## Safeguarding Adults Review in respect of Linda

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### Glossary:

Abbreviation	Definition
BSAB	Bury Safeguarding Adult Board
SAB	Safeguarding Adult Board
SAR	Safeguarding Adult Review
GP	General Practitioner
PLE	Practitioner Learning Event
S42	Section 42 (of The Care Act)
MCA	Mental Capacity Act
MHA	Mental Health Act
IDT	Integrated Discharge Team
INT	Integrated Neighbourhood Team
IMC	Intermediate Care

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### 1. Introduction

- 1.1. Under section 44 of the Care Act 2014 there is a duty for Safeguarding Adult Boards (SABs) to arrange a Safeguarding Adults Review (SAR) when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked together more effectively to protect the adult. If the SAR criteria are not met but the relevant SAB feels that there are lessons to be learnt, an alternative review may be undertaken.
- 1.2. The purpose of conducting a review is to enable members of the SAB to:
- Establish whether there are lessons to be learnt from the circumstances of the case about, for example, the way in which local professionals and agencies work together to safeguard adults at risk.
- Review the effectiveness of procedures and their application (both multi-agency and those of organisations).
- Inform and improve local inter-agency practice by acting on learning (developing best practice) in order to reduce the likelihood of similar harm occurring again.
- Bring together and analyse the findings of the various reports from agencies in order to make recommendations for future action.
- 1.3. Further information on the local SAR process can be found in the BSAB SAR protocol.
- 1.4. SARs are required to reflect the six safeguarding adults' principles, as defined in the Care Act. These are empowerment, prevention, proportionality, protection, partnership and accountability.
- 1.5. The aims of the SAR are to contribute to the improved safety and wellbeing of adults with care and support needs and, if possible, to provide a legacy and support family and friends.
- 1.6. There are clear review objectives which have been addressed to achieve these aims. Through a shared commitment to openness and reflective learning, involved agencies have sought to reach an understanding of the facts (what happened), an analysis and findings (what went wrong and what went right), the recommendations to improve services and to reduce the risk of repeat circumstances, and a shared action plan to implement these recommendations. It is not the purpose of the review to re-investigate the suspected abuse or neglect, or to apportion blame to any party.
- 1.7. The review process to meet these aims and objectives has followed a clear path. The methodology chosen for this review is a "Learning Together" approach. This included a panel to agree terms of reference and a focus on themes, patterns and factors together with family and practitioner discussions. The Independent Reviewer has conducted research by analysing the information provided culminating in an overview report for the RSAB
- 1.8. The review will cover the period of the twelve months prior to Linda's death.

#### 2. Overview of the case and circumstances leading to the review

- 2.1. The SAR referral was received on 19/12/2022 from Adult Social Care, the case was considered on 22/02/2023 and the review was endorsed and commissioned.
- 2.2. This review is about a 68-year-old female who died on 18/12/2022 in Salford Royal Hospital. Linda<sup>i</sup> had a number of health conditions and had been blind from birth. She was in receipt of a package of care in her own home and lived relatively independently until eight months prior to her death. Lindas deteriorating health resulted in several lengthy hospital admissions in that period of time thus changing her care and support needs.
- 2.3. Linda was discharged home six days prior to her death with a care package in place. It is noted during this time that her health significantly deteriorated, and she declined care and support. During this period, Linda and her carers raised concern that equipment that was needed was not in place. At the time of her death, she was awaiting a therapy team review and a full care needs reassessment. When North West Ambulance Service (NWAS) attended her home on the day she died they made a safeguarding referral based on how unwell she was, the condition of her pressure areas, her prosthetic eye was found in her left armpit, and she was found in soiled pads and bedding. On arrival at hospital, the Emergency Department (ED) staff made a second safeguarding referral for the same reasons.
- 2.4. The services contributing to the review are:
- NHS GM Bury- NHS Greater Manchester Integrated Care
- Northern Care Alliance NHS Foundation Trust, Salford Royal Hospital and Fairfield General Hospital sites (NCA)
- Pennine Care Foundation Trust (PCFT)
- Greater Manchester Police (GMP)
- North West Ambulance Service (NWAS)
- Bury Council Adult Social Care
- Whitaker Lane Medical Centre (GP practice)
- Care First Agency
- Six Town Housing
- 2.5. The SAR Panel acknowledged that there were areas of improvement identified for the planning and coordination of multi-agency care.

#### 3. Key Themes identified for this review:

- Transfers of care between acute and community setting
- Mental Capacity and safeguarding
- Listening to the voice of the person

#### 4. About Linda:

4.1. Linda was a 68-year-old lady who resided in Bury. Linda lived alone in a one-bedroom ground floor flat since 2010 and had a care package comprising of a carer visiting three times per day. Linda had been blind since birth and had some mobility and health issues.

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- 4.2. Linda was well known by her GP, and the care agency who provided care to her for a long period of time. Both of these providers of care evidence very frequent contact with Linda prior to and during the timeframe of this review.
- 4.3. Linda was born in Blackpool and had seven brothers and sisters but unfortunately had not maintained contact with them. The professionals involved in her care reflect that she rarely talked about her family and thus little is known about them. She attended a school for the blind and worked as a machine operator for 12 years post education. Linda was very active in her community and was involved in fund raising. Linda was particularly good with technology which she used to access healthcare.
- 4.4. Linda enjoyed music and is described by her care agency as being a "complete music buff" about the music of the sixties, seventies and eighties. She liked entering competitions on the radio and would also phone in to radio chat shows. She enjoyed singing, and shortly prior to becoming unwell was planning to sing at a folk night, she could sing Lancashire folk songs and had friends in a band called the Five Penny Piece.
- 4.5. The people that knew her well highlight that Linda took a long time to get to know people before she entered into a "trusting relationship" and this will be explored in due course. She was very particular about how she liked things to be done and had particular places that she liked her food to be purchased from such as the local butchers and a specific chip shop.
- 4.6. This review demonstrates that Linda's life changed considerably in the last few months of her life when she became unwell, and she experienced significant changes in terms of how her care was provided. Throughout this time Linda's willingness to work with the variety of different teams and services reduced, leading to concerns about what was needed to support her at home and how well she could work with those services to maximise her wellbeing. These issues will be explored throughout this report.

