



# West Sussex Safeguarding Adults Board

## West Sussex meta-analysis of Safeguarding Adults Reviews featuring self-neglect

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## Foreword

The West Sussex Safeguarding Adults Board (Board) has published this meta-analysis of Safeguarding Adults Reviews (SARs) featuring self-neglect. This Review was commissioned by our Board, with contributions from the East Sussex and Brighton and Hove Safeguarding Boards.

The need for this Review was prompted by a referral to our Board for a 73-year-old woman, who for the purpose of this Review will be referred to as IL. IL's referral identified themes of self-neglect consistent with themes which had previously been identified by other SARs, both locally and nationally.

Shortly after IL's referral, another referral was received for a 63-year-old man, who for the purpose of this Review will be referred to as TB. Both IL and TB had died prior to their referral to our Board, and self-neglect had been indicated as a contributing factor.

The Board and the Independent Reviewer wish to express their sincere condolences to the families of IL and TB and those who knew and worked with them.

Our SAR Subgroup agreed that the need for a Review was indicated in both cases, however, given the repeating self-neglect themes, the Review should seek understanding and outcomes needed more widely on self-neglect partnership working, practice and process within Sussex as a whole. In order to do this, it was agreed that a thematic SAR analysis should be undertaken, considering all learning from recent local SARs involving self-neglect. SARs were considered across the whole of Sussex which resulted in the analysis of a total of nine Reviews. The aim of this Review is to identify systemic and practical changes to support responses to those who self-neglect.

This Review found several similar emerging themes, such as difficulties in recognition of risk and seriousness of this, use of policy and guidance, engagement with people who self-neglect, multi-agency working, communication, and challenges in identifying and responding to actions required.

To take forward recommendations made by this Review, further work is required to act on these findings in order to make systemic and practical changes when working with people who self-neglect. Areas of focus have been identified as; effective and prompt multi-agency working, attention to Mental Capacity and reasons for intervention and, knowing what to do to support self-neglect cases. We will ensure that all members are fully engaged in taking forward learning and recommendations together. We will also ensure that learning from this Review is widely shared.

In addition, for 2023/24 self-neglect was also one of our Board priorities, with a number of associated workstreams being taken forward alongside this Review. In recognition of the work which is still required in this area, our Board has agreed to continue this priority into 2024/25.

**Annie Callanan**  
**Independent Chair**

## 1. Introduction

- 1.1. This review was commissioned by the West Sussex Safeguarding Adults Board (WSSAB). The East Sussex Safeguarding Adults Board (ESSAB) and the Brighton and Hove Safeguarding Adults Board (B&HSAB) managers were invited to participate and both joined the review panel. This review, and other development work associated with it, is one of the priorities in the West Sussex Safeguarding Adults Board Three Year Strategy 2022-2025. The other associated work includes a self-neglect survey and the creation of a self-neglect toolkit for practitioners.
- 1.2. The purpose of this review is to consider the circumstances surrounding the death of IL who was a 73-year-old white British woman who lived in a care home. On 14 April 2022, a Sussex Community NHS Foundation Trust falls practitioner raised a safeguarding concern due to IL's risk of falls, pressure damage, infection, dehydration due to her poor compliance with interventions: wearing the same continence pad for more than 12 hours, declining medication, food and fluids, a lack of manual handling equipment, poor environment. The decision was made not to make a safeguarding enquiry but a safeguarding plan was made, which included a requirement that if abuse or neglect was identified then a specific safeguarding concern should be raised.
- 1.3. Despite this, it does not appear that the plan was implemented. IL was admitted to hospital on 22 April 2022 following a seizure which lasted for 30 minutes. IL was discharged back to the care home but was admitted again on 2 May 2022 after not eating and drinking and appearing lethargic for several days. This time, despite IL having not met the criteria for admission, the care home would not accept her back. As a result, IL was admitted to an escalation ward where she died on 16 May 2022.
- 1.4. The WSSAB decided that a Safeguarding Adults Review (SAR) may not identify any additional learning to that which had been identified via the Section 42 enquiry and Learning Disabilities Mortality Review (LeDeR). The request from IL's family regarding learning from her death would already be actioned through these processes. Instead, it was agreed that learning from IL's death should focus more widely on the self-neglect process within Sussex as a whole. To do this, a thematic SAR analysis of findings from recent SARs involving self-neglect would be commissioned to consider practical changes to support responses to complex cases.
- 1.5. During the process of the review, concerns about TB, a further person who was believed to be self-neglecting, were also included in this review.
- 1.6. The need for such a meta-analysis was identified since, despite recommendations having been made in previous SARs locally and nationally, and having been implemented, self-neglect remained a regular topic in new reviews.

- 1.7. This is consistent with national findings, for example the 'Analysis of Safeguarding Adult Reviews (SARs) April 2017 – March 2019' in which self-neglect featured in 45% of the SARs studied. The national analysis of reviews from April 2019 to March 2023 is about to begin and, from the experience of the author of this report, who is also part of the national analysis team, SARs involving self-neglect are likely to feature significantly.

## 2. The review

- 2.1. The review will take place in two stages. The first stage will involve the creation of a thematic review report, which will consider self-neglect practice, process, policy, procedure and strategy. The report will include analysis of the current situation including the use of self-neglect processes. It will consider practical changes in relation to support for complex cases. It will also consider the information obtained and work already concluded on, for example, audits, action plans, learning briefings and podcasts as well as planned actions for 2023/24 in WSSAB's subgroup workplans/the Annual Business Plan.
- 2.2. The second stage of the review will involve practice development based on the findings of the review. This is likely to include:
  - a) Multi-disciplinary team working and practice, including escalation processes to multi-agency forums and their effectiveness in coordinating multi-agency interventions
  - b) Response to substance dependency
  - c) Mental Capacity Assessments, best interest decisions, the Court of Protection and the High Court etc. This will include when to consider mental capacity and recognition of, and response to: frontal-lobe conditions induced by trauma and substance use;
  - d) addiction and substance dependency and coercion and control etc.
  - e) Use of legal powers i.e. Public Health Act 1936 etc.
  - f) The completion and implementation of risk enablement plans and the use of strengths-based approaches, history taking to try to understand how self-neglect began etc.
  - g) Home fire safety awareness and responses to fire risk from smoking, especially in the context of substance use.
- 2.3. The review will include the exploration of barriers to practice, including resource issues and time constraints which may impact upon best practice. This will involve desk-top analysis and Teams meetings with individuals and with groups of practitioners across East and West Sussex and Brighton.

### 3. Key lines of enquiry

3.1. The following key lines of enquiry were agreed to guide the review:

- The use of the self-neglect process, considering practical changes in relation to support for complex cases. This will include consideration of the information/work we have already obtained/concluded/what we have done so far, i.e., audits, action plans, learning briefings and podcasts as well as WSSAB's planned actions for 2023/24 in WSSAB's subgroup workplans.
- Multi-disciplinary team working and practice including, roles and responsibilities in working with self-neglect cases, providing clarity on who can lead on multi-agency interventions. This may also require further guidance for care homes/agencies on their roles in self-neglect, including what to do when someone is refusing care.
- The use of Mental Capacity Assessments, best interest decisions, Deprivation of Liberty Safeguards (DoLS), the Mental Health Act and public health legislation, including determining mental capacity by looking at patterns of decision-making and understanding medical conditions that might influence capacity, especially in those areas influencing executive functioning.
- The completion and implementation of risk enablement plans, to include the difference between keeping someone safe and safeguarding.
- The exploration of barriers to practice, including resource issues and time constraints which may impact upon best practice. This should be considered in a supportive rather than critical way.
- Roles and responsibilities in working with self-neglect cases, including clarity on who can lead on multi-agency interventions.
- Further guidance for care homes/agencies and their roles in self-neglect, including what to do when someone is refusing care.
- The difference between keeping someone safe and safeguarding.
- Determining mental capacity by looking at patterns of decision-making and understanding medical conditions that might influence capacity.
- A supportive approach to ensure there is not a blame culture.

