Salford Safeguarding Adults Board

# Safeguarding Adult Review: Eric

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My Dad, where do I start? A man who lived his life to the full! His quote to me, his daughter, was always “work hard, play hard” and that is exactly what he did.

He was born and lived in Salford with his parents and an elder sister. He attended local schools and college where he obtained his grades and could have joined the police. However, he opted for an oil company where he rose to become a manager.

He was posted to Cyprus where he performed his national service. He married my mother in 1971. Throughout his younger years, from his late teens, he had a passion for cars, motorbikes and a range of sports. In particular, he loved classic cars, including Triumph Stags, Triumph Heralds and the Triumph Vitesse. He loved doing them up and exhibiting them at local car events. He also had a passion for motorbikes and with a friend would renovate them, show them at local motor events and buy and sell them. In his early years he did rally driving as a hobby with his friend. He was a regular spectator at Oulton Park on Saturdays.

Another of my Dad’s passions was watching sport and also participating in a range of sports. Over the years he was in football, tennis, cricket and badminton teams. He played for a local badminton team and won trophies. He enjoyed playing golf regularly and had memberships at two local clubs.

He would go frequently to our static caravan in North Wales. My Dad loved outdoor life and enjoyed gardening. He liked socialising with family and friends, having meals out and having friends over. He also enjoyed a wide variety of music, including country, jazz and classical, and enjoyed listening and watching jazz bands in concert.

From looking back to when my Dad became poorly in 2015, April time, I cannot fault the input he had from Salford Royal Hospital. It is evident from my findings that, when he was discharged in March 2016 from the dietician and July 2016 from the psychology team, he was just “forgotten.”

Personally I cannot believe that there was no follow up sooner by the GPs for a man who was “very” underweight for his height and suffered with mental health issues, such as anxiety and depression. The care he received when he was at home in September 2019 was appalling. I took time off work to help my Dad and my Mum and I can honestly say we were just left. For the last six months he did not look like my Dad.

My Mum and I have been through a harrowing time and to watch our loved one fade before our eyes was awful. The pain and torment my Dad must have gone through must have been horrendous and nobody deserves to die in this way. We were all just left.

In all the years I have worked in the NHS I have never seen a Consultant as shocked as the Consultant was in A&E two days before my Dad died. At my parents’ house none of the professionals knew what to do with my Dad and unfortunately when he was admitted to hospital it was too late.

A lot needs to be learned from this and I hope that no-one has to go through what we have been through.

**Eric’s Daughter**

# Acknowledgement

Members of the Salford Safeguarding Adults Board (SSAB) and the independent reviewer express their sincere regret at Eric's death. Sincere condolences are offered to his wife and daughter. Sincere appreciation is also offered for their courage, resilience and candour with which they have shared their experiences and observations. We acknowledge that the events they have experienced and described remain very raw and upsetting.

The reviewer, working with SSAB members, hope and intend that this review will enable lessons to be learned about what is needed when working with people who self-neglect and who experience anxiety and depression, and will contribute to service development and improvement.

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# 1. Introduction

1.1. Eric[1], a White British man aged 81, died in Salford Royal Hospital on 16th October 2019, having been admitted two days previously. He had been referred by his GP to the District Nursing service for end of life care on 23rd September. Between that date and his admission to hospital, Eric had fairly consistently refused food and water, had remained in bed and had refused treatment and care.

1.2. This was not the first episode of its kind. Three years previously Eric had experienced a period of depression, anxiety and weight loss. Previously, he has been described as happy, loving and outgoing, but a private family man who enjoyed sport. More recently in August 2019 he had refused to eat and drink, and to take prescribed medication.

1.3. Eric lived with his wife who, along with their only daughter, was his main carer.

1.4. Greater Manchester Police (GMP) investigated the circumstances surrounding Eric's death and concluded that there was nothing suspicious. A Coroner's inquest was held in March 2020. Greater Manchester Mental Health (GMMH) had been asked to provide a statement for the inquest and conducted a root cause analysis. Salford Royal Foundation Trust (SRFT) conducted a rapid review and found no evidence of harm being caused by the hospital. The Coroner ruled that the medical cause of death was starvation. The Coroner could not conclusively determine whether or not Eric had capacity but felt that he probably did not have capacity based on the evidence that had been presented at the inquest.

[1] This name has been chosen by the family.

## 2. Safeguarding Adults Reviews

2.1. Salford Safeguarding Adults Board (SSAB) has a statutory duty[2] to arrange a Safeguarding Adults Review (SAR) where:

- An adult with care and support needs has died and the SAB knows or suspects that the death resulted from abuse or neglect, or an adult is still alive and the SAB knows or suspects that they have experienced serious abuse or neglect, and
- There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

2.2. The SAB has discretion to commission reviews in other circumstances where there is learning to be derived from how agencies worked together in cases involving abuse or neglect. Abuse and neglect includes self-neglect. Thus, all reviews are statutory, the difference being whether the case circumstances have been judged to meet the mandatory criteria or whether the review is discretionary.

2.3. Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons in the future[3]. The purpose is not to allocate blame or responsibility, but to identify ways of improving how agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

2.4. The referral for consideration of the case for a SAR followed agreement by multi-agency partners at an adult safeguarding strategy meeting, held shortly before Eric died, and was submitted by Salford Adult Social Care on 23rd October 2019. Further chronological information was received on 11th November. Under type of abuse and neglect the referral highlighted self-neglect, and neglect/omissions. The referrer was particularly concerned at an apparent lack of timely intervention by some agencies, coordination between services, and failures to share information and to make timely referrals. The SAB concluded that referral of this case met the mandatory criteria for review. That decision was taken on 19th November 2019.

2.5. SRFT conducted a rapid review as part of its serious incident procedures. This is largely a description of events in September and October 2019 as recorded by the professionals involved rather than a reflective analysis. However, the rapid review prompted immediate actions to implement learning gained from analysis of the case.

[2] Sections 44(1)-(3), Care Act 2014
[3] Section 44(5), Care Act 2014

# 3. Review Process

## 3.1 Focus

3.1.1. The case has been analysed through the lens of evidence-based learning from research and the findings of other published SARs on adults who self-neglect[4]. In particular SSAB expressed the intention that this SAR should build on a previously published SAR[5]. Learning from good practice was also to be included. By using that evidence-base, the focus for this review has been on identifying the facilitators and barriers with respect to implementing what has been codified as good practice.

3.1.2. Specific lines of enquiry, or terms of reference, were identified as follows:

3.1.2.1. Consider assessment and risk management/responsiveness from agencies after Eric's family started to raise concerns about his health and wellbeing;
3.1.2.2. Appraise understanding and use of the Mental Capacity Act 2005 and consider its interface in this case with the Mental Health Act 1983;
3.1.2.3. Consider how well coordinated services were and whether the different agencies communicated well with all those involved with Eric's care including Eric himself and his family;
3.1.2.4. Appraise the degree of legal literacy shown in this case;
3.1.2.5. Consider the use of escalation procedures by staff involved;
3.1.2.6. Consider how agencies responded to Eric's self-neglect;
3.1.2.7. Given Eric's self-neglect, consider the use of safeguarding processes including a Section 42 Enquiry and the implementation of the SSAB self-neglect policy;
3.1.2.8. Review the pathway into Adult Social Care, how accessible it is and perceived to be, and how timely the response is in high risk situations;
3.1.2.9. Review mental health provision and withdrawal of support and services in this case;
3.1.2.10. Consider the recognition given to the needs of carers, including the impact of the caring role on their own health and wellbeing, whilst recognising also family dynamics;
3.1.2.11. Consider how professionals work individually and collectively with assessing and responding to risk;
3.1.2.12. Consider the decision-making process regarding end of life care and what support was provided to Eric's family.

## 3.2 Methodology

3.2.1. The timeframe for the review covers the period from 1st June 2019 to the date of his death on 16th October 2019. However, medical and social history will be considered for the previous three years also.

[4] Preston-Shoot, M. (2019) 'Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice.' *Journal of Adult Protection*, 21 (4), 219-234.
[5] Preston-Shoot, M. (2019) Safeguarding Adults Review – Andy. Salford Safeguarding Adults Board.

3.2.2. The agencies to be involved in the review were identified as follows:

- GP/ NHS Salford CCG
- Greater Manchester Mental Health (GMMH)
- St. Ann's Hospice
- Salford Royal Foundation Trust – Community District Nurses both day and evening service.
- Salford Royal Foundation Trust - Adult Social Care
- Salford Royal Hospitals NHS Foundation Trust – Acute Accident and Emergency Department
- Salford Royal Hospitals NHS Foundation Trust – Urgent Care Team
- North West Ambulance Service.

3.2.3. Agencies were requested to provide a chronology and reflective review of their involvement with Eric within the agreed timeframe. They were advised to also include anything that they judged significant that fell outside the agreed timeframe for the review.

3.2.4. The individual chronologies were combined. The independent reviewer and the SAR panel then identified specific issues and questions for further exploration by the agencies involved.

3.2.5. A learning event with practitioners involved in Eric's case explored key episodes and events within the timeframe being reviewed based on issues and concerns emerging from the combined chronology and reflective agency accounts.

3.2.6. Thus, a hybrid methodology has been used, designed to provide for a proportionate, fully inclusive and focused review.

