Waltham Forest
Safeguarding Adults Board

Safeguarding Adult Review

John

Lead Reviewer:
Alison Ridley

Submitted to the SAB: September 2017

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1. Introduction

1.1 Why this case was chosen to be reviewed

The Waltham Forest Safeguarding Adults Board (SAB) agreed that this case should be reviewed because it met the statutory criteria for a Safeguarding Adult Review (SAR) under section 44 of the Care Act 2014. John died in a fire at his home in 2016. This case highlighted the complex issues in relation to working in partnership with an adult who was understood to have mental capacity, who misused alcohol and whose behaviour involved elements of self-neglect. John funded his own package of support, so the case additionally provided a chance to explore learning related to the management of risk when an adult's support is purchased privately.

The second part of this review will take into account learning from another recent Waltham Forest SAR (Andrew) that was submitted to the SAB in June 2017 and a previous review (WD) completed in 2014, both of which focused on issues of self-neglect and alcohol misuse. The intention is to see if there are any cross-cutting themes that emerge from the three separate reviews.

1.2 Pen picture of John **DOB**: 14/07/1933

John (d.o.b. 14/07/33) was an 83 year old man. He had been born in Wales and worked as a teacher and lecturer in English language and literature prior to his retirement, and was well-travelled. John had been a long term resident of Waltham Forest. Later in life he had developed type 2 diabetes and osteoarthritis, and in 2012 his mobility decreased to the extent that he became housebound in his two bedroomed terraced house. He found it increasingly difficult to walk, and had difficulty getting up unaided. He needed a walking frame to move about the house. Due to this he re-located to the downstairs of the property and was sleeping on the settee.

Following a stay in hospital in 2015 he experienced a loss of independence, and was very reluctant to have contact with medical services. He moved to live with his daughter in south London temporarily in August 2015, while he recovered from his hospital admission, but had been very keen to return to his own property, and increasingly reluctant to engage with services.

His daughter would usually visit him about twice a month. She arranged his shopping and liaised with the care workers, who were paid for privately. The first package of personal support that was arranged broke down as Mr John was initially resistant to support workers. As his support had been arranged and funded privately Mr John had very limited intervention from statutory services.

John had been a longstanding cigarette smoker, sometimes consuming up to 100 cigarettes in three day period. He had also drunk alcohol for many years, sometimes to excess.

1.3 Review timeframe

It was decided that the critical time period to review in this case was from June 2016 shortly after John began receiving a package of care and support, until December 2016 when he died.

1.4 Terms of Reference

Waltham Forest Safeguarding Adults Board (SAB) identified that the review of this case held the potential to shed light on several key areas of practice:

a) The way in which agencies worked together to safeguard John,
b) the approach to risk assessment and risk management in the context of an adult with limited mobility, alcohol use and smoking and possible self-neglect,
c) exploration of the significance of being a self-funder in a situation where self-neglect and potential fire risks are part of the risk picture.
d) The learning from the John case should also be compared and contrasted to the learning from two related local case reviews (Mr W SCR undertaken in 2014 and the SAR (Andrew) undertaken in 2017).

1.5 Methodology

Statutory guidance requires SARs to be conducted in line with the six safeguarding principles of empowerment, prevention, proportionality, protection, partnership and accountability. In addition :

- "there should be a culture of continuous learning and improvement across the organisations that work together to safeguard and promote the wellbeing and empowerment of adults, identifying opportunities to draw on what works and promote good practice;
- the approach taken to reviews should be proportionate according to the scale and level of complexity of the issues being examined;
- reviews of serious cases should be led by individuals who are independent of the case under review and of the organisations whose actions are being reviewed;
- professionals should be involved fully in reviews and invited to contribute their perspectives without fear of being blamed for actions they took in good faith; and
- families should be invited to contribute to reviews. They should understand how they are going to be involved and their expectations should be managed appropriately and sensitively." (DoH,14:138)

This review uses a hybrid methodology and looks to identify system wide issues that the board and the partnership need to address that relate to cases similar to John.

The methodology included:

(i) all agencies completing a chronology which was integrated to form a merged chronology.
(ii) the Reviewer analysed the chronology and sought related documentation as required.
(iii) a half day workshop was facilitated for representatives of all key agency, with a particular onus on gathering data from front line staff who were directly involved in the case
(iv) involvement (as far as this is possible) with key family members

(v) analysis of two other local reviews for cross cutting themes and issues
(vi) production of a final report with questions for the SAB, to facilitate their development of an action plan.

1.6 Reviewing expertise and independence

The SAR has been led by Alison Ridley (Independent Safeguarding Consultant) who has no previous involvement with this case, or any current relationship with Waltham Forest SAB or partner agencies. Alison is an experienced lead reviewer and is accredited by SCIE and SILP as a lead reviewer.

1.7 Methodological comment and limitations

Perspectives of the family members

Attempts were made to contact John's daughter to offer her the opportunity to contribute to the review, however unfortunately she did not respond and so it has not been possible to understand the perspectives of the family in this case.

Participation of professionals

The key managers (including the care and support agency from the independent sector) involved with the case were able to participate in the workshop. The workshop included the relevant representation from local statutory services who were able to provide a strategic overview and had knowledge of how the local services usually work.

The Review Team

The workshop participants formed the Review Team assisting with relevant local data and with the development of the Appraisal of Practice and the Findings. In additional discussions were undertaken with a Senior Commissioning manager within the Waltham Forest Clinical Commissioning Group and the Head of Strategic Partnerships within the London Borough of Waltham Forest to provide an additional strategic perspective to the development of the Findings.

1.8 Structure of the report

The report has three main sections:

- The Appraisal of Professional Practice section provides an overview of what happened in this case in terms of the professional practice that took place. It clarifies the view of the Lead Reviewer and professionals at the workshop (the Review Team) about how timely and effective the help that was given to John was, including where practice was above and below expected standards.

- The Findings section which identifies the key messages of learning that have emerged from the John case.

- A brief summary of the two reviews undertaken in Waltham Forest that share some similarities to the John case; the Mr W Serious Case Review (2014) and the Andrew Safeguarding Adults Review (2017).

- A separate set of findings which have emerged from the analysis of cross cutting themes and patterns in relation to self-neglect, alcohol mis-use, reduced mobility and the risk of fire incidents, identified across the John review and two other Waltham Forest reviews (Mr W and Andrew).

2. The Appraisal of Professional Practice

2.1 Appraisal of Practice

In March 2016 the care agency were contacted by John's daughter to provide two support visits each day for John. In April John had a general health check undertaken by his GP, and it was noted that he acknowledged drinking 28 units of alcohol a week (twice the recommended consumption). Before starting to provide the support, the agency undertook a comprehensive set of assessments, including an assessment of John's needs, a risk assessment in relation to the home environment and an assessment of John's mental capacity in relation to key decisions. The assessment took place early in the day before he had drunk any alcohol. John had lost some weight in the previous months as he had not been eating well. The quality of assessments was good, and considered his smoking, potential fire risk and issues of capacity (including executive and decisional capacity). In order to reduce fire risks, the agency advised their care workers to ensure that there was no clutter in the home, that John always had an ashtray or ceramic saucer near where he smoked, and to advise the managers if they observed any burn marks.

The clear view of the managers who assessed John was that he had the mental capacity to make decisions about his support and he wanted to be in control of his decision making. A person centred care plan was developed and agreed. The agency recognised the need to build time into the package to enable the support workers to develop a relationship with John and help to manage risks, rather than just to provide practical support. This important approach in working with people who show signs of self-neglect is explored further in **Finding 1.** This was in recognition of the tendency of John to be quite resistant to the involvement of care workers. The care agency were also committed to ensuring as far as possible there was continuity in the workers who supported and build rapport with John. The Review Team recognised that this was excellent practice, as it showed a good understanding of John's particular needs and also an understanding of the importance of building relationships in cases where the adult has behaviours that include self-neglect.

