

# Hampshire Safeguarding Adult Board



## Safeguarding Adult Review (SAR)

Mr. C

## Overview Report

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**Presented to Hampshire Safeguarding Adult Board December 2017**

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## 1. Introduction, Background & Circumstances Leading to the Review

- 1.1. Mr. C was a 66-year-old who had a diagnosis of mild learning disability, epilepsy and a history of psychotic depression. His early life was spent in another area of Hampshire. Mr. C had older brothers, one of whom died in childhood; his mother died when Mr. C was a younger man.
- 1.2. As an adult, Mr. C had lived independently in supported housing in the same village for many years and was well known to both the community he lived in and the care team that supported him. He had well known character traits that at times would see him barred from local shops and pubs, but then this would soon settle and he would again be welcomed. He attended church regularly and enjoyed football and cricket. He maintained longstanding relationships with workers and had a particularly strong bond with a manager at MENCAP who supported him. Mr. C's brother stated that Mr. C appeared to become unsettled after another resident who he had a good relationship moved away.
- 1.3. After a series of moves of placement, Mr. C's behaviour deteriorated, he stopped eating and drinking resulting in a deterioration in his physical health. Concerns were expressed by his care team that there may be an underlying physical cause for him not eating and drinking and losing weight. He was admitted to the local Acute Hospital Trust on 20.04.2016 for observations and diagnostic tests. He was discharged on 13.06.16 as it was felt by the hospital that his condition was due to behavioural and not physical causes. He arrived at the Nursing Care Home in a poor physical state where he received end of life care and he died four days later on 17.06.2016; the coroner recorded the medical cause of death as sepsis, pneumonia and urinary tract infection and severe malnutrition. The conclusion of the coroner at inquest was that death was due to natural causes contributed by self-neglect.
- 1.4. A safeguarding enquiry was commenced due to concerns raised that during his admission to the Acute Hospital, he had not received the necessary tests to rule out a physical health condition as a root cause of his physical presentation. There were also concerns that he was transferred to a nursing home apparently at the end of life when this was not known to those that were receiving him into their care or the community learning disability team. The safeguarding enquiry did not conclude as there was a subsequent referral for a Safeguarding Adult Review. In January 2017, a SAR Panel was set up to commence the process.

## 2. Methodology

- 2.1. The Care Act 2014 states that a Safeguarding Adults Board (SAB) must undertake reviews of serious cases in specified circumstances. Section 44 of the Care Act 2014 sets out the criteria for a Safeguarding Adults Review (SAR).
- 2.2. The Care Act 2014 Statutory Guidance states that the process for undertaking SAR should be determined locally according to the specific circumstances of individual cases.
- 2.3. This SAR was focused on the issue related to how and why Mr. C came to be discharged following a period in an acute hospital and was observed to be at the end of his life when this had not been an expected outcome. The Terms of Reference and methodology were therefore based on a proportionate learning lessons model that would produce a succinct report focused on key learning and recommendations.
- 2.4. The SAR panel agreed to use a mixed methods approach based on systems methodology. Chronologies and a completed case review tool, using an agreed template, were requested from the

agencies that had provided care to Mr. C.

- 2.5. Members of the panel, practitioners and their line managers, report authors and safeguarding leads came together for a Practitioner Reflective Workshop (PRW). Attendees at the PRW had an opportunity to review the written material prior to and during the workshop. The PRW also included group work whereby attendees identified areas where learning had occurred. In line with Care Act statutory guidance, the PRW ensured full engagement from agencies who had provided care to Mr. C and attempted to understand the systems that practitioners were working within to understand why practitioners practiced in the way that they did and how they made decisions.
- 2.6. It was also known at the commencement of this review that there had been two previous SARs related to people with learning disabilities who had physical health concerns and had spent a period of time within an acute hospital and had subsequently died. Although all three cases were very different in some aspects, HSAB had made a decision to undertake a Thematic Review of all three cases. It was therefore necessary to understand the learning in respect of Mr. C before the Thematic Review could be undertaken.

### 3. The Reviewer

- 3.1. Karen Rees is an Independent Safeguarding Consultant with a nursing background. Karen worked in Safeguarding roles in the NHS for a number of years and is completely independent of HSAB and its partner agencies.

### 4. Process and Scope

- 4.1. Full Terms of Reference and Project plan were agreed on 08.03.2017 and are included in Appendix 1. It was agreed that the scope of the review would take account of agency involvement from the time that Mr. C moved from his supported living accommodation in June 2015 to a short-term emergency and assessment unit (AU) until his death in June 2016. During the PRW, it became apparent that it was also important to focus on a key event prior to the scoping period when Mr. C was moved from a private mental health hospital back to his supported living accommodation and was therefore also included.
- 4.2. Agencies who provided information and were involved in this review are included within the Terms of Reference in Appendix 1.

### 5. Family Engagement

- 5.1. Mr. C's brother, was informed of the decision to commission a SAR. The Reviewer wrote to Mr. C's brother (to be known as 'the brother' for the purposes of this report) to encourage the family to be involved in the review. It was noted from reports prepared for the review that Mr. C was largely not in contact with his family and on occasion indicated that he had not wanted contact with them. Decisions that were significant were discussed with the brother in earlier years. The reviewer spoke to the brother by telephone as travel distance prohibited face to face contact. The brother indicated that an older brother was living abroad and that it was largely himself that dealt with day to day affairs as necessary on behalf of Mr. C following the death of their Father in 1989. The brother provided some details of his Mr. C's earlier life and added to the review where indicated. A copy of a final draft of the report was provided for the brother to comment on.

## 6. Key Phases

- 6.1. From the written material gathered from agencies and the discussions at the PRW, it became clear that the issues that provided the key elements of learning could be grouped into two areas that are set out in this section.

