

Salford Safeguarding Adults Board

Andy

Safeguarding Adults Review – Andy (25th October 1985 – 24th April 2018)

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March 2019

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1. Introduction

1.1. Andy¹, a White British man, died in his home on 24th April 2018. A friend had called the Police having found Andy in his bed with no signs of life². When an Ambulance crew arrived, no life support was attempted as rigor mortis had already set in³. The Police referred the case to the Coroner as the cause of death was unknown and the GP had not seen him within fourteen days of his death⁴. The Coroner did not hold an inquest into his death. Cause of death was recorded as acute myocardial infarction, severe coronary atheroma and Type 1 diabetes skin abscesses.

1.2. Aged 32 Andy had been living in a privately rented house where his mother had previously been the tenant. The house was in poor condition, with no heating or hot water⁵. Andy faced several health challenges, including a history of low mood, hereditary angioedema, Type 1 Diabetes and the need for dialysis as a result to kidney damage from poorly controlled diabetes. He was bereaved, having lost both his parents and two brothers⁶. He experienced income poverty and was not claiming all the welfare benefits to which he might have been entitled.

2. Safeguarding Adults Reviews

2.1. Salford Safeguarding Adults Board (SAB) has a statutory duty⁷ 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 circumstances where there is learning to be derived from how agencies worked together but where it is inconclusive as to whether an individual's death was the result of abuse or neglect. Abuse and neglect includes self-neglect.

¹ This was the name chosen by his sister and step-father

² GMP SAR referral individual agency summary form

³ NWAS SAR referral individual agency summary form

⁴ GMP SAR referral individual agency summary form

⁵ Housing agencies' contributions to the combined chronology

⁶ SRFT contribution to the combined chronology

⁷ Sections 44(1)-(3), Care Act 2014

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 future⁸. 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 was made by ASC. The SAB's SAR sub-group considering that a causal link had not been clearly established between Andy's self-neglect and his death, recommended that a discretionary review be commissioned on 10th July 2018. This was subsequently agreed by the Independent Chair of Salford Safeguarding Adults Board. I was confirmed as the reviewer and overview report writer on 1st August 2018.

2.5. The membership of the SAR Panel comprised the members of the Board's SAR sub-group, with the addition of co-opted members representing at senior level the agencies which had commissioned or provided services to Andy.

- Independent overview report writer:
 - Michael Preston-Shoot
- Salford SAB Business Manager
- Greater Manchester Police (GMP)
- NHS Salford Clinical Commissioning Group (CCG)
- Salford Royal Hospital NHS Foundation Trust (SRFT - Adult Social Care – ASC)
- Salford Royal Hospitals NHS Foundation Trust (SRFT – Acute and Community Services)
- Greater Manchester Mental Health (GMMH)
- North West Ambulance Service NHS Trust (NWAS)
- Salford City Council Housing Options
- Housing Welfare
- Salford Welfare Rights and Debt Advice Service

The SAR Panel received administrative support from the Salford Safeguarding Adults Board Business Support Officer.

3. Review Process

3.1 Focus

- 3.1.1. The panel wished to undertake a proportional review that analysed the case through the lens of evidence-based learning from research on self-neglect and the

⁸ Section 44(5), Care Act 2014

findings of other published SARs on adults who self-neglect. The focus of the review was therefore to range across self-neglect, non-attendance at appointments, mental capacity, use of existing policies and procedures with respect to self-neglect, and multi-agency working. Specifically, the panel wished to focus on learning from good practice and from shortcomings as follows:

3.1.2. How primary and secondary healthcare providers worked together.

3.1.3. What was known about Andy's potential for self-neglect and how agencies attempted to mitigate the risks from self-neglect?

3.1.4. What was known about his failure to attend appointments? How effectively did agencies work together to mitigate the associated risks?

3.1.5. Were single and multi-agency policies, especially on self-neglect, sufficient and followed?

3.1.6. Did any agency have concerns about Andy's mental capacity and what actions were taken? Was his mental capacity assessed, why, when and with what outcome?

3.1.7. Could any agency have done more to prevent the decline in his health?

3.1.8. How effectively did the nine agencies involved with Andy work together to address the many issues that he faced?

3.1.9. The links between extreme poverty, housing, self-neglect and safeguarding.

3.1.10. As the review progressed, it became relevant also to explore the links between diabetes and other chronic conditions with self-neglect and mental capacity.

3.2 Methodology

3.2.1. The timeframe for the review covers the period from 30th November 2016 to 24th April 2018.

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

3.2.3. The individual chronologies were combined. Panel members and the independent reviewer then identified specific issues and questions that the nine agencies involved were asked to address in follow-on reports.

3.2.4. A learning event with practitioners involved in Andy's case explored key episodes and events within the timeframe being reviewed based on issues and concerns emerging from the combined chronology and agency responses to the panel's observations and questions.

3.2.5. The learning event and panel meetings sought to analyse learning from this case through the lens of evidence from research⁹ and other SARs¹⁰ that has enabled a framework for policy and practice to be constructed for effective work with adults who self-neglect. The focus was therefore on identifying the facilitators and barriers with respect to implementing what has been codified as good practice. Thus, a hybrid methodology has been used, designed to provide for a proportional, fully inclusive and focused review.

3.3 Family involvement

3.3.1. The friend who found Andy on 24th April made representations to Salford Adult Social Care regarding the care he received from health and social care agencies. She was interviewed by two senior ASC staff members on 2nd July 2018. She offered the following comments:

- 3.3.1.1 Professional staff must be aware that people with scarce financial resources do not use mobile phones in the same way people with finances do. Voicemail messages shouldn't be left as it costs to pick them up and therefore are often not listened to. Younger, financially limited people use WhatsApp instead. In Andy's case she felt that professional staff interpreted this as Andy ignoring them/not wanting to take up offers of assistance/not complying with advice and judged him accordingly.
- 3.3.1.2 She hypothesised that Andy was committing suicide slowly by not attending to his health needs and that a duty social worker agreed with her¹¹; she felt this was not dealt with the seriousness required.
- 3.3.1.3 Issues with regard to organising Andy's funeral. The social care practitioner involved at the time of Andy's death was unaware of

⁹ Braye, S., Orr, D. and Preston-Shoot, M. (2014) *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. London: Social Care Institute for Excellence. Braye, S., Orr, D. and Preston-Shoot, M. (2013) *A Scoping Study of Workforce Development for Self-Neglect*. Leeds: Skills for Care.

¹⁰ Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' *Journal of Adult Protection* 17 (1), 3-18. Preston-Shoot, M. (2016) 'Towards explanations for the findings of serious case reviews: understanding what happens in self-neglect work.' *Journal of Adult Protection* 18 (3), 131-148. Preston-Shoot, M, (2017) 'On self-neglect and safeguarding adult reviews: diminishing returns or adding value?' *Journal of Adult Protection* 19 (2), 53-66. Preston-Shoot, M. (2018) 'Learning from Safeguarding Adult Reviews on self-neglect: addressing the challenge of change.' *Journal of Adult Protection* 20 (2), 78-92.

¹¹ Andy's sister, brother and step-father disagree with this opinion.

the duty of the Local Authority to organise funerals for those people with no funds/relative-friends to do so. When she spoke to staff in the Local Authority she felt their attitude was judgmental and was very unhappy as she was made to feel she was hiding something when she was trying her best to sort out the funeral¹².

- 3.3.1.4 She could not understand why Andy had been prescribed oral morphine medication for toothache. This medication made him sleepy and meant he wasn't able to get to his dialysis.
- 3.3.1.5 No one person was coordinating his care.
- 3.3.1.6 She felt that his GP made insufficient allowances for his health condition, living situation and previous family bereavements.
- 3.3.1.7 The team at the dialysis unit were aware Andy had foot ulcers but she queried whether he was referred for treatment for them – they were not treated on the dialysis unit despite Andy having difficulty walking.
- 3.3.1.8 Professional staff did not appear aware of the impact on Andy of multiple bereavements in his family with both his mother and father and two brothers being deceased.
- 3.3.1.9 He was referred to a nutritionist due to being low in weight but the issue was he had insufficient money to feed himself adequately. He could cook and prepare food as he had an NVQ in catering and had worked as a chef when he was in work.
- 3.3.1.10 He was discharged from a ward in SRFT due to smoking cannabis on the ward when it was someone else smoking cannabis.
- 3.3.1.11 Andy was subject to bedroom tax as he was living in the family home after the death of his mother and brothers and he had rent arrears associated with this.
- 3.3.1.12 She said that AR wasn't an 'easy customer' – and felt he was just the sort of person that requires involvement from services without being judged or dismissed because of his attitude.
- 3.3.1.13 A major issue was finance - she said that Andy was just too poorly and too badly organised to sort out and apply for welfare benefits which would have made such a big difference to the quality of his life.

3.3.2 When interviewed by the two ASC staff members she apparently was content not to have further involvement and to leave further investigation to ASC and this review. Correspondence sent to her as part of this review process has been returned as "no longer at this address."

3.3.3 The independent reviewer and SAB Business Manager met with Andy's sister. She provided contact details for Andy's step-father and Aunt (his mother's sister). Approaches were made to explore whether they wished to

¹² Andy's sister, brother and step-father challenge this opinion.

contribute to the review process. Andy's step-father met with the independent reviewer and SAB Business Manager. The Aunt did not respond to attempts to make contact with her, possibly due to ill-health.

- 3.3.4 The independent reviewer and SAB Business Manager also met with Andy's sister, brother and step-father to work through the final report. Panel members and the independent reviewer are very grateful to Andy's sister, brother and step-father for their contributions to this review. The information they have offered to this review has enabled panel members and the independent reviewer to form a much clearer picture of Andy and his lived experience.

4 . Andy: Pen Picture

4.1. Andy's sister and step-father provided significant details of the family. Andy's parents had five children. Andy's sister is the oldest, followed by an older brother, who died in October 2003 after a vehicle accident, Andy himself, a younger brother who is still alive but with whom his sister is not in regular contact, and finally the youngest brother who died in September 2016 of angioedema, a throat swelling condition from which Andy also suffered.

4.2 Both parents have died; his mother around four years ago of chronic inflammatory demyelinating polyneuropathy (CIPD)¹³ and his father around 10 years ago from angioedema.

4.3 His parents separated when the children were young, his mother and the children moving to the private rented accommodation that Andy was still living in when he died. It is known that his father then had a son with another partner. His mother subsequently had a relationship with the person described in this report as Andy's step-father. The childhood that Andy's sister described included stormy relationships. She moved away when still a young person after one of her mother's rages, and at times subsequently had her brothers to live with her. Both she and Andy were carers for their mother before she died.

4.4 Andy's step-father described the death of his older brother as tragic, believing it to have triggered diabetes in both Andy and his mother. Andy's sister described the death of his older brother as "earth shattering." She thought that Andy was his mother's favourite child but their relationship could be violent.

