Richmond and Wandsworth Safeguarding Adults Board

SAFEGUARDING ADULT REVIEW
Simon

2024

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1. Introduction

1.1. This report covers the findings and recommendations from a mandatory Safeguarding Adult Review (SAR), undertaken on behalf of the Richmond and Wandsworth Safeguarding Adults Board (RWSAB), regarding a Richmond resident, called Simon[1] The SAR referral was made by the Recovery and Support Team of the Mental Health Trust.

1.2. Simon was a 54-year-old white British man who died in March 2023 from a myocardial infarction (heart attack), secondary to him having end-stage alcoholic liver disease and chronic lung disease.

1.3. Simon also had a diagnosis of paranoid schizophrenia and was seen at home by the local mental health service monthly for the administration of antipsychotic injections.

1.4. Simon lived in a one-bedroomed housing association flat in Richmond. Simon's sister and a nephew moved to live with him in 2012, to support and care for him.

1.5. Simon's family told the authors they had tried their best to persuade Simon to access health services as they were concerned about his deteriorating physical and mental health but said they found it very challenging to get professionals to listen to their concerns about him.

1.6. Simon's sister and her sons spoke about what a lovely man he was and that you 'shouldn't judge a book by its cover'. They felt that all people saw was his drinking rather than who he really was.

1.7. Simon's sister shared Simon's photograph so we can see the brother she loved and cared about.

1.8. The reviewers would like to acknowledge and thank Simon's sister and his nephews for their involvement in this review. It was not easy for his sister or his nephews to talk about Simon and to tell his story, but through their courage the health and social care system in Richmond has an opportunity to learn and change practice.

[1] The safeguarding adult review (SAR) was agreed by the Richmond and Wandsworth Safeguarding Adult Board (SWSAB) Executive in on 25th July 2023 as SAR "Ash" following the usual practice of anonymising cases. . However, the request to change the title of the SAR from 'Ash' to Simon was made by Simon's family in February 2024, at a meeting with the SAR reviewers.

2. Undertaking A Safeguarding Adult Review (SAR)

2.1. Decision to undertake a Safeguarding Adult Review

2.1.1. Under the Care Act 2014, sections 44(1), (2) and (3), Safeguarding Adults Boards (SABs) are required to complete a mandatory SAR when an adult with care and support needs has died or suffered serious harm, and it is suspected or known that the cause was due to neglect or abuse (including self-neglect) and there is concern that agencies could have worked better to protect the adult[2].

2.1.2. On 25 July 2023, the RWSAB Executive agreed the criteria to undertake a mandatory SAR was met as Simon had died with indications of self-neglect, and there were concerns that partner agencies could have worked more effectively to protect him.

2.1.3. As Simon's death was recorded as being due to natural causes (myocardial infarction) his death was not subject to a coroner's inquest.

2.2. The Purpose of a SAR

2.2.1. The purpose of a SAR, as defined in the Care Act 2014. is to promote effective multiagency learning to prevent future deaths or serious harm occurring again and to ensure recommended changes to practice are embedded across all agencies.

2.2.2. The purpose is not to hold any individual or organisation to account as other processes are in place to address organisational accountability via by the Care Quality Commission, professional accountability via professional regulators such as the Nursing and Midwifery Council or Social Work England and criminal proceedings overseen by the Metropolitan Police.

2.2.3. The **RWSAB SAR Protocol** supports consistent and robust decision making in keeping with the principles of Making Safeguarding Personal and the Six Principles of safeguarding.

2.3. Agencies involved in the SAR

2.3.1. The following agencies were identifed as being involved in this case:

- Adult Social Services
- London Ambulance Service
- 111 Service
- Simon's General Practitioner
- Mental Health Trust (Recovery and Support Team -RST)

2.4. Systems oriented research questions

2.4.1. The RWSAB SAR Sub- group developed Terms of Reference (ToR) for SAR Simon, which are available in Appendix 1 of this report. Taking a systems-based approach,

[2] Local Government Association (2020) ***Briefing for senior leaders - Analysis of Safeguarding Adults Reviews***

the Terms of Reference captured the intended 'systems' focus of this SAR. The objective was to draw out wider learning from practice in Simon's case. Specifically, the systems-oriented research questions were:

What can we learn from practice in response to Simon's circumstances and experiences about:

- How partners assess risk and communicate it across agencies?
- Is conscious and/or unconscious bias from professionals in the health system impacting on thinking about a person's mental capacity?

2.5. Timeframe

2.5.1. The timeframe for the SAR was from November 2022 until Simon's death on 6th March 2023. This covered the time from the GP's last face to face appointment with Simon and key concerns about how partners worked together as Simon's health deteriorated over this time.

2.6. Independent Reviewers

2.6.1. RWSAB SAR is part of a SWL Community of Practice (a group of professionals from across SWL, who have received training to conduct independent reviews like SARs and Children reviews and meeting quarterly to ensure knowledge is retained). The group provides opportunities for reciprocal arrangements in the provision of lead reviewers.

