Sandwell Safeguarding Adults Board

Thematic Safeguarding Adult Review (SAR)

Richard and Pat

Overview learning report

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1.Introduction

1.1 This Safeguarding Adult Review (SAR) explores the common themes and associated questions identified from the experiences of both Richard and his family and Pat and her family, in the months leading up to their deaths. Key questions developed identified from the themes have been used to explore learning with and for individual frontline practitioners, managers, organisations, and systems.

1.2 Sandwell Safeguarding Adults Board (SSAB) identified common themes in terms of experience and outcomes for both Richard and Pat. Both Richard and Pat had an identified Learning Disability. In addition, Richard was autistic, and Pat had bipolar disorder. Both also had co-morbid chronic physical health needs.

1.3 Further to scrutiny of the referrals and reflection on the 2 previous SARs, SSAB agreed the need to commission a Thematic SAR to maximise the opportunity for system wide learning.

Context of Safeguarding Adult Reviews

1.4 The Care Act 2014 Statutory Guidance states that the process for undertaking SARs should be determined locally according to the specific circumstances of individual cases. No one model will be applicable for all cases. The focus must be on what needs to happen to achieve understanding, remedial action and, very often, answers for families and friends of adults who have died or been seriously abused or neglected.

1.5 The Care Act 2014 places a statutory duty on Safeguarding Adults Boards (SAB) to undertake case reviews in certain circumstances as set out below.

Section 44, Safeguarding Adult Reviews:

(i) A SAB must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if:
(a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and
(b) condition 1 or 2 is met.

(ii) Condition 1 is met if:
(a) the adult has died, and
(b) the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

(iii) Condition 2 is met if the adult has not died but the SAB knows or suspects

that the adult has experienced serious abuse or neglect.

1.6 The Department of Health's six principles for adult safeguarding should be applied across all safeguarding activity[1] . The principles apply to the review as follows:

Empowerment:	The review will seek to understand how the agencies listened to/heard and engaged with Richard and Pat and applied Making Safeguarding Personal. Involving Richard's and Pat's families in the review
Prevention:	The learning will be used to consider actions for prevention of future harm to others, particularly in relation to holistic, person-centred planning
Proportionality:	Understanding whether least restrictive and person-centred practice was used; being proportionate in carrying out our review objectively considering the impact of the pandemic restrictions.
Protection:	The learning will be used to inform ways of working, actions and professional curiosity to protect others from harm.
Partnership:	Partners will seek to understand looking through the lens of person-centred working, how well they worked together and use learning to improve partnership working.
Accountability:	Accountability and transparency within the learning process

1.7 SSAB commissioned an independent author, Judi Thorley, to undertake this Thematic SAR. The author is independent of SSAB and its partner agencies.

1.8 The aspiration of the approach to this SAR is to maximise learning, to harness collective 'ownership' for change and improvements which will be embedded for the benefit of the whole Sandwell population.

[1]Making Safeguarding Personal https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/making-safeguarding-personal (accessed October 2021)

2. Methodology and Terms of Reference

2.1 Methodology

SSAB has chosen to explore learning for both Richard and Pat together using a thematic approach with Appreciative Inquiry methodology. SSAB agreed this approach recognising the similarities in the poor experiences and potentially preventable outcomes for both Richard and Pat and also their families. Recognising these similarities prompted SSAB to reflect back on the published SARs 'Jeff' and 'Anne'[2] which detailed similar experiences and outcomes. The need to appreciate and use learning already available and avoid 'learning anew' has been identified as a key recommendation in the published Analysis of Safeguarding Adult Reviews, 2020[3]. Specifically, 'Independent Authors and SABs are urged to ensure consideration and relevant use of existing learning from local, regional and national SARs along with findings.

The Independent Author has reviewed and utilised learning and recommendations within SARs 'Jeff' and Anne' and key themes from Richard's and Pat's documented and narrated experiences, as described by family, to develop key questions for exploration to identify learning for individual frontline practitioners and managers, organisations, and systems. A person-centred framework based on the '4 plus 1' (Helen Sanderson Associates Ltd)[4] was used to generate discussion to identify learning.

1. What's working/worked well?
2. What's not working/worked well?
3. What needs to stop or change?
4. What does there needs to be started or more of?

Plus 1 - What actions need to happen?

An individual person-centred 'story' was developed to 'bring to life' the themes and individual experiences of Richard and Pat. The Independent Author developed these using facts and details from chronologies and responses received from questions posed to agencies along with articulated experiences from both Richard's and Pat's families. These stories and learning identified in SARs 'Jeff' and 'Anne' were used to draft key questions at facilitated learning events with frontline staff and managers involved in Richard's and Pat's care.

[2] Published SARs 'Jeff' and 'Anne' https://www.sandwellsab.org.uk/safeguarding-adult-reviews/
[3] Analysis of Safeguarding Adult Reviews 2017-2019, Michael Preston Shoot et al 2020. Commissioned by CHIP - the sector-led Care and Health Improvement Programme, co-produced and delivered by the Local Government Association and the Association of Directors of Adult Social Services in England https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019
[4] The 4 plus 1 questions – person-centred thinking tool http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/4-plus-1-questions/

The identified learning was captured under 4 early warning headings of:

Putting people first,

Staff and culture,

Systems and processes and,

Partnerships.

These 4 headings were adapted, by the Independent Author and a colleague, from the '*Review of Early Warning Systems: Acute and Community Services*', *National Quality Board (NQB) 2010.* This national review was undertaken following the failings at Mid Staffordshire Hospital in 2009. The report identified these 4 headings as essential for shared ownership, delivery, and effective monitoring of high quality safe and effective care and support. The Independent Author believed that these headings would help to facilitate shared learning, stimulate ownership and commitment.

'While systems and processes are important, the report highlights the extent to which success or failure rests on the values and behaviours of staff putting patients and service users first, the culture both within and between organisations', NQB 2010.

Identified actions/recommendations generated from the learning event were discussed and explored further with both families and the Sandwell Learning Disability Advisory Group.

2.2 Terms of Reference

Through appreciative inquiry, person-centred actions, inactions and decisions, and the impact of these, were considered for Richard and Pat, their families and also staff.

Key questions were drafted using Richard's and Pat's individual stories, the above identified themes, and reflection on previous SARs 'Jeff' and 'Anne'. These questions were discussed and refined with the families.

2.3 Engagement with and involvement of family

While the primary purpose of the Safeguarding Adult Review is to set out how professionals and agencies worked together, it is imperative that the views of the individual/family and details of their involvement with the SAR are included in this. In doing so it ensures that this enshrines the principles and practice of Making Safeguarding Personal, a core value signed up to by all agencies working as part of the Sandwell Safeguarding Adults Board. For this thematic review families were asked to work with the author to support the drafting of the Terms of Reference and key questions used at the learning events. Families also considered and gave feedback on the identified actions/outcomes from the learning events.

It is always important as part of a review to introduce the person at the centre of the learning. As this review takes a thematic approach based on the experiences of 2 individuals it is

imperative to state that the Author has sought to understand both Richard and Pat. Who they were, what each enjoyed doing in life, what was important to and for them, who was important to them and what each meant to their families, friends and staff who knew and supported them.

