aged 86	68 year old man died in a house fire in early 2018.	Found dead in his home by care agency staff aged 59 in 2019
Referrals to safeguarding/ ASC	2018 Housing Officer Safer Neighbourhood Services made a safe-guarding referral - concerns about “severe self-neglect”, no bathroom, “a big dog that could be vicious”, fire risk.	Safeguarding concerns raised twice 2017 - issues of self-neglect and poor living conditions.	Referred to safeguarding and social care 4 times between 2013 – 2017 with concerns about self-neglect and his inability to self-care.
Mental health	Daughter thinks her Mum had mental health problems, maybe agoraphobia, very anxious, didn’t like going out	Seen by mental health services 2003-2007 with psychotic illness – information not known to social care. Alcohol issue.	OCD and anxiety – Clive cancelled or failed to attend appointments so the only mental health assessment was in hospital when he felt “safe”.
Family contact	Four children, 1 daughter very involved. Did the shopping, paid bills, was phoned a lot, was only allowed in the living room, found out later the rest of the house wasn’t “kept”, eg the bedrooms looked like they hadn’t been touched for about 20 years, empty biscuit boxes all over the house. Knew/ believed she couldn’t change her Mum.	Divorced from wife after about 3 years: one daughter. Supported by Mother and later younger brother who was often refused entry to the property.	Sisters – 2013 concerns: eating little, reclusive/ not leaving house, neglecting self. Later stepped back, as he was aggressive to his sisters when they encouraged greater independence.

	Valerie & Ian	Jack	Clive
Significant bereavements	Ian died in April 2019.	Death of Jack's mother deprived him of significant support	Death of Clive's parents deprived him of significant support.
History	Was very stubborn and set in her ways. Husband worked and looked after the children, did everything until he died. She just sat smoked, watched TV and did sudokus. Refused to see the doctor but made sure her husband kept appointments. The couple had dogs, none of which were aggressive, and after they died Valerie cited them as a reason to exclude people from the house.	Worked as a teacher until early adulthood. Supported by Mother until she went into Care and died in 2015. Jack kept to himself and did not engage with services unless he had a clear reason to do so. He neglected himself and had been reluctant to allow people into his home for a number of years. Fire crews called to his property and found him deceased. Various dead animals throughout the property and "thousands" of empty alcohol bottles.	Lived with parents, ceased work in 20s, attempted to claim benefits but unable to attend necessary appointments so claim for ESA disallowed. Limited contact before his Mother died in 2012. Concerns about self-neglect and hoarding first raised in 2013 (YAS). He requested support from GP and mental health services but didn't engage and failed to attend appointments outside his home. Allowed people into his home. Good relationship with Housing Agency despite rent arrears and threats of eviction, and engaged with a range of assessments whilst in hospital (for hypo-thermia and hypo-glycaemia). No multi-agency risk assessment or action plan.

3.3 Recommendations from the previous SARs

Recommendations from the previous two SARs covered the following areas:

- Embedding the use of the Self-Neglect and Hoarding Policy in practice, including the use of risk tools
- Training in self-neglect and hoarding and use of the policy
- Escalation routes for staff dealing with complex high-risk cases – use of supervision and team meetings
- The need to facilitate relational working over a long term where necessary together with an appreciation that progress is likely to be slow
- Ways to identify individuals who “do not attend” and to make available home visits where possible
- Identifying bereaved individuals at risk and mapping/ making available to them possible interventions
- Information sharing and collaborative working between agencies
- Assessment of mental capacity in relation to decisions about service involvement etc and understanding the role of executive capacity
- The role of family members in service access and the possible role of family group conferences (Manthorpe and Rapaport 2020)

3.4 More of the same?

The analysis of events in relation to Valerie suggests that a number of similar recommendations could have been drawn out again, but the fact that cases of self-neglect are still occurring argues strongly in favour of a new approach to changing practice and for that reason this Review has followed a process of involving people in different parts of the system.

Part 4: Consultations with groups within local systems and learning drawn from them

4.1 Practitioners' Event

A Practitioners' event was held on 8 October 2020 on zoom. During this event some polling questions were posed and the results are set out in Table 4.