2.6.2. The recommendation from the RWSAB SAR Subgroup was that the SAR should be completed by a senior NHS practitioner, supported by a member of the case review subgroup. The RWSAB manager approached Trish Stewart (TS), the Central London Community Healthcare NHS Trust (CLCH) Associate Director of Safeguarding in Autumn 2023 about undertaking the SAR. However due to work commitments, TS was not available to start the review until later in 2023. At the end of November 2023, TS agreed to take forward the SAR, with workshops planned for January and February 2024.

2.6.3. TS had no previous involvement with Simon, services to him or the Richmond case review subgroup panel and is therefore independent to the case. TS was supported to complete the SAR by Charlotte Appleton (CA), who is a Senior Service Manager with Wandsworth Local Authority, who is also independent to this case.

2.6.4. Independence was bolstered further with supervision provided by Dr Sheila Fish, independent reviewer/consultant, review methods expert and lead author of the national good practice standards for SARs, the SAR Quality Markers.

2.7. Methodology & approach

2.7.1. The RWSAB Case Review Subgroup (The Subgroup) used the SAR Protocol decision tree to identify the methodology they believed a root cause analysis (RCA-Option B) was the preferred option, as this methodology was commonly used by the NHS when investigating serious incidents, and it was mainly health agencies who were involved in Simon's care. The Subgroup has now reviewed the SAR Protocol to incorporate the Patient Safety Incident Response Framework (PSIRF) process, which replaced the RCA

approach to investigating NHS Incidents from September 2023.

2.7.2. The reviewers therefore attempted to understand what happened and why, with reference to potential contributory factors. This was achieved through a review of a detailed multi-agency chronology put together by the RWSAB business unit and a practitioner workshop. The aim of the latter was to appreciate the pressures and dilemmas, competing priorities and demands that were at play, in single and multi-agency efforts to respond to and support Simon.

2.8. Involvement of Simon's family

2.8.1. Throughout his life, Simon was supported by family. Simon' sister and his nephew lived with Simon in his one-bedroomed flat, with his nephew sharing Simon's bedroom, and his sister sleeping in the kitchen. Professionals were aware of the living arrangements, including that Simon's sister slept in the kitchen, but seemed to normalise the situation.

2.8.2. Simon's sister was his advocate and understood his care needs. She sought support for Simon time and time again, but there was a view amongst professionals, that she was able to meet his care need on an informal basis.

2.8.3. Simon's sister told the reviewers she had her own mental and physical health needs, and that she consistently reported to professionals she was struggling to meet Simon's complex physical and mental health needs.

2.8.4. Simon's family did not believe he had mental capacity and his sister consistently tried to get professionals to see Simon in a different light.

2.8.5. Simon's death has left his family with many questions and their grief is very evident. His family spoke about having the opportunity to be heard and the authors want to ensure their voice and experience is captured in the SAR report.

2.9. Methodological comment and limitations.

2.9.1. Unfortunately, those who attended the practitioner event for this SAR were not in the main practitioners or clinicians who had had a direct role in working with Simon and/or his sister. This restricted greatly the detail they could provide about the first-hand experience of the work in the context of the time. It meant little could be shared about the rationale behind people's actions and decisions.

2.9.2. The exception was the GP, whose input was invaluable.

2.9.3. The meeting with Simon's sister and his nephews was very helpful as their words and views gave the reviewers insight into who Simon was, his needs and understanding of his physical and emotional health needs and the traumas he had experienced in his lifetime. Meeting Simon's family also provided a window into their experience of how professionals worked with Simon and his family to fully understand their issues, fears, and expectations.

2.10. Completion time

2.10.1. Section 174 of the Department of Health and Social Care (DHSC) **Care and support statutory guidance** (2014) recommends that a SAR should be completed within a reasonable time, ideally 6 months from when the SAR was initiated, unless there are

good reasons why a longer period is required.

2.10.2. In this instance, the SAR has required a longer period due to the demands of the full-time jobs and work pressures of both reviewers, to allow for the invaluable input from Simon's family and some technical difficulties that added to the timeframe.

3. Practice analysis in Simon's case

3.1. Simon's longer history

3.1.1. The following background history of Simon's life was generously provided by Simon's sister. As we will show in section 3.3 understanding of Simon's background was not widely understood by professionals or evident in the practice responses.

3.1.2. Simon's sister told the reviewers Simon was diagnosed as having a severe learning disability and dyspraxia, as his frontal lobe had not developed properly, and he was under the care of paediatricians as a child and young adult. Simon was reported to have always attended a special school and was illiterate when he left school. Simon's sister had letters from the paediatricians he had seen during his childhood, but his learning disability was either not known by professionals or formally recorded in his adult health and social care records.

3.1.3. Simon had a very close relationship with his grandfather and worked with him doing decorating and gardening jobs; this was reported to be a good time in Simon's life. Simon's sister reported he was living independently in his own flat up until 2002, when he had a mental breakdown in response to his grandfather's death. Simon was subsequently sectioned under the Mental Health Act (MHA, 1983) and diagnosed with paranoid schizophrenia. He was discharged with a package of care and was living with his mother. His drinking was reported to be under control at that time.