2.4 Agencies involved.

Agencies: involved summary of contact/relationship with Richard and/or Pat	
Sandwell Adult Social Care - Day Services	Provision of Day Services which Richard attended, continued community support during Lockdown.
Black Country Healthcare Foundation Trust (BCHFT)	Community Learning Disability Team including Learning Disability Nurse with special interest in Diabetes, Behavioural Support Team and Intensive Support Team Psychology Psychiatry clinician and inpatient provision
Black Country Integrated Care Board since July 2022	GP practices
Sandwell Adult Social Care	Hospital and community Social Work and Therapy services Duty and allocated Social Workers Commissioned care home placements
Sandwell and West Birmingham Hospitals NHS Trust (SWBHT)	Community and in-patient physical health care services. Clinician, nursing and therapy intervention
University Hospitals Birmingham NHS Trust – Queen Elizabeth Hospital	Orthopaedic inpatient and outpatient
El Marsh Care	Pat's commissioned community provider
West Midlands Ambulance Service (WMAS)	Responded to emergency calls for both Richard and Pat

3. Richard's story

It is always important as part of a review to introduce the person at the centre of the learning. As this review takes a thematic approach based on the experiences of 2 individuals it is imperative to state that the Independent Author has sought to understand both Richard and Pat. Who they were, what each enjoyed doing in life, what was important to and for them. Who was important to them and what each meant to their families, friends and staff who knew and supported them.

Richard was born on the 1st of January 1992 and remained living in the family home with his mother and father. Richard had a sister and a wider family including his aunt whom he had a lot of contact with. Richard was autistic and had a learning disability. He had type 2 diabetes which was managed with insulin, he was also morbidly obese. In April 2020, during the first 'Lockdown' of the Covid-19 pandemic, Richard's Mum was admitted to hospital. Sadly, she died without returning home.

Richard is described as a fun-loving young man. He loved his mobility scooter and used this to get out and about, for example going to the local newspaper shop to get a newspaper every day. Richard loved watching and playing football, he was a regular attendee watching his favourite team, Aston Villa. Richard enjoyed playing on his PlayStation and using his mobile phone to 'wind people up' particularly about football! He was always up for a laugh and made friends easily.

Richard attended a Day Centre where he had many friends and enjoyed activities including carpentry, swimming and playing football. Richard often made Christmas gifts for his family in carpentry. Following the first Lockdown of the Covid pandemic, Richard was offered and enjoyed outreach support in the community.

Richard's Dad is a coach driver and Richard used to love to go along with him on the coach.

There were a number of agencies involved in supporting Richard with his health and social care needs, including: GP, Diabetic Specialist Nurses, Learning Disability Community Team members including Learning Disability Nurse (special interest in diabetes), Behavioural Support Team, Options for Life - day opportunities provider, and Social Workers.

In the Autumn of 2020, it was recognised that both Richard and his Dad were grieving the loss of his Mum. For Richard his grief manifested at times with some changes to and challenges with his behaviour. Richard had input from the Learning Disability Behavioural Support Team. Richard said that it would be helpful to speak with someone about his Mum's death when asked in October 2020, however this did not happen.

In November 2020 Richard had to self-isolate due to having Covid. Then in December 2020 Richard was doing the shopping as his Dad had a broken arm.

In January 2021 Richard fell on ice and sustained a complex fracture to his leg which required surgery. Richard was admitted to Sandwell and West Birmingham Hospital NHS Trust (SWBHT) on the 25th of January 2021. He was understandably anxious about going to hospital due to his recent experience when his Mum went to hospital and didn't return.

Richard was able to consent for the surgery to have metal pins inserted. During his 5 day stay in hospital Richard was described as distressed and anxious. On 27th January Richard was upset as the outcome of his Physiotherapy assessment was that he needed more practice with transfers before he could be discharged home. A referral was made to the Learning Disability Liaison Nurse who visited with Richard and scanned his Hospital Passport onto the hospital system, which gave staff details of how best to support him and what reasonable adjustments to make. It was noted also on 27th January 2021 that Richard's wound was 'oozing', there is no evidence that this was reviewed or referenced again prior to discharge. Richard was discharged home, with a plan for his bed to be downstairs, some equipment to be loaned and a care package to commence. Richard was discharged on 30th January 2021, with a care package commencing 1st February 2021.

On the 11th of February 2021 Richard's Dad contacted the District Nurses as Richard's carers had noticed an unpleasant odour coming from Richard's leg. Having had Covid, Richard and his Dad may not have been able to smell this. It is stated in the chronology that a referral to District Nurses was made by the ward staff at SWBHT on discharge, however, this was not received on the electronic system used by the District Nurses. District Nurses visited Richard on the 12th of February 2021, cleaned and dressed the wound and a plan was put in place for ongoing wound management. On the15th of February 2021 Richard's Dad had an appointment of his own at the fracture clinic. Richard's Dad asked the Doctor to take a look at Richard's leg, which led to him being admitted to SWBHT with an infected limb. The metal pins implanted into Richard's leg had failed, and his ankle was dislocated. His blood sugar was not stable, running very high on admission, probably due to the infection. Restrictions in terms of visiting were still in place due to the pandemic, however Richard's Dad was allowed to visit to support Richard. Richard was extremely upset and anxious and initially refused surgery which was required to remove the metal pins. It is not clear if a capacity assessment was carried out at this time. Richard consented and underwent further surgery to remove the metal pins.

A referral to the Queen Elizabeth (QE) Hospital, which is part of the University Hospitals Birmingham NHS Foundation Trust, was made for a specialist orthopaedic consultation. This experience would be very challenging and emotional for anyone. As an autistic person Richard needed structure and routine, with clear communication. His needs due to his autism, along with the impact of so recently losing his Mum, not being able to see her when she went to hospital and her death, must have made his situation very difficult to deal with.

On the 3rd of March 2021 Richard was transferred to the QE Hospital. On the 14th of March 2021 Richard had further surgery for a below knee amputation due to the extent of infection in his limb presenting no possibility to re-construct. Richard transferred to Rowley Regis Community Hospital, which is part of SWBHT, on the 15th of April 2021. A safeguarding concern was raised with Sandwell Council by staff at QE Hospital on the 7th of April 2021, having observed Dad 'hitting/slapping' Richard. Richard's Dad admitted that he was finding things very stressful and difficult to deal with. The case was reviewed, and a Best Interest meeting was held. A plan was agreed for additional support to be put in place by Richard's Social Worker on discharge and the case then closed.

Despite the knowledge that Richard would not be able to use his wheelchair at home and would be isolated in one room with no access outside, plans progressed for his discharge home and attendance for rehabilitation as an outpatient, with equipment being delivered to Richard's home. Richard's family raised concerns with his Social Worker on the 30th of March 2021 about the safety of his discharge home on the 30th of January 2021 following his admission to SWBHT and surgery to his leg on the 25th of January 2021. The family raised concerns about the lack of support offered to Richard when he was discharged on the 30th of January 2021 which included concern that Richard did not have a district nursing visit and delays with his package of care recommencing. Richard's family believed that this lack of support resulted in Richard sustaining an infection and requiring a below knee amputation. A Multi-Disciplinary Team meeting was held on the 7th of April 2021 where it was agreed that returning home was not in Richard's best interests, due to the isolation and potential impact on both Richard and his Dad. It was agreed to explore the option for supported living and for the Learning Disability Nurse to discuss with Richard and carry out a Mental Capacity Assessment as required. There was poor and miscommunication with both Richard and his family relating to the above options. One of Richard's family's concerns related to the inconsistency with allocated Social Workers. On reviewing Richard's case for this review, Sandwell Adult Social Care (ASC) confirmed that several different Social Workers were allocated to the case, resulting in little continuity. Communication between ASC, Richard's family and the hospital could have been clearer and there was a lack of clarity of professionals involved.

The safeguarding concerns about Richard's care, treatment, and discharge after his initial admission for the complex fracture raised at the end of March 2021 with Sandwell Council. were investigated and the outcome documented as: -

"there was lack of oversight into the wound care during and after Richard's admission on 25 January 2021; that Richard was discharged without relevant social care assessment being requested by filling the appropriate "Transfer of Care" paperwork. This jeopardised general safety and well-being and contributed to the delay in detecting the infection early. It was not possible to determine the failings as the main causational factor in the ultimate outcome (of the below knee amputation)."