#### 5. Engagement with Family

- 5.1. Engagement with family members and listening to their perspectives and experiences is essential to develop learning when undertaking a SAR. A focus on their understanding about how their family member was supported on a daily basis and their experience of services and whether they found these to be helpful, provides a more personal insight into how agencies managed events.
- 5.2. The statutory guidance requires early discussions with the individual (where possible), family and friends to agree how they wish to be involved. It further requires that families should be invited and understand how to be involved, with their expectations managed appropriately and sensitively<sup>ii</sup>.
- 5.3. Unfortunately, despite several attempts to contact family members, the BSAB were not able to get their input and therefore there is a missing element in terms of family perspective and a deeper insight into Linda.

#### 6. Parallel processes

6.1. For reference, background, and context it is helpful to consider the formal cause of death and other relevant statutory process and their conclusions.

6.2. The certified cause of death recorded by the Bolton Coroner is:

1a) Cellulitis, Acute Kidney Injury, Gastroenteritis, Diabetic Nephropathy, Cirrhosis, Ischaemic Heart Disease and Hypertension

- 6.3. There is not an inquest scheduled and there are no other parallel processes taking place.
- 6.4. To note, a serious incident investigation was undertaken by Northern Care Alliance NHS Foundation Trust prior to the SAR process and that report has been made available for this review.
- 6.5. For reference, Serious incidents that occur within the NHS are investigation in accordance with the current NHS Serious Incident Framework (2015).<sup>III</sup> This will be fully replaced by Autumn 2023 with the new Patient Safety Incident Response Framework (PSIRF).
- 6.6. A Root Cause Analysis (RCA) is a methodology for conducting serious incident investigations and learning from incidents. The reason a RCA was carried out was because Linda had been discharged shortly prior to death from Fairfield Hospital and concerns were raised about skin integrity when she returned to hospital on the occasion of her death. The RCA reviewed the care provided to Linda in the context of pressure areas. It was the finding of this investigation that the patient developed infected pressure ulcers after being discharged with no pressure relieving equipment, due to a lack of joined up working between the multi-disciplinary team, leading to no clarity on who was responsible for clinical decision making on pressure relieving equipment on discharge.
- 6.7. It is not the intention of this SAR to repeat the lines of enquiry in the RCA, however the review will more widely consider the multi-agency processes when a person is transferred from one setting to another.

#### 7. Key learning episodes:

7.1. The below table outlines broadly the key episodes of care within the timeframe of the review, this does not contain each and every contact or conversation and is intended to act as a visual journey. Analysis will be made later in the report. Further detail is contained in the chronology in Appendix one.

Timeframe	Descriptor:
Late 2021/ early 2022	There is recorded activity with the GP which was not out of the ordinary, routine calls and discussions and correspondence from different speciality teams. Linda had an operation to her eye during this time.
April 2022	Evidence of nausea/ sickness and reported reduced appetite starts to be evident in GP records.
April 2022	Hospital admission 1- primary reason recorded as abdominal pain.
May 2022- June 2022 (33 days)	Hospital admission 2- nausea, diarrhoea and vomiting recorded as the reason for admission
June 2022- July 2022 (26 days)	Hospital admission 3- re-admitted same day as discharge- fell over when leaving hospital, sepsis and acute kidney injury recorded
July 2022- September 2022 (48 days)	Hospital admission 4- re-admitted same day- constipation, leg pain, hypoglycaemic episodes. It was particularly noted during this admission that Linda was not wanting to take her medication and was reluctant to work with professionals to coordinate her discharge. A capacity assessment was completed, and Linda was discharged to an intermediate care setting (Killalea House). The Trusted assessment model was applied for discharge planning.
October to December 2022 (61 days)	Admitted to hospital due to reduced nutritional intake and vomiting, this was a lengthy admission, and it was again noted that Linda was reluctant to work with professionals to plan discharge and care package, a mental health assessment was completed during this admission. Linda was discharged home with a new care package.
December 2022 (6 days home) to date of death.	Linda was in receipt of a care package at home, and it became evident that there were concerns about equipment that was needed and continued vomiting and reports that Linda was not taking her medication and declining care. Linda died 6 days after discharge.

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### 8. Initial appraisal of findings:

- Person centred care planning was not as evident as it could have been- there is limited evidence of the time taken to explore Linda's circumstances and voice. The impact of her visual impairment during hospital admissions and her reluctance to interact and work with professionals was not fully explored.
- Processes across hospital teams, and between acute and community were not as clear as they could have been resulting in confusion about who was responsible for what action, this includes:
  - The provision of equipment upon discharge (handrails and raised toilet seat)
  - The purpose of the referral to District Nursing Team was not clearly understood by all professionals.
  - Assessment and provision of a mattress to promote skin integrity was not facilitated.
- It was acknowledged by panel members and practitioners that overall, the way Linda interacted with professionals, as well as her own self-care changed in the six months prior to her death. She was mostly in hospital during this time which was a difficult environment for her to manage. This may not have been recognised as significantly as it could have been.
- There was an opportunity to consider a safeguarding response in alignment with exploration of mental capacity, this is particularly relevant to discharge planning and post discharge period in the last weeks of her life.
- There were many examples of positive practice demonstrated including:
  - multiple "MDT" discussions in hospital
  - exploring different discharge options
  - facilitating a mental health assessment
  - trusted assessments between hospital sites
  - The relationship between Linda and the GP, which was regular, consistent and trusting.
  - The relationship between the longer standing care agency with examples of continued input, support and advocacy during hospital admissions.

#### 9. Overarching Learning

9.1. The review has identified learning following consideration of the following areas of practice that were identified during review process, highlighted within the agency reports and discussed with panel members and practitioners.

Areas of learning:
The coordination of care between acute and community settings
Consideration of mental capacity safeguarding responses
Understanding the person

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### 10. Analysis of findings

