Joined Up Care Derbyshire

NHS
Derby and Derbyshire
Integrated Care Board

# Derbyshire Learning from Deaths of those with a Learning Disability and Autistic People

## The LeDeR Programme

# Annual Report

## 1st April 2024 to 31st March 2025

# Derbyshire LeDeR Learning from Lives & Deaths Annual Report 2024-2025

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|---|---|
| **Responsible Committee** | Derby & Derbyshire LeDeR Steering Group |
| **Target Audience:** | Report for agencies involved in the programme across the Derbyshire system and for sharing across the public domain:-<br>LeDeR Steering Group<br>LeDeR Governance Panel<br>Mental Health, Learning Disabilities, Autism & Children's System Delivery Board<br>Neurodevelopmental Programme Delivery Group<br>Joined Up Care Derbyshire<br>National LeDeR Programme<br>NHS England |
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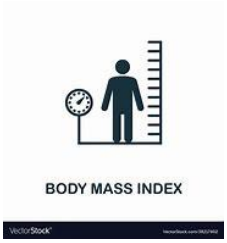
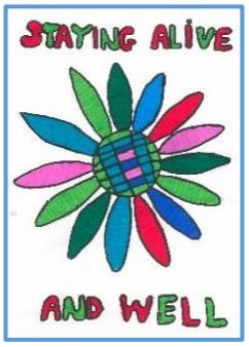
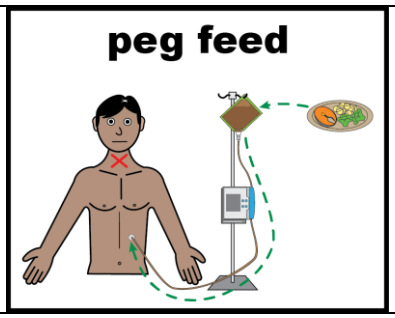
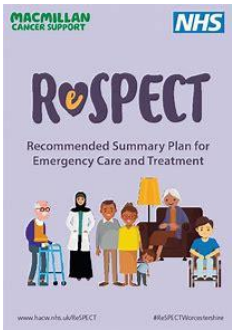
# List of Abbreviations

| Abbreviation | Explanation | Symbol |
|---|---|---|
| AHC | Annual Health Check |  |
| BMI | Body Mass Index |  |
| CCO | Care Coordinator |  |
| CDOP | Child Death Overview Panel |  |
| CLDT | Community Learning Disability Team |  |
| CQC | Care Quality Commission |  |

| | | |
|---|---|---|
| CTR | Community Treatment Review |  |
| DCHS | Derbyshire Community Health Services | NHS Derbyshire Community Health Services NHS Foundation Trust |
| DHcFT | Derbyshire Healthcare NHS Foundation Trust | NHS Derbyshire Healthcare NHS Foundation Trust |
| DNACPR | Do not attempt resuscitation |  |
| EUPD | Emotionally Unstable Personality Disorder |  |
| GP | General Practitioner |  |
| HTT | Home Treatment Team |  |
| IAPT | NHS Talking Therapies | |

| | | |
|---|---|---|
| | |  |
| JUCD | Joined Up Care Derbyshire |  |
| LAC | Local Area Contact |  |
| ICS | Integrated Care System |  |
| ICU | Intensive Care Unit |  |

| | | |
|---|---|---|
| LD | Learning Disability |  |
| LeDeR | Learning from lives and deaths of people with learning disabilities and autistic people |  |
| MCA | Mental Capacity Act |  |
| NCMD | National Child Mortality Database |  |
| NHSE | NHS England |  |
| PEG | Percutaneous Endoscopic Gastrostomy |  |

| | | |
|---|---|---|
| PICU | Psychiatric Intensive Care Unit |   |
| ReSPECT | Recommended Summary Plan for Emergency Care and Treatment |   |

# Executive Summary

The people whose deaths are reported in this report are people who were known and loved by many and whose loss will have had and continue to have a profound impact on those around them. The LeDeR Programme in Derbyshire wishes to thank all those who provided information when requested, especially considering the additional pressures faced during the last year. These include families and carers, GP Practices, NHS Trusts, Local Authorities, Managers, and staff working in Residential and Social Care Homes, Supported Living, Domiciliary, Day Care and other health and social care settings. Further thanks go to the reviewers for their compassion when completing the reviews, keeping the person at the centre of the process, to identify learning and share good practice.

This report is the sixth annual report for Derbyshire on the learning from deaths of those with learning disabilities and autistic people. The report uses data collated from 1st April 2024 up until 31st March 2025. Thanks to those with lived experience who have been involved in producing this report and the Derby & Derbyshire Integrated Care Board LeDeR Team.

The purpose of the report is to share the findings and the learning with those involved in the LeDeR programme and those working with individuals with learning disabilities and autistic people, to demonstrate how Joined Up Care Derbyshire (JUCD) is delivering on local actions as identified in LeDeR reviews. It is signed off through the LeDeR Steering Group and shared with the JUCD System Quality Group, the Neurodevelopmental Delivery Group and the Mental Health/Learning Disability & Autism Board for information. The report, including an accessible version, is published each year and available on the JUCD website. The report is shared with NHSE regional teams by 30th September 2025.

This year's report continues to build on the commitment to improving care, reducing health inequalities, and preventing early deaths for people with learning disabilities and autistic people across Derbyshire. The LeDeR programme is a national NHS England initiative aimed at improving care, reducing health inequalities, and preventing premature deaths among people with learning disabilities and autistic individuals. Locally, Derbyshire delivers LeDeR through Joined Up Care Derbyshire (JUCD), with a strong focus on service improvement, co-production, and system-wide collaboration.

## Key Statistics and Activity

- 520 total death notifications for Derbyshire since programme inception in 2017; 429 Derbyshire reviews completed as of 31 March 2025.
- 97 notifications received in 2024/25 (17% increase from previous year); 55 reviews completed.
- 52 reviews were completed in 2024/25 for individuals with learning disabilities; 3 reviews were completed for autistic individuals without learning disabilities.
- 29% of individuals missed their annual health check in their final year, an improvement from 46% in 2023/24.

## Findings for Autistic Individuals Without Learning Disabilities

- 13 total notifications since inclusion in the LeDeR programme in January 2022; 5 reviews have been completed.
- 80% of completed reviewed deaths were suicides, highlighting urgent mental health concerns.
- All of the 5 completed reviews were males aged between 18 and 45.
- Strong collaboration with Derbyshire's Suicide Prevention Partnership Forum to inform strategic planning.

## Findings for Individuals with Learning Disabilities

- Average age of death: 66 years (males), 62 years (females) – showing a positive trend compared to average age of death over the last 3 years.
- Hospital was the most common place of death (48%), with 32% occurring in hospitals outside Derbyshire.
- Top causes of death: Respiratory infections (31%), Aspiration pneumonia (25%), Cancers (8%), Heart conditions (6%), Frailty (6%).

## Themes and Learning

- Recurring themes: Access disparities, communication barriers, and need for enhanced training.
- Aspiration pneumonia and management of deterioration emerged as critical areas for improvement.
- Constipation was noted as a health condition in 52% of reviews, an increase from previous years.

## Case Studies

- Sarah's case highlighted gaps in suicide prevention, care coordination, and ASD-specific support.
- Barry's case revealed issues in discharge planning, delayed diagnosis, and aspiration risk management.

