

Safeguarding Adult Review

Richard

Died January 2022

Richard is a pseudonym used
for the purposes of this Report.

8 March 2023

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INTRODUCTION

Barnsley Safeguarding Adult Board initiated this Safeguarding Adult Review in 2022.

Richard was a 69-year-old man who had a number of co-morbidities including: heart failure; aorto-iliac disease; hypertension; hypercholesterolaemia; and chronic obstructive pulmonary disease.

He was described as “morbidly obese” and smoked 50 to 60 cigarettes per day, refusing to give them up. He suffered from Korsakoff’s dementia and was resident in a neuro-rehabilitation facility in Barnsley. He was subject to a Deprivation of Liberty Safeguard (DoLS) authorisation from 2018 and at the time of the illness that led to his death. He had no close family involved with him and was supported by a paid advocacy service. An appeal against the Deprivation of Liberty Safeguard was in progress at the time of his death.

He was admitted to Vascular Surgery at the Northern General Hospital on 3 Dec 2021. He had left leg ischaemia with a non-healing ulcer (described as a necrotic infected ulcer) to his calf with surrounding cellulitis. He complained of left calf pain and pain at rest. He died of sepsis in Sheffield Teaching Hospitals on 8 Jan 2022.

His case was notified by a social worker to Barnsley’s Adult Safeguarding Single Point of Contact and the Chair of the Community Safety Partnership as potentially requiring a Safeguarding Adults Review. Questions had been raised regarding the decision-making processes during his final illness, including capacity decisions and best interest decision making.

This Report is organised into five main parts:

- Part 1 gives an overview of the process followed in this review
- Part 2 reviews Richard’s death
- Part 3 describes consultations with groups within local systems
- Part 4 summarises learning from this Review and good practice identified during the process of the Safeguarding Adult Review.
- Part 5 draws conclusions and recommendations

In the interests of readability, the use of acronyms has been avoided as far as possible in this report: however, the short form, DoLS, is used as an abbreviation for Deprivation of Liberty Safeguards¹ and the Glossary lists abbreviations used.

The author would like to thank all those involved who have contributed to this Review, to acknowledge how distressing these events have been for Richard’s family, and to send our sincere condolences.

¹ The Deprivation of Liberty Safeguards (DoLS) procedure is a legal mechanism to protect a person’s rights if the care or treatment they receive means that they are (or may be) deprived of their liberty, and they lack the mental capacity to consent to the care/ treatment arrangements. See <https://www.lawsociety.org.uk/topics/private-client/deprivation-of-liberty-safeguards-a-practical-guide> for more information.

PART 1: OVERVIEW OF THE PROCESS FOLLOWED IN THIS REVIEW

1.1 Introduction

The aim of a Safeguarding Adult Review is to promote learning and improvement action in order to prevent future incidents involving death or serious harm. The Care Act 2014² states the following:

‘(1) (A Safeguarding Adult Board) 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 (Safeguarding Adult Board), members of it or other persons with relevant functions worked together to safeguard the adult, and

(b) condition 1 or 2 is met.

Condition 1 is met if—

(a) the adult has died, and

(b) the (Safeguarding Adult Board) 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).

(3) Condition 2 is met if—

(a) the adult is still alive, and

(b) the (Safeguarding Adult Board) knows or suspects that the adult has experienced serious abuse or neglect.

(4) (A Safeguarding Adult Board) may arrange for there to be a review of any other 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).’

This Review concerns the death of Richard, who died in hospital in January 2022.

Part 2 of this Report provides an overview of deliberations, conclusions and recommendations from the information and analysis contained in Individual Management Reviews relating to Richard, and parts 3 and 4 broaden the context out by including consultations with local communities of interest. Part 5 draws conclusions and recommendations.

² See <http://www.legislation.gov.uk/ukpga/2014/23/section/44>

1.2 Terms of Reference

1. How did your agency 'access' Richard's voice to ensure his wishes and views were obtained and taken into consideration, including any 'past and present wishes and feelings', 'beliefs and values'.
2. How was information shared by organisations to support holistic risk assessments and treatment plans?
3. How did organisations use the legal frameworks to safeguard Richard, including use of the Care Act³ and Mental Capacity Act⁴ and was this in line with internal policies and best practice?
4. How did organisations use advocates and family to support Richard and any decision making?
5. How did the use of health services in different Local Authority Areas, impact on his care?
6. What support was provided to front line practitioners working with Richard?
7. What learning will your organisation take from this review and how will any changes be implemented?

1.3 Process of this Safeguarding Adult Review

1.3.1 Independent Chair/ Author

The Author of this report is by professional background a psychiatrist and systemic psychotherapist specialising in work with older adults. She has broad clinical and multi-agency experience in the North West and West Midlands. She has acted as Chair and/or Author, and expert medical adviser/ consultant to Domestic Homicide Reviews, Serious Case Reviews, Safeguarding Adult Reviews, and Local Case Reviews in the past. She has no connections or ties of a personal or professional nature with the family, with Barnsley Council, or with any other agency participating in this review.

1.3.2 Timescale

The timescale for the Review was set as Jan 2015 to date of death.

1.3.3 Individual Management Reports in respect of Richard

Individual Management Reports and chronologies were requested and provided by six agencies as set out in Table 1. Some agencies had difficulty completing and

³ For details of the Care Act 2014 see <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

⁴ For details of the Mental Capacity Act 2005 see <https://www.legislation.gov.uk/ukpga/2005/9/contents>

returning the Individual Management Report within the timescale set and this caused a slight delay in the Review Process.

Table 1: Details of Agencies and Individual Management Reports

Agency	Provided Richard with	Referred to as	Author
Adult Social Care (Barnsley)	Social care/ support	Adult Social Care	Team Manager Adult Social Care Barnsley Council
Barnsley Hospital NHS Foundation Trust	Emergency Department and acute medical care	Barnsley Hospital	Named Nurse for Adults Safeguarding
GP Practice	Primary healthcare	GP Practice	
Rethink Barnsley Advocacy Service	Independent Advocacy	Rethink	Advocacy Contract Manager, and Head of Advocacy Services
Sheffield Teaching Hospitals NHS Foundation Trust	Specialist vascular services	Sheffield Hospitals	Specialist Advisor Mental Capacity Act and Deprivation of Liberty Safeguards
South West Yorkshire Partnership NHS Foundation Trust	Mental health and community services	The Partnership Trust	Specialist Adviser Safeguarding Adults

1.3.4 Family involvement

The family was contacted by letter early in the Review in May 2022, explaining what was planned. Subsequently the Adult Safeguarding Board Manager spoke with Richard's son/ daughter in law and understood that they wished to be involved in the Safeguarding Adult Review and to speak with the Independent Reviewer. After that, further attempts were made to contact Richard's son, and, in the late stages of the review, a meeting with Richard's son and daughter-in-law took place to share information and obtain their views.

1.3.5 Meetings

The Review followed an evolving process where themes and recommendations were developed through individual management reviews and then in meetings with communities of interest. This is represented in Figure 1.

Dates of meetings were as follows:

24 August 2022 – practitioners’ event

14 September 2022 – managers’ event

Figure 1: The Process of the Safeguarding Adult Review



PART 2: REVIEW OF RICHARD'S DEATH

2.1 Chronology key points: circumstances of Richard's death

- In 2015 after he presented to services:
 - self-neglect was identified as an issue
 - concerns about decisional capacity were noted
 - DoLS first authorised
 - He was noted to be confabulating, ie filling gaps in memory by fabrication
 - He was given a diagnosis of severe amnesic syndrome due to alcohol-related brain damage (Korsakoff's syndrome⁵)
 - He lived in three different care homes (Care Homes H, A and R, indicated in chronology Table by coloured fill – see Appendix)
- From the time of his move to Care Home R in early 2021 problems with his legs were recognised - his new GP noted lower leg ischaemia, chronic leg ulcers, pain/ swelling.
- By November 2021 the social worker realised that Richard was not complying with support needs and identified lack of documentation regarding his refusal of care in the care home.
- Also in November 2021, the neighbourhood nursing team identified that Richard was not following their management advice.
- On 18 November he was admitted to vascular care at the Northern General Hospital - documented that he was refusing care in hospital (removing cannula).
- 20 Nov discharged back to the care home - his condition continued to deteriorate.
- 2 December 2021 he was seen by vascular team at Northern General following scan which showed occluded left femoral artery.
- 3 Dec 2021 he was admitted under Vascular Surgery Northern General Hospital with necrotic ulcer to left calf and surrounding cellulitis. Documented that he refused below knee amputation – no capacity assessment documented.
- 6 Dec 2021 the social worker received a call from care home – a carer informed the social worker that she had told ward she felt Richard did not have mental capacity to consent to amputation.
- 9 Dec 2021 Richard transferred to elderly care ward at Barnsley Hospital - diagnosis critical left leg ischaemia. Allegedly refused surgery saying he would prefer sepsis and death to stopping smoking for surgery.
- 10 Dec 2021 Richard reviewed on ward at Barnsley – told team he would consider below knee amputation if he didn't need to stop smoking. Documented that he had capacity to make this decision.