### Transitions

- 6.2. There were five transitions that were planned or undertaken from February 2015 until Mr. C's death; Mr. C had moved placement four times. These had happened for various reasons and from discussions at the PRW it became clear that, although these were planned transitions, they often actually happened in an unplanned way. It was acknowledged by all those involved that in hindsight this was a significant issue especially as Mr. C found any change particularly difficult and found it hard to build new relationships when workers changed. These difficulties often manifest themselves in a deterioration in behaviour. A particular trait of Mr. C was a refusal to eat and drink when he was distressed. Indeed, Mr. C was fairly particular about his food and had favourite foods that workers always knew he would eat. He was also suspicious of people who had prepared food and staff knew to leave his food and walk away rather than stay to be with him when he ate. These traits became more prominent the more moves that were undertaken. Mental capacity assessments<sup>1</sup> identified that Mr. C did not have the capacity to make decisions about where it was appropriate and safe for him to live and therefore these decisions were made in his best interests using the appropriate frameworks.
- 6.3. The brother told the reviewer that after a visit to the mental health private hospital, Mr. C did not recognise him. That, alongside the distance they lived apart, had led him to request that those that cared for him and knew him best, were best placed to make every day decisions for Mr. C. It is of note that the brother was not involved in any of the placement decisions from that time. He stated that although he had indicated devolvement as above, he would have expected, as next of kin, to be involved in decisions, or at least be informed that his brother was to move. Indeed, he told the reviewer that he had not known that his brother had moved from the mental health hospital, let alone had two further moves and an admission to hospital.
- 6.4. The following table represents transitions and key issues that they raise:

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<sup>1</sup> Under the provisions within the Mental Capacity Act (2005) when it is thought that due to an impairment of mind or brain due to illness or disability, mental capacity must be assessed and should be time and decision specific. If a person has been assessed as lacking capacity then any action taken, or any decision made for or on behalf of that person, must be made in his or her best interests.  
<http://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance>

Transition	Reason	Planning	Move	Outcome
<b>1. February 2015</b> Move from Mental Health Hospital back to supported accommodation	<ul style="list-style-type: none"> <li>No progress being made</li> <li>Not a permanent placement</li> <li>Needed to return to previous home where he had been settled.</li> </ul>	<ul style="list-style-type: none"> <li>Management at hospital had changed</li> <li>Social worker off sick</li> <li>Planning was underway</li> </ul>	<ul style="list-style-type: none"> <li>Mr. C. told going to the Supported Accommodation for a coffee.</li> <li>Worker handed envelope to carer with discharge information</li> <li>Worker left</li> </ul>	<ul style="list-style-type: none"> <li>Other resident not prepared for return</li> <li>Mr. C not prepared for return</li> <li>Behaviour escalated</li> <li>Safeguarding concerns raised</li> <li>Planned for move to assessment unit</li> </ul>
<b>2. June 2015</b> Move from Supported Accommodation to Assessment Unit	<ul style="list-style-type: none"> <li>Disengaged from support staff</li> <li>Behaviour not able to be managed</li> <li>Period of assessment for suitable alternative permanent accommodation</li> </ul>	<ul style="list-style-type: none"> <li>Assessment unit assessed and planning commenced.</li> </ul>	<ul style="list-style-type: none"> <li>Mr. C told going for a coffee</li> <li>Became violent and aggressive when realised not going home</li> </ul>	<ul style="list-style-type: none"> <li>Suggested MHA assessment but ultimately not deemed necessary</li> <li>Refusing food and drink</li> <li>Eventually became more settled</li> </ul>
<b>3. June 2015-April 2016</b> Move from Assessment Unit to permanent suitable accommodation	<ul style="list-style-type: none"> <li>Not a permanent placement</li> <li>Needed suitable onward accommodation</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of needs</li> <li>Identification of suitable accommodation</li> <li>Visits to view various options with Mr. C</li> </ul>	<ul style="list-style-type: none"> <li>Move did not happen (see transition 4)</li> </ul>	<ul style="list-style-type: none"> <li>Behaviour escalated</li> <li>Mr. C wanted to stay at Assessment Unit</li> <li>Food and drink intake reduced and eventually refused to eat and drink.</li> <li>Became unkempt</li> <li>Ongoing involvement for LD Team to support</li> </ul>
<b>4. April 2016</b> Move from Assessment Unit to Acute Hospital	<ul style="list-style-type: none"> <li>Deteriorating physical health</li> <li>Concerns there may be underlying medical reason for presentation</li> <li>Required diagnostic intervention</li> </ul>	<ul style="list-style-type: none"> <li>Staff began to work with Mr. C and LD Team on right timing for planned acute admission</li> </ul>	<ul style="list-style-type: none"> <li>Stumbled on stairs</li> <li>Became very weak</li> <li>Refused to mobilise and was on mattress on floor</li> <li>Required emergency admission</li> <li>Ambulance crew concerned about transfer as Mr. C was refusing to go to hospital</li> <li>Deemed not to have capacity to decide on need for acute admission and on advice of psychiatrist, was conveyed to hospital</li> <li>Mr. C walked to ambulance without protestation.</li> </ul>	<ul style="list-style-type: none"> <li>Mr. C unsettled in strange environment</li> <li>Known aversion to uniforms</li> <li>Various issues presented</li> <li>Refused several investigations and interventions</li> </ul>
<b>5. 13.06.2016</b> Move from Acute hospital to NCH	<ul style="list-style-type: none"> <li>Medically fit for discharge to a NCH</li> <li>Behaviour was causing concern</li> <li>Identified needed nursing care with a view to assessment for further move on if appropriate and rehabilitation possible</li> </ul>	<ul style="list-style-type: none"> <li>Various Best Interest meetings</li> <li>Discharge planning meeting requested</li> <li>Nursing Care Home assessed</li> <li>Required agreement for CHC funding- caused delay</li> </ul>	<ul style="list-style-type: none"> <li>Moved on an agreed date (no discharge planning meeting)</li> <li>After reassurance Mr. C went on stretcher in ambulance</li> <li>Mr. C was in an unexpectedly poor physical condition on arrival at NCH</li> </ul>	<ul style="list-style-type: none"> <li>Mr. C was placed on end of life care pathway</li> <li>Mr. C died 4 days later</li> </ul>

- 6.5. At the PRW it was identified that the number of transitions was necessary but that no one had recognised the cumulative effect that these plans and moves had on Mr. C and are therefore discussed further in the analysis.
- 6.6. The brother told the reviewer that he would concur that Mr. C struggled with change and that it would impact on his behaviour.