John's daughter was advised by the care provider to liaise with the London Fire Brigade who promptly arranged a Home Fire Safety Visit. This was undertaken on 4th June 2016 and two smoke detectors were fitted, one on each level of the house. The Fire Fighter gave advice to John and his daughter who was present with her father for the visit. The advice included a suggestion to consider purchasing a careline (telecare) alarm. The care agency also advised John to consider a careline alarm, however John and his family chose not to pursue that option. John's specific reasons for not arranging for careline do not appear to have been explored by the Fire Fighter or the care workers, which was a potential opportunity that was missed to have gained some further insight into his thinking processes. However at this stage John was not well known to the services, his mental capacity appeared to be intact and the risk factors (e.g. extent of alcohol misuse) were not fully understood. It is understandable that his decision was accepted at this stage without further exploration. The reason for his decision is not known, but managers of the care agency suspect it could have been either influenced by financial considerations or by John's wish for privacy. Care workers also took opportunities to talk with John about the potential fire risks. However he consistently

responded by saying he understood the risks and still wished to continue smoking. This potential indicator that could signal risk factors in relation to how we support adults who show 'symptoms' of self-neglect is explored in **Finding 2.**

The care and support package began and the following week the care worker found blood on John's pillow. John said that this had occurred as a result of a fall but he refused to have any contact with his GP. The care agency updated his daughter, who advised that there was probably not a need for her father to see a doctor and confirmed that there was a first aid kit in the house.

The care workers began to build some rapport with John during this period and managed to encourage him to eat more food, so that he gained a little weight, which was a positive achievement. However concerns were raised when the care workers found smoke coming from the toaster. John had tried to toast cream crackers. The care workers advised John about the fire risk if he used the toaster for that purpose.

The following week concerns were raised further when it appeared that John was still eating very little but was drinking a considerable amount of alcohol. Cigarette burns were also found in the carpet. The care workers gave John fire safety advice and contacted John's daughter to ask whether the support hours could be increased. However the family decided not to increase the hours. His daughter said that she felt it was important for John to remain as independent as possible, and so felt that an additional visit would be counter-productive. John himself said that he did not want any additional visits as he was already reluctant to accept the two existing daily visits. The challenges for practitioners in undertaking open and forthright discussions with adults about their lifestyle choices, where these increase risks, are explored in **Finding 3.**

This was a further signal of concern that appears to have been linked to the 'symptoms' of self-neglect. Several days later at the end of June John fell again and once more refused medical attention. The care agency were concerned but did not regard the situation to have become one that they could intervene in a more directive manner. The challenge of determining how to manage risks and when a series of concerns should be considered as a potential safeguarding concern is explored in **Finding 8**.

In early July the care worker arrived at the house to find John with a wound on his leg which was bleeding. He had been vomiting and was in pain, with diarrhoea. He refused medical attention. The care worker informed his daughter. The following day the same care worker arrived and found John still unwell. The care worker felt sufficiently concerned by his presentation to contact her managers and the decision was taken to override John's wish. The care worker called the ambulance and contacted John's daughter. The Review Team noted that the care worker took appropriate action at this point and provided a sensitive and balanced intervention. Although John had been regarded up to that point as having mental capacity in relation to his decisions about whether or not to seek medical attention, his presentation on that day was clearly sufficiently concerning to raise fresh questions about whether John did indeed still have the capacity to make an informed decision about his involvement with medics. The paramedics tested John and found that he had low blood pressure. They were able to successfully persuade him to attend Whipps Cross Hospital, where he was admitted for tests. He was initially treated with IV fluid and blood. While he was being assessed in hospital John confirmed that he had been drinking a bottle of spirits a day for many years and had lost weight in recent months. The view of clinicians at the hospital was that John had the mental capacity to make decisions about his care and treatment.

However the Consultant noted possible cognitive impairment and advised the GP in the discharge letter to consider referring John to a memory clinic.

John remained in hospital for several days while tests were undertaken. The Consultant confirmed that he had developed severe oesophagitis (inflammation of the lining of the oesophagus), which was thought to account for the blood loss he had experienced. This had caused difficulties with swallowing, ulcers and scarring of the oesophagus, and had been worsened by the use of alcohol and cigarettes. While he was in hospital a number of other assessments were undertaken, including an OT assessment and a physiotherapy assessment. Advice was given about his mobility and a referral was made to the community OT and community Physiotherapist. While he was in hospital John agreed that he would reduce his intake of alcohol and cigarettes.

On 6 July 2016 John was discharged home. A review meeting was held between the care agency and John's daughter, which was good practice. Additional visits were suggested by the care agency but again John's daughter declined this option saying she intended to pursue daily Physiotherapy input instead. John's daughter advised the care agency of John's agreement to reduce his alcohol and cigarette intake, and that these should be rationed, with spare cigarettes and alcohol being kept upstairs out of his way. This arrangement was made between John's daughter and the care agency with the agreement of her father. However John found that after two weeks of the new regime he was unwilling to continue with reduced amounts of cigarettes and alcohol and he brought the arrangement to an end. He often said that his only pleasures in life were drinking, smoking and watching films.

There was no reason for John's daughter or the care agency to think that John lacked the mental capacity to make decisions about his smoking and drinking habits. In addition it is difficult for practitioners to feel confident in venturing into the area of assessing capacity to making individual decisions in relation to life style choices, as it raises complex ethical questions about people's rights. There are also additional challenges intrinsic to trying to assess the mental capacity of an adult who uses alcohol or drugs to excess as they are likely to have fluctuating capacity, which is particularly difficult to assess. These dilemmas are explored further in **Finding 4**. His daughter reluctantly advised the care agency to stop any rationing the alcohol and cigarettes.

The following week a member of the NELFT rehab team arrived to undertake a home assessment. John was able to stand independently from the sofa and when he held onto the rollator frame he could get up. John asked for the raisers (which had previously been installed) to be removed from his sofa as it meant that his feet were not touching the floor. The Physiotherapist explained that the raisers had been put there so that John would be in a better sitting position and that if the raisers were removed the sofa would be too low. John got angry and became verbally abusive and asked the rehab team members to leave and not return. The Review Team noted that there appeared to have been some scope for negotiation here by the therapist with John to support discussion and choice but this did not appear to have happened. The Physiotherapist concluded that John's level of mobility meant that he was not felt to be at a high risk for falls. There were no signs of mental capacity problems noted and he was eating well.

Towards the end of September a care worker arrived at the house to find John had fallen and wounded his arm. She was concerned and called an ambulance against John's wishes. His daughter was unhappy when she heard an ambulance had been called and advised the care agency not to go against her father's wishes as in her view he had mental capacity to make those decisions. The care agency were placed in a

difficult position. The view they took was at this point was that John still had mental capacity in relation to his care decisions but was making repeated unwise decisions. At the end of October a care worker arrived at the house and found John had fallen again. She contacted John's daughter who advised that in line with John's wishes medics should not be contacted. The care agency were understandably increasingly uncomfortable. This period highlights the particular challenges involved when trying to discern when mental capacity to make informed decisions is beginning to be lost. It would have been appropriate for the GP to review John at this point, however his refusal to consider contact with medics remained. This point might potentially have been an opportunity for the provider agency to contact the G.P., however without the agreement of the adult and his family, the care agency did not feel that they had sufficient reason to do this against the wishes of the service user and family member. The agency acted reasonably given the available information and prevailing circumstances, although it does highlight how difficult but important it is to be able to have open and honest conversations with adults and their families if concerns are beginning to emerge about capacity. The dilemma highlights some of the difficult challenges of discerning when symptoms of self-neglect are impacting on an adults capacity to make informed decisions are explored further in **Finding 4**.