## System-Wide Collaboration

- Active engagement with:
    - Safeguarding teams, Adult Social Care, and Mortality Review Groups
    - Acute Trusts (Chesterfield Royal Hospital and Royal Derby Hospital)
    - Primary Care, Community Providers, and Strategic Health Facilitation Team
- Initiatives include audits, training, pathway development, and improved documentation practices.

## ReSPECT and DNACPR

- 41 individuals had DNACPR orders; 80% had documented conversations.
- Improvements in documentation and patient/family involvement noted.
- Ongoing challenges include inconsistent terminology and documentation gaps.

## High Impact Actions

Derbyshire continues to align with Midlands regional priorities:

1. Reducing avoidable mortality in respiratory, cancer, and heart disease.
2. Addressing co-morbidities and DNACPR/ReSPECT processes.
3. Sustaining performance and improving review quality.
4. Enhancing access and understanding of LeDeR.
5. Improving learning disability register accuracy and annual health check uptake.

# Introduction to the LeDeR Programme

LeDeR is a service improvement programme for people with a learning disability and autistic people.

The programme was established in 2017 by NHS England. LeDeR aims to:

- improve care for people with a learning disability and autistic people
- reduce health inequalities for people with a learning disability and autistic people
- help stop people with a learning disability and autistic people dying early.

Annual reports have been produced at a national level and previous reports are available to view here.

It is important to note when looking at any findings in relation to LeDeR that notification to the LeDeR programme is not mandatory, so does not have complete coverage of all deaths of people with learning disabilities and that numbers in some sub-categories are small so must be interpreted with caution.

The "Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) policy" was introduced in March 2021 to serve as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR. The policy includes NHS England's (NHSE) delivery expectations of local areas, which includes a local LeDeR annual report demonstrating how the ICS is delivering on local actions addressing those areas identified in LeDeR reviews and asking that it demonstrates effective delivery of actions from learning from LeDeR reviews.

The *LeDeR Policy* [1] informed of the inclusion of LeDeR reviews for autistic people with no learning disability. This took affect from 1st January 2022.

A new LeDeR platform was introduced in 2021/22 which altered the review process from previously including new formats to the reviews. In February 2023 a LeDeR23 form was introduced which made changes to some of the information that is gathered to complete the review process.

All notifications of death for individuals age 18+ follow the LeDeR process. Anyone under the age of 18 is referred through the separate Child Death Review process. In Derbyshire, referrals to the LeDeR programme are accepted for those registered with a Derbyshire GP practice. For autistic people with no learning disability a clinical diagnosis of autism must be visible.

Depending on the complexity of the person's life and death a decision is made to complete as an Initial Review or Focused Review. However, all LeDeR reviews are automatically Focused if:-

- the person is from a minority ethnic (non White British) background
- an autistic person with no learning disability
- the person had been under mental health or criminal justice restrictions at the time of death or 5 years

[1] See References section

previously

- where there is likely to be learning from the life of the person to inform service improvements
- local priorities for focused reviews
- where the family have requested a focused review
- where there are any concerns about the care the person received

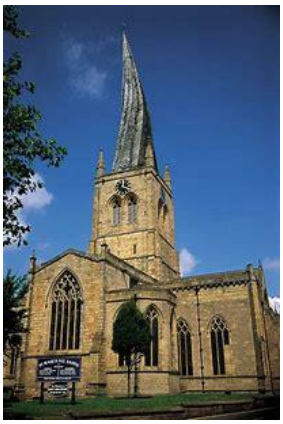
As a service improvement programme locally in Derbyshire, we are working as Joined Up Care Derbyshire to use the learning found through LeDeR to improve our local services for people with a learning disability and autistic people.

# The LeDeR Programme in Derbyshire

Estimates of people with a learning disability for Derby and Derbyshire are slightly more than 2% of the population, which is approximately four times the proportion of the population who are known to services. It is estimated that there are 15,250 people in Derbyshire and 4,950 people in Derby with a learning disability (people with mild to severe learning disability). (*Reference: JUCD website*[2])

It is estimated that 1% of the population have autism. Research has identified between 44% and 52% of autistic people may have a learning disability and between 48% and 56% do not have a learning disability. Data from GPs in Derby and Derbyshire show there are 3,358 autistic people (who have no learning disability). (*Reference: JUCD website*[3])[4]

Work started on the LeDeR programme in Derbyshire early 2017. The first LeDeR Steering Group ran in February 2017 and the first reviews started in April 2017. Since that date we have received 520 notifications for those age 18+, of which 429 have had a review undertaken and completed (local collated data as of 31st March 2025). The information in this report is taken from LeDeR reviews completed between 1st April 2024 to 31st March 2025.



Learning from individual reviews is collated through an action tracker. Good practice is acknowledged and shared with organisations and individual actions are agreed and discussed at the Derbyshire LeDeR Governance Panel and fed back up to organisations through their members that attend the meetings.

Themes are also collated from each review and the theme form is evaluated alongside the review as part of the quality review process. Our reviewers have been collecting themes since 2020/21 that also identify the responsible care provider. Themes are collated and reviewed to identify areas where commissioning concerns may need to be identified. These themes are shared with organisations via the Derbyshire LeDeR Steering Group to enable them to see themed areas of work that are relevant to them for potential review and for discussion as a wider Derbyshire system.


[2] See References section for link to JUCD website
[3] See References section for link to JUCD website
[4] Note that there may be different figures available in relation to local populations within learning disability and autistic people, which reflects some of the uncertainty about prevalence & how many people are known to services.

# Co-production and Engagement

Dan attends our LeDeR Steering Group Meetings as our person with lived experience. Dan has also been involved with producing the Annual Report and worked with us to make it more user friendly. This is what Dan produced to tell you a bit about what his role is and how he supports the LeDeR programme.

| | |
|---|---|
|  | Hello<br><br>My name is Dan Walmsley, I am an assistant Health Facilitator in the Neurodevelopment Team . |
|  | I have been attending the LeDeR Steering Group Meetings. |
|  | I like to attend the meetings to share my views. |
|  | The meetings are important, to help stop people with Learning Disabilities passing away too soon from illness. |
|  | In the meetings we talk about people's lives and the care they had received. |
|  | We talk about things like epilepsy, illness and other things, and about how we can improve. |
|  | I like to give my advice on easy read. |
|  | I like to talk about Annual Health Checks because it is important for people to go to them to try to keep healthy. |

# Partnership working across the Integrated Care System

Throughout the reporting year, sustained efforts have been made to strengthen partnership working and promote information sharing across the LeDeR programme in Derbyshire. Key collaborative activities have included:

**Quarterly LeDeR Steering Group meetings**, attended by individuals with lived experience and partners from across Joined Up Care Derbyshire, to guide programme direction and ensure inclusive engagement.

**Regular LeDeR Governance Panel meetings**, typically held monthly depending on the volume of focused reviews requiring quality assurance and sign-off. These meetings are attended by system partners to uphold review standards.

**Collaboration with the Derbyshire Community Health Services (DCHS) Mortality Review Group**, ensuring that learning from LeDeR is incorporated into their reporting and discussed at their Mortality Review Group meetings. This enables a robust examination of LeDeR themes to support quality improvement across the system.

**Ongoing engagement with the Strategic Learning Disability Health Facilitation Team**, with regular catch-ups to promote shared learning. Particular emphasis is placed on supporting annual health checks for individuals with learning disabilities, health action planning, and the implementation of reasonable adjustments.

**Joint working with Safeguarding teams**, including attendance at Safeguarding Adult Board meetings to share LeDeR insights. LeDeR reviewers collaborate closely on cases progressed as Safeguarding Adult Reviews (SARs), including joint meetings with families and SAR reviewers.