⁵ Various referred to as Korsakoff's syndrome/ dementia/ psychosis. See page 6 of Alcohol and brain damage in adults with reference to high-risk groups, College Report 185, Royal College of Psychiatrists (2014) https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr185.pdf?sfvrsn=66534d91_2

- 13 Dec 2021 risks and benefits of below knee amputation discussed with Richard: said he wanted operation after all as he had not understood risk that he might die without it. Barnsley physician discussed this with Specialist Registrar on call at Northern General. Conversation not documented in Northern General notes – missed opportunity.
- 17 Dec 2021 Social worker told Legal Services she had informed Hospital that she felt Richard did not have capacity to make complex decisions.
- 20 Dec 2021 discharged from Barnsley hospital to the care home.
- 23 Dec 2021 Reviewed in vascular clinic Barnsley – no evidence of capacity assessment. Letter from vascular surgeon advising Richard unlikely to change mind about amputation and it is his choice.
- 2 January 2022 Attended Emergency Department Northern General Hospital. Capacity concerns noted – recorded verbal consent given. Documented
 - he was refusing amputation.
 - DoLS in place
 - best interest meeting awaited with social worker.
 - has Korsakoff's Dementia
 - low-grade infection with intermittent confusion.
 - reports worsening pain to necrotic area and surrounds.
 - awaiting a best interest meeting re amputation
- 3 Jan 2022 ward round noted Richard was awaiting a best interest meeting/ decision with social worker to determine if he will have a below knee amputation. Increasingly more confused.
- 5 Jan 2022 ward round requested GP clarification re residential/care home and if best interests meeting in place.
- 6 Jan 2022
 - DoLS form completed, but unsigned (not authorised).
 - Two incomplete mental capacity assessment templates in folder.
 - Signed do not attempt resuscitation order, documented that it had been discussed with son and Independent Mental Capacity Advocate⁶ (a reference to Richard's advocate/ Relevant Person's Representative⁷) - the form stated that Richard lacked capacity, but no formal capacity assessment documented.
 - Consultant spoke to member of staff at care home who did not know anything about best interest meeting.
 - Call back from care home - hospital must arrange best interests meeting as it concerns medical treatment.
 - Richard seen in bed - clear by now he had a 'non-salvageable' left leg and needed above knee amputation - still did not want an amputation despite possible threat to life.
- 6 Jan continued: advocate/ Relevant Person's Representative contacted and informed Richard extremely unwell: told Vascular Team had decided not to

⁶ An Independent Mental Capacity Advocate (IMCA) is a statutory advocate introduced by the Mental Capacity Act 2005 (the Act) and gives support to some people who lack decisional capacity see https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/365629/making-decisions-opg606-1207.pdf

⁷ If a person is deprived of their liberty under the Mental Capacity Act they must have a representative. This could be a family member or a friend, but if there is no one suitable to take on this role it could be a Paid Representative also known as a Relevant Person's Representative or RPR.

actively treat. Advocate called back later that day and advised a best interest meeting to be arranged for next morning.

- 6 Jan continued: Richard further reviewed - whole limb cold; mottling extended to abdomen. Had now progressed too far for an above knee amputation. No longer any clinical options and he was dying. Palliative care involved.
- 8 Jan 2022 family came to visit - Richard died just after midnight.

Note: see Appendix for a more detailed chronology of events.

2.2 Background information

The background information that follows is taken partly from a meeting with Richard's son and daughter-in-law and partly from information shared by agencies.

A brief history

Richard was the youngest of four boys. Richard disappeared in around 2004 and had no contact with his family for about 18 years. His mother worked on the markets and died while he was missing. His father died about 9 months later, again while Richard's whereabouts were not known to his son and family.

He married twice and had two children, a boy and a girl with his first wife. This marriage ended in divorce when Richard's son was aged about 13, and his daughter took her mother's side. He went on to marry a second time.

At one time Richard was a sticker rep, at another time he sold time shares on Tenerife for 12-18 months after going there for a holiday. He could set up businesses from virtually nothing, and his son thinks that his dad borrowed money from people who were 'not very nice' and that this was probably why he eventually went missing in around 2004. After that his son did not see Richard for about 18 years. His son reported Richard missing to the police and spent time looking for him across the North of England.

Eventually, through a chance conversation with his aunt, his son found Richard in a Care Home, but by the time his son visited, Richard had moved to a different Care Home. The family was told that he had dementia. When his son visited, Richard failed to recognise him: the visit was a 'disaster' and very upsetting. On the phone, however, Richard's son could, successfully, talk with his dad and they had regular phone calls at one time facilitated by staff, but his son noticed that his dad talked about things in the past and referred to his parents being alive: for example, Richard was unaware that his parents had died and still talked of them running the market stall.

They only had one telephone conversation whilst Richard was in his final Care Home, and, despite the fact that Richard's son had asked the Home to keep him updated about his dad, he was not informed of his dad's health issues or of his many

admissions to hospital. He feels very upset about this as he would have made more attempts to see/ talk to his dad had he been aware of the risks to his dad's health. When he collected his dad's belongings after his death, he found a wallet which suggested that, during the years he was missing, his dad had lived in/ visited Burnley, Bolton, Bury, Rotherham and Barnsley. He has no idea where his dad lived or what he did for money during this time.

What was Richard like?

Richard is described as a big man, striking in appearance, being about 6ft 1inch tall and stocky with jet black hair. He was generous and tried his best to help others, although he was often taken advantage of financially, especially when he was drinking, and even by other family members. His son and grandchildren felt loved by Richard: at one time he regularly took his grandson to the pub to play in the garden or out in the car. When his grand-daughter was ill, he rang the family every day to ask about her.

He was a good talker, but rather blunt in his speech: if he had something to say he would just say it. At times he could be verbally aggressive but not physically. He is also described as impulsive, and he enjoyed 'flash cars', travelling, and holidays.

He was a self-starter who set up businesses and factories but sometimes borrowed money and could not pay it back. He was a chain-smoker and also liked a drink throughout his life: people sometimes took advantage of him while he was drinking.

What actions would Richard's son like to see from this process?

- Care homes to keep families updated
- Hospitals to contact families on admission
- Photo of his dad (if available) from the Care Home (this action has been completed)

2.3 Analysis: The key lines of enquiry

This section addresses the terms of reference (see 1.2).

2.3.1 How did your agency 'access' Richard's voice to ensure his wishes and views were obtained and taken into consideration, including any 'past and present wishes and feelings', 'beliefs and values'?

Adult social care was involved with Richard from 2015 until his death and there is evidence that he was involved, and his voice was heard, in decisions related to care needs and place of residence, and that his involvement was supported by an advocate/ Relevant Person's Representative from 2015 and embedded in the DoLS process. The social worker liaised closely with Richard's advocate. Evidence shows that the advocate focused on Richard's views and wishes and established a good relationship with him over time. The advocate also liaised appropriately with other

practitioners involved in his care. Similarly, there is evidence that the neighbourhood nursing team sought Richard's views and wishes when they delivered care.

Sheffield Hospitals noted in their report that there is no documentation regarding discussions about possible treatments, their risks and potential benefits. It is clear that Richard said that he did not want an amputation and this became accepted as his clear and unwavering decision which was respected despite the fact that it is not clear whether he understood the implications of this decision and whether he had been given and understood the relevant information on which to base a decision. There is information to suggest that he might have based his decision, at least initially, on whether or not he could continue to smoke, and it sounds as though he was a strong character in putting this view across. Later it became evident that he did not understand the implications of the decision. There were grounds to question his capacity and to complete assessments of his ability to make complex decisions: in particular he had a diagnosis of a dementia condition and was subject to a DoLS authorisation and both these facts would suggest that he might be unable to make some decisions and that his capacity should be assessed.