### Physical health and complex behaviour

- 6.7. As Mr. C was becoming more distressed and his behaviour was deteriorating, his eating and drinking was becoming of increasing concern to those that were supporting him.
- 6.8. Managing his physical health had been a concern in the past; Mr. C was being treated for epilepsy and anxiety. Mr C often refused treatments and medication was given covertly via a Deprivation of Liberty Safeguards authorisation<sup>2</sup>. This was in place to ensure that this was the least restrictive option but was necessary in order to maintain his physical wellbeing. As stated above, Mr. C had some specific traits regarding food and it appeared that as his distress was increasing due to the identified transitions (albeit this was not the recognised reason at the time), his food refusal was becoming more of an issue and was causing the care and support team considerable concern.
- 6.9. Mr. C was subject to Care Programme Approach (CPA)<sup>3</sup> and this process was used to good effect. All members of the care and support team from the assessment unit and the community learning disability team were involved in identifying strategies to try and manage his behaviour related to acceptance of medication and eating and drinking. The GP also received copies of his current CPA care plan and was involved in supporting diagnosis of physical health conditions.
- 6.10. Strategies included offering the types of food that Mr. C liked, monitoring what he was eating (without him being aware so as not to increase his issues with being monitored) and trying to ensure intake of high calorie food and drinks. A referral to dietetics for support was not undertaken at this point.
- 6.11. During CPA meetings, best interests were discussed on issues that it was assessed that Mr. C did not have the capacity to make decisions about. Eating and drinking was an area where Mr. C did not have capacity. i.e. he did not have capacity to understand that he needed to eat and drink to maintain his well-being and that his health could be seriously impaired if he did not have an adequate nutritional intake.
- 6.12. Despite the best efforts of the care and support team, he continued to eat and drink very little and after six weeks was becoming weak. The GP and others in the care and support team had identified that it was necessary to rule out a medical reason for his refusal to eat and this led to a discussion that Mr. C may need to be admitted to the acute hospital so plans were underway to prepare Mr. C for this.
- 6.13. Mr. C had a hospital passport with essential information within it about his likes and dislikes and the best way to approach him and communicate with him etc.

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<sup>2</sup> The **Deprivation of Liberty Safeguards** (DoLs) are an amendment to the Mental Capacity Act 2005 that apply in England and Wales. The Mental Capacity Act allows restraint and restrictions to be used – but only if they are in a person's best interests. Extra safeguards are needed if the restrictions and restraint used will deprive a person of their liberty. The Deprivation of Liberty Safeguards can only be used if the person will be deprived of their liberty in a care home or hospital. Care homes or hospitals must ask a local authority if they can deprive a person of their liberty.

<sup>3</sup> The **Care Programme Approach (CPA)** is a way that services are assessed, planned, co-ordinated and reviewed for someone with mental health problems or a range of related complex needs. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/care-programme-approach.aspx>

- 6.14. Mr. C then had a stumble on the stairs, possibly as a result of his weakness from not eating and he was on the floor on a duvet and was not able or reluctant to get up. A carer who Mr. C trusted stayed with him overnight and it was clear in the morning that he needed to be assessed in hospital. An ambulance was called but the paramedic was unsure if he should be taken to hospital as Mr. C was stating that he did not want to go. The paramedic was also concerned that there was a queue of ambulances at the hospital and that there may be considerable delay thus adding to Mr. C's distress. This resulted in a telephone call between the psychiatrist and the ambulance crew and as a result the paramedic identified that Mr. C did not have capacity to decide on his care and treatment; Mr. C was now calmer and walked to the ambulance.
- 6.15. Mr. C was admitted to the ward but refused to be examined. The hospital staff stated at the PRW that they found the hospital passport extremely helpful but the fact that Mr. C did not like people in uniforms or loud and busy places, meant that they were challenged to manage him in an environment that had all the features that made him fearful and anxious. The staff at the hospital made what reasonable adjustments they could and used advice from his carer from the assessment unit to manage various aspects of his care. The hospital did not have a Learning Disability Liaison Nurse at the time that Mr. C was an inpatient. Various members of the Community learning disability team, his social worker and the staff from the assessment unit all kept in contact with the ward and visited to offer support.
- 6.16. The following is a summary of the issues that were raised at the PRW regarding the diagnostic possibilities and the conclusions that were drawn from his time on the ward.
- 6.17. On admission Mr. C was restrained for bloods to be taken, he was prescribed anti biotics with a provisional diagnosis of a Urinary Tract infection. On occasions, he refused his medication and his cooperation with medical investigations was variable.
- 6.18. An X Ray had been undertaken and that did not show any issues.
- 6.19. Mr. C was displaying signs of aggression aimed at staff on the ward and refused various interventions and threw his food on occasions if he did not want it.
- 6.20. Mr. C did tolerate a urinary catheter in order that his urinary output could be monitored as he had been diagnosed with Acute Kidney Injury<sup>4</sup> due to his severe dehydration on admission. There was also a plan to undertake an oesophageal gastro duodenoscopy (OGD)<sup>5</sup> to rule out an obvious physical cause for the swallowing difficulties that Mr. C had said were stopping him from eating.
- 6.21. Due to the management problems that Mr. C was causing for the ward staff, the OGD was not progressed in the first instance.
- 6.22. As Mr. C became more hydrated and his kidney function showed signs of improvement the immediate concerns for his physical health were reduced. The ward staff observed, that although Mr. C was not eating well, there were foods that he would and could eat and swallow and these were foods that he would not have been expected to manage well if he had a physical reason for not being able to swallow. This, alongside the difficulties in managing an OGD with Mr. C led to the test being cancelled. There was also a suggestion of a Barium Swallow that would have been less invasive and less risky but would have still

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<sup>4</sup> The kidneys clean the blood by removing waste products. Many different conditions can lead to the kidneys not working well within hours or days. This is called acute kidney injury (known as acute renal failure in the past). Causes include: dehydration; low blood pressure; some drugs; severe infections; blockage of the waterworks (urinary tract); <https://www.nice.org.uk/guidance/cg169/ifp/chapter/Acute-kidney-injury>

<sup>5</sup> **OGD** stands for oesophago-gastro-duodenoscopy, sometimes also called a gastroscopy. An OGD test is performed for both diagnostic and therapeutic reasons. The test is commonly done with sedation. The alternative option to sedation is a local anaesthetic spray to numb the back of the throat, which can be combined with sedation if necessary. <http://www.endoscopyplus.co.uk/site/index.php?page=content&content=3636&slug=3636>



required considerable cooperation from Mr. C. Mr C was referred to the dietician and was reviewed on several occasions. It was decided that it would not be in Mr c's best interests to use other methods of feeding and therefore nutritional supplements were recommended.