## 3.3 Family involvement

3.3.1. Both Eric's wife and daughter expressed a wish to participate in this review. The independent reviewer and the SSAB Business Manager met with them virtually, using Microsoft Teams, owing to the Covid-19 pandemic. His daughter provided a pen picture of Eric, with which this report has opened.

3.3.2. Eric met his wife when she was in her thirties. She did not know him when they were both younger. They were married for 47 years. His wife described him as a loving husband, good at his job, a very caring man, with a good sense of humour, someone who liked a laugh and a joke. He was always "on the go" and was a collector. He liked a bargain. Eric's wife and daughter did not realise the extent of his collecting when he was alive.

3.3.3. The impact of what they have experienced has been profound. Eric's wife described how she is quite "nervy" now and has been questioning her attitude to how she makes decisions now, and her decision-making at the time. The interview with the police after Eric's death, whilst recognised as required being required by protocol, had been an added stress. However, the Coroner and their officials had been very good.

3.3.4. Their further observations about Eric as a person, and about the care, treatment and support that he received, and how professionals interacted with them as family members have been integrated in the sections that follow.

3.3.5. The independent reviewer and the SSAB Business Manager met with Eric's wife and daughter again, using Microsoft Teams, to go through the report. They described Eric as a proud man. They wanted readers to appreciate how anxiety and depression can affect people. They hoped that practitioners would always take full account of what family carers were thinking and experiencing. After a full discussion of the content of the report, and a further period of reflection, Eric's wife and daughter informed the independent reviewer and the SSAB Business Manager that they did not wish to request further amendment or addition. They have expressed the hope that the report will help to improve practice; as they said, "people need to read such things."

## 4. Case Chronology and Initial Commentary

4.1. Between January and July 2016 Eric had a sequence of appointments with a counselling psychologist through GMMH. He was reluctant to leave his home, experienced mood swings and exhibited concerns about eating. A dietician provided advice but it seems that he ate just sufficient to maintain his weight. He experienced bouts of diarrhoea and constipation which, together with how friends and neighbours might respond to his weight and appearance, were presented as reasons for remaining at home. The focus was on goal setting, along with anxiety reducing techniques, to encourage Eric to leave the house. This had some, albeit limited success.

4.2. In April 2016 Eric's GMMH Care Coordinator discharged him from their caseload although counselling continued and occasional psychiatric appointments were to be offered. Towards the end of the counselling sequence Eric's wife expressed concern that the sessions would end, that Eric was not opening up and was still experiencing dips in his mood, and that he was not socialising and continued to be tense and only to eat as much as would maintain his weight.

4.3. Eric's wife declined referral for herself and also the suggestion of couple work through Relate. At the end of the counselling sequence the Hospital Anxiety and Depression Scale was administered. Eric scored 7 on the anxiety subscale and 11 on the depression subscale. Scores of 0-7 may be considered within the normal range. Scores of 11 or more may be seen as indicative of probable presence of the condition. A discharge letter was sent to the GP.

4.4. Commentary: it may have been helpful for Eric and his wife to be seen separately to explore issues that they may have felt unable to disclose in each other's presence. Eric's wife was present for all the counselling sessions. Additionally, the focus of the counselling appears to have been on Eric achieving agreed goals, mainly related to going out. The record of the sessions reveals little, if any, focus on antecedents and certainly none that Eric could or was prepared to identify.

4.5. Commentary: a formal carer's assessment was not offered although Eric's wife did refuse counselling support that was offered to her. It appears that, at one point, Eric's daughter's wish to attend the sessions was raised and Eric refused on the basis that too many people were already involved. It is not clear whether this was explored further and the counsellor has left and cannot be asked. However, later in the chronology, Eric also appears to have been unsettled by the number of people involved.

4.6. Commentary: there are references in the record to Eric taking "movicol[6]" for bowel issues. It is possible that his anxiety was tied up with these issues. However, the counsellor involved at the time has moved on, meaning that it is not possible to check whether this was a focus of the sessions. Bowel and bladder concerns also feature later in the chronology.

4.7. Commentary: it is questionable whether case closure came too soon. Improvement had been limited in terms of the goals set and certainly not embedded in Eric's day-to-day

[6] Medication used for constipation and faecal impaction.

behaviour. Indeed, prior to case closure it had been recognised that Eric was taking longer to improve than expected.

4.8. Thereafter until 29th July 2019 the chronology focuses exclusively on GP surgery contacts for medication reviews and both hypertension and chronic kidney disease monitoring. At one point GP1 considered Eric to be depressed still but Eric was unwilling to increase the dose of his anti-depressant medication. His weight was not at a level where supplements could be stopped and there is a question as to whether attempts to monitor his weight were sufficiently frequent. It appears that Eric missed some monitoring and review appointments, sometimes stating that this was because he was unwell. There is also a record of Eric having been discharged by an NHS Trust following a failure to attend an outpatient review of his hip replacement.

4.9. Commentary: the GP surgery was persistent in following up appointments for review and monitoring. This was good practice. It is, however, unclear whether Eric's self-reporting, that his mood was "okay" and that he was "doing fine", were explored in greater detail. Equally, there was a pattern of Eric not responding to letters and telephone calls reminding him of the need to review his medication. Reliance was placed on Eric responding, which he did occasionally. Eric's wife and daughter have confirmed that Eric was prone to hide his symptoms from them and that he would not let them see medical letters. They have confirmed his reluctance to attend appointments, many of which they were unaware of because of how he guarded his privacy. They expressed their surprise that, given his history of anxiety and depression, no-one came to the house to see him around this time, despite his wife requesting this. The CCG, working with and reviewing the case with the GP surgery, has concluded that non-attendance for regular weight measurements and chronic disease monitoring could have been followed up more proactively, and that reviews of his low mood could have occurred more frequently.

4.10. On 29th July 2019 GP1 recorded having had a very difficult conversation at home with Eric following a request from his wife for the appointment. His wife reported that he was not eating properly, not sleeping well, not letting her cut his toenails, and that he had not left the house for some twelve months. He denied or gave a different account. He did not want the GP to change his anti-depressant and other medication. GP1 did not have any concerns about Eric's mental capacity at this point.

4.11. Commentary: there are signs of self-neglect here and a possible repeat of behaviours from 2016. No referral was made to either mental health or adult safeguarding at this stage. It is unclear what the plan was. It has been clarified that GP1, who knew Eric very well and was fully aware of his history, did not consider referral to other services at this point and that a referral to mental health could have been offered.

4.12. On 8th August Eric's wife and daughter reported concerns to GP1. He had taken to his bed, was hardly eating or drinking, and was refusing to take his medication. The following day, 9th August, GP1 made a home visit. Eric refused to see him. His wife told the GP that he was not eating or taking his medication, was staying in bed and was not changing his clothes or shaving. He had apparently said that he had had enough. The GP was later able to speak to Eric on the telephone, having made a referral to the Urgent Care Team. Eric told the GP that he would not see a mental health nurse for a mental health assessment but might speak to her on the telephone.

4.13. Commentary: the GP record clearly notes this situation as self-neglect and yet the SSAB policy was not activated, although GP1 was aware of it, and there was no referral to adult safeguarding. It has been clarified that a safeguarding referral was not considered at this point. With Eric on medication for anxiety and depression, explicit consideration might have been expected in relation to the impact of his mental health on his decisional mental capacity. However a mental capacity assessment was not considered at this point. The plan appears to have been to have referred Eric to the Urgent Care Team and to evaluate the outcome of their input.

4.14. Also on 9th August members of the Urgent Care Team, which included mental health social workers and clinicians, conducted a triage assessment and then a home visit. Eric declined to engage in examinations and in a mental health assessment. His mood was recorded as guarded and ambivalent. He lacked engagement. Nonetheless, the visiting practitioners concluded that there was no reason to doubt his mental capacity.

4.15. Commentary: SRFT's contribution to this review has noted that it is possible that the Urgent Care Team may not have known of GMMH's previous involvement with Eric since records were held separately. However, GP1 knew Eric well and was fully aware of his history. Further discussion between the Urgent Care team and the GP, following his referral and their first home visit, might have been helpful in focusing this intervention.

4.16. Commentary: the record of this visit clearly notes that no safeguarding concerns were identified on this visit. Self-neglect was not identified and the situation does not seem to have been regarded as a safeguarding concern. There is a missed opportunity here to refer the case to adult safeguarding and to use SSAB's self-neglect procedures. As a result there was no multi-agency plan. A formal mental capacity assessment was not completed and the record does not suggest that there was any assessment of the impact of his mental health on his decision-making.

4.17. Commentary; SRFT's contribution to the review suggests that the self-neglect procedure[7] may not have been activated at this point because it had not been ratified by all individual agencies. This is puzzling since SSAB's self-neglect procedures had been adopted by the Board, including therefore all its partners. SSAB should inquire of partners what processes they follow after the Board has agreed and launched a policy/procedure.

4.18. Staff from the mental health team conducted further home visits on 12th, 15th and 19th August, by which time discharge was being considered. Although his wife and daughter remained concerned, Eric stated that he was feeling a little better, had got up and had started eating (minimally) and taking some (but not all initially) of his medication. He refused to engage with the mental health nurse on 15th and asked them to leave. He could not say why he was not taking all of his medication. His wife saw little improvement in his mental health but Eric was not happy when she spoke of her concerns. She commented that he was not washing or changing his clothes and that he became angry when she encouraged him. It was concluded that the risks did not warrant a Mental Health Act 1983 assessment or a referral to CMHT. On a visit on 23rd August, because Eric stated that he was feeling better, was eating and was compliant with all his

[7] If it had been activated, the first step would have been a multi-disciplinary group meeting.

medication, the rapid response mental health service (Urgent Care Team) closed his case.

