City of York Safeguarding Adults Board

Themed Safeguarding Adults Review (SAR) considering self-neglect

Final report

November 2025

By Sarah Newsam, Independent Safeguarding Author

CONTENTS

1. Executive Summary

1.1 Background and context for the review

The City of York Safeguarding Adults Board (SAB) commissioned this themed Safeguarding Adults Review (SAR) in Spring 2025 to understand the care and support provided to 5 adults living in the city of York who were sadly found in circumstances of extreme self-neglect and/or hoarding at or shortly before the time of their death.

The 5 adults at the centre of the review process are called CD, CL, HP, JW and PD for the purposes of this review. Although the adults were all considered to have died from natural causes (and therefore there have been no Coroner's Inquests into any of the adults' deaths) the circumstances in which they were found generated concern amongst professionals working across York, because of the signs of significant self-neglect and hoarding associated with the death of the adults. Additionally, the fact that 5 adults had died in these circumstances between February 2023 and October 2024 (4 of whom died in 2024) justifiably concerned colleagues.

SAR referrals relating to each adult were submitted to the SAB, three of these referrals were made by the Head of Safeguarding in Adult Social Care, the fourth resulted from multiple agency concerns which were combined into a SAR referral and the final referral came from the Chair of the Review and Learning Sub-group, which is part of the governance of the Safeguarding Adults Board in the City of York.

The referrals highlighted concerns around information sharing between professionals, failure to follow up on concerns, and two of the homes were explicitly stated to be unfit for human habitation by emergency professionals who were on scene at the time the adult was found. In addition, all the adults had care and support needs, which featured significant health problems including dementia, physical frailty, cardiovascular ill-health, a history of recurrent leg ulcers, chronic fatigue syndrome (CFS), and a history of poor mental health. These considerations resulted in this SAR being commissioned.

Two further SAR referrals were submitted after this SAR had been commissioned. They also involved adults who had experienced significant self-neglect and/or hoarding and met the criteria for a SAR. The circumstances of those adults are summarised in an addendum to the main report.

Self-neglect

Self-neglect is a distinct form of abuse or neglect in the Care Act 2014. It does not involve a third party but highlights the harm that can arise from an adult being unwilling or unable to care for themselves, potentially across several different domains.

- **Self-care** – this may involve neglecting personal hygiene, nutrition and hydration, or health and wellbeing more generally, including medical needs (medical self-neglect). Three of the adults were reported as having an appearance of being underweight / malnourished at the time of their death (HP, PD, JW). Examples of medical self-neglect included two adults being seen with open sores and infected wounds (ulcers) on their legs.
- **Care of the home environment** – this may result in unpleasant or squalid home conditions, as well as health, safety, fire and falls risks, and may also involve hoarding. All of the adults were living in conditions which would not be considered safe or fit for human habitation, which included rotten food, rubbish accumulation, human and animal faeces and urine, flea infestation, limited space to sleep e.g. sleeping in a chair or on a mattress on the floor, no heating/electricity, no hot running water, limited cleaning/washing facilities.
- **Refusal of services that could help with health, care or other problems** – this may include the ongoing refusal or avoidance of care services, treatment, assessments or wider forms of support such as mobility equipment/aids, housing adaptations. A pattern seen in this review was avoidance of home visits by some of the adults, or concealment of their living conditions by speaking to practitioners through a half-open door or limiting entry to the hallway only. This could have been motivated by a sense of embarrassment or shame about their circumstances.

Self-neglect often manifests as complex, unusual behaviour which can be very hard to understand at face value. Many forms of self-neglect are a response to past or current emotional distress, which may date back as far as childhood. However, self-neglect can also be associated with lifelong or acquired cognitive and/or neurological conditions such as dementia, and potentially some neurodiverse conditions. It can also be seen where adults have simply become too frail or physically disabled to care for themselves.

Whilst there are numerous examples across this review of practitioners directly seeing or having concerns about the adult not taking care of themselves, or noting a deterioration in their appearance or self-care, unfortunately this was rarely seen as a symptom of their wider emotional, physical, mental or cognitive health.

Hoarding behaviour / hoarding disorder

Across the review, there was a broad consensus that ‘hoarding’ behaviour is not a widely familiar concept across professions. This may explain why the home circumstances of some of the adults were repeatedly described in case notes as ‘untidy’ or ‘cluttered’ and fire and trip hazards were noted but not described in any detail or in context. The extent of the issues in the home environment was typically only documented as hoarding when the emergency services were called to secure entry to the property after the adult had become very unwell or had died.

Hoarding is a recognised mental health condition which may also be linked to Obsessive Compulsive Disorder (OCD) and/or past trauma and adversity.[i] Hoarded items will typically have meaning and significance to the individual – which others may simply perceive to be unnecessary or excessive - and parting with those things may trigger distress, anger or a sense of loss. Hoarding can also lead to squalid living conditions.

Both self-neglecting and hoarding behaviours require psychologically informed responses, which start by building trust and rapport with the adult and work towards gradual change, in which the adult maintains a sense of agency and control.

The family, social and health context of the adults

Across the 7 adults, there were some notable similarities in their circumstances:

- All 7 adults were in late / very late adult life, ranging from 68 – 86 years old
- 6 lived alone, which can lead to social isolation and marginalisation in later life
- 3 were effectively housebound by their conditions
- 4 adults had suffered bereavement or other hidden trauma and adversity that may have triggered or exacerbated their self-neglect
- 2 had clear signs of dementia or cognitive decline
- All had co-morbid physical health conditions
- All had complex physical health needs, including challenges associated with disability, mobility, sensory loss, frailty and fatigue
- 3 had documented poor mental health and wellbeing
- 3 adults had previously expressed fears about losing their independence
- 3 of the adults appeared to mistrust or be suspicious of public services, potentially due to previous negative experiences
- 4 appeared to be suffering from poor nutrition/underweight
- All adults showed a repeated tendency to refuse support, although some of the adults periodically self-selected the contact they wanted with services. 4 adults explicitly avoided, or requested, that there were no unannounced home visits by professionals and would typically refuse entry to the home
- 5 adults appeared to have complex or unusual family dynamics
- 4 adults had a high dependency on benefits and may have been living on the edge of poverty, whilst two adults appeared to be experiencing debt and money worries, possibly linked to over-buying
- 4 of the adults lived in privately rented/owned accommodation and 3 lived in social rented housing

These factors are relevant, not only because numerous characteristics were shared by the adults, but because they also highlight the medical, social and family circumstances that may suggest an increased risk of self-neglect – such as having complex physical and mental health needs, living alone in later life, having limited contact with family, lack of trust/fear of public services, managing within limited financial resources.

SAR timeframe and focus

Whilst the exact timeframe under scrutiny for each adult is different, the review has typically looked at their contact with services in the final 18 months to 2 years of their life. 4 of the adults sadly died in the course of 2024, whilst the other adult passed away early in 2023. The adults in the two additional cases sadly both died in 2025.

For 3 of the adults, their contact with services spans 2021 and early 2022. This period is notable, as whilst the most intensive and difficult phase of the Covid-19 pandemic had largely ended by early 2022, it was a period when services were still re-adjusting and returning to usual practices and many adults may not have been seen face to face for some time. There was therefore additional pressure on all public services at this time.

Whilst this has been considered, the overall evidence from the review falls within the period from mid-2022 to mid-2024, when the worst immediate effects of the pandemic on communities and services had thankfully passed. For this reason, the impact of the Covid-19 pandemic is not considered to be a strong mitigating factor in the public service response to these adults and not materially relevant to the findings of the review.

In the case of each adult, the focus of the review has been to:

- understand their circumstances as fully as possible, through the chronology and input from family and neighbours
- ascertain the extent to which different services were aware of the adults' home situation and their self-neglect/hoarding behaviour – for example, through seen evidence, through self-disclosures, through case notes and records etc
- understand what informed or framed the professional responses to the adults and any barriers that front-line practitioners faced
- identify significant events where services failed to act to safeguard the adult
- explore why opportunities to intervene were consistently overlooked by professionals, until the adult was too unwell to be helped

The findings and learning from this SAR are particularly relevant to services involved in supporting adults who:

- are showing moderate signs of being unable or unwilling to look after themselves on a day-to-day basis, such as struggling to maintain their personal care, their living environment, their nutritional needs and the effective self-care of any medical conditions
- are showing significant and enduring signs of self-neglect, such as health deterioration / frequent recurrence of conditions e.g. leg ulcers, living without hot running water, electricity or a source of heat in their home, or an adult who may already be living in conditions which are close to or not fit for human habitation
- are hoarding belongings or overbuying to the extent that it interferes with their day-to-day living and safety, for example, the hoarding has led to a limited ability to use essential facilities such as kitchens, bathrooms and bedrooms, along with trip hazards and fire safety risks [ii]

The review may also be of interest and contain relevant insight for services that encounter or are working directly with adults who are repeatedly reluctant or refuse to accept social care and/or medical care, often without explanation. These refusals may occur alongside other complex behaviour and/or fear and suspicion of public services.

1.2 The review process

The review process was based around a relatively typical methodology for a SAR consulting widely with family, practitioners, service leads and an oversight panel of representatives from many of the agencies involved in the delivery of care, support and housing for the 5 adults. The SAR was conducted over an approximately 6-month period between June – December 2025 and consisted of the following elements:

- Provision of 5 case chronologies which documented the various contacts of teams/services with each adult, including summary case notes from relevant agencies. It became clear through the Practitioner event that York's Integrated Care Team, Discharge to Assess team and at least one independent home care provider also delivered support in the home to some of the adults (CD and PD). The first-hand input of these services was not part of the chronology and so an understanding of their role has largely been through second-hand reporting by other agencies and family/friends
- The chronologies typically covered a two-year year period prior to the death of each adult, from which the independent reviewer developed key lines of enquiry (KLOE) as the basis and focus for the review
- An initial multi-agency panel meeting to agree/adapt the KLOE and the review process

- Individual agency meetings and record checks to discuss the KLOE and understand the adults' contact with services in more detail
- A multi-agency Practitioner Event where colleagues who knew of or had worked with the adults were able to discuss their experiences of supporting them, along with other agencies or services who wished to participate in and learn from the review process
- An invitation to family members and neighbours/friends to contribute to the review. Only 3 of the adults had a known family member or next of kin contact. Approaches were made to 4 of these contacts and 2 chose to speak to the SAR author directly – they were an extended family member of HP and a neighbour and informal carer of PD. Their very helpful insights have been incorporated into the summary of each of these adults
- Production of an initial analysis report, discussed at a multi-professional SAR Panel meeting
- Production of a final analysis report with draft recommendations for comment by the SAR Panel, with a view to final sign-off and acceptance of the report and its recommendations by the City of York Safeguarding Adults Board

An important aim of the review process is to understand who each of the adults was as a person and identify any relevant life experiences that may have contributed to their self-neglecting behaviour and the circumstances of their death. Unfortunately, it has not been possible to achieve this in a full or meaningful way for every adult. Relatively limited information was recorded about the adults' histories, life experiences or wider circumstances in case notes, which may have reflected their own reluctance to share that information, but it may also point to a lack of curiosity from professionals.