**Engagement with Adult Social Care**, aimed at improving LeDeR processes and ensuring that themes and learning are appropriately disseminated.

**Delivery of LeDeR learning at the Derbyshire County Care Home Forum**, supporting care home staff in applying insights to improve practice.

**Regular meetings with managers of learning disability community care providers**, to share findings from LeDeR reviews and agree on actions to embed learning across services.

**Sharing of quarterly reports and updates with System Quality Groups**, ensuring transparency and alignment with broader quality assurance frameworks.

**Presentation of LeDeR learning to the Good Health Group, Derbyshire Learning Disability Partnership Board, and Derby City LD Voice**, with participation from individuals with lived experience and their carers.

**Contribution to the Mental Health, Learning Disability and Autism Delivery Board meetings**, ensuring LeDeR learning informs strategic planning and service development.

# Child Deaths

A national report has been published by the National Child Mortality Database (NCMD), available here in both full and easy-read formats. The report aims to identify trends in child mortality among children and young people with a learning disability, as well as autistic children.

At a local level, the LeDeR programme in Derbyshire no longer captures data relating to child deaths. All child deaths are reviewed through the Child Death Overview Panel (CDOP) process. Relevant information and emerging themes are captured and analysed separately through this pathway.

# Staffing and Governance Arrangements

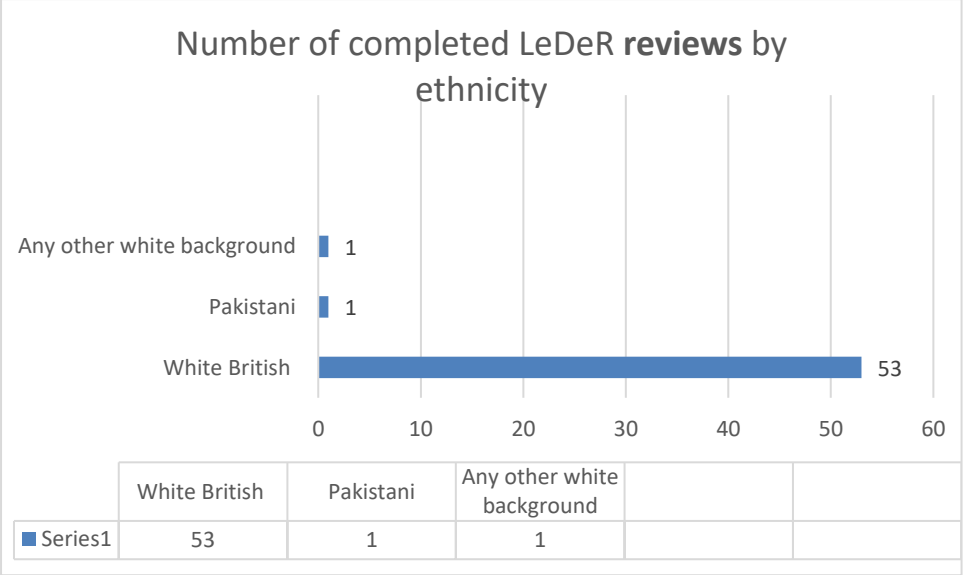
The LeDeR programme operates within the Nursing and Quality team of the Derby and Derbyshire Integrated Care Board (ICB). The dedicated LeDeR team comprises a LeDeR Administrator, Local Area Contact (LAC), Senior Reviewer, and 1.0 WTE Reviewers.

Issues and risks associated with the programme are managed within the broader Nursing and Quality directorate. These are escalated through the LeDeR Governance Panel and the LeDeR Steering Group. Ultimately, oversight and strategic alignment are provided via the Joined Up Care Derbyshire (JUCD) Mental Health, Learning Disability and Autism Delivery Board.

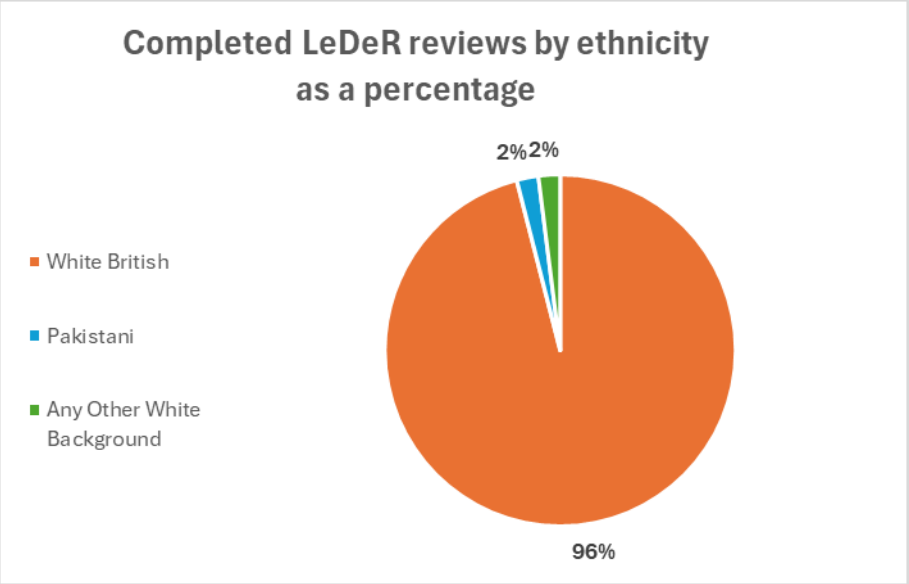
# Equality Impact

## Addressing Inequalities across Minority Ethnic (non White British) communities

During 2024/2025 out of the 55 reviews 2 (4%) were completed for those identifying from a minority ethnic community. This is 1% less than last year. One individual was female and one male. The individual who was male was autistic with no learning disability.