4.19. Commentary: this is the second occasion when it is possible to conclude that closure was premature, that improvement was minimal and not embedded in Eric's activities of daily living, and that the risks of self-neglect remained both likely and significant. The history of this case (the episode in 2016) does not appear to have been taken into account. SRFT's contribution to this review recognises that, although mental capacity is referenced on assessment documentation, it does not appear to have been considered at this time. Although Eric's presentation made assessment difficult, greater professional curiosity might have been shown. The same contribution also accepts that concerns should have been escalated to senior managers and a referral sent to Adult Safeguarding for advice. A similar referral could have been sent to the Older Age CMHT.

4.20. Commentary: the SAR review team and the independent reviewer have concluded that clearer guidance would be helpful for people entering and exiting the Urgent Care Team service. The Urgent Care Team incorporates a mental health practitioner but there are other teams that offer a mental health service. The review team and independent reviewer consider that it might be helpful to explore referral guidance when there is the potential for multiple teams to be involved and how different teams might work together to address the complexities that individual cases present.

4.21. Commentary: no carer's assessment was offered at this point to Eric's wife or daughter. The relationship between Eric and his wife had not been explored and there is no indication as to whether there had been a significant change in their interaction. SRFT's contribution to this review recognises that the absence of a recorded focus on Eric's wife and daughter as carers is an omission.

4.22. Commentary: risks remained regarding his dietary and fluid intake, and his compliance with medication. SSAB's procedures for self-neglect cases had not been activated and it remains unclear what might trigger a multi-agency meeting to review this type of case. When might a referral to adult safeguarding and/or for a Mental Health Act assessment be thought appropriate[8]? When might legal advice be sought, for instance in response to non-engagement with assessments and examinations when there is a significant risk to wellbeing?

4.23. On 29th August 2019 GP1 conducted a medication review with Eric at his home. He was unsteady on his feet but an OT assessment was not considered because Eric was mobilising with a stick. He reported eating a bit more. He was taking most of his medication.

4.24. Commentary: it is not clear that an assessment was made of the impact on his depression of not taking all the prescribed medication. The GP recognised the recent history of self-neglect and low mood and decided to revisit in two weeks.

[8] Indeed, if Eric had been referred to Older Age CMHT a mental health service lens would have given consideration to a Mental Health Act 1983 assessment at the point of referral or in the subsequent few weeks, as well as also giving further consideration to capacity issues and an adult safeguarding referral.

4.25. On 13th September GP1 conducted a further home visit. Eric had fallen twice recently with no obvious cause or injury. He declined referral to the falls clinic and an OT assessment. He agreed to pay for a pendant. He reported eating small amounts and being compliant with his medication. Further monitoring in two weeks was planned. Three days later a fourth letter was sent to Eric about the need for a hypertension and chronic kidney disease review. This highlights Eric's erratic engagement with services.

4.26. Commentary: the chronology hitherto has set the scene for the final few weeks of Eric's life when the seriousness of the situation escalated quite dramatically.

4.27. On 19th September Eric's daughter saw GP2 about her father's rapid deterioration. He had taken to his bed, which he was soiling. He was refusing food and drink. His daughter wondered if he was approaching end of life. GP3 visited the same day and found that he was eating little but drinking well. He had experienced nausea and diarrhoea for a few days. Eric did not want to engage. Worsening depression was suspected. Blood tests were suggested. Eric was deemed to have full capacity.

4.28. Commentary: as Eric would not engage it is unclear how mental capacity was actually assessed. Nor does it seem to have been recognised that use of the Mental Health Act 1983 would not have hinged on mental capacity and establishing incapacity. This further highlights the need to strengthen legal literacy. This situation was coming to be seen as an end of life scenario. Neither a mental health nor an adult safeguarding referral was made, both of which the CCG has indicated would have been appropriate. The impact of a worsening depression on decisional capacity does not appear to have been considered. The blood tests do not appear to have been ordered after a review by GP1 because Eric had declined hospital admission.

4.29. On 20th September GP1 had a telephone conversation with Eric's wife. She reported that he had been in bed for five days and was only drinking water. Another telephone conversation took place on 23rd September. He was still in bed and had not eaten for nine days. He was very weak. GP1 made a home visit and referred Eric to District Nursing for end of life care. Eric declined hospital admission and was only sometimes taking his medication. His wife said that he had not left the house for three years. The GP thought that Eric wanted to die and that medication was unlikely to prolong his life.

4.30. Commentary: GP1 advised Eric's wife that his partners would be consulted but what they might have advised is not recorded in the combined chronology other than a referral for district nursing. Referral for district nursing appears to have been designed in part to support Eric's wife and daughter as primary carers. It is unclear whether Eric had actually told the GP that he wished to die although GP1 thinks not. Eric's depression is recorded as worsening and yet his non-compliance with anti-depressant medication is not recorded as a risk. However, a referral to mental health services was not considered at this point, which has been recognised as an omission. It is not clear whether a formal risk assessment or mental capacity assessment were conducted and whether legal options were considered at this stage. The GP's recall is that Eric was unable to articulate himself very clearly.

4.31. Commentary: the CCG contribution, prepared in consultation with the GPs involved, recognises that this situation was difficult for all those involved with Eric's care. Hitherto,

however, those involved largely carried the responsibility and uncertainty within their own service. Specialist external advice had not been sought.

4.32. The first District Nurse visit in response to GP1's referral took place the next day, 24th September. Eric's wife and daughter could not explain why he appeared to have given up on life. Eric would not allow check of pressure areas. He appeared underweight and very frail. He refused a hospital bed and pressure relieving equipment. He said he did not need District Nurses to visit. It is recorded as being impossible to complete a full assessment as Eric was reluctant to converse. Continued deterioration was expected and anticipatory medication was requested from the GP. There was a high risk of malnutrition and pressure sores. A palliative care plan was proposed. He was at risk of falls and carers could be injured when supporting him.

4.33. Commentary: despite a full assessment being recorded as impossible, the record also states that there was "no reason to doubt" Eric's capacity. It is unclear how this decision was reached. It is doubtful that Eric's executive capacity was considered. No carer assessment is recorded as having been offered. It is not clear whether Eric really wanted to die. Perhaps this was impossible to establish given his lack of engagement. The case already appears urgent. There are legal options that could have been considered if advice had been sought at this stage.

4.34. Commentary: the SRFT contribution to this review recognises that there was a failure to complete a holistic nursing assessment and relevant risk assessments at the time of the visit. Non concordance was not considered at the time, which is not in line with the NHS Trust's non-concordance policy.

4.35. On 25th September Eric fell in the bathroom and his wife had to call for assistance. NWAS visited but Eric refused hospital admission. Bleeding from his bowel was recorded. He declined to talk to his GP. Assessment for a commode was advised. NWAS shared information with GP4. Eric's wife had contacted ASC whilst waiting for the ambulance crew to arrive and information was subsequently shared between NWAS, ASC and District Nursing. A District Nurse visited but Eric declined any intervention. It has not been possible to establish if the ambulance crew felt there was a reason for a safeguarding concern to be raised to Adult Social Care.

4.36. Commentary: a pattern was becoming established of Eric declining any personal care, for example checks of his pressure areas. This case has still not been identified as one of self-neglect requiring an adult safeguarding response. The SRFT contribution to the review comments that there appears to have been a failure to consider Eric's wife as a carer and therefore there was an absence of a referral to social services for additional support. It also observes that District Nurses might have returned on the same day to review the situation and that this incident represents a missed opportunity to refer to the Adult Safeguarding Team. The CCG contribution also observes that the GP practice might have initiated referrals at this juncture.

4.37. GP1 conducted a home visit on 26th September. Eric was deteriorating. The case was seen as one of end of life care. A failed District Nurse visit occurred that day.

4.38. On 30th September GP1 made another home visit. District Nurses had not seen Eric since 25th September. He had not eaten for 15 days and was very weak, unable to stand unaided. His wife was struggling to change his soiled clothes. He was struggling to

swallow. His stools were black and there was fresh blood on his underwear. His wife would have preferred Eric to be admitted to hospital but an RMO had advised the GP that care at home was to be preferred. At this stage no further discussion around the dark stools and bleed was held as Eric did not want to go to hospital.

4.39. After this home visit GP1 referred Eric to ASC for support to help his wife manage. A referral was also made for a hospice bed. GP records state that his wife was struggling but that Eric wanted to stay at home. The GP is recorded as having been unsure what to do about this difference of view.

4.40. Commentary: it is unclear from the combined chronology why District Nurses were not visiting daily. What Eric was actually saying is not recorded. The GP's uncertainty prompts a question of where GPs turn to for advice about care management. There is still no suggestion of seeking legal advice and referring the case to adult safeguarding.

4.41. Commentary: the CCG contribution to the review notes that the GP sought advice from the hospice, family and GP partners. However, it comments further that the GP recognises that advice could be sought for future cases from ASC and mental health services and the safeguarding team at the CCG. The same contribution also observes that the GP did not follow up the referral to ASC, assuming that the action requested would be completed.

4.42. On 1st October ASC considered the GP referral. Health records were consulted but the referring GP was not spoken to. End of life care remained the lens through which the case was being seen. District Nurses were assumed to be visiting regularly. The case was closed. The GP practice does not appear to have been made aware of this decision.