## 4. Method

### 4.1. Data set

- 4.1.1. The meta-analysis was conducted using the following reviews arranged by the WSSAB in coordination with the ESSAB and the B&HSAB:
  - a) IL, events in 2022
  - b) TB, events in 2022 and 2023
  - c) Thematic review (three people DP, AJ and RC), events between 2018 and 2019)
  - d) BK Desktop review, events in 2019
  - e) SAR MT, events between 2021 and 2022
  - f) SAR DJT, events between 2019 and 2021
  - g) SAR Christopher, events between 2015-2017
  - h) SAR James, events between 2016 and 2019
  - i) SAR Ben, events between 2015 and 2019
- 4.1.2. All reviews were published between 2020 and 2023.
- 4.1.3. The reviews were written by different authors, in different areas, at different times and not all directly addressed the areas identified in the key lines of enquiry. Different perspectives and focus on specific details in each case also influenced the relative weight given to the individual and multi-agency practice, procedure and strategic factors identified in each review.
- 4.1.4. It is possible that some of the findings from this meta-analysis are specific to a particular location and time, have already received attention, and progress has been made on practice development. The direct impact of Covid-19 and the response to it, for example, features in most reviews published covering the period between 2020 and early 2022 but this has been replaced to a large extent by the impact of the consequences of the response to Covid-19.
- 4.1.5. Despite these limitations, the findings from the SARs in this analysis are consistent with those found more widely, nationally, in other SARs involving self-neglect.

### 4.2. Causes of death

- 4.2.1. Safeguarding Adults Boards (SABs) have a legal duty under s44 Care Act 2014 to arrange for SARs to learn from situations where an adult with needs for care and

support has died from suspected neglect or abuse (including self-neglect) and there are concerns about how organisations worked together to safeguard them. SABs must also arrange reviews where an adult is still alive but has experienced suspected serious neglect or abuse. SABs can also arrange a review of any other involving an adult with needs for care and support.

- 4.2.2. All the reviews included in this meta-analysis were arranged after an adult with needs for care and support had died. Table 1 gives their causes of death where one was recorded.

**Table 1 Causes of death of the adults**

Name	Cause of death
IL	Not recorded.
TB	Road Traffic Accident.
Ben	Systemic sepsis, cutaneous and soft tissue infection of legs, diabetes mellitus, and idiopathic hepatic cirrhosis.
James	Cardiac arrest and acute myocardial infarction, that were likely to have resulted from the use of synthetic cannabinoids.
Christopher	Heroin toxicity/overdose
BK	Not recorded.
MT	Accidental death.
DJT	The immediate cause of death was multiple organ failure, of which decompensated alcohol related liver disease was the underlying cause.
DP Thematic Review (TR)	Pneumonia and Congestive Cardiac Failure and Coronary Heart Disease.
AJ (TR)	Acute cardiac failure, ischemic heart disease, coronary artery atherosclerosis, hypertension.
RC (TR)	Myocardial Fibrosis (heart failure), which appeared to be a pre-existing condition.

- 4.2.3. Where cause of death was recorded, four deaths were due to heart failure, although this may have been a consequence of other conditions related to substance use or self-neglect. Four deaths were either directly caused, or resulted from conditions caused by, substance dependency. There was one death from cardiac arrest as a likely result of drug use.
- 4.2.4. This indicates that the presence of long-term physical health conditions should be included in risk assessments of people who self-neglect where their self-neglect features refusal of, or reduced adherence to, treatment. These long-term physical health conditions include examples such as substance dependency, diabetes and heart disease.
- 4.2.5. This is consistent with findings from other national SARs where substance use, and especially alcohol use, is a significant risk factor in the deaths of people who self-neglect. Unlike in other national SARs, however, there were no incidences of

deaths from fires, although fire safety did feature in one of the SARs in the meta-analysis.

### 4.3. Protected characteristics

4.3.1. Section 149 of the Equality Act (2010) introduced a public sector duty to:

- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;
- Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- Foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

4.3.2. There are ten protected characteristics under the Equality Act, which are: age, disability, gender reassignment, marriage and civil partnerships, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

4.3.3. Apart from gender and disability, the SARs in this analysis rarely recorded information on protected characteristics (see table 2).

**Table 2 Protected characteristics in the SARs included in the meta-review**

Name	Gender	Age	Any other information
IL	F	73	Learning Disabilities
TB	M	63	Alcohol use
Ben	M	64	Learning disabilities; mental health needs, Korsakoff's Syndrome
James	M	42	Acquired Brain Injury; drug use.
Christopher	M	39	Learning disabilities; drug and alcohol use, mental health needs
BK	M	65	Health needs and physical disabilities.
MT	F	83	Parkinson's; Divorced; Church mentioned in the report.
DJT	M	49	Separated; registered blind; alcohol use; mental health needs; (DJT was born in Poland).
DP Thematic Review (TR)	F	92	Dementia.
AJ (TR)	M	60	Multiple Sclerosis; Divorced
RC (TR)	M	66	Physical disabilities; alcohol use

4.3.4. Slightly over 80% were men. Their average age was 56 years old. The women who were subjects of SARs were older, with an average age of 82.6 years. There is considerable variation between all the ages, with the youngest separated from the oldest by 53 years. However, five people (all men) were aged between 60 and 66 years old. All had some form of illness, impairment or substance

dependency. Similarly to other self-neglect SARs, the most frequently mentioned was alcohol or substance use (45%<sup>1</sup>).

- 4.3.5. This lack of identification of protected characteristics and the normative assumptions that, for example, all subjects of reviews are white British and heterosexual, is not unique to the SARs in this analysis. This may also be a finding of the latest national review of SARs (2020-2023). The WSSAB has a discriminatory abuse action plan and it might be useful to include appropriate demographic information in future SARs.

## 5. Findings for IL

- 5.1. This meta-analysis was prompted by the circumstances surrounding the death of IL, a 73-year-old white British woman who lived in a care home. Whilst the details of the other SARs included in this meta-analysis can be found in the relevant reports and briefings, those of IL are presented here for the first time. No additional information about IL, however, has been gathered at this stage.
- 5.2. Signs of IL's self-neglect and neglect were identified in April 2022. IL was reported to be refusing food, drink and medication and wearing the same incontinence pad for a prolonged time. IL also showed signs of neglect including the lack of manual handling equipment and what was described as a poor environment.
- 5.3. These were not considered to require a s42 Care Act 2014 Adult Safeguarding Enquiry but a safeguarding plan was proposed. Whilst the components of the safeguarding plan were appropriate, without the structure of a safeguarding enquiry there was no process to ensure their completion or to make anyone responsible and accountable for this. A s42 enquiry may therefore have been appropriate to ensure that action was taken and given that IL had needs for care and support and was experiencing abuse or neglect (including self-neglect) and was unlikely to have been able to protect herself, the criteria for a s42 enquiry appear to have been met.
- 5.4. **Learning point:** S42 safeguarding enquiries provide a framework for agreeing actions and monitoring their implementation, If a plan is proposed outside of the safeguarding process, then a system for ensuring that action is taken needs to be agreed.