It is important to note that whilst in hospital it was the anniversary of Richard's Mum passing away, this was understandably emotional and difficult for all the family.

Richard remained at Rowley Regis Hospital SWBHT, which family advise that Richard enjoyed as he was able to access the garden, until the 22nd of April 2021 when he was discharged to Newbury Manor Nursing and Residential Home. This was planned to be for a period of rehabilitation. The placement was reviewed and was quickly assessed as not suitable to meet Richard's needs, as his wheelchair would not fit through the doors. Richard was transferred to Portway House, a Care Home facility registered to support older age adults and those with physical and sensory needs just 5 days later on the 27th of April 2021. Richard was registered with a new GP due to the location of the Care Home. Richard agreed with this placement as a short-term option and a plan was agreed with Richard to seek a long-term placement with adults of his own age.

A swab was taken from Richard's leg stump which confirmed that Richard carried the bacteria Carbapenem Resistant Organism, (CRO)[5]. CRO requires special antibiotics in the event of an infection.

Richard's diabetes was not well controlled throughout his admission both in Hospital and at Portway House. Richard struggled to comply with the regime to control his diabetes prior to admission and had regular and consistent community support with this.

Richard remained at Portway House throughout May and June 2021 attending various outpatient appointments and receiving treatment and review in the home from Occupational Therapy and Physiotherapy. Richard remained anxious and upset, also getting frustrated and angry for periods throughout his stay in Portway House. Following an Occupational Therapy assessment on the 1st of June 2021, Richard was unable to use his mobility scooter as it was deemed unsafe due to Richard's weight being much more than the capacity of the scooter. Richard was supported to use his wheelchair to go outside with staff. Richard was regularly contacting his family, Social Worker and Learning Disability Nurse stating he felt 'like a prisoner'. Friends who visited, as well as family raised concerns about Richard's low mood and him presenting with challenging behaviour and overeating. The lack of consistency with Social Workers impacted on any progress with securing a more suitable placement option. Richard's Community Learning Disability Nurse was the one professional who remained consistently involved, advocated for and with Richard and liaised with family and other professionals. Richard's Aunt had sometimes multiple daily contact with professionals to progress his discharge from Portway House and advocate on his behalf. Prior to Richard's death, on behalf of Richard and his family, his Aunt raised a formal complaint with both the Hospital and Adult Social Care about his care, treatment and failure to facilitate his discharge.

On the 15th of June 2021 Richard complained of pain when passing urine and soreness in his groin area. It was recorded in his notes that his testicles were swollen. An email was sent to the GP about this. Later that day the GP advised Portway House staff to 'check if swollen and if in pain to take to hospital as may be twisted'. Richard was noted by Portway House duty staff to be 'very grumpy' and it was recorded that his testicle did not appear swollen. He refused to go to hospital and Portway House notes state Richard was to be seen by the GP the next day i.e., the 16th of June 2021. Richard required full assistance with all his care and was incontinent on 2 occasions throughout the 16th of June 2021, this was unusual for him. Richard again complained of soreness to his groin area, staff observed and applied emollient cream but no swelling was noted. Richard was not seen by the GP and no follow up detailed on the 16th of June 2021. There is a note entered by Portway House on 16th of June 2021 referencing a request from Richard's previous surgery for information to be resubmitted. During the late evening and night of the 16th of June 2021 Richard complained of soreness to his leg and testicles. Prickly heat was queried to his leg. A small burst blister and 2 intact blisters were noted to his right testicle,

[5] CRO stands for carbapenem-resistant organisms. These are groups of bacteria (germs) that produce carbapenemases (chemicals). These chemicals can destroy antibiotics called carbapenems. This makes the bacteria resistant to the antibiotic. https://www.journalofhospitalinfection.com/article/S0195-6701(15)00320-5/fulltext

a dry dressing was applied. During the night Richard complained of soreness/pain in his testicles and was incontinent of urine. Pain relief was offered but refused by Richard.

Twice daily temperature recordings were carried out in line with Portway House Covid guidance. Records state that Richard's temperature was within normal limits.

On the morning of the 17th of June 2021 Richard was noted to be 'lashing out, kicking and swearing'. Although Richard could be challenging, this was usually verbally and being non-compliant. Lashing out and kicking was unusual behaviour for him. He also refused food and hot drinks, again this was unusual for him. From the 17th June 2021 Richard was monitored using the National Early Warning Score (NEWS)[6]. An ambulance was called in the evening of the 17th of June 2021 as Richard was complaining of pain in his testicles and, on examination, noted to be very swollen and inflamed. Richard stated that he wanted to go to hospital. He was taken and admitted to SWBHT with a suspected infection to testicles, requiring Intra Venous (IV) antibiotics. Richard was extremely distressed wanting to go home to Portway House. The Hospital Learning Disability Liaison Nurse met with Richard and liaised with his Community Learning Disability Nurse. Richard appeared to have had fluctuating capacity. He self-discharged on the 19th of June 2021 having been deemed to have capacity. Richard had oral antibiotics. At this time Richard's Community Learning Disability Nurse raised concerns with both Portway House and Richard's Social Worker about the appropriateness of the placement. Richard's' family also put in a complaint to Adult Social Care as no communication or progress about Richard having a placement with people of his own age and with similar needs.

An ambulance was called on the 22nd of June 2021, where in consultation with Richard's GP the decision was made for Richard to remain at Portway House. An ambulance was called on the 23rd of June 2021 and Richard was taken to SWBHT with suspected sepsis. The placement at Portway House was closed to Richard. Therefore, plans were put in place for an alternative placement should Richard self-discharge again whilst an independent living placement was sought.

On the 28th of June 2021 Richard had clinically improved and was deemed medically fit for discharge. However, no placement was available. Richard was in a room with no TV and was unable to get off the bed or out of the room. Family enquired about Richard having his wheelchair in hospital, they were advised that no further equipment could be accepted due to the size of the bed. Richard was extremely distressed, not wanting to remain in hospital, sometimes refusing care and treatment. Richard's Nan went to hospital every day to support him to stay and comply with treatment.

[6] National Early Warning Score (NEWS) is a system for scoring the physiological measurements that are routinely recorded at the patient's bedside. Its purpose is to identify acutely ill patients, including those with sepsis, in hospitals in England. The NEWS2 scoring system measures 6 physiological parameters:

- respiration rate
- oxygen saturation
- systolic blood pressure
- pulse rate
- level of consciousness or new-onset confusion
- temperature.

https://www.nice.org.uk/advice/mib205/chapter/The-technology

On the 14th of July 2021 Richard deteriorated, he was transferred to the Intensive Care Unit and treatment commenced for a Pulmonary Embolism[7]. Richard's Dad was asked to come to the hospital to support Richard whilst attempts were made to insert an IV tube. Richard's Community Learning Disability Nurse also attended and was able to support Richard and keep him calm to allow intervention. Richard was taken to theatre to carry out sedation and secure central lines for treatment.

Despite interventions, Richard continued to deteriorate and sadly passed away on the 17th of July 2021. His death certificate documented cause of death: 1a Multi Organ Failure, 1b Sepsis (klebisella pneumoniae and enterococcus faecalis), 1c Infected amputated leg stump, 2a Morbid Obesity, 2b Autism, 2c Learning Difficulties. The death certificate was forwarded to the coroner. Further to contact from Richard's Aunt the coroner advised that a digital autopsy would be carried out and confirmed that the Hospital had already commenced an investigation. Diabetes Miletus was added to the death certificate by the coroner.