In December 2021 Barnsley Hospital staff recorded discussions with Richard about his leg and the potential risks and benefits that amputation might involve. They also were aware that the question of whether or not he could smoke was a powerful driver for him. They documented that he told them that he 'wanted operation after all as he had not understood risk that he might die without it' and that he was felt, at the time, to have the capacity to make this decision although unfortunately this was not backed up by a documented capacity assessment. The GP put a letter together to explain about decisional capacity and DoLS, requesting care home staff to take the letter to Richard's vascular appointment.

Past wishes, beliefs and values were difficult for all agencies to access since Richard had cognitive impairment and was unable to share accurate historical information. Contact with family members was inconsistent and therefore not a reliable means of practitioners' accessing this information. Richard's advocate/ Relevant Person's Representative grew to know him well but their involvement dated back to 2015 when he was diagnosed with a dementia condition.

2.3.2 How was information shared by organisations to support holistic risk assessments and treatment plans?

There is evidence of written and verbal information exchange between the Northern General Hospital, Barnsley Hospital and the GP. Unfortunately, there was one major missed opportunity in relation to clinical information sharing, on 13 December 2021, when a Barnsley physician discussed Richard's possible amputation with a Specialist Registrar on call at the Northern General, but the conversation was not documented in the Northern General notes.

The neighbourhood nursing team and GP liaised closely.

The advocate and adult social care liaised regularly to exchange information: both also liaised with care home staff and hospital staff. There is no evidence that

Sheffield Hospitals tried to contact the social worker – this was a missed opportunity to gain a more holistic appreciation of Richard’s situation.

Whether the information exchanged supported holistic risk assessment and treatment plans is arguable, as it appears that concerns expressed by the social worker, advocate and care home staff did not influence the vascular treatment plan, nor did the Barnsley physician’s information, despite the fact that it was passed on to the Northern General on call specialist registrar. A multi-agency meeting could have brought this information together in a more timely manner. To some extent there appears to have been a disconnect between social and health care: this is acknowledged in the adult social care report which notes the difficulty of health and social care using different recording systems.

2.3.3 How did organisations use the legal frameworks to safeguard Richard, including use of the Care Act and Mental Capacity Act and was this in line with internal policies and best practice?

Nowhere in the Sheffield Hospitals records is there evidence that valid informed consent was sought from Richard or that he was given information about the risks and benefits of the surgical treatment proposed, and there is no formal capacity assessment to indicate whether he would have been able to make a decision about treatment at the time. We know that he had a syndrome involving cognitive impairment and confabulation, and was subject to a DoLS authorisation, so there were good grounds to suggest that a capacity assessment was indicated. The practice as evidenced did not comply with the Mental Capacity Act and did not comply with Sheffield Hospitals’ policy. Similarly, after Richard changed his mind whilst in Barnsley Hospital and agreed to have surgery, we are told that he was seen in the vascular clinic at Barnsley and the vascular surgeon wrote to the GP advising that ‘(Richard) unlikely to change mind about amputation and it is his choice’. We understand that there are no vascular surgeons based at Barnsley Hospital and there is an agreement for the Sheffield Hospitals to provide consultants to a Barnsley clinic. However, it is clear that no capacity assessment was documented, and it is likely that Richard’s decisional capacity may have been fluctuating, given his complex problems.

Formal capacity assessments in relation to health treatments and care are conspicuous by their absence from the records.

The DoLS process was appropriately followed and an advocate involved. The advocate subsequently raised a s21A⁸ application to the Court of Protection for Richard to object to the deprivation of liberty he was subject to, and remained in regular contact with Richard until his death.

The social worker informed the Hospital that she felt Richard did not have capacity to make complex decisions and subsequently raised this with the legal department. We

⁸ A section 21A challenge involves applying to the Court of Protection when there is a standard authorisation (restricting a person’s liberty), under the Deprivation of Liberty Safeguards (DoLS), in place in relation to a person who is deemed to lack capacity to make decisions about where they should live and what care to receive.

understand that concerns were passed on to the legal department at Sheffield Hospitals but it appears that no action resulted.

2.3.4 How did organisations use advocates and family to support Richard and any decision making?

An advocate was involved throughout the period scoped and established a good relationship with Richard.

Richard's family were said not to be in contact with him. Indeed, when he first presented to services in 2015, he was unable to give information about his family to hospital staff, probably in the context of cognitive impairment and confabulation.

Later information suggests that Richard had been estranged from his son for some years but had then re-established intermittent contact. It is documented that a do not attempt resuscitation order was discussed with his son (and his advocate) and that family visited Richard shortly before he died.

2.3.5 How did the use of health services in different Local Authority Areas, impact on his care?

Although communication between Barnsley Hospital and Sheffield Hospitals was generally effective, there was one major missed opportunity (referred to earlier) in relation to information sharing, on 13 December 2021, when a Barnsley physician discussed Richard's possible amputation with a Specialist Registrar on call at the Northern General, but the conversation was not documented in the Northern General notes.

2.3.6 What support was provided to front line practitioners working with Richard?

At Sheffield Hospitals there is a Mental Capacity Act Specialist Advisor who offers support and advice on issues relating to the Mental Capacity Act and the Deprivation of Liberty Safeguards. It would have been eminently appropriate to involve this person, but they were not approached for advice or support at any stage.⁹

Similarly at Barnsley Hospital and the Partnership Trust safeguarding teams and legal departments are available to support staff and these might reasonably have been approached for support, but they were not contacted.

The social worker received regular supervision and contacted legal services after passing concerns regarding Richard's decisional capacity on to Sheffield Hospitals.

The advocate also received regular supervision but did not specifically discuss this case, and that is outwith the agency's expected practice.

2.3.7 What learning will your organisation take from this review and how will any changes be implemented?

⁹ See further discussion of facts that might have been expected to trigger concerns about capacity on page 18-19.

Adult social care would like to see:

- Training for practitioners regarding the necessary processes and legislation when clients refuse interventions.

Barnsley Hospital identified:

- An increase in the safeguarding presence within the clinical environment- this involves a member of the safeguarding team visiting all inpatient adult wards regularly and approaching staff to discuss complex patients.
- Daily attendance of the safeguarding team to 'complex needs meetings' where members of the multi-disciplinary team have the opportunity to discuss the care of complex patients to provide a coordinated approach.
- There is significant work being undertaken to improve the education of staff regarding safeguarding. As a result, the opportunities to attend formal safeguarding training have been increased. In addition to these other forms of training in a more case review structure is being introduced to the inpatient areas to focus on learning from complex cases.
- Staff at Barnsley Hospital are being encouraged to complete a formal Mental Capacity Act assessment, especially when a patient appears to lack capacity or there are major decisions being made, and there is excellent pre-recorded training on completing assessments available to staff via the intranet.
- The safeguarding team will be working with medical colleagues to improve the use of best interest discussions for patients who require a consent form completing prior to procedures and there is evidence of a lack of mental capacity.
- The safeguarding team are in the process of strengthening links within the Barnsley Hospital team through engagement with operational management, lead nurses and senior nurses.

GP Practice:

- Will review the report with all staff.

The Partnership Trust identified:

- Learning about communication between organisations
- Recording the 'voice' of the adult using their own words
- Promotion of formal capacity assessments accessible through SystemOne¹⁰
- Use of specialist support services such as legal services and the safeguarding team

Rethink is:

- Reviewing the report template and guidance
- Reminding advocates to record facts and observations rather than opinion

Sheffield Hospitals learning:

- This case is subject to a Serious Incident review¹¹, which will produce an improvement plan with actions for the care area involved.

¹⁰ SystemOne is a clinical computer system that enables NHS staff to record patient records/ information securely.

¹¹ The Serious Incident Key Findings Report was shared with the Independent Author in early January 2023 and recommended education and training in respect of the Mental Capacity Act.