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<sup>1</sup> One other person was noted to have Korsakoff's Syndrome, which is most frequently associated with sustained high levels of alcohol use. Alcohol use was not, however, mentioned in the SAR so they are not included in this figure. If they were included, the figure would be 55%.

- 5.5. The safeguarding plan was that a multi-disciplinary team (MDT) approach and the self-neglect policy and procedures should be used, a mental capacity assessment be made, a risk enablement plan developed, and IL be considered for referral to the Complex Case Panel. These appropriate actions were not implemented. It appears that no one took responsibility to arrange the MDT meeting. In hindsight, IL's declining appetite for food and fluids may have been an indicator that she was dying, but this does not appear to have been suspected.
- 5.6. **Learning point:** Tasks need to be allocated to specific person to be actioned within an agreed timescale. There is a potential point of failure if there is no review or accountability process for ensuring that actions are carried out.
- 5.7. IL was admitted to East Surrey Hospital on 22 April 2022 following a 30-minute seizure. IL was admitted again on 2 May 2022 after not eating and drinking and being lethargic for "a couple of days" (Sussex Safeguarding Adults Referral Form for IL). IL did not meet the criteria for admission, however, but care staff with her refused to return IL to the Care Home, so she was admitted to the escalation ward. IL died on 16 May 2022.
- 5.8. During the s42 Care Act 2014 safeguarding enquiry after IL's death, IL's sister said that she was not impressed by the previous manager of the Care Home who communicated poorly including not responding to telephone calls or supplying requested information for IL's funeral. According to IL's sister, the Care Home had also been slow to respond to IL's falls.
- 5.9. IL's sister had been shocked by IL's appearance when she visited over many weeks and felt that IL was neglected. IL's sister gave examples of staff saying that they would address issues (hair care) but did not do so. IL's sister felt that the Care Home could have done more to support IL. This included the number of falls and the length of delay in addressing actions.
- 5.10. **Learning point:** Care services may need support to recognise that self-neglect, including refusal of care or of food or hydration, may be a safeguarding concern and to seek help from other services to assess and, where appropriate, intervene. Lowered food and fluid intake may also be a sign that end-of-life care is required. Careful attention is needed to individual circumstances and context when determining which approach to take in these situations. The reasons for the approach taken should be recorded.
- 5.11. IL's sister also stated that there were also challenges with support for IL when she was in hospital due to staff shortages.

## 6. Findings for TB

- 6.1. During the process of this review, the circumstances leading to the death of TB in a road traffic accident were added to the analysis. TB was a 63-year-old man who was brought to the attention of adult social services due to concerns about his safety in October 2022. Home visits to the cottage in which TB lived were attempted until in December 2022, police forced entry and found TB in a confused state in very impoverished circumstances. The cottage, which was considered uninhabitable on 14 December 2022, was owned by one of TB's sons. The fire service attended in response to a water leak and raised a safeguarding concern.
- 6.2. TB had an allocated social worker and further information about TB was gathered from his GP. This emphasised the difficulties in engaging with TB and the GP surgery's lack of capacity to actively engage with him. The safeguarding process began on 15 December 2022.
- 6.3. TB first came the attention of the police in 2019. Contacts with the police continued after the adult safeguarding concern was raised and during the adult safeguarding process. TB was arrested on at least two occasions and also brought to the attention of the police many times for walking in the road causing traffic to swerve to avoid him and for throwing items at traffic. Several police SCARF reports were raised due to concerns about TB's safety and since he appeared to have mental health needs and also to be intoxicated. TB declined liaison and diversion assessments whilst in custody.
- 6.4. TB had a history of alcohol use and in 2019 had been diagnosed with a personality disorder. Agencies including a drug and alcohol service did not successfully engage with TB, whose family lived elsewhere and had limited contact with him.
- 6.5. **Learning point:** Evidence suggests that strengths-based and relationship focused approaches can help to support engagement with people who self-neglect. Finding out more about someone who self-neglect's life story can assist with identifying opportunities to do this.
- 6.6. On 11 January 2023, TB was admitted to hospital after being found on the floor at a train station. TB was assessed as lacking mental capacity to make decisions about remaining in or leaving hospital and stayed there as a Best Interests Decision. Support from homelessness services was requested as was mental health input. The latter could not be provided until TB's self-neglect was resolved as no record of a diagnosis could be found.
- 6.7. TB left the hospital without being discharged on 18 January 2023, was found by the police and was kept in custody overnight. Despite this, TB returned to, and remained in, the cottage, when he was released from custody.

- 6.8. **Learning point:** Assess mental capacity and, where indicated, use Deprivation of Liberty Safeguards. This is especially important when people who are self-neglecting are in hospital. This can allow time for observation, assessment (including of mental health needs) and planning for their discharge.
- 6.9. On 1 February 2023, A Self-Neglect Professionals meeting was held as part of the adult safeguarding process. A number of actions were set, which included contact with TB's son, access to mental health services, housing and fire safety input in TB's cottage, contact with homelessness services and TB's GP and consideration of referral to the Multi-Agency Risk Management Forum.
- 6.10. As a result, mental health services wrote to TB offering him an appointment but he did not attend.
- 6.11. A further adult safeguarding meeting was held on 8 March 2023 at which further actions were agreed. These included assessing whether the cottage was uninhabitable, further family contact, installing fire alarms making the cottage safer. This was considered to be a less risky option than TB becoming homeless.
- 6.12. On 27 March 2023 a Housing Officer visited the cottage with TB's son. They were unable to gain entry.
- 6.13. Incidents continued and after refusing to leave a bus whilst intoxicated, TB was banned from using buses in April/May 2023 and further assaults on minors were reported. In May 2023 there two further interventions, by the police, including taking TB home, in response to reports that he was walking in the road. Local residents expressed concerns to the police about TB's living conditions and that he might be hit by a car.
- 6.14. At 12.39am on 18 May 2023, a member of the public reported to the police that they had found TB deceased in the road near his home. He had been hit by a car. The driver of the car was found and arrested.
- 6.15. **Learning point:** It is sometimes hard to delineate one risk from another when working with people who self-neglect and who present a range of challenges to services. These might include substance dependency, uncertainty about mental capacity, refusal of help and risky behaviours. Detailed risk assessments which consider each risk, how it relates to another, what the likelihood and severity might be and how it could be managed, can help to identify areas to focus interventions and limited resources on.
- 6.16. A number of key factors emerge from combining the findings from IL and TB with those from other SARs considered in this review.

## **7. Findings from audits**

7.1. The WSSAB Self-Neglect and Safeguarding Case File Audit Feedback presentation August 2022 and the WSSAB Multi-Agency Action Planning: Self-Neglect Case File Audit November 2022, identified the following areas for multi-agency practice development, all of which have had action plans which have since been delivered.

### **7.2. The identification of self-neglect and timely recording**

7.2.1. Understanding what each agency's referral mechanisms and processes are, including sharing resources to allow some consistency and identify opportunities between agencies.

7.2.2. The action relating to this finding was for the WSSAB Learning and Policy subgroup to look into creating a learning briefing about the audit and its outcomes. This resulted in re-promoting existing resources and consideration of new resources that can be created. These resources have since been published and promoted.