On the 20th of December 2021 Richard's Aunt, on behalf of the family, sent a formal complaint to the Clinical Commissioning Group about the care and treatment afforded to Richard at SWBHT. Richard's Aunt received a response from SWBHT dated the 22nd of March 2022. Richard's Aunt found the response unsatisfactory and following a meeting with a Trust representative in August 2022, further questions and concerns were raised. This complaint has been raised with the Health and Social Care Ombudsman, who instructed SWBHT to respond by the 31st of May 2023. Richard's Aunt was contacted by SWBHT to advise that a full report with timeline, actions, learning and recommendations has been prepared and once signed off by all executives will be shared and a meeting arranged to discuss. Richard's family have been significantly impacted by the fact that they still do not have a response from SWBHT almost 2 years on (at the time of writing) from Richard's death.

The Independent Author requested sight of the Serious Investigation report and findings undertaken by the Trust to prevent any duplication in learning/actions and recommendations. As outlined above neither the family nor the Independent Author have received a copy of the report (please note this has now been received).

4. Pat's story

Pat was born on the 17th of October 1963 into a large family with 7 siblings. Pat's sister describes their upbringing as strict and happy. Pat had 4 nephews and nieces whom she loved and was loved by them all. Pat is described as happy and jolly with an infectious laugh and good sense of humour. Pat loved all things furry and fluffy including cuddly toy animals. She had 2 cats when she was settled living in her own flat but sadly one died and one found a new home when Pat returned from a hospital admission in 2016.

[7] Pulmonary Embolism is a blocked blood vessel in your lungs, can be life threatening. https://www.nhs.uk/conditions/pulmonary-embolism/

Pat loved music and singing, with a wide range of taste in music. She liked to have 'nice' things and respected and looked after them. Pat was quite house proud and kept her home lovely and tidy. She was generous and caring, looking out for others. Pat liked brightly coloured pens and drawing. She enjoyed eating out and shopping when she was well. One of Pat's sisters has fond memories of Pat making mince pies which were always really good!

Pat started to get into 'trouble' when she was 13 years old (coinciding with puberty). She was arrested by police when a young woman and subsequently sectioned under the Mental Health Act (MHA). Pat spent a total of 5 years at various institutions including All Saints (former Mental Health Hospital Birmingham), Risley Specialist Hospital (Cheshire) and Rampton High Secure Specialist Hospital (Nottingham). Despite the distance from home, Pat's Mother visited her regularly. Pat was discharged under Section 117 aftercare[8] and was very stable living in her own flat with community support for 18 years until 2016. Pat was detained under the Mental Health Act (MHA) and admitted to hospital again in 2016.

Pat had a mild learning disability and was formerly diagnosed at the age of 35 with bipolar disorder[9], she was prescribed Lithium Carbonate[10] to help to manage this condition. Pat's mental health was significantly impacted when her parents passed away, exhibiting behaviours which resulted in Pat being detained under the MHA again.

Pat was discharged to her own home under a Community Treatment Order (CTO)[11]. The CTO was put in place to support Pat and provide a mechanism to recall Pat to hospital should she become uncompliant with her medication, become unwell and require hospital

treatment. Since 2017 Pat had been living in her own rented property with support in the community. To support her Pat had 2:1 staffing from EL Marsh Care. EL Marsh Care provides independent living services to support individuals with a learning disability, autism, mental health and other complex needs. Individuals are supported to live in their own home or a home owned by EL Marsh Care. Pat had person-centred care plans including relapse plans which were developed by Community Learning Disability staff

[8] Section 117 MHA The aftercare provided to patients detained under the Mental Health Act when discharged. Given to try to prevent deterioration in mental health condition and to avoid needing to be re-admitted. https://www.nhs.uk/conditions/social-care-and-support-guide/care-after-a-hospital-stay/mental-health-aftercare/

[9] Bipolar disorder, previously known as manic depression, is a condition that affects your moods, which can swing from one extreme to another. https://www.nhs.uk/mental-health/conditions/bipolar-disorder/overview/

[10] Lithium Carbonate is a type of medicine known as a mood stabiliser. It's used to treat mood disorders such as bipolar disorder. Lithium can also help reduce aggressive or self-harming behaviour. https://www.nhs.uk/medicines/lithium/

[11] Community Treatment Order 'an order made by your responsible clinician to give you supervised treatment in the community' 'CTO gives your responsible clinician (usually your community doctor) the power to recall you to hospital if necessary' https://www.mind.org.uk/information-support/legal-rights/community-treatment-orders-ctos/overview/

from both the Behaviour Support and Intensive Support Teams. These plans detailed Pat's known presentation when experiencing a manic, hypomanic or depressive phase in her condition, how to support her and requirements of her CTO including blood testing for Lithium Carbonate levels.

From March 2020 'Lockdowns' were imposed due to the Covid-19 pandemic. This obviously impacted on Pat's contact with family and doing the things she enjoyed. In August 2020 Pat's Consultant Psychiatrist (Responsible Clinician regarding CTO) met with Pat for a review. The outcome of the review was for the CTO to remain in place.

Pat had several health conditions including type 2 diabetes, arthritis, overactive bladder and visual impairment which required regular input from Ophthalmology. Pat was a smoker, smoking approximately 20 cigarettes a day.

During October 2020 Pat received treatment from Ophthalmology due to pain and not being able to see out of her right eye. A scan identified that Pat had bleeding behind her eye which was affecting her vision. A follow up scan was arranged for 4 weeks. Pat had a further scan and intervention to her eye under a local anaesthetic. Advice was given to keep the area clean and dry. Two days later Pat complained of severe pain to her eye and swelling was visible. Pat attended the eye clinic and was admitted to a ward at SWBHT due to diagnosed infection in the eye. A carer remained with Pat whilst in hospital. Pat was at times non-compliant with her treatment which was described as intense requiring eye drops every 1-2 hours. A capacity assessment was not undertaken. Pat was noted to be agitated and aggressive at times, this being directed towards her carer.

Prior to attendance and admission to hospital Pat had self-harmed the back of her hand with a pair of scissors. Carers had a telephone consultation with her GP one week after the injury was sustained as it appeared red with a discharge. Pat's GP prescribed antibiotics for infection. Following this prescription Pat attended the GP surgery for review of her hand with the Practice Nurse. The Practice Nurse reviewed, cleansed, and re-dressed the wound and made a plan for a further appointment for dressing change in 2 days with Health Care Support Worker and for review with Practice Nurse in 5 days.

Pat remained in hospital until the 4th of November 2020 when she was discharged due to improvement in the eye infection with a take home prescription for eye drops three times daily. Pat's hand wound was swabbed and re-dressed prior to discharge. Pat's blood sugar levels were high and she was noted to have sugary drinks and inappropriate quantity and types of food. Staff provided advice to Pat about the potential impact on her health. Staff also made a diabetes referral and the Diabetes Specialist Nurse made adjustments to Pat's prescribed medication.

Pat continued to have reviews with the eye clinic in November 2020. There were 4 telephone consultations and 1 face-to-face appointment with her GP during December 2020. These telephone consultations considered the need for prescription of eye drops –

GP liaised with consultant ophthalmologist, pain management, cuts/sores to fingers with very dry and cracked skin on hands and Pat not sleeping. A face-to-face consultation on the 16th of December 2020 focused on Pat experiencing increased shoulder pain and also not sleeping. Her carers requested medication for insomnia. Pat's GP detailed a plan to

alleviate Pat's pain first then review her sleep in one week. At this consultation an X-ray form was given to Pat's carer for Pat to have her shoulder X-rayed. On the 23rd of December 2020 Pat's carer had a GP telephone consultation as Pat's pain was described as not controlled, she had been very agitated throughout the night, in and out of her room. Pat's pain relief was increased and a short course of medication for insomnia was prescribed.