3.1.4. In 2012 Simon's mother died, and this bereavement triggered a relapse in his mental health difficulties and an increase in his drinking, leading to him having repeated involuntary hospital admissions under the MHA. Simon was receiving monthly depot injections of antipsychotic medication to maintain his wellbeing but would at times refuse treatment. Simon's reliance on alcohol increased and he was reported to be drinking bottles of whiskey daily. Simon's sister moved in with him to support and care for him.

3.1.5. By 2015 Simons physical health had deteriorated and he was hospitalised for treatment of ascites (excess abdominal fluid), which was a complication of him having alcoholic liver disease. However, Simon's sister told the reviewers that during an admission for drainage of his ascites Simon had a cardiac arrest, resulting in him being admitted to intensive care. Simon's sister said she was told it was unlikely he would recover, and if he did it was likely he would have brain damage. Simon did recover, but it was 6 months before he was able to come home.

3.1.6. Simon did not drink for a year after his discharge home, but then started drinking again and as time went on his sister was struggling to care for him and was reaching out to professionals to get him help.

3.2. Narrative chronology of timeline.

Date	Contact with professionals
November 2022	Simon agreed to his general practitioner (GP) referring him for urgent tests and medical assessment as he was presenting with jaundice (yellowing of his skin) and ascites (excessive fluid in the abdomen restricting his breathing) which was symptomatic of him having liver failure due to his alcohol intake.
December 2022	TRST advises Simon to contact his GP about red mark on his arm
19 January 2023	Simon's sister calls an ambulances as he had fallen in his bedroom and sustained a head injury; he was reported to have drunk half a litre of whiskey that morning. Paramedics observed Simon as unkempt, unshaven, underweight and had an extremely distended abdomen (ascites). The paramedics discussed the need for a safeguarding referral with Simon and his family and all agreed a safeguarding referral for self-neglect was required Simon seen in A&E, clinicians note a nasal fracture and ascites. He was referred to ENT and although attempts were made for Simon to see the gastroenterology team, he was discharged home.
20 January 2023	Safeguarding referral triaged by Local authority and passed to Mental Health Social Work (MH SW) Team. MH SW tried to speak to Simon on phone but he refused to speak to duty worker. She booked home visit for 7 Feb
30 January 2023	Simon did not attend hospital appointments.
6 February 2023	RST visits to give depot injection and observes Simon's abdomen is distended and he reported he was experiencing pain. Simon encouraged to go to hospital.
7 February 2023	MH duty social worker does home visit. Simon explains trauma of previous medical intervention as why he does not want medical intervention now. Sister describes her carer role and how stressful it is. SW follows up with GP. As Simon unlikely to attend continence advice appointment, Sister advised to continue to buy incontinence products for Simon.
10 February 2023	Carers assessment completed by MH SW. Outcome that no support

	or package of care was needed.
20 February 2023	Simon's sister contacted RST duty team to raise concerns about Simon refusing to go to hospital, his incontinence, and internal bleeding. She raised concerns about her own ability to provide adequate care and his self-neglect. Sister given reassurance that concerns would be raised with team manager and psychiatrist
22 February 2023	Simon's GP spoke to Simon and his sister. She detailed his deterioration. He denied it and shared his worries given his previous experience of having his ascites drained.
2 March 2023	GP and Psychiatrist discuss concerns raised by Simon's sister. Attempt to arrange a joint home visit following day but GP2 who knew Simon not available
2 March 2023	Practitioners from the Integrated Urgent Care Clinical Assessment Service (IUCCAS) spoke to the mental health nurse on the evening of 2nd March 2023. An advanced nurse practitioner (ANP) listened to the history given by the mental health nurse, read the GP record, spoke to Simon's sister, and tried to speak to Simon. The IUCCAS decision was that as Simon had capacity to refuse treatment, the ambulance service could not convey him to hospital against his will. This was communicated to the mental health nurse, Simon's sister and the duty community psychiatric nurse who had also contacted the IUCCAS ANP. Simon's sister was advised to call back if Simon's condition worsened or he had changed his mind about accessing treatment.
3 March 2023	Simon did not attend appointment with Psychiatrist. Nurse from MH service flags this and calls 999
5 March 2023	Simon's family contacted London Ambulance requesting they attended as Simon was complaining of having chest pain. Simon was deemed to have mental capacity and he was left in the care of his sister.
6 March 2023 (morning)	An ambulance was called to Simon's home as he was reported to be bleeding and had respiratory problems. When the ambulance crew arrived, they found Simon to have had a cardiac arrest, and Simon sadly did not respond to cardio-pulmonary resuscitation.
8 March 2023	Simon's sister contacted the RST manager to report Simon's death. On the 8th March 2023 the RST manager spoke to Simon's sister, who was distressed and voiced concerns her brother was neglected by services, and she said he had lacked mental capacity. The team manager offered condolences to Simon's sister and referred Simon's case to be considered for a safeguarding adult review.

