

Hertfordshire Safeguarding Adult Board
Multi-Agency Partnership Case Review (MAPCR)

James L

Overview learning report

Independent author: Judi Thorley

Independent chair: Pete Morgan

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1. Background to commissioning of this Multi Agency Partnership Review (MAPCR)

- 1.1 Subsequent to James' admission to hospital in December 2015 and admission to care home in March 2016, his family had raised concerns with Health and Community Services, Hertfordshire County Council (HCC), about the quality of care and support he was receiving. These concerns related to his support at his bungalow in Hitchin and his subsequent placement at care home, the care plan in place there and the lack of any physiotherapy input to him.
- 1.2 The family's' continued dissatisfaction up to and after James' death led them to raise concerns with HCC whilst James was at OC, when they were seeking help to improve James' quality of life. Subsequent to his death in August 2016, family raised further concerns, requesting that a Safeguarding Adults Review be commissioned under the Care Act 2014. The Director of Adult Social Care, HCC enquired whether the criteria for a SAR were reached but was advised that they were not. The family were offered an Independent Investigation of their complaint.
- 1.3 The family accepted the offer of an Independent Investigation of their complaint though questioned how a Hertfordshire County Council Complaint Investigation could consider the actions of other agencies.
- 1.4 The Complaint Investigation was completed in April 2017; however, the family were not satisfied and referred the case to the Local Government & Social Care Ombudsman. In July 2018, the Ombudsman found fault in the investigation commissioned by the Council in that it "was not properly multi-disciplinary and failed to provide a comprehensive response". As a result, the Council agreed to commission a new review that would include "all the relevant health organisations".
- 1.5 In November 2018 the Independent Author and the Independent Chair of the Hertfordshire SAB met with the family and discussed how to take the new review forward and it was subsequently agreed that an Independent Chair would be commissioned for this Review, which would be held under the power rather than the duty to commission a SAR contained in the Care Act 2014.

2. James L

It is important within this Review to introduce James; who he was, what he enjoyed doing in his life, who was important to him and what he meant to his family, friends and staff. The following introduction has therefore been drafted from listening to his family and staff and reading what was shared as part of the Independent Management Reviews (IMR's)¹.

James was a gentleman of 68yrs, much loved by his sister and brother and wider family, friends and staff, some of whom had known James for over 20 years. James is described as an intelligent and thoughtful man with a friendly nature and 'big character'. With a good sense of humour, James was very popular, he loved meeting new people and was good at building and keeping relationships, which was evidenced by his popularity with neighbours and people in town.

James had many interests including cricket and 1940s films, his knowledge of which is described as encyclopaedic! James also had an amazing memory which he sometimes used to have a bit of fun with his family and staff. James loved traveling both locally and in Hitchin, across London to visit his family and to the seaside. James often had food out, particularly at the weekends, when he travelled into town.

Although James is described as having a moderate learning disability, it should be noted that there was no evidence of a formal diagnosis or assessment of the nature and/or impact of James' learning disability provided as part of this Review. He was unable to read or write. James lived with his parents until 1997 when they passed away. His family were concerned about how James would manage his life without his parents, but James negotiated a housing swap to return to living in Hitchin after a brief move to Knebworth with his father. James lived independently in his own bungalow for almost 20 years, having daily support from carers.

James attended a Day Service in Hitchin for over 25 years, he was very popular here too. Many staff had built a good relationship with James, knowing him very well over several years. These staff went above and beyond their duties to support James and it is evident that James had good and trusted relationships with many of the Day Service staff as well as some of his carers.

James had, until the last few months of his life, been registered with the same GP surgery. As his time with the practice spanned more than 25 years most of the staff in the practice knew James very well and his named GP had good connections and contact with the Community Learning Disability Team.

James had a number of complex long-term physical health conditions: type 2 diabetes which was treated/managed with Insulin following hospital admission in December 2014; ulcerative colitis; duodenal ulcer; hypertension; mitral regurgitation; he had a heart monitor in place under his skin; heart failure; incomplete bladder emptying and repeated infections; chronic kidney disease and age-related macular degeneration resulting in James being partially sighted.

¹ IMRs are narrative reports completed by each identified agency responding to the Terms of Reference agreed within the MAPCR process

3. Context of the Review

- 3.1 Section 44 of the Care Act 2014 puts a 'duty' on Safeguarding Adults Boards (SABs) to arrange a Safeguarding Adults Review (SAR) if an adult (for whom safeguarding duties apply) dies or experiences serious harm as a result of suspected abuse or neglect and there is cause for concern about how agencies worked together. The SAB can also arrange a review under the 'power' within the same section of the Act when safeguarding duties do not apply but there is evidence to suggest possible system learning from both good and poor practice. A review undertaken using the power within the Act is known in Hertfordshire as a Multi-Agency Partnership Case Review (MAPCR) and is carried out in line with the SAR process.
- 3.2 The Hertfordshire Safeguarding Adults Board (HSAB) commissioned both an Independent Chair and Author to carry out this Review. The Chair and Author are independent of HSAB and its partner agencies. The Chair has been a qualified social worker for almost 40 years and has specialised in Safeguarding Adults for the past 16 years. Since leaving local authority employment he has chaired 2 Safeguarding Adults Boards, been a member of the Advisory Group supporting the drafting of the Safeguarding Sections of the Care Act 2014 and authored several Safeguarding Adults Reviews. The Author holds a professional background as both a Registered Learning Disability Nurse and Registered General Adult Nurse, with over 33 years' experience in the NHS. Since leaving the NHS the Author has worked as an Independent Consultant carrying out work encompassing service review, review of arrangements for adult safeguarding, and SARs.
- 3.3 The purpose of this MAPCR is to establish whether there are lessons to be learnt from the circumstances of James and the context of his death for the way in which local professionals and agencies work together to safeguard adults with care and support needs. It will review the effectiveness of procedures (both multi-agency and those of individual organisations) to inform and improve local inter-agency practice by acting on learning (developing best practice).
- 3.4 MAPCRs are not concerned with attributing blame or identifying the cause of any abuse or harm and are not part of any disciplinary proceedings.

4. Terms of Reference and Methodology

4.1 Terms of Reference

The purpose of the MAPCR is to:

- hold the mirror up to reflect and review practice and procedures
- identify learning including any gaps or missed opportunities along with areas of good practice in the circumstances of James and the context of his death.
- establish whether there are lessons to be learnt from the way in which local professionals and agencies work together to safeguard adults with care and support needs.
- review the effectiveness of procedures (both multi-agency and those of individual organisations).
- inform and improve local inter-agency practice by acting on learning (developing best practice).
- identify and advise of any learning including gaps or omissions and good practice that may inform future good practice, together with, where necessary and appropriate, to advise on what steps might be taken to address any areas that may be strengthened or improved.

4.1.1 The Terms of Reference (ToR) sought to place the experiences of those directly involved with James' care and support at the heart of this Review, ensuring that James' brother and sister (family) were enabled to contribute throughout the MAPCR.

4.1.2 MAPCR covers the period 01.12.2014 to 31.07.2016.

Terms of Reference
1. Were the care and support needs of JL identified, assessed and responded to appropriately and effectively to enable him to achieve his desired outcomes, such as returning to live in his bungalow?
2. Were the single and multi-agency responses appropriate, person-centred and proportionate?
3. Did the communication between the agencies involved with JL ensure the effective coordination of service delivery and multi-disciplinary working?
4. To consider whether the policies/procedures, systems and processes of all relevant agencies are adequate to ensure safe care in the community, recognising change in need.
5. To consider whether such policies/procedures, systems and processes that were in place leading up to and at the time of JL death were adequately followed by agencies involved in the process.
6. To consider any specific equality and diversity issues; exploring if and how agencies recognised JL's learning disability and considered JL's needs in relation to understanding, choice and control.
7. To consider whether the Mental Capacity Act was implemented correctly.