Pat continued to have medication for insomnia which her carers reported to her GP was helping although they voiced that Pat seemed to be deliberately not wanting to sleep, 'keeping an eye on staff'. Pat missed an appointment for a blood test in mid-January 2021. Pat would regularly refuse treatment, interventions and to attend appointments. It was described to the Independent Author that Pat responded well to discussion about treatments and appointments etc. with her sister Teresa. Often Pat would choose to go to appointments/have treatment following a chat with her sister. Pat did attend for a blood test and a review with the pharmacist for medication review later in January 2021.

Throughout January 2021 Pat continued to experience pain and present with infection to her right eye requiring further laser treatment and regular drops. On the 25th of January 2021 Pat saw the GP Specialist Advanced Nurse Practitioner (SANP) for her annual health check. The Independent Author noted good practice in relation to the SANP noticing that Pat was anxious about breast screening, which was due later in the year, and took steps to reduce/minimise her anxiety by making contact with Pat's Community Learning Disability Nurse to plan an approach.

In early February 2021 Pat's carers had several contacts with her GP during which Pat's increased agitation was discussed. It was noted that Pat was known to become more agitated at this time of year as it coincides with her father's death. Pat's GP notes detail that EL Marsh staff were supporting Pat following the care plans in place and they didn't feel that any additional clinical input was required at this time. Following a blood test which showed low B12[12], a repeat blood test was requested. On the 15th of February 2021 Pat's carers had a discussion with her GP as Pat had been off her food and vomiting in the evening for 3 days. Her GP made an amendment to her prescribed pain relief and advised Pat's carers to observe Pat, encourage diet and fluids and if unwell, e.g., temperature, poor oral intake of both diet and fluids, or fluctuating blood sugar, to contact the doctor.

[12] Vitamin B12 or folate deficiency: B12 and folate perform several important functions in the body, including keeping the nervous system healthy. A deficiency in either of these vitamins can cause a wide range of problems, including: extreme tiredness, a lack of energy, pins and needles, a sore and red tongue, mouth ulcers, muscle weakness, problems with your vision, psychological problems, which can range from mild depression or anxiety to confusion and dementia, problems with memory, understanding and judgement https://www.nhs.uk/conditions/vitamin-b12-or-folate-deficiency-anaemia/ .

Pat continued to present with low mood and motivation in early March 2021. On the evening of the 16th of March 2021 an ambulance was called as Pat had smashed a ceramic tile the previous day, which had caused swelling to her left hand. EL Marsh carers

reported to the ambulance crew that Pat had also fallen on 8th March 2021 causing bruising to her face and that she was struggling with her mental health. Pat was taken to SWBHT where an X-ray identified that she had a soft tissue injury to her left hand. Pat was seen by Liaison Psychiatry whilst at hospital and it was agreed for Pat to be discharged home under her CTO to continue with her care from the community psychiatric team. Pat continued to deteriorate; EL Marsh staff contacted her GP on the 22nd of March 2021 with concerns over past 2 weeks about Pat's mental health which had deteriorated. Pat was described by EL Marsh staff as tearful, agitated, aggressive, mumbling, having poor or no sleep, not eating well, she had also had some vomiting and diarrhoea in the previous 3 weeks. Pat's GP noted that she had lost some weight. With the history given Pat's GP queried Lithium Carbonate Toxicity and advised EL Marsh staff to call an ambulance. Pat was conveyed by ambulance to SWBHT and admitted to a medical ward for investigation into weight loss. Pat's weight was recorded on the 25th of January 2021 as 17 stone and 2 lbs, on this admission Pat's weight was recorded as 14 stone 7lbs. A blood test confirmed that Pat's Lithium Carbonate levels were chronically toxic. Pat underwent several tests and investigations whilst in hospital, during which a porcelain gallbladder[13] was identified. Further appointments were arranged to review this condition which Pat was not taken to due to recall to hospital under her CTO and subsequent detention under MHA. Pat refused to have a cannula inserted initially, there was no documented Mental Capacity Act assessment to determine whether a best interests decision should be made. Pat had a witnessed fall whilst in hospital with no harm identified. Pat remained in hospital until the 26th of March 2021 when a blood test confirmed that her Lithium Carbonate levels were back to within therapeutic range. Further to hospital clinician discussion with Psychiatric Liaison it was confirmed that Pat's bipolar disorder had never been successfully controlled but that Lithium Carbonate offered the best level of control. Pat was discharged back home with follow up bloods to happen in the community. Pat's GP made arrangements for the District Nurse to take blood and also to expedite her outpatient appointment with her Consultant Psychiatrist. Her GP also followed up the X-ray results of Pat's shoulder, which showed calcification.

Prior to Pat's admission there were increased visits/input from both the Behavioural and Intensive Support teams and staffing was increased to 3:1 via NHS Continuing Healthcare. This support was put in place to try to support Pat to remain at home.

Pat was seen by her Responsible Clinician on the 30th of March 2021 when the prescribed dose of Carbamazepine, an anticonvulsant medication also used as a second line medication for bipolar disorder, was increased. Pat's carers had a GP telephone

[13] Porcelain gallbladder is a calcification of the gallbladder believed to be brought on by excessive gallstones, although the exact cause is not clear. As with gallstone disease in general, this condition occurs predominantly in overweight female patients of middle age. https://en.wikipedia.org/wiki/Porcelain_gallbladder#:~:text=Porcelain%20gallbladder%20is%20a%20calcification,female%20patients%20of%20middle%20age.

consultation on the 31st of March 2021, blood test results showed Lithium levels were again high therefore the dose was reduced. Blood test repeated 7 days later. A discussion took place between the GP and the Hospital Consultant, who had treated Pat whilst in hospital, following receipt of the discharge summary letter on the 23rd of April 2021. During this call it was identified that the prescribed dose of Lithium was incorrect and needed to be increased, it is not clear how this error occurred.

Pat continued to deteriorate, refusing intervention and self-care, exhibiting self-harm, not wanting to eat, or dress, walking outside barefoot. A multi-disciplinary team meeting took place on the 29th of April 2021 when it was agreed that Pat required an admission to hospital due to deterioration in her mental health presentation. Police and ambulance were called to potentially convey Pat to a general hospital. Pat was refusing to comply and therefore the ambulance crew and police were unable to legally transfer her as it was against her wishes. On the 30th of April 2021 Pat's Responsible Clinician recalled her to BCHFT under her CTO. It was recorded on Pat's admission that she presented with significant deterioration in both her mental and physical health. Significant weight loss was noted, Pat appeared to be unkempt and was not able to take care of herself, her clothes were described as dirty, and she was not washing. Pat was refusing medication and was manic in her presentation. Pat's CTO was revoked, and Pat was detained under Section 3 Mental Health Act. Hospital staff raised a safeguarding concern regarding possible neglect by her care provider pre-admission to hospital. Pat's family, EL Marsh Care and hospital staff were consulted. The outcome was that no evidence could be found to confirm any neglect. In the safeguarding investigation it was documented that the focus of and for Pat's presentation seemed to be around severe deterioration of mental health which family had stated was a pattern. Pat remained under section 3 of the Mental Health Act until her discharge home with EL Marsh Care on the 26th of July 2021. During her hospital stay, Pat was noted to have lost a significant amount of weight, she was agitated, mumbling, not giving eye contact. Pat required support with eating and other activities of daily living, and she was doubly incontinent. Both Pat's family and her Social Worker described her as 'unrecognisable'.