- The case was allocated to the Sheffield Hospital Mental Capacity Act Specialist Advisor who completed a compliance review in respect of the Mental Capacity Act. The lack of compliance was reported on Datix¹², the Trusts incident reporting system which triggers a Root Cause Analysis by the care group concerned.
- Additional training regarding the Mental Capacity Act and DoLS has already been provided for the vascular consultants, surgeons and junior doctors.
- Positively, there has been support from the clinical director and nurse director for vascular services to promote Mental Capacity Act/ DoLS training and to embed the principles of the Mental Capacity Act in order to improve practice.
- Future training sessions are planned for the senior nursing staff in the care group.
- There will also be an internal learning the lessons event as part of the action plan from the Serious Incident to improve knowledge and practice around the Mental Capacity Act/ DoLS.

2.3.8 Conclusions from key lines of enquiry:

- Mental Capacity Act processes are not well embedded in health contexts
- This raises questions about Mental Capacity Act training as it appears not to be influencing practice
- Formal capacity assessments appear not to be routinely recorded in (at least) some health settings despite triggers to suggest a formal capacity assessment would be appropriate
- Advocates and families are not always utilised as resources and sources of information to support staff in health settings faced with complex cases
- Social workers are resources and sources of information that can assist with complex health cases
- Avenues that staff can use to seek support may need to be actively promoted as they appear not to have been used in this case

2.4 Analysis: additional contextual themes

2.4.1 Alcohol-related brain damage

Richard was diagnosed with alcohol-related brain damage in 2015 and noted to have cognitive impairment across multiple domains together with confabulation, which has been described as:

‘the experience of false memories (confabulation) in which the patient will mix up past experiences with current circumstances and may ‘remember’ quite complicated events which have never happened’ (page 6, Royal College of Psychiatrists College Report CR185, 2014)¹³

¹² Datix is a Risk Management Information System used to collect and manage data on incidents/ adverse events and in risk management.

¹³ See https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr185.pdf?sfvrsn=66534d91_2

2.4.2 The Mental Capacity Act 2005

The first principle set out in the Mental Capacity Act is that:

‘A person must be assumed to have capacity unless it is established that he (sic) lacks capacity.’¹⁴

The Code of Practice elaborates on this, saying (pages 20-21)¹⁵:

‘2.3 This principle states that every adult has the right to make their own decisions – unless there is proof that they lack the capacity to make a particular decision when it needs to be made. This has been a fundamental principle of the common law for many years and it is now set out in the Act.

2.4 It is important to balance people’s right to make a decision with their right to safety and protection when they can’t make decisions to protect themselves. But the starting assumption must always be that an individual has the capacity, until there is proof that they do not.’

The Code later (4.36, p.53) sets out reasons why a person’s capacity to make a particular decision might be called into question:

- *‘the person’s behaviour or circumstances cause doubt as to whether they have the capacity to make a decision*
- *somebody else says they are concerned about the person’s capacity,*
- *the person has previously been diagnosed with an impairment or disturbance that affects the way their mind or brain works and it has already been shown they lack capacity to make other decisions in their life.’*

Richard had been diagnosed in 2015 with a condition involving what was described as ‘multi-domain cognitive impairment’, and later described as a severe amnesic syndrome due to alcohol related brain damage (Korsakoff’s syndrome). Also, in 2015 it had been established that he lacked capacity to make decisions about placement, treatment and care and a Deprivation of Liberty Safeguards authorisation had been granted. These two facts would be expected to trigger a formal capacity assessment in respect of a decision regarding surgery, but there is no evidence that a formal capacity assessment was carried out.

In addition, we know from the reports that concerns about Richard’s capacity to decide about possible amputation were expressed by the social worker and a carer from his care home. On 6 December 2021 a carer from the home where Richard normally resided told the social worker that she had told the ward she felt Richard did not have mental capacity to consent to amputation. On 17 December 2021 the

¹⁴ See <https://www.legislation.gov.uk/ukpga/2005/9/section/1>

¹⁵ See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf

social worker told legal services that she had informed the hospital that she felt Richard did not have the capacity to make complex decisions.

Any one of these four factors would be expected to trigger a formal capacity assessment and it seems likely, on the evidence available, that assessment would have found that Richard did not have the capacity to make a decision about amputation, in which case the process to be followed would be that of determining Richard's best interests in line with the Mental Capacity Act¹⁶. It appears that there was uncertainty about who was the decision-maker, and who should be involved in the best interest process. Unfortunately, this process was only followed at a very late stage, by which time Richard was dying.

2.4.3 Self-neglect, refusal of care and safeguarding

In 2015 it was established that Richard was reluctant, or refused, to accept care and was at risk of self-neglect. When he attended the Emergency Department early that year there was evidence of self-neglect but, because of his cognitive impairment, the history was unclear. There are references at intervals in the reports to the ongoing issue of him being reluctant to accept, or refusing, care and support. His refusal of amputation could have been understood within the context of his refusal of care, and a safeguarding concern might have given access to multi-agency planning under the Barnsley Multi-Agency Self-Neglect and Hoarding Policy and Procedure¹⁷. On 4 January, not long before his death, the social worker advised the care home to submit a safeguarding concern.

¹⁶ See <https://www.legislation.gov.uk/ukpga/2005/9/section/4>

¹⁷ See <https://www.barnsley.gov.uk/media/15373/self-neglect-and-hoarding-policy-approved-bsab-may-2020.pdf>

PART 3: CONSULTATIONS WITH GROUPS WITHIN LOCAL SYSTEMS AND LEARNING DRAWN FROM THEM

3.1 Practitioners' Event

A practitioners' event was held online on 24 August 2022. Ten practitioners attended from a range of agencies including Adult Social Care, Barnsley Hospital, the Partnership Trust, Rethink, and Sheffield Hospitals.

Table 2 below summarises the areas of discussion, actions arising and learning points following the practitioners' event.

Table 2: Areas of discussion at the practitioners' event

Area of discussion	Theme	Action/ learning arising
<i>Mental Capacity Act and associated processes</i>	<i>Capacity</i> – most organisations did not assess Richard's capacity regularly or on key decisions despite evidence to suggest he may have an 'impairment of brain or mind'. He was subject to DoLS and had a diagnosis of Korsakoff's syndrome. Suggested possible confusion about health versus social decisions.	All organisations to reflect on their role in capacity assessments and share thoughts with managers. Use of the Mental Capacity Act is not well embedded. Hospitals seem to have specific challenges: large organisations, significant change of personnel, questions about efficacy of training.
	<i>Documentation</i> - absence of documentation relating to capacity assessments. Health organisations felt that documentation of capacity assessments was not robust. Many commented that colleagues stated that assessments had been completed, but no written evidence was available to support this.	To consider whether it would be worth sharing templates to develop a shared resource. All assessments must be recorded.
	<i>Best interest decision maker</i> - organisations lacked clarity about who the decision-maker was, and who should coordinate a best interest decision about his health treatment.	As above

Area of discussion	Theme	Action/ learning arising
	<i>Best interest decision meeting</i> - were the right people in attendance?	Is there a need for a 'how to call a best interest meeting and who needs to attend' guide if not in place.
	<i>Deprivation of Liberty</i> - absence of a DoLS application - Sheffield Hospitals did not complete DoLS application though it was started.	Use of the Mental Capacity Act is not well embedded.
	<i>Advocates</i> - increase knowledge of Independent Mental Capacity Advocates/ Relevant Person's Representatives. Ensure that referrals are made as early as possible to facilitate positive involvement.	Review whether training and internal resources support good practice. Referrals should be made as early as possible to facilitate involvement. Consider how to achieve this.
	<i>Mental Capacity Act Training</i> - is training the answer? Sheffield Hospitals confirmed lots of training/ master classes. Discussion about culture and practice and how this is changed, particularly in large organisations	To consider what would make a difference.
	<i>South Yorkshire Directory of Mental Capacity Act and safeguarding leads in health</i> - would this be helpful?	To consider. Possible learning point and might improve communication.
Inter-agency communication	<i>Communication between Barnsley Hospital and Sheffield Hospitals.</i> Richard was able to change his opinion about the amputation - unclear if this was linked to his physical health (free from infection?) or the way in which the issue was approached. This was communicated to Sheffield Hospitals but not recorded and not used to inform decision-making.	Hospital colleagues to consider and share thoughts with managers or directly with author/ board manager. Communication between hospitals should be recorded.
	<i>Communication between Barnsley Council legal and Sheffield Hospitals legal</i> - it appears that attempted escalation by Barnsley adult social care to Sheffield	It appears that contact took place but processes are not robust enough. Consider a pathway document between South Yorkshire Health partners.