4.2 Methodology

4.2.1 A MAPCR Panel (the Panel) was established to support and inform this Review.

4.2.2 The following agencies were represented/members of the Panel:

- East and North Hertfordshire and Hertfordshire Valley Clinical Commissioning Group (CCG), Associate Director Adult safeguarding and Named Nurse Adult
- Hertfordshire Adult Social Care: Head of Adult Safeguarding and Deputy head of adult social care
- East and North Herts NHS Trust, Lead Nurse Adult Safeguarding
- Head of Operational Quality - England South, Four Seasons Health Care, Care home
- Principal Business Development Manager, HCPA
- Hertfordshire Partnership Foundation Trust, Consultant Social Worker/AMHP (Adult Safeguarding)
- Named Nurse for Safeguarding Adults, Hertfordshire Community NHS Trust
- General Practice- both Regal Chambers and Baldock surgeries
- Head of research and engagement- Healthwatch
- Chief Inspector Hertfordshire Police
- Hertfordshire Safeguarding Adults Board- Safeguarding Board Manager and safeguarding business manager

4.2.3 The Independent Chair and Author met with the family to inform the drafting of the ToR and confirm the Review's process.

4.2.4 Following this meeting with the family, the Panel revised the Review period to December 2014-July 2016 and jointly agreed the amended and updated ToR.

4.2.5 James' family helpfully provided a pen picture of James and suggested areas for exploration at the learning event for which the Independent Chair and Author are grateful.

4.2.6 The Panel received a detailed chronology from all agencies along with Independent Management Review (IMRs)² narrative reports.

4.2.7 Following review and analysis of the chronology, IMRs and comments and questions shared with the Independent Chair and Author by James' family, a learning event was facilitated with frontline staff from all agencies. The aim of the learning event was to collectively consider emerging themes and identify learning to inform the drafting of recommendations for improvement.

² IMRs are narrative reports completed by each identified agency responding to the Terms of Reference agreed within the SAR process

4.2.8 Further to the learning event, a first draft of the report was authored. The Independent Chair and Author met with the family again to discuss and seek their views/contribution to this first draft of the report.

4.2.9 Following this second meeting the family helpfully provided their points/comments about the first draft of the report in written format. Many of the points/comments made by the family provided factual accuracy and/or additional detail and have therefore been reflected in the main body of the report.

4.2.10 For openness and transparency and to provide the maximum opportunity for learning the following is a summary of the points/comments considered by the family to be important for all those who were involved in James' care and support:

- The family are very clear that maximising learning from this and any review is very dependent on the quality of the information in the agencies' IMRs.
- They were concerned about the impact, as acknowledged in the report, of the fact that three agencies lost James' notes on the completion of the review and on the level and quality of learning which might occur.
- Care home is a residential home for people with dementia. Whilst it is acknowledged within the report that the care home was not an appropriate placement to meet James' chronic and escalating health needs other than on a very short-term basis, the family believe that the care home was a completely unsuitable placement for an adult with a learning disability
- From discussions with staff at the care home it was clear to the family that staff there had little if any information about James, his life and his health needs, though this has been impossible to clarify due to the lost records – see above.
- They also consider that James' deteriorating health should have been considered by all professionals as should have supporting him to remain at home or finding an alternative nursing home.
- The experience of the family was that no attempts were made to involve them in planning for and with James. As identified in the report, planning and person-centred coordination were lacking and there should have been an early review of James' care and support at the care home and, prior to his being placed there, a comprehensive needs assessment completed and consideration given to possible interventions and support to enable James to remain at home.
- The family view is that the poor care and planning meant that James' quality of life after admission to care home was impacted greatly and that individual and collective failings by the authorities led to poor decision making 'with disastrous consequences for James'. They would therefore not accept the review's conclusion that '*The review has found that individual and collective actions or any omissions did not lead to James' death*' but do support the report's recommendations
- The family's wish is for sustained and wide-ranging learning to take place across all the agencies involved with James as a result of this review.

5. Summary of Events

From the review of the chronology and IMRs, events have been grouped into 3 key time periods.

- 5.1 **The first key time period is December 2014- December 2015** and considers James' changing health needs following his admission to hospital in December 2014, assessment/review, support and care interventions and planning.
- 5.2 Throughout early December 2014 James attended Day Service where it was noted that he was 'in good spirits' and enjoying some of the early festive activities.
- 5.3 During the early hours of 17th December 2014 James was admitted to the Acute Cardiac Unit, E&NHT following a query cardiac episode, syncope³ and collapse at home.
- 5.4 James received treatment and interventions including the insertion of an Implantable Loop Recorder⁴ to monitor his heart rhythm. During this admission the management of James' diabetes was affected, which resulted in him being commenced on insulin.
- 5.5 James was discharged home on 4th January 2015 to a nursing home in Stevenage, for a short stay whilst a care plan/package was established. James had a follow up appointment date for outpatient's cardiology.
- 5.6 James' sister kept in touch with the Day Service. At this time James' brother contacted the Day Service requesting that his details be added along with his sister's as next of kin.
- 5.7 James was discharged home on 12th January 2015 with a care package x 2 daily care visits plus District Nurses x 2 daily for insulin administration and blood sugar monitoring. 19.01.2015 James queried with Day Service staff that he had not had his weekly bladder wash out/flush. It should be noted that this is the only reference in all of the chronologies and IMRs to James requiring or receiving a weekly bladder wash out/flush.
- 5.8 Communication between Adult Disability Service (ADS), Community Learning Disability Team (CLDT) and the Day Service about James' discharge, changes in his health needs, the updating of his health protocol and his return to the Day Service was documented. The CLDT Health Care Assistant (HCA) was advised of the urology appointment on 14th January 2015 which she would support James to attend
- 5.9 James returned to the Day Service on 13th January 2015. James' sister was Appointee with the Department of Work and Pensions for James and supported him with his financial affairs and all correspondence. James would usually take letters to his sister when visiting at the weekend. If James wasn't able to get to see his sister, then he would take the letters to the Day Service. The Day Service supported James to understand any correspondence that he had, liaised with CLDT staff and his family about appointments, copying letters to CLDT and his

³ Syncope- temporary loss of consciousness caused by a fall in blood pressure

⁴ Implantable Loop Recorder- also called implantable cardiac monitors, are very small devices that go underneath your skin to monitor your heart rhythm

- family at James' request. Day Service staff also supported James with his banking and money.
- 5.10 Due to James' complex comorbidities⁵ he had numerous hospital appointments throughout 2015 for both bladder and heart conditions as well as regular appointments with his GP and other primary care services such as dental, optician and chiropody.
 - 5.11 Several incidents of incontinence were noted throughout 2015 by Day Service staff and of James raising concerns about frequency and discomfort with passing urine with staff. Day Service staff passed on concerns to CLDT HCA who arranged and supported James with any GP appointments.
 - 5.12 A letter was received by his GP following an appointment with the Urology Consultant on the 14.01.2015, advising that the Consultant was seeking an anaesthetic opinion regarding the risks of bladder neck incision surgery⁶ for James.
 - 5.13 James told Day Service staff that he was worried about having the operation and that his family would like him to have it. James was reassured that he can talk with staff and contact made with CLDT.
 - 5.14 James' sister was contacted by the Day Service to advise of the date of an outpatients' appointment for James at the Pacemaker Clinic. She advised that she would attend with James and asked to be informed when a date for the anaesthetic review was received as she would like to support James with this too.
 - 5.15 James received a letter with a date of 19.02.2015 for the anaesthetic review. The date was conveyed to his sister who advised that she was not able to attend but would ask her brother if he could.
 - 5.16 James' sister contacted the Day Service to advise that neither she nor James' brother could attend the appointment and as James' brother had discussed with the consultant at the last appointment, she would cancel the appointment and discuss at the next appointment in March. James was informed of this conversation
 - 5.17 There was some difficulty in the first few weeks following James' discharge with the timing of District Nursing visits to administer his insulin. Administration of James' insulin by the District Nurse did not always happen as it should have, prior to attending the Day Service. His GP made a referral to the Diabetes Specialist Nurses.
 - 5.18 CLDT HCA contacted the Day Service to advise that she had met with James about making his own decisions after concerns were raised about his family making decisions for him. James said he didn't want the anaesthetic or hearing appointment. On the 23.02.2015 James was asked if he wanted medical correspondence sent to his sister and he said that he did not.
 - 5.19 On the 26.03.2015 James was supported by the HCA from CLDT to attend the cardiology outpatient's appointment. A slight increase to his medication was prescribed, with a review in 12 months.
 - 5.20 On the 31.03.2015, James complained to Day Service staff of a painful neck and again on 02.04.2015 along with a painful arm.