3.3. Practice appraisal and explanation

3.3.1. The chronologies provided by agencies to inform the SAR did include Simon's voice. Professionals were trying to engage Simon in accessing support to attend appointments for his physical and mental health, and while he would give consent for referrals, he frequently refused the service or did not attend appointments. For example, the RST referred Simon to the Look Ahead Service (specialists in delivering mental health, learning disabilities, homelessness and young people services) for support as he had agreed, but he then declined the service.

3.3.2. Simon's physical health was reported by professionals and his sister to be deteriorating due to his chronic liver disease, confusion, falls, incontinence, self-neglect, and continued alcohol intake. Simon's sister reported she was struggling to manage his care.

3.3.3. On 3rd November 2022 Simon spoke to GP1 and reported feeling tired, said he had gained weight, said he was no longer passing blood and he had stopped drinking whiskey. On 7th November he met with GP2 and seems to have been more open about his alcohol intake, which was circa 95 units of alcohol a week. GP2 was worried Simon was showing signs of decompensating liver disease i.e., he was presenting with ascites, jaundice, and bleeding; Simon's sister was present at this appointment which may have been why a clearer picture of Simon's alcohol intake was established. Simon seems to have built trust with GP2 and therefore may have felt less judged and at a point where he could contemplate treatment.

3.3.4. The assessment completed by GP2 suggests Simon understood the need for him to have treatment for his chronic liver disease, and his acceptance of referrals for further assessment may have indicated his wish to access treatment.

3.3.5. However, Simon did not access appointments and whether that was due to his inability to read letters or texts sent to him and /or that his fears about treatment prevented him from attending appointments.

3.3.6. By January 2023 Simon's cognition is more questionable. His inability to recall facts about his health or ongoing treatment when asked by paramedics attending his home after he had fallen may have been due to him sustaining a head injury, but it is unlikely he had mental capacity prior to the fall, not just because he was intoxicated, but because of the impact of his liver failure. However, he did agree to a safeguarding referral when the paramedics and his family suggested it was in his best interests to get the local authority involved due to his self-neglect.

3.3.7. Simon was seen in the accident and emergency department (A&E) on 19th January 2023 regarding the head injury, and he was noted by clinicians to have sustained a nasal fracture and that he had ascites.

3.3.8. Simon was subsequently referred to the Ear, Nose and Throat (ENT) clinic regarding his nasal fracture. The A&E clinicians tried to get Simon seen by the gastroenterology team while he was in A&E. Unfortunately, the gastroenterology team could not see him at that time but arranged to see him at the hospital the following day. Simon was then discharged home; It is unclear if the option of admitting Simon to hospital on 19th January 2023 was considered, but Simon did not attend any of the arranged hospital appointments.

3.3.9. The safeguarding referral made by London Ambulance was triaged by the local authority on 20th January 2023. Simon's comorbidities were listed as: learning difficulties, paranoid schizophrenia, alcohol issues, previous cardiac arrest, liver

problems and ascites (large and distended abdomen which has not been drained for 4 years), non-compliant with medication, and reports he does not know what medications to take. Simon was described as wearing dirty clothes, having long dirty fingernails, and he looked malnourished. The safeguarding referral was passed to the mental health team social worker.

3.3.10. The mental health social worker telephoned Simon to discuss the concerns raised by the London Ambulance Service. However, Simon refused to speak to the duty social worker; his sister told the social worker that Simon 'does not like social workers'. The social worker booked to see Simon at home on 7th February 2024.

3.3.11. On 6th February 2023 Simon was seen by the RST for his depot injection.; his nephew was present during the consultation. The RST clinician observed Simon's abdomen was swollen and he was in pain. Simon said he was taking his water tablet medication and he had cut back on his alcohol intake. Simon was encouraged to attend hospital. Simon was reported to have mental capacity and consented to having his injection. The worker followed up with Simon on 14th February 2023 to see if he had attended hospital. Simon reported he had not attended A&E and was no longer in pain. However, he was unclear as to whether he had attended hospital appointments.

3.3.12. A home visit to Simon was completed by the mental health duty social worker on 7th February 2023. Simon's sister was present, and she confirmed she was his carer and she prompted Simon with his personal care and did his housework, shopping, cooking and laundry. She said she found the caring role stressful.

3.3.13. The social worker spoke to Simon who said he did not want medical care for his physical illness as when he had previously a procedure to drain abdominal fluid, he had started to bleed internally.

3.3.14. Simon told the social worker he had spoken to his GP, was taking his medication, was happy with the care provided by his sister and that she was happy to continue caring for him. The social worker followed up with Simon's GP regarding Simon being assessed by the continence service. The outcome of the discussion was that it was unlikely that Simon would attend a hospital appointment for continence advice. Simon's sister was then advised to continue to buy incontinence products for him.