- 10.1. The coordination of care between acute and community settings
- 10.1.2. Linda was a person with multiple health needs who up until April 2022 had lived fairly independently with a package of support around her. Prior to the timeframe of this review, it should be acknowledged that Linda did have lengthy periods of time in hospital which can be attributed to applying the specific case package that Linda wanted. There is evidence of services working hard with Linda on these occasions to listen to her wishes and accomplish positive outcomes in the way that provided support to her.
- 10.1.3. Linda was in receipt of a long-standing package of care from one care agency that consisted of a single carer visiting her home three times per day and she was very particular about what care was provided and how it was provided, she liked consistency and needed to get to know people well before a trusting relationship formed. Linda's GP was also a consistent, trusted and supportive professional who knew her well and had very regular contact with her over the course of her latter years.
- 10.1.4. This provides a picture of a person with care and support needs who managed her health and wellbeing well with a small number of trusted professionals. Therefore, when Linda started to become very unwell in 2022, this was a significant change in her circumstances, requiring her to spend long periods of time in hospital and without regular/ daily access to the people she knew and trusted. One can consider that this must have been de-stabilising and upsetting for Linda particularly when being mindful of her visual impairment.
- 10.1.5. Already acknowledged are the positive findings of this review that the acute multi-disciplinary team worked extremely hard to care for Linda and plan for her safe discharge throughout her admissions- there was not a lack of action. Let us consider the context of care between acute and hospital services and acknowledge that this is an area that has been explored in previous SARs both locally and nationally.
- 10.1.6. Admission to hospital and discharge from hospital can both be considered as a transition of care. The Department for Health and Social Care (2022) state that "multi-disciplinary teams should work across hospital and community settings including with services provided by community health, adult social care and social care providers to plan post-discharge care, long-term needs assessments and, where appropriate, end of life care".
- 10.1.7. We can see multiple ways that Lindas needs were assessed whilst in hospital. There is evidence of multiple multi-disciplinary discussions in the hospital and in planning for discharge, the Integrated Discharge Team comprising of the therapy teams, Social Worker and Transfer of Care Nurses were consistently involved. Discharge from hospital was not done in a "rushed" manner.
- 10.1.8. Also evidenced is the application of the "trusted assessor" model. This was utilised between the different hospital sites of Northern care Alliance and then with the Intermediate care team.
- 10.1.9. Trusted Assessor' schemes are a national initiative designed to reduce delays when people are ready for discharge from hospital. It is based on providers adopting assessments carried out by suitably qualified 'Trusted Assessors' working under a formal, written agreement. Research has shown that delayed discharges can have a significant negative impact on people's well-being. There are also risks associated with premature or poorly planned discharges. Assessments and care planning can be undertaken by Trusted Assessor schemes in a way that meets both people's needs and legal requirements on providers. Schemes must be set up robustly to achieve this; it is vital that participants have confidence in them.<sup>iv</sup>

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- 10.1.10. Mentioned above is that this method of assessment was used to facilitate Linda's discharge from Salford Royal Hospital in July 2022 (Linda was re-admitted the same day) and again later in the admission when Linda was discharged into intermediate Care (Killalea House). On the last occasion it is evidenced that the receiving team identified that the assessment needed to be strengthened and this was undertaken without delay. There is also evidence of good exploration of the options in view of Lindas specific needs. The review does not find that the first discharge necessarily failed because of insufficiency in the trusted assessment-more so that there may have been specific issues that Linda had with the discharge plan, and this will be explored in due course. The review does not make a specific finding in relation to the trusted assessment.
- 10.1.11. Moving to the second lengthy period of hospitalisation which was from October 2022 until 6 days prior to her death. The chronology demonstrates significant activity whilst Linda was in hospital, this included consistent oversight from the Integrated Discharge Team Social Worker, facilitation of a mental health assessment and several occasions of the therapy team trying to work with Linda. It is evidenced that different options were explored for discharge including an intermediate care home or a package of care at home. The option that was agreed was a new package of care via a different care agency who could provide two carers, four times per day. It may have been helpful for the GP to have been included in these discharge discussions to strengthen clinical oversight following discharge.
- 10.1.12. It should also be acknowledged that Lindas behaviour was different to how she presented ordinarily. Although Linda remained vocal about what she wanted and didn't want, she was reluctant to mobilise or to work with the therapy team who would assess this aspect, additionally she was reluctant to eat due to persistent nausea and/or vomiting of which the clinical teams could find no specific cause. When she returned home, she would not accept any personal care, and this included changing continence pads, mobilising, nutrition and hydration. During these 6 days, these elements could be considered as indicators of self-neglect and will be considered shortly in relation to mental capacity.
- 10.1.13. This brings us to other aspects of risk assessment on discharge, namely equipment and skin integrity. We will firstly consider equipment, Lindaspecified that she would like a handrail and a raised toilet seat as she thought that would help with her mobility at home. However, this was deferred to the community therapy team and was not facilitated prior to her death. Linda raised complaints about this issue with the IDT, with the carers at home and with her local MP. The rationale for this delay was explained within the Social Workers notes and was attributed to Linda declining to work with the hospital therapy team and therefore her need for specialist equipment could not be accurately assessed. However, it is noted that Linda identified that she needed this equipment early on in the admission and given that she is familiar with her own home and able to voice her worries and concerns, it was not unreasonable for this equipment to have been put in place prior to discharge. It appears that between the therapy staff, the Social Worker and the transfer of care nurses, this message got lost in the discharge process and should have been facilitated. This evidently distressed Linda and may have aided and promoted her mobility on her return home.
- 10.1.14. The second issue was that of skin integrity and the question of whether a specialist bed was required at home. The new care agency raised this question on the day of discharge with the IDT Social Worker because they were worried about pressure areas as Linda was not mobilising. Linda was assessed in hospital as at risk in relation to pressure area care, even though her skin was intact at the time. The hospital uses an assessment known as Purpose T which is a nationally recognised assessment tool. This assessment should have highlighted the need for pressure relieving equipment and a management plan to be in place prior to discharge from hospital.

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- 10.1.15. Regarding the bed, it was identified earlier that NCA conducted a RCA review about the issue of pressure areas. It identified that there was a lack of joined up MDT discussion between the clinical ward staff and the transfer of care nurses- this may in part may have been attributed to human error as the person involved in the discharge was absent. Additionally, Linda was not identified as "high risk" because she did not have actual skin damage at the point of discharge therefore this resulted in the referral to the District Nursing Team focusing only on catheter related issues and not on skin integrity. However as highlighted above, she was identified at risk whilst in hospital and therefore a plan to manage this need should have been in place prior to discharge. The referral for routine catheter care would have not initiated an urgent response but a routine visit within 7 days.
- 10.1.16. The result of this confusion is summarised in the finding of the RCA "the patient developed infected pressure ulcers after being discharged with no pressure relieving equipment, due to a lack of joined up working between the multi-disciplinary team, leading to no clarity on who was responsible for clinical decision making on pressure relieving equipment on discharge".
- 10.1.17. The review notes that the RCA report was shared with the reviewer, it contains a robust action plan for NCA to share the learning and strengthen their processes in this area of practice. The review does make an additional observation that the role of the District Nursing team, the referral process and feedback mechanism is not sufficiently understood from a multiagency perspective and the requirement for the bed may have been better assessed after discharge if this could be strengthened- this is a finding of the review.
- 10.1.18. Overall, the review has considered principles of multi-agency working and how well this worked during Linda's admission to hospital and on discharge. In the widest sense there is evidence that teams and professionals worked very hard to ensure that services working with Linda considered all her options for discharge. The RCA identifies a disconnect between the specialities sitting within the acute service and the review identifies a lack of understanding of the role of the District Nursing service. The British Journal of Community Nurses identify that the role of the District Nurse has evolved significantly and there are multiple challenges and complexities related to the complexities of discharge planning from a district nursing perspective with a lack of understanding of the role as a key factor.
- 10.1.19. It is helpful to refer to the National Discharge and Community Support Guidance (2022)<sup>v</sup> which makes clear the principle that "people do not have a right to remain in a hospital bed if they do not need acute care" but does highlight the need for multi-disciplinary teams comprising professionals from all relevant services to work together in a timely way to facilitate discharge. In Lindas case her last admission exceeded the time she needed to be in hospital and significant efforts to facilitate discharge are evidenced.
- 10.1.20. Let us consider the post discharge period. Considering the findings from the S42 enquiry, which was carried out following Lindas death, it is evidenced that several areas of concern were raised by the new carers.
- 10.1.21. The new care agency did not know Linda, and their provision included two carers visiting Linda four times a day. Over the course of the 6 days after discharge and prior to her death, the carers spoke to the hospital Social Worker because they were worried about:
- Lack of equipment- hand rail, raised toilet seat and they questioned why there was not a specialist bed in situ.
- They reported that Linda was declining to mobilise and would not allow them to change her continence pads.
- They reported that Linda was having problems with finances, and they had to buy continence products for her.