Table 4: Practitioners' Event Polling questions and results

Question	YES	NO	Comments				
Have you received any training on self-neglect	87%	13%	How long ago? What training?				
Has self-neglect been discussed in team meetings	87%	13%					
Has self-neglect been discussed in supervision?	80%	20%					
Have you used the self-neglect policy?	67%	33%					
Are you aware of previous SARs in Barnsley involving self-neglect?	53%	47%	BSAB asks all organisations to cascade SARs so this is a concern.				
Question	1	2	3	4	5	6-10	>10
How many cases of self-neglect have you worked with	13%	33%	0	7%	0	27%	20%
Question	No		Yes in theory		Yes in practice		
Are you supported by management in self-neglect work	7%		20%		73%		

Most people reported that they had received training in self-neglect but no details were collected of how long ago this took place and what it consisted of. Most people reported that self-neglect had been discussed in team meetings and supervision and about two-thirds of the practitioners had used the policy. Only just over half were aware of previous SARs in Barnsley involving self-neglect and this is a concern given that the Safeguarding Adults Board asks partners to cascade SARs to staff.

Table 5 on the next two pages summarises key points from the Practitioners' event.

Positive	Challenges
<i>Working practices</i>	<i>Working practices</i>
Those with experience in self-neglect work get allocated more cases	Practitioner time (self-neglect work is time intensive) Compassion fatigue Challenges of other work and pressure to close cases Workers with expertise left holding cases and asked to mentor workers with cases with limited support from managers/ organisations.
Co-working	Limited supervision SYFR
Possibility of a specialist team – multi agency OR champions/ SPOC within each team	Does this deskill others?
Professionals meetings, shared risk assessments and action plans	Balancing resources against risks – how robust and multi-agency are risk assessments Capacity assessments - making “unwise choices”. Accessing information – especially names of GPs (noted CCG can provide)
Flexibility in individual – gender/ age and ability to continue to work with the person longer term Professional curiosity. Persistence.	Relational consistency. Valuing small steps.
Support for the creation of a senior management team to review cases that have not been resolved by robust operational practice. Explore if cross funding or more flexible working across organisations may assist	
	Lack of bereavement support for adults who self neglect/hoard. Lack of support for other losses/ bereavements – job/ relationships??
Partnership/ collaborative working	Services screening people out.
<i>Useful resources</i>	
Having a “map”/ directory of local resources and legal powers (SNS)	

Positive	Challenges
Self-neglect and Hoarding policy	Lack of knowledge of the policy and legal powers – training needed? How much self-neglect constitutes self-neglect
Clarity about roles and responsibilities	
SYFR questionnaire from Hoarding disorders UK. Asks the person how they feel about their living arrangements	Lack of clarity about capacity issues, especially when working with adults using drugs and/or alcohol. Especially when MH issues identified
Share learning from positive cases – add to newsletter and/or training	To ensure all agencies engage with training
Families as resources - consider involvement of families – family group conferences?	When can we attempt contact without permission?
<i>Additional ideas</i>	
Professional curiosity - if the outside of the property looks “grim” likely to be “grim inside”. Possible early intervention?	Respecting choices of adult and maintaining contact.
Can we learn from/replicate the Magpies scheme in Sheffield (worked with Hoarders)	
Public awareness – eyes and ears on issues (similar to ASB reports)	

Table 5 (previous page and above): Key points from the Practitioners event

4.2 IMR Authors’ event

IMR authors were invited to an event on zoom on 4th November 2020.

The IMRs were shared with them prior to the event and the key points from the Practitioners event were shared and discussed in the context of the recommendations that had been made in the IMRs.

New recommendations made in the five IMRs are set out below by agency.

Barnsley Hospital NHS Foundation Trust

- a) Review of adult safeguarding training offer
- b) Update of the overarching Safeguarding Policy
- c) Survey Monkey to review staff knowledge

d) Review of the Barnsley Multi Agency Self-Neglect and Hoarding Policy and Procedure

Barnsley MBC Adult Social Care

- a) The organisation would benefit from visiting cases not dissimilar to this one and consider how the policies would apply – this would then identify the broader issues and learning for the practitioners that are employed.
- b) Training ***must be made available*** to explore whether the self-neglect policy is understood when implemented alongside safeguarding.