7.2.3. Personal ownership of members to ensure the dissemination of self-neglect resources throughout their agencies. Where possible, establish what level of audience material has been shared with, for reassurance of awareness. This has now been requested of WSSAB members.

### **7.3. The need for a lead agency/professional to be identified to coordinate support**

7.3.1. The action relating to this finding was for the WSSAB to reshare and educate around the self-neglect policy and reiterate that the most involved agency should lead on coordination (which is not always the local authority). This has since been communicated to the WSSAB.

7.3.2. There was also an action relating to reviewing the flowchart within the Sussex self-neglect policy of which agency should lead on cases. This has been actioned and was also included in the review of the Safeguarding Thresholds document, which was reviewed in January 2023.

### **7.4. Undertaking mental capacity assessments**

7.4.1. The action relating to this finding was for the WSSAB to share best practice guidance with agencies around areas that should be considered when carrying out a Mental Capacity Assessment. In response to this the WSSAB created a Mental Capacity learning briefing and podcast.

## **7.5. Making Safeguarding Personal**

- 7.5.1. The action relating to this finding was for the WSSAB to re-promote WSSAB learning resources around Making Safeguarding Personal and Professional Curiosity from the point of raising a concern. This has now been actioned.

## **7.6. The need for multi-agency meetings to be held which are well coordinated and useful to manage concern/risk**

- 7.6.1. The action relating to this finding was for the WSSAB to reshare the self-neglect policy to reiterate that the agency most involved with the client should lead on coordination of multi-agency meetings (which isn't always the local authority). This has now been actioned.
- 7.6.2. These findings and actions will be considered along with the findings from the meta-review of SARs in section 10 of this report.

## **8. Findings from the meta-analysis**

- 8.1. This meta-analysis considers the findings and conclusions of previously published Sussex SARs. It involved a comparative reading of each review to identify similarities and differences between them and the compilation of these into emergent themes consistent with the terms of reference. It did not involve reanalysis of the information, including contemporary records, chronologies, individual management reviews, reflections of practitioners etc, that were used in the reviews. Consequently, the findings of the meta-analysis are to a degree influenced by the different styles of each review and their attention to specific topics.
- 8.2. The following analysis draws out the different aspects of single and multi-agency practice and the use of policies, procedures and processes identified in the SARs. Each SAR included recommendations for change. It is usual practice for an action plan to be created to implement the recommendations from each SAR so some of the recommendations made may already have been implemented. For brevity, the recommendations made in the SARs are not included in this report. Four SARs analysed in this report were commissioned by WSSAB. A summary of the actions taken by WSSAB to implement the recommendations in these SARs is included in appendix 1.

### 8.3. Process and multi-disciplinary working

#### 8.3.1. The terms of reference for this review included:

- The use of the self-neglect process, considering practical changes in relation to support for complex cases. This will include consideration of the information/work WSSAB have already obtained/concluded/what WSSAB have done so far, i.e., audits, action plans, learning briefings and podcasts as well as WSSAB's planned actions for 2023/24 in WSSAB's subgroup workplans.
- Multi-disciplinary team working and practice including, roles and responsibilities in working with self-neglect cases, providing clarity on who can lead on multi-agency interventions. This may also require further guidance for care homes/agencies on their roles in self-neglect, including what to do when someone is refusing care.

#### 8.3.2. All of the SARs considered in this analysis identified difficulties in responding to the needs of people who self-neglect. Some of these were also connected with challenges with multi-agency working. Consequently, significant practice factors in the use of self-neglect processes were:

**Table 3 Significant practice factors in the use of self-neglect processes**

**Please note: The factors listed in the table below are specific to a particular review, location and time and may have already received attention and progress regarding process or practice development.**

Findings	Factors
Confusion over which agency should lead and Application of lead professional role/named worker	<p>Any practitioner could call a multi-agency or multi- disciplinary meeting but:</p> <ul style="list-style-type: none"> <li>• There were problems finding time for them in diaries</li> <li>• Practitioners asked themselves, am I the "right person?" and what responsibilities will I take on if I take the lead?</li> <li>• There were differences in opinion on whether the self-neglect process was clear on which agency should take a leadership role.</li> <li>• There was uncertainty about who would coordinate decision-making when there were several health care professionals and services involved, alongside social care.</li> <li>• There was uncertainty about which service was responsible when there are multiple needs or concerns including physical health, mental health, mental capacity and learning disability, substance use needs and concerns.</li> <li>• There was uncertainty about which service was responsible for drawing other organisations together and for ensuring that there was a more collaborative, holistic approach.</li> <li>• There was a lack of escalation routes when practitioners experienced obstacles.</li> <li>• Without a lead professional actions are unlikely to be taken.</li> </ul>

<p>Lack of multi-agency meetings/only meeting at times of crisis, otherwise working as single agencies in parallel</p>	<ul style="list-style-type: none"> <li>• Practitioners across different services were unaware of how to access multi-agency panels and complex case forum discussions.</li> <li>• There were no triaging and feedback mechanisms or sharing of information about referral outcomes between West Sussex Adult Social Care and housing.</li> <li>• The remit of Careline and Hyde Housing in the West Sussex Thematic SAR in responding to welfare concerns involving their clients/residents was not understood.</li> <li>• More effective information sharing between agencies and professionals is needed to prompt the use of the multi-agency Safeguarding policy and procedures.</li> <li>• There was a lack of attention to completing mental capacity assessments, looking at the Self Neglect policy, completing a Risk Enablement Plan or considering if a complex case panel submission may assist.</li> <li>• There was much inter-agency communication about trying to involve additional services and asking others to act, but little evidence of a mutually agreed coherent care plan with identified tasks for all involved agencies that was reviewed and adapted over time.</li> <li>• The need for an updated capacity assessment was never addressed despite repeated requests for this work to be prioritised.</li> </ul>
<p>Not using strengths-based and relationship-based approaches</p>	<ul style="list-style-type: none"> <li>• There is a need to identify and respond to moments of motivation prompted by the person who is self-neglecting's own ambitions even if these are not met by statutory services.</li> <li>• The difficulty however was that the social work role which should have been as lead professional and coordinator was not effective and there was no real attempt to utilise the strengths of the relationships built by the other practitioners to achieve goals such as an effective capacity assessment.</li> </ul>
<p>Insufficiently wide range of organisations at multi-agency meetings</p>	<ul style="list-style-type: none"> <li>• The Fire service was not involved even when fire was a concern.</li> <li>• Information from different agencies was not triangulated to gain a holistic picture of risk or opportunities.</li> <li>• Lack of use of services such as Careline or housing in West Sussex.</li> </ul>
<p>Lack of clarity on how to escalate concerns when requests for support, advice and involvement did not result in more collaborative engagement</p>	<ul style="list-style-type: none"> <li>• Need for greater understanding of self-neglect, including where the adult safeguarding pathway was appropriate because the person was unable to protect themselves.</li> <li>• This is made harder when working across local authority areas.</li> </ul>

Recognition of self-neglect	<ul style="list-style-type: none"> <li>• Professionals still struggled to understand self-neglect and to incorporate it effectively into the safeguarding processes.</li> <li>• This is particularly the case where service users have mental health problems or are substance dependent.</li> <li>• Self-neglect procedures are not used.</li> </ul>
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#### **8.4. Summary of findings/areas for development in process and multi-disciplinary working**

- 8.4.1. The WSSAB Self-Neglect Briefing Note: Sussex procedures to support adults who self-neglect, Version 2, June 2020<sup>2</sup>, sets out updates to the self-neglect procedures within the Sussex Safeguarding Adults Policy and Procedures to take account of learning from SARs involving self-neglect. The briefing sets out the key sections of the Sussex Self-Neglect Procedures. The procedures provide a clear pathway to assist professionals from any organisation to use a multi-agency approach when working with adults who are displaying self-neglecting behaviours.
- 8.4.2. The SARs included in this analysis identified a series of problems applying procedures in practice. These include: identifying the need for, and agreeing, a lead agency to coordinate multi-agency actions; identifying a lead professional to maintain contact with the person who is self-neglecting; and insufficient recognition of the need for multi-agency meetings. There was a lack of clarity about when to escalate from single to multi-agency work.
- 8.4.3. The relevant policies and procedures appear to be in place, but the challenge is implementing them, especially across different agencies.