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- They reported that Linda was continuing to feel nauseous and said she was vomiting, she declined to eat, drink or take her medications although they did keep encouraging her.
- They reported that Linda was keen to maintain contact with her GP and did not want anyone to liaise on her behalf.
- 10.1.22. As a result of these issues, the Social Worker referred Linda to the Integrated Neighbourhood team and requested an urgent review of her care package. Input from the community therapy team was also pending at the time of her death.
- 10.1.23. To conclude on this thematic area;
  - There is strength in the way that services worked to get the right package of care in place for Linda and this is evidenced through the timeline.
  - NCA have identified learning and are progressing an action plan to strengthen the interface between ward staff and transfer of care nurses to ensure line of sight over clinical related risk indicators.
  - Options for discharge were explored several times with Linda.
  - The GP was not included in the discharge discussion which may have strengthened clinical oversight post discharge.
  - There is some uncertainty about the roles and responsibilities across community teams and services which may lead to inaction when assumptions are made about actions **this is key finding 1**
  - Post discharge there was a rapid deterioration in Lindas presentation and although steps were taken to facilitate a care package review and therapy team assessment, there may have been more urgent action taken including a safeguarding response (self-neglect) and a formal capacity assessment (in view of decision making).

#### 10.2. Consideraion of mental capacity and safeguarding responses

- 10.2.1. It is helpful to consider the various legal framework and how they can be applied correctly to each case. Identified in the summary above is an observation that towards the end of Linda's last hospital admission, and after her discharge it there was opportunity to consider self-neglect and mental capacity.
- 10.2.2. The Care Act 2014 recognises self-neglect as a category of abuse and neglect. It is helpful to consider what we mean by self-neglect and how this relates to Lindas case. Linda had always been the coordinator of her own care and support needs and provision, she liaised regularly with her GP, she built meaningful relationship with her long-standing care provider, and she was known to always articulate what she wanted and highlight if something was not right. In summary, with the assistance of her carers, she took good care of herself and got enjoyment from her life.
- 10.2.3. Discissions with practitioners who knew her well reflect that they have a sense that she had "given up" during her last hospital admission, she had been so ill for a number of months, she was in a strange environment, and she likely knew that her needs had changed. There was distinct change from good self-care to a lack of self-care and this was very notable immediately after discharge.
- 10.2.4. Self-neglect is an extreme lack of self-care, it is sometimes associated with hoarding and may be a result of other issues. The Care Act 2014 clarified the position of self-neglect and safeguarding. Under the Act, self-neglect now falls under the definition of causes to make safeguarding enquiries. To note, Care and Support Statutory Guidance (2016) clarified that

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self-neglect may not necessarily prompt an enquiry under section 42 of the Care Act (often referred to as a 'Section 42 enquiry').

10.2.5. An assessment should be made on a case-by-case basis, and a decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. However, there may come a point when they are no longer able to do this without external support. Section 42 of the Care Act states:

#### 'Enquiry by local authority

(1) This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there) – (a) has needs for care and support (whether or not the authority is meeting any of those needs), (b) is experiencing, or is at risk of, abuse or neglect, and (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

(2) The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case (whether under this Part or otherwise) and, if so, what and by whom.'

- 10.2.6. The most common type of abuse identified in the National SAR analysis was selfneglect<sup>vi</sup>.
- 10.2.7. Regarding the above points it is timely to consider the degree of self-neglect and in the context of the legal frameworks and safeguarding responses. "Safeguarding duties will apply where the adult has care and support needs, and they are at risk of self-neglect and they are unable to protect themselves because of their care and support needs. In most cases, the intervention should seek to minimise the risk while respecting the individual's choices".
- 10.2.8. There is no evidence that self-neglect had been explored to a great extent however there was a rapid onset of the indicators, during her last hospital admission when staff didn't know her well and again when she returned home and care staff did not know her at all but were sufficiently alarmed by Lindas refusal to allow them to help her and carry out personal care. Therefore, in the context of the legal powers available when there are safeguarding concerns outlined in S42 of the Care Act:
  - needs for care and support (whether or not the authority is meeting any of those needs)
  - is experiencing, or is at risk of, abuse or neglect
  - as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.
- 10.2.9. We know that Linda came under this category by virtue of this SAR. The review finds that the concerns raised the day after discharge could have facilitated a safeguarding response but also acknowledges that assessment, responses and reviews were in progress, and this may have been a reasonable course of action with the presenting issues. It is difficult to conclude without hindsight bias as to whether "urgent" action could and should have been taken to safeguard Linda in the 6 days leading to her death. However, there is an absence of consideration of a safeguarding response.
- 10.2.10. The review carefully considered how The Care Act (2014), The Mental Capacity Act (2005) and the Mental Health Act (2007) could be used to help people but there was not a general consensus reached in panel or practitioner discussions about whether they could have been better applied.