**Note that the minority ethnic backgrounds/descriptions used are as requested through the LeDeR programme.*

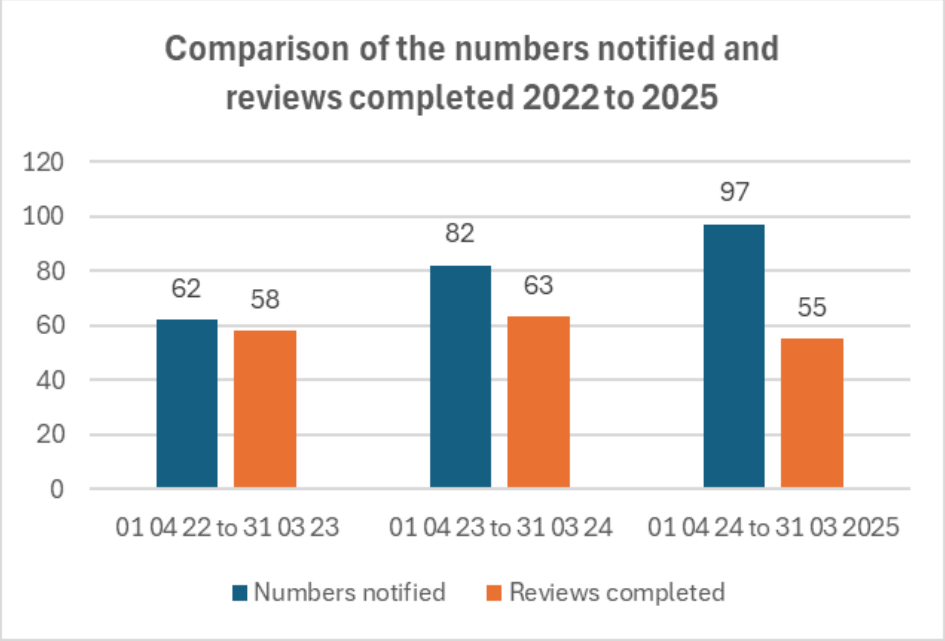



# Local Demographic Data & Findings

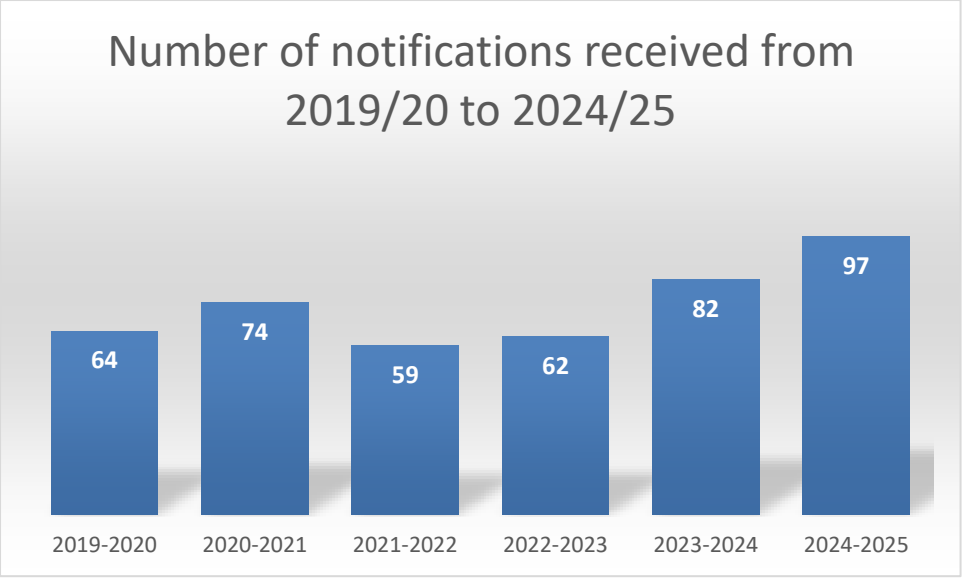
Since the inception of the LeDeR programme in Derbyshire in April 2017, a total of 520 deaths have been reported, covering the period up to 31 March 2025. Of these, 429 deaths have undergone a review which has been completed.

*Note: All notifications referenced pertain exclusively to individuals aged 18 and over.*

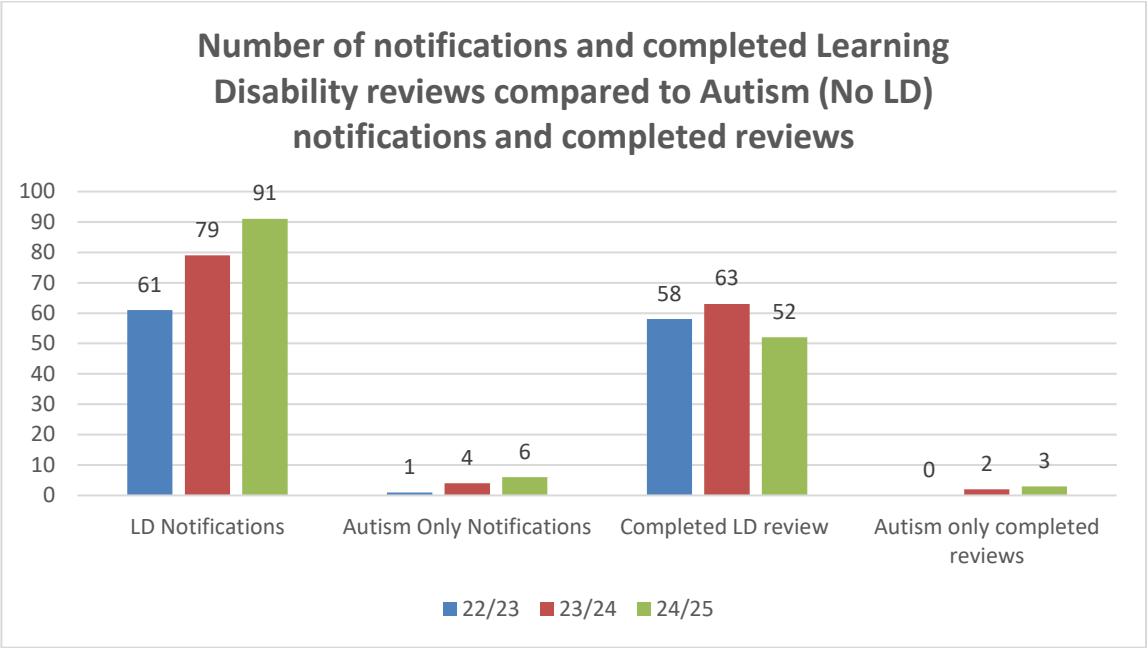
During the reporting year 1 April 2024 to 31 March 2025, there were 97 notifications, representing a 16.9% increase compared to the previous year. Within the same period, 55 reviews were completed. These completed reviews include cases notified both in the previous year and within the 2024/25 reporting year. The data and analysis presented throughout this annual report are based solely on the reviews completed during 2024/25.



The graph below presents the number of notifications to the LeDeR programme in Derbyshire from 2019 to 2025, highlighting a consistent upward trend over recent years. This increase is attributed in part to the inclusion of notifications for autistic individuals without a learning disability, effective from 1 January 2022, and also to enhanced awareness and engagement with the LeDeR programme through local promotional efforts.



## Findings for Autistic Individuals Without a Learning Disability




On 1 January 2022, the LeDeR (Learning from Lives and Deaths – People with a Learning Disability and Autistic People) programme expanded its remit to include reviews for autistic individuals who do not have a learning disability.

### Notification Trends

Analysis of notification data over the past three years indicates a significantly higher volume of death notifications for individuals with a learning disability compared to those for autistic individuals without a learning disability. While notifications for the latter group have shown a slight upward trend, the overall numbers remain low.

Since the introduction of this review category, Derbyshire has received a total of 13 notifications concerning deaths of autistic individuals without a learning disability. It should be noted that two of these notifications occurred during the 2021/22 reporting year and are therefore not represented in the accompanying graph.

As of 31 March 2025, three reviews remain on hold pending coroner investigations.

### Review Completion and Emerging Themes

During the 2024/25 reporting year, three reviews were completed for deaths of autistic individuals without a learning disability, with six notifications received in total.

Due to the limited number of completed reviews (five since 2022), thematic analysis is constrained. However, preliminary findings indicate the following:

All five deaths were subject to coroner investigation due to the nature of the incidents. All were male and between the ages of 18 and 45.

Four of the five cases (80%) were determined to be suicides.

The fifth case was ruled as “death unascertainable” due to the circumstances.

**Organisational Themes**

Themes have been identified for each of the five completed reviews and have been categorised by organisation. See Appendix 4 at the end of this report. While the sample size is small, these themes will be used to inform future reviews and support the identification of recurring concerns.

The most frequently reported theme was that individuals did not accept or attend appointments, primarily attributed to mental health services appointments.

The LeDeR team in Derbyshire is actively collaborating with the Public Health Lead for Mental Health and Suicide Prevention at Derbyshire County Council, who also serves as the Chair of the Derbyshire Self-harm and Suicide Prevention Partnership Forum (DSSPPF). The DSSPPF is a multi-agency group operating across Derby and Derbyshire and functions as a system delivery group under the Joined Up Care Derbyshire (JUCD) Mental Health, Learning Disability, Autism and Children’s Board.