4.43. Commentary: ASC has accepted that the referring GP should have been contacted. In addition, however, the combined chronology does not indicate that the SSAB self-neglect procedures were considered. The case was not referred to adult safeguarding. There was no multi-agency risk management approach adopted at this stage. ASC's contribution to the review highlights the importance of information-sharing when referrals are made. No history was provided and the referral did not refer to Eric not having eaten for 15 days. It suggested assessment for support with washing, dressing and toilet needs. The contribution suggests that the self-neglect policy was not considered as no indication was given that this was a concern in the referral.

4.44. Commentary: the SAR review team and independent reviewer have observed that the lens through which this case was now being seen, namely end of life, might have obscured the appropriateness of seeing the case as one of severe self-neglect. Eric had not been eating for around 15 days at this time and was virtually bed bound. His wife was struggling to cope. Whilst it was appropriate to request extra support, it would also have been appropriate to have made an adult safeguarding referral and, possibly also, a mental health referral for an urgent psychiatric assessment. The review team and independent reviewer have discussed whether referral forms into ASC should require referrers to answer the question of whether what is being requested is a safeguarding and/or care and support response. It might be timely also to review awareness across agencies of how and when to make a safeguarding referral, especially in cases of self-

neglect when the three components of section 42 (1) Care Act 2014[9] have to be considered alongside whether the person can control their own behaviour. By this time it is probable that Eric could not do this.

4.45. The hospice referral is recorded on 1st October, when a District Nurse visit also occurred. Once again Eric refused any intervention and once again he is said to have had full mental capacity. He was lying in a heavily soiled bed. He was not eating and his health was deteriorating. He is recorded as stating that he would accept personal care tomorrow. His wife and daughter are recorded as having been very upset.

4.46. District Nurses visited on 2nd October. Eric's bed and shirt were very wet with urine and there was a very offensive smell. His bowels had opened. He tolerated some limited personal care but would not allow a change of shirt and vest even though these were very wet. He allowed only a minimal cleanse of his face but did permit foam dressing to two pressure areas to prevent further skin deterioration. He continued to refuse a hospital bed and pressure relieving equipment despite high risk of pressure damage. He refused to allow removal of his socks to check is feet and heels. A referral was made to the bladder and bowel team.

4.47. Commentary: a District Nurse liaised with GP1 about mental health input, which is good practice, but the GP thought this was unnecessary as Eric was not engaging. This appears a puzzling decision. A further independent view might have been helpful at this point, which might have been prompted if District Nurses had escalated their concerns. The assessment remained that Eric had full capacity and wanted to die. How this assessment was made is interesting since it remained a struggle to converse with Eric. There remained many outward signs of depression that could have been impacting on his decision-making.

4.48. On 3rd October, following a District Nurse referral, the Older Adults CMHT determined, following discussion with GP1 and the family, that the referral was not appropriate[10]. The GP was seen as best placed to complete a mental capacity assessment. However GP1 is recorded as regarding the case as one of end of life rather than for mental health review. The Urgent Care Team did not think a referral to that service was appropriate either. The District Nurse referral had followed a discussion with the MDG Nurse. Subsequent advice was to follow safeguarding procedures, escalate to a lead nurse, and refer to adult safeguarding. A District Nurse is recorded as saying that she had never seen anything like this case.

4.49. Commentary; this is the first mention of safeguarding in the combined chronology. As will be seen, several further days elapsed before a safeguarding response can be identified. Pathways into mental health assessment and intervention seem difficult to access, such that it appears that specialist assessment of Eric's mental health is not made available immediately.

[9] The three criteria are: that the person has care and support needs, is experiencing abuse and/or neglect, which includes self-neglect, and as a result of care and support needs, is unable to protect themselves from the abuse and neglect.

[10] Again, the end of life lens may have influenced this decision.

4.50. District Nurses and Hospice at Home visited the same day. Eric allowed removal of his heavily soiled and wet clothes. The odour was recorded as very offensive. He was washed and a clean pad applied. He once again declined a hospital bed and pressure mattress. He refused pain relief. He stated that he did not want a visit tomorrow. Hospice at Home offered support to Eric's wife. He was difficult to assess as he was reluctant to engage.

4.51. GP1 conducted a home visit and determined that Eric lacked capacity regarding hospice care. With his wife, who was saying that she could not cope, and his daughter, a best interest decision was taken to admit Eric to the hospice but no bed was available and he was declining admission. In any event the hospice required a new referral, which was sent, because of the change in mental capacity assessment.

4.52. Commentary: the combined chronology records GP5 as having had a discussion with the hospice in which it was noted that Eric should be encouraged to accept a bed. If admission was a best interest decision, Eric could have been moved, with the case referred to the Court of Protection if the best interest decision could not be implemented[11]. So, were all those involved now clear that Eric did not have capacity to make the decision about hospice care? The CCG contribution to the review suggests that it was the deterioration in Eric's physical condition that triggered the change in thinking about mental capacity and also that seeing the case was one of end of life clouded decision-making about mental health assessment. The same contribution indicates that Eric's resistance to engagement with healthcare professionals made assessment and determination of capacity difficult. This highlights the importance of seeking (legal) advice in such circumstances, especially in situations of considerable risk.

4.53. Commentary: the combined chronology records for the first time that Eric had a long history of hoarding letters and newspapers. This raises a question about how much was known about him.

4.54. On 4th October GP1 liaised with the MDG Nurse and Eric's daughter. A fast track referral, with District Nurse support, was made to NHS CHC. Eric allowed District Nurses to administer some personal care but not to apply cream to dry skin areas. He was still not eating but was taking a small fluid intake. GP1 and a Consultant from the hospice made a home visit. Eric was hard to engage, making it impossible to complete a mental capacity assessment. He declined pain relief. At the home GP1, the Palliative Care Consultant and District Nurses discussed his future care with his wife and daughter. It is recorded that there was no medical diagnosis of end of life. It was decided to seek an urgent mental health opinion to see if Eric had a depressive illness or underlying and undiagnosed mental health condition. The intention appears to have been that this mental health assessment could also enable a more extensive mental capacity assessment. The Urgent Care Team was contacted but no mental health practitioner was in the team.

4.55. Commentary: this decision is puzzling since Eric already had a diagnosis of depression for which he had been prescribed medication and he had been assessed by

[11] Moreover, if Eric had strongly resisted, legal advice could have been sought on whether to either get an interim order from the Court before moving him or to move under sections 5/6 Mental Capacity Act 2005 and then apply straight after – either way it could have happened very quickly.

GP1 as lacking the capacity to take at least some decisions. Might a Mental Health Act 1983 assessment have been requested? Might a referral to the Court of Protection have been indicated here if it was felt that Eric's capacity was fluctuating or uncertain? No adult safeguarding response to his life threatening self-neglect is as yet evident.

4.56. The Hospice Consultant has indicated that they found this to be a challenging and distressing situation. Eric was unwell but without consent the Consultant was unable to examine him in any detail. Eric reassured the Consultant that he had no physical symptoms but wouldn't engage to explain why he was refusing more support. The referral for mental health assessment is explained as follows: the Consultant was concerned that the lack of engagement meant that it was not possible to adequately assess Eric's capacity and also his previous history raised the possibility of a mental health disorder. The Consultant did not consider the Court of Protection.

4.57. On 5th October Rapid Response offered to assist with meals but GP1 said that this was not appropriate at this stage. Hospice at Home conducted a home visit and saw Eric's wife who said that she was struggling.

4.58. On 6th October Eric accepted personal care from District Nurses. He was not eating but had taken a little water. An urgent podiatry referral was made.

4.59. On 7th October GP6 is recorded as noting that this was a case of self-neglect, with concerns about mental health and mental capacity. Blood tests were considered but appear not to have been completed because Eric was end of life. A mental health review was anticipated. The same day GP1 conducted a home visit with a Mental Health Nurse from the Older Adults CMHT. Eric agreed to hospice admission. The combined chronology records self-neglect due to severe depression. Cognitive functioning was not formally assessed but no concerns were noted. Eric had minimal insight into his behaviour and its likely consequences. He was reluctant to engage and repeatedly asked the Nurse to leave. He is recorded as saying that he did not wish to die but could not link this to his not eating. He refused pain relief. The Mental Health Nurse is recorded in the SRFT rapid case review as describing the case as "very complex" and as unable to complete a mental capacity assessment due to his lack of engagement.

4.60. Commentary: this visit appears to have concluded that Eric had capacity, although for what decisions is not recorded, and that there was no mental health input required. This too is surprising given the reference at this point in the combined chronology to severe depression. How assessments were done and these conclusions were reached is unclear when he did not readily engage. There is also another mention of Eric having chronic kidney disease, having had a hip replacement, and a history of oesophagitis and Barratt's oesophagus[12]. Risk to self was noted as high. Yet the SSAB self-neglect procedures were not being followed, although GP1 is recorded as having been aware of them.

4.61. District Nurses also visited on 7th October. Eric accepted personal care. Creams and a pad were applied. He was in pain and discomfort. An urgent podiatry referral was sent.

[12] Oesophagitis is an inflammation of the lining of the oesophagus. Barratt's oesophagus is a change in the tissue lining of the oesophagus, the main cause of which us long-standing reflex of acid from the stomach.