4.5 Andy was described by his sister as "a lost soul." He had a tendency to push happiness and people away. He was inclined to say that no-one cared about him and yet, in her

¹³ CIPD is a rare neurological disorder involving progressive weakness and impaired function in legs and arms as a result of inflammation of nerve roots.

view, he could not help himself. Andy's step-father, who knew him for approximately twenty-five years of his life, described someone who had been very friendly, out-going and sporty, an independent person who would not seek assistance but who would accept help if offered.

4.6 Andy was on steroids for most of his life as a result of the angioedema, which had been diagnosed when he was an adolescent. His step-father described how this diagnosis had "knocked him for six" and "affected his outlook on life." He had wanted to join either the Army or the Police but this was now not possible. The angioedema could result in severe swelling to his face and hands, which made him "unrecognisable." He could no longer play sport. According to his step-father, at times he "shuffled around like an old man" as a result of his disabilities. He became a chef after training but was unable to retain his jobs. His college courses and his employment were interrupted by his angioedema. Shortly after his older brother died, Andy became ill and was diagnosed with Type 1 Diabetes. His mother was also diagnosed with the same condition.

4.7 He did not attend a diabetes review in October 2016. There is a history of non-engagement, declining services and self-neglect. His sister knew that he rejected offers of support but was also inclined to accuse people of not caring. She acknowledged that he had a temper but thought that his aggressive outbursts were due to frustration and a belief that no-one was listening. His step-father also said that Andy was "not the easiest person" but that Andy believed that he had been ignored, that people were not interested, and that he was too much trouble for them. Rather than rejecting support, his step-father believed that the combination of his living circumstances and the impact of his ill-health made it very difficult at times for him to respond. As his step-father observed, "he could feel so poorly that he could not keep appointments; he could be exhausted by his dialysis."

4.8 For the period under review both his sister and step-father stated that Andy was living in the family home without running hot water and central heating. They described the house as "a hovel", which was cold, wet and damp. The electrics had been condemned and he lived on a settee with one convector heater for warmth. He could not climb the stairs. There were no facilities for washing and for laundry, the latter sometimes being done by the friend who subsequently became an effective advocate for Andy. His step-father commented that the deterioration of the house mirrored Andy's own decline, dating from the death of his mother. He described how Andy had said "I don't know what I will do without mum."

4.9 In relation to renal dialysis his sister thought that Andy was "scared" and "fighting" but eventually "lost the will." His step-father described how the initial diagnosis of angioedema affected his moods, with Andy sometimes being depressed and/or aggressive. He thought that the dialysis exhausted him and that sometimes he just felt

too poorly to go to appointments. He did not believe that Andy willingly missed appointments. He had been buoyant when he thought that he would receive a kidney transplant. His step-father believed that Andy had wanted to get better and that he still had will-power. His step-father described someone who could be meticulous about medication and who knew when to refer himself in relation to his angioedema.

- 4.10** In relation to his tenancy, Andy's sister thought that he was frightened of the landlord and did not want to upset things further. She wondered why no-one appeared to understand that this might be the case. His step-father thought that the landlord, and the intermediaries whom Andy dealt with about his accommodation, had been completely remiss. "Social Services" had also known about the condition of the accommodation, he suggested, and yet he had been discharged home without support.
- 4.11 Andy's sister observed that he "was often out of order" but thought that, while some staff were very good and caring towards him, for example on the dialysis ward, others rejected him, for example when he presented at hospital with open wounds on his ankles and with chest pains. His step-father also observed that not all healthcare staff appeared familiar with angioedema or appeared to understand his needs. This had on occasion prompted Andy to take his own discharge.
- 4.12 His sister said that Andy did self-medicate with both soft and hard drugs, partly to overcome lethargy that sometimes would mean that he could take 15 minutes to be able to answer the front door. The panel and independent reviewer wonder whether this lethargy might explain when it appeared to professionals that Andy was not at home and when he did not keep appointments. His step-father described how at times Andy felt very ill. Sometimes he could be buoyant; at other times he could be depressed by the state of his health.
- 4.13 Andy was found by a friend and his surviving brother was also present during that morning. The sister could not understand why she was only told early afternoon. She was also concerned at the volume and type of prescribed medicines that she then found in Andy's home, including Fentanyl patches and OxyNorm¹⁴.
- 4.14 In relation to his decision-making capacity, his sister did not believe that Andy could process information at times, something which Andy also acknowledged on occasions (see below). She attributed this to the drugs he was taking, his living conditions and the impact of his ill-health.
- 4.15 In conclusion, his sister expressed the view that "everyone should have got together" so that her brother received one consistent message. She was grateful for the opportunity to contribute to the review – "someone is now listening." His step-father did not believe

¹⁴ Prescribed for treatment of moderate and severe pain requiring a strong opioid but to be used with caution in patients with renal impairment.

that Andy deliberately self-neglected. Rather, he did the best he could in his circumstances and was neglected by the system.

5 . Chronology

5.1. The events outlined below are derived from the combined chronology compiled from the submissions by the nine agencies involved with Andy. Italics are used in this section to denote evidence-based components of the approach for working effectively with adults who allegedly self-neglect. The following section puts these components together into one model and this is then used as the basis for the subsequent thematic analysis of the learning within this case.

5.2 On 30th November 2016 Andy's GP referred him to Adult Social Care. ASC failed to make contact by letter and telephone with Andy. *His case was closed* because of lack of contact. This is one of many instances in the chronology of *non-engagement and declining services*.

5.3 NWAS transported Andy to SRFT following a 999 call on 17th January 2017. He had a swollen tongue¹⁵, which is described as being part of his on-going condition. He is reportedly anxious but clinical observations are within normal parameters. He appears unkempt, with weight loss and shortness of breath. The NWAS chronology records that he did not have his rescue medication available. Whether NWAS might have referred a safeguarding concern on this occasion is discussed below (section 7.6.3). The GMMH records that Andy has a *history* of severe anaemia and angioedema but has not been engaging with physical care services or taking prescribed medication. Concerns are expressed regarding his poor self-care. He is reported as having experienced recent *bereavements*.

5.4 The following day he is admitted to SRFT and only discharged on 24th February 2017. During this hospital stay he informs a Consultant that he has no money, is unable to eat and drink, and lives alone in a house without central heating. A Diabetic Nurse assesses Andy as needing additional support by a community team *but he declines*¹⁶. Concerns are noted regarding his poor self-care and living circumstances. This was one occasion when all those involved with Andy might have pooled their assessments, especially of risk, and considered the impact of his circumstances on his decision-making. Mental capacity assessment is further considered below (sections 7.2.8 and 7.2.9).

5.5 Whilst in hospital an initial mental health *assessment* is completed by a Registered Mental Health Nurse. He is recorded as being moderately depressed in the context of

¹⁵ Angiodema

¹⁶ Andy's sister, brother and step-father have emphasised throughout that Andy did not have confidence that he would be adequately supported. This belief, coupled with the impact of his ill-health and the treatment for it, influenced his engagement.

bereavements and frustration with his physical health problems and poor living conditions. He does not appear to harbour thoughts of self-harm. He was apparently aggressive to staff working for NWAS and in SRFT A&E but he has not been aggressive or violent since admission¹⁷. Concerns relate to poor self-care (self-neglect) and withdrawal. The plan is for a Mental Health Consultant to review antidepressant medication to explore whether there is an alternative antidepressant that would be more effective; referral to ASC for support with housing needs and activities of daily living; referral to bereavement services/talking therapies. It was advised that Nurses should inform Andy at the earliest opportunity of any procedures or interventions he would be required to have and the reasons for this to be explained to him in attempt to increase concordance whilst at the same time empowering him to make informed choices about his treatment and care. If he refused medication or intervention the advice was to take *time to explore with him* why this was the case and see whether there was anything that could increase the chance of engagement.

- 5.6 When reviewed by a Mental Health Liaison doctor, monitoring concordance with medication and referral to Community Mental Health on discharge were advised. He was advised that he might require dialysis. He denied that he was omitting to take insulin and was angry that this was being alleged. He was assessed as presenting depressogenic cognitions (worthlessness, hopelessness, perceived loss of control and low self-esteem) and due to other demographic factors (young male, living alone, no social networks) was vulnerable to low mood and depressive symptoms. He again denied thoughts of harming himself or others. The plan was to involve him in decisions about care and to review his medication.
- 5.7 He is referred to ASC (social work) because of issues surrounding his self-neglect, bereavements, depression and housing situation. He is assessed as eligible for ASC but *declines services* other than a referral by ASC to Housing for assistance with relocation, which is made along with referral for the MDG¹⁸ process and to the Citizens Advice Bureau regarding his benefits. ASC do not *follow up* in their attempts to engage Andy. Section 7.1 highlights the importance of agencies recognising that practitioners should follow-up their attempts to engage individuals who are seriously self-neglecting.
- 5.8 By 24th January 2017 he is showing signs of improvement and is medically well-enough to be discharged. Medication and dialysis have commenced. Referral to Community Mental Health and Primary Care Psychology is planned, to which he has apparently agreed. The outstanding issue is his poor living environment.
- 5.9 Thereafter the SRFT chronology records several occasions when Andy refused treatment despite being warned of the dangers. The chronology notes that there was no reason to doubt his *mental capacity* but it is unclear how this was assessed as there is no record of

¹⁷ Andy's sister, brother and step-father point out again that Andy felt isolated and frustrated.

¹⁸ Multi-disciplinary group meeting where cases of self-neglect can be referred where needs relate mainly to health, as outlined in Salford SAB (2017) *Self Neglect and Hoarding Multi-Agency Guidance and Procedures*.

a formal assessment. He also withdraws his consent to referral to a Renal Psychologist and is recorded as being ambivalent to talk when one visits him subsequently on the ward. This represents the emergence of a *repeating pattern*.

5.10 The combined chronology records that during this hospital stay an Aunt visited him. As she had not seen him for some time, she was unable to comment on his mental health but did indicate that his physical appearance was the worst she had seen him. She offered that he could stay with her on discharge but he declines. Family members have pointed out that this was because she lived in a different town which would have meant that Andy would have lost continuity of treatment and their support. The individual agency chronologies record little information about *family relationships*.

5.11 Three attempts by Housing services to contact Andy in late January and early February fail to elicit a response. ASC is notified and a leaflet sent to Andy advising him of services available. There are email exchanges between Housing and an ASC Social Worker, with advice given about how to deal with disrepair issues relating to a private tenancy. However, Andy refuses to give the Social Worker permission to contact his landlord and he also declines domiciliary care. Family members believe that Andy did not want the landlord to be contacted because of a threat of eviction. Ultimately he is *discharged* to the same living conditions about which there had been significant concern. A visit by Housing staff to his home address is, however, arranged.

5.12 Prior to discharge his case is reviewed in a multi-disciplinary team meeting by the relevant Community Mental Health Team¹⁹. His history of poor compliance with medication is noted, also his multiple physical and mental health issues, and his lost support network. He is assessed as high risk and both medication reviews and outpatient appointments arranged. He is recorded as stating that *he does not want help*.