- 6.23. When the decision not to proceed with OGD was discussed at the PRW, there were mixed feelings expressed. All agreed that it would not be appropriate to undertake an OGD unless it was clinically indicated due to the risks of sedation and the procedure. The disagreement was about whether the signs that Mr. C was eating some selected foods was enough to identify that the OGD and other investigations were not clinically indicated.
- 6.24. A further discussion at the PRW centred on the use of sedation to undertake medical and diagnostic investigations if necessary, when patients who lack capacity are refusing or display behaviours that prevent the procedure being carried out. All agreed that this could and should be done provided that it is a proportionate response and that a formal mental capacity assessment was undertaken and that a best Interest decision was made and recorded. This was not the contention of the discussion and disagreement. The hospital did use sedation on occasion but this was not applied consistently, and it was not clear to the community team, which investigations were being prioritised and therefore required the consideration of sedation.
- 6.25. The hospital identified that an IMCA<sup>6</sup> was necessary to support Mr. C in identifying what his wishes and feelings were. This would aid staff in making best interest decisions on medical treatment options. His family were not in contact or involved in day to day decision making and lived some distance away so an IMCA was an appropriate option. Mr. C had previously failed to engage with an IMCA in the community and there was confusion regarding the hospital IMCA role that resulted in the IMCA identifying that there was no role for her at that time.
- 6.26. The brother told the reviewer that, although he had left day to day decision making with the care team, that in fact, he did not consider this episode of care a day to day issue and that he was disappointed not to have been consulted. The brother indicated that the first he knew of his brother's admission, was when he received a letter from the IMCA. The brother contacted the hospital but was told that no information could be shared with him as he was not recorded as Mr. C's next of kin in hospital records but this was recorded as the manager at the assessment unit. The brother did convince the hospital that he was the next of kin and then details were shared.
- 6.27. By 03.05.2016 the hospital was happy that Mr. C was 'medically fit for discharge', which means that he no longer required an acute hospital bed or intervention.
- 6.28. Mr. C was not mobile though and was not engaging with physiotherapy. He could no longer return to the type of placement that he had come from and was assessed as requiring nursing care and eligible for Continuing Healthcare (CHC)<sup>7</sup> funding. It was felt that the hospital environment was probably adding to the difficulties that Mr. C was facing and it was identified that a placement needed to be found as soon as possible.
- 6.29. There were delays in the agreement for CHC funding even though a placement had been identified and the Nursing Care Home (NCH) had assessed Mr. C as suitable for their care.

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<sup>6</sup> **Independent Mental Capacity Advocate (IMCA)**: The Mental Capacity Act 2005 introduced the role of the independent mental capacity advocate (IMCA). IMCAs are a legal safeguard for people who lack the capacity to make specific important decisions: including making decisions about where they live and about serious medical treatment options. IMCAs are mainly instructed to represent people where there is no one independent of services, such as a family member or friend, who is able to represent the person. <http://www.scie.org.uk/mca/imca>

<sup>7</sup> National framework for NHS continuing healthcare and NHS funded nursing care <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

- 6.30. During the time between the NCH assessing Mr. C and the funding being agreed, the hospital recognised a further deterioration in Mr. C's physical condition. They identified that his environment was causing him distress and that was further affecting his behavioural difficulties and his eating and drinking.
- 6.31. By 07.06.2017 it is recorded in hospital records, that Mr. C had a likely infection and was clinically dehydrated again. It was agreed following consultation with a senior clinician that an alternative environment was likely to have a positive impact on Mr. C's condition. It is at this point that there was a suggestion that Mr. C was approaching the end of his life. This was not communicated to other professionals.
- 6.32. Mr. C was discharged to the NCH on 13.06.2016 in a very frail state and was placed on end of life care pathway. This had not been an expected outcome as on assessment in hospital, the NCH had identified that Mr. C would be on a rehabilitation pathway. This issue of communication regarding this deterioration in Mr. C's physical condition has remained a contentious issue and is discussed in the analysis. The NCH contacted the brother to inform him of the frailty and end of life status of Mr. C.

## 7. Thematic analysis

- 7.1. The analysis section focusses on areas where learning has occurred

### Understanding complex behaviours in Physical Health Care

- 7.2. Throughout Mr. C's adult life, those that worked with him and provided care learned about his needs and how best to meet them and used legal frameworks provided by the Mental Capacity Act and Mental Health Act to underpin care plans. Use was also made of evidence based practice and ensuring that his placement could meet his complex needs.
- 7.3. When his behaviour began to impact on his physical health and he was refusing to eat and drink, the community learning disability team and social worker along with the GP, initially believed that they could work with him to encourage him to eat and focussed on high calorie foods and close monitoring of his intake.
- 7.4. As the situation worsened and it was clear that Mr. C's physical condition was deteriorating they were mindful of the research and findings related to diagnostic overshadowing<sup>8</sup> and were clear that they could not rule out that there may be a physical health cause of his refusing food and drink. Initially they commenced medication that would help any heartburn or gastric pain that was present when he ate; when this did not improve things, they began to consider preparing Mr. C for a hospital admission for further tests.
- 7.5. As can be seen in section 6, Mr. C rapidly deteriorated and ultimately was admitted in an emergency. This was not ideal but was the only course of action in the circumstances.
- 7.6. Hospital staff, whilst finding the hospital passport helpful, struggled to manage his behaviour and were not able to undertake all the investigations that they needed to. After he initially improved from the Acute Kidney Injury and was seen to be eating and drinking on occasions with no apparent swallowing issues, the decision that the behavioural issues were causing the physical symptoms indicated that he was 'fit for discharge'.
- 7.7. Whilst this may well have been so, the way it was communicated and how the discharge was coordinated and planned became an issue and is therefore discussed separately below.

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<sup>8</sup>Emerson, E. & Baines, S (2010) Health Inequalities & People with Learning Disabilities in the UK: '**diagnostic overshadowing**' (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities); [https://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_7479\\_IHaL2010-3HealthInequality2010.pdf](https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf) accessed 04/05/2017

- 7.8. Staff reflecting at the workshop stated that they had a renewed understanding of the cumulative impact that the number and nature of the transitions that occurred that may have been having on Mr. C's distress. There was however, agreement that there was a need to exclude medical reasons for Mr. C's physical presentation. With hindsight staff stated that they should have acted earlier to plan hospital admission at an earlier stage before he had deteriorated to the extent that he did and also been clearer with Mr. C about the impact that not eating was likely to have had on him.

**Learning Point 1:**

It is important to plan for transitions wherever possible and to have multi agency contingency and crisis plans that serve to provide all those that are involved with a person information about the possible impact of unplanned and crisis moves (Recommendation 1).

**Communication and coordination**

- 7.9. Much of what is detailed in Section 6 would have benefitted from a more robust approach to communication. It was not that agencies and organisations were not communicating but that there was no one lead person who was coordinating that communication.
- 7.10. The Hospital Trust were communicating within their own departments and various members of the hospital team were communicating with various members of the community teams. There were three multi agency professional's meetings that took place whilst Mr. C was an inpatient. This was recognised as good practice and a significant improvement on previous SAR findings.
- 7.11. Two of these meetings however, were recorded differently by various agencies, some believing them to be a 'professionals meeting' and some believing that there was a discharge planning purpose to them. The third meeting on 24.05.2016 was recorded by all as a best interest meeting and appeared to communicate that there was no physical cause found and that progression was being made to discharge.
- 7.12. Whilst there had been challenges at previous meetings about the lack of diagnostic procedures having been undertaken, this meeting did not appear to have challenges about plans and there appeared to be an acceptance that causes of physical presentation were behavioural in nature. This appeared to have an element of discharge planning but was not a formal discharge planning meeting.
- 7.13. There were no further multi agency meetings that communicated the deterioration and changes in Mr. C's physical state prior to discharge or that communicated a view that Mr. C was approaching end of life.
- 7.14. Whilst Mr. C had been in the community, his day to day assessment, intervention and care planning was managed using Care Programme Approach (CPA) which appeared to work very well with regular and ad hoc meetings that resulted in review of care plans that were shared with all, including the GP.
- 7.15. This process was not continued when Mr. C was admitted to the acute hospital as it is not generally used in those settings, being specifically to manage complex mental health and learning disability. Thus, there appeared to be a 'hand-off' from one process to another resulting in a break down in effective care planning that was both inpatient and community based.