3.3.15. On 10th February 2023 a carers assessment was completed by a mental health social worker. The outcome of the assessment is that no support or package of care was needed, despite is sister reporting she was struggling and that she had her own care and support needs.

3.3.16. Simon's sister contacted the RST duty team later in February to raise concerns that Simon was refusing to go to hospital, he was incontinent, and having internal bleeding. Simon's sister reported she as buying mattresses weekly due to his incontinence and she and her son struggled to change Simon due to his body weight. Simon's sister said she was worried about him passing away and feared she would be convicted of his manslaughter, given how neglected he was. She said Simon knew what he was doing, implying he was pushing professionals away. Simon's sister was given reassurance and that her concerns would be raised with the team manager and a psychiatrist.

3.3.17. On 22nd February 2023 Simon's GP spoke to Simon and his sister. Simon's sister reported his mobility and health had deteriorated, he was declining care, and although a safeguarding referral had been raised by London Ambulance, the outcome was that no further action was needed. Simon denied his health had deteriorated, but said he was worried about having his ascites drained, given his previous experience. Simon

was considered to have capacity to decline treatment.

3.3.18. On 2nd March 2023, professionals did seem to be worried about Simon's health and wellbeing. There was discussion between the GP and psychiatrist that considered the situation and concerns raised by Simon's sister. There was discussion that Simon had capacity to refuse treatment. The psychiatrist suggested a joint home visit the following day, but the GP who knew Simon was not available then. Simon did not attend the appointment with the psychiatrist on 3rd March 2023, and this was flagged by a nurse from the mental health service, who called 999 regarding Simon's deteriorating physical health.

3.3.19. Practitioners from the Integrated Urgent Care Clinical Assessment Service (IUCCAS) spoke to the mental health nurse on the evening of 2nd March 2023. An advanced nurse practitioner (ANP) listened to the history given by the mental health nurse, read the GP record, spoke to Simon's sister, and tried to speak to Simon. The IUCCAS decision was that as Simon had capacity to refuse treatment, which as documented in the chronology shared with the reviewers was based on GP2's assessment in November 2022, and so the ambulance service could not convey him to hospital against his will. This decision was communicated to the mental health nurse, Simon's sister and the duty community psychiatric nurse who had also contacted the IUCCAS ANP. Simon's sister was advised to call back if Simon's condition worsened or he had changed his mind about accessing treatment.

3.3.20. On 5th March 2023 Simon's family contacted London Ambulance requesting they attended as Simon was complaining of having chest pain. His sister spoke to the ambulance crew before they entered the flat, explaining that Simon was refusing hospital visits or to see a doctor. Simon was assessed as not having "an obvious neurological deficit" and despite the ambulance crew explaining the serious risk to his heart and lungs from the ascites, Simon declined to go to hospital. Simon was deemed to have mental capacity and he was left in the care of his sister.

3.3.21. On the morning of 6th March 2023, an ambulance was called to Simon's home as he was reported to be bleeding and had respiratory problems. When the ambulance crew arrived, they found Simon to have had a cardiac arrest, and Simon sadly did not respond to cardio-pulmonary resuscitation. Simon's sister and nephew were present during the resuscitation and reported their distress at what they witnessed.

3.3.22. On 8th March 2023, Simon's sister contacted the RST manager to report Simon's death. The RST manager spoke to Simon's sister, who was distressed and voiced concerns her brother was neglected by services, and she said he had lacked mental capacity. The team manager offered condolences to Simon's sister and referred Simon's case to be considered for a safeguarding adult review.

3.3.23. The cause of Simon's death is recorded as:

1: Myocardial Infarction (heart attack),
2: Alcoholic Liver Disease, Chronic Obstructive Pulmonary Disease (lung disease)