5.13 On discharge it is expected that he will attend the renal unit three days each week for dialysis. Four days after discharge, information about grants is posted out to Andy.

5.14 In March he fails to attend appointments with a GMMH Doctor and with a Renal Social Worker. A letter is sent by GMMH regarding his missed appointment. The *pattern* of missed appointments continues.

5.15 On 22nd March he attended A&E as a result of having run out of fast acting insulin. He was admitted into SRFT. The following day he was seen by a Diabetes Advanced Practitioner but became abusive when questioned about missed appointments. He self-discharged but was given two Levemir pens²⁰ to take home. Home delivery of insulin was arranged.

¹⁹ On 3rd February 2017. This was not a multi-disciplinary team meeting held under the auspices of the Salford SAB self-neglect guidance but was a referral meeting.

²⁰ A prefilled insulin pen

- 5.16 Andy attended a GP examination on 26th April and 16th June 2017 but *failed to attend GP appointments* on 15th June and 26th June. Andy's sister, brother and step-father continue to emphasise that Andy felt very tired as a result of his ill-health and the dialysis treatment in particular. At times he could hardly walk. They believe that his failure to answer his door or to keep appointments should be understood in this light. They have also stressed that they were not asked to assist in supporting Andy. As section 6.2.9 highlights, *involving family and friends* can be helpful.
- 5.17 On 1st May SRFT contacted GMP because Andy did not answer the door when transport called to take him to hospital for an appointment. This is the first of several occasions when the Police are asked by SRFT to conduct a welfare visit in response to *missed appointments*.
- 5.18 *Reluctance to engage* emerges from other agency accounts at this time. Housing sent a letter to Andy and his landlord on 2nd May, with officers attending the property but unable to gain access on 17th May. A second letter to both landlord and tenant was sent. Housing staff visited the property on 5th June but Andy refused them entry. A strong smell of cannabis is recorded. Andy would not engage and declined assistance and another visit. Housing staff spoke to the landlord's agent who was willing to try to engage Andy. *The case is kept open*. A follow-up call to the agent on 7th June elicits the information that Andy has been reluctant to let contractors into the house so they have been unable to progress repairs²¹. The combined chronology does not record any further follow-up concerning attempts to rectify the condition of the property in the ensuing months.
- 5.19 On 17th May GMMH send an opt-in letter following a missed appointment on 7th March, requesting contact within ten days if he would like to be seen. On 29th June a discharge letter is sent following no response. His GP is informed. On 19th May a Renal Social Worker telephoned Andy but could only leave a message.
- 5.20 On 18th July NWS transported Andy to SRFT after he had complained of a swollen throat, although all clinical observations were within normal parameters. Hospital records note some abusive swearing and threatening behaviour before he discharged himself. SRFT records also begin to note that on occasions he was not attending for dialysis.
- 5.21 Through the Renal Social Worker a referral is sent on 27th July for a Welfare Rights Worker to explore his benefits because of the same financial issues that had been recorded at the beginning of the period under review. Contact is made with Andy on 31st July. He was advised to contact the Department of Work and Pensions to claim additional benefits and to get back in contact when the necessary forms had been received for completion. In August various attempts were made to contact Andy as the benefit forms had not been completed.

²¹ Andy's sister and step-father are strongly of the view that the landlord had refused to sanction repairs to the house.

- 5.22 On 14th August at SRFT Andy saw the Dietician who recorded problems with weight loss, money and chronic illness. The combined chronology does not record what action, if any, was taken as a result of these identified problems.
- 5.23 On 15th August *his case is closed* by Housing Standards. This has been explained as an outcome following repeated attempts to gain access to the property and offers of support to Andy to help address the housing conditions with the landlord. Once again, family members have pointed out their view about the attitude of the landlord and also the difficulty that Andy often experienced in answering his door because of the impact of his ill-health and treatment for it. The case officer had also concluded that it would have been inappropriate and disproportionate to attempt to obtain a Magistrate's warrant to force entry.
- 5.24 The SRFT chronology records that in early September he missed appointments with a Social Worker who was unable to make contact with him. On 15th September he asked a Nurse to administer medication for another condition via his central line. He was told this was dangerous but he administered the medication himself. He swore and threatened staff before leaving the hospital.
- 5.25 *He did not attend* a GP appointment on 2nd October and declined a dietetic assessment at SRFT on 9th October. He did attend a chronic disease review with his GP on 10th October and a further GP appointment on 18th October when he described pain all over and received a prescription based on the GP's assessment. However, he did not answer when his GP made a home visit on 9th November.
- 5.26 On 11th October SRFT again contacted GMP because *Andy failed to attend* for dialysis. This too is becoming a *repeating pattern*. The same occurs on 9th November because Andy had not arrived for treatment and he had also missed dialysis appointments on 6th and 8th November. SRFT were aware that the GP had visited the house but had been unable to see Andy. NWS sent a rapid response vehicle. Andy was seen and advised that he would not be attending his appointments because of diarrhoea and vomiting. He was left at his home address. On 16th November he did not attend for dialysis²².
- 5.27 NWS again transported Andy to SRFT on 24th November as he was losing consciousness and vomiting. He was admitted to hospital. His blood sugars were high. The SRFT chronology records that he refused investigations and treatment, despite being told of the risks, on 28th November. He is noted as having *mental capacity* and to have understood the risks. It is unclear whether this was a formal assessment or simply a judgement that there was "no reason to doubt his mental capacity." His compliance remains limited and he is suspected of having a serious infection. He was advised not to use his dialysis catheter to administer other drugs due to the risk of infection but insisted that he would continue to do so.

²² This is a *repeating pattern*, with the combined chronology recording that on at least 20 occasions Andy did not attend for dialysis, sometimes with the reason that he felt too unwell.

- 5.28 On 6th December a *multi-disciplinary meeting* was held, with Andy present. Issues discussed included non-compliance and its impact on his health. He was reassessed by a Social Worker and agreed to receive home care services, and to referrals to MDG, Welfare Rights, Mental Health and Housing.
- 5.29 On 15th December an SRFT discharge planning note records issues regarding self-neglect, health, low mood, finance and housing. A further note on 22nd December records his agreement to referral for intermediate home support, a benefits check with Welfare Rights, and MDG for monitoring in the community, recorded as being made by ASC on 2nd January 2018. GMMH received the mental health referral on 22nd December and an assessment was attempted the following day but Andy had a visitor. He reported his mental state as fine. His room had a strong smell of cannabis. When the Mental Health practitioner returned on 25th December he refused to engage with the assessment, ostensibly because it was Christmas Day. The same practitioner attempted to complete the assessment again on 28th December but Andy *refused to engage*. Having poor balance and mobility he fell on the floor soon after getting out of bed. He began to cry and apologised to staff. He is recorded as saying that he was refusing treatment as he wanted to die. Family members see this as further evidence of how low Andy had become as a consequence of the impact of his ill-health and the treatment for it. Indeed, SRFT records note that he refused dialysis on 24th December for the same reason. Medical and Mental Health staff were concerned that he would deteriorate if he continued to reject treatment and that he was at risk of losing limbs due to vascular damage. The GMMH chronology records that his behaviours were consistent with personality disorder.
- 5.30 A further mental health assessment was attempted on 30th December but again Andy *refused to engage*. His *case was closed* and the GP informed. The GMMH chronology records that there was no reason to suspect cognitive impairment and therefore to question his *mental capacity* to make decisions. He had, however, agreed to care and support at home, which it is noted might delay his discharge depending on the time needed to make the arrangements.
- 5.31 Meanwhile, on 27th December SRFT referred Andy for a housing assessment.
- 5.32 On 30th December Andy discharged himself without waiting for services to be set up. The following day *he did not attend* for his dialysis appointment. This *pattern* is repeated on 3rd January and SRFT once again request that GMP undertake a welfare check. When the Police attended, Andy asked them to leave. An ambulance crew was unable to gain access to his home but no follow-up action appears to have been taken, discussed below (section 7.6.3).
- 5.33 Welfare Rights and Housing failed to make contact with Andy in early January, the latter service sending a letter to Andy requesting that he contact Housing Options, and his GP was refused entry to his home on 4th January 2018. The same day the ASC chronology records that he declined intermediate home care support and had stated that he was

staying with his sister. Also on 4th January he refused to attend for dialysis but he did attend on 8th January. He missed dialysis again on 12th, 18th, 22nd, 23rd, 26th and 27th January. GMP were contacted on two occasions who notified ASC and the GP, with concerns about his mental health. There is no documented action taken by the GP in response to the “vulnerable adult” referral from GMP. *The patterns continue*. On one occasion Andy told Police that he had fallen asleep.

5.34 On 9th January the GP was informed by a Pharmacist that he had failed to collect his medication since before Christmas, stating that he was too ill.

5.35 On 18th January ASC was contacted by a friend for advice about securing rehousing for Andy as he owed rent and his heating was still not working. Following reference earlier to his sister and Aunt, this is the third reference to a *family and friends network*.

5.36 On 29th January Andy was admitted to SRFT for further investigation, having complained of chest pain. At the end of the month MDG records note his consistent refusal of services despite offers of support and his being *hard to engage*. Referral to the Hospital Social Work Team is agreed but Andy does not engage with the Social Worker when they visit. A Social Worker tried again on 13th February but with the same outcome. Andy also declined a joint appointment with Housing. On 23rd February *his case was closed* by the Hospital Social Work Team, with the expectation that he would be monitored by MDG.

5.37 During February 2018 Housing practitioners also attempted to engage with Andy, including visiting him in hospital. He had not previously replied to letters. Again, he *refuses to engage* and *his case is closed* by Housing Options.

5.38 On one occasion whilst in hospital when he refused dialysis, the risks of hypokalaemia²³ including cardiac arrest are discussed with him.

5.39 Throughout February until his discharge home on 22nd, his mental health is the focus of some activity. He is recorded as reporting that he feels depressed. His *loss* of family support owing to bereavements is also recorded. He is described as hostile to a mental health review on 1st February, perceiving that different services did not help him. He is recorded as likely to experience low mood due to his chronic health problems, and as having suicidal thoughts, but as not presenting with any acute symptoms of mental illness that would affect his ability to make decisions. His long history of non-compliance is recorded as being selective and therefore suggestive of *mental capacity*. On 21st February he is discharged by GMMH back to the GP, having once again declined further involvement with mental health assessment. He is recorded as not displaying any signs of clinical depression, and as eating, drinking and sleeping well.

5.40 On 2nd March Andy was examined in A&E for shortness of breath and feeling overloaded with fluid. He was discharged with arrangements made for extra dialysis. However, on 7th

²³ Low level of potassium in the blood

March the GP was informed that he had not attended for dialysis. The GP was also informed on 29th March that he had *failed to attend* the heart failure clinic. On 20th and 21st April the SRFT chronology records that he failed to attend for dialysis. On the latter occasion SRFT once again contacted GMP. Police visited and saw Andy. He appeared dishevelled but coherent and refused all offers of help²⁴. GMP referred him to ASC. On 23rd April he refused to attend for dialysis when the regular driver called to collect him.