- 7.16. Whilst those that attended the PRW identified that CPA is not used in acute hospital settings, nor is it well understood by acute hospital staff, it was acknowledged that a continuance of its use to manage the multi-agency assessments and needs of Mr. C would have been beneficial. It may have provided a robust method of communicating and coordinating the plans for his discharge and would have represented a coordinated approach to communication.

#### Learning Point 2:

Communication and coordination in complex cases is key to ensuring that everyone, including the person and their family have clarity of purpose, needs and planning (including discharge planning) that is understood and shared by all. This can provide a vehicle for professional curiosity and challenge; if a process is working well in a community setting, there is benefit for continuing this. (Recommendation 2)

#### Learning Point 3:

It is helpful to have agreement as to who will be the key worker when a person with learning disability, who has significant support in the community, is admitted to an acute hospital (Recommendation 3).

### Mental Capacity and Best Interest Decisions

- 7.17. Whilst the above analysis provides some learning and will lead to recommendations, the crux of what may have been done differently draws on the previous learning but it is the use of the Mental Capacity Act which may have been pivotal in understanding issues that appear to be self-neglect in someone that does not have capacity to understand the impact that their behaviour is likely to have on their health and well-being.
- 7.18. The health and social care professionals working with Mr. C used the provisions under the Mental Capacity Act to identify best interest decisions where it was believed that Mr. C lacked capacity. This section will focus on decisions related to impact of not eating and those of treatment and diagnosis.
- 7.19. A key issue discussed at the PRW was that it was not clear if anyone had specifically ensured that, as much as possible, Mr. C understood that by not eating and drinking that he may well die. Not eating and drinking is an act of self-neglect. Good practice in managing self-neglect is to identify if the person has capacity to understand the impact of their behaviour.
- 7.20. It was assessed that Mr. C did not have capacity to understand the need to eat and drink regularly but not to the extent that he may die. It was noted by the manager that attended A and E with Mr. C, during a conversation about living for a long time, Mr. C had stated that he did not want to die.
- 7.21. When considering best interests, this was important. He clearly stated that his wish was not to die. All future assessments and decisions should have been based around this fact and a reassessment of wishes and feelings as time moved on.
- 7.22. All decisions regarding diagnostic interventions that Mr. C refused should have resulted in an assessment of capacity to understand the need for the treatment/intervention. This should then be followed by a best interest decision by the person who was going to be in charge of ordering or delivering that intervention, with the support of those that knew him best.
- 7.23. Capacity Assessments with Mr. C were difficult as he often refused to engage. The hospital had appointed an IMCA but that had not been a successful intervention as the IMCA felt that it was not within her remit to support decision related to medical intervention. Whilst that is true, there should have been a challenge to

that. There was a role for an IMCA albeit not to make the decisions about treatment but to work with Mr. C to identify his capacity to understand the need for treatment and establish his wishes and feelings.

- 7.24. Best Interest meetings were taking place but there was dissent initially about whether enough was being done to exclude medical and physical reasons for the physical presentation of Mr. C. There was a further best interest meeting where there appeared to be agreement that the issue was behavioural in nature. At that point, Mr. C had improved and there were plans for rehabilitation. There was a need to manage his behaviour within a community setting away from the acute hospital where it was believed that the environment was adding to the issues and presenting behaviour.
- 7.25. When Mr. C again started to deteriorate, there was an indication from the hospital that he was approaching end of his life. Mr. C had now got a further infection, was dehydrated and refusing treatment and fluids but was not showing signs of sepsis. This was not communicated to those in the community and the NCH who still believed that he was improving and that rehabilitation was the plan.
- 7.26. This was a significant missed opportunity to have a further mental capacity assessment regarding Mr. C's decision not to eat and drink or accept treatment for infection given that these were the issues that he was originally admitted with. Now that the decision had been made that this was behavioural, there appeared to be a feeling that there were no other options and that a move back to the community was all that was needed. A best interests meeting, however, to include all health and social care professionals to identify next steps should have been undertaken.
- 7.27. It was noted at the PRW that, at that point, most options of alternative methods of feeding Mr. C may not be appropriate as they would have been invasive and Mr. C may not have tolerated those options. It was, however, given that it was difficult to engage Mr. C in capacity assessments, and that it was felt that further ways to preserve his life were not an option, that an application to the Court of Protection should have been the next step.
- 7.28. The decision by a court of protection judge cannot be pre-empted and therefore it is not clear what the outcome would have been. What is clear though is that all those caring for Mr. C would have been aware of the gravity of the situation and there may have been an acceptance that Mr. C was approaching end of life but this would have been planned for and understood by all. This action would have been done with the underpinning of the Mental Capacity Act being applied fully and robustly.

#### Learning Point 4:

The Mental Capacity Act provides a legal framework not only about assessing capacity and best interest but more specifically about next steps where best interest decisions are not leading to solutions and that may have a negative outcome.

Case Law examples provide useful practice guidance and legal advice is useful at an early stage to support practitioners where issues are complex (Recommendation 4).

#### Learning Point 5:

The role of the IMCA is an important one where family live away and are not able to be actively involved in decisions; where expectations of the IMCA role are not being met, these should result in challenge and escalation. (Recommendation 5).

#### Learning Point 6:

Involvement of next of kin in important decisions is important, even where they may have devolved day to day decision making to carers. Where families choose not to be involved, it is good practice to share information related to decisions made (Recommendation 6).