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- 10.2.11. Let us take each framework in turn and explore how Linda's circumstances apply:
  - The Care Act (with the inclusion of self-neglect as a form of neglect)- there was opportunity to consider this in the days leading to Linda's death.
  - The Mental Capacity Act- capacity could have been formally assessed
  - The Mental Health Act a mental health assessment was conducted whilst Lindawas in hospital
- 10.2.12. The first principle of the MCA is to assume the adult has capacity unless proven otherwise. The correct application of the presumption of capacity in s.1(2) MCA<sup>vii</sup> is a difficult question and often misunderstood by those involved in care. It is sometimes used to support non-intervention, lack of engagement or non-concordance with treatment but this can leave people with care and support needs exposed to risk of harm. In Linda's case the issue of capacity is referred to fairly frequently in terms of an assumption of capacity, but it is not evidenced whether a formal assessment was considered. This point is made in the S42 enquiry report.
- 10.2.13. With reference to principle 3 of the MCA, the Code of Practice<sup>viii</sup> highlights "the difference between unwise decisions, which a person has the right to make, and decisions based on a lack of understanding of risks or inability to weigh up information about a decision, particularly if someone makes decisions that put them at risk or result in harm to them or someone else".
- 10.2.14. Towards the end of Linda's hospital admission there is reference to various decisions such as ; Lindas decision to return to her home with a package of care when professionals felt that an intermediate care home may meet her needs better, Lindas refusal to work with the therapy team to assess her mobility needs, Linda wanting to go home but then saying she didn't think she was fit to be at home. Following discharge there are concerns raised by the carers with reference to; Lindas refusal to mobilise, Lindas refusal to receive any personal cares including changing continence pads, Lindas refusal to allow the carers to carry out their visit, Lindas refusal to eat or drink or take medication.
- 10.2.15. To conclude on this thematic area
  - It is noted that self-neglect can be a difficult area for intervention as issues of capacity and lifestyle choice are often involved, which includes individual judgments about what is an acceptable way of living and degree of risks to self. Even in cases where it appears the risk to the individual may be significant, there may be no clear legal grounds to intervene. It is also noted that in this case Linda went from being very particular about self-care to the other degree that there was concern about decisions and significant concern about self-care. Therefore, this could have been more strongly investigated under the Care Act in the context of neglect and capacity **this is key finding 2**

#### 10.3. Understanding the person

10.3.1. It was not difficult to capture a sense of Linda's voice from the agencies who had contact with her, in fact people seemed to know her well, and were able to articulate the challenges and difficulties she experienced. The message received was that Linda could articulate herself very well.

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- 10.3.2. In terms of the longstanding role of Lindas initial care agency and her GP, services should be commended in their persistence and efforts to develop the trusted relationship that they gained with her over a number of years. The review has identified that whereas these groups may have clearly known that Linda's presentation changed, the acute staff who did not know her well may not have readily recognised that. It is always helpful to consider who might best know a person to gauge whether there is any change.
- 10.3.3. Linda had been visually impaired from birth, and we can see from the records and hear from the practitioners that the way Linda interacted with agencies was suggestive of high anxiety related to her health issues and a strong sense of needing to be in control of decisions relating to her care packages. She liked to be in familiar surroundings, in control of her healthcare needs, communicating with providers directly and she would raise concerns if care fell below her expectation. It was very important for the care she received to be right. Her care agency speak very fondly of her and provide multiple examples of how they worked with her to gain trust and build relationships. The GP was also extremely intuitive with the approaches taken with Linda.
- 10.3.4. To add context to the point above, in the 8 months leading up to her death, Linda spent all but 6 days in hospital and the intermediate care setting. This was a completely abnormal environment from which to navigate herself and her care. It is very likely that this impacted on her behaviour and/or the degree of engagement with teams and professionals. However, the extent to which the impact of her visual impairment together with her environment was explored is not evidenced as clearly as it could be.
- 10.3.5. There is no direct reference to Linda ever being identified as "depressed" or "anxious" although it would not be unusual for such a lengthy period of hospitalisation to have caused some degree of anxiety, particular in the context of visual impairment. Data demonstrates an elevated prevalence of mental health issues in people with visual impairments but identifies that these problems remain largely untreated.<sup>ix</sup> For example, a high prevalence of clinically significant anxiety and depression are reported by visually impaired people, yet studies indicate that up to 91% are not receiving treatment for these mental health issues.<sup>x</sup>
- 10.3.6. It is helpful to try and consider the world from Linda's perspective, it would feel manageable and ordered if things were going well but if her circumstances or environment changed it would extremely disorientating and distressing. One could consider Lindas presentation over the years to indicate anxiety, but this was not formally explored, and she did not seek support and therefore it was not recognised. This is speculative and outside the key lines of enquiry for this review and as such this is a view formed from the history and background provided by people that knew her for a longer period of time. However, we can see that as her health significantly deteriorated, her independence was compromised, she required long periods of time in hospital and a stay in an intermediate care unit- during these periods of time we can see repeated observations of behaviour changes, and increased non-engagement with services- this may be due to a loss of control over her life.
- 10.3.7. Linda did not like being in hospital, it was disorientating, she felt out of control, she was physically very unwell and likely frightened. It was important for her to be in her own home Linda voiced during a long prior hospital admission far back as 2016 that "I've declined going to a residential home for the simple reason that I'm blind. I need to be back in my own home, where I feel safe amid familiar surroundings and staff. I'm worried that if I went into a residential home then I'd be forgotten about. I've been blind since birth and I usually have care workers who visit me at home in Bury, helping me with washing, cooking and shopping"
- 10.3.8. This one paragraph adds significant insight into how Linda must have felt during those last months when she felt so unwell. We can see a pattern of her being mistrustful of carers until she got to know them well. Therefore, changes to care provider at a very vulnerable time was not likely to be well received (after discharge) as she hadn't yet built up a therapeutic relationship.