5.41 A major focus of activity during March and April 2018 related to Andy's financial and housing problems, triggered by a referral from his friend to ASC for assessment and to Housing for support for relocation due to defects in his living accommodation and the impact on his health. This led ultimately to Andy being registered with Salford Home Search after advice to the friend and Social Worker that Andy needed to provide identity documents which is one reason why the case had not progressed previously. It also led to a joint visit by ASC with the friend on 27th March although Andy was too unwell to contribute to an assessment. This was the first time that a Social Worker had seen the inside of Andy's home. Welfare rights and re-housing were discussed as was home care for meals/drinks. The Social Worker contacted Housing Choices on the same day about the condition of Andy's property. A further visit was arranged for 4th April 2018, which took place.

5.42 On 28th March the Housing Improvement Agency referred Andy's case back to Housing Standards so that the condition of the property could be addressed. The Social Worker followed this up and a medical form was forwarded to the friend for completion with Andy. This was completed and then submitted to the Housing Improvement Agency and Salford Home Search. Identity documentation was still required. Housing staff were now in contact with the friend who submitted identity documents for Andy on 11th April. Andy's registration with Salford Home Search was reinstated on 17th April on medical grounds. On the following day a Social Worker discussed Andy with an MDG Nurse and telephoned and sent an email to his GP.

5.43 There followed liaison between Housing staff and a Social Worker. It was agreed on 20th April that any formal action regarding Andy's house by serving a notice on the landlord would put too much pressure on his physical and mental health, and that the best course of action was to re-house him. On the same day his friend enquired about a property that Andy had bid for, which did not look ready. She apparently stressed the urgency of his case. At that point he was in fourth position for the property on Salford Home Search. On 23rd April Housing Improvement Agency agreed to contact Housing Options in the hope of getting Andy prioritised. There were further email exchanges between Housing staff and a Social Worker, the latter stressing the urgency of a move. By 23rd April Andy was first on the list for two properties. He was made an offer.

²⁴ Once again, family members point out here that Andy felt let down and frustrated; he also was exhausted by the treatment for renal dialysis in particular.

5.44 On 23rd April a Welfare Rights Worker contacted Andy's friend in order to provide assistance in completing a benefits application. She described horrible living conditions and low income. She said that the property he was renting used to be a shared house but everyone else had left and he was liable for the full rent – housing benefit was being paid at the shared room rate which would not cover half of the rent on a full sized property. There was no answer when the Welfare Rights Worker telephoned the following day to offer the friend further support.

5.45 This was 24th April 2018. A Social Worker spoke to Andy's friend who said that Andy was refusing to attend hospital. This friend subsequently contacted the Police, having discovered Andy. NWS dispatched an ambulance and AR was confirmed dead. The same day SRFT renal unit contacted GMP as Andy had not attended dialysis on this day and a welfare check was requested. GMP advised SRFT of his death.

5.46 The same day Andy was offered a property by City West Housing Trust.

6 . Evidence-Based Model of Good Practice

6.1. Reference was made earlier to research and findings from SARs that enable a model of good practice to be constructed. The model comprises four domains. In line with Making Safeguarding Personal, the first domain focuses on practice with the individual. The second domain then focuses on how practitioners worked together. The third domain considers best practice in terms of how practitioners were supported by their employing organisations. The final domain summarises the contribution that Safeguarding Adults Boards can make to the development of effective practice with adults who self-neglect. The domains are summarised here.

6.2 It is recommended that direct practice with the adult is characterised by the following:

- 6.2.1 A person-centred approach that comprises proactive rather than reactive engagement, and a detailed exploration of the person's wishes, feelings, views, experiences, needs and desired outcomes;
- 6.2.2 A combination of concerned and authoritative curiosity appears helpful, characterised by gentle persistence, skilled questioning, conveyed empathy and relationship-building skills;
- 6.2.3 When faced with service refusal, there should be a full exploration of what may appear a lifestyle choice, with detailed discussion of what might lie behind a person's refusal to engage; loss and trauma often lie behind refusals to engage;
- 6.2.4 It is helpful to build up a picture of the person's history;
- 6.2.5 Recognition and work to address issues of loss and trauma in a person's life experience;
- 6.2.6 Recognition and work to address repetitive patterns;

- 6.2.7 Contact should be maintained rather than the case closed so that trust can be built up;
- 6.2.8 Comprehensive risk assessments are advised, especially in situations of service refusal;
- 6.2.9 Where possible involvement of family and friends in assessments and care planning;
- 6.2.10 Thorough mental capacity assessments, which include consideration of executive capacity;
- 6.2.11 Careful preparation at the point of transition, for example hospital discharge and placement commissioning;
- 6.2.12 Use of advocacy where this might assist a person to engage with assessments, service provision and treatment;
- 6.2.13 Thorough care plans and regular reviews.

6.3 It is recommended that the work of the team around the adult should comprise:

- 6.3.1 Inter-agency communication and collaboration, coordinated by a lead agency and key worker, which may be termed working together;
- 6.3.2 A comprehensive approach to information-sharing, so that all agencies involved possess the full rather than a partial picture;
- 6.3.3 Detailed referrals where one agency is requesting the assistance of another in order to meet a person's needs;
- 6.3.4 Multi-agency meetings that pool information and assessments of risk and mental capacity, agree a risk management plan, and consider legal options;
- 6.3.5 Use of policies and procedures for working with adults who self-neglect;
- 6.3.6 Use of the duty to enquire (section 42, Care Act 2014) where this would assist in coordinating the multi-agency effort, sometimes referred to as safeguarding literacy;
- 6.3.7 Evaluation of the relevance of diverse legal options to assist with case management, sometimes referred to as legal literacy;
- 6.3.8 Clear and thorough recording of assessments, reviews and decision-making.

6.4 It is recommended that the organisations around the team provide:

- 6.4.1 Supervision that promotes reflection and critical analysis of the approach being taken to the case;
- 6.4.2 Support for staff working with people who are hard to engage, resistant and sometimes hostile;
- 6.4.3 Specialist legal and safeguarding advice;
- 6.4.4 Case oversight, including comprehensive commissioning and contract monitoring of service providers;
- 6.4.5 Attention to workforce and workplace issues, such as staffing levels, organisational cultures and thresholds.

6.5 SABs are recommended to consider:

- 6.5.1 The development, dissemination and auditing of the impact of policies and procedures regarding self-neglect;
- 6.5.2 Workshops on practice and the management of practice with adults who self-neglect.

6.6 This model enables scrutiny of the chronology in this case and exploration of what facilitated good practice and what acted as barriers to good practice in this case.

7 . Thematic Analysis

Working with Andy – Maintaining a Relationship

7.1. As identified in the model of good practice regarding direct work with an individual, *responses to service refusal* should be characterised by active attempts at *engagement* and exploring a person’s wishes, choices and desired outcomes, *concerned curiosity* and *relationship-building*.

7.1.1. A key feature of this case was Andy not attending for dialysis and other medical appointments, and declining to engage with practitioners who were attempting to assess and/or to meet his care and support needs.

7.1.2. As the chronology identifies, in response to referrals contact was sometimes attempted by telephone or letter, often concluding with a request that Andy make contact if he wished to opt-in to an assessment or service offer, and giving or sending leaflets for consideration or forms (to apply for welfare benefits) to complete. When agencies were new to the case, they may not have been aware of Andy’s history of not attending appointments and not responding to offers of assessment, care and support. They therefore did not identify the case as high risk.

7.1.3. This was the approach adopted by ASC when Andy did not respond to their attempts to make contact by telephone after the GP’s referral in late November 2016. As a result ASC did not make a home visit at that time. Had ASC sought more information from the GP, a different risk picture might have emerged. Salford SAB’s guidance on self-neglect advises that letters are unlikely to prove an effective way of building a relationship. Noteworthy too is the statutory guidance that accompanies the Care Act 2014²⁵ that cautions against wholesale reliance on telephone assessment other than for simple assessments.

²⁵ Department of Health and Social Care (2018) *Care and Support Statutory Guidance: Issued under the Care Act 2014*. London: The Stationery Office.

7.1.4. During the period under review a clear *pattern* emerges of the challenges of securing Andy's engagement. The downfall of opt-in letters is that agencies are none the wiser as to why someone has not engaged or attended appointments. Salford SAB's guidance on self-neglect emphasises the importance of on-going engagement with an individual in cases of significant vulnerability, not least to obtain their view of their situation.

7.1.5. At the learning event it was noted that there were a pile of unopened and therefore unread letters in the house when Andy was discovered deceased. It was also observed that he did not always respond to visiting cards pushed through the letter box. Andy's step-father knew that he would ignore letters, as had his mother, which underscores again the importance of being aware of *history* and engaging where possible with *family members/carers*. More positively, some staff used personal mobiles so that the number would come up. Andy was known not to respond to calls from "unknown" numbers.

7.1.6. There were occasions when Andy gave clues as to how he saw his situation. He is reported as having said to a renal psychologist on 8th February 2017 that he had had to deal with problems all his life and that he felt overwhelmed with information. Almost one year later, on 1st February 2018, he is reported as having told a mental health liaison worker that "you want to help me when I am here [in hospital] but when I go home I am left on my own ... in the past I have been told that I need to be proactive but I can't be expected to chase people when I feel ill and depressed. I expect people to chase me." It does not appear that these potential openings were followed up.

7.1.7. Particularly when a *repeating pattern* is discernible, assertive outreach and an exploration of a person's choices is indicated. GMMH staff can exercise discretion and undertake home visits in cases where risks are judged to be high. However, the panel and independent reviewer have heard that the criteria to help staff determine when assertive outreach would be indicated are underdeveloped.

7.1.8. Both his sister and practitioners who knew him have acknowledged that Andy could be "a very difficult character" who was often unwilling to engage. However, had a key worker been identified they might have been able to build up greater trust. At the learning event, it became apparent that Andy held healthcare professionals responsible for the death of his brother who had angioedema and that he was frightened of dying from the same condition. Not only does this highlight once again the significance of *loss, bereavement and trauma* in self-neglect cases, but it also serves as a reminder that *time and persistence* are required to begin to sensitively address someone's lived experience.

7.1.9. Sometimes Andy was engaged in discussion, for example by SRFT after failed dialysis appointments in November 2017, when alternative appointments were offered and the risks of missing treatments clearly outlined. There was also *good practice* in SRFT regarding attempts to engage, with an alert on hospital systems enabling immunology, diabetic and/or renal teams to meet him when he presented somewhere within the hospital, and deployment of particular staff members with whom he had established a relationship. On one occasion when this was done, Andy is recorded as openly admitting that he did not like dialysis and therefore sometimes did not attend. As family members have pointed out, who would like dialysis? Engagement with a renal psychologist might have proved beneficial here but Andy did not respond positively to that approach.