1.3 Overview of the cases and care scenarios

CD

CD (also known as M) – died on 24 January 2024 age 86. The evidence from the review strongly suggests that she was living with dementia, although this may not have been formally diagnosed. She lived with her also elderly but slightly younger sister, who is registered blind and now lives in a care home and is also living with dementia. The GP notes suggest that CD was a carer for her sister and the chronology shows that CD claimed attendance allowance from November 2018. Across the 18-month period that this review has considered, there is little evidence that CD was able to care for herself, which makes it very unlikely that she was able to provide care for her sister.

The sisters had a brother and sister-in-law who appeared to also care for CD's sister and helped to clean the home at one point (this was noted in a record from July

2020), however, the family were already expressing concerns at that time about the state of the home and CD's refusal of support.

Notes from the chronology also suggest that CD did not have a bank account which is very unusual and poses questions around how CD and her sister managed their domestic payments such as utilities. Shortly before CD died, there is an account of one of the sisters telling a passer-by that they had no electricity. They claimed their state benefits in vouchers which could be cashed at a Post Office. It seems likely therefore that they paid for all their day-to-day outgoings in cash. This was a set of circumstances that the Department for Work and Pensions (DWP) were actively trying to change to a more secure financial arrangement shortly before CD's death.

CD was found unresponsive and in a very poor physical state by a joint visit from a DWP visiting officer and a home care provider who were both attending the property for the first time. CD was found by paramedics to have large sores around her chest and groin and she was heavily soiled. She was also hypothermic and sadly died from a cardiac arrest on the way to the hospital in an ambulance.

The account of the property at the time CD was found can be reasonably described as squalid due to the presence of human and animal faeces around the home and its overall very poor state, including food/food waste covering surfaces, no heating/hot water and generally high levels of dirt and soiling which were considered indicative of long-term domestic neglect. The Yorkshire Ambulance Service crew's documented view was that the state of the property and the conditions that the sisters were living in had contributed to CD's death.

The first and only safeguarding *response* to CD's circumstance was prompted by a safeguarding referral by the local pharmacist shortly before CD died, despite CD being well known in local community and by the GP practice. Numerous other professionals had seen the sisters' living environment first-hand in the 18 months before CD's death, including the Police, Ambulance crews, a District Nurse, the York Integrated Care Team who are reported to have visited the home in September, November and December 2023, and two social workers who visited the sisters the day before CD died.

The first significant event that appears to have brought CD and her sister to wider attention in the 18 months before her death was an episode of illness whilst at the local takeaway. The Ambulance Service was called due to CD vomiting and becoming incontinent and she was taken home at her request. The Ambulance crew made a Social Care referral for assessment, and a letter was also sent to the GP setting out the circumstances. Unfortunately, despite a full account of the sisters' circumstances and needs in the referral to Adult Social Care, when it was screened by the customer contact centre it does not seem that the concerns raised in the referral were fully discussed in the subsequent telephone conversation with CD. The outcome of the call was that CD was given a telephone number for a private cleaning company. There was no recorded follow up by the GP practice.

There was no further significant contact with services until March 2023 when the Police were called by CD herself. She was considered vulnerable because she presented as very confused at the start of the call, which resulted in the Police making a welfare check. The officer in attendance noted deep concern about the state of the home and the safety and wellbeing of the sisters. It was also noted that the family dog had been observed urinating on the sofa but that neither sister had noticed this. This resulted in a safeguarding referral to ASC which was followed up in an initial conversation with CD. The case note suggests the need for escalation to a manager for consideration, however, there is no record that this happened and consequently no further action was taken.

It is notable that CD made 3 other direct calls to the Police in June, September and November 2023, all reporting concerns of suspicious people or events at or around her home.

Around a month later in April 2023, CD had a fall and paramedics were called by her sister. CD was thought to have had a long lie on the floor overnight and perhaps for as long as 24 hours. The Ambulance crew are documented as making a safeguarding referral, however, case notes from Adult Social Care suggest that this was interpreted as a request for Care Act assessment by Adult Social Care. Whilst in hospital, CD was visited by a social worker and she explained her fears about losing her independence.

Although the intention had been to admit CD to a ward, she refused and discharged herself against the advice given to address the conditions in her home first. Both the ward and the social worker are noted as stating that CD had mental capacity, but it is not clear what aspects of her decision-making capacity had been considered. Neither agency appeared to consider these circumstances through a safeguarding lens.

In mid-August, the pharmacy contacted the GP due to seeing CD in the shop with a large ulcer on her leg. The GP practice followed this up and seemingly persuade CD to attend an appointment a few days later. CD require immediate antibiotic treatment as the ulcer was infected, but she declined hospital admission despite being told this was necessary. Later in August there appears to have been a follow-up home visit to CD by a District Nurse to dress her leg ulcer. After this visit the District Nurse reported to the GP Practice nurse an account of the circumstances in which the sisters were living, which included a flea and fly infestation, with faeces covering CD's wound dressings and carpet. It was the judgement of the District Nurse that CD was self-neglecting and did not have the capacity to make reasoned decisions to address her circumstances. No safeguarding concerns were raised in relation to these observations.

CD attended 3 further appointments for ulcer/wound care at the GP practice but then stopped attending. At this point the GP made a referral to the York Integrated Care Team for further assessment and a home visit. The review process has not been

able to ascertain what happened on these visits, but they are documented as having taken place.

Over the same period, CD appeared to intermittently re-attend ulcer care appointments, sometimes at the prompting of the surgery who called to remind her. On two of the visits the wound dressing was noted as being very dirty and when asked how this had happened, it was recorded that CD said that she didn't know but suggested that she may have been outside with no shoes on. No further exploration of this comment or cause for concern about CD's capacity were raised.

During October and November CD appeared to attend weekly wound dressing appointments regularly but there are no GP records after 1 December 2023, which may suggest that CD's wound treatment had ended. CD's acceptance of regular wound care during this period may have been in response to an explicit strategy adopted by the practice to develop greater rapport and trust with her.

On 22 January, the pharmacist made a formal safeguarding referral to Adult Social Care. This was in response to CD experiencing incontinence whilst in the shop and she had to be supported to return home by the pharmacist's son. His report of CD's living conditions led to the pharmacist making the safeguarding referral and sharing the concern with the GP.

Two social workers made a home visit the following day in response to the safeguarding referral and found CD in a very poor physical state. They also recorded concerns about possible cognitive impairment and requested an urgent GP home visit and emergency home care support for the next day. It was not recorded if consideration was given to calling for immediate medical support via the Ambulance Service.

CD was found unresponsive the following day and very sadly she died soon after.

CL

CL was found on 14 April 2024, although he may have died some time before. He was aged 68 and lived on his own. His cause of death was a deep vein thrombosis (DVT) causing a pulmonary embolism.

At the time of his death, entry to his property had to be forced and the house was found to be in a poor state with significant hoarding. The chronology documents that his home had no electricity, no washing facilities and he did not have a home telephone, so contact with professionals was in person or by letter only. He was said to not allow anyone into his home and was described as a private and somewhat eccentric man.

He was known to have been a carer for his mother until her death in 2014 and previously his brother who had a learning disability. It is not known if CL had ever worked but it seems he had been a family carer for many years, possibly across his

lifetime. He was known to ASC largely in respect of his previous caring roles and again in 2016 due to generalised river flooding in the area he lived. Case records suggest that he had declined any support in response to the flood. There is some insight from historic ASC records which point towards CL feeling let down by public services in relation to the care of his brother and a having a general distrust of services. Relatively little else is known about CL.

It was reported that he had been observed by neighbours to have open sores on his legs and it is clear from the chronology that his pattern of behaviour was usually to decline health treatment and other forms of support, although he did accept some help with finances, benefits and treatment for leg ulcers.

There is evidence that he responded well to the Practice Nurses at the GP surgery, with whom he appeared to have a good relationship, but CL would not necessarily engage with other practitioners e.g. the social prescribers. The Practice appeared to take steps to be more proactive with CL due to his reluctance to initiate/receive help e.g. appointments to treat his leg ulcers were booked proactively for him, and after the third episode of care for leg ulcers, 2-monthly monitoring had been put in place.

The first episode of care was in January 2022 when CL was seen in the GP Practice leg ulcer clinic, however the next appointment is almost 3 months later in April and the practice then set up regular appointments for the treatment and monitoring of his leg ulcers. There was an acknowledgement of some issues at this time as it was documented that the PNs had sensitive conversations around his self-care and hygiene, offering support. It was later recorded in a visit to the Practice to manage his leg ulcers in June that CL was not suitable for stocking style dressings as he did not have laundry facilities at home.

Appointments continued regularly until September 2022, when there was a gap. Within this period CL declined a long-term condition review in December 2022.

In March/early April 2023 CL was admitted to hospital for several days following a collapse. Whilst the hospital accident and emergency department (ED) documented their concerns around self-neglect at this time, this letter was filed by the practice without being reviewed by the GP, however, neither the hospital discharge letter to the GP, nor wider references in the chronology, made any reference to social concerns or self-neglect at the point of discharge.

The GP practice followed up the discharge in late April after which CL recommenced leg ulcer treatment and was prescribed vitamin supplements in May, following blood tests which showed a deficiency. The support for CLs leg ulcers continued until mid-August.

During this period CL suffered 2 blackout episodes whilst at the GP (June and August 2023). He was transported to hospital and admitted, and attempts were made to investigate the cause of his collapses. He was placed under the care of a

cardiologist, however, in September 2023, he declined the proposed treatment to investigate/resolve the blackout episodes, without any explanation.