Area of discussion	Theme	Action/ learning arising
	Hospitals legal failed to escalate concerns.	
Relationships	<i>Strength of advocacy relationship</i> - Richard had a very positive relationship with the advocate who operated as a Relevant Person's Representative whilst Richard in hospital in the absence of an Independent Mental Capacity Advocate being appointed.	Sheffield Hospitals might want to include this in review /training. Identified as good practice.
	<i>Continuity of relationship</i> - the strength of the relationship between Richard and the advocate evidenced the benefits of continuity of contact.	Health and primary care to reflect on this point. How can continuity be facilitated – is it realistic in current services?
	<i>Strength of relationship and communication between advocate and adult social care</i> - social worker and advocate had a positive relationship, despite Richard's section 21A appeal against his DoLS.	To consider how this might be replicated. Identified as good practice.
	<i>Relationship with district nurses</i> - strong support from district nurses and appropriate engagement with other relevant services. Nurses maintained a close relationship with Richard despite his refusal of care/ actions that would have reduced the risks. Appropriate involvement of tissue viability and memory services. Close communication between nurses, adult social care and advocate.	To consider what facilitated this. Identified as good practice. Possible learning point.
	<i>Involvement of the GP</i> - they had not known Richard long, but would have had access to all his notes. Would it have been helpful to clarify their role in the management of the issues of self-neglect and decision-making around the proposed amputation?	To consider how the GP was involved.

Area of discussion	Theme	Action/ learning arising
	<i>Family</i> – confusion about the role of Richard’s son and daughter in law both at the care home and in hospital. Were family aware of his cognitive difficulties? If not, would it have been beneficial to have shared this?	To consider how the family was involved.
Self-neglect	<i>Self-neglect flags</i> - on health records. Barnsley looking to adopt, would this be helpful in other hospitals/health settings?	To consider whether this would be beneficial – and how it would be led.
	<i>Use of Self-neglect policy</i> - Richard had a long history of refusing interventions. Unclear if he always had capacity to do this. If he did have capacity, should the Self Neglect and Hoarding Policy have been used to inform risk assessment and possible referral for a safeguarding response or a multi-agency meeting.	Consider using this case to highlight the existence of the policy and how to get support if concerned.
Safeguarding	S42 enquiry ¹⁸ - The meeting heard that the care home was subject to a S42 enquiry that was not centred on Richard. Were there (generic) aspects related to Richard’s care, eg wound care, communication with other organisations?	Is it possible to access some information about issues that might have been relevant to Richard’s care, and could the care home have been more involved in decision-making? Possible learning point as relatively few health referrals locally and regionally about cases involving health.
Working with complexity	<i>Complex patient framework/protocol</i> - discussed the benefits of creating a cross boundary tool to manage people who are complex and often refusing care and/or have fluctuating capacity. This would include a virtual meeting with all relevant professionals.	To consider whether this would be beneficial. Difficulty of working with complexity and possible ways of improving management.

¹⁸ This refers to Section 42 of the Care Act which requires a local authority to make (or cause to be made) necessary enquiries to enable a decision to be made on whether any action should be taken, when the local authority has reasonable cause to suspect that an adult in its area has needs for care and support; is experiencing, or is at risk of, abuse or neglect, and, as a result of those needs, is unable to protect themselves against the abuse or neglect (or the risk of it). See <https://www.legislation.gov.uk/ukpga/2014/23/section/42/enacted>

Area of discussion	Theme	Action/ learning arising
	<p><i>Universal passport</i> - Richard had complex needs and was 'difficult to treat' due to his refusals and medical history. Would he have benefited from a health passport to provide consistent information to all health professionals?</p>	<p>To consider whether this would have made a difference. Sheffield and Barnsley both have universal health passports. The latter is being piloted. Difficulty of working with complexity and possible ways of improving management.</p>
	<p><i>Supporting patients to make significant/ complex medical decisions</i> – British Medical Association produces good practice guides¹⁹. Mental Capacity Act includes clear guidance for adults who lack capacity. Is this well understood especially for complex patients like Richard?</p>	<p>Would a regional event to share best practice be useful? The need to support patients to make significant/ complex medical decisions.</p>
<p>Escalation processes</p>	<p><i>Lack of escalation within Sheffield Hospitals</i> – Richard's care was delivered by vascular services, Emergency Department and wards. The internal resource offered by the Mental Capacity Act team and the support the lead for safeguarding/MCA was not accessed.</p>	<p>It appears that processes are not robust enough.</p>
	<p><i>Escalation processes</i> - would a South Yorkshire or 4 local escalation processes that 'talk' to each other be helpful between health organisations. This is based on the failed communication between Barnsley and Sheffield Hospitals, and Barnsley and Sheffield Hospitals legal teams.</p>	<p>To consider whether this might be in addition to internal escalation. Would one policy for South Yorkshire be preferable to four local ones? Communication between Barnsley and Sheffield Hospitals did not work at a critical point for this patient.</p>

¹⁹ See British Medical Association (2019) Best interests decision-making for adults who lack capacity A toolkit for doctors working in England and Wales at <https://www.bma.org.uk/media/1850/bma-best-interests-toolkit-2019.pdf>

3.2 Managers' event

A managers' event took place online on 14 September 2022. Seven people attended from adult social care, Barnsley hospital, the Partnership Trust, Rethink, and Sheffield Hospitals.

Table 3: Summary of discussions at the managers' event

Area of discussion	Theme	Action/recommendation
<i>Mental Capacity Act and associated processes</i>	<i>Poor recording of Mental Capacity Act and DoLS -</i> The group endorsed the views of the practitioners. A discussion was held about the fragmented record systems including both electronic and paper records, complicated by the lack of access to all records by all employees. Sheffield Teaching Hospitals and Barnsley Hospital are moving to a new patient record but this will not be in place until 2024. Group agreed that all Mental Capacity Act discussions should be recorded.	All to review current record systems and consider amends, if possible, considering the learning from this review. All to consider inclusion in supervision/team meetings to improve use of the Act. Consider a postcard/other with the 5 principles of the Mental Capacity Act being issued to all relevant staff.
	<i>Decision-makers -</i> Agreed that the Mental Capacity Act is the responsibility of all staff. Need to make sure that staff know when they should take on the role of decision-maker and if not sure seek advice.	All to consider how this will be communicated to staff including internal escalation and monitoring.
	<i>Mental Capacity Act training versus learning in practice -</i> discussion that training is not always the answer. Confirmed that active training has been delivered in Sheffield Hospitals following feedback from the Care Quality Commission in 2021. Adult social care - it was suggested that reflective practice is more effective, supported by a strong management culture.	All to consider and share how they will evidence that learning from this will be embedded.
	<i>Documentation –</i> 'Common front sheet' - explored the benefits of a common front sheet that includes	Barnsley Hospital happy to share/ develop a complex

Area of discussion	Theme	Action/recommendation
	any issues with capacity – this will not negate the need for assessments; risk of self-neglect; DoLS status; if open to safeguarding or other processes. Whilst in principle agreed, significant challenges about adoption.	lives pro-forma for use locally or regionally. If the latter, aim to share with other safeguarding managers.
Inter-agency communication	<i>Communication between Barnsley Hospital and Sheffield Hospitals</i> - The group supported the views of practitioners that this had not worked well. Sheffield Hospitals do not get all the Barnsley notes with a transferred patient. Call from Barnsley registrar to equivalent in Sheffield Hospitals regarding Richard's decision to accept the below knee amputation was not documented.	How can we improve the recording of phone calls between hospitals to ensure they are not lost, eg recorded on the phone, email, phone log, other.
	<i>Communication between Barnsley Hospitals legal and Sheffield Hospitals legal</i> - The group supported the views of practitioners that this had not worked well.	Consider a South Yorkshire wide process for sharing information between legal teams.
	<i>Communication between adult social care and care provider</i> – regarding care provider not meeting DoLS conditions.	
Relationships	<i>Lack of history for Richard</i> - The group reflected on the learning from research/ Safeguarding Reviews that indicates that knowing the person is key to addressing self-neglect. The group agreed that it was not well understood that Richard's self-neglect was longstanding, complicated by alcohol misuse. A discussion about the importance of relationships took place and the positive impact of the advocate was noted.	How do we encourage workers to be curious about the person? What do we expect from specialist placements who could have completed this work? Action – Barnsley Council Adult Joint Commissioning to be asked about their expectations of specialist placements.
	<i>Family and friends</i> - the meeting acknowledged that Richard was not supported/encouraged to rebuild relationships with family.	How do we support practitioners to explore the option of contact with family and friends?