⁵ Comorbidities- or "**comorbid condition**" are common medical terms. A **comorbidity** refers to one or more diseases or **conditions** that occur along with another **condition** in the same person at the same time. **Conditions** considered **comorbidities** are often long-term or chronic **conditions**

⁶ Bladder Neck Incision- is a surgical procedure performed on a male to widen the upper part of the bladder located next to the prostate.

- 5.21 On the 13.04.2015, the Day Service chronology states an appointment at E&NHT with the Urology Surgical Consultant for the 14.04.15 was cancelled and that James did not receive a letter. NB Correspondence address checked with E&NHT who confirmed only James address on system/used.
- 5.22 On the 27.05.2015, a Day Service Support Worker phoned James' sister to confirm if an appointment had been received from the Consultant Urologist; no appointment had been received, but she agreed to tell them when one was. On the 13.06.2015, James' sister contacted the Day Service to advise that James had a cardiology appointment on the 18.06.2015.
- 5.23 On the 18.06.2015 a Day Service Review was held, attended by James, the CLDT nurse and HCA, the Day Service Manager and Support Worker, James had requested that his sister and brother were not to be invited. It was agreed that James would bring post to the Day Service for staff to support him with, to notify CLDT of any health appointments and to support him to attend - James confirmed that he did not want support from his sister and brother - and Day Service staff would support James with any continence issues.
- 5.24 On the 23.06.2015, James' sister telephoned the Day Service Support Worker to advise she had arranged for a gardening company to work in James' garden that afternoon and asked that staff inform James. Sister also advised that she was exploring decorating options for his bungalow.
- 5.25 On the 30.06.2015 the Day Service was contacted by Homecare staff to advise that James was leaving his front door open. Home safety was discussed with James - he had been leaving the door open for care staff, but he was reminded that staff have a key in a key safe. Day Service staff also contacted CLDT who advised they would contact the property owners about closure devices.
- 5.26 On the 02.07.2015, James was advised that Day Service staff were no longer able to support him to access the bank due to risks and financial procedures. The CLDT HCA agreed to arrange support from a colleague instead.
- 5.27 On the 07.07.2015, James' sister contacted the Day Service to request that James be informed that a decorator will be visiting his bungalow that afternoon, as James may dislike the disruption. Day Service staff contacted CLDT HCA who advised that she would discuss with the team (health and social care) due to James' vulnerability and dislike of disruption. It was noted that a period of respite care might be an option. James said he was not happy about the re-decoration but seemed to be in agreement about a possible period of respite care.
- 5.28 On the 21.07.2015, a Community Care Officer (CCO) met with James about re-decoration of his bungalow. James was not keen about re-decoration but would like a new chair and carpet. The CCO discussed this with James' sister. The CCO was now supporting James with his banking.
- 5.29 There were frequent incidents of James being incontinent and complaining to Day Service staff about the frequency of his having to pass urine. The CCO took James to a GP appointment on the 30.07.2015 antibiotics were prescribed for a UTI. At his annual health check on the 04.08.2015, James advised that he was continuing to have symptoms of UTI, GP changed antibiotic prescription.
- 5.30 On the 06.08.2015, James was confused and agitated at the Day Service, concerned about money, despite having a large amount of money in his wallet. James was reassured and CLDT contacted. On the 10.08.2015, it was noted 'not himself/seems down'; he was asked how he was and stated he didn't know but

- wasn't in pain. CLDT were contacted and an GP appointment arranged for the following day.
- 5.31 On the 11.08.2015 James had a GP appointment, medication was prescribed for bladder frequency and James was re-referred to the urologist to consider bladder neck incision and the risks of surgery; blood tests were arranged, and a plan made to see him in one week. The GP noted a change in circumstances with James not wanting his family as involved, alert to be amended on his notes, his sisters' contact number to be removed and all letters to be copied to CLDT.
- 5.32 On the 12.08.2015, James told Day Service staff that his sister does not speak to him and he does not visit her because of the decoration of his bungalow. James said this was upsetting him.
- 5.33 On the 01.09.2015, concerns were raised by Day Service staff with ADS about whether James was having meals at weekends as he was not walking into Hitchin anymore as well as leaving his door open and giving money to care staff without receipts. The ADS CCO looked at Meals on Wheels and also arranged for a review of the standard of care provided by the care agency following concerns about the quality of support being provided to James.
- 5.34 On the 7.9.2015, during a Needs Assessment carried by the ADS CCO, James stated that he no longer wanted to live at home but would like residential support. A referral was made by the CCO to Hertfordshire County Council accommodation.
- 5.35 The frequency of the need to urinate and pain was affecting James' life to the point where he was no longer going out or visiting his family. He had repeated appointments with his GP, medications including antibiotics were prescribed and an appointment with the consultant urologist expedited.
- 5.36 12.10.2015, James was supported by CLDT staff to attend an appointment with the Consultant urology surgeon. The outcome was that although he was suitable for surgery, the Consultant noted some improvement in James' symptoms and therefore the benefits of surgery would not be as great. James declined to have the surgery.
- 5.37 On the 21.10.2015, James requested that Day Service staff post copies of his letters to his sister as he was unable to visit her. James brought a pack of 12 first class stamps for onward posting.
- 5.38 On the 13.11.2015, the Day Service Chronology indicates that they were contacted by James' sister informing them that she had received a cardiology appointment for James on 07.12.15. James had previously stated that he wanted appointment letters to go to him; E&NHT confirmed that they only have an address for James so it was not clear if letters had been copied to his sister as James had requested - see point 7.32.
- 5.39 James' sister completed the paperwork for the change in James' benefits from Disability Living Allowance to Personal Independent Payment (PIP).
- 5.40 On the 19.11.15, James spoke to Day Service staff to say his sister had phoned him to say she had been contacted by ADS to say 'found somewhere for him to move to near to the day service'. They reassured him that ADS staff would visit and chat with him.
- 5.41 On the 25.11.15, ADS staff visited James to discuss re-housing. James signed the application forms for re-housing with supported living.
- 5.42 **The second key time period covers the period 20th December 2015- 15th March 2016** and considers James' hospital admission, period of rehabilitation,

- discharge home, community support and interventions, and planning following his admission, his changed health needs and falls resulting in attendance at hospital following his discharge home after a period of rehabilitation.
- 5.43 During the morning call on the 20.12.15, James was found by his carers with a large amount of blood on his clothing and bedding. He was taken and admitted to Lister Hospital, E&NHT with rectal bleeding.
- 5.44 Following various investigations and a further major bleed requiring a blood transfusion, James was diagnosed with Ulcerative Colitis⁷, and the appropriate treatment commenced. Daily physiotherapy and support from the Health Learning Disability Liaison Team was provided whilst in hospital.
- 5.45 On the 12.01.2016, the ADS CCO and HCA were advised that James was medically fit for discharge; the CCO wanted a discharge meeting and care package arranged prior to discharge. Due to concerns about his mobility safety – James was using a frame and had had ‘falls’ in hospital – he was discharged to Queen Victoria Memorial Hospital (QVM) Intermediate Care Team on 8.02.2016 for 3 weeks rehabilitation before returning home. The Day Service record that they were informed that James was ‘to be assessed by Anderson House, residential care near to Day Service, for possible accommodation’.
- 5.46 James’ sister remained in contact with the Day Service throughout this period, stated she was concerned about James becoming institutionalised and not doing much for himself.
- 5.47 The ADS CCO contacted the Day Service to advise that James was using a walking frame but that no extra equipment would be needed at home when he was discharged. His sister also contacted the Day Service to advise that James wanted to return to the Day Service following his discharge home; she was advised that the Day Service Manager would need to visit James at home to assess his needs before he returned to the Day Service.
- 5.48 On the 22.02.2016, James was discharged home to bungalow, E&NHT chronology states that discharge was planned with his family. On the 23.02.2016, his sister contacted the Day Service to enquire how James’ day had gone and was informed that he had not attended as the Day Service Assistant Manager needs to visit him tomorrow (24.02.2016) to assess his needs before he returned.
- 5.49 On the 24.02.2016, the Day Service Assistant Manager visited James at home, and observed that he appeared frail, and said he felt unwell. James said he would return on the 29.02.16.
- 5.50 On the 25.02.16, James was found at home by his carers having had a fall. They called an Ambulance and James was taken to E&NHT Emergency Department (ED). A Falls Referral (this goes to the GP to initiate checks) made by the ambulance crew, who noted the need for an assessment for mobility aids, that James was sleeping in a chair as his bed was too high and had no rails. He was assessed in ED and it was concluded he had had a mechanical fall and he was discharged home the same day. His GP undertook a pre-arranged home visit but was advised by the carer James was at the hospital. The GP alert was updated. The Care Navigator at the E&NHT made a referral for a Rapid response

⁷ Ulcerative colitis- is an inflammatory bowel disease (IBD) that causes long-lasting inflammation and ulcers (sores) in your digestive tract. Ulcerative colitis affects the innermost lining of your large intestine (colon) and rectum.

assessment at home. An Occupational Therapist visited James at home and recorded that he was unsteady but had refused a frame. It was recorded that a pendant alarm should have been in the bungalow but was not found on James' person or in the property.