## 8. Good Practice

- 8.1. It is important to note that many practitioners offer a good level of service to their clients/patients and follow policies and procedures that are provided to guide practice. Whilst recognising gaps in practice, Safeguarding Adult Reviews can also provide evidence of this as well as practice that goes over and above what is expected. Attendees at the PRW were asked to identify these from their own and other agencies involvement. It is important to highlight these as areas where learning can occur.
- 8.2. The following was identified as good practice by the reviewer and PRW attendees:
- CPA was utilised well in the community setting.
  - Staff gathered information from previous placements to inform assessments and care plans.
  - Covert medication was given appropriately under a DoLs authorisation.
  - There was good engagement and communication between psychiatry and consultant in the hospital.
  - There was good continuity of the team in the community.
  - The assessment unit continued support when Mr. C was in hospital.
  - There was good communication between the NCH to Adult Services Community Team.
  - The hospital sought a second medical opinion.
  - The hospital passport was used and hospital staff found it helpful.
  - Multi agency best interest meetings were held when Mr. C was in hospital.
- 8.3. The above listed good practice is important to recognise considering the learning and recommendations from two previous SARs in the locality, as it represents improvements in the systems and practice that were not evident previously.

## 9. Conclusions and Learning

- 9.1. This review has recognised the complex challenges faced by practitioners who support those with Learning Disability. This is particularly the case when change is inevitable as those challenges escalate due to the impact on a person who struggles to manage and adjust to change.
- 9.2. In this case those changes caused distress to Mr. C that manifested in the behaviour of refusing food and drink. Staff working to support Mr. C tried to use their knowledge of what had previously worked in encouraging eating and drinking but these strategies did not work and Mr. C began to show physical signs of weight loss and frailty due to not eating.
- 9.3. Staff were mindful of the issues of diagnostic overshadowing and therefore sought medical help in the first instance from his GP and latterly from the acute hospital.
- 9.4. The challenges faced in trying to manage Mr. C's distress in an environment that had all the hallmarks of environments that were known to add to Mr. C's distress were evident.
- 9.5. At the time that Mr. C was an inpatient, there was no Liaison Nursing Service in place for learning disability that Mr. C could benefit from.
- 9.6. There were disagreements regarding how far diagnostic testing should be undertaken but more latterly an acceptance that Mr. C's presentation was likely to be behavioural in nature and therefore a move to an environment that was likely to cause less distress was agreed to be the best option following a best interests meeting.
- 9.7. Due to delays in agreement for CHC funding the issues that Mr. C was experiencing continued to have an impact on his physical health and after some initial improvement he again deteriorated and hospital staff

believed he was approaching end of life. This information was not communicated to those in the community, who were not prepared for Mr. C to be in such a frail and physically deteriorated state.

- 9.8. This review has identified that communication was not robust between hospital and community staff at this point. That is not to say that there was not any communication but that it did not provide information between agencies that was understood by all and did not provide a robust plan of care that was in place across all agencies.
- 9.9. Robust application of the Mental Capacity Act by all who were involved with Mr. C would have provided a focal point with Mr. C at the centre, when in fact Mr. C appeared to be lost in the midst of the apparent confusion by the professionals involved.
- 9.10. Hampshire County Council has a Mental Capacity Toolkit and a Care Planning, Risk and Capacity Information sheet. It is not in use in all organisations across the County as it is a county council tool, although its use is encouraged. Many organisations have their own Mental Capacity Act policies and paperwork. Use of the toolkit would have provided a robust method of assessing capacity and enabling best interest decisions. This may have led to a decision that an application to the court of protection could have been required if it was felt that Mr. C was going to die from his decision not to eat and drink and that methods of preserving his life, by other methods of feeding, were not going to be in Mr. C's best interests.
- 9.11. Outside of those best interest decisions and meetings this review has identified that it may well have been appropriate to continue the use of CPA to manage and coordinate care.
- 9.12. The professionals also mistakenly believed that Mr. C's brother had devolved all decisions to those supporting him, when in fact that was not the case from the brother's perspective and therefore there is further learning for communication and checking back with families.
- 9.13. This review has also found that on most day to day issues, the staff that knew him best were able to advocate for him, but for larger and more complex decisions the use of an IMCA was not robustly applied for Mr. C. In some instances, this was due to his non-engagement with the IMCA and on another instance because the advocate identified that there was no role for her. There were missed opportunities to find an IMCA that Mr. C could work with. There should also have been challenge and escalation regarding the decision of the IMCA that there was no role for her in the decisions required related to treatment and understanding Mr. C's wishes and feelings. There were also occasions where a Care Act advocate could have been used for assessment, planning and reviewing care.
- 9.14. This review has identified key learning across several areas and has also found some key improvements that appear to have taken place following learning and recommendations from two previous SARs.
- 9.15. The learning in this review is not unique and has similar features to many other SARs regionally and nationally. A recent 'Key Findings' report by the University of Bristol<sup>9</sup> identified all of the learning from this review in their findings, indicating that this review provides a window on wider system issues. Similarly, a recent analysis of SARs in London<sup>10</sup> also identified issues with embedding of Mental Capacity Act, lack of involvement of family and carers and failure by professionals to escalate issues of concern.
- 9.16. The thematic review being undertaken will analyse what is now working well and identify any key barriers to full implementation of all learning across the three SARs undertaken in the locality in order the people

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<sup>9</sup> University of Bristol, School for Policy Studies Key findings of repository 2015/2016 available at <http://www.bristol.ac.uk/sps/leder/repository/summary-of-themes/> accessed 04/05/2017

<sup>10</sup> Braye, S. & Preston-Shoot, M. (2017) Learning from SARs: A Report for the London Safeguarding Adults Board <https://londonadass.org.uk/learning-from-sars-report/> Accessed 08 September 2017

with learning disabilities being cared for and supported by several agencies, will experience more coordinated care with improved outcomes.

## 10. Recommendations

- 10.1. Where agencies have made their own recommendations in their review of Mr. C's care, HSAB should seek assurance that action plans are underway and outcomes are impact assessed within those organisations.
- 10.2. Arrangements should be made to share the learning with Portsmouth SAB.
- 10.3. The following recommendations are made as a result of the learning in this case and require that **HSAB seeks assurance from the appropriate partners** that the following are addressed:
  1. CPA for people with complex needs and learning disability should include a clear transition plan that considers all the needs of the person and should incorporate:
    - Mental Capacity Assessment summary
    - Best interest Decisions summary
    - Reasons for transition
    - Specific planning requirements based on needs of individual and issues likely to be raised
    - Contingency arrangements
    - Crisis plans
    - Details of advocacy arrangements
    - Plan for involvement of next of kin  
(Learning Point 1)
  2. Consideration of use of CPA during acute hospital admissions where it is in place pre- admission that would include planning for discharge (Learning Point 2)
  3. How a key worker for a person with learning disabilities will be identified and coordinate care, being a key point of contact for other professionals and families where a person with complex needs and learning disability is admitted to hospital – this should be identified within the hospital passport. (Learning Point 3)
  4. Work on policies and procedures and training related to MCA includes the use of the endorsed HCC MCA Toolkit across all agencies and guidance of when there should be application to the Court of Protection. (Learning Point 4)
  5. Guidance should be developed/updated related to the different IMCA and advocacy services that includes details of how and when challenge and escalation are appropriate. (Learning Point 5)
  6. Where families are not involved in day to day decisions, that this does not preclude them from being involved in important decisions or being informed of important information such as change of placement, admission to hospital and serious illnesses. (Learning Point 6)
  7. That where a care provider is listed as NOK, that the rationale for this is recorded and family details are included where relevant in order that information can be shared as required and NOK are not challenged about their relationship. (Learning Point 6)
  8. HSAB to consider a model for multiagency communication such as that suggested in Appendix 1.
  9. HSAB must ensure that the learning from this review is disseminated to all agencies.