Area of discussion	Theme	Action/recommendation
	<i>Family and friends</i> - the use of “next of kin” in the decision about final treatment may not have been in line with best practice.	Can we improve recording to show that family have no rights to make decisions unless they have a valid Lasting Power of Attorney?
Working with complexity	<i>Processes for responding to adults with complex lives/multiple issues</i> - discussed the use of self neglect and hoarding policies, complex case management process (Sheffield), Multi Agency Panel (Barnsley) and agreed that a multi-agency response is always preferable.	Consider creation of a document that maps out the range of panels and supports practitioners to refer to the most appropriate one
Escalation processes	<i>Lack of escalation</i> - this did not happen robustly, eg the Partnership Trust did not contact their internal legal. Sheffield Hospitals did not contact safeguarding team or legal services. Sheffield Hospitals legal services did not contact the Metal Capacity Act or Safeguarding Teams. Adult social care – is this the sort of case that should have been shared with service managers/head of service. Care home staff were unaware of how to escalate their concerns.	All to consider review/adoption of escalation processes?

PART 4: SUMMARY OF LESSONS LEARNED AND GOOD PRACTICE IDENTIFIED

4.1 Lessons learned

4.1.1. The Mental Capacity Act and associated processes are not well embedded in health care and residential social care practice.

This was evident in: the lack of capacity assessments; poor recording relating to capacity; confusion about the best interest decision-maker and the best interest process. The context is one of lots of training but it appears that this is not resulting in consistent appropriate legal practice.

4.1.2 Communication between agencies is not robust.

This was evident in the failed communication between the two hospitals; and communication between Barnsley Council and Sheffield Hospitals legal services.

4.1.3 Some practitioners were able to establish good relationships with Richard despite the fact that he appears to have been an assertive character with strong views and someone who did not always comply with care and support.

This may support the need for continuity of relationship and the importance of professional curiosity, particularly with people who present with complexity.

4.1.4 Practitioners in both health and social care were not clear about the role of Richard's family.

This was evident in the inconsistent approach to involving Richard's family which appears to suggest lack of clarity regarding family members' rights to influence/ decide matters relating to his treatment.

4.1.5 Richard had a long history of self-neglect/ refusal to accept interventions and it is not clear whether he had capacity to do so. The use of the self-neglect and hoarding policy was not considered.

Use of the policy could have contributed to risk assessment and given access to multi-agency support.

4.1.6 It proved difficult for agencies to address Richard's complex needs particularly given that he was a strong character, refused care, and probably had fluctuating capacity for decisions about his health and care.

There is a need for ready access to/ use of a multi-agency response in these situations.

4.1.7 Escalation processes did not work; or were not in place.

Escalation between Barnsley legal and Sheffield legal did not work and internal Sheffield Teaching Hospital resources were not accessed. Care home staff were not aware of how to escalate their concerns.

4.2 Good practice identified

4.2.1 Strength and continuity of the relationship between Richard and his advocate.
Richard had a positive relationship with the advocate who operated as a Relevant Person's Representative whilst Richard was in hospital in the absence of an Independent Mental Capacity Advocate.

4.2.2 Strength of relationship and communication between the advocate and adult social care.

Richard's social worker and his advocate had a positive relationship, despite Richard's section 21A appeal against his deprivation of liberty.

4.2.3 The close relationship between Richard and the district nurses.

The district nurses maintained a close relationship with Richard despite his refusal of care/ actions that would have reduced the risks. The nurses maintained this relationship whilst appropriately involving other services (tissue viability and memory services), and communicating with adult social care and the advocate.

4.2.4 The care taken to discuss possible amputation, possible risks and benefits, with Richard whilst he was on a ward at Barnsley Hospital, despite the fact that he had previously refused surgery.

Richard told the team he would consider below knee amputation if he didn't need to stop smoking, and it was documented that he had the capacity to make this decision at the time. The risks and benefits of below knee amputation were discussed with him, and he said that he wanted to go ahead with surgery after all, as he had not understood the risk that he might die without it. The careful documentation of this stands out in this case.

PART 5: CONCLUSIONS AND RECOMMENDATIONS

The main conclusion from this Safeguarding Adult Review is that Mental Capacity Act processes are not well embedded in practice despite much effort to train practitioners in the use of the Act.

5.1 New single agency recommendations

5.1.1 Adult Social Care

1. It is recommended that when adult social care place individuals in specialist placements it would be good practice to ensure that they understand compliance with the Mental Capacity Act – section 5²⁰ and section 6²¹.
2. It is a recommendation that managers within adult social care sign up to practitioners being given the skills to have better / stronger conversations with care homes in relation to refusal of care and steps needed to safeguard individuals.

5.1.2 Sheffield Teaching Hospitals

1. A 'Legal Documents' divider is being pursued for insertion into the paper patient records to file deprivation of liberty safeguards applications; Do not attempt cardiopulmonary resuscitation forms; Power of Attorney documents etc.
2. Learning Lessons Programme to be implemented in vascular services in response to this case.

5.2 Multi-agency recommendations

The recommendations below are linked to the lessons learned and grouped thematically but numbered sequentially.

5.2.1 Recommendations aiming to embed use of the Mental Capacity Act in practice

1. Hospitals to investigate whether it is possible to build use of the Mental Capacity Act into appraisal processes for doctors.
2. South Yorkshire Integrated Care Board to develop best practice templates for recording capacity assessments and consider cascading across South Yorkshire.

²⁰ Section 5 of the Mental Capacity Act concerns acts in connection with care or treatment.

²¹ Section 6 of the Mental Capacity Act concerns restraint or deprivation of liberty.

3. Commissioners and regulators to survey/ audit current practice with regard to Mental Capacity Act processes and advise on improvements ²².

4. Agencies involved in this Review to provide evidence that training includes best interest processes and incorporates case examples such as Richard's case.

5. A directory of Mental Capacity Act and safeguarding leads to be produced including team email addresses rather than professional work email addresses in the interests of longevity.

6. Agencies involved in this Review to investigate innovative ways of staff having to hand the five principles of the Mental Capacity Act and sources of advice.

The recommendations here aim to address the learning point about the Mental Capacity Act and associated processes not being well embedded in health and social care practice.

5.2.2 Recommendation aiming to improve communication between agencies

7. The two hospitals involved in this Review to evaluate failures to record communication between them, including phone communications, and agree actions to improve communication.

This recommendation comes from the learning point related to failed communication between the two hospitals; and communication between Barnsley Council and Sheffield Hospitals legal.

5.2.3 Recommendations to improve clarity with regard to family's members role in relation to patients

8. Health agencies to routinely check and robustly record Lasting Powers of Attorney.

This recommendation addresses the learning point that health and social care practitioners were not clear about the role of Richard's family.

5.2.4 Recommendation to address self-neglect and failure to consider using the self-neglect policy

9. Agencies to introduce agreed self-neglect flags recognisable across agencies for people with a known history of self-neglect.

This recommendation aims to address the finding that, despite a long history of self-neglect/ refusal to accept interventions, the use of the self-neglect and hoarding policy was not considered.

²² Sheffield Teaching Hospitals has been subject to an Appreciative Enquiry by NHSE with regard to application of the Mental Capacity Act.

5.2.5 Recommendations to reinforce a multi-agency approach to the care of people with complex needs

10. The benefits of a universal passport that travels with the patient should be implemented where practicable and particularly for complex patients.
11. To explore the benefits of a regional event to share best practice in relation to supporting patients with complex decisions.
12. Safeguarding leads and/or the South Yorkshire Integrated Care Board to develop a complex patient framework/protocol which includes escalation processes where there is disagreement.

These three recommendations aim to address two learning points, firstly that agencies found it difficult to address Richard's complex needs, particularly given that he was a strong character, refused care, and probably had fluctuating capacity for decisions about his health and care; and secondly that escalation processes did not work or were not in place.