The hospital record from the June 2023 event stated that he was seen by the Rapid Assessment Therapy team but he declined all support. Whilst it is recorded that there were no doubts about CL's capacity to make this decision, his ongoing 'vulnerability' was noted. There was no indication in the chronology of what these vulnerabilities were considered to be however.

From mid-August 2023 until early 2024, it appears that CL had no direct contact with the surgery. In mid-January 2024 he returned to the GP practice for support with his leg ulcers – this was the third time that he had received treatment for leg ulcers. It is unclear if the possible reasons for the deterioration to his legs was explored with him, however he received antibiotics and was then seen every 3-4 days at the surgery until 9 February 2024. At this point the practice nurse proposed to see CL every 2 months to monitor his legs and health, which he agreed to.

There is no further recorded contact with services until CL was sadly found deceased at home in April 2024, following concerns expressed by his neighbours that he had not been seen for some time.

HP

HP died on 15 October 2024. She was aged 70 and lived on her own in general needs social housing. Forced entry by the Fire and Rescue Service was necessary to access her home, after the alarm was raised by her neighbour who could hear HP calling out for help. The professional reports of HP's living environment at that time was that it was heavily hoarded (judged as clutter rating 6) and unfit for human habitation. They also observed that HP appeared to be very vulnerable and was visibly malnourished. Both the ambulance service and the fire and rescue service raised safeguarding concerns due to the conditions in which HP was found.

HP was living with osteoarthritis and had been diagnosed with Chronic Fatigue syndrome (CFS) around 2014. She had also received treatment for cancer during her lifetime and specifically in the preceding 2 years before her death. She self-reported as part of her assessment for CFS that she experienced ongoing cycles of struggle, exhaustion, pain, anger, and despair as part of her CFS. She had stopped working/became unemployed in 2004, but her family said that she was a keen life-long learner and liked to pursue further education courses. Prior to her ill-health she had been very active and adventurous and had loved travelling.

HP was last seen by her extended family (who live in another UK region) in 2015 at her mother's funeral, however, they were in contact regularly by letter as this is how HP preferred to communicate. Her family reported that she had always been reluctant to allow them in her home and refused to share her phone number. Despite this, the letters from HP were usually upbeat and did not create any cause

for concern. However, this changed during the Covid-19 pandemic when HP stopped writing and receiving letters due to concerns that she could be exposed to the virus through the letters.

One of the specific observations of HP's family was that when they came to her home following her death, there was very little clear floor space. They also found boxes of medical correspondence that HP had kept, which set out in detail her medical conditions. Alongside this, there were multiple boxes of newly purchased but unused items.

HP had a level of disability significant enough to qualify for higher rate Disability Living Allowance (DLA) from Summer 2007 and appeared to be a wheelchair user. One record suggests that HP was virtually housebound due to her CFS and because of this, routine GP contact was sometimes conducted over the phone or by letter e.g. in relation to medications, to request a flu vaccination. However, this also seems to have been HP's general preference, and she often requested that agencies should not attempt any unannounced home visits.

Although the review period begins in late 2022, there are numerous relevant examples prior to this where HP asked for or clearly needed help, but administrative errors or poor communication meant that she did not receive the support she needed. These are:

- In January 2021 HP made direct contact with Adult Social Care stating that she required support and described her needs. The account suggests that her concern was around an upcoming hospital admission for cancer treatment, including transport to hospital and support to recover afterwards. She also contacted York advocacy services to help with her concerns. ASC appears to have tried to provide reassurance and further contacts, but HP had already been admitted to hospital before full follow-up could take place
- During 2021, a discharge from a Leeds hospital should have resulted in HP being placed in a Discharge to Assess bed in York, but this request was said to have been closed in error
- Another discharge from a Leeds hospital in July 2022 appeared to result in the hospital patient transport service leaving HP at a local hotel in her wheelchair, having found that her home was not habitable. This was reported to the Police by the hotel as a Public Welfare concern

During late 2022 and early 2023, HP was seen in her home twice by the GP practice and once by an ambulance crew. Although all professionals noted the state of HP's home and the practice initiated a conversation about her living conditions, this did not prompt any further action.

The next contact with HP was in late June 2023 when she was transported to hospital by ambulance, initially due to her CFS symptoms, however, she seemed to be admitted to hospital due to poor appetite and significant weight loss. Records

show that HP disclosed considerable problems with her home environment, which was shared with different professionals during this admission, including the lack of a proper bed to sleep in and she also described her home as ‘full of faeces and urine’. At the time a social care assessment was discussed with HP, she agreed but specifically asked that the social worker be sympathetic to her circumstances and CFS symptoms. This suggested she had insight into her situation and may have been embarrassed or worried about the interpretation of her CFS symptoms and home environment.

Despite this disclosure being documented and the ward making referrals to Adult Social Care and the hospital mental health adult liaison team (MHALT), HP was ‘urgently discharged’ before these professionals could speak to her in person and assess the situation. Neither of these referrals resulted in further direct action, but a request was made by the MHALT that the GP mental health practitioner make a home visit to HP. Adult Social Care followed up in writing but there is no evidence that a home visit to HP was considered, despite the reports about her living conditions. The GP practice home visit took place over two months after the discharge, at which time HP said that she did not need a home visit and refused entry to her home. No agency raised a safeguarding concern.

HP’s last contact with a health professional was on 14 December 2023 when she received a flu vaccination at a flu clinic - this was 10 months before her death and in the intervening period e.g. December 2023 to early October 2024 she seems to have had no other contact with any public services.

A concern for HP’s welfare was made by her neighbour in early October 2024 and this resulted in a Police visit to her home, where she spoke through a window to the officers and reported that she was well. 8 days later, an emergency call was made to the ambulance service by her neighbour and HP was transported to hospital but sadly died soon after.

JW

JW was found in her York home on 22 February 2023 although it was likely that she had died some time before. She was aged 71 at the time of her death. The Police supported by the North Yorkshire Fire and Rescue Service attended JW's address following a call for concern from a neighbour who reported not having seen her for several weeks. The property was extremely difficult to access due to the significant amount of hoarding and the risk of structural collapse. JW was found after entry to her home was made via a window. The Police reported that the property was so heavily hoarded that there was only a single narrow ‘passage’ to allow movement around the ground floor.

JW was known to several services and was thought to have lived between York and Scotland where she had 2 other homes, both of which were heavily hoarded (one of

which it seems JW was evicted from). She is also reported to have slept in her car/van and this appears to have been the case during the Winter that she died. Hoarding and concerns about her mental health were ongoing concerns in Scotland and there had been safeguarding information gathering in Scotland in Spring 2021, which had distressed JW when contact was made with her. Records suggest that she self-defined as a hoarder.

JW appeared to have a deep mistrust of services and did not generally accept offers of help when these were made. However, she did selectively seek out or accept some forms of help e.g. for a skin lesion, dental care and foot care. She appeared suspicious about the information public services had and shared about her, alleging breach of confidentiality/Human Rights on several occasions. Her responses seemed to indicate that she was actively distressed by 'unsolicited' contact or welfare checks from services and this led her to withdraw from support. The experience of one professional was that JW's suicidal ideation became more severe if services pressed issues, involved or spoke to other services, despite it being legitimate to do so and to support JW.

Case notes suggest that JW was in dispute with services in Scotland (potentially linked to unpaid Council Tax) and neighbours at some of her homes, largely due to the hoarding issues and the state of the properties inside and out, which had prompted health and safety concerns. She appeared to have been in debt and had money worries – at one point she disclosed that she had been made bankrupt.

JW was best known to community mental health services in York, first being referred in February 2019. She self-identified as a hoarder and said that she experienced flashbacks from her experiences working as police officer and suffered with depression. It was confirmed by the clinical psychologist that worked with her that she was being treated for depression and post-traumatic stress disorder (PTSD).

A significant episode was noted in August 2020, in which North Yorkshire Police reported safeguarding concerns about JW to the ASC customer contact centre, regarding hoarding and poor mental health. However, this referral was closed after speaking to JW, without any further consultation with the safeguarding team or managers. The rationale for this decision at the time was not recorded, although it was at the height of the Covid-19 pandemic.

In February 2021, the Aberdeenshire adult protection team requested a meeting with York community mental health team (CMHT) colleagues in relation to concerns about JW self-neglecting. However, this seemed to fracture JWs relationship with the CMHT and the therapeutic relationship that she had developed with the clinical psychologist. Although multiple attempts were made to re-engage JW across May and June 2021, these were unsuccessful, and JW was discharged from the CMHT in July 2021.

In March 2021 Scottish safeguarding colleagues made a direct approach to York Adult Social Care with concerns for JW relating to self-neglect and a history of

suicidal ideation. The account of this conversation in case notes was vague and there is no evidence to suggest that the substance of the safeguarding concern was discussed with anyone else within the service or partner organisations. This was the only other contact ASC had relating to JW.

Across Summer 2021 JW got in touch with her GP in relation to a skin lesion and this resulted in face-to-face appointment where JW raised concerns about breach of confidentiality and data protection. JW wrote twice to the GP in the next 2 months with similar complaints. The GP treated this complaint seriously, investigated and replied in writing. Following this there was an 8-month break in any contact by JW with York services until she presented at York and Scarborough Teaching Hospitals NHS Foundation Trust ED complaining of dental pain on 10 May 2022.

On 18 May 2022 a report was received from Police Scotland to North Yorkshire Police advising of concern for JW as she had recently been evicted and they were treating her as a missing person, against a background of previous suicidal ideation. The Police followed up by visiting JW's York property which appeared to be barricaded and difficult to enter. Although phone contact was made with JW, she refused to say where she was and stated she was going to complain.

The next significant contact with JW was in December 2022 when she appeared to re-register with her with York GP and requested an immediate appointment. She was seen 3 days later where she disclosed sleeping in her car, living without heating and having no recent hot meals. This was discussed at the practice debrief - no safeguarding concern was raised but a referral to social prescriber was expedited, which was followed up urgently by phone. It was established that whilst JW wasn't homeless, the state of her home was a problem, but JW refused a home visit. However, the social prescriber was persistent and ensured that calls were made to JW before Christmas and into the New Year. JW declined all support but said that she would keep the number of the social prescriber.

However, shortly after this JW called the surgery for an urgent appointment. On 16 January 2023 she saw the GP face to face and again disclosed that she had been sleeping in her van for 3-4 months, had no running water and was experiencing weight loss and pains in her legs and feet. Notes say that she presented as upset, however, she declined support other than a podiatry referral and follow-up by a social prescriber.