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- 10.3.9. Therefore, the review poses the question of; was there enough attention given to the impact of her visual impairment in terms of her behaviour before, during and after the hospital admission? The reviewer has considered the concept of "therapeutic relationship" which in its simplest terms refers to the relationship between a healthcare professional and a client or patient.
- 10.3.10. Furthermore, a therapeutic relationship is a close and consistent association between a healthcare professional and a person in therapy. The purpose of this relationship is to assist the individual in therapy to change their life for the better. It is essential as it is often the first setting in which the person receiving treatment shares intimate thoughts, beliefs and emotions regarding the issue(s) in question. Trust, respect, and congruence are major components of a good therapeutic relationship. Therapists are encouraged to show empathy and genuineness.
- 10.3.11. Of course, we know that Linda was not in receipt of "therapy" however the same principles can be applied to the relationship between professionals in acute or home care settings. For Linda it is demonstrated that she valued those relationships where she had the opportunity to build them. We have heard from home care providers in her case that it took a long time and a lot of perseveres for her to trust a person.
- 10.3.12. It is important to consider Linda's perceptions and experiences of health care professionals and consider this in the context of how she "engaged" or "didn't engage" with them and the plans and arrangements they put into place for her. Certainly, we know that the way people interacted with her impacted on her level of trust and respect for them. She did not like decisions and things being done to her and when this happened without proper consultation, she did not feel confident trusting in that person and/or organisation.
- 10.3.13. Trust in healthcare providers is associated with better patient health outcomes, engagement in the treatment plan, and patient satisfaction with the health care provider. <sup>xi</sup>Perceived discrimination stemming from a lack of perceived respect (e.g., perceptions of being treated as low in competence) leads to mistrust of medical authorities and medical information. <sup>xii</sup>Blind patients become mistrustful towards healthcare practitioners as a result of negative interactions and may attribute their negative experiences to perceived discrimination leading to dissatisfaction and disengagement in healthcare. Patients' perceptions that their HCPs do not view them as competent may undermine the trust that is fundamental to encouraging health-promoting behaviours.<sup>xiii</sup>
- 10.3.14. To note, Northen Care Alliance have redeveloped and reintroduced a Nursing and Community Assessment and Accreditation System (NAAS and CAAS) which is a formal process. This framework is based on the Trust's Safe, Clean, Personal approach to service delivery and incorporates Essence of Care standards, key clinical indicators and each question is linked to Compassionate Care the 6cs of nursing: care, compassion, competence, communication, courage and commitment. The process also provides evidence for the Care Quality Commission's five Key Lines of Enquiry: Safe, Effective, Caring, Responsive and Well-led.
- 10.3.15. The framework is designed around 14 standards with each standard subdivided into Environment, Care and Leadership. The 14 standards are: Organisation and Management of the Clinical Area, Safeguarding Patients, Pain Management, Patient Safety, Environmental Safety, Nutrition and Hydration, End of Life Care, Medicines Management, Person Centred Care, Tissue Viability, Elimination, Communication, Infection Control and People Management. In terms of assurance, the framework is designed to support staff in practice to understand how they deliver care, identify what works well and where further improvements are needed.

#### 10.3.16. To conclude on this thematic area

On balance, services that predominantly knew Linda including her first care agency and her GP can articulate a good knowledge and understanding of Linda's personality and the way she preferred them to work with her. However, in the timeframe of this review, she was largely in hospital and people did not know her particularly well thus making it difficult to form trusting relationships. There is evidence that acute staff spent time trying to ascertain her wishes and feeling and this is evidenced in the care package that Linda requested being put into place (albeit via a new care agency). However, there is minimal evidence that her sensory impairment was well enough understood at the point of her life that she was most vulnerable. There could have been more weight given to the impact of her particular disability in increasing her vulnerability and risk. **This is key finding 3.** 

#### 11. Key Findings and recommendations:

Key Finding:	Key points:
1) Community teams and services	The review finds that on more than one occasion there was a misunderstanding about the roles and responsibilities across community teams and services leading to assumptions and confusion over actions that may be taking place.
	The review considers this to be a risk and will make a recommendation relating to this
	<b>Recommendation:</b> The BSAB to seek assurance from the Integrated Community, Health and Care Services regarding how we can deliver a smooth transition between acute and community services, where the discharge route is not into intermediate care, to ensure there are safe pathways for individuals.
2) The Care A and The Mental Capacity A	and therefore safeguarding action was only applied after Linda's death. Consideration of mental capacity would have aligned with
	<b>Recommendation.</b> The BSAB are asked to review existing and previous SAR learning related to the application of statutory frameworks and to seek assurance that it is well enough embedded into practice.
3) Person Centred Ca	Linda was a visually impaired person, and the review finds that approaches and ways of working could have been more reflective of the impact of this particular disability on her vulnerability. The review found strength in the Northern Care Alliance assessment framework in terms of future assurance.
	<b>Recommendation</b> The BSAB are asked to consider the degree to which visual impairment as a disability is taken into account when assessing vulnerability and care and support needs across its agencies.

### 12. Conclusion

- 12.1. This SAR Overview Report is the Bury Safeguarding Adult Board's response to the death of Linda to share learning that will improve the way agencies work individually and together.
- 12.2. The issues that Linda experienced in the latter stage of her life were rapid and destabilising. The degree of ill health impacted on her normal way of life, the way she functioned and her connection to the people who she knew well and trusted. This manifested itself in changes to behaviour, a reluctance to work with professionals and elements of self-neglect.
- 12.3. It is not possible to conclude in hindsight whether Linda lacked capacity and/or whether exploration of self-neglect in her last weeks may have changed the outcome for her but she may have experienced a better quality of life if the following areas had been strengthened:
- Listening and hearing voice and daily lived experience and taking into account the impact of disability.
- A robust understanding of pathways, roles and responsibilities
- A quicker identification and safeguarding response to rapid deterioration
- 12.4. It is hopeful that the outcomes from this review will recognise thematic areas of learning from previous reviews. The findings and recommendations should be monitored for compliance, implementation and assurance by the BSAB.

### Appendix 1: Chronology

DATE	EPISODE
02/12/2021	Telephone consultation with GP, noted to be awaiting eye operation and vascular appointment. Prescription offered for intertrigo (Intertrigo is a common inflammatory skin disorder caused by skin-on-skin friction within skin folds, as a result of moisture becoming trapped because of poor air circulation). <sup>xiv</sup>
08/12/2021	Telephone consultation with GP regarding side effect of recently prescribed medication.
09/12/2021	GP home visit cancelled due to staffing pressures
10/12/2021	GP home visit done, dermatology referral made
15/12/2021	GP contacted Vascular consultant secretary to chase up appointment. No clinics appointments available until January 2022 due to staffing pressures. Linda informed.
16/12/2021	GP practice received text message about COVID vaccine booster, a telephone message was left to say that GP would phone again early the following week
17/12/2021	Telephone contact, Linda said she would not make any more calls to GP as she didn't receive a call back
24/12/2021	GP received clinic letter reporting that routine mammogram was normal
30/12/2021	District Nurses visit to administer B12 and do pressure area check
31/12/2021	Podiatry face to face appointment
31/12/2021	Linda contacted surgery through "askmyGP" app to report side effect of medication (askmyGP is an online consultation and workflow system that helps GPs manage caseload through operational change and digital triage). <sup>xv</sup>
04/01/2022	GP received letter from Manchester Eye Hospital about pre-operative assessment
06/01/2022	GP consultation, Linda has vascular appointment on 11/01/2022 and eye operation at the end of the month- both discussed at length
10/01/2022	GP received letter from vascular team, Linda has left upper limb swelling that can be attributed to flu vaccine, scan to be done to rule out DVT and if normal can continue treatment with lymphoedema team.
11/01/2022	GP informed that abdominal scan shows umbilical hernia.
12/01/2022	GP telephone contact with Linda who stated that she had been in a car accident the previous day. She said her arm scanned is booked later in the week but she wants a head and neck scan due to headaches after the car accident. Advised to attend ED or contact 111
13/01/2022	GP receive information from 111 to say that Linda was advised to attend but declined as she was worried it would interfere with her scheduled appointments.
14/01/2022	GP receives information from North Manchester General Hospital (NMGH) to say that Linda attended, and scans show no acute injury however her right lower lobe shows new nodule-GP to follow up after 6 months.