- 5.51 On the 29.02.2016, when the Day Service transport arrived to collect James, he told staff that he felt too unwell to go. The ADS CCO contacted and visited James later that day - James said he was feeling tired and not himself. James' brother visited the Day Service later that afternoon stating staff need to dress James and be more forceful. James contacted the Day Service Manager to say that his brother had visited and made him get dressed. James said that lunch time calls from the care agency had been arranged by the ADS CCO for the week and that he wanted another week at home before returning to the Day Service.
- 5.52 On the 04.03.2016, his GP undertook a home visit: they noted James had swollen legs, ankle oedema⁸ - queried if this was due to James sleeping in a chair as he finds his bed too high - and mobilising but unsteady on his feet. The GP discussed the above with the Social Worker who had arranged the Occupational Therapy assessment and was looking at possible respite. The Day Service staff phoned James to enquire how he was feeling, James said he was unsure about returning as he was worried about falling.
- 5.53 On the 07.03.2016, James confirmed on the telephone that he wanted to attend the Day Service but said that he wasn't dressed and feared falling. When the Day Service transport support staff arrived, James was in a chair with his trousers at his ankles. Whilst transport staff waited with him, other Day Service staff helped James to dress but he felt he was falling, although he wasn't, and he wanted to remain at home. The ADS CCO was contacted.
- 5.54 The ADS CCO visited James; his care package was increased to manage the level of risk including lunchtime calls, a referral was made for an OT assessment along with a referral for 2 weeks respite care. The District Nurses carried out a Waterlow score assessment⁹, treated an area of dry skin on his sacrum with his consent and provided a pressure relieving cushion. This was documented in James' care plan.
- 5.55 On the 07.03.2016, an OT visited James, he mobilised with their assistance but became distressed and afraid that he would fall. Possible equipment was discussed with James.
- 5.56 On the 9.03.2016, the GP undertook a home visit due to James having pain in his left side and on walking; the GP noted James' left buttock was sore and tender. The GP documented that urgent referrals for community physiotherapy and an OT assessment to be arranged. A message was left for the Community Learning Disability Nurse to contact the GP
- 5.57 On the 10.03.2016, an OT technical instructor visited James at home; a walking frame was delivered, and James was assessed using it.
- 5.58 On the 11.03.16, District Nurses noted James had a red sacrum and was sitting on a pillow rather than the pressure relieving cushion provided. They advised James to use cushion provided.

⁸ Oedema (Edema) is the abnormal accumulation of fluid in certain tissues within the body. The accumulation of fluid may be under the skin - usually in dependent areas such as the legs (peripheral edema, or ankle edema), or it may accumulate in the lungs (pulmonary edema)

⁹ Waterlow score assessment gives an estimated risk for the development of a pressure sore in a given patient.

- 5.59 On the 14.03.2016, James had a further fall at home; an ambulance was called by carers and James was taken to Lister Hospital, E&NHT Emergency Department. A respite bed was identified at a residential care home primarily for people with Dementia, available from 15th March. James agreed to go there for a 2-week respite period.
- 5.60 **The third key time period covers 15th March 2016- 31st July 2016-** explores the decision making, actions/in-actions and outcomes relating to why James' initial agreed 2-week period of respite in a Residential Care Home continued for several months until his admission to hospital on 24th July 2016. James extended admission to the Care Home continued **without** an assessment and despite an expression of preference by James and his family to return home or move to a care facility closer to family.
- 5.61 On the 15.03.2016, James was admitted to care home for 2 weeks respite care. District Nurses continued to visit daily to support James with monitoring of his Diabetes including administration of insulin. The GP was informed.
- 5.62 On the 16.03.2016, James registration with the previous GP practice was ended and a "GP to GP" message sent to the GP surgery linked to the care home (noted that process commenced by social worker). On the 18.03.2016, James had a "New patient consultation" with the new GP, though limited medical or social information was available.
- 5.63 On the 20.03.2016, an OT visited James at OC. His bed height was assessed, but no further input was recorded. During March 2016 the OT notes record several attempts to contact James' sister but got no reply or return call.
- 5.64 On the 23.03.2016, the "old" GP contacted James' Social Worker as they had noted that James had de-registered and queried this due to understanding that the respite stay was for only 2 weeks. They advised that James would need to be re-registered on his return to his bungalow.
- 5.65 On the 01.04.2016, the ADS CCO completed a 2-week review of James' placement at the care home. James was needing a substantial amount of support and not clear if he wanted to return home. His family reluctantly agreed for James to remain in the care home – though it is not clear for how long or what the support/intervention plan was. It is recorded that the Home Manager was to refer James for Physiotherapy. The Day Service was advised by the ADS CCO that James did not wish to return.
- 5.66 On the 12.04.2016, the GP visited James who had been refusing food and complaining of sore mouth. Poor dental hygiene was noted – a spray and mouth wash were prescribed.
- 5.67 On the 23.04.2016, James' family raised concerns with the ADS Team Manager about James' placement in care home and him wanting to return to his bungalow. The family requested that James be placed near to them. The Team Manager arranged for a Social Worker (SW), who was not James' allocated SW to visit him in the care home. A different SW than James' allocated SW was requested by Team Manager due to some of the concerns raised by his family. The SW recorded that James said he doesn't want to be near his family but that he would like to go home to his bungalow. SW noted James' posture and queried the pressure this was placing on his neck.
- 5.68 On the 20.05.2016, further to a letter from the cardiac consultant requesting a reduction in his medication for congestive cardiac failure – this had been increased

- in clinic – the GP undertook a review of James’ medication. The GP’s notes state that OC staff report that James is still unsteady on his feet and had had a fall 2 weeks previously.
- 5.69 On the 01.06.2016, James’s family emailed the ADS chasing the physiotherapy referral and the possibility of James living closer to them. ADS records state that an Independent Advocate is to be requested due to the differing views of his family and James about his future placement. They also recorded a grade 2 pressure ulcer on his sacrum.
- 5.70 On the 29.06.2016, ADS received an email from the Independent Advocate concluding that James did not want to remain in the care home, he wished to return to bungalow or a placement closer to his family. ADS record an email sent to nursing colleagues to ask about the physiotherapy referral.
- 5.71 08.07.2016 James’ family raised their concerns and sought help to address these with the Director of Health and Community Services HCC. A meeting was held between the family and senior managers within Health and Community Services, at which a number of actions were agreed: James was allocated a Social Worker as his case manager, a private physiotherapist was to be commissioned; arrangements were to be made for befriending and talking books for James; Needs Assessment Form ‘C’ to be completed; referrals to be made to explore Local Authority accommodation nearer to his family; and a referral to be made for a Speech and Language Therapy (SALT) assessment due to James’ eating and drinking difficulties and weight loss. It was noted that James had developed a grade 2 pressure ulcer. The family were advised that their concerns were to be treated as a formal complaint and investigated under the HCC Complaints Procedures.
- 5.72 On the 15.07.2016, the Social Worker and Physiotherapist requested the GP visit James as they were concerned that he might be depressed. His family were also concerned about the deterioration in his mood, though the care home staff did not believe James was depressed. There were concerns also about James’ posture: he was noted to be sitting with his head bowed and his chin almost on his chest. This had worsened in care home; the Physiotherapist was concerned that there might be some underlying damage. GP made a referral for an X-ray further to Physiotherapist concerns. The GP suggested that the family speak with her directly if they were concerned about James’ mental state.
- 5.73 On the 17.07.2016, the GP visited James out of hours – he had a cough/chest infection and antibiotics were prescribed.
- 5.74 On the 18.07.2016, the ADS Case Manager (Social Worker) made a joint visit with James’ brother following his raising his concerns about a possible chest infection being treated with antibiotics. The ADS Case Manager emailed the Learning Disability Health Team staff about James’ neck, weight loss and purple folder. It is recorded that referrals were made for a Speech and Language and Dietician assessments and alternative living arrangements for James.
- 5.75 On the 19.07.2016, nutritional and skin assessments were completed by the District Nurses. James’ sacral area was noted to be ‘sloughy’, with no dressing in place. This was discussed with the care home staff. James was also noted to have a 1.5cm x 1.0cm scab to his left elbow. A Dysphagia screening was carried out with the care home via telephone by a SALT, who was advised that James was worried about choking but that this had not happened, and care home staff now assist James to eat. A face to face SALT assessment booked for 26.07.2016.