4.62. On 8th October a safeguarding referral from District Nurses was received by ASC and CCG. The hospice Consultant spoke with GP1, concerned whether a treatable mental health illness had been missed. The hospice would not be able to manage depression in a specialist way. The Mental Health Nurse in the Older Adults CMHT was taking the case to MDT for a Consultant Psychiatrist to reach a definitive diagnosis. A hospice bed was being held.

4.63. Commentary: Eric already had a diagnosis of depression. Why, therefore, was an additional diagnosis felt necessary? It may have been because, amongst the number of practitioners involved, there were diverse views about whether Eric had decisional capacity. A multi-agency meeting, with legal, mental capacity and mental health specialist advice present, may have helped to clarify the position. An urgent referral to the Court of Protection for a determination could also have been considered. The safeguarding referral was good practice albeit arguably overdue. The Hospice Consultant spoke with the Mental Health Nurse with a request to explore whether depression was behind his presentation. This Consultant could, however, have completed a mental capacity assessment. Admission to the hospice was planned for 10th October. The focus on arranging for Eric's admission to the hospice has been given as a reason for not activating SSAB's self-neglect procedures at this point.

4.64. Also on 8th October District Nurses visited with a Podiatrist. Eric consented to treatment for his feet but not to washing of his face and hands. His pad was changed but he refused to change his top. He was in pain when moved but refused pain relief and a hospital bed.

4.65. Commentary: District Nurses liaised with the Mental Health Nurse, which is good practice. The Mental Health Nurse was planning to speak to a Consultant Psychiatrist. The record notes both that Eric might have had capacity regarding his care but also that assessing his capacity was very difficult because of his lack of engagement and the complexity of the case. Might not consideration of a referral to the Court of Protection have been considered?

4.66. On 9th October ASC decided to allocate the case. The combined chronology states that a Psychiatrist had not agreed to visit that day. Older Adults CMHT MDT met and concluded that a mental health cause was unlikely. Support was to be offered to Eric and the hospice. GP7 had a telephone discussion with ASC regarding the safeguarding referral. GP7 and GP1 discussed the case and understood that the CMHT had concluded following a multidisciplinary team discussion that there was no sectionable mental health issue.

4.67. Commentary: how such a conclusion could have been definitive without Eric being seen is puzzling. Why the Psychiatrist apparently did not agree to visit on this day is a concern. Additionally, it is possible that the focus on mental health obscured the need for a detailed specialist mental capacity assessment and also consideration of other legal options, namely referral of the case to the Court of Protection or High Court. The CMHT/GMMH multidisciplinary team discussion apparently suggested that a wider multidisciplinary team meeting be convened but no-one appears to have taken the lead on arranging for this to happen. It also appears from contributions to the review that Eric's physical symptoms were now seen as the primary need.

4.68. Also on 9th October, District Nurses visited. He declined to remove his top so that his shoulder wounds could be checked. He was wet with urine. Dressings were applied to some skin damage.

4.69. On 10th October a Duty Officer in ASC discussed the case with the CCG Adult Safeguarding Specialist Nurse. A Social Worker and Advanced Social Work Practitioner visited Eric and his family to commence a Section 42 enquiry. His wife and daughter are recorded as having declined ASC support. Eric was seen on this visit and "felt" to have capacity. A strategy meeting was confirmed for 15th October.

4.70. Commentary: "feeling" that someone has capacity is not a formal assessment. ASC's contribution to this review has stated that a formal mental capacity assessment was not undertaken because Eric was not medically stable. Setting a strategy meeting for five days hence when the risks were significant seems like undue delay.

4.71. GP1 discussed the case with the CCG Adult Safeguarding Nurse, during which referral to the Court of Protection was raised as a possibility. The CCG contribution to the review has recorded that GP1 accepted that they had limited knowledge of the role of the Court of Protection. This highlights the importance of legal literacy.

4.72. Eric refused to be admitted to the hospice, perhaps because of pain on movement. He refused oral analgesia. Treatment with a pain patch was suggested when the Mental Health Nurse from the Older Adults CMHT spoke with GP1. The CMHT sent a carer pack to Eric's wife.

4.73. Commentary: did Eric have decisional capacity when refusing admission?

4.74. District Nurses visited. Eric agreed to a change of clothes and pad. He was very wet. His body was washed and cream applied. His wife and daughter were very distressed that he had refused to go to the hospice and were threatening to leave him. He appeared then to change his mind. Hospice at Home offered them support.

4.75. Commentary: again it is thought that Eric had capacity despite his lack of engagement. What had happened to an earlier assessment that he lacked decisional capacity regarding admission to the hospice? A specialist and thorough mental capacity assessment seems indicated, even if it had to be ordered through a Court of Protection direction. District Nurses liaised with the Mental Health Nurse and discussed whether his condition was due to mental health and depression. In the record for this discussion it appears that this was felt to be the case. So, there also seems to have been divergent views about the impact of depression in this case.

4.76. On 11th October the CCG Adult Safeguarding Nurse, GP and ASC staff met, prompted by CCG concern at the delay in holding a strategy meeting. A strategy meeting was held. There were questions about the adequacy of consideration of Eric's decisional capacity regarding his care and treatment. Legal advice was to be sought and also a mental health assessment. That advice, when received, was that the existing DNAR was valid, that this was an expected death and that a mental capacity assessment was to be completed regarding care and treatment, to be done by District Nurses. If the

assessment concluded that Eric did not have capacity, an assessment by an AMHP was to be done[13].

4.77. Commentary: the decision to bring forward the strategy meeting was highly appropriate given the risks in this case[14]. However, might not a referral to the Court of Protection have been explicitly considered? Equally, given the difficulties that practitioners had encountered when attempting previous capacity assessments, might commissioning a specialist assessment have been appropriate? A contingency plan might also have been advisable in case Eric declined to engage (again) in any assessment.

4.78. Commentary: the SAR review team and independent reviewer have concluded that legal advice should have been sought much earlier. By the time it was sought (Friday) the case was rightly judged as being urgent. CCG sought legal advice as legal practitioners for the local authority could not be contacted[15]. The advice obtained was that a Court of Protection direction could not be sought because it was not clear whether a good quality mental capacity assessment had been completed. Legal services were made aware of the precariousness of Eric's life. The review team and independent reviewer have concluded that there is important learning about how and when legal advice is sought, especially in cases of complexity and urgency.

4.79. District Nurses visited on 11th October and also GP1. A pain patch had been in place from the day before. Eric had been very restless at night, hallucinating and rambling. He refused admission to hospital and the hospice. He had difficulty swallowing and the GP doubted his intention to take food. However, a referral for a swallowing assessment was made. He had lost weight but had bowel motions. NWAS was called at one point because his breathing changed and the crew asked for a District Nurse who, having contacted the Out of Hours Doctor, administered medication.

4.80. When District Nurses visited on 12th October, they learned that Eric had been very anxious overnight. He was agitated and his sheet sodden. He agreed to a wash and for the sheet to be changed but refused a change of vest and pyjama top. His dressings were intact. District Nurses also visited the following day.

[13] It has been suggested that, arguably, this may represent a misunderstanding of how the Mental Health Act 1983 can be used, as it does not hinge on demonstrating incapacity like the Mental Capacity Act 2005. It would have fitted the situation well as there would have been no need to definitively conclude incapacity at the point of assessment – this could have been assessed further post admission if it was not possible to conclude on this at interview. Also it is worth mentioning that, at this point, use of the Mental Health Act 1983 may have been too late and the situation may have been irretrievable, or possibly that a Mental Capacity Act 2005 admission to focus on his deteriorated physical condition would now be seen as the primary aim.

[14] The panel and independent reviewer have heard that CCG staff (Named GP and Adult Safeguarding Specialist Nurse) felt that they had to persist and strongly argue for a strategy meeting to be brought forward and held as a matter of urgency. The panel and independent reviewer believe that this raises a question about the adequacy of triage in respect of urgency when referrals are received by ASC.

[15] This is somewhat surprising as there is an urgent duty number, together with an established system to obtain advice out of hours.

4.81. On 14th October legal advice to ASC was for a mental capacity assessment to be part of a mental health assessment. District Nurses administered personal care but Eric declined fluid and mouth care. He was in pain. A Consultant Psychiatrist visited with the Mental Health Nurse at a time when District Nurses were also present. By this time Eric had probably not eaten for about 29 days and had not drunk water for three days. He was confused. His blood pressure was low and his heart and respiration rates elevated. He was very frail. A Mental Health Act 1983 assessment was felt inappropriate at this time but the Psychiatrist concluded that Eric did not have decisional capacity regarding his care and treatment. He said he did not want to die but could not link this to his current behaviours. With NWAS support he was taken to SRFT and admitted. He was referred for a swallowing assessment. A DNA CPR was in place.

4.82. Commentary: NWAS submitted a safeguarding concern, which was good practice. There appear to have been no recent physical health investigations, so it is unclear what the outcome had been of previous requests for blood tests. It remained unclear if his current situation had been driven by his mental ill-health.

4.83. Reviews by medical staff on admission to SRFT concluded that Eric was at imminent end of life and that medication would not alter this outcome. End of Life care was initiated. He was seen by a Palliative Nurse. SRFT completed a safeguarding alert, and ongoing safeguarding and Coroner investigations were felt to be required. Eric was very emaciated.