GP Practice 1

- a) The medical secretary who normally registers a death of a patient will put a flag on the relative's medical records to highlight that a significant other has died. Adopting this could identify at-risk patients in future.
- b) An internal audit to identify patients over 75 who have not been seen for 2 years with no known chronic diseases and not prescribed any repeat medication.

South Yorkshire Fire and Rescue

- a) Supervision –skill development and promotion (robust/effective practice)
- b) Skill development: assertive challenge & escalation to other agency –
– asking for reasons, advice; service user – probing about refusal of a service – developing questioning style; persistence and curiosity.
- c) Operational crews – shared learning and improvement
- d) Gap analysis & action plan

South Yorkshire Police

- a) A recommendation to the force Vulnerability Working Group that training provision is reviewed, and action taken to address any identified gaps.

In completing the IMRs authors had been asked to rate “how satisfied are you that your organisation has embedded the training and practice of the self-neglect and hoarding policy?” on a scale of 1 to 10 where

1=not at all confident

10= totally confident, delivered, staff routinely adhere to policy,

and their ratings are set out in Table 6.

1	2	3	4	5	6	7	8	9	10
		SYP ASC	BHNFT			YH's GP	SYFR SNS		
		ASC rating of 3 thought to be an under- estimate			SNS rating of 8 thought to be an over- estimate				

Table 6: Ratings of IMR Authors' satisfaction with embedding the Self-Neglect and Hoarding Policy in training and practice within their organisation.

Table 6 shows that authors were aware that the training and practice of working with self-neglect in line with the policy is not well embedded, although at the Authors' event revisions to two ratings were suggested in that the ASC rating was felt to under-estimate and the SNS rating to over-estimate the position in those respective organisations. Regardless of suggested revisions the ratings demonstrate that more needs to be done to improve practice.

Discussions in the IMR Authors' event

There was some cross-over between the IMR recommendations and key points from the practitioners' event. It was acknowledged that, although training is important, it is not the “answer”. These areas were discussed and themes drawn from that and broader discussions are set out below:

The relationship between the service user and professionals

- Flexibility in individual working
- Sensitivity to gender/ age and
- Ability to work with the person long-term
- Importance of professional curiosity (“concerned curiosity”) and persistence.

- Managers need to support those workers who get in regardless of their role, by committing time and space in supervision to discuss the challenges of this work.
- Accept that progress will be slow, and work will be time-consuming
- Tools to help practitioners be care-frontational – concerned curiosity

The role of the service user's family

- Families as resources in a strengths-based approach to seeking solutions to the risks faced by adults who self-neglect and/or hoard
- Possible family group conferences
- When can practitioners attempt contact with family members without the service user's permission?

Person centred collaborative understanding of risks

- Risk assessments reflecting/ acknowledging the adult's views of what success might look like
- Professionals meetings leading to shared risk assessments and action plans

Ways of bringing agencies/ practitioners together, suggestions were:

- A professional community of interest page on SAB website
- Multi-agency practice forum to review cases – successes and challenges
- Learning from each other – sharing successes not just deaths
- Clarity re roles and responsibilities
- Address tensions between organisations and link to organisational risk

The Self-Neglect and Hoarding Policy

- Lack of knowledge of legal powers
- Embed self-neglect in practice, in team meetings, supervision, and induction

Innovative interventions

- Magpies scheme in Sheffield cited as success
- Ways of sharing success stories eg newsletters, SAR learning events.
- Cross-funding possibilities to finance new interventions

Possible relatively quick wins

- Ready access to information about local resources
- Resources cascaded/ available to all staff
- Note specialist environmental officers in SNS and part-time post for adults stepped down from safeguarding

- Senior managers checklist suggested for closing self-neglect cases (possible basis for audit/ learning events)
- Strong manager support for practitioners
- Escalation processes within agencies – suggestion of escalation team to deal with cases not managed on the ground
- Attention to record-keeping

Targeting specific groups

- Challenges of owner occupiers
- Engaging with private landlords
- Engaging the public – link to early intervention

4.3 Managers' meeting

A managers' event took place on 12th November 2020 on zoom, and key points/ themes from both the Practitioners' event and IMR Authors' event were shared with the managers. Discussions addressed identified themes and broader issues.