14/01/2022	Linda contacted GP via telephone to say that she had been sick on the way home from NMGH and she doesn't think she
	can take her medication that night.
17/01/2022	Linda contacted surgery through "askmyGP" app to report continued headaches, pain relief discussed.
21/01/2022	Linda contacted surgery through "askmyGP" app to discuss issues. Appointment made later in the week.
27/01/2022	GP records that Linda's eye operation has been cancelled and she report issues with the vascular team, she has contacted PALS (The Patient Advice and Liaison Service (PALS) offers confidential advice, support and information on health-related matters). <sup>xvi</sup>
31/01/2022	GP received outcome from doppler scan of upper arm, upper limb normal with no evidence of DVT
01/02/2022	Telephone contact with GP to discuss vascular appointment
03/02/2022	Linda contact GP via telephone- call back arranged later that day. Failed call later that day, message left on her answerphone.
11/02/2022	Asthma review, Linda requested her phone number is taken off the system.
17/02/2022	Referred to surgeons regarding hernia
Feb 2022	Eye operation
24/02/2022	Contacted GP to report that covering to eye has come off and she is concerned about infection, requesting morphine for pain relief as this is what Linda had in hospital. Referred to District Nurses for management of eye dressing
03/03/2022	GP records that eye operation has apparently not gone as well as expected.
15/03/2022	GP has telephone consultation with Linda who reports discharge from one eye socket, otherwise systemically well but wanted to provide update to GP.
17/03/2022	Telephone contact with Linda who reports she has been seen at the eye hospital and a washout done and eye drops provided.
22/03/2022	Telephone contact with GP- Linda reports that eyes are improving
24/03/2022	District Nurses visit to administer B12 and do pressure area check
24/03/2022	Podiatry appointment
05/04/2022	GP referral to lymphoedema service, referral for shoulder pain
08/04/2022	Linda informed GP that she has spoken to orthopaedics and has been put on a waiting list.
14/04/2022	Linda contacted GP to report that she had a bad night with sickness and doesn't feel like eating or drinking, reported that carers were due to attend. Anti sickness medication prescribed.
19/04/2022	Telephone consultation with GP. Linda reported that she had worsening pain over hernia site and had not had much oral intake for a few days. Ambulance arranged
20/04/2022	Admission to Salford Royal Hospital with abdominal pain. Endoscopy showed small hernia. Discharged home with care
to	package
27/04/2022	
27/04/2022	GP notes discharge letter from Salford Royal Hospital
28/05/2022	Telephone consultation with GP

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03/05//2022	Telephone consultation with GP, hernia operation cancelled due to Linda having COVID symptoms
06/05/2022	Telephone consultation with GP, COVID, reports that she is struggling to eat
12/05/2022	Telephone consultation, Linda reports that she is recovering slowly
13/05/2022	Telephone consultation with GP, reports that left eye socket is red and swollen
16/05/2022	COVID booster
17/05/2022	Telephone consultation with GP, reports eye socket is improved and she is still recovering from COVID
20/05/2022	askmyGP, reporting that she isn't eating and her carers are worried as weight is "dropping off"
20/05/2022	Home visit from GP, no evidence of COVID pneumonia- referred to District Nurses for blood tests
24/05/2022	Telephone consultation and home visit due to continued vomiting- no severe dehydration noted
27/05/2022	Telephone consultation with GP, continued vomiting, advised to contact 111 if no better
28/05/2022	Admitted to Salford Royal Hospital with nausea, diarrhoea and vomiting. Treated for gastroenteritis and given antibiotics
to	for urinary tract infection (UTI). Discharged on 30 <sup>th</sup> June but readmitted same day.
30/06/2022	
30/06/2022	Re-admitted to Salford Royal Hospital after discharge earlier the same day, fell over leaving hospital. Treated for sepsis,
to	and acute kidney injury: Acute kidney injury (AKI), also known as acute renal failure (ARF), is a sudden episode of kidney
26/07/2022	failure or kidney damage that happens within a few hours or a few days.xvii Discharged on 26/07/2022 and re-admitted
	same day.
22/07/2022	Liaison between the Salford Royal Hospital Integrated Discharge Team and the Fairfield Hospital Integrated Discharge
to	Team to request a restart of care package for hospital discharge. Trusted Assessment sent over and a confirmation was
23/07/2022	received that the existing package of care at home would be restarted, and a case transfer would be done to the
	Integrated Neighbourhood Team.
26/07/2022	Re-admitted after being discharged home earlier the same day. Long standing constipation recorded, left leg pain,
to	hypoglycaemic episodes. It is noted that during this admission Linda was not concordant with her medications and would
12/09/2022	not discuss discharge options, she only wanted to liaise with the care agency that she knows. A capacity assessment
	was done, and it was recorded that she has capacity to make decisions about her care package and discharge options. It
	is noted that she was due a review by the eye hospital as there were some problems with her prosthetic eyes. Discharged
06/00/2022	on 12/09/2022 to Killalea House
06/09/2022	Salford Therapy team sent trust assessment to Fairfield Integrated Discharge Team to request Intermediate Care at Killaloa. On receipt, the Fairfield IDT requested further information and the trusted assessment was re-sent. Eairfield IDT
to 09/09/2022	Killalea. On receipt, the Fairfield IDT requested further information and the trusted assessment was re-sent. Fairfield IDT completed action plan and the referral was to be discussed in MDT. There is a record of discussion between Fairfield
09/09/2022	Social Worker and the IMC Killelea team and feasibility of the care package at home discussed in view of Linda's visual
	impairment- familiar environment may be better for her however in view of the two failed discharges and the ward MDT
	discussions it was agreed that IMC at home was not appropriate at this time.
04/07/2022	Several contacts to GP via askmyGP whilst in hospital requesting updates and consultations
to	
06/09/2022	
00/03/2022	