4.84. On 15th October a second strategy meeting was held. This concluded that staff needed to be reminded to use SSAB's self-neglect policy. Referral for a SAR was also agreed. The meeting discussed the challenges of applying the Mental Capacity Act 2005 and of completing assessments when capacity fluctuated and when there were different professional opinions. It was reported that no blood tests had been done since early 2017, with Eric having cancelled appointments because he would not leave the house.

4.85. On 16th October Eric died.

# 5. Analysis

5.1. The analysis that follows draws on the contributions from Eric's wife and daughter, from the practitioners who worked with Eric and from managers and panel members who were involved in decision-making about how to respond to the needs that Eric presented and the risks inherent in his decision-making.

5.2. The analysis is organised around key components of the evidence-base for working with adults who self-neglect[16]. Where relevant, links will be made with other SARs and with case law.

5.3. The first key component relevant to this case is *Making Safeguarding Personal* (MSP). This comprises a person-centred approach that includes proactive rather than reactive engagement and a detailed exploration of a person's wishes, feelings, needs and desired outcomes. It involves concerned and authoritative curiosity characterised by gentle persistence and skilled questioning. What might lie behind a refusal to engage is a key line of enquiry.

5.4. Eric's wife and daughter felt that retirement was a big change for him. Although he had friends outside work and lots of hobbies, he missed having a scheduled day. However, it was later into retirement that he really began to struggle, especially as friends passed away, and he would not talk about how he felt. In addition, he became less active, initially as a result of two hip replacements, the anticipation of which brought on an onset of anxiety and loss of weight. The aforementioned evidence-base is clear about the role of loss in self-neglect.

5.5. His wife and daughter have confirmed that Eric's anxiety post-dated his retirement and increased as his health changed and he grew older. This became especially noticeable in 2015, as did his more negative attitude towards food, around the time he suffered acute kidney injury. He became more anxious before meals. They wondered whether his anxiety was linked to the knowledge that his father had died of throat cancer and his sister of bowel/stomach cancer. The independent reviewer also wonders whether this anxiety was compounded by the oesophagitis that Eric experienced[17].

5.6. However, Eric would not speak about his health or his feelings with his wife and daughter. He would not let them see his correspondence and he became increasingly private, seeing his wife's concern as intrusive rather than supportive. It was only after his death that they became fully aware of all the appointments that he had missed, and of a psychologist's report that referred to Eric talking about feeling anxious and experiencing a lot of wind before meals.

5.7. In the learning event GP1 recounted how, despite visiting Eric more often than any other patient in his longstanding practice, and despite a long history of caring for Eric, it had always been difficult to obtain information about what was going on for him. Primary care staff attending the learning event recounted how there was evidence that a structured and assertive approach with Eric had achieved some movement and

[16] Preston-Shoot, M. (2019) 'Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice.' *Journal of Adult Protection*, 21 (4), 219-234.
[17] See section 4.60.

engagement. It was also recognised that, whilst practitioners might be adept at using different communication styles when necessary, it took confidence and bravery to explore difficult issues with someone who was disinclined to engage.

5.8. It is possible, therefore, that whether or not Eric really wanted to die, and whether or not he could connect his behaviour with likely outcomes, were not consistently pursued. It is not clear that anyone hypothesised with Eric about whether there was a link between his experience of chronic kidney disease, and bowel problems[18], and his disinclination to leave his home and his refusal to eat or drink. Other SARs have referred to the importance of authoritative practice, which includes active efforts to understand an individual's position[19], and to attempting to explore why a person is living the way they are[20]. Family members may have important information to share in this respect. As it is, no-one appears to have learned much about what had for Eric triggered his disregard for his health and wellbeing in the final weeks of his life.

5.9. The second component of the evidence-base focuses on *assessment and responses to health, mental health and mental capacity*. The evidence-base advises thorough assessments of health, mental health and care and support, with updated planning and regular reviews. Thorough assessment of mental capacity should include a focus on executive capacity. Comprehensive assessments should include a focus on risk, especially in cases of service refusal.

5.10. Eric's wife and daughter have expressed surprise and disappointment that no-one followed up missed or cancelled appointments other than with further letters, which Eric would not allow them to see, and telephone calls. They felt that Eric had been "forgotten in the system" despite his known history of anxiety and depression, and felt that the approach to missed appointments should be reviewed concerning adults at risk.

5.11. They have also expressed surprise at his discharge by a dietician in 2016 when he had been previously assessed as a high nutritional risk, and by a counselling psychologist when he was still underweight and not opening up. They have recounted that increasingly, as he struggled with anxiety and depression, he just wanted his wife to sit with him. When she had to go out shopping, she had to telephone him and say where she was and how long she would be. He increasingly withdrew into himself and stopped doing all the things that he had previously enjoyed. When asked, his stock answer was "maybe tomorrow."

5.12. When the Rapid Response Team visited in July 2019, Eric's daughter kept a diary of event. His wife and daughter understand that a connection was made at that time between depression and Eric not eating but his case was closed. Eric's wife and daughter have queried whether he had developed an eating disorder brought on by anxiety. A possible contributory factor to anorexia in older age is depression. Indeed, one SAR[21] has found that a possible depressive illness was not considered when a person was refusing nutrition and hydration. In another SAR involving a person who stopped eating and

[18] See, for example, sections 4.1 and 4.8. Section 4.6 refers to treatment for and anxiety about bowel issues.
[19] For example, Sandwell SAB (2019) Adult A.
[20] For example, South Tyneside SAB (2017) Adult D.
[21] Newham SAB (undated) "Ann".

drinking[22], there was a history of psychotic depression alongside epilepsy and learning disability.

5.13. Eric's wife and daughter have questioned whether healthcare professionals considered all his health and mental health problems holistically – kidney injury, bowel concerns, anxiety and depression, erratic compliance with medication and the impact of all this on his mental capacity.

5.14. Eric's wife and daughter have surmised that those visiting Eric may have felt out of their depth. They recognise that Eric was "difficult as a patient" but felt that more could have been done. Indeed, the chronology refers at one point to GP1 being unsure what to do[23]. At the learning event there were references to heightened anxiety when faced with complex and challenging cases.

5.15. At the learning event healthcare professionals reflected that there could have bene greater curiosity shown with respect to his incontinence and the timing of visits to attempt to explore issues with Eric and assess his needs. There were, they reflected, missed opportunities to assess his physical wellbeing, for example after his falls, and to review the care plan. As Eric's wife and daughter have also reflected, he stopped eating and was incontinent or doubly incontinent from 16th September 2016 but District Nurses only began to visit from 24th September. There was no District Nurse input for four days (26th, 27th, 28th and 29th September)[24] and from then on one visit daily. Moreover, GP1 had not realised the number of appointments that Eric had missed or cancelled[25].

5.16. At the learning event health and mental health practitioners thought that there were missed opportunities to assess his mental health. There were also reflections that it had proved difficult to secure the involvement of mental health services. Indeed, Eric's daughter has recorded two occasions in October 2019 when the family was expecting staff from a mental health team to visit to review the situation but no visit happened.

5.17. Other SARs have noted the importance of assessing priority for mental health assessment and intervention in the context of other needs and risks being presented by a case. They have also noted the challenge of securing the involvement of mental health services in assessment and treatment, especially mental health support at home[26].

5.18. At the learning event it was also acknowledged that there were missed opportunities to complete mental capacity assessments and to escalate concerns when this was not possible because of Eric's refusal to engage. One reason for this, it was suggested, was that assessment was not straightforward in this case. Eric was difficult to assess and there were differing opinions due to his longstanding mental health issues and how anxiety and depression might have affected his decision-making.

[22] Hampshire SAB (2017) Mr C: Overview Report.
[23] Section 4.39.
[24] It is possible that this may have been because Eric asked them not to visit.
[25] It is more difficult to track when patients cancel appointments than when they do not attend.
[26] See, for example, Salford SAB (2019) Andy. Oldham SAB (2020) Thematic Safeguarding Adult Review: Self-Neglect with Substance Misuse and Multiple Exclusion Homelessness.

5.19. An earlier SAR in Salford[27] found that mental capacity assessment continues to challenge practitioners, especially when capacity fluctuates as a result of physical health and mental health issues. Another SAR[28] has, because of the complex interplay between mental health and mental capacity, recommended training in this area. A further SAR[29] noted that the person stopped eating and drinking when distressed and often refused treatments. Such refusals, it emphasised, should have prompted assessments of capacity to understand the need for treatment and intervention, and of whether he understood that, by not eating and drinking, he may well. As with Eric, it appears that Mr C had said that he did not want to die. The SAR also emphasised the importance of seeking legal advice at an early stage, given the complexity of the case, and of removing the possibility of underlying physical causation. Finally, it stressed the importance of communication and coordination between practitioners involved in order to ensure clarity of purpose and planning, professional curiosity and challenge.

5.20. Another explanation for how practitioners responded to Eric may lie in the "lenses" through which his situation was viewed. One lens that was prominent, especially for GP1, was that this was an "end of life" scenario. Whilst completing a statement of intent and putting in place a DNAR may have been designed to reduce trauma for the family, it has been recognised that doing so early on in the final weeks of Eric's life was "an error of judgement." It also appears to have influenced ASC's decision not to intervene on 1st October[30] and may have influenced initial decision-making about the timing of a strategy meeting and why CCG staff felt that they had to persist and argue strongly for the meeting to be brought forward.