Pat had a further fall whilst in hospital, hitting her head with swelling and bruising evident and Pat complaining of a headache. The Consultant requested an ambulance crew convey Pat to hospital for neurological observations. Due to Pat's aggression the crew had to administer medication for anxiety. Pat had a head CT scan which identified no trauma detected; Pat returned to BCHFT. On the 3rd of July 2021 Pat was taken to SWBHT with a 10-day history of redness and pain to her left leg. Pat was diagnosed and treated for cellulitis[14]. A scan was carried out which ruled out a Deep Vein Thrombosis. Pat was discharged back to BCHFT on the 7th of July 2021. Pat's sister visited and saw Pat through the window whilst in hospital.

Several discharge planning meetings took place with a discharge date set for the 26th of July 2021. Assessment under the Mental Capacity Act was planned to be carried out in

[14] Cellulitis is an infection of the deeper layers of skin and the underlying tissue. It can be serious if not treated promptly. https://www.nhsinform.scot/illnesses-and-conditions/skin-hair-and-nails/cellulitis#:~:text=Cellulitis%20is%20an%20infection%20of,and%20can%20be%20life%20threatening.

the community and an application for Deprivation of Liberty Safeguards was made. EL Marsh staff supporting Pat received training from Intensive Support Team (IST) staff about

Pat's mental health, relapse plans and support intervention. Pat was discharged back to her bungalow and care of EL Marsh staff as planned on the 26th of July 2021.

On the 27th of July 2021 Pat's GP records state that there was an outbreak of Covid at EL Marsh Care provision.

Pat appeared unwell on the 5th of August 2021. EL Marsh chronology describes that 'PCR test completed and Pat positive, need to isolate for 10 days'. As the test was done in the home this will have been a Lateral Flow Test (LFT). EL Marsh staff contacted Pat's GP on the 11th of August 2021 to advise of positive home test for Covid, Pat's GP notes detail 'advised need for PCR test'. It is not clear if this happened.

Pat's sister visited on the 5th of August 2021 having done an LFT herself, which she routinely did throughout the pandemic. Pat's sister describes that she observed no evidence of PPE, hand sanitation, and no requirement to sign in as a visitor. Whilst visiting Pat, a member of staff from another home walked in without speaking to Pat, this staff member then joined 4 staff members in the hallway of Pat's bungalow. Pat's sister observed staff doing LFT's in the bedroom. Pat's sister raised concerns with EL Marsh manager about this and the lack of PPE, hand sanitation and procedure to sign in. The manager apologised to Pat's sister and advised that she would ensure PPE was in place. EL Marsh chronology states that Pat appeared unwell later in the day on the 5th of August 2021. EL Marsh advised that a PCR test was carried out and that results received on the 7th of August 2021 confirmed that Pat was positive for Covid-19. Pat's sister received a text message advising her that 'Pat is positive for Covid' on the 7th of August 2021. Pat had a Podiatry home visit on the 6th of August 2021. Agencies and Pat's family were not able to visit due to Pat's isolation.

BCHFT community Intensive Support Team (IST) staff raised a safeguarding concern about Pat being left with staffing levels that were insufficient to meet her complex needs. The safeguarding concern detailed that there was only 1 staff member present, not 2. The IST staff queried this and were advised that the other staff member was out completing shopping. Pat was requesting pain relief medication and the EL Marsh staff member present was not able to administer this as she was not trained to. The safeguarding alert was investigated and substantiated. The safeguarding alert was closed as EL Marsh Care mitigated the risk and ensured that Pat had sufficient levels of staff to meet her needs with the appointment of an external/additional staff member to carry out the shopping for Pat. It was raised as part of the review by some staff and Pat's sister that due to the Covid outbreak in the home, staff present were not familiar with Pat and had not received the training given prior to Pat's discharge home following recent detention in hospital. It was noted as part of the review that Pat had refused to have a Covid vaccination, Pat's sister was not made aware at the time. As described, Pat would often choose to comply with treatment/intervention following a chat with her sister.

From when Pat tested positive with Covid her sister was calling to ask about her progress. On the 17th of August 2021 Pat's sister was told that Pat was recovering well and out of isolation. On the 18th of August 2021 Pat refused her breakfast at 9am, having yogurt only to take her medication. Pat returned to bed, EL Marsh staff reported regularly

checking Pat throughout the morning. The chronology details that at 11.45am Pat was found to be not breathing. At 11.50am EL Marsh staff called their manager, at 11.51am a call was made to 111, then at 11.52am an ambulance was called. At 11.56am EL Marsh Deputy Manager arrived and commenced Cardiopulmonary Resuscitation (CPR) whilst another staff member remained on the call with the ambulance operator. Pat's sister was contacted. At 12.03pm the ambulance crew arrived and commenced advanced life support.

Pat was sadly pronounced dead at 12.40pm. The documented cause of death on Pat's death certificate is Covid Pneumonia.

5.Key themes and questions

The table below represents the themes identified from both Richard's and Pat's stories.

Identified themes from Richard's and Pat's referrals, chronologies, agency response to questions and family narratives.	
Richard	Pat
• Co-morbid chronic health needs • Learning disability • Autistic • Loss and bereavement • Restrictions and changes in routine and ways of working during the pandemic and 'Lockdowns'. • Decision making and communication. • Empowerment including working jointly with Richard and his family. • Mental Capacity/Best Interest and Depravation of Liberty Safeguards • Escalation and professional curiosity • Recognition of deterioration and timely intervention • Need for reasonable adjustments. • Diagnostic overshadowing and unconscious bias	• Co-morbid chronic physical and mental health needs • Learning disability • Loss and bereavement • Restrictions and changes in routine and ways of working during the pandemic and 'Lockdowns'. • Decision making and communication. • Empowerment including working jointly with Pat and her family. • Mental Capacity/Best Interest and Depravation of Liberty Safeguards • Escalation and professional curiosity • Recognition of deterioration and timely intervention • Diagnostic overshadowing and unconscious bias

The table of questions below were drafted with input from both Richard's Aunt and Pat's sister. These were used at the learning events with frontline staff and managers. The aim of using this approach was to give staff the opportunity to 'step into the shoes' of Richard and Pat, consider what worked well and not well, what are the gaps and opportunities, what needs to stop or start happening. Those present were also asked what learning/actions had already happened both as individuals and by their respective organisations. Importantly the question

was asked about consideration given as to the impact of any learning/actions on other agencies and individuals.

NB the Independent Author sought confirmation from Sandwell Local Authority about investigations and actions that had already been actioned in relation to EL Marsh Care staff delay in commencing CPR prior to commencing the SAR process.

Key questions
1. Both Richard and Pat had experienced recent loss and bereavement, significant change in routine, had physical health needs and trauma. How did this feel and affect them? How might Richard's and Pat's behaviour have affected you?
2. Diagnostic overshadowing (seeing the person's disability or mental illness only) or unconscious bias - Do we, you, sometimes make assumptions about behaviour, expressions of pain or distress? What can you do to always see and hear the person? What support do you need for this?
3. Communication - What needs to happen with and for the person and their family, within and between organisations?
4. Who or what can help you understand the person particularly when time and staffing is pressured? Consider each of the 6 safeguarding adult principles: proportionality and empowerment being particularly important for Richard and Pat
5. Decision making - Were Richard and Pat supported and empowered in decision making? Ask questions too about the Mental Capacity Act, your duties and responsibilities.
6. Delays and failure with referrals/treatment/tests and interventions. Were actions taken timely and proportionate, followed up? If not, why and what would have made a difference?
7. Clear risks for Richard in terms of impact of diabetes, his mobility, understanding and fear of being in hospital on healing. Clear known risks and relapse plans for Pat with cycle of diagnosed condition. Also, the impact of pandemic for both. What is needed to have person centred co-ordinated care with risks identified and actions planned to mitigate, reduce?
8. Opportunities to recognise deterioration in condition, what questions would you ask and of whom?
9. Restrictions during the lockdowns and the impact of the pandemic - What questions would you ask now and what actions would you take?
10. Professional curiosity, ask 'why', 'so what….' And 'is that ok…?'