3.3.24. There was no inquest into his death as he died from natural causes.

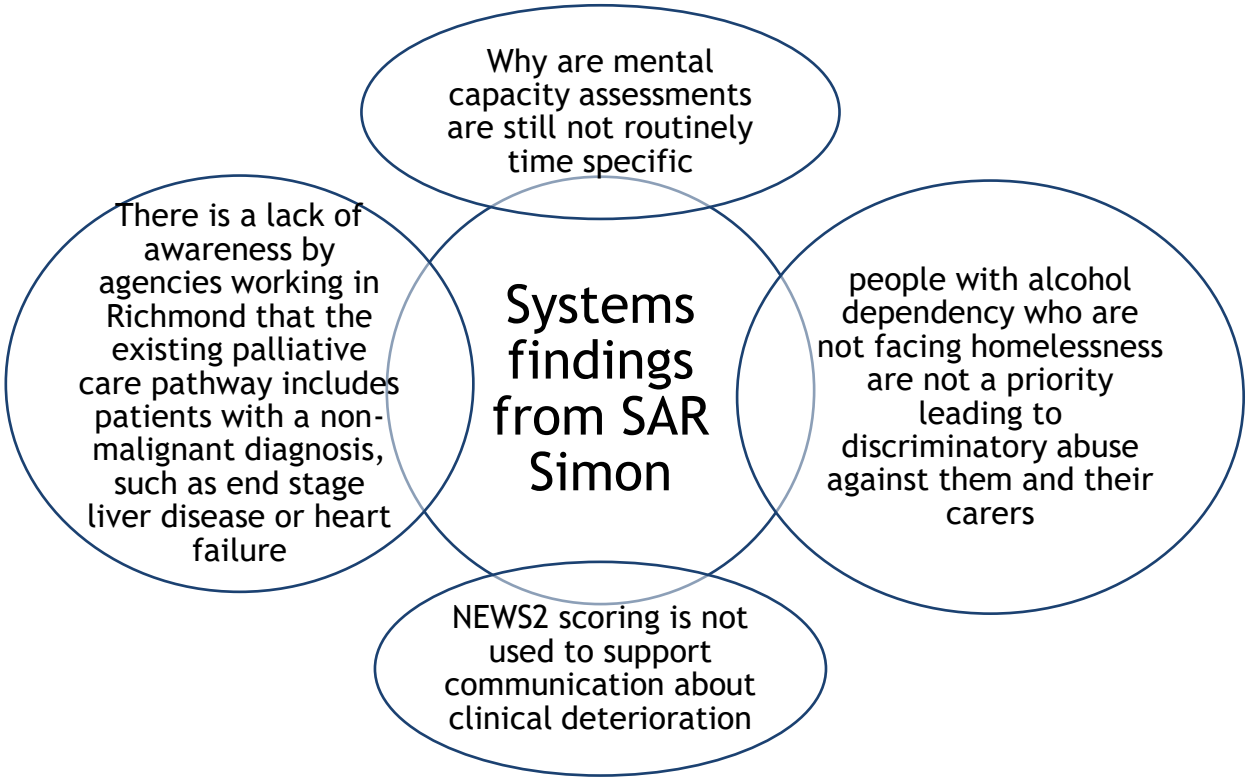
3.3.25. Simon's family do not believe he had mental capacity. Simon's sister and nephews feel that he was misunderstood by professionals and those in the community, who didn't really know him.

3.3.26. Simon's sister and his nephews' wish is that professionals listen to patients and their families, recognise when a person they are treating lacks mental capacity and to seek to support the person rather than possibly just seeing and judging them through the

lens of their addiction.

4. Systems findings

4.1. Four systems findings have been drawn out from the analysis of practice in response to Simon's circumstances. In practice these will interact and compound each other. They are presented separately here, in order to support consideration of how each gap can best be tackled.



4.2. FINDING 1 – Assessing Mental Capacity

Why are mental capacity assessments still not being routinely conducted in a time and decision specific way across health and social care agencies in Richmond? This means cognitive impairments linked to chronic alcohol dependency can be overlooked, even when the need for medical intervention is acute.

4.2.1. The Mental Capacity Act (2005) identifies the impact of a cognitive impairment on a person's ability to make decisions about or consent to care. According to **Alcohol Change UK** at least 35-40% of chronic dependent drinkers have alcohol related brain damage. Research by **Alcohol Change UK** (2023) confirms that cognitive impairment is very common in dependent drinkers as a result of brain damage caused by alcohol and poor nutrition as well as damage to the brain from falls.

4.2.2. Similarly, Wernicke-Korsakoff's Syndrome (WKS) is one of the most serious types of alcohol related brain damage (ARBD), which comprised of a brain swelling known as

Wernicke's Encephalopathy, and a severe confusion known as Korsakoff's Psychosis.

4.2.3. Damage to the frontal lobe can also affect decision making, goal setting and planning, assessing and prioritising risk and actions (**Alzheimer's Society,** 2021) Patients with frontal lobe damage can be plausible despite having limited function or cognition, known as the "frontal lobe paradox"/lacking executive function, and this should be considered by practitioners when assessing an individual's capacity to refuse care or treatment (**Alcohol Change UK**, 2023, p.23).

4.2.4. Hepatic encephalopathy is common in patients with decompensating liver disease **(NICE**, 2023). Hepatic encephalopathy (HE) is defined as brain dysfunction due to the build-up of toxins in the bloodstream as a result of liver failure (**NICE,** 2023). Symptoms of HE includes irritability, disorientation, short-term memory loss and confusion, loss of concentration, lethargy, balance problems, slurred speech, behaviour, or personality changes and increased mortality (**Mansour,** 2023).

4.2.5. The ability of a person who self neglects to act on their decisions should also be considered.

In Simon's case

4.2.6. In Simon's case he was not able to protect or care for himself, or to stop drinking. And while he alluded to being able to self-care and professionals believed he had (decisional) capacity, he was not able to do what he said he could, and so lacked executive capacity (the ability to carry out the decision).

4.2.7. Striking and tragic in Simon's case is that by March 2023, when Simon was becoming much more unwell, and refusing care or admission to hospital for treatment there was a reliance on the assessment undertaken by GP2 in November 2022.

4.2.8. Despite the RST nurse's attempts to get Simon admitted due to his physical health condition, the belief that he has mental capacity was not questioned or tested.