5.21. A second lens through which this case was seen was that Eric was making a lifestyle choice or unwise decision. This too may have obscured the importance of considering the link between his mental health and his mental capacity, and of exploring his executive capacity. Especially where there are repetitive patterns, as in this case, it is essential to assess executive capacity as part of mental capacity assessment. Guidance has commented that it can be difficult to assess capacity in people with executive dysfunction. It recommends that assessment should include real world observation of a person's functioning and decision-making ability[31], with subsequent discussion to assess whether someone can use and weigh information. Assumptions should not be made about people's capacity to be in control of their own care and support[32]. There were missed opportunities to assess Eric's executive functioning and to consider referral to the Court of Protection when it proved difficult to conduct or complete an assessment. Feeling that he had capacity is very different from carrying out a formal assessment, which explores the areas that have been indicated here and the significant risks that were inherent in his behaviour.

[27] Salford SAB (2019) Andy.
[28] Newham SAB (undated) "Ann."
[29] Hampshire SAB (2017) Mr C: Overview Report.
[30] See section 4.42.
[31] NICE (2018) *Decision Making and Mental Capacity*. London: National Institute for Health and Clinical Excellence.
[32] NICE (2018) *People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services*. London: NICE.

5.22. One lens through which the case might have been seen earlier was assessment under the Mental Health Act 1983. Had as assessment concluded that the criteria for a section 2 admission been met, a pathway would have opened up to address risk and mental health concerns.

5.23. The third component of the evidence-base refers to *working with the family*. This comprises seeking information from family members that may help to shape assessment and intervention, and offering carer assessments and support.

5.24. Eric's wife and daughter have described the experience of watching his deterioration as "harrowing." His daughter took time off work to support her parents. The combined chronology indicates that professionals who were visiting the home recognised their struggles to cope. Support was offered and information about carer assessment sent.

5.25. At the learning event GP1 and District Nurses said that they thought they had a good relationship with Eric's wife and daughter, and consulted with them on home visits. However, on reflection, his wife and daughter may not have fully understood what a carer assessment could actually offer and/or that the support that they wanted was something that would prevent Eric's deterioration, which seemed elusive. Moreover, Eric's wife and daughter have acknowledged that Eric did not like his wife talking about the situation and her concerns, and would give her "a look." The combined chronology also references occasions when he explicitly contradicted her. This may have prevented her from reaching out for more support. It could have been something that those visiting might have explored with her.

5.26. Balancing a person's wishes and autonomy against a duty of care is often a significant challenge in cases of self-neglect[33], which is why multi-agency risk management meetings[34] form part of the recommended evidence-base, enabling options to be appraised and reviewed. Embedded within this case is this moral/ethical dilemma, verbalised by Lord Justice Munby: "what good is it making someone safer if it merely makes them miserable?"[35] The counter argument, however, was that increasingly the situation in which Eric found himself deprived him of his dignity and compromised his wellbeing. To help practitioners resolve the dilemma, risk and mental capacity assessments are key.

5.27. LGSCO decisions[36] recognise the complexity of self-neglect cases, especially when having to *balance autonomy and protection* (LGSCO and Buckinghamshire County Council, 2017), but emphasise the importance of taking action when *services are refused* in situations of obvious deterioration (LGSCO and Windsor and Maidenhead Council, 2019). They remind local authorities of the importance of thorough *mental capacity assessments* when an individual's behaviour presents significant risks (LGSCO and

[33] Braye, S., Orr, D. and Preston-Shoot, M. (2017) 'Autonomy and protection in self-neglect work: the ethical complexity of decision-making.' *Ethics and Social Welfare*, 11(4), 320-335.
[34] Discussed below in section 5.30.
[35] Re MM (An Adult) [2007] EWHC 2003 (Fam)
[36] LGSCO and Blackburn with Darwen Council, 2017, Case Number 15 020 170. LGSCO and Buckinghamshire County Council, 2017, Case Number 16 011 871. LGSCO and Dorset County Council, 2019, Case Number 18 000 204. LGSCO and Windsor and Maidenhead Council, 2019, Case Number 17 019 298.

Blackburn with Darwen Council, 2017; LGSCO and Buckinghamshire County Council, 2017; LGSCO and Dorset County Council, 2019; LGSCO and Windsor and Maidenhead Council, 2019).

5.28. Case law also indicates how the Court of Protection is available when it may be unclear to practitioners and family members what is in a person's best interests. In one case the judge determined that the individual lacked mental capacity to understand the risks he was living in, namely extremely neglected accommodation and self-neglect. Orders in his best interest were made under the Mental Capacity Act 2005 (London Borough of Croydon v CD [2019] EWHC 2943 (Fam)).

5.29. The discussion in the sections immediately above highlight the relevance of aspects of the evidence-base that focus on how professionals and agencies work together. One component of this part of the evidence-base refers to *seeking specialist advice*. At the learning event it was acknowledged that the level of legal knowledge held by GPs[37] and primary care practitioners may vary and, further, that not all health and social care staff will have a clear understanding of the pathway for accessing legal advice through safeguarding procedures. Legal advice was obtained by the CCG and through the Council's legal service but those attending the learning event recognised that advice had been sought very late (too late) in the case[38].

5.30. Part of the advice obtained was that a good quality mental capacity assessment should be obtained[39]. However, it had proved difficult to engage Eric in some attempted assessments and there may have been a case for immediate referral to the Court of Protection.

5.31. This illustrates another component of the evidence-base regarding how practitioners and agencies work together, namely the *referral process*. There are several aspects here. The first is the pathway for accessing legal advice. In a previous SAR in Salford[40], it appeared that there were different organisational cultures with respect to seeking legal advice. At the learning event it appeared that this may still be the case, with ASC staff having a culture of direct access to legal services but with healthcare staff going through a safeguarding pathway.

5.32. The second is the content of referrals. In that same previous Salford SAR, clarity was advised in terms of what is being requested in any referral and why. Other SARs[41] have also pointed out that referrals, including from GPs, need to highlight clearly what is being asked for. The accuracy of the "ask" in referrals is illustrated by GP1's referral[42] to ASC. As was recognised at the learning event, more information could have been provided or sought so that the severity of the situation became clearer. There was no mention in the referral on 1st October to a diagnosis of depression, which could have been impacting on Eric's decision-making. GP1 was not asked for further information but reliance was placed on family members who, it was felt, had not raised concerns.

[37] See sections 4.71 and 4.72.
[38] See sections 4.31, 4.33 and 4.52 for commentary on when legal advice might have been sought.
[39] See section 4.78.
[40] Salford SAB (2019) Andy.
[41] For example, Wiltshire SAB (2019) Adult C.
[42] See section 4.43.

5.33. GP1 did make referrals to various services, including District Nursing, the Hospice, ASC, the Urgent Care Team and GMMH. As already indicated, observations were shared at the learning event to the effect that accessing mental health services and the support that mental health assessment and provision can offer was difficult. The combined chronology does highlight that securing mental health (re)assessment of Eric appeared challenging. Thus, the third component of learning from this case is the pathway for accessing mental health assessment and service provision[43], for example by members of a primary care team.

5.34. As illustrated by the analysis of learning with respect to referrals, *information-sharing* is a key component of best practice identified within the evidence-base. A few examples of positive communication between practitioners involved were mentioned at the learning event. For instance, communication between GP1 and a Hospice Consultant, which included a joint visit, and between GP1 and a Mental Health Nurse.

5.35. However, GP1 did not seem to have full knowledge from surgery staff regarding the number of appointments that Eric had either missed or cancelled. The response by ASC to referral from GP1 has already been noted as having been influenced by the information that was omitted. It would have been helpful to have known the challenges that had been encountered when attempting to assess his mental capacity or to address his evident health care needs.

5.36. It was also observed that information about Eric was spread across a number of different systems, which hampered communication, because access was restricted. Different case recording systems used by health and social care impedes information-sharing and analysis. Diverse recording systems and lack of access hamper the development of a more coordinated approach, as was highlighted also in another Salford SAR[44].

5.37. Information-sharing is one aspect of another component of the evidence-base, namely *inter-agency collaboration*. This includes the use of multi-agency meetings to pool information and share assessments of risk and mental capacity, to agree risk management and contingency plans, and to consider legal options.

5.38. At the learning event positive experiences of communication and collaboration were itemised, for example the support given to GP1 by the CCG Designated Nurse for Safeguarding Adults, and to District Nurses by the Multi-Disciplinary Group Nurse. It was also acknowledged that, when the two strategy meetings were convened shortly before Eric died, professionals came together at very short notice to share information and discuss how to respond.

5.39. However, it appears that mental health professionals had to be instructed to attend the second strategy meeting, leading to concerns that there was a lack of acknowledgement of the severity of the situation and of the need for a multi-disciplinary coordinated response. It was accepted that there were missed opportunities to convene the adult safeguarding system in earlier multi-agency meetings, either using the section 42 Care Act 2014 duty to enquire process or the procedures outlined in the Salford SAB's

[43] See, for example, section 4.67.
[44] Salford SAB (2019) Andy.

self-neglect policy. As the combined chronology and associated commentary makes clear, the self-neglect policy was not drawn upon. The first strategy meeting was held too late, perhaps because of the influence of the "lenses" through which the case was being viewed, as discussed above. SSAB may wish to consider whether it would be helpful to specify that any agency should be able to call a strategy meeting and to specify the timing of it.