6.Summary of learning identified

It needs to be acknowledged that all those present embraced the thematic review and inclusive appreciative inquiry approach to learning. Many expected to attend the learning event to be given the learning already identified for them to comment on. Having the opportunity to consider the key questions together, discussing different perspectives facilitated a better understanding and encouraged curiosity which led to positive learning. Some individuals identified actions and questions to take back to their organisations immediately.

'…makes you question not just how we can work better but what happens in other areas to see a way of communicating to make patient journeys a positive experience.'

'Thematic review seems an ideal means of having very valued practitioner involvement and a voice. How else can the learning be relevant?'

'Good way to identify issues and how we can learn and implement change together.'

'Even though it's a difficult subject, the way the information about Richard's and Pat's experience was discussed gave a good way for learning and taking action.'

Participants were asked what stands out for them having read Richard's and Pat's 'stories' and the identified themes. Then participants considered the key questions in terms of what worked well, what didn't work well, what needs to stop or change, what needs to start or be made more of? The table below summarises the collated points for both Richard and Pat.

What stands out for you from Richard's and Pat's stories and identified themes?	
What worked well?	**What didn't work well/Gap?**
• Continuity from Community Learning Disability Nurses • Some flexibility for visiting • Hospital passport available • Multidisciplinary involvement and liaison • EL Marsh support staff received training prior to Pat's discharge • Some assessments, tests and follow up actions • Some reasonable adjustments and person-centred working to support activities off the ward • Community Treatment Order in Place • Contact and communication between Ambulance crew and GP	• Communication - both with Richard and Pat and their families but also within and between agencies • Hospital passport - did staff know that it was in place/use and value it? • Escalation of concerns about deterioration in condition, discharge planning, presentation • Clarity of goals/boundaries • Person centred care planning • Lack of follow up care • Appropriate consideration of capacity to consent, implementation of MCA and DoLS • Lack of familiar support staff • Lack of PPE and adequate testing (Pat)

• Increase in visits from community team staff when advised of change in Pat's presentation • GP had established mechanism to engage with carers-documented that ID checked, arranged flexibility re blood test • Annual health check and initiating proactive support for Pat re breast care • Continued and regular visits from Social Worker with Pat to ensure she understood her rights in terms of CTO	• Recognition of and action to support each person with loss and bereavement • Recognition of deterioration in condition/presentation • Not always following up previous agreed actions/concerns raised • Delay in commencing active resuscitation • Change to ways of working due to pandemic - most contact was virtual • Referral to District Nurses • Number of safeguarding referrals could a 'deep dive' meeting have been convened?
What needs to stop or change?	**What needs to start or be more of/opportunities?**
• Making assumptions about behaviours/presentation • 'Ping ponging' between professionals, some silo working • Co-ordination of care/actions and understanding of roles/responsibilities particularly in terms of initiating an MDT meeting • Terminology, abbreviations, and language needs to be consistent • Understanding of roles and responsibilities and ensuring continuity of care • Discharge planning with and for patients with complex needs • Consistent allocated Social Worker • 'Virtual' assessment and review • Flexibility with agreed protocols • Improve all staff understanding about capacity and reduce conflict • Professionals meetings - opportunity to share current concerns/actions • How families are supported to have a voice and advocate for person • Approaches to clarify person/family understanding • Information sharing	• Prioritise the 'whole' person- Physical, intellectual, emotional and social needs • Change in circumstance e.g. admission to hospital should trigger a MDT meeting to be convened • Access to records across multidisciplinary team- currently have different systems • Flag on systems to identify additional needs, care co-ordination with action required to convene MDT meeting • Informal networking/reflection • Ensure the voice of the person, carer and family is ALWAYS sought, listened to, heard and documented • Missed opportunity to utilise MCA to support compliance with prescribed medication, tests and vaccinations • Information sharing with family and carers about signs and symptoms of infection • Missed opportunity to use technology to support and assess person and communicate with family and colleagues • Some missed opportunities due to pandemic restrictions and change to ways of working • More questioning and curiosity about changes in behaviour - ask why, what and is that ok? • Timely discharge summary to GP

	• Being curious - routinely asking why, what, talking with those who know the person well

From the above learning it is evident that poor, limited and delayed communication with Richard and Pat, their families, and also importantly within and between services, is a factor which impacted on timely interventions, joint planning and review, decision making and outcomes. Recognising that both Richard and Pat did not always find it easy to understand and be understood which could lead to frustration and some challenging presentations, this will have impacted on building of relationships and trust.

There were limited attempts made to understand what was usual for both Richard and Pat, to think holistically or be curious about individual presentations, challenges, changes from a Physical, Intellectual, Emotional and Social perspective. Some behaviours and presentations were assumed to be due to learning disability, autism or existing mental health condition. This type of assumption is known as diagnostic overshadowing.[15]

Richard and Pat both had known and well understood chronic health conditions. Both had type 2 diabetes which increased other health needs and put them at an increased risk of poor healing. Both struggled to comply with health advice and intervention and treatment required to keep them well.

There was little evidence that the Mental Capacity Act 2 stage test was carried out for Richard and Pat.

There were several single agency actions shared that had already been implemented or agreed further to the learning event. These are detailed in the table below. It should be noted that SWBHT have not shared the Serious Incident Investigation with either the Independent Author or Richard's family. Both families have raised their complaints with the Health and Social Care Ombudsman.

Actions already implemented or agreed	Actions and/or questions agreed following learning event
SWBHT • Safeguarding Champions in place • MCA and DoLS training • Referrals to District Nurses are followed up to confirm receipt • Wound assessment is completed on Unity (electronic system open to hospital and community staff) • Training from Tissue Viability Team about wound assessment for ward staff	Diabetic Foot Clinic will: • Query HBA1C (fasting blood sugar test), raise any concerns with GP in report to allow earlier intervention of specialist care to optimise diabetic control • Refer to Expert programmes for education and support • Make an adjustment to Did Not Attend correspondence to recognise that a vulnerable adult 'Was not Brought'

[15] Diagnostic overshadowing is the attribution of a person's symptoms to a psychiatric problem when such symptoms actually suggest a comorbid condition.[1] Diagnostic overshadowing occurs when a healthcare professional assumes that a patient's complaint is due to their disability or coexisting mental health condition rather than fully exploring the cause of the patient's symptoms.
https://en.wikipedia.org/wiki/Diagnostic_overshadowing

• Training from Learning Disability Team GP • revised the pathway to identify need for a face-to-face consultation • GP now requires any newly admitted patient have a full care summary and list of medications and a Multi-disciplinary meeting is initiated • Weekly ward round by GP introduced each patient has a weekly contact then additional as required • Risk assessment of needs criteria agreed and now used by nursing home	• Consideration of how the Hospital Passport can be utilised better across hospital and community services

The table below details the actions suggested by and with participants at the learning events