**The above recommendations are also made in the HSAB Thematic Review that was undertaken following this SAR and are addressed in the action plan that is associated with that work.**

**Hampshire Safeguarding Adults Board**  
**Safeguarding Adult Review in relation to Mr C**  
**Terms of reference**

**Background**

Mr C was 66 years old had a learning disability and complex needs and behaviours. He was being supported in residential care funded by Hampshire County Council. He was admitted to an acute hospital on 20/04/16 due to a deterioration in his physical presentation following a period of time when he was not eating and drinking. Mr C was assessed as lacking capacity regarding care and treatment decisions. Mr C remained in hospital for approx. 8 weeks until his discharge on 13<sup>th</sup> June 2016.

Mr C had complex needs and behaviours. The deterioration in his physical health and refusal to eat or drink was perceived throughout by all the agencies involved as behavioural in nature. There is no record of an annual health check.

During Mr C's period in hospital, the community learning disability service provided advice to the acute hospital regarding the management of his apparent non-compliance with investigations. Despite a long admission, investigations were not undertaken into the cause of Mr C ceasing to eat and drink. Serious physical deterioration was categorised as behavioural by the hospital staff who appeared to reject investigation paths because of the level of adjustment that would need to be made for Mr C's learning disability and needs. The hospital also appears to have requested alternative psychiatric opinions despite it being clear the community learning disability service and a consultant psychiatrist were involved. Mr C was discharged from hospital without a clear diagnosis or management plan. No discharge planning meeting coordinated with the community learning disability service.

Mr C Adult was discharged from hospital to a nursing home on 13<sup>th</sup> June 2016 where he arrived in a severe physical state (which was not expected by the home). When the nursing home contacted the hospital for advice and support they were informed Mr C was 'end of life'. Apparently, there was no end of life plan upon discharge or discussion with the community learning disability service or family to inform them of this fact. Mr C died at the nursing home on 17/06/16. The death was referred to the coroner who ruled the cause of death as: 1a Sepsis due to B Pneumonia and urinary tract infection Part 2 Severe malnutrition. An coroner's inquest is to held on 16<sup>th</sup> March 2017.

In addition to internal reviews by partner agencies, this case was subject to a s42 enquiry (now complete) led by Portsmouth City Council as the host authority. The s42 enquiry commenced prior to Mr C's death as a result of an alert from his care home provider. The safeguarding process was unable to conclude definitively that abuse or neglect was a casual factor in the death.

## Appendix 1: Terms of Reference

The case was referred to the Hampshire Safeguarding Adults Board (HSAB) for consideration for a SAR. The HSAB Learning and Review Subgroup (LRS) met on 30<sup>th</sup> November 2016 and it was decided that statutory criteria for conducting a safeguarding adult review were met and so a statutory review will be held using a bespoke methodology.

### **Methodology**

As this is the third case since 2012 of very similar circumstances involving the death of an adult with a learning disability which raised concerns about the way deteriorating physical health needs of people with complex needs and behaviours are managed, it is likely that root causes and learning in the Mr C case will be very similar to that already highlighted in the two previous cases. Therefore, rather than repeat the same review process highlighting very similar issues and learning, the LRS has recommended that a 'systems review' is undertaken in response to this case and also Mr A (2012) and Ms B (2015).

However, in order not to lose sight of the key issues and learning in the case of Mr C this SAR will encompass a review of the information and internal investigations to ensure that any identified issues and learning are factored into this review process.

The SAR will be carried out in two stages:

- a) A review of the circumstances of the Mr C case to draw out specific learning relating to his support, care and treatment. This will include compilation of a chronology and completion of a case audit against specific questions by the individual agencies involved. As part of the SAR process, there will be a multi-agency reflective workshop to bring together the practitioners and operational managers involved in the care and support of Mr C prior to his death. This workshop will focus on the individual's journey through the system in order to reflect on and share learning and also to identify opportunities for improved working within and between agencies in the future. A 'lessons learnt' report will be produced around the key learning identified which will be shared with organisations.
- b) A thematic review and analysis of common issues and root causes across each of the three cases followed by a full day multi-agency event, to explore with partner agencies the blockages and barriers that have hindered implementation of the learning and recommendations from the previous cases. Partner organisations will then have an opportunity to agree actions to address blockages and barriers identified.

Compared to traditional SAR methodology, the approach outlined should be less time intensive but better focused on learning and why responses to date have not led to the improvements and outcomes sought in the previous SARs.

A multi-agency SAR Panel has been established to oversee the SAR. This will be chaired by an independent reviewer who will produce a report outlining key findings and multi agency recommendations to address any blockages and barriers identified.

## Appendix 1: Terms of Reference

### Timeline for the review

The timeline for this systems review will be 2012 – 2016 in order to ensure that key circumstances from the Mr A, Ms B and current case can be considered and the cases compared.

### Agencies participating in the SAR

<b>Organisation</b>
Area 1 County Council
Area 2 City Council
Health Care Foundation Trust
Acute Hospitals Trust
Nursing Home
Private Mental Health Hospital
GP Practice
CCG 1
CCG 2
NHS England

### Composition of the SAR Panel

Independent reviewer  
Strategic Partnerships Manager, Area 1 CC  
Safeguarding Nurse, CCG 1  
Head of Vulnerable Adults, CCG 2  
Safeguarding Consultant, Area 1 CC  
Advocacy Services  
Health Care Foundation Trust  
Acute Hospitals Trust  
NHS England, Area Team  
Service Manager, Area 2 CC  
Consultant Psychiatrist, independent specialist advisor