At the end of November care workers noticed dried blood on John's head. He did not remember how he had been injured but that he did not want to see a doctor. The care worker contacted the daughter, who advised that they should not contact a doctor and instead she would take any action that was needed. Two days later on 1st December 2016 the care worker arrived to find a large amount of dark smoke coming from the house. The care worker and next door neighbour were unable to enter due to the smoke and intense heat. The London Fire Brigade and John's daughter were immediately called. The Fire Brigade responded quickly and entered the house, but sadly when they arrived they found John was already dead.

2.2 Summary of Findings in relation to the John case

Introduction

This review considers several complex areas of practice that are often inter-linked; self-neglect alcohol mis-use and addictive behaviours, looking into the responses by professionals working alongside adults who often resist interventions. The review focusses on the use of risk management frameworks and the application of the Mental Capacity Act in particularly.

Since the implementation of the Care Act 2014 the category of self-neglect[1] has been added to other categories of abuse and harm to be considered as potential safeguarding cases. The inclusion of self–neglect has posed some difficult questions for practitioners, as the nature of this complex collection of behaviours does not involve a perpetrator or incident of abuse that can be investigated. Self-neglect is a chronic issue, so it does not lend itself to the typical one off safeguarding enquiry. Additionally the ethos of Making Safeguarding Personal which is so central to safeguarding does naturally support cases of risk where the adult is deemed to have capacity (which is typical of many cases of self-neglect behaviours) and the adult choses to refuse support or intervention.

[1] Care Act statutory guidance chapter 14.17

In recognition of this, safeguarding partnerships across the country are developing approaches to provide other ways of supporting good practice both in terms of respecting the adult's needs and wishes and in terms of supporting multi-agency risk-assessment and risk management.

Working with self-neglect in Waltham Forest

In the London Borough of Waltham Forest a self-neglect policy[2] provides agencies with well researched good practice guidance and a useful flowchart to indicate the pathway to follow. There are a number of multi-agency risk forums (e.g. MARAC) where cases can be referred to, however these are run by the statutory agencies. It is less clear what colleagues from the independent sector do if cases they are concerned about do not already have regular involvement from the statutory agencies.

The Anti-Social Behaviour Risk Assessment Conference[3] (ASBRAC) is run by Community Safety Partnership and is well attended by partners (e.g. adult social care, police, housing providers, lifeline agency). The focus is anti-social behaviour, Prevent, hate crime and safeguarding. Adult Social Care representatives will provide advice and guidance, and colleagues from the independent sector can refer cases to the panel and are invited as required.

Feedback that we have received from front line staff suggests that in line with the self-neglect flowchart (in the London Borough of Waltham Forest Self-Neglect policy) cases where the adult has care and support needs and also has features of self-neglect which are generating high risks, are referred through as safeguarding concerns, irrespective of whether the adult has mental capacity in relation to their support decisions or not. However if the adult has mental capacity to make their support decisions and they actively refuse support, then Adult Social Care services still actively consider some form of support or intervention, such as monitoring, signposting or advice/guidance. Where the risks to the adult are felt to be low, interventions would be provided through care management rather than a safeguarding framework.

The definition of self-neglect in the LBWF Multi-Agency Self-Neglect Policy[4] is that the area of concern "involves any failure by an adult to take care of him or herself, which causes or is reasonably likely to cause serious physical, mental or emotional harm, or substantial loss of assets".

[2] Waltham Forest Self-Neglect Policy Dec 2016
[3] Taken from the ASBRAC protocol (Sept 2015)
[4]

Table of Findings in the John case

	Finding	Category
1.	**Assessment and support planning in relation to adults who show signs of self-neglect, should be holistic, and build in opportunities for relationship building.**	Assessment and care planning
2.	**Where an adult is prone to behaviours of self-neglect and refuses measures to reduce risk, active consideration should be given to exploring their reasons for refusal as part of the assessment process.**	Assessment and risk management
3.	**It can be particularly challenging for practitioners to openly address issues relating to the adult's lifestyle choices, even when these are associated with increased fire risk.**	Risk assessment and risk management
4.	**Practitioners can struggle to assess mental capacity and to know when to intervene to reduce risk in cases where adults' behaviours involve self-neglect and/or substance misuse**	Self-neglect and mental capacity

2.3 Finding 1: Assessment and support planning in relation to adults who show signs of self-neglect, should be holistic, and build in opportunities for relationship building. (Category – assessment and care planning)

In the case of John the Home Instead care agency demonstrated excellent practice by recognising the need for a holistic approach to assessment in order to gain a thorough understanding of his views and personality including his mental capacity in relation to decisions about his care and support arrangements. They were aware that his previous support package had broken down and he was reluctant to receive care and support, so they put additional time into the assessment process. Research[5] undertaken by Braye et al has identified best and the most effective practice in cases of self-neglect. It advises that holistic assessment should cover "observation of the individual and the home, activities of daily living, functional and cognitive abilities, nutrition, social supports and the environment …. and that interviews with significant others are important because people who are neglecting themselves often minimise their behaviours" (Braye et al p.48). In this case the care agency approached assessment in a holistic way.

In this case the support package was shaped and delivered by the care agency to allow visits of a sufficient time to enable care workers to develop a meaningful relationship with John. This kind of approach is excellent practice and is not standard, as the majority of care and support packages generally have shorter visits which focus primarily on practical, physical tasks and personal care. While this approach may be appropriate for adults with less complex and physical needs, if an adult exhibits signs of self-neglect, it is important to recognise and respond to the complex psychological needs in addition to the more obvious physical needs and risks.

[5] SCIE Report 46: Self-neglect and adult safeguarding: findings from research (September 2011) Braye, S et al

In relation to relationship building, research confirms the importance of "devoting considerable time on an ongoing basis to the gradual development of a positive relationship of trust" (Black and Osman, 2005). The focus on relationships, and especially building a therapeutic relationship .... involves a person-centred approach that listens to a person's views of their circumstances and seeks informed consent where possible before any intervention (Braye et al p.50).

Questions for the Board

a) Does the Board feel that practitioners in Waltham Forest have a good general understanding of the variety of complex interplay of history, emotional and psychological factors that are relevant when assessing an adult whose behaviours show signs of self-neglect?

b) Would the Board want to see specific emphasis in support plans to provide time for care workers to develop a relationship with the adult if they show signs of self-neglect?

c) Does the Borough have a range of care providers to use which include agencies that have a known specialist expertise of being able to work effectively alongside adults in cases of self-neglect?

2.4 Finding 2 : Where an adult is prone to behaviours of self-neglect and refuses measures to reduce risk, active consideration should be given to exploring their reasons for refusal as part of the assessment process. (Category – assessment and risk management)

In this case at an early stage in the delivery of the support package, John accepted the offer of the Fire Brigade to install two smoke alarms free of charge. He was advised by the Fire Brigade and by the care agency to consider installing a careline alarm, but he chose not to. The reasons for his decision were not explored by the care agency or the Fire Brigade, but the agency have reported that they think it was likely that his decision may have been due to either a concern about cost and/or a concern about intrusion into his privacy.

While the addition of a careline alarm might have reduced risks to some extent, the local Fire Brigade have found that in other cases when older people have had careline alarms installed they have not always used them when a fire occurred. It is not possible to know whether or not a careline alarm would have made a difference in this case.