5.40. At the learning event, other examples of poor communication were highlighted, for example between GP1 and District Nurses regarding the statement of intent. However, of equal if not greater concern were the expressions of lack of support for each other in a very difficult situation, of the need for a greater understanding of each other's roles and responsibilities, and of the importance of being willing to share expertise. A sense was conveyed of practitioners having worked in isolation in a very complex and stressful case, and of the need to ensure better ownership by everyone in any future case. In essence, what was being pointed out was the need for an embedded multi-disciplinary and multi-agency approach to complex safeguarding cases.

5.41. There are several reasons why this does not appear to have happened in this case. One is hesitation about escalating concerns and challenging the approach of others. Although, as the evidence-base recommends, an *escalation procedure* is in place, staff may not have the confidence, based on their experience, to challenge the approach being taken by colleagues. High staff turnover, involving the need to acquaint new staff with local policies and procedures, may also be a feature here.

5.42. Another reason is the failure to *use policies and procedures* that did exist, namely on self-neglect and also the non-concordance pathway. Indeed, as was pointed out at the learning event, with clear echoes of mental capacity, executive functioning needs to form part of considerations regarding non-concordance. Even if Eric had decisional capacity regarding treatment and was making unwise choices, for example regarding medication, the non-concordance pathway should have come into effect. That it did not might be a result of training not yet delivered or, for primary care, the procedure still being developed.

5.43. When reflecting on this at the learning event it was observed that no-one seemed able to observe the complexity arising out of the multiple issues that Eric was presenting. Equally it was only relatively late on that the case came to be seen through an adult safeguarding lens. Indeed, if a safeguarding concern had been referred earlier, this should have brought all the practitioners and services together. All services, including community healthcare, need to be aware that they can refer concerns to trigger safeguarding procedures. Crucial here, additionally however, is the role of *supervision* and *peer support*. The purpose of both is to enable those intimately and intricately involved in a case to step back to reflectively explore how the case is being seen and whether one lens is obscuring what another way of approaching the case might offer.

5.44. At the learning event District Nurses referred to having instituted monthly meetings to discuss complex cases, and to attendance at a safeguarding steering group. However, for much of the time of this case, any management or multi-disciplinary team approach did not appear sufficiently robust to raise the level of concern about the risks involved. Also concerning are the references made in the learning event to the absence of

supervision and opportunities to debrief and reflect after Eric's death. For those involved this was an upsetting case, which has affected those involved. There is an organisational responsibility here.

# 6. Revisiting the Terms of Reference

6.1. One focus at the learning event was exploration of what changes needed to be made to minimise the likelihood of a similar case happening again in Salford. This section draws further on the candid and open reflections that were offered at the learning event and from reviewing the terms of reference against what can be discerned from the combined chronology and what can be learned from the contribution offered by Eric's wife and daughter.

6.2. One key line of enquiry was to consider how services responded to assessment and management of risk. Eric's behaviour from early September 2019 onwards was a significant escalation of previous episodes. The significance of that escalation and of the risks inherent within it did not result in immediate multi-disciplinary and multi-agency collaboration to share information and to agree a holistic approach. Possible hypotheses for what might have triggered this escalation could have been explored further with Eric, with his wife and daughter and across the health and social care partnership.

6.3. A second key line of enquiry was to consider how the Mental Capacity Act 2005 was understood and use, including its interface with the Mental Health Act 1983. It is possible to conclude that there was insufficient support available for, or accessed by those involved when undertaking mental capacity and/or mental health assessments provide difficult because of Eric's non-engagement and because of the complexities that practitioners faced. Further training, however useful in strengthening people's knowledge of legislation, is only part of the answer. What is also necessary is a focus on workplace development and training transfer to ensure that practitioners are able to apply the knowledge and skills gained. Peer support and supervision, with a particular focus on complex cases, is also essential, alongside early access to advice and assessment from specialists, for example on how mental distress may be impacting on a person's decision-making.

6.4. The third key line of enquiry was communication between agencies and coordination of their contributions. Several teams and services were involved at different stages in this case. There is evidence of communication between them. However, not until the two adult safeguarding strategy meetings in October, shortly before Eric died, did the whole professional system begin to come together. When a system comes together, the whole can be greater than the sum of the parts. The level and timing of integration necessary to address the risks, and the physical health and mental health elements inherent in this case, was insufficient. As it was, those attending the learning event felt that professionals and services needed to support each other and to work together. Reinforcement was needed of the role and importance of multi-agency meetings. There was too much of "that is not our role" or "that is not for our service."

6.5. The fourth key line of enquiry was legal literacy. Those attending the learning event recognised that legal advice should have been sought much earlier in this case. There may be benefit in clarifying the pathways through which that advice can be sought. It must also be recognised that the interface between the Mental Capacity Act 2005 and the Mental Health Act 1983 is complex. For example, as illustrated by this case, which piece of legislation might a practitioner think is engaged and when? Mental capacity is not wholly determinative of action under mental health legislation.

6.6. The fifth key line of enquiry was use of escalation. There were missed opportunities to escalate concerns, using recognised procedures. The sixth ley line of enquiry is engaged here, namely use of safeguarding procedures. Safeguarding concerns were referred but could have been raised earlier if the situation had been seen through the lens of self-neglect and of safeguarding. Pathways for sharing safeguarding concerns and for making formal safeguarding referrals need to be clearly known. Supervision, peer support mechanisms and multi-disciplinary team discussions need to be asking the safeguarding question.

6.7. The seventh key line of enquiry was the response to self-neglect. It is clear that Salford SAB's self-neglect procedures were not used in this case and that the case was not seen through the lens of extreme self-neglect. It is also clear that non-concordance procedures and pathways were not activated either.

6.8. The eighth key line of enquiry focuses on pathways, both into mental health assessment and provision, and also into ASC. In the final weeks of Eric's life, although there were referrals into both mental health services and ASC, neither pathway resulted in effective intervention with the urgency that was required. One explanation may lie in the quality of referral information; another may reside in the lens through which the case was being seen, namely end of life; a third may hark back to whether the assessment required was one of mental capacity and/or mental health. There may also be a question of thresholds, especially for secondary as opposed to primary mental health care.

6.9. The ninth key line of enquiry was recognition of the needs of carers. This was a harrowing situation for Eric's wife and daughter. The report has suggested that, whilst support was offered both during Eric's final few weeks and after his death, further explanations could have been given as to what that support might entail and the family's responses revisited. This was a complex and harrowing case also for those professionals who were in almost daily contact with Eric. Supervision and debriefing should be a part of everyday practice, a safe environment in which to reflect on what has happened and the emotions that are circulating.

6.10. The final key line of enquiry was the decision-making process about end of life. The report has already acknowledged that GP1 has reflected that seeing the case through the lens of end of life obscured other potentially useful ways of looking at the case. For example, it may have been helpful to have asked "why is Eric dying?" Such a question may, for example, have led into assessment of the impact of anxiety and depression on his behaviour.

Salford Safeguarding Adults Board

# 7. Recommendations

7.1. Arising from the analysis undertaken within this review, the SAR Panel and independent reviewer recommend that the Salford Safeguarding Adults Board:

7.1.1. Revisits the recommendations contained within the previous SAR that involved self-neglect, assesses the evidence for the impact and outcome of these recommendations, and identifies further steps to embed learning in policy and practice.

7.1.2. Reviews and strengthens the pathways through which health and social care professionals can seek legal advice, including urgently when necessary, and outlines its expectation that legal practitioners will be invited to adult safeguarding strategy meetings and multi-agency risk management meetings when cases are particularly complex.

7.1.3. Conducts multi-agency case file audits to evaluate the degree to which procedures on self-neglect, escalation and non-concordance are being used, and on the basis of the results considers what further action is necessary to embed their use in practice.

7.1.4. Considers what further steps are necessary when the Board agrees and launches a policy to seek reassurance from partner agencies that practice now reflects the agreed procedures.

7.1.5. Conducts an audit of referrals for section 42 enquiries, including subsequent decision-making.

7.1.6. Considers with partner agencies whether procedural change is indicated to emphasise that any agency can convene a multi-agency meeting to seek agreement on a risk management and mitigation plan.

7.1.7. Commissions multi-agency training on self-neglect and on legal literacy (including mental capacity assessment and awareness of the role of the Court of Protection) but also reviews with partner agencies their approach to ensure that training transfers into practice.

7.1.8. Requests that commissioners and providers review pathways into mental health assessment and services, and Mental Health Act 1983 assessment, from primary care and social care, and report back with proposals to strengthen integrated and collaborative working.

7.1.9. Engages with partners on how to achieve the widest possible access to records to promote integrated and collaborative working.

7.1.10. Concludes a work stream to agree a multi-agency escalation policy.

7.1.11. Reviews practice with respect to offering and conducting carer assessments.

# Appendix: Glossary

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| ASC | Adult Social Care |
| CCG | Clinical Commissioning Group |
| CMHT | Community Mental Health Team |
| DNACPR | Do not attempt cardiopulmonary resuscitation |
| DNAR | Do not attempt resuscitation |
| GMMH | Greater Manchester Mental Health |
| GP | General Practitioner |
| LGSCO | Local Government and Social Care Ombudsman |
| MDG | Multi-disciplinary group |
| MDT | Multi-disciplinary team |
| MSP | Making Safeguarding Personal |
| NHS CHC | NHS Continuing Health Care |
| NWAS | North West Ambulance Service |
| RMO | Registered Medical Officer |
| SAR | Safeguarding Adult Review |
| SRFT | Salford Royal Foundation Trust |
| SSAB | Salford Safeguarding Adults Board |