Insights from LeDeR reviews will be shared to inform strategic planning and service improvement. The Derbyshire Suicide Prevention Strategy, which is currently undergoing a refresh for 2026, is a key framework guiding this work. The current strategy is accessible via the following link:

https://derbyandderbyshireemotionalhealthandwellbeing.uk/suicide-prevention/about-us

A case study has been compiled for an autistic individual following the completion of a LeDeR review. Although the review was submitted in May 2025 and therefore falls just outside the 2024/25 reporting period, the insights gained remain highly relevant. While the themes and learning from this review are not reflected in the statistical data presented in this report, the case study itself highlights several emerging themes and areas of learning. These have been identified and disseminated across the Derbyshire system, contributing to ongoing improvement efforts and informing future practice.

# Case study 1 - Sarah's Journey Through Trauma, Mental Health, and Care Systems

***Note: The name "Sarah" has been used to protect the individual's identity.***

This case study, produced from a review conducted through the LeDeR programme, examines the life and challenges of Sarah, a 32 year old woman who had a clinical diagnosis of autism (received at the age of 27). It highlights the chronological journey of her struggles, interventions, and care, as well as the lessons learned for future practice.

## Background and Early Life

Sarah relocated from another county to Derby in 2016 to escape domestic abuse. She had a young daughter who resided with her ex-partner under a residence order granted in 2017. Sarah, who retained parental responsibility, had not seen her daughter since 2015. Allegations of abuse were investigated by the community children's service but were dismissed in 2018. Despite consulting a solicitor to establish contact with her daughter, the process did not progress.

## Mental Health History and Hospitalisations

Sarah first became known to mental health services in Derbyshire in 2016, when she was admitted to the Radbourne Unit as an informal patient. Over the next few years, she experienced repeated hospital admissions. These included detentions under Sections 2 and 3 of the Mental Health Act and several voluntary admissions. Diagnosed with complex Post-Traumatic Stress Disorder (PTSD) and Autism Spectrum Disorder (ASD) in 2017, she also received Electroconvulsive Therapy in 2018 for severe depression. Sarah previously had a diagnosis of Emotionally Unstable Personality Disorder (EUPD), which she did not accept.

In 2019, she was referred to out-of-area care following an admission to the psychiatric intensive care unit (PICU) due to risks such as self-harm and absconsion. During her Section 3 assessment, Sarah acknowledged her trauma and abuse history but struggled to articulate her emotions. She expressed a desire to cease self-harm and regain contact with her daughter, while also resisting placements focused on trauma or ASD.

## Residential Instability and Housing

Sarah experienced periods of homelessness between hospital admissions. She held a tenancy with a home provider from June 2017 to September 2018, after which she moved into private housing with a partner. However, allegations of domestic abuse led her to leave in early 2019. She resided at a homeless shelter, until February 2019, when she attempted suicide through an overdose. This resulted in an ICU admission.

After her discharge in 2021 under Section 3, she chose a specialist rehabilitation unit to be closer to her daughter. However, her relationship with the supported housing placement broke down later that year, and she transitioned to independent living in her own flat.

## Challenges in Care Coordination

Throughout her treatment journey, Sarah interacted with numerous professionals from Derbyshire and another county. Despite efforts to support her, Sarah often felt that care was fragmented and lacked coordination. She articulated feelings of neglect and frustration, particularly regarding the quality of care provided. This tension was attributed to her EUPD diagnosis, which often created a dichotomy of seeking acceptance while mistrusting support systems.

Key issues included the absence of a sensory assessment despite its recommendation in a 2021 Community Treatment Review (CTR), limited ASD-specific support when residing out of Derbyshire and missed opportunities to address flagged suicide plans effectively. It was noted that Sarah's upcoming suicide plan date was not adequately explored or acted upon, a concerning oversight in her care pathway.

# Personal Interests and Protective Factors

Despite her challenges, Sarah had passions that brought her joy and connection. She excelled in medieval re-enactment, creating props and engaging with a supportive social circle. She also cared deeply for her pets, including cats and rabbits, and had a dry sense of humour. Sarah aspired to attend college and rebuild her life.

# Final Events and Reflection

In February 2022, Sarah attended A&E after expressing suicidal thoughts, citing feelings of being overwhelmed. She was admitted but discharged three days later. Shortly before her death, she experienced bereavement, attending the funeral of one friend and grieving the suicide of another. These events compounded her feelings of rejection and hopelessness, particularly following the Home Treatment Team's decision to discharge her.

Her final CTR in 2021 had shown glimpses of hope and future orientation. However, the lack of coordinated action on her expressed needs and struggles with articulating her desires left critical gaps in her support network.

The day before her death Sarah had an interaction with the Home Treatment Team (HTT) and her Care Coordinator (CCO). During this visit, she discussed her self-harm behaviour, clarifying that it was not intended to end her life but rather a means of expressing her frustration. She was advised about the risk of death by misadventure if she were to use helium. Sarah was also advised to attend A&E if she could not keep herself safe. It was noted that she was unwilling to collaborate therapeutically and was ambivalent about any offers of support. The CCO was to follow up on referrals and arranged a professionals meeting to establish ongoing mental health service involvement, given her unwillingness to engage therapeutically. Ultimately, she was discharged from the HTT.

The following day Sarah rang the crisis line at 1:15 am. The entry notes that she felt better after the chat and thanked them for their time. Sadly, she died at home later that day of asphyxia due to suffocation with helium gas.

# Key Learnings and Actions

- A sensory assessment should be prioritised for individuals with ASD and PTSD to address their environmental needs.
- Improved coordination among care professionals is essential to provide consistent and personalised support.
- Suicide safety plans must be rigorously reviewed, with flagged dates proactively addressed.
- Increased training on EUPD and ASD for care teams is crucial for enhancing awareness and compassion.
- Positive practice, such as accommodating Sarah's requests for care coordinator changes, should be acknowledged and replicated.

Sarah's case underscores the complexities of supporting individuals with intersecting mental health, trauma, and social needs. While care teams worked diligently, the systemic challenges and missed opportunities highlight areas for improvement in holistic and compassionate care delivery.

## Findings for Individuals with a Learning Disability

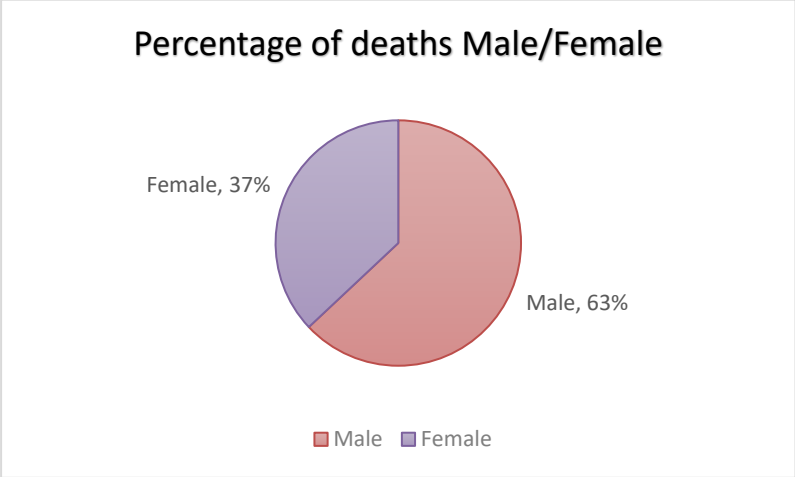
The remainder of this report focuses on the 52 LeDeR reviews completed during the 2024/25 reporting year for individuals diagnosed with a learning disability. It is important to note that some individuals within this cohort may also have been autistic.