When adults who are self-neglecting refuse measures that might help, it is important that as a starting point that care workers and/or professionals sensitively explore with the adult the reasons for their refusal. This may provide a basis for looking at alternative ways of moving forward. If the reasons are financial ones then it would seem likely that in many cases the adult may be eligible for financial assistance to purchase the careline

(or other mechanism that is being considered). However in this particular case the picture was complicated by the fact that John was funding his own care package and so would not be eligible for financial assistance.

Another aspect relating to fire risk reduction in this case was the lack of awareness amongst key professional groups about the risks associated with a combination of common factors; an adult with reduced mobility who smokes and who is treated with paraffin based emollient creams. Data collected recently by the London Fire Brigade has shown the dangers of using these creams as they increase the ferocity of a fire if one starts. Unfortunately there are very limited alternative treatment options available, but it important that the increased risks posed are fully understood by the adult and the professionals working with him/her.

Questions for the Board:

a) Does the Board feel that practitioners (including care workers in the independent sector) are guided to undertake sensitive discussions with people about the reasons they have chosen to refuse services that might reduce risks as a way of broadening their understanding of the adult's wishes and needs?

b) Could the development in Waltham Forest of Fire, Safe and Well Visits pilot offer opportunities for practitioners where appropriate to undertake those kind of sensitive discussions ?

c) How can the Board seek reassurance that agencies (including the independent sector) are up to date on guidance about fire safety in the home such as smoking, cooking, candle use and hoarding, as well as the free Fire Home Safety visits completed by the London Fire Brigade. Additionally are they aware of the benefits of linking the careline to a smoke detector rather than just to a pendant alarm as these are often not used by fire victims?

d) Is the Board assured that key health practitioners are fully aware of the risks associated with paraffin based emollient creams when they are used to treat adults who have poor mobility and smoke?

2.5 Finding 3: It can be particularly challenging for practitioners to openly address issues relating to the adult's lifestyle choices, even when these are associated with increased fire risk (Category - risk assessment and risk management)

In this case the care workers did at times undertake discussions with John about the risks associated with his wish to continue smoking and drinking, but it was clearly

difficult. John would tend to become very agitated if he felt that other people including family members were interfering with how much he drank or smoked.

The combination of poor mobility with the use of alcohol (or drugs) and cigarettes is known to be a combination of factors that increases the risk of fire incidents. However while the risks are understood, there are some difficult practice issues associated with this, which raise complex ethical questions about the adult's rights to make lifestyle choices and life state intervention.

The general approach taken by health and social care agencies in Britain to the dilemma of intervening in the lives of adults whose lifestyle choices generate risk of harm, has tended to be liberal in line with our legal and human rights frameworks. Services provided for adults who mis-use drugs and/or alcohol are voluntary and require the adult to actively opt into and engage with the service. This is in part due to adult citizens' rights to self-determination, and partly because if an adult is not actively committed to addressing their substance mis-use then the outcomes for change are poor.

Practitioners may understandably feel uncomfortable about how appropriate it is for them to intervene proactively even with advice or guidance about lifestyle choices. However it is important that risk assessments invite these uncomfortable discussions so that risk management plans can overtly address these risk factors. Even where the adult refuses to change their behaviours, it is essential that honest and open conversations take place with the adult to ensure they are fully aware of the potential consequences of these combined risk factors. Risk assessments should overtly note the causes of risk and the measures offered to reduce risk. Contingency planning is also needed (in line with the Waltham Forest Self-Neglect Policy) and arrangements that include how risk will be monitored are required. Where the adult chooses not to make changes or to accept the risk reducing measures, this should be clearly recorded as a part of the risk plan, with the full involvement of the adult and where appropriate family members.

<u>Questions for the Board</u>

a) Does the Board wish to gain assurance from individual agencies that practitioners are aware of the particular risk generated by the combination of poor mobility, alcohol mis-use and smoking?

b) Are practitioners comfortable undertaking conversations about the risk implications of certain lifestyle choices? And does the exiting Self-Neglect policy place sufficient emphasis on this task?

c) Do existing risk assessment formats in all agencies support practitioners to consider and address the factors that are known to generate an increased fire risk?

d) Do practitioners know how to minimise the risk of fire and the referral pathway to obtain information or support?

2.6 Finding 4: Practitioners can struggle to assess mental capacity and to know when to intervene to reduce risk in cases where adults' behaviours involve self-neglect and/or substance misuse (Category - self-neglect and mental capacity)

Through the period under review John was thought to have mental capacity to make his decisions. However there were times when the care workers clearly had significant concerns about whether his capacity had diminished. In particular these concerns arose on a number of occasions when care workers arrived at the house and found him injured or unwell. The most significant episode occurred in July 2016 when the care worker found him very unwell but he was still determined not to see his GP. The following day when the care worker returned she found him in a worse state and even though he was adamant that he did not want to see his GP or go to hospital, the care worker (in liaison with her manager) ignored his requests and called the ambulance.

The care workers faced making some very difficult judgements and in this case were well supported by their managers, who were available to discuss the situation with and were willing to support the care workers in the practice decision they made. This moment was one in which John's circumstances gave the care workers and their managers a greater insight into the extent to which his decision-making had been impaired by his fear of intrusion, and it enabled them to act decisively against his wishes in his best interests on the assumption that he lacked capacity. However these were rare moments.

Research into self-neglect has shown that generally working in partnership with the adult is far more effective and appropriate than trying to pressure the adult to make certain choices they do not wish to. A consistent message that has come through research is the importance of seeking to work through 'consensus and persuasion' (Payne and Gainey). Working to support the adult's rights respects their autonomy and has been shown to be more effective than trying to pressure the adult to change. Lauder et al (2005) suggest that 'excessive professional intrusiveness is more likely to alienate self-neglecting clients and may exacerbate the initial presenting problem' (Braye et al p.50)[6].

However there are differing professional and ethical standpoints on the most appropriate approach in cases of self-neglect where the adult is assessed to have capacity. In America academics Black and Osman (2005)[7] argued that a preoccupation with client self-determination and wish not to act paternalistically can risk obscuring the importance of the principle of intervening to reduce harm[8].

O'Brien et al[9] explored the dilemmas faced by practitioners in cases of self-neglect, and also noted that where the need for an individual's autonomy and personal rights are prioritised over a more paternalist approach can reduce the likelihood of proactive professional intervention being undertaken at an earlier stage in the case, even though early intervention could potentially result in a better outcome (2000, p 16).

[6] Braye et al "SCIE Report 46: Self-neglect and adult safeguarding: findings from research" 2011

[7] Black, K. and Osman, H. (2005) 'Concerned about client decision-making capacity? Considerations for practice', Care Management Journals, vol 6, no 2, pp 50–5.

[9] O' Brien et al … *O'Brien, J., Thibault, J., Turner, L.C. and Laird-Fick, H.S. (2000) 'Self-neglect: an overview', Journal of Elder Abuse & Neglect, vol 11, no 2, pp 1–19.

In line with the Mental Capacity Act in Britain, we tend to think of mental capacity in a black or white way, you either have capacity or you lack capacity. However academics have highlighted that it may be more helpful to consider decision-making capacity as a spectrum rather than a simple dichotomy (Dong and Gorbien)[10]. In this way we can remain more alert to the subtle ways that capacity can change and be impacted.

In the Serious Case Review undertaken into the circumstances of the death of WD (2014) the Lead Reviewer Dr Hilary Brown noted that the MCA and Code of Practice does not specify when to intervene to assess mental capacity when an adult at risk has made cumulative decisions that damage him or her over time (p.55). Dr Brown raised concerns about how well the test of capacity that is outlined in the Mental Capacity Act is suited to cases of self-neglect, as it was in her view "formulated to guide professionals when faced with single, well delineated decisions, specifically serious medical treatment decisions and decisions about accommodation. The assessment of a person's decision making capacity, within a narrow time frame does not do justice to the deterioration of a person's capacity over time or over the linked domains that affect their well-being, tending to create a snapshot rather than an on-going story with background and context from which a person's ability to make, and act on, decisions could be properly inferred" (p.47-48).