The last contact with JW seems to have been in early February 2023 with a podiatrist. The assessment highlighted a concern about possible diabetes due to symptoms described by JW during the treatment. It was also recorded that JW was teary and upset.

Sadly, JW was found deceased on 22 February, following concerns raised by neighbours.

PD

PD was found in her home in June 2024 by an ambulance crew called by her neighbour, although she may have died several days before. She had lived alone in her bungalow and was aged 76 at the time of her death.

A home visit made by her GP a few days earlier resulted in an ambulance call-out due to concerns around a possible health emergency. The ambulance service raised a safeguarding concern following this call-out due to the state of her property which was heavily hoarded, with rotten food seen around the home and numerous potential fire risks noted. They also expressed concern about her ability to cope living alone without any support. PD was admitted to hospital but discharged back to her home 2 days later (4 days before her death), despite the concerns raised by the ambulance crew.

PD had significant co-morbid health problems for which she took medication. She had also previously suffered a hip fracture in April 2023. Due to her medical conditions and general frailty, PD was housebound and was recognised as being socially isolated. Whilst there is evidence that she was signposted to different forms of support e.g. a supported house clearance provider, it is questionable whether she was realistically able to follow-up on this help and therefore benefit from it, due to her physical frailty and levels of self-motivation. There does not appear to have been any follow up by statutory services after community referrals were made.

PD's neighbour said that she had got to know PD, initially because of a mutual interest in gardening and PD had offered to lend her gardening and DIY tools. PD actively sought her neighbour's help after she had fallen and experienced a long lie on the floor. As their rapport developed, PD disclosed that she had suffered domestic abuse and as a result her child had been taken into care. The neighbour felt that PD had lived a hard life, and this helped to contextualise some of her behaviour and wariness of others.

The neighbour also noted that at least part of the challenge with PD's living conditions was due to her prolific online and TV shopping-channel overbuying, which the neighbour described as a 'shopping addiction'. This led to several rooms in her home being filled with new boxed goods and PD was believed to have several credit cards which funded these purchases.

Between April and October 2023, PD was in contact with a series of different health and social care services following a hip fracture which she suffered in April 2023. After a period of rehabilitation following her hip fracture, the neighbour said that the extent of PD's vulnerability seemed to be acknowledged at this time, as her home was seen for the first time by services. This led to her family helping to clear PDs home, for her to be safely discharged from hospital. PD then had a period of reablement with regular visits across the day from a home care provider, initially to help her with meals and her medication.

During this period of reablement, it became clear to the neighbour that PD could not manage her personal care or toileting, as she found multiple soiled items of clothing in the bath and the bathroom floor was also heavily soiled. Although this may have partly been a side-effect of the medication PD was taking, the neighbour raised these additional needs with the home care provider, who initially said that personal care and clothes washing was not their responsibility. However, the care plan was revised when the home carer visited the property and found the neighbour helping PD to take a bath.

On 25 July, PD received a social worker home visit. There were no case notes associated with this visit, so it is not possible to understand what the social worker's assessment of PD's circumstances and needs was, however, the home care package was ended the following day apparently on the basis that the home care provider had no concerns and judged that PD was able to live independently.

However, there were ongoing concerns for PD very soon after the home care support ended. At the end of July, PD was referred to dietetics by her GP due to her being very underweight and on 1 August PD's neighbour called Adult Social Care with concerns about her ability to cope with personal care, toileting and hygiene management relating to use of a commode, and memory problems. This resulted in a further social care assessment for long-term care on 1 September which identified that PD required support to take medications as prescribed, to maintain nutritional intake and help with her personal care and hygiene. However, PD did not wish to pay for care and support, and the neighbour was advised that as PD had the mental capacity to make this decision, she was closed to Adult Social Care on 13 September. The neighbour said that at the point of Adult Social Care closing her case, PD did not have sufficient strength in her legs to do anything for herself and was also noticeably suffering from memory problems, which led to her forgetting to take her medications.

The GP also made a home visit to PD in mid-August to follow-up after the hospital admission and had what seemed to be a holistic conversation considering PD's social, financial and medical needs. The presumed outcome of this visit was a referral for Comprehensive Geriatric Assessment which took place in PD's home during October 2023. Although PD disclosed that she was worried about her memory during this assessment, she declined further memory assessment.

Following some input from an Occupational Therapist and the provision of small aids to support bathing, there was then a long gap in professional contact or input (estimated to be around 6-7 months) until 14 June 2024, shortly after which time PD unfortunately died.

1.4 The key issues under consideration

Initial key lines of enquiry (KLOEs) were developed by the independent reviewer based around the chronology, which were then discussed with the SAR Panel. The

KLOEs were used across the review to explore with agencies and practitioners how the adults' circumstances were understood or interpreted by professionals, including their needs for care and support.

One of the issues the review has sought to understand is why the extreme living conditions of these adults were only seen as a safeguarding issue by relatively few of the professionals that had contact with the adults. This included hoarding to the point where properties were inaccessible and living in conditions which should have been considered unfit for safe human habitation e.g. human and animal faeces present across the home, heavy soiling or unsanitary living conditions, flea infestations, soiled clothes left in bathtubs because there were no other accessible clothes washing facilities, inaccessible or unsanitary kitchen facilities, and sometimes no proper bed/place to sleep.

The KLOEs were:

1. Why do you think the terminology of 'self-neglect' and 'hoarding' wasn't widely used by professionals to describe the circumstances they saw?
2. Are self-neglect and hoarding widely understood concepts across different professions in York? What needs to be done to address any gaps in professional awareness and understanding?
3. Is there evidence that self-neglecting behaviour and its causes has been misinterpreted by professionals in the case of these 5 adults?
4. What processes / systems need to be developed at hospital discharge to ensure that adults who are suspected or reported to be self-neglecting are not returned to an unsafe home environment?
5. What do you believe are the barriers that professionals face when encountering and supporting adults who are showing evident self-neglecting behaviour, yet declining help?
6. How should professionals be supported to use appropriate professional enquiry, persistence and curiosity in the context of self-neglect?
7. Is there a clear pathway of support and/or good practice guidance for professionals when they suspect or see direct evidence of self-neglect?
8. Failing to make safeguarding referrals resulted in several significant missed opportunities to potentially prevent further deterioration and harm for some of the adults. Is this typical of safeguarding practice and the response to self-neglect in York? Do you have a view on why this was?
9. There appears to have been a misconception that professionals cannot make a safeguarding referral unless the adult consents to it. Do you recognise this thinking or practice?
10. How should mental capacity judgements be applied more robustly in the context of self-neglect in future?

11. Across all 5 cases, there was a pattern of no further action, no follow-up and limited consultation with other professionals/family despite, for example, practitioners being aware of the adult's pattern of behaviour, recognising their vulnerability and having ongoing concerns for the adult. What do you attribute this to?
12. Does your organisation have a policy/guidance around working with adults that self-neglect?
13. Does your organisation have standards/a policy around professional case-note recording, for example, expected content, suitable levels of detail and timeliness?

Based on these initial KLOEs and discussion with the agency leads in the first stage of the review, 3 key themes of interest were generated by the independent reviewer with sub-themes added to address the most important emerging issues from the review process. These are:

Professional recognition of and responses to seen evidence of self-neglect or disclosures of self-neglect

a. Practitioner confidence to name and address self-neglect and hoarding behaviour
b. Effective case-note recording and follow-up
c. Hospital discharge and post discharge support

Barriers to practice when working with adults who show ongoing self-neglect behaviours

a. Working with and interpreting complex behaviour
b. Trauma and adversity-informed practices
c. Preserving the therapeutic/professional relationship

Using available legislation and local policies to positively address the harms and risk of enduring self-neglect

a. Effective use of the safeguarding system
b. Consideration of mental capacity
c. The multi-agency response to self-neglect and hoarding behaviour

1.5 Good practice learning points

- Some professionals within Primary Care e.g. GP, practice nurses, social prescribers recognised that building trust with the adults (CL, CD, JW) was important to sustaining their engagement with the healthcare they needed

- There was evidence that Primary Care professionals tried on occasion to have holistic conversations with some of the adults regarding their self-care and living conditions (CL, HP and PD)
- Some GP practices showed flexibility around the adults' needs and took additional steps to make appointments for them and proactively reminded them to attend (CD, CL)
- Blue Light services (the Police, the Ambulance Service and the Fire and Rescue Service) who attended the homes of the 5 adults were generally more attuned to the signs of self-neglect and hoarding, and they were also more likely to raise a safeguarding concern. Discussions with the agency representatives highlighted that these organisations have invested time in employee training and awareness raising around self-neglect and hoarding, partly in response to what professionals in frontline roles were seeing. All 3 agencies also remained committed to improving practice further and had a clear sense of what was required to achieve this in their own organisation.

1.6 Summarising commentary

The review has considered the circumstances of seven adults who very sadly died in conditions involving extreme and enduring domestic, personal and often medical self-neglect that appears to have evolved over many years. Four of the adults were found to have been living in severely hoarded homes, where normal use of the home was no longer possible e.g. kitchens, bathrooms and bedrooms could not be used for their intended purpose. Some of the adults were reported to sleep on the floor or in a chair, whilst others had no means to cook a meal or heat their homes. Several were living without electricity. All seven adults were living in conditions that were not safe for human habitation.

The demographic, social and health similarities between the 7 adults is striking. They were all White British adults in later adult life, aged between 68-86. 6 of the adults lived alone and appeared to be highly socially marginalised - only one adult had family that lived locally. There was also a pattern of apparent estrangement from family members. All had complex co-morbid physical health needs, including challenges associated with long-term conditions, disability, mobility, sensory loss, frailty and fatigue. 4 of the adults were noted to be visibly suffering from poor nutrition/underweight when they were found.

This pattern seen in the review offers an insight into the characteristics that may be associated with a vulnerability to self-neglect and may therefore help services to be more alert in the future to the potential for self-neglect amongst older adults, especially where an adult is not accessing services in the expected way for their age or health status, or if they actively refuse care without discussion or a clear rationale.

Whilst several of the adults actively attempted to conceal their circumstances, this was not always the case and there were multiple missed opportunities for

professionals to document or report what they saw - or visit the adults in their home after concerns had been raised.