- 5.76 On the 21.07.2016, the GP received the result of the X-ray of James' spine: it was satisfactory with no collapse identified.
- 5.77 On the 22.07.2016, the GP visited James due to further concerns regarding his chest infection; further antibiotics were prescribed. James' general condition had worsened. The GP records that all agree that the care home is not the right place for James. The District Nurses provided the care home staff with wound care advice, including turning, for James' pressure ulcer and his sacral wound was photographed.
- 5.78 On the 24.07.2016, the care home requested a GP out of hours visit. Based on a 10-day history of cough, antibiotics for chest infection, lethargy and feeling unwell, James was admitted to Lister Hospital, E&NHT. The Hospital records state he was admitted and treated for severe pneumonia¹⁰, acute kidney injury and microcytic¹¹ anaemia. The treatment included Intra-Venous fluids, antibiotics and a blood transfusion. James also diagnosed with moderate oropharyngeal dysphagia¹².-he was prescribed thickened fluids and mashed or smooth food, with attention to his postural position when eating and drinking, due to his neck weakness. James was supported by the Hospital's Learning Disability Liaison Nurses.
- 5.79 On the 26.07.2016, a SALT assessment of James was completed in hospital, and a plan put in to place for stage 1 fluids via spoon, pre-mashed food, upright positioning and post meal mouth care.
- 5.80 On the 28.07.2016, James' condition deteriorated, Oxygen therapy and other interventions were continued. His Consultant had a discussion with his family about Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) due to James' multiple co-morbidities and being deemed incapacitated at this point. The Critical Care Outreach Team was contacted. The SALT review assessment noted new curvature to James' neck and difficulty in moving food and fluid to his palate. There were no obvious signs of aspiration, SALT had a discussion with Doctor.
- 5.81 On the 29.07.2016, James' condition was not improving; the Critical Care Outreach Team undertook a review on the ward.
- 5.82 On the 30.07.2016, a discussion was held with James' family about his deterioration. It was agreed to contact them if James' condition changed.
- 5.83 On the 31.07.2016, James' condition deteriorated further, and he passed away at 12.00 midnight, RIP.

¹⁰ Pneumonia- is swelling (inflammation) of the tissue in one or both lungs. It's usually caused by a bacterial infection. At the end of the breathing tubes in your lungs are clusters of tiny air sacs

¹¹ Microcytic anaemia-is defined as the presence of small, often hypochromic, red blood cells in a peripheral blood smear and is usually characterized by a low MCV (mean corpuscular volume). Iron deficiency is the most common cause of microcytic anaemia. Common symptoms of microcytic anaemias include: fatigue, weakness, and tiredness

¹² Oropharyngeal dysphagia- is a difficulty with swallowing caused by disorders of the nerves and muscles in the throat. These disorders weaken the muscles, making it difficult for a person to swallow without choking or gagging

6. Findings and Analysis of Themes

- 6.1 The findings identified from the chronology, IMRs and learning event have identified good practice along with opportunities for improvement and some gaps. The learning points are described under the themes below:

6.2 Joint working, communication and information sharing

It was clearly evident that James was a popular character in his community, where he had lived independently for over 20 years with minimal support. James had built strong trusted relationships with staff at the Day Service, the Community Learning Disability Team (CLDT) and Adult Disability Service (ADS), his GP and the Practice staff and the care agency. There was good evidence of consistent and regular joint working and communication between the Day Service and CLDT and also between CLDT and the GP surgery. Indeed, there were examples of staff, particularly Day Service staff but also CLDT and his GP going the extra mile and supporting James in a very person-centred way, making reasonable adjustments to empower James. This included support with banking, additional care planning and his physical health and wellbeing. The chronology and IMRs highlighted compassionate and caring actions with staff making time for and with James, listening to and supporting him with his worries and promoting his independence.

There were clear and defined mechanisms for communication in relation to James' physical health and wellbeing between the Day Service, his family and CLDT and the GP and CLDT. However, as James' needs changed and his health declined there was almost an over-optimism about James' ability and capacity and their implications for his long-term prognosis, which wasn't communicated or discussed and planned for with James, his family and all agencies/services together. At the learning event, front line practitioners recognised this and posed the question 'whose job was it to talk with family, who was the overall co-ordinator and communicator between James, his family and all agencies?' It was identified that if this had been clear, continuity and consistency would have been improved. One of the recommendations in the Learning from every Death Review (LeDeR)¹³ annual report 2018 was the continued need for guidance on co-ordination and information sharing. The Government response recommended 'establishment of a named care coordinator for all people with learning disabilities with two or more long term conditions (related to either physical or mental health)'. At the learning event it was identified that co-ordination and communication is a recommendation from a recently published SAR and is being actioned via the local LeDeR group, overseen by the SAB.

There was a missed opportunity to recognise the combined impact of James' complex co-morbidities and ageing with James and his family to plan based on James choices and wishes. This Review and learning event have identified that communication with James and family about his health conditions, specifically when newly diagnosed with ulcerative colitis and his health was deteriorating, could have been better. It is not clear what information James was given about ulcerative colitis. The chronologies and IMRs did not

¹³ LeDeR- is the first national programme of its kind aimed at making improvements to the lives of people with learning disabilities. Reviews are being carried out with a view to improve the standard and quality of care for people with learning disabilities.

make any reference to any accessible/easy read information that James was given or had at home. 'My Purple Folder' ¹⁴ is used locally for and with people with a learning disability to support and empower understanding and management of an individual's health needs and interventions. There was no reference to 'My Purple Folder' by any agency in the chronologies and IMRs. This was raised as a question and it was clarified at the learning event, that James did have a 'My Purple Folder' but that he chose not to use this. Whilst this was James' choice, with increasing and changed health needs this should have been explored jointly with James, his family and all those who knew him well to inform planning and maximise opportunities for consistent understanding of current holistic needs. Family members advised the Independent Chair and Independent Author that they were not aware that James had such a folder, which they would have been happy to promote use of.

James was coping with significant, increasing and distressing symptoms due to his bladder condition during 2015; then in December 2015, he suffered a large rectal bleed and was diagnosed with ulcerative colitis which impacted on the control of his diabetes; opportunities to help James, as well as his family and support staff, understand this were not maximised. James' quality of life, independence and wellbeing were impacted on greatly by the symptoms of his existing health conditions, then following the emergency hospital stay in December 2015 and the diagnosis of ulcerative colitis, his declining physical health and confidence affected him further.

There was evidence of good practice with discharge planning with the Clinical Care Navigator, E&NHT, being part of this along with James, his family and ADS, who then made timely referrals to the Rapid Response/Home First team, HCT, for an OT assessment which happened on the day of discharge. Planning and understanding of James' changed health needs could have been co-ordinated more consistently if a post-discharge review and planning meeting had been facilitated with James, his family and all agencies/services involved with him.

James could not read and write and had given permission for CLDT staff to support him with medical appointments, which was flagged on his GP records at the surgery he was registered with for over 25 years. When James was admitted to care home and registered with the local GP surgery, due to each practice using different clinical electronic systems which restricted sharing information, this flag and detail was not visible to the new GP surgery. Although, paper records were requested these were not received until after James had passed away. It is noted that at the time GP records management was going through a major change with a new national provider/co-ordinator, which may have impacted on the lack of timely delivery of James' records. One of the questions raised at the learning event however, is 'how can records be shared and viewed across and between agencies to improve continuity between social care, health, care homes, consider reviewing information sharing?'