4.2.9. At no time did we see the lack of formal and time specific assessment challenged or escalated, apart from by Simon's family.

4.2.10. Simon's family did not believe he had mental capacity and his sister consistently tried to get professionals to see Simon in a different light.

4.2.11. Due to the methodological limitations described earlier, whereby the reviewers were not able to engage directly with the practitioners who had been directly involved with Simon during the time period, we have not been able to get to an appreciation of why it would still be so usual to operate in this way regarding mental capacity.

Questions for consideration

4.2.12. What has already been done to embed assessments of mental capacity as required by the Mental Capacity Act and what is known about the effectiveness of these efforts?

4.2.13. How can sufficiency of expertise be achieved in the Richmond health and care network for conducting sophisticated capacity assessments involving issues of executive functioning? What effective models exist?

4.2.14. Does the SAB need to initiate a wider systems-based research project in order to appreciate why there is such a difference between 'work as done' and 'work as

imagined' and prescribed, concerning mental capacity assessments?

4.3. FINDING 2 – Discriminatory Abuse

Research shows that individuals with alcohol dependency who are not homeless are often overlooked culturally and organisationally, resulting in inadvertent discriminatory practice. Although unintentional, this increases the likelihood that their rights to health and care support are not fulfilled in Richmond, they do not get the right a safeguarding response for self-neglecting behaviours and their loved ones and carers are not listened to or supported.

4.3.1. There is a growing body of research into working with change resistant drinkers such as Simon. A recommendation from the review undertaken by Professor Michael Preston Shoot and Mike Ward [**Learning from Tragedies,** 2019] is that all professionals working with alcohol-dependent adults should be trained to recognise the need to safeguard the adult who is alcohol dependent and who may appear to be self-neglecting, rather than normalising their behaviours or accepting there is nothing that can be done to help or support them (**Alcohol change** UK, 2023).

4.3.2. Adults who are, or have, experienced trauma or shame which may be the driver for their drinking can refuse help or support as a way of disassociating from upset, stress or emotional turmoil. Professionals need to be sensitive and curious about how best to engage with the person and have the competence, resilience, and determination to keep the person at the heart of decision making, using a trauma-informed approach to care planning.

4.3.3. A key theme from SARs is the need for professional continuity in order to build trust, develop practice and ensure systems, including pathways for managing chronic liver disease, are in place to support change resistant drinkers.

4.3.4. The **Blue Light Manual** provides guidance on the development of alternative approaches and care pathways for drinkers who are not in contact with treatment services, but have complex needs. The guidance supports practitioners re: managing care using interventions built around assertive outreach and multi-agency working.

4.3.5. The Care Act 2014 does not require a person to lack mental capacity to be considered as vulnerable or self-neglecting. Free or lifestyle choices that lead to increasing risk or self-neglect require professionals to act to uphold Article 2 of the Human Rights Act 1998. The checklist in the guidance **How to use legal powers to safeguard highly vulnerable dependent drinkers in England and Wales** (2021) should be incorporated into RWSAB guidance.

4.3.6. Supporting families caring for someone they love who is alcohol dependent has significant benefits as family are often key to the alcohol user engaging in treatment and possible recovery (**Alcohol and Families Alliance,** 2020).

In Simon's case

4.3.7. Practice responses and oversight in Simon's case were far from the ideal described above.

4.3.8. Simon's history, including learning disabilities and significant bereavement traumas were not understood. Professional did not seem to be aware Simon was illiterate and there were few reasonable adjustments made to ensure he fully understood what and why professionals were referring him to services. Similarly, they were not aware of how traumatised Simon was by his experience of being admitted to intensive care and inpatient for 6 months, the one-time his ascites had been drained – only in 2023 did this become known.

4.3.9. From November 2022 Simon did not access appointments and whether that was due to his inability to read letters or texts sent to him and /or that his fears about treatment prevented him from attending appointments. This was not explored, or efforts taken to understand why he seemed to be at a point where he wanted treatment but could not follow through.

4.3.10. London Ambulance service raised a safeguarding concern that clearly captured the views of both Simon and his sister that they needed help. It created a real opportunity. There was a home visit as part of the safeguarding screening process, but the social worker determined that Simon was not experiencing or at risk of abuse or self-neglect (against the concerns about self-neglect described in the referral) and the decision was made by the SAM to close it was not to progress a S.42 safeguarding enquiry, on the basis that the sister was happy to continue to care for him. There was no contact with the GP or other professionals, who had serious concerns at this point and were also struggling to know what to do, nor any consideration of a multi-agency response outside statutory safeguarding.

4.3.11. Nor was a safeguarding concern raised while he was in A&E.

4.3.12. Despite Simon's sister continually raising concerns and seeking support, she was not heard. Her carer's assessment appears perfunctory as there was little curiosity regarding her needs or the living arrangements she and her son were experiencing.