#### **8.5. Mental Capacity**

- 8.5.1. The terms of reference for this analysis included:
- The use of Mental Capacity Assessments, best interest decisions, Deprivation of Liberty Safeguards (DoLS), the Mental Health Act and public health legislation, including determining mental capacity by looking at patterns of decision making and understanding medical conditions that might influence capacity, especially in those areas influencing executive functioning.
  - Determining mental capacity by looking at patterns of decision-making and understanding medical conditions that might influence capacity.
  - Roles and responsibilities in working with self-neglect cases, including clarity on who can lead on multi-agency interventions.

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<sup>2</sup> [Self-Neglect Briefing Note: Sussex procedures to support adults who self-neglect \(PDF\)](#)

**Table 4 Significant practice factors in mental capacity**

**Please note: The factors listed in the table below are specific to a particular review, location and time and may have already received attention and progress regarding process or practice development.**

Findings	Factors
Lack of consideration of other legal options i.e. Court of Protection (CoP).	<ul style="list-style-type: none"> <li>• When there was no apparent disagreement about treatment, there was no referral to the Court of Protection (CoP) to confirm this.</li> <li>• Reluctance to seek emergency orders from the CoP.</li> </ul>
Assumption of mental capacity	<ul style="list-style-type: none"> <li>• There was uncertainty about when to doubt capacity.</li> <li>• There were difficulties engaging people who self-neglect in capacity assessments due to their unwillingness to accept professional's analysis and were sensitive to any judgements that were made about their cognitive capacity or mental health.</li> <li>• Appearance of ability meant no reason to doubt capacity.</li> </ul>
Making decisions about protection vs freedom	<ul style="list-style-type: none"> <li>• Misconception of a "Right to make unwise decisions" resulting in no use of mental capacity assessments.</li> <li>• Uncertainty about how to apply more restrictive and protective actions.</li> <li>• Deprivation of Liberty Safeguards were not applied for.</li> </ul>
Over-reliance on substance use to explain presentation	<ul style="list-style-type: none"> <li>• Limited involvement by Substance Misuse services (often as a result of difficulties with engagement) understood as an ambivalence to address their drug use. It was felt that 'someone has to want change to be able to achieve change'. This can underestimate the coercive and controlling nature of addiction.</li> </ul>
Fluctuating Capacity	<ul style="list-style-type: none"> <li>• There is varying experience of managing fluctuating capacity in the work force.</li> <li>• It is difficult to assess fluctuating capacity when a person's ability to make safe and rational decisions is intermittent.</li> </ul>

Acquired Brain Injury (ABI) and frontal lobe damage	<ul style="list-style-type: none"> <li>• There is insufficient awareness of the impact of ABI and little access to expert knowledge about it, leading to a lack of capacity assessments.</li> <li>• Few specialist services are available to directly work with people experiencing ABI and this means that most of the support provided to people with ABI is from generic services with minimal specialist support available to the staff working there.</li> <li>• Lack of recognition of the need for specialist support or guidance with ABI.</li> <li>• Assumption that mental capacity assessments are not required when a person apparently is able to communicate their wishes and feelings even if their executive functioning may be limited.</li> <li>• Little provision of long-term community neurological input for people with ABI as the Community Neurological Rehabilitation Team (Brighton &amp; Hove) only provides targeted interventions against specific goals focussed on rehabilitation. Given that ABI often leads to long-term difficulties and many people with ABI will require long-term support this seems to be a shortfall in the service. In East Sussex, Headway Sussex, a charity, offers long term support, reablement and respite but were not able to engage without additional interventions from substance use services.</li> <li>• Much of the intervention with people with ABI is provided by care agencies with little expertise and apparently no access to specialist support. When there are problems other agencies become involved to work to resolve difficulties, but these interventions are often short term and focussed on resolving immediate problems not providing long term support.</li> <li>• Lack of specific policies, processes and training in ABI.</li> </ul>
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## 8.6. Summary of findings/areas for development in mental capacity

- 8.6.1. The assessment of the mental capacity of people who self-neglect, as evidenced by SARs, is a challenging area of practice. Key challenges identified in this analysis and other SARs include when to question mental capacity, particularly when someone is able to show decisional capacity (they are able to comprehend questions and formulate and express answers with sufficient verbal skill) but do not show the executive capacity to put expressed decisions into action.
- 8.6.2. This is an especially important factor in the assessment of the mental capacity of people with ABI, often but not exclusively associated with prolonged substance use. Trauma can result in a similar mismatch between decisional and executive capacity, although most frequently at a cognitive and brain chemistry rather than at a brain structural level. Executive mental capacity can also be affected by the coercive and controlling effects of substance dependency and addiction. ABI can also be caused by alcohol exposure before birth.
- 8.6.3. The Sussex Safeguarding Adults Procedures include references to ABI in Sections 2.6, 2.7 and 2.8 which are concerned with self-neglect and mental capacity. These procedures make clear reference to the need to distinguish between

'decisional and executive capacity' described as 'the difference between capacity to make a decision (decisional capacity) and capacity to actually carry out the decision (executive capacity)'. The procedure continues that 'Good practice includes considering whether the adult has the capacity to act on a decision they have made (executive capacity)' and 'Where decisional capacity is not accompanied by the ability to carry out the decision, overall capacity is impaired and interventions by professionals to reduce risk and safeguard wellbeing may be legitimate'. These procedures acknowledge that such work is complex and suggest that legal advice may be required but do not provide any specific guidance as to how practitioners should undertake the assessments required to distinguish between decisional and executive capacity.

- 8.6.4. In addition, one SAR identified that there was no suggestion in the Procedures that such assessments should involve the use of other professionals with specialist expertise. There is also no specific reference in the Procedures to the need for specialist input when working with people who have an ABI.
- 8.6.5. Panel discussions for this review also identified the actions to take when, for example, a person who self-neglects refuses a s42 Care Act 2014 enquiry. Guidance for practitioners should be created which includes the provisions under s11(2a) and (2b) of the Care Act 2014 and the need to consider vital and public interests in these situations.

## **8.7. Risk management**

- 8.7.1. The terms of reference for this analysis included:

- The completion and implementation of risk enablement plans, to include the difference between keeping someone safe and safeguarding.