The review saw a widespread professional knowledge gap, particularly amongst health and social care professionals, around self-neglect and hoarding, including the circumstances in which a safeguarding concern should be raised. However, on the occasions when safeguarding referrals were made e.g. by blue light services, these often happened when it was too late for services to intervene, as the adult had already died or was very unwell. On other occasions, even detailed referrals into Adult Social Care by different professionals were not screened as potential self-neglect or hoarding and therefore limited or no further action was taken.

Other tools such as mental capacity assessment, that could also have supported professional decision-making, appeared to largely be used to confirm unspecified mental capacity in response to the adult declining services. This happened in one case even when there was contextual information which should have prompted professionals to have reasonable doubts about the adult's mental capacity i.e. self and independent reports of memory problems. The role of genuine physical incapability to self-care e.g. due to physical frailty and failing health was also overlooked as a contributory factor to self-neglecting behaviour.

Whilst improving knowledge about self-neglect and hoarding will certainly lead to practice improvements across the City of York Safeguarding Adult Partnership, equally important will be measures to support psychologically informed and relationally led practice amongst front-line practitioners. Extreme self-neglect and hoarding typically have a psychological basis, often linked to distressing life experiences as an adult but also dating back to adverse experiences as a child. Best practice in working with adults who are at risk from self-neglect requires investment in building a trusting working relationship with the adult, which starts from a place of compassion and understanding.

There is significant learning from the review around the opportunities to identify and intervene earlier in suspected or report cases of self-neglect. The primary aim of safeguarding should be to prevent serious harm to adults, and these seven very sad cases pointedly highlight the sometimes extreme consequences of late professional identification and inadequate proactive intervention around self-neglect.

However, there are many opportunities to improve practice, including prioritising home visits to properly assess an adult's circumstances first-hand, supporting practitioner confidence to be candid but compassionate about what they have seen, more assertive and robust safeguarding, developing clear professional pathways for risk management in cases of self-neglect, and training around psychologically informed support for adults who show self-neglecting or hoarding behaviours.

1.7 Recommendations

The recommendations from this Safeguarding Adult Review aim to follow the evidence and learning from the review process. They are organised under the 3 primary themes of interest identified for the review.

Professional recognition of and responses to seen evidence of self-neglect or disclosures of self-neglect

1. The York City Safeguarding Adults Board, with the support of organisational development and learning expertise from its partners, should consider a variety of methods to address the professional knowledge gaps around self-neglect behaviours and hoarding. This could include:

    - Promoting the existing self-neglect guidance published by the SAB and its partners
    - Developing additional practice learning tools, such as real case studies and scenarios
    - Creating a network of 'champions' across York organisations who are trained and supported to disseminate and advise on best practice around self-neglect and hoarding in their setting
    - Hosting practice learning events that focus on embedding understanding of self-neglect and hoarding and best practice responses

2. The York City SAB should agree with partners a standardised response to public or professional referrals that report concerns about home conditions/hoarding/self-neglect and self-disclosures of domestic or self-neglect/hoarding. This should include:

    - Making enquiries about the adult's home ownership / tenancy arrangements and in cases of social housing tenants, also advising the social landlord of the concerns
    - The expectation of a home visit by a professional to investigate the concerns – even if this would not be usual practice
    - The use of capacity assessment, including a consideration of executive functioning e.g. where an adult refuses support and this puts them at risk
    - The timeliness of the response

3. Statutory partners to the SAB (Police, Adult Social Care and healthcare partners) should agree within their organisations how serious and enduring self-neglect and hoarding are properly and candidly documented and/or flagged on electronic

systems, and individual adults' records and case notes, including medical records. The York SAB should seek assurance, in due course, that required changes to professional systems of recording self-neglect and hoarding have been made and are being used.

4. Adult Social Care should reflect on the findings of the review and take steps to improve weaknesses in practice relating to:

    - Appropriately interpreting referrals or safeguarding concerns about self-neglect and hoarding by the Adult Social Care customer contact team, including improved awareness of escalation or the need for safeguarding advice
    - Proper recording of professional social work judgements and the rationale for decision-making when working with vulnerable adults who have a history of past/current self-neglect
    - Following-up adults who have a history of self-neglect and have refused support with capacity, when there are ongoing professional concerns that the adult is vulnerable

5. All statutory agencies should review their approach to follow-up and case closure for adults with care and support needs who refuse support, where professionals have ongoing concerns about their physical or emotional health and welfare, which may include previous or ongoing self-neglect

6. York and Scarborough NHS Foundation Trust should review how concerns about self-neglect or hoarding are recorded and communicated across the entire patient pathway, from the emergency department through to discharge and patient transportation. The findings and proposed changes arising from the review should be shared with the York City SAB

7. Partners to the hospital discharge process should agree a discharge protocol that will enable the safe discharge of adults whose homes are unsafe for them to return to, due to issues such as domestic neglect, uninhabitable living conditions and hoarding. The protocol should consider practical steps such as the use of deep cleans and temporary step-down accommodation, alongside psychologically informed support for the adult

8. Given that long-term non-engagement with routine primary health care may be an indicator of enduring self-neglect and/or vulnerability, particularly in later life, Humber and North Yorkshire Integrated Care Board should consider with GP leaders how proactive but proportionate checks and balances in the 65+ age group might support the earlier identification of unmet needs

Barriers to practice when working with adults who show ongoing self-neglect behaviours

9. The York City SAB should seek assurance from its statutory partners that formal and informal professional training and development opportunities, including supervision, adequately support professionals' understanding of how to work with adults whose behaviour is complex, and the principles of relational and trauma-informed good practice. Identified gaps in professional learning and development should be addressed.

10. Considering the learning from this review, the York City SAB should request that the current self-neglect guidance is reviewed to ensure that it gives clear guidance on how to manage trusted relationships between a practitioner and an adult, within a safeguarding scenario

Using available legislation and local policies to positively address the harms and risk of enduring self-neglect

11. The York City SAB and its partners should take active steps to address professional misconceptions about self-neglect and consent, clarifying that:

    - Severe or enduring self-neglect or hoarding that threatens the health, safety or welfare of the adult should be treated as a safeguarding matter
    - Professionals who are concerned about the welfare of an adult who is self-neglecting or hoarding, can use their professional judgement to make a safeguarding referral, even if the adult has the capacity to refuse support, including refusing permission for a safeguarding referral
    - In cases where an adult is not at immediate risk from self-neglect/hoarding, best practice is to share information and work collaboratively with other colleagues to develop a plan to support the adult

12. The York City SAB and its statutory partners should reflect on whether current multi-agency safeguarding policy and training communicates a balanced approach to respecting the autonomy of adults, including consent to support, with the professional duty to safeguard a vulnerable adult with care and support needs

13. The York City SAB and statutory partners should review multi-agency/organisational policies and training relating to the Mental Capacity Act, given the practices seen in the review, and consider refresher training for frontline professionals. Particular attention should be given to:

- Using capacity assessment proactively as a positive tool rather than as a defensive practice e.g. to justify case closure after a vulnerable adult has declined help
- Proper and specific recording of decision-making around assumptions of capacity
- Consideration of an adult's executive functioning

14. The York City SAB and senior statutory partners should lead a discussion about how to develop and fund local pathways for responding to self-neglect and hoarding, which works towards achieving an integrated, multi-agency best practice model over time. These pathways should address support for adults/residents, as well as mutual or peer support for professionals

15. The York City SAB and senior statutory partners should consider the development of a Multi-agency risk management (MARM) approach and how this model may support more collaborative and co-ordinated responses to vulnerable adults who have capacity but remain at a high risk of harm or neglect

2. Analysis by the key issues explored in the review

2.1 Professional recognition of and responses to seen evidence of self-neglect or disclosures of self-neglect

a. Practitioner confidence to name and address self-neglect and hoarding behaviour

Across the chronologies and case-notes that were made available to the review, it became clear that the language of 'self-neglect' and 'hoarding' was not widely used by professionals to clearly describe what they were seeing - and in turn, identify a safeguarding risk to the adult. Some case notes referred to 'clutter', bags of rubbish, falls and fire risks in the home, and wider housing conditions e.g. flea infestations, no form of heating, and instances of repeated medical self-neglect or challenges with self-care e.g. weight loss, continence issues, repeated / infected leg ulcers. In addition, there was little indication that different signs of self-neglect in one adult e.g. poor personal care, weight-loss and hoarding were seen as symptoms of the same underlying issue.

Although there were some relatively limited direct references to self-neglect or hoarding noted by professionals, several of which were characterised as a safeguarding concern, nearly all these instances were either when the adult had been found deceased or were recorded in the period immediately before their death. This is significant because had professionals accurately characterised, recorded and acted on the adults' situations earlier, it may have been possible to intervene with more robust assessments – including Care Act Assessment (CAA), a full mental capacity assessment with potential consideration of the need for a Best Interests decision, or 'section 42' safeguarding enquiries. Earlier intervention may have also enabled some of the adults to benefit from the health and social care support that they clearly required (notably PD, CL, HP) prior to their deaths, affording them a better quality of life and dignity in death.

It is fair to say that much of the language used in case notes to describe the adults' behaviour or circumstances appeared to minimise the situation, using words such a 'clutter' or the description was unspecific referring obliquely to 'living conditions'.

When the possible reasons for this were explored with agencies, one of the suggestions was that professionals may be uncomfortable using direct and specific language in case records that could appear to be judgemental, especially as NHS patients can now see their medical records. Whilst this is a legitimate observation, both self-neglect and hoarding are well-known formal/technical terms that are recognised and used across health and social care e.g. the Care Act identifies self-neglect as a distinct form of neglect, and the Diagnostic and Statistical Manual of Mental Disorders (DSM) has a separate clinical classification of Hoarding Disorder.

The prevailing observation across the review is that the primary cause of professionals failing to describe and accurately identify self-neglect and hoarding was due to poor awareness and understanding of both issues, along with the safeguarding implications of severe and enduring self-neglect. Perhaps the clearest example of this is in the safeguarding response to JW. Despite direct approaches to Adult Social Care and Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) in Spring 2021 by Scottish Authorities, with safeguarding concerns for JW around self-neglect and suicidal ideation, there was no local safeguarding follow-up or action taken by York colleagues to investigate the safeguarding concerns.

One agency felt reasonably confident that self-neglect would be recognised as an expression of poor mental wellbeing by front-line professionals (TEWV) but said that hoarding is a generally less familiar concept and may not be recognised as a mental health condition. This was echoed by other agencies who said that hoarding was a newer concept.