A summary of areas to reflect on/ develop and areas for possible actions/ recommendations was later circulated and feedback invited in order to help develop some firmer recommendations. The summary is set out below with minor edits in the interests of clarity.

Areas to reflect on/ develop

This list includes areas that were discussed and might lean towards recommendations but didn't come up with clear actions/ recommendations.

- Do people consider the IMR ratings to be “good enough”
- What is meant by mental wellbeing – where is this sited – is more resource needed?
- How to get shared ownership and shared responsibility of complex cases
 - owning risks together
 - sharing ideas
- Who owns /oversees high risk cases at senior level?
- Escalation processes
- Engaging with private landlords
- Making every contact count - Do we need to explore use of MECC?
- Awareness of SARs – how to better cascade?
- How to better involve GPs?
- Consistency across boroughs.
- Cross funding initiatives?
- Access to therapy services?
 - Bereavement?

- Do organisations need to try and identify “at risk” adults who have been bereaved – role of registrars/ GPs etc
- Early intervention? – public awareness, other services eg waste
- How might the Board more effectively challenge organisations when the same recommendations come up repeatedly?
- Supporting practitioners with complex cases
 - someone asked how do you teach empathy?
- Would diversion of money from house clearances to creation of a hoarding support service be more cost effective/ beneficial to the adult
- Engagement of Mental Health when adults are not eligible – this is already included in the Self-Neglect and Hoarding policy.
- Would the work going on in SNS around complex lives be part of the solution?
- Can Barnsley work regionally to support SYP/SYFR etc.
- Would the creation of core groups help – how is this different to a multi-agency response under S42?

Possible actions/ recommendations

This list includes areas that came up with reasonably clear possible actions/ recommendations.

- Celebrating (and learning from) successes – pieces in newsletter, on website
- Develop involvement of families
 - practitioners to routinely record family information
- A checklist for closure of cases used (and signed off) across all agencies/ organisations – where will this be held?
- Explore assessment of mental capacity to address executive capacity and fluctuating capacity – produce resources to support practitioners to assess
 - Issues with adults who use alcohol/drugs – do they have capacity to make choices – often screened out of safeguarding. However, if deemed to have capacity they ARE eligible for support under self-neglect and hoarding policy
- Check legal basis for contacting family when consent not given. What can be shared and what can't? In what circumstances can families be contacted without consent of adult – legal advice needed?
- Directory of resources/ contacts map (SPOC) to support management of cases.
- Set up professional network/ community of practice/ learning community?
- Explore innovative schemes.
 - Hoarding Disorders & self-help groups
 - Magpie scheme in Sheffield
- Consider extending Vulnerable adults panels (now called Multi-Agency Panel) to be area based?
- Do we need regular reflective practice sessions to learn from both positive and negative cases? Webinars?

- Explore role of PCSO's in early intervention
- Adopt connect system for all organisations
- Address issue at next BSAB meeting and
- Take to BSAB development event as this is a repeated challenge to all organisations

4.4 Analysis in relation to the Terms of Reference

4.4.1 Compliance with agreed Self-Neglect and Hoarding Policy (formerly known as VARMM) including risk assessments

4.4.2 Examine the effectiveness of multi-agency information sharing and joint working

These two key lines of investigation are considered together.

There were two missed opportunities to implement joint/ multi-agency working in relation to Ian and Valerie. The first was when the HO raised concerns related to self-neglect and a social worker became involved. At that point VARMM was considered but not followed up. Similarly, the Self-Neglect and Hoarding Policy was not invoked and a risk assessment was not completed. The second missed opportunity was when Ian was admitted to hospital and died shortly afterwards. Nursing staff raised safeguarding concerns but their concerns were not followed up.

4.4.3 Evaluate if the learning from previous SARs/ lessons learnt has been embedded in practice and how this has been evaluated

There are two main reasons to consider that lessons learnt in previous SARs have not been embedded in practice: firstly, that people are still dying in circumstances of self-neglect when they had been in contact with services, and secondly that the practitioners who informed this Review were themselves clear that the Self-Neglect and Hoarding Policy is not embedded in practice.