As all records held by the Care home about James' admission and stay have been lost, it is not clear what information the Care home received and requested about James and his

¹⁴ 'My Purple Folder' is a locally developed folder containing important information about an individual's health needs, this includes a 'grab sheet' which details critical information for consideration if admitted to hospital. The folder uses accessible/easy read information

needs or what the person-centred care plan was that was agreed for the initial 2 weeks of respite.

Learning points 1-5: Joint working, communication and information sharing

1. Where there are multiple agencies and professionals involved in the care and support of an individual with a learning disability and complex/multiple physical health care needs, it is critical to have a clear plan and effective mechanisms for communication and information sharing, including who or which agency takes the lead on co-ordination, communication and information sharing. This should include involvement of any family.
2. It is critical to have a clear plan, with effective mechanisms for communication and escalation to inform decision making when needs change and/or concerns arise about the care and support provided.
3. Using mechanisms such as accessible information/easy read information for and with a person with learning disability who cannot read or write supports understanding and promotes independence.
4. Post-discharge joint working and planning to review support needed, provided by who, when and why. Jointly drafting with an individual and, where appropriate, those that know the person well, an agreed plan.
5. Improved mechanisms for information sharing, considering what can be done electronically and ensuring that mechanisms are well understood and embedded.

Recommendations:

- 1) Joint working across health and social care to review and revise as necessary, the process for care co-ordination and communication for any adult at risk¹⁵ with two or more long term conditions (related to either physical or mental health) and support and intervention from more than one agency**
- 2) Information sharing agreements to be reviewed across health and social care and clarification sought that both electronic systems and ways of working are in place to share relevant information for an adult at risk:**
- 3) Review of Easy Read information available relating to complex health conditions across health and social care**

6.3 Person centred assessment, planning and working, understanding complex co-morbidities, frailty/ageing and changing health and wellbeing

From the chronologies, IMRs and learning event, there is a clear picture that, with support from his family, the Day Service, health and social care colleagues including his GP, the Community Learning Disability Team, his Social Worker and other community colleagues, James had, until 2015/16, lived a good quality independent life in the community. The support included managing his multiple and very complex co-morbidities. In December 2014, James suffered a significant heart episode resulting in the fitting of an Implantable

¹⁵ The Care Act 2014 defines an adult at risk as: Someone over the age of 18 who has a need for care and support. Someone who is experiencing or is at risk of neglect or abuse.

Loop Recorder to monitor his heart rhythm. During 2015, James was struggling with increasingly distressing symptoms of UTIs, frequency to pass urine with increasing incidents of incontinence as well as diabetes for which he now had daily administration of insulin due to its management being affected following the heart episode. James was supported to attend many appointments throughout 2015, these included regular reviews with his GP and other primary health needs such as vision, hearing, cardiology, and urology. The changes and deterioration in his health affected his confidence to live his life as he had previously - for example he stopped going out at the weekends, visiting his family and socialising. This necessitated the provision of 'meals on wheels' and increased support. Possibly recognising that he needed more support and the fact that he was getting older, at his care needs review meeting with his Social Worker in September 2015, James indicated that he no longer wished to live alone in his bungalow, he would like to live with more support, such as in a residential care home. A referral was made for local provision, close to the Day Service as James wanted to continue going.

James' Consultant Urology Surgeon sought a view from a Consultant Anaesthetist about the risks of surgery for Bladder Neck Incision; James, with support from CLDT, attended an appointment in October 2015 where he was deemed suitable for the surgery, but James declined to go ahead. It is documented that James' family wanted him to have the surgery, but it is not known how the information about the surgery and what it entailed, as well as the benefits and risks, were presented to James.

In December 2015, James was admitted to Lister hospital following a large rectal bleed; he underwent investigations resulting in the diagnosis of ulcerative colitis and had a range of treatments, including blood transfusions, and the management of his symptoms with medication. Again, this episode of ill health impacted on the management of his diabetes. James was in Lister Hospital for a total of 7 weeks, then a further 2 weeks in Queen Victoria Memorial (QVM) Hospital, a total of 9 weeks. It is well documented that 'a stay in hospital over 10 days leads to 10 years of muscle ageing for some people who are most at risk'¹⁶. Since 2015, there has been increased understanding and recognition of frailty due to ageing and complex co-morbidities. What we have learnt from the chronologies, IMRs and learning event is that James was 'optimised to pre-admission mobility'; however, when discharged home, he had lost confidence and continued to say that he felt tired and unwell. He was mobilising less and sleeping in a chair due to his bed being too high. As described, 'frailty' and approaches to minimise its impact are now much better understood, with helpful national guidance and campaigns such as 'End PJ paralysis' (national campaign to increase mobility when in hospital). Due to records being lost from QVM, there is no documented evidence of any discharge planning, joint assessment or care plan. There is also no documented evidence of any consideration of whether or not James' complex healthcare needs met the Continuing Health Care Criteria.

Whilst James' package of care was increased and referrals for assessment and support regarding walking aids and physiotherapy were made, there appears to have been an over-optimistic view and unrealistic expectations of James' ability to cope with his changed health needs. James was expressing concern that he would fall and more latterly feared choking. His reduced mobility and sleeping in a chair impacted on his existing health conditions. It would have been beneficial for all agencies involved to come together

¹⁶ 'A guide to reducing long hospital stays, NHS Improvement 2018

with James and his family to clarify James' health and wellbeing, frailty, co-morbidities and plan together to minimise the risks and maximise his quality of life. This should have included a difficult discussion about current preferred living arrangements and future end of life planning. James' complex and co-morbidities were being managed well but the impact on James' frailty, physiological and psychological wellbeing of additional conditions, exacerbations with current conditions and general ageing were not openly discussed with James, his family and agencies together. It would then have been possible to have a realistic, whilst still being ambitious, shared and understood plan to maximise James' quality of life and independence. Plans should also have included escalation actions should James deteriorate further.

Within 3 days of his discharge home following rehabilitation at QVM Hospital, James had a fall at home necessitating a visit to hospital. Whilst arrangements were made to increase his care package, his GP was asked to visit him at home and referrals made for Occupational Therapy and Physiotherapy assessments at home, a multi-disciplinary meeting was not convened to review James' care needs under relevant health and social care processes, which is a missed opportunity to ensure communication and co-ordination to meet James needs. This led to the expectation of James' family that he would be returning to the Day Service.

There is now a widening body of research and evidence of experiences of unmet health needs and premature deaths of people with a learning disability. One of the acknowledged issues is that of 'Diagnostic overshadowing'¹⁷ where clinicians tend to attribute physical and mental health symptoms to the person's learning disability. Part of the learning from and a theme identified within this Review is the opposite, whereby some professionals and his family were over optimistic about the prognosis for James and viewed action or in-action as being due to unequal treatment of and for James due to his learning disability as opposed to being focused on the complexity and co-morbidity of health conditions and the impact of ageing.

Learning points 6-8

6. It is important that all levels of staff in different agencies as well as individuals and families understand complex co-morbidities, the impact of ageing and frailty as well as changing health needs to be able to recognise and support/promote quality of life and maximising potential. Engagement with and input from relevant health specialists such as frailty services, and community matron for long terms conditions is essential.
7. Use of formal and joint review and planning processes, across health and social care. Focusing on the person as a whole to appreciate their needs, wants and choices along with escalation actions resulting in a well understood plan, actions and clarity of lead communicator and co-ordinator.
8. GP approach to personalised care planning, with a mechanism for flagging and tracking changing needs, was beneficial.