Adults who mis-use alcohol significantly will often also experience self-neglect. In addition to the potential co-morbidity of these issues, there are also some parallels in terms of the psychological impact of these issues on the adults mental capacity, the way that capacity can fluctuate and the way that addictive or obsessional type thinking can impact on capacity. The Mental Capacity Act (MCA) Code of Practice[11] advises that assessments should be undertaken when the adult is best able to respond, however, for some adults, capacity may be fleeting and variable depending on their alcohol or substance intake during the day.

The MCA Code of Practice provides limited guidance in relation to the assessment of fluctuating or variable capacity[12]. An individual with a condition that is progressively deteriorating may be easier to assess because the trajectory of their condition is more easily understood. An individual with a condition who has improved capacity at certain times of day provides specific 'windows' when assessment of capacity can be undertaken. However if an individual's condition and/or capacity changes in an un-predictable way, practitioners are in a far more difficult position in terms of assessment and planning.

The recent review of 27 Safeguarding Adults Reviews (SARs) that were undertaken in London since the implementation of the Care Act in 2015, found that 21 of those reviews had commented on shortcomings relating to use of the Mental Capacity Act[13]. This shows that the issue of practitioners struggling to put the MCA into practice effectively remains a widespread concern.

The addictive thinking present in adults who mis-use alcohol is usually present consistently whether or not the adult has had a drink. Addictions can be thought of as a form of compulsive disorder in which the person's thinking and control over their use of

[10] Dong, X. and Gorbien, M. (2006) 'Decision-making capacity: the core of self-neglect', Journal of Elder Abuse & Neglect, vol 17, no 3, pp 19–36.
[11] MCA Code of Practice chapter 3
[12] MCA Code of Practice 4.26
[13] "Learning from SARS: A report for the London Safeguarding Adults Board" Braye et al (July 2017)

drugs or alcohol is impaired. Where this is the case, then the practitioner needs to consider carefully how the adult's capacity to make informed decisions is being impaired.

In most areas the way that services are structured means that specialist substance mis-use services exist. While this has many advantages, it can also mean that the practitioners in other community teams have relatively little knowledge about how to work with adults who have substance mis-use issues, which can be quite challenging particularly when practitioners need to consider assessing the mental capacity of an adult who mis-uses substances.

Questions for the Board

a) In this case, the care agency managers were well informed and were accessible to their staff. The scope of this SAR did not allow for any checks to be made about how typical this excellent performance was across the local care agencies. Do the Board feel it would be worthwhile to request some checks to be undertaken by other provider agencies to assured that care workers are well supported by their managers to be able to make difficult judgements about intervening against the adult's wishes in certain circumstances of risk?

b) Does the Board feel that practitioners in Waltham Forest community teams that are not substance mis-use specialists have the right skill set and knowledge base to assist them in the task of assessing the mental capacity of an adult who uses alcohol (or drugs) to excess?

c) There are mental capacity assessment decision–making tools and some guidance available to assist practitioners, but does the Board know how effective these are and whether practitioners feel they need further support in this complex area?

3. Cross-cutting patterns that have emerged

The review has also explored the links between learning from the John case and learning that was gained in two earlier reviews within Waltham Forest; WD (2014) and Andrew (2017). There were differences in how the adults died, but there were some themes and patterns in aspects of their lives that generated high risks. All three men lived alone and showed signs of self-neglect and/or refusal of services, were mis-using alcohol, and were largely thought by the professionals working with them to have mental capacity in relation to decisions about their care, support and treatment[14]. None of the three cases were opened to safeguarding processes. The review has identified three themes that cut across either two or all three cases.

3.1 Brief summary of Waltham Forest Adult SCR (WD) undertaken in 2014

In 2014 the MCA 2005 had been implemented since 2007, so should have been understood by staff working across all agencies within adults health and social care. However there was limited understanding about self-neglect, and it was at that time (pre Care Act 2014) not a category that was incorporated within safeguarding policies and procedures. The SCR was led by Professor Hilary Brown.

Case - MR W (dob. 1938) was a man who is thought to have had a mild LD, however he had not had any formal contact with statutory services through most of his life. He lived with his mother. When she died he remained living in their home alone and began drinking alcohol. He had little contact with the local community or services, and would not respond to letters or notes left by workers. He became anxious about services following an incident when he was the victim of a scam by two thieves masquerading as officials. He resisted contact with his GP and tended to have contact with medics only if he happened to require emergency treatment. He disconnected his electricity and gas at one stage, and his living conditions deteriorated until he was living in squalor.
Professionals who had some limited contact with him (e.g. housing, amenities, GP and adult social care) assumed that he had mental capacity in relation to decisions about how he lived. He was known to use alcohol. No formal mental capacity assessment was undertaken, and no multi-agency approach was taken. MR W was found dead in 2012 (age 74).

Summary of key findings:

- Key professionals had insufficient understanding of the MCA, assessment of capacity, substance misuse in people with learning disabilities, the stigma associated with substance misuse or managing cases where the adult has capacity and is not engaging with services.
- Workers should not take reluctance to engage as a signal to close a case where the adult is at risk
- The referral process for alcohol services requiring adults to have capacity and be willing to engage is too rigid
- There is a lack of escalation processes are in place within and across agencies
- There is no mechanism to support multi-agency management of complex cases where they do not fall into safeguarding frameworks

[14] See summary chart at Appendix 8

- There is a need for substance misuse services and MH services to work more closely
- The hospital discharge process does not ensure safe discharge for adults who are at risk of harm due to DV or self-neglect.

Summary of key recommendations:

- Consider use of Alcohol Liaison Workers 24/7 at A&E
- Each GP surgery to have one GP who has some specialist knowledge re subs misuse
- LA to review contracts to ensure they have access at short notice to agencies who can undertake deep cleans.
- Develop screening tool (multi-agency) to use with adults who exhibit self-neglect and capacity issues
- Guidance for staff on what thresholds are required which need action to be taken.

3.2 Brief summary of Waltham Forest SAR (Andrew) undertaken in 2017

Lead Reviewers: Suzanne Elwick and Caroline Budden

Andrew was an independent and private man. He had long standing alcohol dependency, which he had managed for a number of years, and allowed him to work and retain a tenancy until 2014. Andrew was supported by professionals at different times; the most consistent being from Wardley Lodge supported living setting. Andrew had a long standing relationship with a drug and alcohol worker; which stemmed from an outreach service, which was decommissioned during 2016. Support was focussed on harm reduction and practical targets. He was firmly of the belief that he could stop drinking himself when the time was right.

In the spring of 2015 a fellow resident and close friend of Andrew's died suddenly and unexpectedly. This death had a profound impact on Andrew's emotional well-being and marks the onset of a steady decline in his physical and emotional well-being and his eventual death from alcohol related conditions arising from his self-neglect. During the last year of his life professionals tried to gain support for Andrew, amidst what appears to be a growing sense of helplessness. He was referred between services for his emotional well-being, self-neglect and alcohol dependency but none were able to successfully work with him to redirect his addiction or behaviours on a voluntary basis. He was always considered to have mental capacity.
Andrew remained living in the community at Wardley Lodge, latterly medically supported by a local GP until he died in hospital in February 2016 from alcohol related illnesses.