### Exclusions

This section does not include data pertaining to autistic individuals without a learning disability, as this group is addressed separately within the report.

The following graphs represent data taken from the 52 completed reviews in 2024/25:-

### Split of deaths by gender

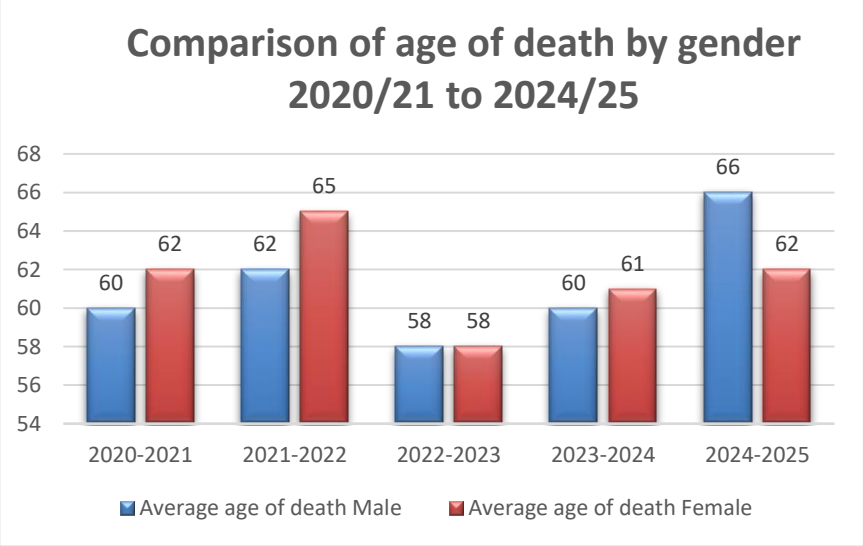



### Average age of death

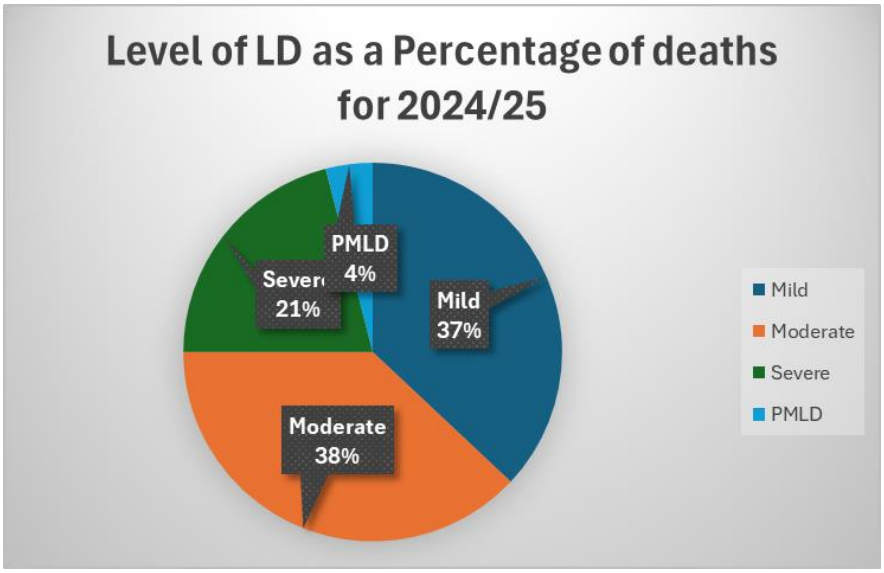
Insights from the LeDeR reviews completed in Derbyshire during the 2024–25 reporting period indicate the following:

- The average age of death for males was 66 years.
- The average age of death for females was 62 years.

These figures represent a positive trend, reflecting an improvement in the average age of death over the past three years.

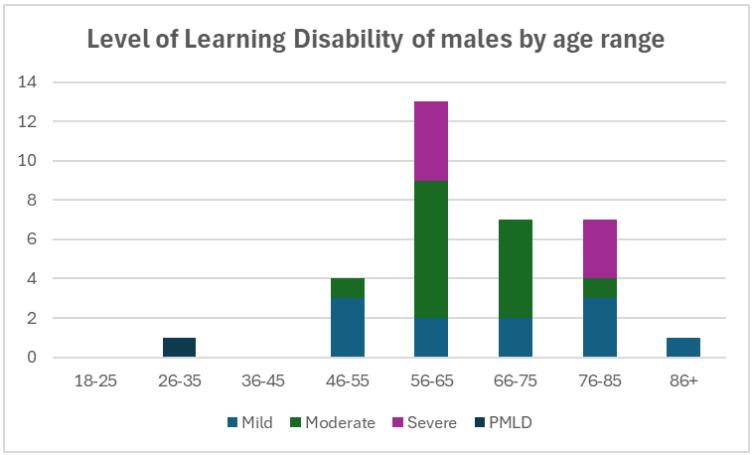


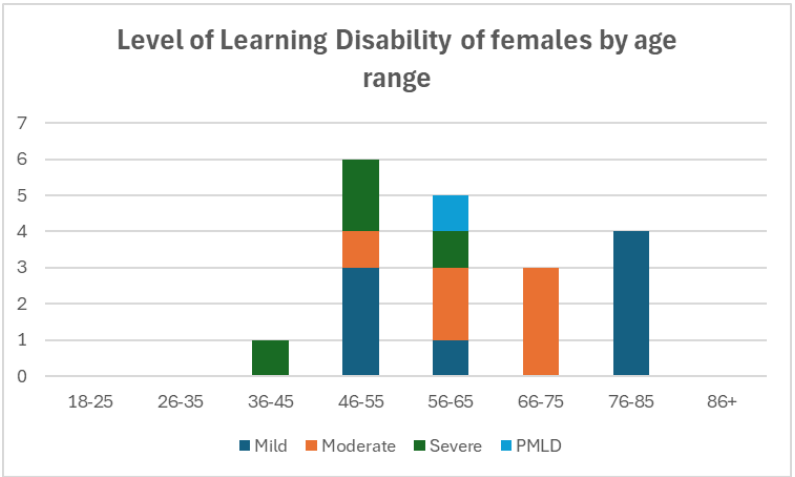
## Level of Learning Disability




Analysis of the age and gender distribution among reviewed deaths indicates a variation across age groups:

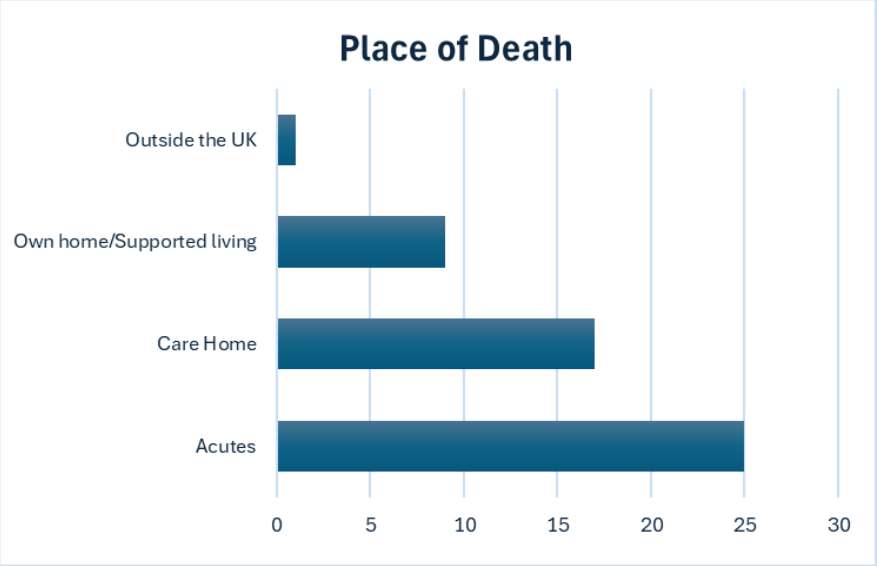
- A higher proportion of female deaths occurred within the 46–55 age range.
- Male deaths were more prevalent in the 56–65 age range.