5.2.6 Recommendations addressing points raised by the family

13. Commissioners of care home care to investigate including in contracts a requirement for homes to keep families informed of their relative's admission to hospital where that relative is unable to keep family informed themselves by reason of physical and/ or mental incapacity and it is in that person's best interests to do so.
14. Commissioners of care home care to investigate including in contracts a requirement for care homes to keep families updated regarding changes in their relative's condition where the resident is unable to do so themselves by reason of physical and/or mental incapacity and it is the resident's best interests to do so.

These recommendations address points raised by the family and accord with the person-centred care key lines of enquiry for adult social care services in the Care Quality Commission guidance to providers²³ which asks 'how are people encouraged and supported to develop and maintain relationships with people that matter to them, both within the service and the wider community, and to avoid social isolation?'

²³ See <https://www.cqc.org.uk/guidance-providers/adult-social-care/key-lines-enquiry-adult-social-care-services>

APPENDIX

Summary chronology of events leading up to Richard's death

The Table (overleaf and following) summarises the chronology of events leading up to Richard's death in January 2022.

Key to fill in left column:

- grey fill = resident in Care Home H
- green fill = resident in Care Home A
- blue fill = resident in Care Home R

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
3 Feb to Mar 2015	<p>Information for Partnership Trust: Richard attended Barnsley Emergency Department, confused, dishevelled, unkempt, smelt of urine, soiled clothing. Said he was looking for his father (deceased). Talked of his ex-wife cooking for him but later found ex-wife estranged. Confabulating. Notes indicated he lacked capacity to make decisions about placement, treatment and care - cognitive impairment, self-neglect and possible diagnosis of alcohol-related dementia. DoLS authorised.</p> <p>Known to Adult Social Care from time of admission.</p> <p>Discharged to Care Home H for short stay/ further assessment.</p>				
1 May 2015	<p>Residing at Care Home H (grey fill). Memory Service practitioner and Social Worker involved, lack of history, and he was unable to remember a 10-year period. Later information: from Huddersfield, had three brothers, married twice, divorced, has son and daughter, estranged from family, been in prison, no insight into memory loss. History of heavy alcohol use – not drinking at Home. Happy to stay.</p>				
28 May 2015	<p>Memory Service practitioner visit to care home - issues with aggressive behaviours around smoking. Reluctant to care for personal hygiene.</p>				
8 Jun 2015 Jun-Jul	<p>Memory Service Practitioner and Consultant Psychiatrist. No evidence of aggression or hostility. 6-month history of multi-domain cognitive impairment; history of excessive alcohol consumption; disorientation to time and place with marked confabulation. Subject to standard DoLS. Diagnosis: severe amnesic syndrome due to Alcohol Related Brain Damage (Korsakoff's syndrome).</p> <p>References to best interests meeting and Independent Mental Capacity Advocate.</p>				

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
8 Oct 2015	Meeting discussed potential risks of self-neglect, relapse of alcohol consumption, and vulnerability. Occupational Therapist found Richard lacked insight into current health/ care needs. Required prompting to maintain hygiene. Lacks insight into previous alcohol misuse. Meeting agreed Richard needed 24-hour care because of risks.				
19 May 2016	Transferred to Care Home A (green fill). Review noted not always compliant with care and could be hostile to others.				
June 2018	Best interests meeting re placement - agreed high level of risk to self from self-neglect/ refusal of care – best interests = 24 hr care.				
25 Feb 2021		Joined GP practice, in Care Home R (blue fill) –noted Korsakoff's psychosis, lower leg ischaemia, chronic leg ulcers. 04/21 - Various appointments related to leg pain/ swelling.			Transferred to Care Home R due to closure notice on Care Home A. Placement reviewed 03/2021 and 07/2021 – no concerns documented.
14 June 2021		Advance care planning discussed. Richard wanted a do not resuscitate			

Date	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
Fill = care home					
		agreement, GP noted he 'does not have capacity'.			
July 2021- various dates	Neighbourhood nursing team involved - ongoing	Attended Emergency Department on 2 July and 3 July diagnosed with lower respiratory tract infection.	26 July: Attended Emergency Department. Aware of DoLS at care home.		
7 Sept 2021		7 Sept – attended Barnsley Emergency Department – left before seen.	Attended Emergency Department with leg pain and short of breath.		
9 Sept 2021		Care Home R asked for home visit – can't walk, legs give way, right leg swollen. Home advised to call ambulance.	Attended Emergency Department - leg pain and breathlessness. Assessed – has capacity for short-term decision		

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
			making: best interests meeting for long-term decisions.		
5 Oct 2021 & later Oct/ Nov dates	Neighbourhood Nursing (SWYPFT) involvement ongoing: 5/10 concern re leg wound - superficial tear to skin on inner knee. Advised use of pillow to prevent pressure area damage - may have been caused by legs rubbing together. 8/11 noted cellulitis. 12/11 advice re tight jeans. 15/11 antibiotics.				
16 Nov 2021					Social Worker visit – Richard refusing support with needs

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
					eg washing, dressing; sleeping in clothes; wound on leg. Legs deteriorated from Sept, 'very swollen'; now uses wheel-chair to go out.
17 Nov 2021	Neighbourhood Nursing team ongoing - visited Home to treat leg wound.	Seen by doctor on home visit, referred for hospital admission – cellulitis, on second antibiotic course.			Social Worker contacted Care Home R concerned re lack of documentation re refusal of care.
18 Nov 2021				Vascular Consultant letter to Barnsley Physician. Admitted to Northern General due to left upper calf leg ulcer - arterial circulation fine, no evidence of venous	

Date	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
Fill = care home					
				disease. Treatments recommended – plan discharge once cellulitis settled.	
19 Nov 2021	Member of Neighbourhood Nursing team contacted by Social Services as Richard was refusing to accept care in hospital. Discharged 20 Nov.	Discharge letter Barnsley hospital. Diagnosis- infected leg ulcer, seen by vascular team- no surgical input needed.			Social Worker contacted district nurses and Barnsley Hospital – ulcer on calf necrotic, intra-venous anti-biotics unsuccessful (removes cannula).
23 Nov 2021	Neighbourhood Nursing team: becoming more unwell, vomiting, shaking, leg tender to touch and swollen.	Seen by doctor and referred to hospital. Seen in Emergency Department.			
29 Nov 2021	Richard did not want to use pillow to support legs, Team felt he was able to				

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
	consent to treatment, but capacity fluctuated.				
30 Nov 2021		Seen by cardiology and discharged but referred to Emergency Department to rule out deep vein thrombosis.	Reviewed in cardiology clinic – left leg ulcer & necrotic tissue – sent to Emergency Department for review. Admission recommended – he refused. No capacity assessment documented.		
1 Dec 2021	Neighbourhood Nursing liaising with Home.		Returned to Same Day Emergency Care - leg ultrasound – discussed with vascular consultant. Appointment in 2		

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
			months made at Northern General.		
2 Dec 2021		Seen by vascular team at Northern General following scan which showed occluded left femoral artery. Vascular doctor arranged vascular rapid access pathway next day.		Clinical letter to GP from vascular surgeon - swollen legs secondary to heart failure, in poor general health; multiple co- morbidity - active smoker, obese and aorto-iliac disease. To attend vascular rapid access pathway next day; may need urgent admission.	