The limited evidence from the review would suggest that Blue Light services (the Police, the Ambulance Service and the Fire and Rescue Service) who attended the homes of the 5 adults were generally more attuned to the signs of self-neglect and hoarding than health and social care services, and they were also more likely to raise a safeguarding concern. The only exception to this is the local pharmacist, who made two safeguarding referrals with concerns for CD. However, all Blue Light services openly acknowledged that they still have some way to go towards embedding consistent awareness, practices and responses when their front-line colleagues encounter self-neglect or hoarding.

b. Effective case-note recording of self-neglect and follow-up

One of the consequences of indirect, minimised or limited recording of self-neglect and hoarding behaviour in professional/clinical case notes is that other practitioners are blind to the extent of the issues and their longevity. One mental health professional highlighted this specific point at the practitioner discussion and recalled that the wider concerns around JW and her history of hoarding were ‘invisible’ in her general medical records. It is possible of course that other health professionals also did not know about JWs hoarding behaviour, but this seems less likely in JWs case, as she self-defined as ‘a hoarder’ and was open about it, unlike HP and CL for example who actively concealed their hoarding and limited professionals’ access to their homes.

For all 5 adults, their self-neglect appears to have been an enduring pattern of behaviour over many years, but the lack of professional enquiry about their circumstances, often by multiple different practitioners in different settings, and accurate recording of what the practitioner had seen or heard first-hand, probably led to each episode being seen in isolation. This may have also contributed to the

numerous occasions seen across the review, of the adults being discharged back to an unsafe and unsanitary home environment (CD, HP, PD, CL).

Although it may not be usual practice to record wider social circumstances or home/living conditions in medical records, where the self-neglect is significant, problematic or compromises the adult's physical health and wellbeing – as it was in the case of each of these 5 adults – proportionate case-note recording in medical/clinical records seems an essential and protective measure.

An additional approach is to improve the functionality of clinical recording systems so that direct evidence of or professional concerns about self-neglect or hoarding can be readily 'red flagged' on each episode of care. For example, York and Scarborough Teaching Hospitals NHS Foundation Trust (YSTFT) noted that it would be beneficial for self-neglect and hoarding safeguarding coding to be more obvious and accessible on the system used in the Emergency Department (ED). This may also be true of the information held on hospital wards and in primary care records.

The final point around accurate and complete recording relates to Adult Social Care customer contact and care management records. There were numerous examples seen across the chronology of limited recording by social care professionals, relating to both the adult's circumstances and the rationale for the practitioner's decision-making around the need for CAA or a safeguarding response. Most of these examples were at the point of first contact with ASC i.e. the customer contact team, however, there is another notable example of failure to document a professional social work review and decision-making around the care package for PD. In this example, within two weeks of the care package ending, PD was referred to a dietician by the GP due to significant weight loss and PD's neighbour requested a new social care assessment due to her ongoing inability to manage independently. This raises questions about the diligence of this social work review and the lack of professional recording adds to this perception.

c. Hospital discharge and post discharge support

It was striking across the review that some of the most concerning missed opportunities to address reported self-neglect and hoarding happened on discharge from hospital. These examples include where Ambulance Service and ED professionals had reported concerns around self-neglect, and in the case of HP, she also directly disclosed that there were significant problems with her home environment in July 2023.

These instances relate to CD, HP, PD and CL, and although the circumstances were slightly different on each discharge, in each example the concerns about the safety of the home conditions the adult was returned to, or self-neglect, had been reported at the point of arrival / on admission to hospital. It has not been possible for the

review to identify the precise circumstances of each discharge, but the following factors appear to have played a part:

- Hurried discharges that appeared to be made in response to wider pressures on hospital beds, but without proper assessment of the adult's needs post-discharge
- Poor communication between ED and wards
- Poor recognition of the implications of self-neglect on wards, even when it was disclosed directly by the adult
- Reluctance of wards and social workers to consider using the safeguarding system to respond to circumstances where the adult was deemed to have capacity but refused support or self-discharged against advice
- A lack of professional curiosity and rapport-building with the adult on the ward
- Unclear policy/guidance for hospital discharge transport arrangements i.e. the explicit expectation that an adult would be immediately returned to hospital if their home was found to be uninhabitable or unsafe on discharge (this applies to both York and Scarborough and Leeds hospital transport)

The examples seen across the review highlight deficits in recognising, recording and responding appropriately to self-neglect/hoarding across the hospital patient journey, which requires urgent attention.

2.2 Barriers to practice when working with adults who show ongoing self-neglect behaviours

a. Working with and interpreting complex behaviour

Although there is some evidence that several professionals understood the importance of building trust and rapport and showing flexibility with the adults, as a way of sustaining their engagement with health or social care, this strategy was not universally applied. In fact, it was more common for professionals to close the case/cease support:

- on the grounds of non-engagement / DNA ('did not attend')
- by taking the adults' word that they did not need help, without any further follow-up
- in one instance the practitioner refused to attend the adult's home again

The review process explored views and attitudes to adults who have complex and sometimes difficult to interpret behaviour and some contrasting viewpoints were shared:

- Some contributors felt that the professional behaviour seen towards these 5 adults was likely to have been influenced by unconscious bias, including the

broader social stigmatisation and lack of understanding about what drives adults to extreme self-neglect and hoarding

- However, there was an equally strong view from some contributors that there was no direct evidence of unconscious stigmatisation of self-neglect in their agency's response. A poor understanding of self-neglect, accompanied by a lack of professional curiosity, were considered to be the more likely explanations
- It was largely accepted that self-neglect may be more likely to be interpreted by professionals in York as a 'lifestyle choice' rather than an indication of poor mental wellbeing or the genuine inability of an adult to care for themselves. This was said to be due to system-wide professional knowledge-gaps around self-neglect and hoarding

Other barriers to working successfully with the adults were identified as:

- A strong mistrust of professionals, sometimes linked to previous experiences, which may have led the adults to reject professional help as they interpreted any intervention as a threat, or a route to losing their independence
- Most of the adults appeared to mask or conceal their circumstances at some point, although this was not consistently the case, except for CL who did not appear to allow anyone into his home
- The working reality that if professionals identify self-neglect, there are few local services that provide practical, ongoing solutions to support such adults, other than a small number of oversubscribed voluntary sector services in York that offer house clearance/cleaning
- The time-commitment involved in working slowly and carefully with adults over many months to achieve sometimes small improvements - and having access to practitioners with the right skills and roles to make this way of working feasible
- No professional forum for discussing the challenges of working with adults who are showing concerning and/or escalating levels of self-neglect

b. Trauma and adversity-informed practices

The review developed some limited insight into the personal histories of each adult, however, even within these small glimpses into their life experiences, a reasoned assumption may be drawn that each adult's tendency towards self-neglect and/or hoarding may have been driven by some of these accumulated, distressing life experiences. These included:

- Domestic abuse (PD)
- Removal of a child (PD)
- Working experiences that led to PTSD (JW)
- Loss and bereavement (CL, HP)

- The impact of acquired sensory loss / disabling condition / Chronic Fatigue Syndrome during adulthood (HP, PD)
- Multiple cancer diagnoses (HP)
- Fear of losing independence (CD, HP)
- Past negative experiences of formal care - direct care or the care of close family members (CL, HP)

Across the chronologies, there was little evidence of professionals seeking to understand *why* each adult was self-neglecting or hoarding. It is possible that more in-depth and exploratory conversations did take place with some of the adults e.g. HP and PD, however, there is no substantive record of them. There was also very little explicit recognition that self-neglect and hoarding behaviours are typically rooted in the poor mental wellbeing of the adult. Instead, it was more likely for professionals to recommend practical input, such as signposting to cleaning/house clearance services or support for personal care, without any follow-up.

All agencies accepted that professional curiosity and relational practice was widely lacking in the professional interactions with the adults. It was suggested that more general education and training around self-neglect and hoarding, may support more focused professional enquiry and persistence in the future, along with some best practice guidance for front-line practitioners on how to begin a non-judgemental, supportive but candid conversation with an adult who is seen or suspected to be self-neglecting/hoarding.

It is the author's recommendation that this training/guidance incorporates content designed to develop awareness of the impact of traumatic or adverse life experiences on adult behaviour, so that professionals understand the psychological and emotional basis of self-neglect and hoarding and can apply the basic principles of trauma-aware and psychologically informed practice. This insight will also help practitioners to look beyond the adult's presenting circumstances or behaviour, enabling them to see the adult's needs or risks with greater clarity.

c. Preserving the therapeutic/professional relationship

It was expressed several times across the review process that there is a perceived tension between the good practice of building trust and rapport with adults that show self-neglect and hoarding behaviours or wider mental health issues, and using the safeguarding system to protect them, typically without their agreement and sometimes in direct opposition to their wishes. Several practitioners said that using the safeguarding process felt counter intuitive because of this, but they also acknowledged that this also led to them holding all the risks around the adult's support needs in isolation.

An important piece of learning from the review is how to manage trusted relationships between a practitioner and an adult, within a safeguarding scenario. Although JW was the only adult using therapeutic services provided by a mental health professional, when this professional was asked to take part in a joint safeguarding meeting with Scottish authorities, it irreparably damaged the therapeutic relationship with JW and she did not access York mental health services again. It was also reported that JW's suicidal ideation was exacerbated when practitioners pressed issues or suggested getting other services involved. This demonstrates the dilemma that some practitioners were faced with.

Whilst this dilemma is real, services should consider and balance the risk to the adult of *not* taking any safeguarding action, against the effects of potential damage to the working relationship with the adult. Because these decisions could be complex, they should ideally be escalated to or discussed with managerial, supervisory or specialist safeguarding colleagues and the rationale for action / non-action carefully documented.

The other key learning is that if an adult is in an established therapeutic or other trusted relationship with a particular practitioner, services should consider how to manage the reporting of safeguarding concerns, with a view to preserving the primary trusted relationship if possible.

2.3 Using available legislation and local policies to positively address the harms and risk of enduring self-neglect

a. Effective use of the safeguarding system

One of the central themes throughout this review has been to understand why so few professionals appeared to view the adults' circumstances through a safeguarding lens, especially because the levels of self-neglect and hoarding were so obviously extreme and enduring.