**Table 5 Significant practice factors in risk management**

**Please note: The factors listed in the table below are specific to a particular review, location and time and may have already received attention and progress regarding process or practice development.**

Findings	Factors
Risk management	<ul style="list-style-type: none"> <li>• Risk enablement plans were not used.</li> <li>• There was a slow response to needs.</li> <li>• Inappropriate communication methods (use of email rather than face-to-face or telephone), lack of discussion between agencies, lack of leadership when risks were identified. Record keeping needs to be accurate, comprehensive and up-to-date.</li> <li>• Risks were not articulated and not explored.</li> <li>• In West Sussex, "agencies were working in a vacuum, where key agencies were experiencing operational pressures...Workflow processes between agencies did not ensure robust assessment of risk and information sharing. This created an environment where the decisions made, and actions taken, did not deliver safe outcomes at all levels: individual casework, organisational priority setting and multi-agency accountability for safeguarding policy and procedure".</li> <li>• Fire risks not recorded, shared, understood and responded to.</li> <li>• Detailed risk assessments, delineated the interrelationship between risks were not used for people who presented a range of challenges to services.</li> </ul>
Case closure when no funded services are provided	<ul style="list-style-type: none"> <li>• This reduces opportunities for relationship-building, assessment, planning, coordination, and oversight.</li> <li>• It limits opportunities is for early intervention.</li> <li>• Limited cross-referencing opportunities when new information is received.</li> </ul>

## **8.8. Summary of findings/areas for development in risk management**

8.8.1. Problems in awareness, assessment, recording and communicating risks was a pervasive theme in the SARs analysed and is again a feature seen more widely in other national SARs. Risk management is fundamental to effective work with people who self-neglect and may be foundational for all the other aspects of effective practice in this area. One particular area for further development is fire safety risk assessment. Management oversight of practice is essential.

## **8.9. Barriers to practice**

8.9.1. The terms of reference for this analysis included:

- The exploration of barriers to practice, including resource issues and time constraints which may impact upon best practice. This should be considered in a supportive rather than critical way.

- Services working with people who misuse substances, self-neglect, self-harm, and become homeless need to recognise how trauma can affect treatment, presentation, engagement, and the outcome of behavioural health services. A person can be blamed for their substance misuse or homelessness when their actions are in fact coping strategies.

**Table 6 Significant practice factors in barriers to practice**

**Please note: The factors listed in the table below are specific to a particular review, location and time and may have already received attention and progress regarding process or practice development.**

Findings	Factors
Disengagement	<ul style="list-style-type: none"> <li>• Need for trauma-informed understanding of disengagement: it is predictable; may be due to trauma responses; is a reason to keep cases open and not close them; requires sensitive and flexible responses.</li> <li>• Recognition of when withdrawal indicates that a significant problem is developing and updating risk assessments in response to this.</li> <li>• Withdrawal becomes normalised and sensitivity to risk reduces. One reason for this may well have been that there are limited options for professionals. "The statutory options are limited and quite draconian however the absence of a clear assessment of capacity with the reasons detailed explaining why there was no intervention meant that the professionals involved did not have a defensible position".</li> <li>• Plans do not account for practical difficulties in implementation and how to manage service refusal.</li> </ul>
Trauma informed approaches	<ul style="list-style-type: none"> <li>• Need to find what happened to a person who is self-neglecting rather than what is wrong with them.</li> <li>• Recognise the problems someone presents (homelessness, substance misuse, self-neglect and self-harm) as possible responses to past trauma. Trauma-informed care (TIC) involves a broad understanding of traumatic stress reactions and common responses to trauma.</li> <li>• Recognise that self-neglect may be a symptom of mental ill health. Do not preclude mental health interventions on the basis that other factors (which may be related) have not been resolved.</li> <li>• Do not wait until people are stable or settled before interventions can be made.</li> </ul>
Covid-19	<ul style="list-style-type: none"> <li>• Impact on availability of services and staff; reduced face-to-face contact.</li> </ul>

Temporary(?) service problems	<p>These were specific to certain agencies and may have been time specific too and included:</p> <ul style="list-style-type: none"> <li>• IC24<sup>3</sup>: high demand on the service and high volume of calls leading to delays and no updates; lack of access to case notes (NHS Smart Card not activated).</li> <li>• WSCC: there were recording inaccuracies identified relating to specific actions, timelines, and detail about the adult's circumstances; operational circumstances included Community Team staff absences, managing Safeguarding concerns and enquiries on duty as unable to allocate, working with other high risk safeguarding concerns and trying to process and assess the risks associated with bulk Police SCARF (single combined assessment of risk form) downloads.</li> </ul>
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## 8.10. Summary of findings/areas for development in barriers to practice

8.10.1. The key structural barriers to practice not already identified in the previous sections of this meta-analysis concerned the application of trauma-informed approaches which are time intensive and require considerable flexibility in application. Effective approaches to working with people with self-neglect are widely recognised to require, amongst others, relationship and trust building over time, history taking, consistency of contact, persistence and the ability to identify and capitalise on moments of motivation. Many professionals do face competing demands for their time and attention which militate against these approaches.

8.10.2. One of the systems change priorities for the Sussex Changing Futures programme is to build a Trauma Informed workforce across Sussex. There are 52 Sussex organisations and 190 members who are part of the Changing Futures Trauma Informed Community of Practice. This could also consider models elsewhere (including Bristol, Plymouth and London Borough of Camden). There is also a need to consider the impact of barriers to access to services faced by people who self-neglect and this could form part of the work being undertaken by WSSAB on discriminatory abuse.

## 8.11. Care homes/care agencies and self-neglect

8.11.1. The terms of reference for this analysis included:

- Further guidance for care homes/agencies and their roles in self-neglect, including what to do when someone is refusing care.

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<sup>3</sup> NHS IC24 provides services across the South and East of England, including the NHS 111 service, clinical assessment services, face-to-face urgent care appointments and home visiting.

**Table 7 Significant practice factors in care homes/care agencies and self-neglect**

**Please note: The factors listed in the table below are specific to a particular review, location and time and may have already received attention and progress regarding process or practice development.**

Findings	Factors
Safeguarding practice	<ul style="list-style-type: none"> <li>• There is a need for direction for care providers on what to do when services are refused (see also table 4: Significant practice factors in mental capacity).</li> <li>• Better communication and transparency with providers is required about the progress of safeguarding cases and decisions.</li> <li>• There is a need to escalate concerns between agencies where actions are not completed, or updates are not provided.</li> <li>• There is a need for effective timely plan for safeguarding enquiries and/or clear recording of the decisions regarding the timescale of the enquiry.</li> <li>• GPs are often not made aware of Safeguarding Adult referrals (including self-neglect).</li> </ul>
Responding to self-neglect in care homes	<p>There is a need for:</p> <ul style="list-style-type: none"> <li>• Clarification of responsibilities for reporting and responding to self-neglect.</li> <li>• Clarification of when to raise safeguarding concerns about self-neglect.</li> <li>• Clarification of the distinction between abuse and neglect and poor quality of service.</li> <li>• Guidance and direction for care homes on responsibilities in mental capacity assessment.</li> <li>• Clarification on the difference between self-neglect and neglect/acts of omission in a care setting.</li> <li>• Some indicators of neglect may result from self-neglect.</li> </ul>

## **8.12. Summary of findings/areas for development in care homes/care agencies and self-neglect**

8.12.1. Care home and care agencies need to pay as much attention as statutory services must do to self-neglect and to the legal context of mental capacity. They often, however, are unaware of their responsibilities in these areas. This requires both a contracts and commissioning approach and a training and development approach which considers care providers as part of a system of care in which they are considered as partners performing an equally important role to that of, for example, statutory organisations. Any weaknesses or challenges within the system of care should be considered to be the responsibility of all partners to resolve through, for example, training interventions.