7.1.10. Some agencies have recognised that a more proactive or assertive outreach approach might have been beneficial. The response from Welfare Rights reflected that Andy had struggled to follow up previous advice. Responsibility was left with Andy when he might have needed more intensive support. Given that Andy did not follow up the advice given, consideration could have been given to adopting a more intensive approach, namely allocating a case worker for a face to face appointment. With an allocated case worker there would have been a process for chasing up or liaising with the referrer if Andy had not attended the appointment.

7.1.11. Analysis by the CCG also notes that it would have been good practice for the GP surgery to have contacted Andy to try to understand the reasons for his non-engagement with retinopathy screening in early March 2017 and again in early June 2017. There is a link here also to another component of good practice, namely *recording*, since the GP practice did not record whether Andy was contacted to reinforce the importance of screening as requested by letter from the service.

7.1.12. The CCG observes that there is no primary care adult DNA policy either locally or apparently nationally. In Andy's case, there was *good practice* when staff at the GP surgery took advantage of unplanned visits to the practice by Andy to record his pulse and blood pressure and/or to complete a chronic disease annual review, which included review of his diabetes and reinforcement of the importance of complying with treatment and attending his appointments. Also in his case, because of his co-morbidities and complex needs the practice considered it unwise to deregister him as a result of regular missed appointments. It would also have been good practice to use these unscheduled occasions to explore his reasons for missing appointments or indeed record these reasons if conversations had taken place.

7.1.13. On 19th October 2017 a practice nurse followed up his diabetes and recent high blood sugars in a telephone call with Andy who said he would make an appointment to attend the surgery to see the practice nurse; he appears to have recognised that he needed someone to assess his feet. There is no *record* of Andy making this appointment or of any immediate follow-up either with Andy himself or with primary and secondary healthcare professionals to address the *risks* arising from the *repeating pattern* of non-engagement.

7.1.14. A home visit was attempted on 9th November 2017 by an Advanced Nurse Practitioner and a Trainee Doctor on receipt of information that Andy had not attended a second dialysis appointment. The renal unit was informed that Andy did not appear to be at home. It was not possible to see inside his property.

7.1.15. The GP undertook a home visit on 30th November 2017 following notification by GMMH of non-engagement with mental health assessment. Andy refused to allow the GP in with the result that his mental and emotional health, and his living conditions could not be assessed, and his consent to referrals could not be obtained. Once again, *involvement of family members* might have been helpful in promoting contact with Andy. However, no-one asked family members to assist. On 4th January 2018 the GP visited the home and once again Andy would not allow access but did confirm that he would attend dialysis the following day. The renal unit was informed of the outcome of the visit, namely Andy undertaking to attend SRFT for dialysis the following day. On 17th January 2018 the GP practice received a vulnerable adult referral from GMP as a result of non-attendance for dialysis but on this occasion no action has been *recorded* by the GP surgery.

7.1.16. Home visits and reporting back to the concerned referrer represent *good practice*. However, drawing on *safeguarding literacy* and *working together* to safeguard adults at risk of harm, explored below in detail, when might repeating patterns of non-attendance coupled with foreseeable risk of significant harm prompt either a multi-agency conference or a referral recommending a section 42 enquiry?

7.1.17. One response from GMMH, when considering events around 21st February 2018, described that a comprehensive *risk assessment* would have been completed, considering risk of harm to self, harm to others, vulnerability, serious self-neglect, adult and child safeguarding, and public protection issues. As Andy fell under risk from 'serious self-neglect', repeated attempts were made to try to engage him and his case was kept open until he was discharged from hospital, despite him declining the service. Since another component of good practice in self-neglect cases is to avoid *case closure*, this represents *good practice*. However, although some

professionals were aware of Salford SAB's *self-neglect policy* and MDGs held at which Andy's case was discussed, there was no request for a section 42 enquiry in order to bring all the agencies involved together to share information about the risks and to put together a risk management plan. MDG discussions do not appear to have concluded with a risk management plan.

7.1.18. This point is picked up by GMP in their consideration of the use of the Police to undertake welfare checks when Andy did not attend for dialysis, which is clearly documented in the chronology. GMP reflected that each occasion was dealt with on an individual basis and there was no long term discussion between the police and the renal unit about how this was to be managed going forward. On the fourth occasion, the triage officer deemed that they would refer the matter to ASC. However, again there was no meeting between the agencies regarding a plan for the future. It appears that the Police referral to ASC was passed on to the GP as a notification of welfare concern rather than treated as a safeguarding alert.

7.1.19. SRFT has also commented on their use of the Police when Andy did not attend for dialysis, concluding that the processes followed when patients at risk do not attend for appointments and treatment should be re-examined.

7.1.20. Housing responded that home visits are not considered where there is no response to letters. Where a client doesn't respond to letters requesting information in relation to their application for rehousing they will be sent a 7 day letter advising them that their application will be closed in 7 days if no response is received. In Andy's case the application was closed because the home visit to him was being arranged by the social worker in hospital and Andy was refusing to speak to her. She advised she would contact Housing if he changed his mind but nothing further was heard. It is questionable whether such a blanket policy regarding home visits is appropriate, referring back to earlier comments about Salford SAB's guidance on self-neglect cases that letters are unlikely to be effective in cases of significant vulnerability.

7.1.21. On other occasions, however, standard procedures were followed, such as sending leaflets and opt-in letters, or *closing the case*, without any attempt to follow-up in other ways. Salford SAB's guidance on self-neglect advises that case closure is unacceptable without risk assessment and engagement with the individual as it exposes the person to increased and/or on-going risk of harm. Good practice (section 6) confirms this advice, which applies whether or not the case is managed through local self-neglect procedures. It is not entirely clear whether the *history* of the case was used as a check against such decisions. Arguably, these occasions represent missed opportunities to see Andy in his home environment.

7.1.22. One further *repetitive pattern* in this case involves arrangements with Pharmacy to ensure that Andy had sufficient medication and it underscores the importance of involving Pharmacists closely in cases of self-neglect. The chronology contains references to (failed) arrangements for home delivery of medication and/or to Andy's failure to collect medication in January and March 2017 and again in January 2018. On 19th July 2017 Andy ran out of medication. The CCG contribution to the review observes that, where patients have capacity, it is their responsibility to make arrangements with the Pharmacy. In this case it was known that Andy would regularly not answer the door to accept medication deliveries. This sometimes resulted in attendance at A&E. On one occasion the GP surgery arranged for immunology medication to be delivered to the GP practice in an effort to help Andy to collect his medicine, to encourage compliance and to avoid missed deliveries. Equally, as a result of poverty, Andy might not have had phone credit to make contact when his medication was running low. Overall this feature of the case does not appear to have prompted *review and re-assessment of risks*.

7.1.23. The Pharmacy contribution to the review observes that there had been medication labelled for Andy between 15th August 2016 and 24th November 2016. There was no medication labelled for Andy between 24th November 2016 and 6th March 2017. On 6th March there were tablets and boxes of insulin pens for Andy but no insulin. He was admitted to SRFT on 23rd March 2017 having run out of Levimir²⁶. This raises a question about the coordination of his medication.

7.1.24. The Pharmacy contribution also outlines what action is taken when medication cannot be delivered. A card is left, with further follow-up attempted after four weeks prior to the medication being returned to the prescriber. There is no *record* of when Andy started to fail to collect his medication.

Working with Andy – Assessing Needs, Risks and Mental Capacity

7.2 Another key component of effective work with adults who self-neglect is *assessment* – particularly of *risk* and of *mental capacity*. Salford SAB's self-neglect guidance refers to the importance of assessment, not least to tease out the significance of past *trauma* and *loss*, and the presence of social networks. A risk assessment tool is contained within the guidance, to facilitate focus on significant health issues causing risk, isolation and service refusal. In this case, risks associated with living in poverty and with suicidal ideation are also clearly present. It is noteworthy that not everyone present at the learning event was aware of the existence of risk assessment tools.

²⁶ Insulin treatment for diabetes

- 7.2.1** Andy was not visited by Citizens Advice Bureau during his first hospital stay in the period under review before he was discharged on 23rd February 2017. He was apparently reluctant to remain in hospital any longer and was refusing social work input.
- 7.2.2** In late July and early August, when there were concerns again that he was not claiming all the benefits to which he might be entitled, these were not escalated when he did not complete the necessary forms. There was no consideration at that point of whether to *use the available self-neglect policy and procedures*, or whether to suggest a *safeguarding* section 42 enquiry. When in the middle of August 2017 Andy mentioned in hospital that he had no phone credit and therefore could not access his messages, it is not clear that this information was shared with a Social Worker. It is not until the intervention of a friend that Andy's financial position begins to be addressed effectively.
- 7.2.3** Comprehensive *referrals* are a crucial component of addressing risks effectively. At the learning event it was highlighted that welfare rights staff were unaware of the extent of the risks to Andy's health and consequently his referral received a lower priority than would otherwise have been the case. He was indeed entitled to significantly higher amounts of benefit than he had been receiving.
- 7.2.4** It is that same intervention by the friend that enables movement with respect to Andy's housing needs. Indeed, this case demonstrates another feature of working with cases of self-neglect, namely the *use of family and friends* to support practitioners in engaging and working effectively with individuals.
- 7.2.5** Not all agencies had *records* of next of kin but there was some awareness of dynamics between *family* members. The impact of the friend's interventions also highlights the potential of *advocacy* but the use of advocates does not appear to have been considered in this case.
- 7.2.6** As the chronology records, Andy did not decline a social work referral to Housing when in hospital at the beginning of 2017 but progress in addressing his housing needs was not made at that time. There was another focus on his housing needs in May and June 2017, with a similar outcome. Ultimately it was the friend who facilitated movement in addressing Andy's housing needs.
- 7.2.7** As the chronology also records, at times Andy exhibited suicidal ideation. This is recorded on several occasions by SRFT, observing that he was referred but declined to speak with a renal psychologist and that he was also referred to mental health practitioners because of his low mood linked to

chronic health problems. At the learning event, practitioners who had worked with Andy, for example in SRFT, knew that he was saying that he did not care if he died but felt that, in reality, he did care. This was endorsed by his step-father. Nonetheless, the response to expressions of suicidal ideation and to this apparent paradox whilst in SRFT is not always clear. It is also known that he had experienced several bereavements. *Loss and trauma* often feature in self-neglect cases and influence how people respond to their living situation and to offers of care and support. In discussions with mental health practitioners, however, he denied thoughts of self-harming.