Putting people first	**Staff and culture**
• Prioritise physical health balanced with holistic needs **P**hysical **I**ntellectual **E**motional and **S**ocial- **PIES** • Empower and listen to the voice of the person and family • Consideration of circumstances prior to admission – taking a holistic view, from an acute perspective often the condition/ill health is focused upon. • Effective use of patient passports to assist staff, care providers and external agencies about the care the individual needs. Requirement to consider prior to, during admission and prior to and on discharge. • Knowledge of communication tools • Person centred planning/care planning- including relapse and transition • Increased understanding about MCA/DoLS responsibilities (action within 'Jeff' and 'Anne' SARs). What this can mean – best interest, reasonable adjustments, less restrictive option and how this applies to the patient journey and care.	• Diagnostic overshadowing to be part of Learning Disability awareness training • Review of existing care plans, person centred plan prior to or if emergency on admission to hospital-led by community staff undertaken jointly with hospital staff • Increase access to staff with specialist knowledge e.g. Learning Disability, Mental Health, Tissue Viability, Diabetes • Trauma informed learning for individual, family and staff • Skills and knowledge of care home and community support staff about National Early Warning Score (roll out across all care homes is an action within 'Anne' SAR), medication, signs and symptoms of Sepsis • Hospital passport and flags about reasonable adjustments - (action within 'Jeff' SAR) • Create a culture to recognise that an individual's behaviour may be influenced by learning disability, recent changes within their life,

	coming into hospital, pain- may need reasonable adjustment • Encourage professional curiosity – ask why, is that ok?
Systems and processes	**Partnerships**
• Multidisciplinary meeting prior to discharge for all adults with additional needs/complex cases • Develop a directory of services and agree which agency takes responsibility for update • Care co-ordination process signed up to by system agencies (recommendation from 'Jeff' SAR) • Alert generated to Community staff/agencies to indicate admission or possible admission • Develop an adult MASH to facilitate better interagency communication and early intervention/prevention for adults with learning disability and one or more chronic condition • Risk and impact assessment in relation to changed ways of working	• Clarity of roles and responsibilities when delivering shared care- mental health, learning disability, Primary and community care • MDT working – review how and at what point information is passed between service providers to ensure all elements of individualised patient care, • Network for shared learning • Greater patient/family partnership – communication, responsiveness to concerns queries as often can be resolved. Offer to support families • Engagement with safeguarding – social/external agencies

7.Conclusions

The aspiration in using a thematic review approach to consider the learning from the poor experiences and very sad outcomes for both Richard and Pat is to maximise learning, to harness collective 'ownership' for change and improvements which will be embedded for the benefit of the whole Sandwell population. The Independent Author is encouraged that this has started to happen.

The reflections with families, learning identified from the 2 events with frontline staff and managers along with review of the information provided for this thematic review have identified some things that worked well, some things that didn't work well/were gaps, some things that need to stop or change and some things that need to start/be more of.

The overarching issue which impacted on Richard's, Pat's and their families' experiences was poor and inconsistent communication. The failure in relation to timely effective communication led to missed opportunities to carry out actions with and for both Richard and Pat, delays in interventions, and at times facilitation of the most basic of care and compassion. Richard's, Pat's and their families' voices were not heard, and some assumptions were made in relation to behaviours and challenges different staff were faced with.

Participants at the learning events identified a number of factors where care and support to Richard and Pat could have been improved. Had this been in place at an earlier stage, it is likely that this would have changed the course to the events that followed and could have averted the very sad outcome.

The Mencap report 'Death by Indifference' 2007 and then the subsequent report '74 Deaths and Counting' 2012 also from Mencap described the premature deaths of people with a learning disability where basic care, poor communication, late diagnosis or intervention, and not seeing the person were common features of their experiences which contributed to their death. NHS England funded the LeDeR[16] programme in 2017 which requires the reporting and investigation of all deaths of people with a learning disability and autistic people. A national report identifying the learning from these reviews is published annually. The Independent Author made a recommendation about care co-ordination in 'Jeff' SAR. Care co-ordination is outlined in the 2018 Annual LeDeR report. As identified in the methodology section the National report of the Analysis of SARs identified that SABs and SAR authors should use learning already available at a local, regional, and national level. To realise the aspiration detailed in this review 'to maximise learning, to harness collective 'ownership' for change and improvements which will be embedded for the benefit of the whole Sandwell population' it is strongly recommended that the SSAB facilitate review of the 2021 Annual LeDeR report alongside the learning and recommendations from this review and 'Jeff' and 'Anne'.

The impact on Richard's Aunt and Pat's sister and their families has been significant. The Independent Author is extremely grateful for their time, patience, and resilience in working with

her to carry out this review. Although extremely painful both have shared their experience and invested time and energy into supporting learning to be realised. Their contribution has been invaluable, and the Independent Author would like to extend heartfelt thanks to both.

Learning is only effective if implemented, it is hoped that the small number of recommendations and the suggestion above will harness collective 'ownership' to achieve real and lasting improvements for autistic people, those with a learning disability and their families.

[16] LeDeR is a service improvement programme for people with a learning disability and autistic people. Established in 2017 and funded by NHS England, it's the first of its kind. LeDeR works to: improve care for people with a learning disability and autistic people, reduce health inequalities for people with a learning disability and autistic people, prevent people with a learning disability and autistic people from early deaths https://leder.nhs.uk/about

8. Recommendations

Putting People First, Staff and culture, Systems and processes and partnerships

1. Each of the 7 recommendations in 'Jeff' SAR are applicable to this review. SAB should seek assurance that actions are progressing to implement each of these. The lived experience detailed in Richard's and Pat's 'stories' should be used to 'test' ownership for each action.

2. Designated and named safeguarding adult staff lead a piece of work which engages representatives from all disciplines and levels of community and hospital staff to review the detail in and perceived value of the Hospital Passport. Changes and updating to reflect expectations and requirements using learning from other areas where this has already happened, e.g., Hertfordshire Safeguarding Adult Board 'Josanne' SAR. The updated Hospital Passport needs to be linked to tracking and flagging alerts. SSAB to seek assurance that the updated Hospital Passport is embedded across the health and social care system.

3. SSAB to facilitate a number of sessions which allows frontline practitioners the opportunity to appreciate and understand each other's roles and responsibilities. Introduce into these sessions the concept of restorative practice which is built on the values of **RESPECT**:-

   Respect
   Empathy
   Safe
   Personal accountability
   Equality
   Community
   Trust

   Ask what these values mean for each, how might it help person centred holistic working?
   'Restorative practices which informs the lens we communicate, interpret, and engage through', Michelle Stowe[17].

   .

4. SSAB to seek assurance about the development of pathways which facilitate better interagency communication and person-centred and joined up working to promote early intervention for adults with a learning disability, mental health need and autistic people with one or more chronic health condition.

5. SWBHT to share the delayed Serious Incident investigation report, recommendations and actions with SSAB.

6. SSAB members to agenda a discussion that facilitates a review of the process for co-ordination of complex complaints involving multiple agencies or providers. Discussion

[17] Restorative practice is a **values**-based philosophy which honours the understanding that we are profoundly relational, interconnected and inherently good https://www.connectrp.ie/about

should result in an agreed process as a whole system and include routine sharing of learning from complex complaints with SSAB.

About the Independent Author

Judi Thorley

Judi was commissioned to undertake this Review and act as Independent Author. Judi is both a Registered Learning Disability and Registered General Adult Nurse with over 36 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 2010 until 2013. From 2013 until 2019 Judi held the role of Chief Nurse and Executive Director of Quality and Safeguarding within 2 Clinical Commissioning Groups.

Judi retired from her full-time NHS role in 2019 and continued in a part-time role within the NHS until July 2022. Judi has recently been appointed as a Trustee with a charity.

Judi has carried out a range of independent consultancy work encompassing service reviews in community and hospital services, review of arrangements for adult safeguarding, SARs and development and delivery of leadership development programmes.