8.12.2. The National Institute of Clinical Excellence has produced guidance on this area Safeguarding Adults in Care Homes (nice.org.uk) in recognition that care homes often struggle to understand:

- the difference between safeguarding issues and poor practice;
- when and how to make safeguarding referrals to the local authority.

### 8.13. Use of Adult Safeguarding processes

8.13.1. The terms of reference for this analysis included:

- The difference between safeguarding and keeping someone safe.

**Table 8 Significant practice factors in safeguarding and keeping someone safe**

**Please note: The factors listed in the table below are specific to a particular review, location and time and may have already received attention and progress regarding process or practice development.**

Findings	Factors
No use of safeguarding processes	<ul style="list-style-type: none"> <li>• Workers with most involvement are sometimes those with least direct experience of undertaking formal safeguarding assessments.</li> <li>• Disengagement should be recognised as a safeguarding concern.</li> </ul>
Timely response	<ul style="list-style-type: none"> <li>• Delays, sometimes even of a day, can result in poor outcomes in some cases of self-neglect. This has service capacity (backlog, annual leave etc.) and risk assessment components.</li> <li>• There is a need for follow-up to check that commissioned services are working as planned but this is compromised by lack of resources to do this consistently.</li> </ul>
Safeguarding thresholds	<ul style="list-style-type: none"> <li>• There is a need to ensure that these are consistent with the Care Act 2014 and associated guidance.</li> <li>• There is a lack of recognition that self-neglect (including substance dependency or not accepting or arranging necessary health treatment) is a safeguarding concern.</li> <li>• There is confusion about how statutory guidance is interpreted and implemented, particularly about how self-neglect may not prompt a Section 42 enquiry. Assessment is made on a case by case basis, and a decision on whether a safeguarding response is required depends on the adult's ability to protect themselves by controlling their own behaviour without external support.</li> <li>• There is a belief that if someone is intermittently engaging with services then there are no safeguarding concerns.</li> <li>• There is a question of when to make "other" (non-statutory adult safeguarding) enquiries.</li> <li>• Agencies need to improve communication and information sharing to make effective use of the Sussex safeguarding threshold document and also maximise joined-up approaches to planning to make efficient use of their resources.</li> </ul>

## 8.14. Summary of findings/areas for development in safeguarding and keeping someone safe

- 8.14.1. The Sussex Safeguarding Thresholds: Guidance for professionals' document (January 2020) is used across Sussex to support professionals, partners and providers to decide on whether to report a safeguarding concern for an adult with care and support needs.
- 8.14.2. It is important to ensure that guidance of this kind is consistent with the Care Act 2014. National adult safeguarding guidance warns against the use of threshold documents since these may become a mechanistic "tick box" process (see [Making decisions on the duty to carry out Safeguarding Adults enquiries: A suggested framework to support practice, reporting and recording Appendices](#)).

## 9. Next steps

- 9.1. All the findings in this meta-analysis are consistent with the findings from other SARs nationally. The SARs analysed in this review do not always provide insights into the reasons behind the findings but the overall picture that emerges is that of difficulties in the recognition of risk and seriousness; difficulties in recognising the need to use policy and guidance; difficulties with engagement with people who self-neglect; difficulties in multi-agency working, including with care providers; and communication and difficulties in deciding and implementing the correct responses.
- 9.2. The next step for the thematic review is to arrange practice sessions to explore these findings further and then identify and make changes to procedures/guidance on working with people who self-neglect, including:
  - The use of risk factors to identify cases to escalate to multi-agency interventions using methods set out in practice guidance to engage with and support people who self-neglect
  - Legal literacy
  - Fire and other high risks
  - Questioning, considering and assessing mental capacity
  - Identifying any specific tailored training or guidance needs
- 9.3. In addition, each SAR made several recommendations for development and each Safeguarding Adults Board will have created and implemented action plans to implement these and monitor progress.
- 9.4. Despite this and consistent with the national picture, policies and procedures, guidance, training and forums for escalation exist but their impact is uncertain.

- 9.5. Based on these findings and experience from other national SARs, in addition to the aims already identified for this thematic review, there would appear to be a need to integrate the different policies and procedures, guidance, training, systems, forums for escalation, multi-agency processes etc. at an intra- and inter-organisational level.
- 9.6. At an intra-organisational level, their use could be incorporated in case supervision and discussions as standing items. Targets for their use could be included as appropriate in professional development plans and in appraisals. Practitioners could present cases and learning from them in case forums and seminars. As part of continuing professional development, practitioners could be required to demonstrate how they applied these directions, guides and processes and encouraged to reflect on their further development.
- 9.7. The results of this could influence training commissioning and content. Responses to self-neglect and the use of policies and procedures, guidance, training and forums for escalation etc. could be included in case audits and reviews.
- 9.8. A number of practice aids could be developed. These could include embedding guidance notes in electronic forms and designing forms so that they require practitioners to explain their decision-making and prompt them to consider, for example, multi-agency working and sharing information, or assessing mental capacity when there may be concerns about a person's ability to put their decisions into action. Decision support tools could similarly be embedded to assist practitioners and managers with risk identification and assessment.
- 9.9. At an inter-organisational level, policies and procedures, guidance, training and forums for escalation could be operationalised into shared tools and forms to be used with across agencies, and their use and effectiveness could be monitored by Safeguarding Adults Boards.
- 9.10. The discussions about this review and its findings led the panel to recommend that a separate policy and procedure may also be useful to provide additional focus and attention to self-neglect and hoarding and to emphasise the long-term, time intensive and relationship-based nature of effective interventions. This would respond to the need to refer early for multi-agency discussion and involvement and to the challenges of engaging with people who self-neglect and hoard. It would also promote that supporting people who self-neglect and hoard is not just a safeguarding matter.

## 10. Summary of findings

### 10.1. Summary of findings for IL

- 10.1.1. **Learning point:** S42 safeguarding enquiries provide a framework for agreeing actions and monitoring their implementation. If a plan is proposed outside of the safeguarding process, then a system for ensuring that action is taken needs to be agreed.
- 10.1.2. **Learning point:** Tasks need to be allocated to a specific person to be actioned within an agree timescale. There is a potential point of failure if there is no review or accountability process for ensuring that actions are carried out.
- 10.1.3. **Learning point:** Care services may need support to recognise that self-neglect, including refusal of care or of food or hydration, is a safeguarding concern and to seek help from other services to assess and, where appropriate, intervene. Lowered food and fluid intake may also be a sign that end-of-life care is required. Careful attention is needed to individual circumstances and context when determining which approach to take in these situations.

### 10.2. Summary of findings for TB

- 10.2.1. **Learning point:** Evidence suggests that strengths-based and relationship focused approaches can help to support engagement with people who self-neglect. Finding out more about someone who self-neglect's life story can assist with identifying opportunities to do this.
- 10.2.2. **Learning point:** Assess mental capacity and, where indicated, use Deprivation of Liberty Safeguards. This is especially important when people who are self-neglecting are in hospital. This can allow time for observation, assessment (including of mental health needs), and planning for their discharge.
- 10.2.3. **Learning point:** It is sometimes hard to delineate one risk from another when working with people who self-neglect and who present a range of challenges to services. These might include substance dependency, uncertainty about mental capacity, refusal of help and risky behaviours. Detailed risk assessments which consider each risk, how it relates to another, what the likelihood and severity might be, and how it could be managed, can help to identify areas to focus interventions and limited resources on.

### 10.3. Demographics

- 10.3.1. The SARs included in this meta-analysis included little data on protected characteristics under the Equality Act 2010. The WSSAB has a discriminatory

abuse action plan and it might be useful to include appropriate demographic information in future SARs.