- 7.2.8** ASC, CCG, GMMH and SRFT, when considering the question of *mental capacity assessment*, have stated that there was no reason to doubt his capacity, that there was no impairment of mind or brain, and that there were no apparent issues with his reasoning. Thus, for example, there was no formal assessment of his decision-making regarding acceptance of medication or treatment. Andy could clearly articulate what his medication was for and what the consequences could be if he did not accept treatment.
- 7.2.9** On at least one occasion, the chronology records, following mental health assessment, that his behaviour was consistent with personality disorder²⁷. There were other times when Andy was recorded as experiencing low mood, to be “moderately depressed” and to experience depressogenic cognitions (worthlessness, hopelessness, perceived loss of control and low self-esteem). He also had multiple physical health issues that might have affected his decision-making and engaged in substance misuse. Health professionals on the panel and at the learning event, for instance, have questioned the impact of untreated diabetes and missed dialysis appointments on his ability to make capacitous decisions²⁸. All this might have indicated the appropriateness of a formal multi-disciplinary mental capacity assessment with respect to a number of decisions that Andy faced, not least with respect to his dialysis treatment. However, there does not appear to have been a formal mental capacity assessment.
- 7.2.10** SRFT records indicate that on 15th December 2017 it was concluded that it would be beneficial to look at his self-neglect. However, this was not formally considered, possibly because there was no decision as to how this would be undertaken or by whom. This underscores the importance of *multi-agency meetings* to share information, collate a risk assessment, agree a risk management plan and appoint a lead agency and key worker. The panel and independent reviewer have also heard that working with adults who self-neglect, especially within an adult safeguarding context, is

²⁷ However, Andy was not formally diagnosed as having a personality disorder.

²⁸ There were occasions when Andy was described by professionals as unkempt and dishevelled; at other times he “did not stand out.” This fluctuation might have been explored as part of an assessment.

relatively unfamiliar for staff, for example on hospital wards. Further work to embed the learning and approach outlined in *available procedures* for working with people who self-neglect and hoard appears indicated.

- 7.2.11** Andy's health was a major risk. SRFT's responses to this review record that Andy was self-caring regarding management of his diabetes and insulin, with his case periodically reviewed by a Diabetic Specialist Nurse. This accords with an observation made by his step-father (see above), namely that Andy could be meticulous regarding medication. However, it does not appear that this risk was re-assessed when he did not attend reviews or when his diabetes was out of control. SRFT responses to this review identify that the risks of non-attendance were clearly outlined to Andy, as were the risks of misusing the line that had been inserted to facilitate his dialysis.
- 7.2.12 SRFT has also provided a detailed analysis of the arrangements for prescribing C1 – Esterase Inhibitor for his condition of hereditary angioedema. All patients are flagged on patient records to highlight that they have this rare condition and how to treat it. All patients are provided with a letter for A&E which again highlights their condition and how to treat it. They are asked to bring this letter and their medication along with them in the event of a severe attack. Specialist Nurses were actively involved in managing the approach to this treatment. Arrangements were made for delivery of his supply to his GP surgery; Andy would then be informed of the date of delivery and he would collect. It was also agreed with the receptionist at his surgery that they would also contact Andy when his medication was ready to be collected. This worked well at first. Andy had been trained to self-administer but was never fully engaging with the immunology team. He would very rarely answer the phone to numbers he would not recognise; hence the home health care delivery organisation being unable to contact him.
- 7.2.13 One final SRFT contribution regarding *risk assessment* concerning his health refers to Andy reporting weight loss on admission on 17th January 2018. It is not recorded whether this was formally assessed or how much weight he had actually lost.
- 7.2.14 GMMH has identified that, around 29th June 2017, there is no *record* of his medication (venafloxine²⁹) being reviewed before discharge, as had been recommended as required. It is possible that this was because Andy refused to speak to mental health liaison staff.
- 7.2.15 Finally, when reviewing their involvement with Andy on 21st April 2018, GMP observe that, when undertaking a welfare check, the Police record the

²⁹ An anti-depressant

circumstances of the incident, whether it is a repeating *pattern*, any legal powers used, whether the individual consents to information-sharing and the *risk* level. GMP advise that there is no risk assessment tool for the Police. On that occasion the judgement against the criteria in use was one of low risk. He had missed dialysis, appeared very dishevelled, and was refusing assistance but he appeared lucid and coherent. Given the repetitive nature of the Police involvement in this case and the serious risks to health of any of Andy's untreated conditions, perhaps the development of a formal risk assessment tool might be indicated.

7.2.16 As panel members and the independent reviewer have observed, what makes long-term on-going cases of self-neglect particularly complex to work with is their incremental nature. There may not be a major event or episode that increases concern significantly but rather "more of the same" or subtle changes. Practitioners in such cases can become desensitised to how people present. Keeping these cases continually under *review* and, through *supervision* and *multi-agency meetings* revisiting *risk assessment* and the effectiveness of mitigation plans, is good practice.

Working with Andy – Managing Transitions

7.3 A further key component of effective practice concerns *transitions*, such as *hospital discharge* arrangements. It should be acknowledged that there were occasions when Andy self-discharged, which in the case of someone with such complex needs and significant risks of harm should trigger a multi-agency meeting. Nonetheless, best practice would indicate a coordinated approach to hospital discharge involving all those agencies with a potential contribution to make to address Andy's health, housing and social care needs. The SRFT response to this review has recognised that *multi-agency meetings* prior to hospital discharge, for someone with such a complex array of needs and risks, would have been appropriate. There do not appear to have been any multi-agency meetings prior to his discharges from hospital in 2018. Indeed, his step-father related that Andy had told him that two such meetings had been cancelled because not all relevant professionals were available. As a result Andy was discharged without any care support. Such meetings could have shared all available information and agreed a risk management plan and a discharge plan, with the appointment of a lead agency and a key worker to oversee and coordinate its implementation.

7.3.1 At the learning event, the pressure on hospital beds was acknowledged, coupled with changes in practice which mean that Occupational Therapists no longer visit the person's home to check its suitability and, if necessary, consider alternative arrangements. Had a visit been undertaken the full extent of the conditions within which Andy was living would have become

apparent³⁰. However, some indication of his living conditions was known to at least some of the agencies involved and a multi-agency discharge planning meeting might have discussed the risks to his health and wellbeing of Andy returning home without a plan to address this aspect of his case.

- 7.3.2 Good practice principles surrounding transitions from hospital to home include effective communication between health and social care practitioners and between community and hospital-based staff in order to prevent readmission and coordinate person-centred support.³¹ Good practice then recommends that hospital and community-based multi-disciplinary teams should work closely together to provide coordinated support, identifying and seeking to manage factors that could prevent safe discharge and/or trigger readmission. Those at risk of readmission should be visited at home within 72 hours of discharge, with plans in place to address on-going health and social care support needs, including those relating to activities of daily living and social/emotional wellbeing.
- 7.3.3 The panel and the independent reviewer have concluded that a review of case transfers between hospital and community teams would be appropriate, responding to learning from this case.

Working with Andy – Reviewing Complex Needs

7.4 Finally in relation to direct practice with Andy, it was known to some practitioners involved in the case that he was using illegal drugs. He was also being prescribed a range of drugs for treating his physical illnesses and depression. It is unclear whether and the extent to which the interaction between these different drugs was *reviewed*. Additionally, on reviews, the panel and independent reviewer have questioned whether, following MDT and MDG meetings that did occur, the agreed frequency for *review* of his case was adequate.

- 7.4.1 Equally, whilst the MDT meetings when Andy was in hospital were opportunities to consider his complex health needs in the round, as opposed to separately, thereby demonstrating “parity of esteem”, it is unclear how the focus on the totality of his healthcare needs was to be maintained in the community. Thus, GMMH looking at his mental health as an individual issue may have assessed case priority to be lower than if his mental health was seen alongside his other needs, both physical health, financial and housing.

³⁰ The panel and independent reviewer have seen photographs of Andy’s accommodation, provided by his sister and taken after he had died.

³¹ NICE (2015) *Transition between Inpatient Hospital Settings and Community or Care Home Settings for Adults with Social Care Needs*.

Agencies Working Together – Use of Policies and Procedures

7.5 Moving from direct practice with the adult at risk to a focus on the team around the adult, one core component of effective practice is the *use of policies and procedures*. Salford SAB has published procedures for working with adults who self-neglect, launched in March 2017, part-way through the time period under review in this case. There were many occasions when consideration should have been given to using these procedures, for example when Andy did not respond to offers of support regarding his financial and housing difficulties. However, ASC, SRFT and GMMH have recognised that this did not happen, possibly because practitioners were unaware of what the procedures advised or required.

7.5.1 There was a multi-disciplinary team meeting in SRFT in early December 2017 at which Andy was present (paragraph 5.28). Advice was given to Andy about his treatment and referrals agreed to address his housing and financial needs. However, this meeting was not initiated under Salford SAB's self-neglect guidance, where multi-disciplinary team meetings are advised when an individual has needs relating mainly to social support.

7.5.2 The SRFT response to this review observes that a policy on patients who do not attend appointments was followed. However, it would benefit from review given that it refers to contacting the Police in such instances and that approach may not always be appropriate.

7.5.3 ASC has advised the review that a written policy is required for situations when potential service users do not respond to approaches offering assessment following referrals. Such a policy should also cover ensuring that the referrer is aware of the outcome of their referral.

7.5.4 There does not appear to have been any use of escalation policies. The panel and independent reviewer have concluded that consideration should be given to clarifying escalation pathways.

7.5.5 In summary, whilst there may have been occasions when Salford SAB's documentation on self-neglect was considered, for example, by social work staff based in SRFT, the policy and procedures do appear insufficiently embedded in practice across agencies. Review would also be appropriate of procedures relating to escalation of concerns and response to dis-engagement that may result in significant harm.

Agencies Working Together – Understanding and Using Adult Safeguarding Pathways

- 7.6 Another component for effective practice by the team around the adult at risk is *safeguarding literacy*. When reviewing practice in the final weeks of his life, ASC has observed that there does not appear to have been any consideration of conducting a section 42 enquiry. Earlier in the chronology it has been suggested that there was no evidence to warrant such consideration. However, section 42 enquiries should be considered where someone has care and support needs, is experiencing or is at risk of abuse and/or neglect (including self-neglect) and, as a result of their care and support needs, is unable to protect themselves from such abuse or neglect (including self-neglect). In the period under review it is difficult to identify a time when these criteria would not have been met.
- 7.6.1 It has been suggested, for example by SRFT, that some practitioners are unsure how to respond in self-neglect and other cases where an individual appears to have mental capacity to take relevant decisions. Hospital staff may have been unsure whether to refer Andy to adult safeguarding.
- 7.6.2 It is important to note that a person's consent to an adult safeguarding referral recommending a section 42 enquiry is not required. The GMP response to this review records that a referral to ASC on 21st April was made in his best interests because he did not consent. If the referral was for a social care assessment, then his consent is required unless he is deemed to lack mental capacity in that respect. If the referral was designed to trigger an adult safeguarding investigation, consent is not required. This illustrates the importance of other components of effective practice, namely *legal literacy* and clarity within *referrals* about what is being requested and why.
- 7.6.3 The NWAS contribution to the review comments that there were four call-outs prior to Andy being found deceased. No notifications of concern were made, nor was information shared with ASC. On 18th July 2017 his blood sugars were high, indicative of non-compliance with his insulin regime. This would have been an opportunity to explore further support for his medical conditions and self-neglect. On 24th November 2017 his home was cluttered, with evident hoarding. He apparently stated that he was not taking his insulin as prescribed and that he had no means of checking his blood sugar level. He also stated that he was not complying with dialysis. The NWAS submission concludes that this was a missed opportunity to discuss safeguarding concerns with Andy and to refer him. Activating an MDG using Salford SAB's self-neglect guidance or notifying adult safeguarding formally of a safeguarding concern could have been considered.
- 7.6.4 All NWAS staff receive level 2 adult safeguarding training and self-neglect is covered. However, specific SAB policies may not be familiar to ambulance crews because of regional variability.