The analysis and discussions as part of the review processes have indicated that there were numerous factors that influenced professionals' interpretation of what they saw and whether it was a risk to the adults' health, wellbeing and safety - and subsequently how they used the safeguarding system to protect the adult. The key issues were:

- A poor understanding of self-neglect as a distinct form of neglect in the Care Act, and as a safeguarding issue, which was partly attributed to the low profile of self-neglect across the SAB and its partners. One of the repeated findings is that self-neglect as a topic is typically subsumed into generic agency safeguarding policies or methods of recording, contributing to its lack of visibility as a safeguarding issue. Some agencies said that current guidance around self-

neglect may also be process-driven, rather than giving practitioners the tools to work relationally with an adult.

- There were relatively few instances of professionals recognising or acting on concerns or evidence that the adult lacked the physical, cognitive or emotional resilience to self-care due to the conditions they were living with e.g. it seems very likely that CD had dementia, PD was extremely physically frail, HP had struggled with Chronic Fatigue Syndrome for many years, JW was living with PTSD, and although it is not documented anywhere, the possibility that CL may have been neurodiverse (based on his observed patterns of behaviour) was also discussed
- Associated with the first point, a prevailing belief that abuse and neglect involves a third party, and neglect of oneself (self-neglect) was therefore not recognised as a safeguarding issue
- A sense that the harm arising from self-neglect would not meet the expected threshold for safeguarding for some professional groups. This point has some merit, as not all self-neglect and hoarding should be seen as a safeguarding issue. However, extreme and enduring self-neglect, which is problematic for the individual and has serious safety, health or wellbeing implications, is very likely to meet the safeguarding threshold. The findings from the review indicate that most practitioners did not make these differentiated judgements and apparently did not recognise that for most of the 5 adults', their circumstances had tipped over into being unsafe and/or a repeated cause for concern
- Professional fatigue associated with safeguarding referrals that are perceived as not adequately followed up by Adult Social Care and/or feedback that the safeguarding issue did not meet the threshold for further investigation or action
- A misinterpretation of the primary purpose of making a safeguarding referral (i.e. to protect the adult and reduce the risk of potential harm), such that some professional groups said that they may be less likely to make a safeguarding referral if they believed that it would not substantially change the outcome for the adult
- A widely held misconception, which was confirmed through the SAR Panel and agency discussions, that safeguarding referrals should not be made without the express consent of the adult. Some agencies, whose geographical remit extends outside of York City, said that this was also a broader regional pattern. Another speculated that professionals may be misunderstanding or interpreting 'Making Safeguarding Personal' too literally. For clarity, whilst it is good practice to always discuss and explain any safeguarding concerns with the adult themselves and seek their involvement in the safeguarding process from the earliest opportunity, a lack of consent by the adult does not 'release' a practitioner from their safeguarding duty of care to the adult. Therefore, safeguarding referrals can

and should be made without the adult's consent if the practitioner is sufficiently concerned.

These findings suggest not only a broad misunderstanding of self-neglect and hoarding but a more concerning trend of health and social care professionals in particular being unclear about their professional duties and responsibilities under the adult safeguarding legislation in the Care Act. The sense from the review is that some of these safeguarding views are long-held and engrained in professional mindsets, and as such they will need to be squarely addressed as myths and inaccuracies.

b. Consideration of mental capacity

Across the agency case-notes it is evident that there was a consideration of the mental capacity of some of the adults, for CD and PD in particular, and on one occasion for CL. However, these assumptions of capacity were usually only documented when the adult had declined social care support or medical care against advice.

There is evidence from the chronologies that both CD and PD were showing signs of cognitive decline or had disclosed this e.g. PD acknowledged to a social worker during a social work assessment and during a Comprehensive Geriatric Assessment that she had memory problems and her neighbour confirmed that she regularly forgot to take her medications. The Adult Social Care safeguarding lead's assessment of the social care intervention for PD was that was not in line with expected practice. They would have expected the social worker to have explored PD's mental capacity in a more in-depth way, if necessary, escalating the issue to managers or seeking advice from the safeguarding team.

For CD, the signs of cognitive decline were perhaps more subtle as memory or cognition issues were not directly identified until very close to her death, however, the GP practice had noted a general deterioration in CD in the two years before her death, she regularly presented as confused in calls to the Police, she required ongoing prompting around the care of her leg ulcer, and her continence issues could also have been linked to dementia onset.

For CD and PD, the use of mental capacity assessment appeared superficial and did not record whether either woman understood and could articulate the consequences of their decisions to refuse support. The review could find no evidence that their wider patterns of behaviour and information that was contextually relevant to a mental capacity decision was considered, despite both women being vulnerable. For PD, an exploration of her executive functioning would have been very helpful and may have revealed that although she *said* that she could cope or would seek help, this was not the case – as the account of her neighbour confirmed.

There was a wider point that emerged during the review around the use of mental capacity assessment in cases of self-neglect. Multiple agencies voiced a concern that when adults decline services, the application of the MCA is too often used by professionals as a route to 'legitimately' closing the case, on the basis that the adult has a right to make an unwise decision if they have mental capacity. One agency described this as MCA being used as a 'licence to walk away'. Unfortunately, many of the professional interactions with these 5 adults would seem to confirm this view and perhaps suggest limited legal literacy around the provisions of the MCA.

The overall impression from the review is that:

- Professionals were too ready to assume capacity when the adult declined support, despite sometimes having contextual evidence to the contrary or ongoing concerns about the adult's vulnerability
- Recording around adults' capacity was typically vague i.e. the case notes shared with the reviewer do not show what specific decisions professionals deemed the adult to have capacity to make and whether the adult could understand or retain information about the decision, use or weigh that information, or communicate the rationale for their decision
- Although not directly relevant to mental capacity, the physical capacity of some adults to self-care was also not properly considered e.g. due to frailty, long-term disability, challenges with mobility and extreme fatigue

There was wide acceptance across the review, that more needs to be done at a York system level to support legal literacy around the MCA, to improve professional confidence and ownership of mental capacity decisions. It was also mentioned that the principle of professionals having a duty to objectively decide a course of action that is in the Best Interests of an adult, if lack of capacity is established, was poorly understood by professionals, which may make it more likely for them to assume capacity even if they have reasonable doubts. Although training for front-line practitioners may inevitably be part of improving legal literacy around the MCA, the emphasis should be on practical training with real-world examples and scenarios.

c. The multi-agency response to self-neglect and hoarding behaviour

It is recognised that the York SAB and its partners have taken steps to enhance the local response to self-neglect, which has included recently issuing new Self-neglect Practice Guidance and a York SAB/ASC-led working group is actively looking at the topic through a safeguarding lens.

Numerous contributors to the review said that one of the ongoing professional challenges in working proactively and productively with adults who show self-neglect and hoarding behaviour is the lack of a local support pathway. The elements of such a pathway could include:

- A forum or route for professionals to be able to seek advice or 'supervisory' support from other trusted professionals
- A single, multi-agency process/forum for escalating discussions around adults that self-neglect/hoard, where risks can be jointly assessed and managed, and wrap-around support is co-ordinated between professionals – this was referred to both as an MDT approach and a vulnerable adult risk management (VARM) approach
- Engagement of and greater collaboration with social housing providers
- Services or skilled workers that can provide a practical but psychologically informed response to adults who are displaying concerning levels of self-neglect or hoarding, alongside 'deep cleans' in more urgent situations and use of step-down beds when safe hospital discharge is not possible
- Community-led support solutions e.g. safe spaces and mutual support for adults who are living with a hoarding disorder or show repeated self-neglect

Creating a clearer multi-agency infrastructure for responding to hoarding and self-neglecting behaviours will undoubtedly support professional responses to the issues. However, as several contributors pointed out, and wider sources of good practice also indicate[iii], a comprehensive response involving close co-operation between statutory, voluntary and community sector services offers the most effective and sustainable solution.

Addendum to the Themed Safeguarding Adults Review considering self-neglect

This addendum to the SAR summarises the circumstances of 2 additional adults who had experienced self-neglect, whose deaths were identified after this SAR had been commissioned. SAR referrals were made in relation to both adults.

Following screening by a SAR multi-agency decision panel, it was agreed in Summer 2025 that both referrals met the criteria for a SAR to be conducted and that the primary safeguarding issue for each adult was self-neglect and/or hoarding. At this point, the analysis relating to the 5 adults who were the original subjects of the SAR had already been completed in a full draft form.

It was agreed between the SAR author and the multi-agency SAR panel that the circumstances of the two additional adults should be considered by the SAR author alongside the findings from the existing themed self-neglect review. This would be achieved by providing an addendum to the main report and analysis, which highlighted any similarities or differences in the lived experiences of the adults, the professional response, and the learning from the review process.

This was considered a proportionate and pragmatic response, and importantly, it supported the independent consideration and oversight of the circumstances of both adults by the same SAR author, allowing the learning from all 7 scenarios to be incorporated into a single themed SAR.

To provide this addendum, the author competed a largely a desk-top review which was informed by the original SAR referral, the composite screening documents and a combined chronology for each adult. The details of family members and/or next of kin were available for PH but there were no contact details for AC, although it is thought that he may have had adult children and a nephew. The brother of PH was contacted by the Safeguarding Adults Board Manager and the information gathered was shared with the author.

A further draft of the SAR report and this addendum were considered by SAR Panel 3 on 26 November 2025. The analysis of these two additional cases has also informed the SAR recommendations.

Summary for adult AC

AC was found at his home address on 1 March 2025, although he was thought to have sadly died some time before. He was aged 79 and lived on his own in a City of York social housing tenancy. His cause of death is not known at the time of writing. His next of kin was thought to be a nephew, but there were no contact details available. GP records suggest he had been married at some point prior to 2003 and friends said that he may have had 2 sons that lived elsewhere.

AC was discovered following a concern raised by one of his friends, as he had been seen through the window of his property and appeared unresponsive. They reported that AC had previously been ill with a chest infection and suffered from COPD and his mobility had become worse in the months prior to his death. A Yorkshire Ambulance crew attended the property and with the assistance of North Yorkshire Fire and Rescue, forced access into the property was gained through a window. AC was found behind the kitchen door, surrounded by piles of papers and books. The property was reported to be heavily hoarded, with only limited movement around the address possible.

AC's friend reported that he was known to hoard and that his home was heavily cluttered with stacks of papers. In addition, the friend reported that the property had no working electricity and no oven or microwave, which meant that AC always ate out, and as a result he was regularly seen out and about in the community. When Police attended the property following AC's death, there were no working lights in the flat. There also were no agency records of a phone number for him and this may be because he did not have a mobile phone or landline.