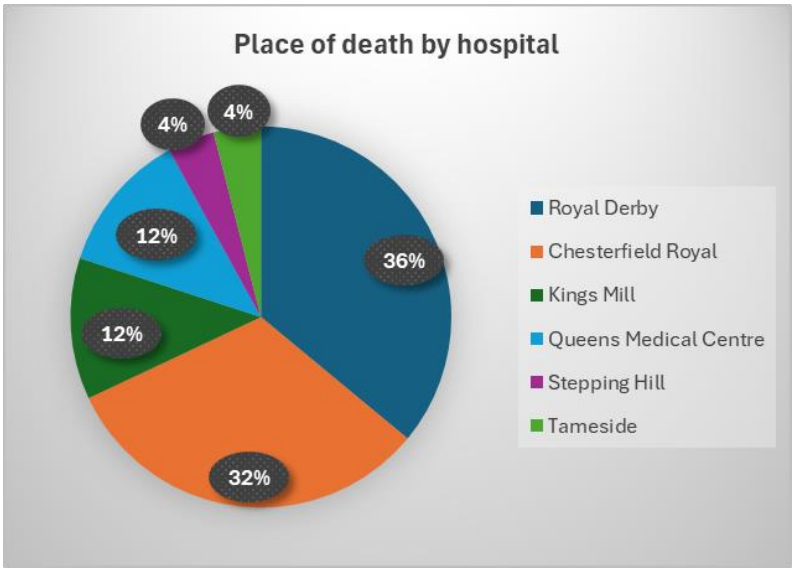



## Place of death

Hospital was the most common place of death, with 48% or 25 of the 52 completed reviews showing hospital as the place of death.  But in total 50% of people died in the place they called home.



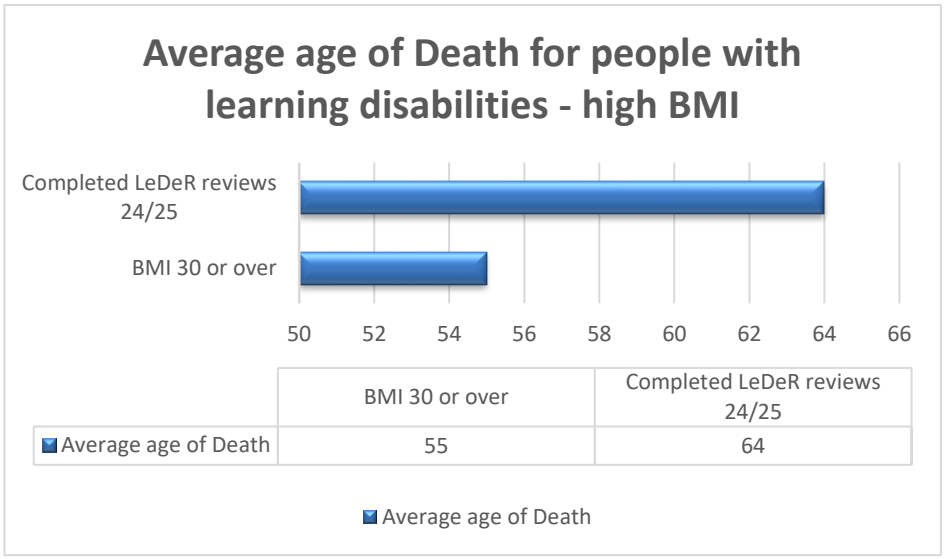

Of the 25 deaths which occurred in hospital, 32% of these took place in hospitals outside of Derbyshire.



## Healthy Lifestyles

During the 2024/25 period, a total of 52 LeDeR reviews were completed. Of these, 11 individuals (21%) were identified as having a high Body Mass Index (BMI). For the purposes of LeDeR reviews, a high BMI is defined as equal to or greater than 30.

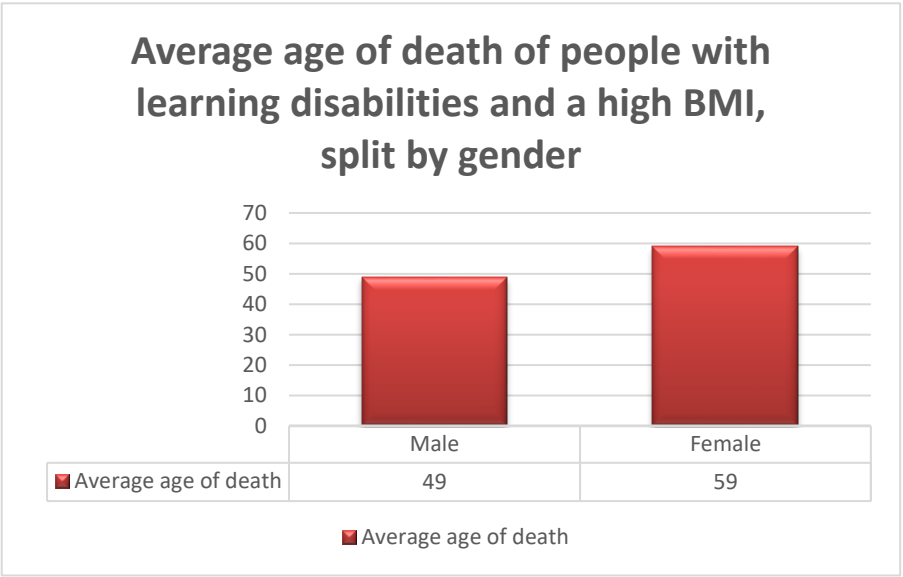
This outcome is considered positive when compared to national data. According to the Office for Health Improvement and Disparities, approximately 28.3% of adults in England aged 18 and over were classified as obese (BMI ≥ 30) during the 2023–2024 reporting period. This indicates that the proportion of individuals with high BMI in the Derbyshire cohort is notably lower than the national average.




Among the 11 individuals identified with a high Body Mass Index (BMI), the age at death ranged from 38 to 79 years. The average age of death within this group was 55 years, which is notably younger than the average age of death across all 52 completed reviews, recorded at 64 years.

Seven of the deaths with a high BMI were female. The average age of death was 59.

Four of the deaths with a high BMI were male. The average age of death was 49.




Only one death was directly attributed to obesity (where obesity associated cardiomyopathy was listed as the reason for death at 1b of the death certificate.