Finding1
Outside of the safeguarding framework, there are limited mechanisms, particularly when adult social care is not involved to bring together staff from across agencies, involving high risks, to plan and review work, increasing the chances of interventions being less effective.

Finding 2
It is not routine or shared practice to accept that chronic alcohol misuse is

a form of self-neglect and when this becomes a safeguarding issue, particularly when the person has capacity. This directly affects the response by professionals and the support that is offered and provided to service users.

Finding 3
People with alcohol dependency and emotional distress are left with limited options of help because services are not equipped or commissioned to provide support for both issues together which ignores the interconnected nature of people's dependency and emotional distress.

Finding 4
There is no widely used care pathway, or allocation of role or responsibility for the palliative care of self-neglecting adults who are terminally ill, as a consequence of their addictions. This leaves frontline workers trying and often not succeeding to respond appropriately, increasing the risks that people with alcohol dependencies die with little support or dignity.

3.3 Findings – the Cross Cutting Themes

Finding 5	**The ethical dilemmas about lifestyle choices raised when working with adults who self-neglect are closely linked to those raised in cases where the adult has a significant addiction, and would benefit from increased focus by practitioners and managers.**
Finding 6	**The issue of how to manage risk across agencies in response to cases of self-neglect that do not meet safeguarding criteria (or are not suited to safeguarding processes) has continued to generate difficulty for practitioners and care workers.**
Finding 7	**Practitioners need additional support and guidance to respond effectively to the complexities of assessing the mental capacity of an adult who shows signs of self-neglect and/or addictions.**

3.4 Finding 5: The ethical dilemmas about lifestyle choices raised when working with adults who self-neglect are closely linked to those raised in cases where the adult has a significant addiction, and would benefit from increased focus by practitioners and managers.

All three adults in the cases that were reviewed mis-used alcohol. Behaviours associated with self-neglect and those associated with addiction may appear separate, however both sets of behaviours tend to develop over time in response to complex and traumatic life experiences, and usually have complex psychological origins. Two moral viewpoints tend to underpin the way that these two behaviours or conditions are understood and responded to. One perspective is to see the adult as having an inability

to care for themselves, and requiring support. The other viewpoint is that the adult has made a lifestyle choice not to care for themselves. This viewpoint would tend to result in a reluctance or ambivalence about whether it is appropriate to intervene. Society at large can be quite judgemental about adults who self-neglect, but seem to judge adults who mis-use alcohol more harshly. It is useful for practitioners to reflect on their own standpoints and values in relation to these questions, as it can have a significant bearing on decisions made about intervention.

How did this feature in the three case reviews?

Mr W's case review – in this case there was a lack of meaningful intervention by the services. Mr W was seen as an adult who had the mental capacity to make his lifestyle choices. The review notes that if Mr W had been seen as an individual with a mental illness or a learning disability and as being unable to care for himself, the professionals would have been more likely to have thoroughly assessed him and he would have been less likely to have been harshly judged by professionals. One of the report recommendations Dr Brown proposed was that "all agencies should work to dispel stigma so that people suffering from addictions and the illnesses that are associated with them, are not marginalised within mainstream health services and receive health care and palliative care equitably alongside other citizens" (Recommendation 2).

Andrew's case review highlighted the links between self-neglect and chronic alcohol mis-use, noting that it is not routine practice to accept chronic alcohol misuse as a form of self-neglect, particularly if the adult has capacity (Finding 2). The finding also noted that self-neglect demonstrated by hoarding was often easier for professionals to see and name as self-neglect, whereas the effects of chronic alcohol mis-use become apparent over a long time period and could be less tangible.

In an echo of recommendation 2 in the Mr W report, the Andrew review identified that "There is no widely used care pathway, or allocation of role or responsibility for the palliative care of self-neglecting adults who are terminally ill, as a consequence of their addictions. This leaves frontline workers trying and often not succeeding to respond appropriately, increasing the risks that people with alcohol dependencies die with little support or dignity" (Finding 4).

In John's case the adult was generally assessed as having capacity, however there were occasions, particularly in the last six months of his life, when care workers instinctively felt that he had lost capacity and that his repeated refusal to seek medical assistance indicated that he was no longer making informed decisions. The care workers struggled to know how appropriate it was for them to intervene to try to reduce John's use of alcohol and cigarettes or to insist on him seeing a doctor. He was repeatedly found injured following falls that he could not explain. It seems likely these falls may have been linked to his alcohol use, however this was never addressed in a direct way with John or his family.

What is the significance for the system?

This finding highlights the ethical dilemmas that practitioners working with addiction and with self-neglect need to actively engage with. There are no easy answers to the

questions of when and how to intervene. These areas of work challenge core values, and the technicalities of how we interpret the relevant legislation. A need for supported and thoughtful reflection on the ethical issues on a case by case basis is required as a starting point to support thoughtful decision making.

Relevant actions that the Board are already planning in response to the Andrew SAR:

- To refresh the existing multi-agency self-neglect policy and bitesize video by emphasising alcohol and substance misuse as forms of self-neglect and including a positive case study example of the multi-agency approach described in finding 1.
- The multi-agency policy and bitesize guide will be re-launched at the Residential, Nursing and Domiciliary Care provider forums, at the WFSAB and any other relevant event.
- Guidance to staff in this area will be strengthened in the SGA policies and procedures.
- To work with the End of Life Care task and finish group to ensure they map current end of life provision in the borough and develop a flexible end of life care pathway which includes adults that are continuing to misuse substances in order to enable choice for those individuals.
- To host an event to launch the new end of life care pathway in the borough to practitioners and share guidance on working with adults that misuse substances through end of life care without stigma or judgement, for example, through a train the trainer session.
- Commissioners to consider how substance misuse treatment services can work with health care partners to create and promote a pathway into end of life care for substance misusing service users.

Questions for the Board

a) Does the Board feel it would be useful for practitioners to be supported to consider the ethical dilemmas involved, ideally through multi-agency discussions.

3.5 Cross-cutting Finding 6 : The issue of how to manage risk across agencies in response to cases of self-neglect that do not meet safeguarding criteria (or are not suited to safeguarding processes) has continued to generate difficulty for practitioners and care workers.

The Care Act 2014 confirmed that self-neglect is a category which can fall within the scope of safeguarding processes, however there are difficulties for staff when

considering whether or not the safeguarding criteria are met. None of the three cases considered were opened to safeguarding enquiries.

The Care Act 2014 confirmed that the eligibility criteria for section 42 safeguarding enquiries are met if the adult :

a) has needs for care or support, and

b) is experiencing or at risk of experiencing abuse or neglect and

c) is unable to protect him/herself from that harm due to his/her care and support needs.

The first two safeguarding criteria are more straightforward to meet in most cases of self-neglect. It is the third criteria that is more difficult to interpret in relation to adults who are prone to self-neglect. The safeguarding criteria requires a direct link to be made between the adult's care and support needs and their inability to protect themselves.

Even where cases are felt to meet the safeguarding criteria, the safeguarding process is not well suited to responding to chronic situations of self-neglect which need a long-term approach. An adult who is prone to self-neglect is likely to be very resistant to the involvement of professionals and so would not be likely to engage with a typical short-term safeguarding enquiry process. The 'Making Safeguarding Personal' ethos requires the choices of the adult to be central to how any safeguarding intervention is undertaken. The Act confirms that "what happens as a result of an enquiry should reflect the adult's wishes wherever possible"[15].

For these reasons it is likely that a formal safeguarding process will struggle to assist effectively in reducing the risks generated for the adult, however research does support the need for a multi-agency approach[16]. It is important that local processes support practitioners to adopt an approach to supporting adults who self-neglect which is sensitive to the wishes and fears of the adult. Alternative frameworks or approaches are needed that still support practitioners to draw together a multi-agency meeting so that risk assessment and risk management can be comprehensive and be shared across agencies.