Recommendations:

- 4) Awareness raising to improve understanding about Frailty, rehabilitation, complex health conditions and co-morbidity**

¹⁷ Diagnostic overshadowing- is the term used which describes the tendency for clinicians to overlook symptoms of mental and physical health problems in clients/patients with learning disabilities and attribute them to being part of the "having a learning disability", Mason and Scior (2004)

5) Review of formal assessment and review processes for social care and person-centred planning

6.4 Mental capacity, choice and control

James relied on his trusted relationships with Day Service staff to help him with his correspondence and banking. This support was in addition to support provided by his sister and brother. Acknowledging that James needed support with understanding the complexities of his health needs and decision making, plans were in place and there was clarity that the CLDT supported James with all medical appointments etc. and liaised with his GP regularly. His GP had a personal care plan which was reviewed regularly detailing James' needs and any necessary adjustments. The Day Service were the 'glue' for James, connecting with his family, health and social care colleagues and the Care agency. Staff acted on behalf of James, as requested by him, to contact relevant colleagues and also raised concerns about his wellbeing, safety and vulnerability e.g. when he was leaving his door open and giving money to care agency staff without receipts, when sharing with staff his frustration, distress and pain with frequency of needing the toilet and UTIs. Staff at the Day Service also raised concerns about decisions being made for him by family which he was not happy about e.g. gardener and decorator coming to his home. The question was raised about James' choice and control; this was based on there being some evidence of James not being listened to e.g. about where he lived and not wanting his bungalow decorated. In early 2015, an appointment for review the risk of an anaesthetic and surgery for bladder neck incision had been cancelled by his sister; she had contacted the Day Service to say this was thought to be best as had been discussed at the previous appointment with the Consultant Urologist and could be discussed again at the upcoming appointment. This was not however queried in terms of James' right to make any such decision himself.

James requested that his sister and brother not attend his Day Service review in July 2015 and at the review stated that he no longer wanted his family to be contacted or copies of health appointments sent to them. This was respected but it is not clear if this was discussed openly with his family. It is evident that his family were very important in James' life and whilst staff rightly should empower, uphold and respect his decision making, knowing how important his family should have raised their curiosity as to this change of mind and was a missed opportunity to empower James' voice through Independent Advocacy. In October 2016, James asked for his sister to be sent copies of his letters/appointments as he was not getting out to see her, when he would usually take letters with him. James was inconsistent in some of his decision making and the reason for this was not explored with him.

Implementation of the Mental Capacity Act 2005 was tacit but not suitably evidenced relating to James' medical treatment and his wishes relating to information sharing. Although very capable of talking about what he wanted and needed, this Review has identified that James 'didn't like to upset people' and this may therefore have affected his choice and control. The learning event has highlighted that James may have been sharing a different opinion or voicing different wishes to his family and agencies. The engagement

of an Independent Advocate didn't happen until James was at care home and James and his family had differing views about his future placement. Use of advocacy to support James with decision making for specific decisions such as medical treatment and housing was not considered until the last few months of James' life. James indicated that he wanted to return to his bungalow or live near to his family. Although this was confirmed by the Independent Advocate on the 29th June 2016, and James' needs assessment shared with local authorities where his sister and brother live, this was not until the 18th July 2016 when James' health was deteriorating, and he was subsequently admitted to the Lister Hospital on 22nd July 2016. Also, it has been identified that the concept of living at home or near to family with his changed health needs required further exploration with James.

The first principle of the Mental Health Act 2005 (the MCA) is '1) Assume Capacity- Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise'. This means that you cannot assume that someone cannot make a decision for themselves just because they have a particular medical condition or disability. However, the Act goes on to describe the 2 stage functional test of capacity:

Stage 1. Is there an impairment of or disturbance in the functioning of a person's mind or brain? If so,

Stage 2. Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?

The MCA says that a person is unable to make their own decision if they cannot do one or more of the following four things:

- understand information given to them
- retain that information long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals to inform any assessment of someone's capacity.

The assessment must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? You should be able to show in your records why you have come to your conclusion that capacity is lacking for the particular decision.

Whilst this Review has found that James was supported to make decisions, as he had a learning disability there should have been documented evidence of applying the 2-stage test. There was no formal assessment of James' capacity documented or considered in relation to key complex decision making e.g. housing and health.

There were concerns raised about James' vulnerability in relation to some of his actions, e.g. leaving his door open, withdrawing and keeping on his person large amounts of cash and giving money to care staff without receipts. The MCA recognises an adult's right to make Unwise Decisions, but its supporting Code of Practice does require their capacity to be reviewed if they continue to make the same Unwise Decisions. This does not appear to have happened in James' case. Whilst these concerns were escalated to ADS and CLDT, the lack of any active consideration of safeguarding or the application of the 6 safeguarding adult principles was identified in the learning event as a missed opportunity/area for development. Consistent and regular supervision for and with James' allocated Social Worker would have provided the opportunity for reflection on James' needs, actions taken and identification of any gaps or opportunities to maximise health, wellbeing and quality experience for 'service users' on practitioners caseloads. The gap in terms of regular supervision for James' allocated SW was highlighted as part of the learning in the IMR from ADS.

Learning points 9 and 10

9. The Mental Capacity Act provides a legal framework to assess capacity and use 'best interest' decision making, involving those who know the person well e.g. family, when the individual has been identified as lacking capacity. This should be adhered to and communicated and documented effectively.
10. Awareness of the 6 Safeguarding Adult principles, individual responsibilities within the Care Act 2014 as well as good understanding of the management of process to report and respond to concerns/complaints including escalation was not consistently utilised or followed.

Recommendations:

- 6) Mental Capacity Act 2005, its principles and 2-stage test; there needs to be further joint working to increase understanding and subsequent compliance with MCA and the supporting Code of Practice**
- 7) Supervision and reflection**

7. Conclusions

This Review has provided the opportunity to collectively hold the mirror up to reflect and review and identify learning, including any gaps or missed opportunities along with areas of good practice, in James' circumstances, his life in the community and the context of his death.

The findings identify a number of areas of good practice with individual staff and agencies going above and beyond expectations and their duty to support James to live a full and good quality life, building and sustaining relationships.

James lived with a large number of complex physical health needs, each on their own presenting challenges for James and how he lived his life; they also combined to have a major impact on his long-term prognosis. Having more than one long term condition with episodic exacerbation and then experiencing a significant potentially life-threatening rectal bleed leading to a prolonged stay in hospital, must have been distressing for James and those who loved and cared for him. Timely and joint planning with James and his family, involving those who knew him well and understood his health and other needs may have facilitated proactive planning informed by James' wishes to enhance his quality of life at the end of his life.

There are 9 key learning points which have been identified relating to how James' choice and control, hopes, wishes and quality of life, particularly as his needs changed due to the impact of his deteriorating health, could have been maximised. The learning highlights the need for change in systems and culture to work better across organisational boundaries to recognise and meet holistic individual needs for any individual with complex co-morbidities whom has support and intervention from multiple agencies. Service focused rather than person focused decision making, reactive responses rather than planned and a lack of co-ordination negatively impacted on James' experience and quality of life.

There was a lack of 'professional curiosity' following James' admission to care home, which saw staff accepting his frailty and the lack of information available, including structured care plans. Failing to be curious, asking why, or what or how, impacted on the quality of care James' experienced in the last few months of his life and therefore on his quality of life. Improved communication, co-ordination and effective joint person-centred planning will, if implemented, facilitate culture change which will be beneficial for individual experiences of care and support. In addition, the care home was registered to provide residential care for individuals with dementia not rehabilitation for individuals with complex physical health needs and/or a learning disability. Staff awareness and understanding relating to James' complex co-morbidities as well as any impact that his learning disability may have had on his understanding of his condition and needs was very limited. Oversight and support for James' health needs e.g. diabetes came from daily input from the District Nursing Service.

It is a concern that the effectiveness of this Review was limited by the loss of certain crucial records; the lack of any records from the Queen Victoria Memorial Hospital and the loss of Care home's records has meant that important information that should have

illuminated this Review has been lost. It is of particular concern that the care home sent their records, which contained personal information about James, to ASC unrequested by an unsecure method. This has been raised formally as a concern and it is understood that changes have now been made to ensure that such records are managed appropriately in future.

His family have highlighted that staff at the care home were not made aware of James' medical conditions and told his family that they didn't know why James was placed there or where he came from. As detailed above, due to loss of notes this Review has not been able to view any records relating to James' admission to OC and therefore cannot confirm whether any admission care plan and/or person-centred plan was completed and in place for James or not.

Whilst this Review has found that individual and collective actions or any omissions did not lead to James' death, a lack of person-centred planning and co-ordination impacted on single agency and multi-disciplinary decision making. This Review has found that the impact of poor decision making, co-ordination and planning impacted on the quality of life that James could and should have had.