4.4.4 Identify mechanisms, if needed, to embed learning and lessons learnt

Braye, Orr and Preston-Shoot analysed a series of Serious Case Reviews and proposed what they described as “a layered approach for good practice” emerging from the recommendation themes that they identified (Braye, Orr et al. 2015). The four layers they identified are:

- The adult

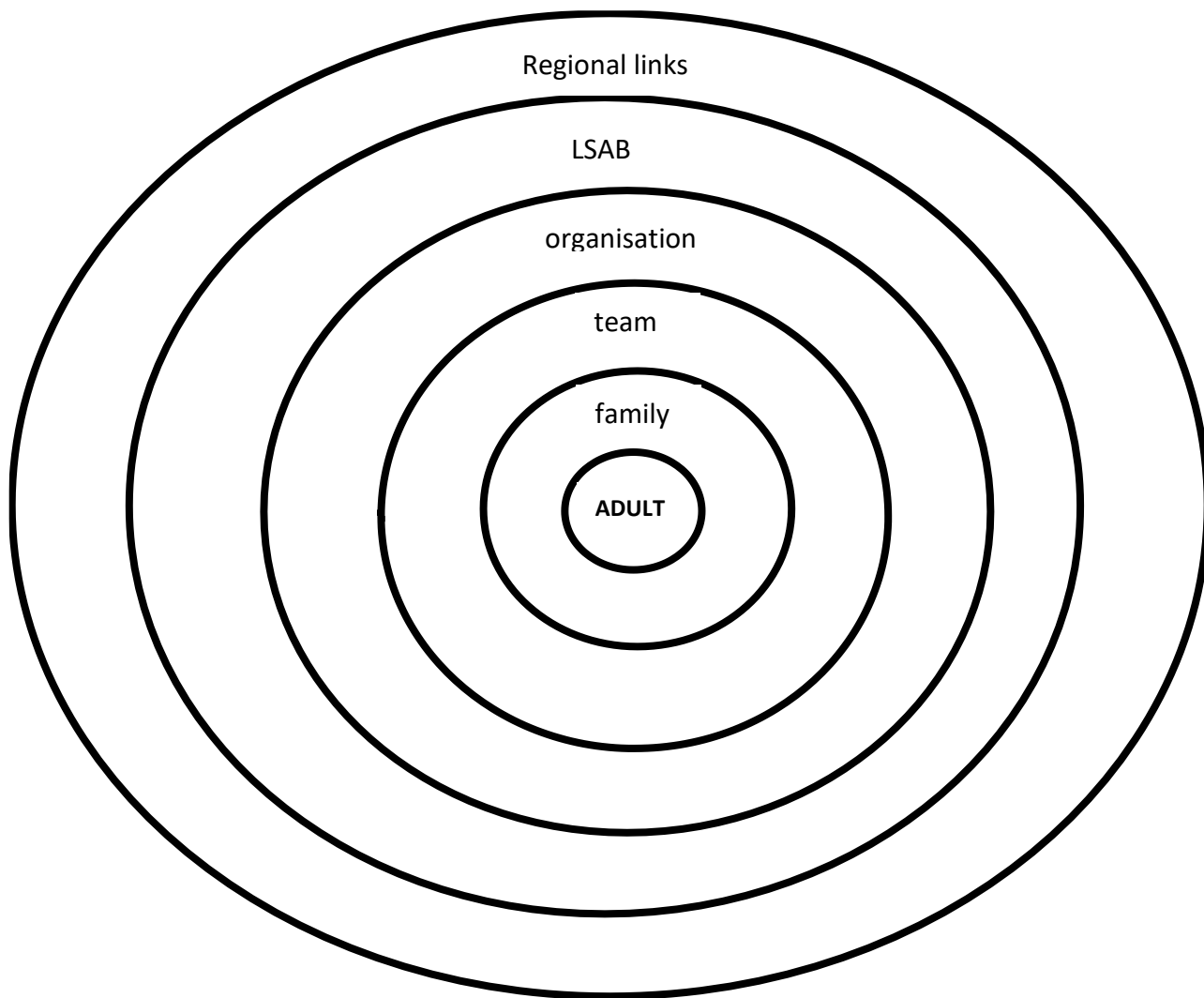


Figure 2: Suggested layers around an adult who has presented with self-neglect – modified from Braye, Orr and Preston-Shoot (2015)

Part 5: Lessons learned and good practice identified

5.1 Lessons learned

5.1.1 People are still dying in Barnsley in situations of self-neglect and hoarding, when they had been in contact with services, despite previous SARs producing recommendations and action plans designed to improve service responses. This suggests that a new approach is needed that does not rely on the areas/ themes highlighted previously.