Date	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
3 Dec 2021	Neighbourhood Nursing team visited the care home and re-dressed the wound, advised by carers that Richard was going into hospital every day, as he had a blood clot. Carer also advised that Richard may have to be admitted to hospital.			Admitted under Vascular Surgery with necrotic ulcer to left calf and surrounding cellulitis. Documented patient unfit for vascular intervention and refused below knee amputation - to return to Barnsley. Not for vascular admission unless willing for intervention.	
4 Dec 2021				Richard able to use call buzzer and communicate. Documented left foot was viable.	
6 Dec 2021	Discharged from Neighbourhood			Ward round: on oxygen, uncomfort-	Social Worker call from care home –

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
	Nursing team - re-refer when discharged from hospital.			able lying and short of breath. Insistent on going out for cigarette - strongly advised against it. Warned about smoking whilst on oxygen.	carer had told ward she felt Richard did not have mental capacity to consent to amputation. Contacted advocate, informed of above.
7 Dec 2021				Regularly wheeling himself to dayroom for cigarettes; looked comfortable but complaining of pain in left leg. Explained to Richard that if he is fit for treatment, will likely need a below knee amputation.	
9 Dec 2021			Repatriated to elderly care ward Barnsley Hospital from Northern	Medical records state - transfer to Barnsley, has previously refused	

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
			General - diagnosis critical left leg ischaemia – managed conservatively. Allegedly refused surgery saying he would prefer sepsis and death to stopping smoking for surgery.	any vascular intervention. Not for re-admission unless he is willing for vascular interventions. Plan – oral antibiotics and see face to face in three weeks.	
10 Dec 2021			Reviewed on ward – told team he would consider below knee amputation if he didn't need to stop smoking. Documented that he had capacity to make this decision. Northern General medical team contacted - told he		

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			didn't need to stop smoking but they felt he would decline if decision revisited.		
13 Dec 2021			Medical records – Richard agrees to below knee amputation, is able to repeat back risks of infection, necrosis, sepsis and death. Plan - discharge with vascular follow up.	Documentation on internal referral Barnsley Hospital - when seen, risks and benefits of below knee amputation were discussed: said he wanted operation after all as he had not understood risk that he might die without it. Physician discussed this with Specialist Registrar on call at Northern General. To be seen in Barnsley outpatients for consultation regarding operation.	

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				Conversation not documented in Northern General notes – missed opportunity.	
17 Dec 2021					Social Worker told Legal Services she had informed Hospital that she felt Richard did not have capacity to make complex decisions.
20 Dec 2021		Discharge letter from Barnsley Hospital - to come in if leg becomes red/ hot/ tense/ painful/ or he becomes systemically more unwell.	Discharged to care home.		Social Worker liaised with care home and discussion with Legal Services – NHS notified of concerns in relation to capacity to consent to operation.

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
21 Dec 2021 & 22 Dec 2021	Re-referral to Neighbourhood Nursing Team post discharge. Visited care home for wound care. Referral indicated that below knee amputation advised, but Richard refused. Discussion between Tissue Viability Team and Neighbourhood Nursing noted Richard had mental health issues and not concordant with treatment. Larvae treatment ²⁴ unlikely to be tolerated.	On call GP spoke to care home staff and was informed of discharge from hospital as patient deemed to have capacity. Appointment with vascular consultant in two days. GP put a letter together to explain re capacity and DoLS - Home to take letter to appointment.			22/12 Social Worker visited care home. Richard did not appear to understand seriousness of health and implications of non-treatment.
23 Dec 2021		Letter from vascular surgeon advising	Reviewed in vascular clinic	Richard seen in clinic: letter dated	

²⁴ applying maggots to a wound to help it heal

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
		Richard unlikely to change mind about amputation and 'it is his choice'.	Barnsley – no evidence of capacity assessment.	06/01/22 from Consultant stated 'my understanding is that (Richard) has declined intervention previously but now has constant pain with the infected ulcer which is causing leg cellulitis. Although ... engaging with us, my understanding is that we would have to work with him, and he is unlikely to change his mind about below knee amputation. The leg is severely ischemic, ... cellulitic, and has a necrotic ulcer...' Noted Richard very	

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
				short of breath when lying down. Also documented 'Going forward it is (Richard)'s choice to live with his ischemic leg and I can respect that... I do not think this ulcer is ever going to heal or his skin get better, but we can reduce some elements of his discomfort ...'	
26-27 Dec 2021		Out of hours contacts – referred to Emergency Department Emergency Department letter - query sepsis – discharged.	27/12 attended Emergency Department by ambulance with swollen left leg. No evidence of deep vein thrombosis.		

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			28/12 reviewed and prescribed morphine.		
2 Jan 2022	<p>Team visited Home. Staff member identified Richard had been unwell the previous day - 111 had been contacted and photographs of wound sent. Wound re-dressed, - staff member contacted District Nurse who advised Best Interests meeting to formulate a plan of care.</p> <p>Admission to Sheffield Teaching Hospital</p>	<p>Attended Emergency Department Northern General Hospital with limb pain.</p>		<p>Attended Emergency Department Northern General Hospital. Capacity concerns noted – recorded verbal consent was given. Documented</p> <ol style="list-style-type: none"> 1. He was refusing amputation. 2. DoLS in place & best interest meeting awaited with social worker. 3. Has Korsakoff's Dementia - states he still drinks alcohol though care 	

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
				<p>home staff say not.</p> <p>4. Low-grade infection with intermittent confusion.</p> <p>5. Reports worsening pain to necrotic area and surrounds.</p> <p>Discussion with Consultant who stated that, given DoLS, he does not have capacity, and this is complex case. Community Nurses concerned about increasing necrotic area; purulent discharge; low grade fever. Richard adamant 'they are not</p>	

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
				<p>chopping my leg off'; aware in hospital but thought it Rotherham. Unable to recall age/ year.</p> <p>Plan for ongoing vascular involvement and awaiting a best interest meeting re amputation. If Richard attempted to leave, he would need a DoLS. If he does not spike a temperature in next 24 hours can be discharged.</p>	
3 Jan 2022	Neighbourhood Nursing Team contacted care home who advised Richard had been admitted to			Diabetes and Endocrinology ward round – Richard is under DoLS and awaiting a best	

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	hospital, DoLS in place and Richard had advocate and Social Worker.			interests meeting/ decision with social worker to determine if he will have a below knee amputation. Has become increasingly more confused.	
4 Jan 2022	Discharged from Neighbourhood Nursing Team			Sitting out in chair - not very co-operative. Does not answer questions or allow examination.	Home contacted Social Worker – advised to forward safeguarding concern to adult social care.
5 Jan 2021				Ward Round – requested GP clarification re residential/care home and if best interests meeting in place.	
6 Jan 2022				DoLS form completed, but unsigned so not authorised. Two incomplete mental	Advocate called Emergency Duty Team – consultant at Northern General did

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
				<p>capacity assessment templates in folder, one not fully completed - another blank with the words 'patient under DoLS' written across it. Signed do not attempt resuscitation order, documented discussed with son and IMCA - form stated that Richard lacked capacity, but no formal capacity assessment. Consultant spoke to member of staff at care home who did not know anything about best interest meeting, will talk to manager and get back to ward. Call back from care</p>	<p>capacity assessment and deemed lacked capacity but not willing to amputate in face of patient's refusal.</p> <p>(Evidence of social worker liaising with others.)</p>

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
				<p>home - hospital must arrange best interests meeting as it concerns medical treatment.</p> <p>Richard seen in bed – confused - clear by now he had a ‘non-salvageable’ left leg and needed above knee amputation - still did not want an amputation despite possible threat to life.</p> <p>Plan documented:</p> <ul style="list-style-type: none"> • Not for major amputation as patient refused before and now. • No next of kin • No further vascular surgery input needed - 	

Date Fill = care home	South West Yorkshire Partnership NHS Foundation Trust	GP practice	Barnsley Hospital NHS Foundation Trust	Sheffield Teaching Hospital NHS Foundation Trust	Adult Social Care
				<p>IMCA contacted and informed Richard extremely unwell: told Vascular Team had decided not to actively treat. IMCA called back later that day and advised a best interest meeting to be arranged for next morning.</p> <p>Richard further reviewed - whole limb cold; mottling extended to abdomen. Had now progressed too far for an above knee amputation. No longer any clinical options and he was dying.</p> <p>Palliative care involved, all active treatment ceased:</p>	

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				comfort care provided.	
8 Jan 2022				Family came to visit - Richard died just after midnight.	

NOTE: The references to the IMCA (above – 6 Jan 2022) refer to the advocate/ Relevant Person’s Representative.

Glossary of abbreviations

Note: In the light of feedback from readers of previous reports, the author has written this report with attention to minimising the use of acronyms. The few acronyms used in the report are listed below.

DoLS	Deprivation of Liberty Safeguards
GP	General practitioner
IMCA	Independent Mental Capacity Advocate – <i>this is a statutory role introduced under the Mental Capacity Act to support some people who lack decisional capacity.</i>
NHS	National Health Service
RPR	Relevant Person’s Representative - <i>If a person is deprived of their liberty under the Mental Capacity Act they must have a representative. This could be a family member or a friend, but if there is no one suitable to take on this role it could be a Paid Representative also known as a Relevant Person’s Representative or RPR.</i>

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