#### **10.4. Process and multi-disciplinary working**

- 10.4.1. The WSSAB Self-Neglect Briefing Note: Sussex procedures to support adults who self-neglect, Version 2, June 2020, sets out the key sections of the Sussex Self-Neglect Procedures. The procedures provide a clear pathway to assist professionals from any organisation to use a multi-agency approach when working with adults who are self-neglecting.
- 10.4.2. The SARs included in this analysis identified a series of problems in putting these procedures in practice. There is a need for procedures on processes that include:
- identifying the need for, and agreeing, a lead agency to coordinate multi-agency action.
  - identifying a lead professional to maintain contact with the person who is self-neglecting.
  - recognising when multi-agency meetings are required.
  - clarity about when to escalate from single to multi-agency work and that this can be done outside of a s42 enquiry.
- 10.4.3. A safeguarding tool kit of options, assessments and escalation routes might support practitioners in their work.
- 10.4.4. These findings were consistent with those from the WSSAB Self-Neglect and Safeguarding Case File Audit which identified, amongst other actions, a need to improve identification of, and response to, self-neglect, including the identification of a lead agency or professional. There was also a need to make responses to self-neglect more personalised, to make safeguarding personal and to increase professional curiosity.
- 10.4.5. Appropriate multi-agency forums already exist in the form a Multi-Agency Risk Management (MARM) process in WSSAB and ESSAB. B&HSAB is also in the process of introducing a MARM process.

#### **10.5. Mental Capacity**

- 10.5.1. There is a link between Acquired Brain Injury (ABI) and self-neglect. The Sussex Safeguarding Adults Procedures include references to ABI and make reference to the need to distinguish between 'decisional and executive capacity', that good practice requires consideration of both and that a person's mental capacity is impaired if they are unable to put their decisions in action. In these cases, 'interventions by professionals to reduce risk and safeguard wellbeing may be legitimate'.

- 10.5.2. Specific guidance should be included in the Sussex Safeguarding Adults Procedures on how practitioners should undertake mental capacity assessments to distinguish between decisional and executive capacity, and when to involve other professional expertise in this, particularly for people with ABI. This could also be supported by role specific training in this area.
- 10.5.3. These findings were consistent with those from the WSSAB Self-Neglect and Safeguarding Case File Audit, which identified a need to share best practice guidance with agencies around areas that should be considered when carrying out a Mental Capacity Assessment.

## **10.6. Risk management**

- 10.6.1. Risk assessment and management processes in self-neglect need to be further developed to improve:
- Awareness, assessment, recording and communicating risks.
  - Fire safety risk assessment.
- 10.6.2. Management oversight of practice is essential and should be improved.

## **10.7. Barriers to practice**

- 10.7.1. Trauma-informed approaches need to be further developed. One of the systems change priorities for the Sussex Changing Futures programme is to build a Trauma Informed workforce across Sussex. This could also consider models elsewhere (including Bristol, Plymouth and London Borough of Camden). There is also a need to consider the impact of barriers to access to services faced by people who self-neglect and this could form part of the work being undertaken by WSSAB on discriminatory abuse.

## **10.8. Care homes/care agencies and self-neglect**

- 10.8.1. Contracts and commissioning approach and training and should consider care providers as part of a system of care in which they are considered as partners performing an equally important role to that of, for example, statutory organisations. Any weaknesses or challenges within the system of care should be considered to be the responsibility of all partners to resolve through, for example, training interventions. Care home and care agencies need to pay as much attention as statutory services must do to self-neglect and to the legal context of mental capacity.
- 10.8.2. The National Institute of Clinical Excellence has produced guidance on Safeguarding Adults in Care Homes ([nice.org.uk](https://www.nice.org.uk)). This guidance should be used in care home practice development and contract monitoring.

## **10.9. Use of Adult Safeguarding processes**

- 10.9.1. Safeguarding Adults processes for self-neglect and any adult safeguarding thresholds should be compliant with the Care Act 2014 and should be informed by subsequent national guidance. Management oversight of the application of processes and interventions is essential.
- 10.9.2. The discussions about this review and its findings led the panel to recommend that a separate policy and procedure may also be useful to provide additional focus and attention to self-neglect and hoarding and to emphasise the long-term, relationship-based nature of effective interventions. This would respond to the need to refer early for multi-agency discussion and involvement and would promote that supporting people who self-neglect and hoard is not just a safeguarding matter.

## **11. Implementation**

- 11.1. Practice development sessions should be arranged to explore these findings further and then identify and make changes to procedures/guidance on working with people who self-neglect, including:
  - The use of risk factors to identify cases to escalate to multi-agency interventions using methods set out in practice guidance to engage with and support people who self-neglect
  - Legal literacy
  - Fire and other high risks
  - Questioning, considering and assessing mental capacity
  - Identifying any specific tailored training or guidance needs
- 11.2. Based on these findings and experience from other SARs, in addition to the aims already identified for this thematic review, there would appear to be a need to integrate the different policies and procedures, guidance, training, systems, forums for escalation, multi-agency processes etc. at an intra- and inter-organisational level. This should also include reference to the work on discriminatory abuse by WSSAB.
- 11.3. At an intra-organisational level, case seminars, supervision, professional development plans and appraisal targets, could be used to facilitate safeguarding practice development.
- 11.4. A number of practice aids could be developed. These could include embedding guidance notes in electronic forms and forms could be designed so that they require practitioners to explain their decision-making and could prompt further

actions. Decision support tools could similarly be embedded to assist practitioners and managers with risk identification and assessment.

- 11.5. At an inter-organisational level, policies and procedures, guidance, training and forums for escalation could be operationalised into shared tools and forms to be used across agencies, and their use and effectiveness could be monitored by Safeguarding Adults Boards. This could include the creation of a separate Self-Neglect and Hoarding Policy and Procedure.
- 11.6. Additional work could be completed on any outstanding actions in the WSSAB Multi-Agency Action Planning: Self-Neglect Case File Audit November 2022.

## **12. Recommendations**

- 12.1. The review panel concluded that the focus for practice and policy development should be on a small number of recurring themes. After discussion, the panel chose the following areas:
  - Multi-agency working at an earlier time in a case, with appropriate leadership.
  - Attention to Mental Capacity and reasons for intervention.
  - Knowing what to do: what approaches work and acceptance of the time that it takes to work self-neglect cases.
- 12.2. After the necessary approval processes have been completed, it is recommended that an action plan is created to commence the development work in these areas in line with the findings from this review.

## Appendix 1

Actions taken by WSSAB in response to recommendations in the four SARs which it commissioned, and which are analysed in this report, include:

- Promotion of existing internal Board resources, policy and process and resources of other Board partners.
- Creation of new resources such as learning briefings and podcasts for all SARs and also specific areas of learning such as self-neglect, risk assessment and quality and safeguarding.
- Seeking assurance of Board partner forums and processes from specific agencies, such as complex case forums, self-neglect guidance, making safeguarding personal, supervision processes and hospital discharge processes.
- Carrying out an audit of self-neglect cases and complex cases.
- Promotion of sessions/training opportunities offered by our Board partners.
- Carrying out a staff surveys in relation to the use of the pan-Sussex Escalation and Resolution Protocol, assurance of the awareness of safeguarding processes and a separate survey to seek assurance that practitioners are aware of the resources that have been designed and promoted by the WSSAB and that they are using these to inform their practice.