Feedback that we have received during the review process suggests that in Waltham Forest the Self-Neglect policy does effectively guide practitioners to co-ordinate a multi-agency network meeting[17] and also provides a pathway to escalate cases to the Waltham Forest Anti-Social Behaviour Conference Plus, where high risks are continuing. However it is important to ensure that this referral routes into this pathway are understood and well used by colleagues from the independent sector, particularly for cases where the statutory services are not involved.

<u>How did this feature in the three case reviews?</u>

Mr W's case (2014) was not opened to safeguarding processes and there was a lack of co-ordinated multi-agency response. The review at the time suggested that a default

[15] Care Act 2014 Statutory Guidance 14.66

[16] For a more detailed exploration of the question of how self-neglect fits or does not fit with formal safeguarding processes see chapter 4 of the SCIE Report 46 on Self-Neglect Braye et al). However note this report was written prior to the inclusion of self-neglect within statutory safeguarding processes in Britain.

[17] P.9 Waltham Forest Self-Neglect Policy

agency (Adult Social Care) should take primary responsibility if it is unclear which agency should take coordinating role (p.56).

Andrew's case (2017) was not opened to safeguarding. The review highlighted that although the Care Act 2014 has widened the reach of safeguarding to cover self-neglect in this case professionals worked in isolation or made referrals to other teams (Finding 1, p.11) rather than working in a joined up way. The review noted that a key challenge for services is the chronic nature of self-neglect, which are not usually characterised by single abusive events that lend themselves to a traditional safeguarding enquiry. Formal opportunities for information sharing and joint working were limited due to a lack of accepted practice of joint working outside of the formal framework of safeguarding. This was particularly relevant when adult social care was not involved and not taking the lead. The review highlighted the many other situations that fall outside the safeguarding criteria, where high risk is managed by services in isolation and suggested that "these situations require an alternative system wide process" (p.13).

John's case was not thought to meet safeguarding criteria by staff involved. John was assessed as having mental capacity to make decisions about his support arrangements and lifestyle choices, and he had agreed to have daily care visits (albeit reluctantly). However he particularly avoided contact with medical services, even when he was very unwell and as time went on there were questions about his capacity in this particular area of decision-making. He had high risk factors for fire risk (i.e. reduced mobility, excessive alcohol use and high use of cigarettes), but he was thought to be capable of making informed decisions relating to those risks. The judgement about his mental capacity is separate from the question of whether his situation met the safeguarding criteria, but it is central in determining what professional responses are indicated. An adult in this position would not usually be seen as an adult who requires the protection of a safeguarding process.

<u>What is the significance for the system?</u>

Although the Care Act 2014 has broadened the types of cases that can be considered for safeguarding approaches to include self-neglect, there is a lack of clarity for practitioners about when to raise a safeguarding referral in this kind of case. That is in part due to a lack of clear practice guidance that identifies how to apply the safeguarding criteria in these kind of situations, but it is also a reflection of the more significant underlying question about how useful or appropriate formal safeguarding enquiries are in responding to cases of chronic self-neglect. Alternative approaches to support information sharing and risk management are required to bring professionals together that can be initiated by statutory agencies and by colleagues in the independent sector.

<u>Actions that the Board are already planning that are relevant to this Finding</u>

In response to the Andrew Safeguarding Adults Review which was recently presented to the Board, the Board agreed to:

- Produce guidance with positive case studies including guidance on information sharing, to support multi-agency risk assessment and management in cases where there is risk but the safeguarding criteria are not met.

- The aim is to encourage practitioners to organise professionals meetings around an adult to identify a lead professional and develop a joined up approach for cases that do not involve Adult Social Care.
- This approach to multi-agency working will be included in the refreshed self-neglect bitesize guide and will link with work on the integration of Adults in to the Multi-Agency Safeguarding Hub.

Questions for the Board

a) Does the Board have a sense of how often practitioners and service users are using the multi-agency network meetings and the Anti-Social Behaviour Conferences used in cases of self-neglect?

b) Would the Board wish to gain a sense from those practitioners and service users about the effectiveness of the existing multi-agency forums?

c) Does the Board feel confident that colleagues in the independent sector are making referrals to the available multi-agency network meetings when they are needed?

3.6 Cross-cutting Finding 7: Practitioners need additional support and guidance to respond effectively to the complexities of assessing the mental capacity of an adult who shows signs of self-neglect and/or addictions.

How did this feature in the three case reviews?

In Mr W's case - In Mr W's case professionals assumed the adult had capacity, however the facts viewed after his death seemed to suggest to the Coroner and the review team that he was unlikely to have been making informed decisions. All agencies involved "laboured under the impression that Mr W had capacity to make decisions and to put them into effect. In fact it seems highly unlikely that his decisions were informed or that information had been "used and weighed up" as is required by the Mental Capacity Act 2005 (Mr W SCR p.63). In the case of Mr W the "incremental deteriorations in his circumstances did not register on the radar in the way that a one-off crisis might have done" (p.61). None of the decisions he made or did not make, were deemed significant enough to warrant a thorough assessment and nor was his ability to carry them through properly evaluated (p.49). Dr Brown noted that "adults who self-neglect do not make a specific decision not to care for themselves, but instead they will experience a gradual slide into non-action"[18].

In Andrew's case questions were raised about how far it is possible for a chronic alcohol user to be able to make informed decisions. The Mental Capacity Act advises you need to wait until a person is sober before you assess capacity, however when a person is a chronic alcohol user it could be argued that they are never sober, and that

[18] WD SCR (2014)

their ability to make informed decisions about whether to stop drinking is significantly impaired due to the addictive nature of their alcohol use. The review questioned whether a chronic alcohol user is ever in 'a space' where their addiction is not impacting on their ability to reason.

John's case also highlighted the challenges faced by professionals who are assessing the capacity of adults who use alcohol (Finding 5) due to the variable and unpredictable nature of their capacity.

What is the significance for the system?

The challenges involved in the assessment of mental capacity are linked to the wider issues that have been signalled in this review. Practitioners are struggling to respond confidently in this area of practice. The Waltham Forest Self-Neglect policy does provide some excellent guidance however in practice, the challenges inevitably remain. This issue is not only a local one, it has been highlighted in the recent review of SARs undertaken in London[19], which refers to seven SARs which did not take account of the full complexity of the factors influencing decision-making, including in one the impact of long term alcohol consumption. The review "points to the need for multi-disciplinary involvement in capacity assessments in complex circumstances" (p.19).

Questions for the Board

a) Does the Board feel that there is any scope for enhancing the existing guidance available locally to assists practitioners and managers in the assessment of capacity when adults are showing signs of self-neglect or are addicted to alcohol or drugs?