AC's contact with services was collated for a period of 2 years before he passed away. It is striking how little contact he had with any services, in particular healthcare, given that he was an older adult. In fact, GP records suggest that AC had only ever consulted the practice twice between 2003 to the point of this death in 2025, a period of over 20 years, and had ignored all invitations for routine care, such as vaccinations.

Police records show that AC had numerous contacts with the Police in the context of anti-social behaviour / an ongoing neighbour disagreement where AC was documented as both the victim and the alleged perpetrator of the anti-social behaviour. In the period immediately before AC's death there were two 'concerns for safety' welfare calls by agencies. In total there were 9 contacts with Police linked to AC between 2015 and the time of his death.

What *was* known about AC was his tendency to hoard. He had been a social housing tenant of City of York Council since 2002 and in 2022 action was taken by the social housing provider to support AC to clear his property. However, this did not go ahead as he refused entry to the property. Around the same period, North Yorkshire Fire and Rescue also attempted to make a Home Fire Safety Check and were also refused access, although AC reported that he had working fire alarms.

It is not clear when the hoarding at the property was first identified, but a visit to an adjacent property in early 2017 by North Yorkshire Fire and Rescue Service, led to a hoarding concern due to an observed build-up of belongings in the property (seen through the window), which was reported to Adult Social Care. However, no further action appears to have been taken at that time by either Adult Social Care or North Yorkshire Fire and Rescue Service.

In March and June 2024, further attempts were made by the housing management team to discuss the state of AC's property with him, both without success. In the month before AC was found deceased in his home, concerns were raised by neighbours. A Police welfare check was undertaken which confirmed significant hoarding at the property and the housing management team made a formal safeguarding referral to the Adult Social Care safeguarding team at this time. This led to the commencement of a formal s42 safeguarding enquiry at the end of February 2025, however, AC was sadly found to have passed away shortly after.

North Yorkshire Fire and Rescue Service subsequently made a SAR referral.

Analysis

There are clear parallels between the circumstances of AC and the other adults who were considered in the review. These include:

- Living in poor housing conditions which were not habitable and/or compromised the welfare and safety of the adult e.g. heavy hoarding which did not allow full use of the home, living without electricity, no access to cooking facilities, no access to a mobile or landline phone. Although it was not explicitly reported, it is possible that the level of hoarding prevented AC from using his bed/bedroom and he was found sat in a chair
- An appearance of being personally unkempt
- A reluctance to voluntarily engage with services and support, alongside an active resistance to professional attempts to legitimately enter the property
- Living alone
- Limited or distant family connections, although AC's neighbours and friends from his local pub were clearly concerned about his welfare

In terms of the professional response, although a call (presumably in the context of a safeguarding concern) was made to Adult Social Care in February 2017 to report the visible hoarding at the property, observed from the outside by North Yorkshire Fire and Rescue, there was no follow up by either agency. (Adult Social Care did not report a parallel record of this contact as it was outside the SAR timeframe.) In addition, it does not seem that the social housing provider was consulted about or advised of the hoarding at the property, however, it is reasonable to expect that effective screening of the safeguarding concern could have led to the identification of AC as a social housing tenant and information subsequently shared with City of York Housing Services.

This was a significant missed opportunity to act on what was a visible problem, observable even from the outside of the property, some 8 years before AC was found to have passed away. It was not until 2022 that the social housing provider attempted to intervene to address the hoarding at the property, without success,

followed by two further attempts to contact AC in 2024, one in an in-person visit and one by letter. No safeguarding concerns were reported on any of these occasions, which is consistent with what was seen across the review more generally, which points towards poor professional recognition of significant and sustained hoarding as a form of self-neglect and a legitimate safeguarding matter.

A distinct piece of learning arising from AC's scenario relates to his long-term lack of engagement with primary health care for a more than 20-year period and his last recorded use of secondary health care services was in 2011. This would seem particularly unusual as someone ages, when it is more likely for health problems to emerge.

The GP practice acknowledged through the SAR screening process that AC's circumstances had caused them to reflect on the potential for periodic monitoring of adults over 65 years of age who have had no contact with the GP practice for 12 months or more. In that Practice, this cohort of adults equates to around 600 people or 7% of registered patients aged 65+. Such an approach could offer multiple benefits by reaching potentially vulnerable patients and identifying unmet health care and wider social support needs.

Summary for adult PH

PH sadly died in June 2025 and he was 80 when he passed away. His brother contacted the police in early January 2025 after being unable to reach him for two days. Police Officers carried out a welfare check, forcing entry to the property because PH was seen lying on the living room floor of his flat, where he later told the Ambulance crew he regularly slept. He was in a very poor physical condition with visible signs of self-neglect, including inadequate food and fluid intake. He was taken to York and Scarborough Teaching Hospitals NHS Foundation Trust (YSTFT) for immediate medical attention. At this time, he consented to a referral to Adult Social Care and recognised that he needed help.

The Ambulance crew who attended the property noted that PH had an insulin-dependent form of diabetes and poor mobility. It was also reported that he regularly drank alcohol and PH later disclosed that he had a history of problematic alcohol use. It was also said that he suffered from hypertension.

PM was wearing soiled clothing when he was found and it was judged that he was unlikely to have been able to attend to his personal care and hygiene needs. Wider observations of the home environment noted very unsanitary conditions and a fly infestation. The bathroom was unusable and there was no fresh food or drink at the property. The professionals in attendance documented that the environment posed a serious health and safety risk to PH and others. The Police documented that the strong odour from the property had previously prompted complaints from neighbours,

however, is not clear if the neighbours had reported this to City of York Housing Services, who were the social landlord of PH's flat.

PH's brother said that he was a private man. After a period of estrangement, they had reconciled in recent years. His brother visited his flat after PH had been admitted to hospital and said that PH appeared to have been overbuying 'pills' as his drawers were full of them – the assumption is that these may have been painkillers. He also confirmed that the home was uninhabitable and very dirty with a strong smell. PH's brother also expressed disappointment that no-one had noticed the conditions in which his brother had been living.

On admission to hospital after he had been found in his flat, PH was also found to have necrotising otitis externa which is a serious invasive infection of the ear canal, which can be associated with diabetes. He spent just over a month in hospital and although PH maintained that he wanted to return home, a health-funded Continuing Health Care placement was made to a nursing home to provide end of life care. In fact, PH died around 4 months later. During his time in the nursing home he initially experienced some mental health issues and low mood, including suicidal thoughts. However, he was prescribed anti-depressants, and this improved the situation although his physical health deteriorated, and he could not mobilise without a hoist and wheelchair. Very sadly his physical health continued to fail and he died in June 2025.

Prior to January 2025, PH had limited contact with services including his GP, however, there were numerous visits to his home in 2023 and 2024, the most significant of which were:

- In January 2023 a pharmacy delivering medication to PH reported concerns about the very poor state of the home to the GP, including having seen faeces in the living room. The GP contacted the Adult Social Care (ASC) Contact Centre. It was explained that ASC had 'no consent' to become involved and the GP or a social prescriber should make initial enquiries through a home visit to explore if it was a health issue or a social care issue. Although the GP did follow up, it was not through a home visit as PH was not regarded as being housebound and he was invited into the surgery instead. His home conditions were discussed.
- In May 2023, a gas engineer visited PH's home to service the boiler. No issues were reported to CYC Housing Services.
- In June 2023, an annual review and test of the telecare call and response equipment at PH's property was undertaken. Following this visit, the provider emailed the ASC Contact Centre reporting the conditions and unpleasant smell at the flat. It was reported that a deep clean was necessary in every room, especially the bathroom. PH agreed to the deep clean. The Contact Centre made a follow up phone call to PH, giving him advice on numbers and services to call for support with cleaning. At the time, he was asking for 3 hours help a week

to clean his home and support with moving furniture so that new carpets could be fitted. There was no further action by ASC.

- In July 2024, an electrician visited the flat to resolve a partial loss of power. No issues were reported to CYC Housing Services.

Analysis

There are multiple similarities between the circumstances of PH and AC as well as the other 5 adults. In addition to the characteristics already described for AC, PH also appeared to be suffering with low mood and the additional dimension of excessive alcohol use, for which he received medical support to detox when he was admitted to hospital in January 2025. Based on the very poor condition in which PH was found and his physical frailty and state of health, along with the professional views documented at the time, it seems likely that PH had been physically unable to care for himself for some time, possibly exacerbated by his use of alcohol.

He was also known to be living with insulin dependent diabetes, but the GP reported that he did not regularly engage with long-term condition support or reviews. Because of this PH was asked to sign a waiver, presumably because of the particular risks associated with using and monitoring insulin and steps were also taken by the Practice to follow up if PH did not attend appointments. The Practice acknowledged however that he had raised concerns about long-Covid which were not discussed.

Unlike some of the adults considered in the review, PH allowed different service providers into his home. Unfortunately, while these were all opportunities to report and address the very poor conditions in which he was living, two reports which clearly suggested there were significant problems were not thoroughly followed up. These two concerns were not characterised as hoarding, self-neglect or as a safeguarding matter by the professionals that raised them, but they did give enough detail for ASC colleagues to recognise there was a considerable and long-standing problem and PH was living in unsanitary conditions.

It is also concerning that a barrier to the GP Practice making a home visit to assess the situation in person, which was the advice given to the Practice by ASC, appeared to be that PH was not considered to be housebound.

None of the services involved in these processes – the telecare provider, the ASC contact centre nor the GP – seemed to recognise that PH was a CYC social housing tenant, so unfortunately the concerns were not shared with the agency that had the most direct and legitimate interest in PH's circumstances, as he was a tenant in their property.

There is also direct learning for CYC Housing Services. It has long been a common practice for the annual gas safety checks required by social landlords to be an

opportunity for engineers to report any welfare concerns about tenants. In the timeframe the two engineer visits (referenced above) were made, PH's home had already been reported to have been in an extremely poor state, but this was not reported to CYC Housing Services.

In comparison with the review findings relating to the other 5 adults, there are both similarities in the professional response, such as the failure to recognise extreme self-neglect and report it as a safeguarding issue, and specific differences, such as the oversight of multiple professionals to recognise the role of the social housing provider in addressing welfare concerns regarding the domestic conditions of adults living in their properties.

[i] https://www.nhs.uk/mental-health/conditions/hoarding-disorder/

[ii] Link to the international clutter image ratings scale via Hoarding Disorders UK

[iii] https://www.foundations.uk.com/guides/hoardingbestpractice/