Recommendations

1. Joint working across health and social care to review and revise as necessary, the process for care co-ordination and communication for any adult at risk with two or more long term conditions (related to either physical or mental health) and support and intervention from more than one agency. The process should ensure that:

- All involved are clear about their own and others' roles and responsibilities
- There are clear and explicit communication mechanisms
- All involved are clear of what circumstances should trigger calling a Multi-Disciplinary Team (MDT) and their accountability for this
- There are clear and explicit escalation processes including to and with whom
- Expectations and actions relating to Admission and Discharge to in-patient and residential facilities are clearly defined and
- There are clear and explicit processes for End-of-Life decisions and planning – also linked to 4 below

2. Information sharing agreements to be reviewed across health and social care and clarification sought that both electronic systems and ways of working are in place to share relevant information for an adult at risk (It should be noted that considerable work has taken place in this area since this case was explored and therefore this recommendation reinforces the continued joint working to review and update through the various workstreams on information sharing:

- Existing information sharing policy/policies should be reviewed to ensure that there is sufficient detail to instruct and empower all frontline staff of circumstances to and method for information sharing for an adult who may be deemed to be at risk
- The review should include 'permissions' within electronic systems and protocols to enable information sharing between different electronic systems and
- Clarity of understanding of 'flags' on systems for additional needs/reasonable adjustments

3. Review of Easy Read information available relating to complex health conditions across health and social care:

- Learning disability staff in both health and social care, including Health Facilitators, to work with representatives from hospital and community staff including GPs to review easy read information available relating to specific health conditions, consider raising awareness of and giving access to the 'Easy health' website which has a large number of easy read leaflets about common health conditions and investigations;

- Review the use of and information within the 'My Purple Folder'. This review should include work with people with a learning disability and families to understand and embed what works well and/or needs to change within the 'My Purple Folder' and
- Review and monitor actions to promote the use of the 'My Purple Folder'

4. Awareness raising looking at Frailty and rehabilitation-, complex health conditions and co-morbidity:

- Representatives from hospital and community (senior clinical, nursing, community nursing, GPs, General Practice nurses and social workers) to lead a learning session for health and social care colleagues focused on complex health care, co-morbidity and frailty. What these are and the impact on the person at the centre and
- To consider development of information for patients with a learning disability and families which describes co-morbidity, frailty and the impact for the patient to empower the patient and family with choice and control in planning for quality of life
- Health Liaison Team to lead training sessions to improve professional knowledge

5. Formal assessment and review processes: Adult Social Care should take the lead on working in partnership with other relevant stakeholders to:

- Review processes and procedures to ensure that assessments under the Care Act 2014 are person-centred and completed using Independent Advocates where appropriate and that these are reviewed at least annually
- Provide assurance that all assessments are holistic and involve health and other partner agencies and those who know the person well
- Review and seek assurance of implementation of clear escalation processes should agencies be concerned that multiagency working is not happening/being appropriately implemented
- Review the process for person centred planning (PCP), development of a PCP which is followed by the MDT and
- Provide assurance that all care packages are reviewed at least annually and always following a change in need

6. Mental Capacity Act 2005, its principles and 2-stage test; there needs to be further joint working to increase understanding and subsequent compliance with MCA and the supporting Code of Practice:

- Seek assurance that MCA and its Code of Practice (CoP) are effectively implemented and that staff feel confident to be able to inform families/significant others of their rights under the MCA i.e. Power of Attorney or deputyships etc, or signpost to agencies who can do this.
- Review how the current MCA training and current systems facilitate the involvement of others who know the person well
- Adult Social Care should review current processes to monitor adherence to the MCA and CoP and in the implementation of assessments under the Care Act 2014

- Training on MCA and CoP should be reviewed to include case scenarios such as James' where the need for professional curiosity is highlighted

7. Supervision and reflection:

- Seek assurance that mechanisms for supervision and reflection are embedded across health and social care
- Review the extent to which the supervision process facilitates/triggers escalation and review and
- Review arrangements for supervision to facilitate the opportunity for health and social care staff to review actions and consider implications of individual needs on system working and communication

8. About the Independent Chair and Independent Author

Independent chair

Pete Morgan was commissioned to act as Independent Chair for this MAPCR, chairing the SAR Panel and working with the Independent Author to draft the report. Pete has been a qualified social worker for almost 40 years and has specialised in Safeguarding Adults for the past 16 years. Since leaving local authority employment he has chaired 2 Safeguarding Adults Boards, been a member of the Advisory Group supporting the drafting of the Safeguarding Sections of the Care Act 2015 and authored several Safeguarding Adults Reviews.

Independent author

Judi Thorley was commissioned to work with the SAR Panel to undertake this Review and act as Independent Author. Judi is both a Registered Learning Disability and Registered General Adult Nurse with over 33 years' experience working within the NHS. Judi has worked in a range of services in leadership and clinician roles within Learning Disability, Acute services, Education and commissioning. Judi's previous roles include strategic regional Lead for learning disability health and safeguarding adults and from 2013 until 2018 Chief Nurse and Director of Quality and Safeguarding within 2 Clinical Commissioning Groups.

Since 2018 Judi has continued in a part-time role within the NHS and has carried out a range of independent consultancy work encompassing service review, review of arrangements for adult safeguarding, SARs and development and delivery of leadership development programmes.

James' Family Statement

Thank you for meeting us recently to discuss the review. We have received the amended version following our meeting on October 23rd. We would like to acknowledge the thoroughness of your review compared to the earlier report. It is clear that you are very dependent on the quality of the information in the agencies IMRs. The fact that three agencies managed to lose their notes has not helped you in your investigations.

We would like to make some points that we consider to be important for all those who were involved in James's care and we would like to be included in the report. If you can't include them in the report then we would like you to consider attaching this statement in an appendix. The reasoning behind this is that the review is dependent on the data in the IMRs. The IMRs reflect the thinking, decision-making and actions of the agencies. James voice, experience and his families are not central or particularly evident. In our view this limits the impact of the review and reduces the learning that might occur. Here are the points we wish to make in our contribution to the review.

1. The care home where James was placed is a residential home for people suffering with dementia and it has not been acknowledged that therefore it was a completely unsuitable placement for an adult with learning disabilities.
2. Furthermore, Judi pointed out in our meeting that James' complex and long-term physical needs could not be catered for in this care home.
3. James' health problems were never raised in any discussions with us.
4. We think that the staff at the care home had not been informed about his medical condition. In fact when we spoke to members of staff they said they did not know why he was there, where he came from or anything about his life circumstances.
5. It was pointed out in your review that James's health was deteriorating, and he would need more care. This was a known fact by the agencies and yet was not considered by them when placing him in the care home.
6. The over optimistic attitude regarding James's capacities seems to contradict the medical evidence that was available to all which made clear that James was not going to get better due to the chronic health problems he faced.
7. Being placed in the care setting that resulted in a worsening of his condition because his physical health was not being regularly monitored could also be emphasised.
8. We are not disputing his serious health problems, but we are raising a serious question as to why the agencies did not take them into consideration when placing him at the care home. For example, why was not a nursing home considered or more help at home i.e. someone to stay with him overnight?
9. We would challenge the 'over optimistic' rationale as a convenient way to explain away what a lack of planning was clearly, coordination, and frankly incompetence on the part of all the agencies.

10. In our view the total lack of any attempt to involve the family in planning for James is not really brought out clearly enough.

11. In the review it is stated that:

'The review has found that individual and collective actions or any omissions did not lead to James' death.'

But we think that the poor care and planning meant that his life after admission to the care home was demeaning, painful and led to an early death due to contracting institutional based pneumonia, which if he had been a resident in a home that was better equipped to look after physically frail people with more knowledgeable staff, it could be argued James' chest infection leading to pneumonia could have been treated more rigorously at an early stage.

12. We believe that this is an important point that needs to be conveyed as it has implications in regard to the consequences of the poor decision making.

13. At no point was there any real attempt to maintain James in his own home. An assessment should have taken place as to how to sustain him in his home with extra support i.e. overnight care with staff staying with him, rather than just placing him in a totally unsuitable placement.

14. Personalised care was completely lacking.

15. The review is about systemic failures and points for action that agencies can carry out in the light of the review. But we think the painful reality that James had to endure as a consequence of the poor and almost non-existent care he received is also part of the learning and should be acknowledged.

16. There were systemic and individual failings by the authorities, which led to poor decision making with disastrous consequences for James.

17. The three agencies having lost his notes and the subsequent impact this has on the review process also needs acknowledging.