- 7.6.5 Awareness and use of section 42 (Care Act 2014) might have enabled a greater degree of coordinated multi-agency working together than was actually achieved in this case. The panel and independent reviewer have concluded that Salford SAB might review its guidance about when to use this legislative provision.

Agencies Working Together – Multi-Agency Meetings

- 7.7 This leads naturally into analysis of this case against a further component of effective practice, namely *working together*. Salford SAB's self-neglect guidance advises that multi-agency meetings are helpful in complex cases of high risk. They provide a means to coordinate actions. In this case such meetings could have brought Police, Housing, SRFT, ASC, GMMH and the GP together to assess risk and agree a risk management plan. As the guidance further advises, the focus should be on person-centred engagement and risk management, with moderate and significant risks actively monitored.
- 7.7.1 Whilst Andy was in hospital, multi-disciplinary team meetings did take place but none were initiated under Salford SAB's self-neglect guidance. In February 2017, one involved a Dietician, Diabetes Specialist Nurse, the Heart Failure Service, Podiatry and Mental Health Liaison. Another, on 6th December 2017, took place with Andy present and involved a Renal Consultant, Immunology Consultant, Dialysis Unit Registrar, Diabetes Nurse, Social Worker, Ward Manager, Renal Staff Nurse and Immunology Staff Nurse.
- 7.7.2 Referring back to *risk assessment*, the multi-disciplinary team meeting on 6th December 2017 discussed concerns about poor nutrition, the history of poor compliance with treatment and the episodes of aggression/antisocial behaviour. It was proposed to administer twice-weekly infusion of C1 esterase treatment when Andy was in the dialysis unit to remove the need for self-infusion which had proven to be intermittent. This was *good practice*. There was a clear statement made to Andy about the risks of using the dialysis catheter for self-administration of any drugs for any purpose, as the risk of sepsis (such as the current life-threatening episode) was high. It is recorded that he understood the need for a fistula to provide any prospect of long-term health, yet insisted on continuing to use the dialysis catheter - against advice - for regular C1 esterase infusions which he said would be necessary with or without prophylactic dose twice weekly on dialysis. It is recorded that Andy became extremely aggressive, with threats of violence towards staff. An approach was agreed with the objective of providing Andy with safe treatment.

- 7.7.3 As has been recognised, these meetings were coordinated by medical staff and were not convened under the auspices of the Salford SAB self-neglect procedures.
- 7.7.4 There does not appear to have been a multi-agency meeting at which all agencies with a potential contribution to make towards addressing Andy's health, housing and social care needs were present.
- 7.7.5 There are several references in the chronology and in the responses by agencies to questions asked by the panel and independent reviewer to referral to MDG, with the objective of providing AR with closer support in the community. During his hospital admission in January/February 2017, referral to MDG is agreed but there does not appear to have been a formal record of an MDG prior to December 2017. The reason for this is unclear.
- 7.7.6 The multi-disciplinary team meeting in SRFT on 6th December 2017 agreed that an MDG referral was appropriate. His case appears to have been discussed at MDG on 31st January 2018 (paragraph 5.36), with ASC, the GP, District Nurse and a Consultant present, but there is no evidence of the original referral or outcome in GP *records*. At the learning event it was stated that the outcome included review in three months and that Andy appeared to have capacity to refuse treatment. In any event Andy did not engage with the Social Worker and this did not prompt escalation of concern.
- 7.7.7 On 23rd February 2018 Andy's case was closed by the hospital social work team and referred to MDG for monitoring. His case was discussed by a Social Worker and MDG Nurse on 18th April 2018 (paragraph 5.42). When Salford SAB's guidance refers to the inappropriateness of case closure without risk assessment and meaningful engagement with the person, it is questionable whether this approach was sufficient in a context of on-going risks.
- 7.7.8 This approach does not appear to have facilitated the involvement of the GP, Community Social Work or Housing in multi-agency meetings designed to agree a coordinated approach to meeting Andy's health, housing and social care needs. At the learning event it was also pointed out that Pharmacists are not routinely included in MDG meetings and yet would have a significant contribution to make. Pharmacists knew that Andy was often unkempt, to such an extent that it was thought that he might have been living on the streets, and that his responses to arrangements to receive his medication were erratic and inconsistent. The panel and independent reviewer understand that if Pharmacists have concerns, these are sent to the relevant GP surgery. It is unclear whether these concerns are actually seen by GPs and equally unclear, referring back to *safeguarding literacy*,

what might prompt Pharmacists to refer cases as an adult safeguarding concern.

- 7.7.9** The importance of involving Housing practitioners is illustrated by the complexity facing individuals when seeking to obtain a different property in which to live and/or to address standards of their privately rented accommodation. Someone with Andy's complex needs would have needed considerable assistance. This might have been one occasion when appointing a Care Act advocate was considered but the contribution of *advocacy* for someone with difficulty in engaging does not appear to have been considered.
- 7.7.10** Someone in Andy's position could be referred to the council's Housing Choice Team who can assist with registering / offering support and bidding on behalf of clients. Each client, if a homelessness case is taken on, would be allocated a Housing Options Advisor who can place bids on behalf of customers and arrange a call back for them to be registered onto Salford Home Search. Sometimes a client in this position may already have a Support Worker / Social Worker with whom Housing practitioners could liaise. Those individuals with some support needs around accessing accommodation can also be referred to the Supported Tenancies Team. This architecture might have worked more effectively for Andy had Housing practitioners been routinely involved in multi-agency meetings.
- 7.7.11** The panel and independent reviewer understand that a Housing Officer is now located within SRFT. Such co-location might assist with *hospital discharge* planning in future.
- 7.7.12** Welfare Rights, in reviewing their involvement with Andy on 31st July 2017, conclude that correct advice and appropriate offers of assistance were given. However, given that Andy did not act on this advice or initiate further contact, it would have been more appropriate to have a more intensive approach and to have allocated him to a case worker for a face to face appointment at that point. With an allocated case worker there would have been a process for chasing up or liaising with the referrer if Andy had not attended the appointment.
- 7.7.13** The chronology clearly identifies those instances when SRFT requested GMP to undertake a welfare check because Andy had not attended for dialysis. The GMP response to this review observes that each referral was dealt with on an individual basis and there was no long term discussion between the Police and the Renal Unit about how this was to be managed going forward. On the fourth occasion, the triage officer deemed that they would refer the matter to ASC but that referral was not judged as requiring an adult

safeguarding (section 42 enquiry) response. Once again there was no meeting between the agencies regarding a plan for the future.

- 7.7.14** The CCG suggests that some clarification would be helpful regarding terminology relating to MDG and MDT meetings. In Salford SAB's self-neglect guidance an MDG is advised where needs relate mainly to health and an MDT is advised if needs relate mainly to social support. However, Andy's case involved multiple health and social care needs to be managed. It would be advisable to review the guidance in terms of the interface between MDGs and MDTs, and their interface with section 42 enquiries in cases of self-neglect when significant risks remain despite monitoring and risk management planning.
- 7.7.15** The CCG also recommends that referral criteria to MDG require further exploration in Salford. The GP surgery may have been under a misapprehension that referrals to MDG were only for people aged over 65³². With reference back to the *repeating pattern of non-engagement*, and to *working together* and *safeguarding literacy*, greater use of escalation to MDG might have been appropriate as a result of Andy not keeping hospital appointments.
- 7.7.16** Whilst it may not have been practical for the GP to have attended hospital discharge planning meetings or multi-disciplinary meetings during Andy's hospital admissions, given the significant concerns about Andy not attending appointments, not taking medications and his housing and financial position, a coordinated multi-agency plan would have been preferable rather than reliance on discharge summaries alone.

Agencies Working Together – Sharing Information

7.8 *Information-sharing* is another important component of effective work by the team around the adult. Thus, the Police could have been clearer, when notifying ASC of their concerns, whether they were referring Andy for social care support or for adult safeguarding.

- 7.8.1 In other agency responses to this review, it has been noted that SRFT Nurses could not access the notes held by the Renal Psychologist, which impedes a coordinated approach to the case.

³² This was the case up until the procedures were revised. Further dissemination of the policy therefore needs to clarify current MDG practice.

- 7.8.2 SRFT staff do not appear to have been aware that it had been observed by mental health practitioners that his behaviour was consistent with someone with a personality disorder. Once again, professionals meeting together to share information and to discuss management of risk would have enabled discussion of how best to approach treatment of his physical ill-health when his presentation was influenced by his mental wellbeing and when he was being treated for depression.
- 7.8.3 Welfare Rights observe that information was available in CareFirst but not routinely accessed. Using available information might have enabled staff involved to appreciate the seriousness of Andy's circumstances.

Agencies Working Together – Use of Records

- 7.9 Accurate and comprehensive *recording* also facilitates case management and working together. For example, SRFT records note that ASC was made aware on 18th January 2018 that Andy still had financial difficulties. However, the records for 14th August 2017 do not provide clarity regarding whether Social Workers were informed at that time of his stated financial difficulties.
 - 7.9.1 It has not been possible to ascertain from GP records what action was taken when letters were received, for example from GMMH, about his non-engagement with services.
 - 7.9.2 The CCG observes that there is a lack of detail within primary care records to show how staff tried to engage with Andy or respond to his refusals to attend appointments. More detailed records would help to demonstrate how primary care staff tried to engage him and would serve as a record for escalation of concerns.

Organisational Support for Practice – Staffing and Supervision

- 7.10 The third domain for effective work with adults who self-neglect is the context provided by the organisations that support the work of the team around the adult.
 - 7.10.1 In contributions to the review several agencies have commented on *workforce and workplace* issues. In reviewing their involvement around 31st July 2017, Welfare Rights comment that limited staff resources impacted on their approach to Andy.
 - 7.10.2 GMMH observe that the departure of a locum staff member was a possible reason for delay in sending out an opt-in letter in May 2017 after his earlier non-engagement.

7.10.3 SRFT comment on a longstanding vacancy for a Renal Social Worker.

7.10.4 ASC *supervision* records for December 2017 note the Social Worker's concern about Andy, especially whether he was fully aware of the risks regarding his self-neglect, and there are references to safeguarding. It is not clear, however, how *repeating patterns* were factored into this discussion and therefore to what degree different approaches to case handling were required.