5.1.2 An emphasis on training has not changed practice – this does not mean that training is not required but rather that it needs to take place alongside a change in culture and working practices.

5.1.3 Cases involving self-neglect continue to be closed without a risk assessment and without an understanding of what lies behind the individual's refusal to accept help, and despite research and practice evidence that maintaining contact is important.

5.1.4 It appears that a person's right to a private life and their perceived "life-style choices" are still prioritised over duty of care.

5.1.5 Executive capacity appears not to be understood, and is not assessed in practice.

5.2 Good practice identified during this Review

5.2.1 Involvement in research

BSAB has engaged with a research project led by King's College London and the London School of Economics which is looking at social care responses to self-neglect and hoarding among older people, and what works in practice. BSAB has also committed to engage with research by Orr, Braye and Preston Shoot, if they are successful in obtaining the necessary funding.

5.2.2 SNS Pilot Project

Safer Neighbourhood Services are starting a pilot project which will involve a Support Officer offering follow up to closed cases which involved self-neglect/ hoarding, perhaps over a period of 12 months initially. She will start with some re-visits to people whose cases have been closed but it is planned that she will eventually be introduced to individuals as part of a hand over process when professionals are at the point of considering withdrawing/ closing the case. The aim is to give the Support Officer the opportunity to create a relationship with the individuals concerned, which will facilitate long term checks/ support visits to spot early signs of decline.

Glossary of abbreviations

ASB	Anti-social behaviour
ASC	Barnsley MBC – Adult Social Care
BHNFT	Barnsley Hospital NHS Foundation Trust
BSAB	Barnsley Safeguarding Adult Board
CCG	Clinical Commissioning Group
DHR	Domestic Homicide Review
DWP	Department of Work and Pensions
ESA	Employment and Support Allowance
GP	General Practitioner
HO	Housing Officer
IMR	Individual Management Review
LSAB	Local Safeguarding Adults Board
MCA	Mental Capacity Act
MECC	Naking Every Contact Count
MH	Mental health
OCD	Obsessive compulsive disorder
PCSO	Police Community Support Officer
SAB	Safeguarding Adults Board
SAR	Safeguarding Adult Review
SCIE	Social Care Institute for Excellence
SNS	Safer Neighbourhood Services
SPOC	Single Point of Contact
SW	Social worker
SYFR	South Yorkshire Fire and Rescue
SYP	South Yorkshire Police
TV	television
VARMM	Vulnerable Adult Risk Management Model
YAS	Yorkshire Ambulance Service

Bibliography

Braye, S., D. Orr and M. Preston-Shoot (2011). "Conceptualising and responding to self-neglect: the challenges for adult safeguarding." The Journal of Adult Protection **13**(4): 182-193.

Braye, S., D. Orr and M. Preston-Shoot (2015). "Learning lessons about self-neglect? An analysis of serious case reviews." The Journal of Adult Protection **17**(1): 3-18.

Department for Constitutional Affairs. (2007). "Mental Capacity Act 2005 Code of Practice." Retrieved 30 December 2020, from

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf

Manthorpe, J. and J. Rapaport. (2020). "Conferences in Adult Services Methods Review." from https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-methods-review_MR026.pdf.

Social Care Institute for Excellence. (2014). "Self-neglect policy and practice: building an evidence base for adult social care Report 69."

Retrieved 22 December 2020, from <https://www.scie.org.uk/files/self-neglect/policy-practice/report69.pdf>.

Social Care Institute for Excellence. (2018). "At a glance 71: Self-neglect."

Retrieved 22 Dec 2020, from <https://www.scie.org.uk/files/self-neglect/self-neglect-at-a-glance.pdf>.

Tammes, P., R. A. Payne, C. Salisbury and e. al. (2019). "The impact of a named GP scheme on continuity of care and emergency hospital admission: a cohort study among older patients in England, 2012–2016." BMJ Open **9**: e029103.

Draft 25 Feb 2021