## Appendix 1: Terms of Reference

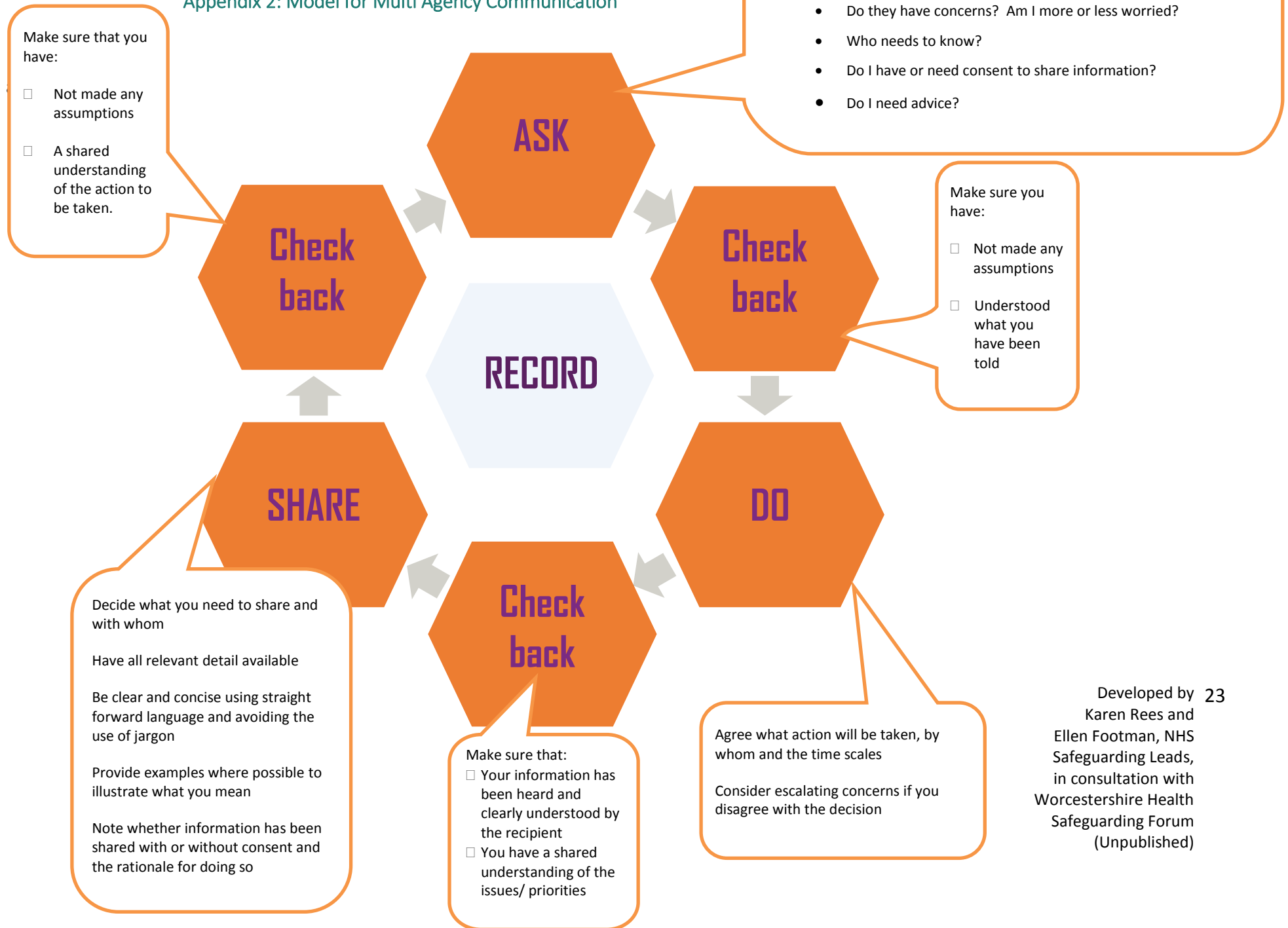
### Programme and timetable for the review

<b>Activity</b>	<b>Who</b>	<b>Date</b>
Scoping meeting to draft terms of reference	HSAB Manager and SAR Panel	11 <sup>th</sup> Jan 2017
Collation of information gained from the s42 enquiry process relating to Mr C	Safeguarding Consultant, HCC (MG)	February 2017
Source independent review chair and specialist advisor	HSAB Manager	February 2017
<u>First meeting of the SAR panel</u>	Full SAR Panel	8 <sup>th</sup> March 2017
Formal notification to involved agencies	HSAB Manager	8 <sup>th</sup> March 2017
Meeting and discussion with family	Independent reviewer	March 2017
Partner agencies to be requested to complete and chronology and case audit of their contact with Mr C (one year up to DOD)	HSAB Manager	10 <sup>th</sup> March 2017
Involved agencies submit their chronology and case review regarding Mr C	Involved agencies	13 <sup>th</sup> April 2017
Review of all documents and information and produce a composite report	Independent reviewer	April 2017
Multi-agency reflective workshop	Independent reviewer and SAR Panel	26 <sup>th</sup> April 2017 (12.30pm – 4.00pm)
Mr C SAR report – key learning and recommendations	Independent reviewer	22 <sup>nd</sup> May 2017
<b>Activity</b>	<b>Who</b>	<b>Date</b>
Version 1 of thematic review circulated	Independent reviewer	30 <sup>th</sup> June
<u>V1 comments from SAR panel</u>	Full SAR Panel	7 <sup>th</sup> July
Version 2 of thematic review circulated	Independent reviewer	13 <sup>th</sup> July 2017

## Appendix 1: Terms of Reference

Version 2 thematic review circulated to multi-agency event attendees	HSAB manager	
Multi-agency event (full day) chaired by Independent reviewer	SAR Panel, Dr Mark Scheepers, agency leads	19 <sup>th</sup> July 2017
Version 1 of Review Report circulated to SAR panel	Independent reviewer	W/B 21 <sup>st</sup> Aug 2017
<u>2nd SAR panel meeting</u>	Full SAR Panel + Dr Mark Scheepers	W/B 11 <sup>th</sup> Sept 2017
Version 2 of Review Report circulated to SAR panel and LRS	Independent reviewer	W/B 20 <sup>th</sup> Sept 2017
Final comments on version 2 of the Review Report	SAR Panel (email)	W/B 27 <sup>th</sup> Sept 2017
Version 3 of the Review Report completed	Independent reviewer	9 <sup>th</sup> Oct 2017
3rd SAR Panel		1 <sup>st</sup> November 2017
Final version of the Review Report to HSAB	Independent reviewer	12 <sup>th</sup> Dec 2017
Case file audit to evidence changes in practice and in outcomes for service users.	HSAB Quality Assurance Subgroup via a TFG	June 2018

## Appendix 2: Model for Multi Agency Communication



Developed by 23  
 Karen Rees and  
 Ellen Footman, NHS  
 Safeguarding Leads,  
 in consultation with  
 Worcestershire Health  
 Safeguarding Forum  
 (Unpublished)