Organisational Support for Practice – Accessing Advice and Support

7.11 The importance of how organisations support staff is demonstrated in the zero tolerance policy adopted by SRFT. Andy was advised regarding his behaviour whilst in the hospital and arrangements were agreed at one multi-disciplinary team member for safe treatment, both for Andy and the staff treating him.

7.11.1 However, as SRFT observes in its contribution to the review, hospital staff felt that they had little room for manoeuvre as Andy required life sustaining treatment. What might have assisted here is another component of how organisations seek to support staff working with cases of self-neglect, namely *provision of legal advice*.

7.11.2 Panel members have acknowledged that there are different organisational cultures with respect to seeking legal advice. ASC representatives have stated that there is a culture of seeking legal advice whereas SRFT representatives have noted that there is a reluctance to request such guidance. The provision of legal advice may have been helpful with respect to health and safety obligations towards staff alongside duties of care towards Andy in the face of his behaviour. It would also have been helpful when, if judged to have capacity to make decisions about his treatment, he was placing himself in a situation where the risks of significant harm were foreseeable.

7.11.3 At the learning event a sense emerged of wanting senior managers to value the work done by practitioners and operational managers, often in difficult circumstances. As this review has identified there were examples of person-centred *good practice*, for example when SRFT staff enabled him to take a shower. Opportunities for staff to debrief and reflect are important when someone dies with whom staff have attempted to work closely.

8 . Concluding Discussion

8.1. It is important for reviews to try to answer “why?” questions, to focus not just on what did or did not happen but on what facilitates good practice in respect to self-neglect and what acts as barriers that get in the way of good practice. This section therefore summarises and reflects on the key findings, with reference back to the terms of reference for the SAR (section 3).

8.2 The panel and independent reviewer have concluded as follows:

Were policies sufficient and followed? Self-neglect (section 3.1.5)

- 8.2.1 Self-neglect has been officially included in safeguarding adult arrangements only since the implementation of the Care Act 2014 on 1st April 2015. Salford SAB’s own procedures on self-neglect are more recent still, having been published in March 2017. Whilst acknowledging that these procedures are still relatively new, and therefore perhaps not fully integrated into single and multi-agency practice, nevertheless understanding of this policy change and of good practice in response to self-neglect varies amongst staff groups and Salford SAB’s recommended procedures appear insufficiently embedded across agencies in operational practice.

Were policies and procedures sufficient and followed? Escalation of concerns and mitigating the risks from non-engagement (sections 3.1.4 and 3.1.5)?

- 8.2.2 The panel and independent reviewer have concluded that there was uncertainty about pathways to follow when Andy did not engage with respect to his care and support needs, complex healthcare issues and housing conditions. Salford SAB might usefully revisit best practice with respect to following up non-attendance and non-engagement.
- 8.2.3 Similarly, there were occasions when escalation of concern would have been appropriate in response to non-engagement and the known risks to his health and wellbeing. Revisiting and disseminating protocols for escalation of concern would be appropriate.

What actions were taken regarding Mental Capacity Assessment (section 3.1.6)?

- 8.2.4 Mental capacity assessment continues to challenge practitioners, especially where capacity may fluctuate as a result of untreated serious physical ill-health coupled with mental health concerns.

Prevention of health decline (sections 3.1.7 and 3.1.10)

- 8.2.5 Workload pressures, when combined with individuals who appear to have capacity to refuse treatment and/or care and support, may result in insufficient (time for) professional curiosity and an emphasis on respecting a person's autonomy rather than persistence in raising concerns about risks of significant harm.
- 8.2.6 Resource pressures may also lead to neglect of a focus on prevention within adult safeguarding. The learning event, panel and independent reviewer have heard the question posed: "when did ASC stop undertaking welfare checks?"
- 8.2.7 This case also highlights the need for greater understanding of the links between diabetes and other chronic conditions with self-neglect and mental capacity, especially executive capacity. Diabetes and trauma are common factors in many self-neglect cases and their impact needs to be explored in each case.

How effectively did agencies work together (sections 3.1.2 and 3.1.8)?

- 8.2.8 In Salford health and social care are integrated within one organisation. This review highlights questions about the degree to which integration has been achieved, for example between secondary care and community teams, between contact point and community ASC teams, and between community health and social care teams. The circumstances reviewed here could be a case study with which to chart what good practice, working across intra and inter-agency boundaries, is expected to be for someone with Andy's complex needs and where the barriers are to achieving that degree of working together.
- 8.2.9 Similarly, and with reference back to Salford SAB's self-neglect procedures, this review raises questions about the relationship between and quality assurance oversight of MDT and MDG meetings, their terms of reference and their interface with section 42 enquiries. Where there are risks of significant harm, which are likely to arise without a mitigation plan, it is unclear who might trigger a multi-agency risk management meeting.

- 8.2.10 Working together in adult safeguarding has to involve all those with a contribution to make, including private landlords, utility companies, postal delivery workers, drivers who deliver medications, and Pharmacists. Any or all of these might have been in a position to raise concerns about Andy's circumstances. The inclusion of Pharmacists in MDT and MDG meetings would have enhanced the information available.
- 8.2.11 Learning from this review highlights that sharing detail of concerns in all referrals and holding full multi- agency meetings with all relevant agencies represented is key to shared understanding of risk and a joint approach to managing this.

How did agencies attempt to mitigate the risks from self-neglect (section 3.1.3)?

- 8.2.12 Adults who self-neglect, evident for example in unkempt appearance, might present in ways similar to others in the community. This may lead to desensitisation rather than a focus on the history of concerns in a specific case.
- 8.2.13 At the learning event some of those who worked with Andy expressed their sadness at the conditions which Andy experienced. Given his relationship history and experiences it is not surprising that he had difficulty placing trust in health and social care staff. Time is a crucial ingredient in enabling practitioners to build sufficient of a relationship to begin to explore people's life experiences, in this case involving Andy facing his own mortality. As participants in the learning event articulated, there needs to be a greater focus on loss and trauma. Adverse childhood and adult experiences, involving loss and other trauma, are known to lie behind many manifestations of self-neglect.³³ These adverse experiences can impact on people's behaviour, such as disengagement, and on their physical and mental health, including diabetes and depression. Developing a trauma lens in health and adult social care practice is indeed required.³⁴

³³ Braye, S., Orr, D. and Preston-Shoot, M. (2014) *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. London: Social Care Institute for Excellence.

³⁴ Sweeney, A., Clement, S., Filson, B. and Kennedy, A. (2016) 'Trauma-informed mental healthcare in the UK: what is it and how can we further its development?' *Mental Health Review Journal*, 21(3): 174 – 192.

Exploring links between poverty, housing, self-neglect and housing (section 3.1.9)

8.2.14 Understanding of the impact of poverty on physical and mental health and on wellbeing, and the importance of a coherent anti-poverty practice, is underscored by this case. It is known that Andy sometimes left hospital appointments in order to return home to put money in the electric metre to keep his freezer on. It is known that Andy sometimes stayed with the friend who acted as an advocate in the months before he died because of state of his own accommodation. It is known that Andy was living in poverty and that levels of family poverty are higher in Salford than the national or Greater Manchester average. “70% of Salford’s population live in areas classified as highly deprived and deprivation is significantly worse than the national average.³⁵ Recorded diabetes is significantly better than the national average but the prevalence of alcohol and drug-related harm, and the percentage of physically active adults is significantly worse.³⁶ This case underscores the importance of Salford SAB and its partner agencies engaging with work underway in Salford to tackle poverty and its impact on health and wellbeing.

9 . Recommendations

9.1. Andy’s sister, brother and step-father believe that this case demonstrates the importance of multi-disciplinary and multi-agency meetings, awareness and timely responses to people’s needs, recognition of the impact of chronic health conditions and poverty on people’s ability to keep appointments and respond to advice, and making efforts to see people in their own homes. As previously stated, they do not believe that this was a case of deliberate self-neglect.

9.1.1. Andy’s sister, brother and step-father have offered five points for the agencies involved with Andy to consider as part of the action plan to implement the findings of this review. In no particular order, they recommend that all staff should:

- 9.1.1.1 involve family members in order to assist a person to engage with appointments and meetings;
- 9.1.1.2. be aware of why people might fail to engage since this may be the result of ill-health and tiredness rather than lack of interest;
- 9.1.1.3. consider the appointment of a key worker to whom the person can relate;

³⁵ Salford City Council Annual Public Health Report: Work and Health 2016-17

³⁶ Salford Unitary Authority Health Profile 2015

- 9.1.1.4. work together rather than in isolation, ensuring that record keeping is comprehensive, accurate and up-to-date, and referrals and concerns followed-up;
- 9.1.1.5. review how medication is monitored by GPs and other healthcare practitioners.

9.2 Review of the findings and conclusions at the learning event and panel meetings resulted in the shared view that Andy's case was not unique. Interlocking systemic factors are recognisable that could, if unchecked, reappear in other cases. The recommendations that follow are designed to strengthen how agencies work together in similar cases in the future.

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

Guidance

- 9.3.1 Refines guidance on MDG and MDT meetings within the self-neglect policy.
- 9.3.2 Disseminates the self-neglect guidance through team briefings and learning and service development workshops.
- 9.3.3 Summarises expectations in a flowchart.
- 9.3.4 Develops guidance on "did not attend" cases across integrated provision.
- 9.3.5 Reviews available guidance on escalation of concerns.
- 9.3.6 Reviews guidance on assertive outreach.

Audit

- 9.3.7 Audits cases to evaluate use of the self-neglect guidance once the revised procedures have been disseminated.
- 9.3.8 Audits use of multi-agency meetings and of section 42 enquiries in self-neglect cases.
- 9.3.9 Audits the use of advocacy.

Training

- 9.3.10 Arranges for multi-agency training on mental capacity assessments, risk assessments and self-neglect, focusing on practice and on the alignment between the evidence-base on best practice and organisational and multi-agency arrangements.
- 9.3.11 Promotes training that explores the impact of chronic health conditions on self-neglect and mental capacity, especially executive capacity.

Partnership Working

- 9.3.12 Engages with NHS England on the inclusion of Pharmacists in adult safeguarding; with health, housing and social care partners on collaboration and coordination of assessments and interventions with respect to individuals with complex and multi-faceted needs, and with the Department

of Work and Pensions and partner agencies within Salford on developing an anti-poverty lens within adult safeguarding.

- 9.3.13 Reviews the learning from this case on where integration between community and secondary healthcare providers, and between health and adult social care is working well and where further work on embedding integration is necessary.
- 9.3.14 Continues to engage with Salford partners in the development and dissemination of an anti-poverty strategy.

Practice

- 9.3.15 Encourages partner agencies to adopt systems and processes that enable a person-centred approach to practice, including a focus on the impact of adverse experiences and a recognition of responses to poverty and chronic conditions.
- 9.3.16 Encourages partner agencies to “think family” and to recognise the potential contribution of informal carers in understanding and working with individuals at risk of abuse and neglect, including self-neglect.
- 9.3.17 Continues to promote an anti-poverty lens in risk assessments, healthcare interventions and assessments of care and support needs.