[19] "Learning from SARs: A report for the London Safeguarding Adults Board" Braye et al (July 2017),

4. Appendices

4.1 : Appendix 1 - Waltham Forest (John) SAR process and meetings

Key Meetings/Activities		
Date	**Key Activity**	**To achieve**
30.06.17	SAR Workshop for frontline practitioners and managers directly involved in the case and local agency representatives with strategic perspectives	To gather and analyse case data
July	Analysis of emerging data from John's case and comparison of learning from the key learning themes generated by the MR W's SCR (2014) and the Andrew SAR (2017), and cross reference with 2 other recent SARs undertaken in London boroughs.	To verify developing analysis of practice and systemic patterns
August 2017	Discussion of findings at One Panel	To quality assure and support development of robust findings
Sept 2017	Lead Reviewer presents report to the SAB to support the development of the action plan	To share findings with SAB and facilitate development of SAB action plan

4.2 Appendix 2 - Agency representatives who were either present at the workshop or had an advisory role in relation to the development of the report findings

Name	**Role**	**Agency**
Alison Ridley	Lead Reviewer	Independent
Fahima Khazun	Director	Home Instead Care Agency
Shenzad Rana	Director	Home Instead Care Agency
Jamie Jenkins	Borough Commander	LFB
Pat Smith	Head of Unplanned Care, Rehab and Therapy	NELFT
Mehiunnisha Pater	Team Manager	LBWF
Raylene Winter	OT	LBWF
Caroline Jackson	MPS Detective Inspector	Met Police
Allison Hamer	Detective Sergeant	Met Police
Matthew Lazard	Clinical Lead (Safeguarding)	NELFT
Jane Callaghan	Head of Safeguarding	Barts Health Trust
David Culley	Senior Commissioning	Waltham Forest CCG

	Manager	

4.3 : Appendix 3 - Summary chronology of key events

The period under review is June 2016 – December 2016

Date	Activity
16/3/16	Care agency commissioner by John's daughter to provide morning and evening visits with another agency visiting at lunchtime
5/4/16	GP health check – alcohol intake 28 units per week (twice the recommended amount)
2/6/16	Care agency undertake home environment risk assessment and advise daughter to make a referral to LFB. Care agency undertake assessment of capacity (on this date??) including decisional and executive capacity – and John is thought to have capacity.
4/6/16	LFB undertake home safety visit, fit 2 smoke detectors and give advice to John and his daughter, suggest a care line 'panic alarm' is fitted. House was clean, no sign of any alcohol issues, no concerns noted other than his mobility issues.
8/6/16	Care agency undertake second home environment assessment
13/6/16	Care commences – care worker finds blood on John's pillow – he says it was from a fall but refuses contact with medics. He tended not to trust medics or care workers.
14/6/16	Email from daughter to care agency : "Thanks for the update. If the cut doesn't look too deep and my dad is feeling ok, then we probably don't need to call a doctor. There's a first aid kit in a red bag in the bathroom in case that's of use. I'll get a phone extension lead so the phone can be reached more easily. I'll be going up on Saturday do I'll sort then. Thanks so much."
15/6/16	During this period the care workers focussed on building rapport with John and gaining his trust. John had initially been eating very little but the care workers managed to encourage him to take more food. The care worker finds crumbs of cream crackers in toaster that cause smoke – advice given to John re fire risk.
22/6/16	Care agency request additional hours. Issues- John not eating much but still drinking alcohol, cigarette burns found in carpet, advice given
26/6/16	John falls and refuses medical attention
29/6/16	John's daughter confirms they are not increasing care hours
1/7/16	Care worker finds John with leg bleeding, has been vomiting, in pain and with diarrhoea - but refusing medical attention. Daughter informed by care worker.
2/7/16	Care worker calls GP out against John's wishes – paramedics and daughter arrive. Medics confirm low blood pressure, John is persuaded to attend Whipps Cross hospital, where he is admitted. John confirms he has been drinking a bottle of spirits daily for many years and has lost weight in recent months. Consultant notes possible cognitive impairment and requests GP to make referral to memory clinic.

3/7/16	Consultant confirms severe oesophagitis (Oesophagitis is an inflammation of the lining of the oesophagus, the tube that carries food from the throat to the stomach. Symptoms include problems with swallowing, ulcers, and scarring of the oesophagus. An Occupational Therapy (OT) assessment was undertaken and advice given re mobility. John was referred to the London Borough of Waltham Forest community OT for follow up for grab rails in shower and pendant alarm. Hospital physio undertook an assessment and made a referral to community physio for follow up at home. At this point daughter and John agreed to reduce the intake of cigarettes and alcohol once he got home.
6/7/16	John discharged home – Note from care agency manager to the care workers: "John has ulcers in his throat which the hospital have said is likely down to his excessive smoking and drinking. His daughter would like you to encourage him to cut down on this. For example: before hospital admission John would have 20 cigarettes a day. She would like you to leave a box of 10 cigarettes (daily) only downstairs for the next week, then 8 daily the next week, then 6 daily the next week and so on... Likewise she would like John to have no more than one glass of sherry per day should he request some. With beer intake, she would be happy for John to drink this as long as he is eating sustainable food to compensate. Spare cigarettes, beer and sherry should be left upstairs out of John's reach. Remember that John is likely to comply because he does not want to go back into hospital again. Daughter has said she will be arranging physio input".
15/7/16	NELFT community rehab team undertake home assessment – John not deemed high risk for falls as can mobilise and transfer independently, no sign of mental capacity issues, no sign of clutter in the home. However noted that he was verbally aggressive towards his family members and his health workers. He is eating well.
25/7/16	Daughter asks carers to bring additional cigarettes for her father
26/7/16	John refuses community physio input
2/8/16	Email from daughter to care agency: My dad is low on cash and has run out of cigarettes. I'm going to put some in the post today... I want to arrange a Sainsbury's delivery for Thursday morning (cigarettes)….Could the care givers check with my dad before they buy food, that he wants it. The reason I am asking is because my dad is fussy about food and will only eat a certain type of bread that I need to order from Yorkshire.
4/8/16	Daughter sends email to Care Agency : My dad is raging about the cigarettes. Probably best to leave 100 cigarettes in top left drawer. He has full mental capacity and knows the harm it is doing to his throat, so it's his decision.
17/8/16	Daughter sends email to Care agency manager - I managed to get all the shopping bits done on Sunday and I left £200 cash in the envelope. My dad is asking me today for beer and sherry as he says he's running low. Could you ask the caregiver this evening to bring from upstairs a box of beer and some bottles of sherry.
27/9/16	Care worker finds John following a fall and wound to arm, she calls ambulance against his wishes. Daughter is unhappy and advises care agency not to go against John's wishes as he has mental capacity
30/10/16	Care worker finds John has fallen – John does not want medics contacted. Carer contacts

	daughter who advised the care agency to take no further action.
04/11/16	Call from John to London Borough of Waltham Forest. He explains that he no longer requires the involvement of an Occupational Therapist to assess / install grab rails.
29/11/16	Care worker notices dried blood on John's head – he doesn't remember how he got the cut and does not want to see a medic. Care worker contacts daughter who says that she will take any action necessary.
1/12/16	At 16:35 – neighbours heard smoke alarm going off but did not locate it At 17:30 - Care worker arrives at the house which is on fire but driven back by smoke. At 17:38 – LFB called, and then daughter called. Fire Service pronounce John dead at the scene. Cause of fire was subsequently thought to have been due to a cigarette having fallen onto a pillow which then fell under the sofa and John was unable to put it out. (emollient cream and incontinence pads)

4.4 : Appendix 4 – Chart showing key aspects and significant factors in these cases

Please note this chart examines the significant factors as they relate to the wider management of the case and the adult's wellbeing and safety over time as opposed to just looking at the factors that were significant to the specific incident cause of death.

Case Features	**Mr W (2014)**	**Andrew (2017)**	**John (2017)**
Gender	Male	Male	Male
Cause of death?	Thought to be alcohol related	Alcohol related organ failure	Fire death
Significant alcohol mis-use?	Yes	Yes	Yes
Significant smoking	Not known/ not relevant	Not known/ not relevant	Yes
Mobility	Not known/ not relevant	Not known/ not relevant	Significant factor
Self-neglect/ service refusal?	Yes	Yes	Yes
Lived alone?	Yes	Alone and in a hostel	Yes
Assumed by professionals to have mental capacity ?	Yes (though SCR concluded this was unlikely)	Yes	Yes on most occasions