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13/09/2022	GP had contact from Linda whilst in Killalea. Call between GP and Killalea for urine test
to	
05/10/2022	
13/10/2022	GP received information about ED attendance at Fairfield hospital
13/10/2022 to 13/12/2022	Admitted to Fairfield Hospital, concerns about dietary intake noted as Linda was declining food. A referral was made to the Dietician Service which she did not wish to engage with, and it is documented that she refused to be weighed throughout the admission. Vomiting continued throughout the admission and hypoglycaemic episodes which was reviewed by the Endocrinologist. Regarding mobility, Linda did not want to work with the Therapy team. A Social Work assessment was undertaken during this admission Linda expressed that she wanted the same care agency and she said she needed some equipment. There were several occasions where it is recorded that Linda has capacity but there is no record of a "formal" capacity assessment.
	Discharge: The Hospital Social Worker (Integrated Discharge Team) explored the option of a discharge to assess placement which Linda did not want therefore a care package was arranged for discharge which consisted of a new care agency who would have two carers conducting four visits per day and some equipment which was to be discussed. Linda requested handrails and a raised toilet seat and was advised that this would be arranged by the community therapy team. Following discharge, the provision of equipment and the discussion about a requirement for a pressure relieving mattress were raised by Linda and her carers. She was discharged and transported home via ambulance on 13/12/2022 and it was noted that all pressure areas were vulnerable with a high risk of pressure damage. The discharge letter was sent to the GP. A referral was made to the District Nursing team for a trial without catheter. The diagnosis within the discharge notes was:
	<ul> <li>Persistent vomiting- nil cause identified.</li> <li>Gastritis and oesophagitis</li> <li>Hiatus hernia</li> <li>Acute Kidney Injury</li> <li>Anaemia</li> <li>Fungal infection axilla (armpit)</li> </ul>
13/12/2022	GP received communication that Linda had been referred for a trial without catheter, noted that they did not know she had a catheter and did not know of her location. They had not received any information about hospital admission/ discharge at this point.
13/12/2022	The new care agency raised concerns on the day of discharge with the hospital Social Worker- they thought that Linda should have a pressure relieving mattress as her mobility was variable and some pressure areas were red and that she was declining to receive care such as having her pads changed. They also reported that she was vomiting and refusing

	medication. A referral was made to the Integrated Neighbourhood Team and the hospital Social Worker spoke to Linda on
	the phone to encourage her to follow her care plan.
15/12/2022	Linda left a message with the INT to say that she was trying to contact her GP and she needed to get her heating sorted.
	Attempts were made to contact her unsuccessfully.
16/12/2022	Linda contacted the INT Social Worker to say that she needed handrails and a raised toilet seat. A referral was made to
	the "Intermediate care at home therapy team". The Social Worker also spoke to the care agency who reportedly that the
	care package was not going well as Linda was declining to have her continence pads changed and they were worried that
	this was making her bottom sore, and they planned to phone GP for some cream. They also highlighted that they had
	bought continence products for Linda as she did not have any money to buy any. The Social Worker also contacted the
	District Nursing team to request a hospital bed. An urgent review of care plan was planned.
16/12/2022	GP attempted telephone contact with Linda on two occasions, no reply
17/12/2022	Linda contacted 111 in the early hours to request an ambulance due to nausea and vomiting. The crew attended and
	noted abdominal pain and mild dehydration. Linda declined to go to hospital and said she would contact her GP on
	Monday (20th December). There were no concerns regarding capacity noted and nothing to suggest imminent medical
	health risks. She said she would press her carelink should she feel worse. Her skin was not checked but no issues
	apparent. There was a note left for home carers to advise of NWAS input and that Linda had refused to attend hospital
17/12/2022	Carers record that Linda continues to be nauseous and to vomit although they were supplying and offering hydration and
	nutrition. Also recorded that she had declined two of the four visits that day including the bedtime one- the carers did
	attend the address to do a welfare check but Linda would not let them into the property.
18/12/2022	Carers attended home for the first visit of the day and found Linda to be unwell/ unresponsive and called for an
	ambulance
18/12/2022	NWAS attend the call to Linda's home and take her to Salford Royal Hospital. They also made a safeguarding referral
	due to how unwell she was, they observe that there were minimal notes from the care agency, she was in soiled sheets,
	soiled pads and there were significant areas of pressure to the skin.
18/12/2022	Linda was taken to the ED at Salford Royal Hospital and died that day. A safeguarding referral was made by the ED staff
	due to concerns about pressure areas and because of the report from NWAS who had also made a safeguarding referral.

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- iii serious-incidnt-framwrk-upd.pdf (england.nhs.uk)
- iv 20180625\_900805\_Guidance\_on\_Trusted\_Assessors\_agreements\_v2.pdf (cqc.org.uk)
- Hospital Discharge and Community Support Guidance (publishing.service.gov.uk)
- vi National analysis of safeguarding adult reviews

<sup>vii</sup> MCA (2005)

<sup>ix</sup> Nyman SR, Gosney MA, Victor CR. Emotional well-being in people with sight loss: lessons from the grey literature. *Br J Visual Impairment*. 2010;**28**(3)

<sup>x</sup> Senra H, Balaskas K, Mahmoodi N, Aslam T. Experience of Anti-VEGF treatment and clinical levels of depression and anxiety in patients with wet age-related macular degeneration. *Am J Ophthalmol.* 2017

<sup>xi</sup> Williamson, L. D., & Bigman, C. A. (2018). A systematic review of medical mistrust measures. *Patient Education and Counseling*, *101*(10)

<sup>xii</sup> Cuevas, A. G., O'Brien, K., & Saha, S. (2016). African American experiences in healthcare:"I always feel like I'm getting skipped over". *Health Psychology*, *35*(9)

xiii Dovidio, J. F., & Fiske, S. T. (2012). Under the radar: How unexamined biases in decision-making processes in clinical interactions can contribute to health care disparities. *American Journal of Public Health*, *102*(5)

xiv British Journal of Nursing - Intertrigo: causes, prevention and management

<sup>xv</sup> www.askmygp.uk

xvi What is PALS (Patient Advice and Liaison Service)? - NHS (www.nhs.uk)

<sup>xvii</sup> www.kidney.org

<sup>&</sup>lt;sup>i</sup> Name is anonymised

<sup>&</sup>lt;sup>ii</sup> Department of Health and Social Care (2020) Care and Support Statutory Guidance: Issued under the Care Act 2014. London: The Stationery Office (section 14.165)

viii Mental-capacity-act-code-of-practice.pdf (publishing.service.gov.uk)