4.3.13. Her efforts to raise a complaint about her concerns that her brother was neglected by services, and that he had lacked mental capacity, were not supported. This was a missed opportunity for a review the file of the adult social care responses in Simon's case and pick up early-on necessarily learning.

Questions for consideration

4.3.14. Has the SAB previously sought data from partners on responses to self-neglect by people with chronic alcohol dependencies who are not homeless?

4.3.15. Is there sufficiently robust managerial oversight of safeguarding referrals related to people with alcohol dependencies, that are closed after initial screening?

4.3.16. What is known about Care Act Assessments, and carers assessments and support to carers of Richmond residents with chronic alcohol dependencies?

4.3.17. Why were Simon's sister and her son's living arrangements not reviewed when professionals saw she was sleeping in the kitchen and her son sleeping in Simon's room and since Simon's death have their housing needs been assessed?

4.3.18. Has Richmond SAB considered adopting the Blue Light approach? Who and how might this be championed and endorsed?

4.4. FINDING 3 – Communication Tools

Available tools to support communication across professionals and teams about clinical deterioration in adults, are not being used in Richmond. This increases the likelihood that the severity of a person's condition is not recognised and hospital admissions are too late

4.4.1. The NHS England National Early Warning Score 2 (**NEWS2**, 2019) was introduced to improve the detection and response to a clinical deterioration of adult patents to improve patient safety and outcomes. NEWS2 supports a standardised approach and language in relation to patients whose clinical condition is changing and the need for hospitalisation.

In Simon's case

4.4.2. In Simon's case there were clear communication problems between professionals regarding him as a patient with deteriorating physical health.

4.4.3. The RST nurse saw Simon at home on 2nd March 2023 and called for an ambulance to take him to hospital. She was seen as being a health professional who could /should deal with the situation she was raising and despite her efforts she could not get the 111 service or the integrated urgent care (IUC) service to triage Simon as requiring transfer to hospital.

4.4.4. The RST nurse escalated Simon's case within her agency and although a manager tried to negotiate with the 111/IUC practitioners, it did not result in an ambulance attending Simon's home. The RST nurse was and continues to be upset by what happened.

4.4.5. Neither the RST nurse, the manager, nor 111/IUC seem to have been familiar with the NEWS2 or suggested using its scoring. This would have given them a common scale in which to understand the seriousness of the situation – and avoided the discussion being all about assumptions of mental capacity which are discussed further below.

Questions for consideration

4.4.6. Has there been consideration of NEWS2 training across the Richmond health economy to support clinicians in accessing timely care, support and transfer for patients who are seriously ill?

4.4.7. Is there a role for RWSAB to advocate for this development?

4.5. FINDING 4 – Management

There is a lack of awareness by professionals working in Richmond that the existing palliative care pathway includes patients with a non-malignant diagnosis, such as end stage liver disease or heart failure. This means people with chronic alcohol dependencies (and their families) may not benefit from palliative care services or support to die with dignity.

4.5.1. Advanced liver disease is the second leading cause of premature mortality in the UK, and this is higher than for lung and breast cancer, stroke, and diabetes[3].

4.5.2. The mortality rate for advanced liver disease in the UK increased by 400% since 1970, and although there is an acceptance that patients with have symptoms comparable to or worse than that experienced in other life limiting illnesses, there is poor access to end-of-life care for alcohol dependent drinkers.[4]

4.5.3. Access to palliative support, either delivered by specialist services or by GPs /nurses has been shown to support the person and their family with advanced care planning and/or decisions about resuscitation and place of death.

4.5.4. While the benefit from having access to palliative care support is now widely accepted, the care needs of patients with liver cirrhosis and their caregivers are all too often overlooked.[5]

In Simon's case

4.5.5. In November 2022 GP2 was worried Simon was showing signs of decompensating liver disease i.e., he was presenting with ascites, jaundice, and bleeding. However, GP2 explained in the workshop for this review, that they were not at all clear then or now about end stage liver disease management. Neither it appears were others in the multi-agency team around Simon.

4.5.6. Ultimately, due to problematic practice around mental capacity assessments (Finding 1), lack of response to self-neglect and listening to Simon's sister (Finding 2), and difficulties communicating the level of clinical deterioration (Finding 3), Simon was left to die a painful and horrible death, without opportunities to prepare himself or to die with dignity.

Questions for consideration

4.5.7. Is the RWSAB assured that professionals working across Richmond health and social care services are aware the South-West London Palliative Care Pathway is available to people with a non-cancer diagnosis such as long term alcohol dependencies?

[3] Karlsen, TH · Sheron, N · Zelber-Sagi, S., 2022 **The EASL-*Lancet* Liver Commission: protecting the next generation of Europeans against liver disease complications and premature mortality**

[4] Woodland, H., Hudson, B., Forbes, K., McCune, A., and Wright, M., (2020) **Palliative care in liver disease: what does good look like**? British Medical Journal, Vol 11, (3)

[5] Langberg, K.M., Kapo, JM, Taddei, TH., (2018) **Palliative care in decompensated cirrhosis: a review**