A second death had ischaemic heart disease listed at 1b on the death certificate (1a was cerebral hypoxia) and a further death was due to congestive heart failure (1a on death certificate) with valvular and ischaemic

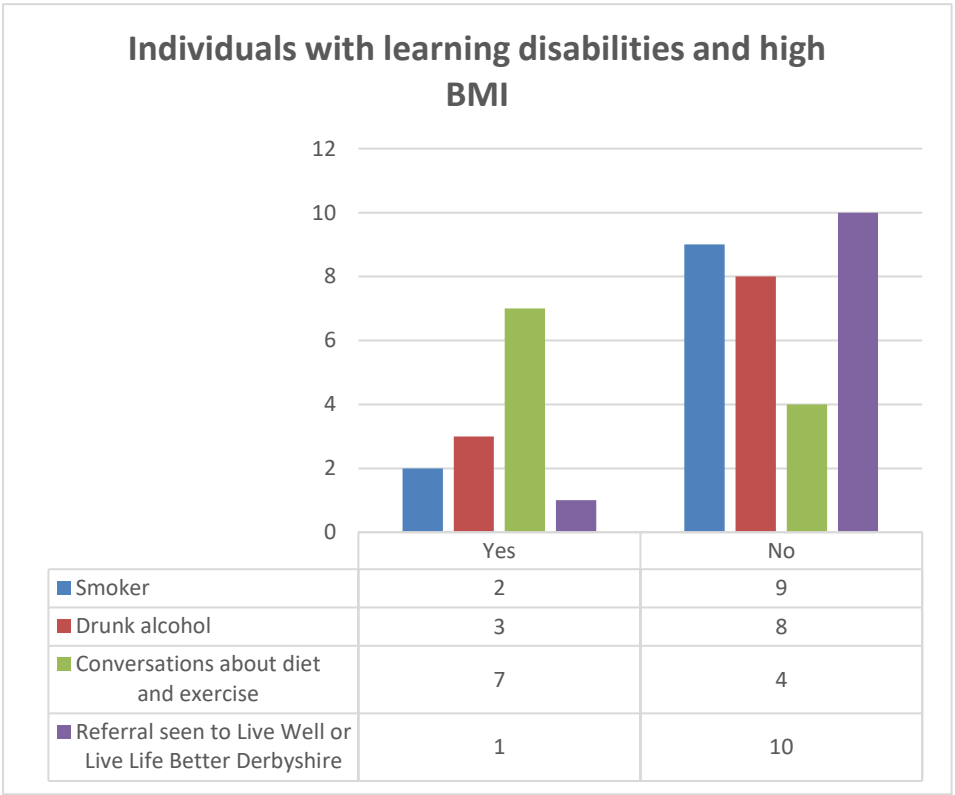
heart disease as 1b.

It is plausible that some of the other reasons for death of these individuals with high BMI may have had some relation to obesity. Reasons are listed below:-

- Individual died of Pneumonia with type 2 respiratory failure due to obesity hypoventilation syndrome listed at part 2 of the death certificate
- Two deaths were caused by respiratory failure
- One death was due to bronchopneumonia (at 1a on death certificate) with part 2 of death certificate listed as asthma
- One death was shown on the death certificate as natural causes by a spinal fracture sustained in a fall at home

Other deaths not related to obesity were:-

- 2 deaths due to cancers
- One death due to sepsis



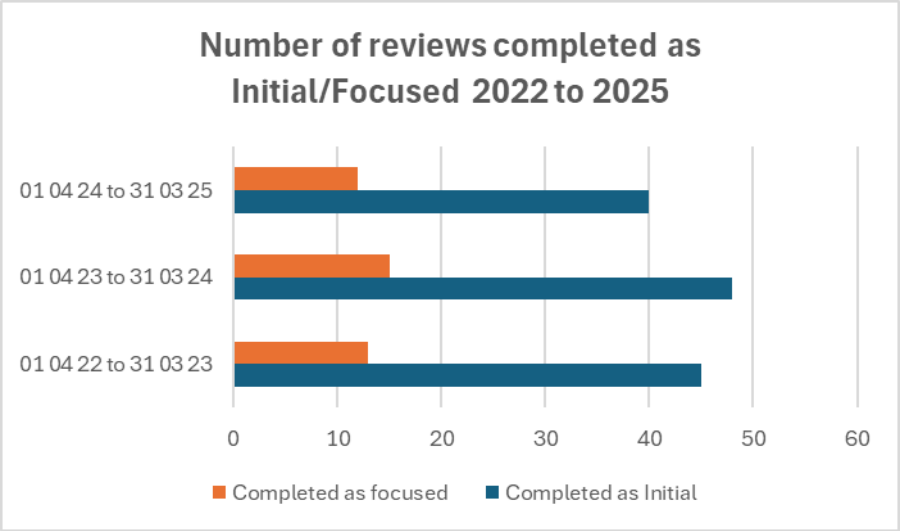

| | Yes | No |
|---|---|---|
| Smoker | 2 | 9 |
| Drunk alcohol | 3 | 8 |
| Conversations about diet and exercise | 7 | 4 |
| Referral seen to Live Well or Live Life Better Derbyshire | 1 | 10 |

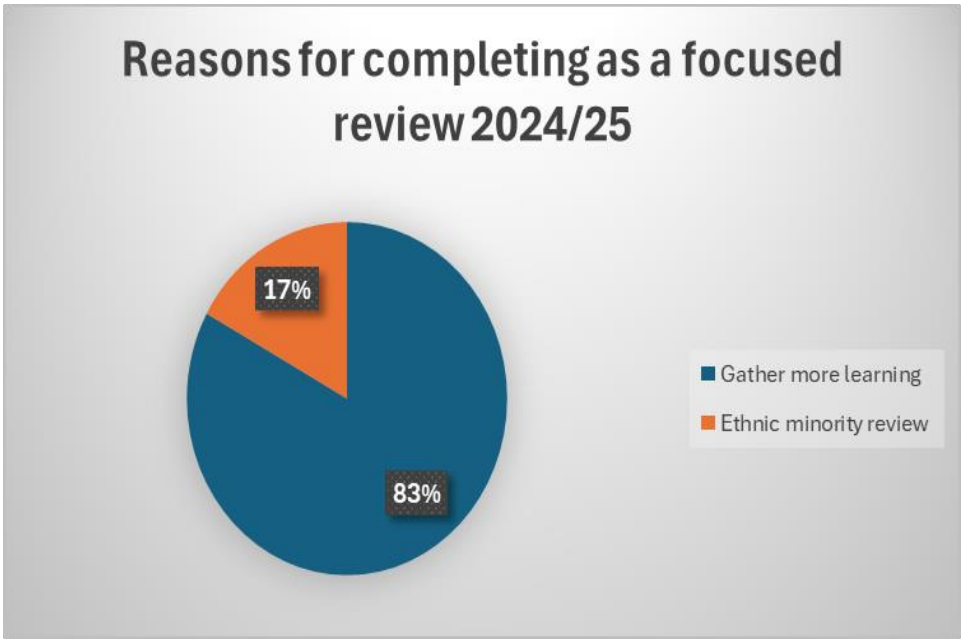
**Referrals to Live Well or Live Life Better Derbyshire** were documented in only one of the LeDeR reviews. Smoking was noted in two of the eleven reviews, while alcohol consumption was reported in three. Discussions regarding diet, exercise, or both were observed in seven of the eleven reviews.

It is important to acknowledge that in some cases, this information was not available to the reviewer.

## Focused and Initial Reviews

All reviews are completed either as Initial or Focused as per the national LeDeR policy. During 2024/25 there were 40 reviews (77%) completed as initial reviews and 12 (23%) completed as the more detailed focused review.




Of the 12 reviews completed as focused 83% of them were moved to a focused review from an initial review in order to gather more learnings for service improvement.

17% were automatically completed as focused due to being individuals from a minority ethnic background (as per the national LeDeR policy).

Individual actions are identified from each review; this may show good practice and/or areas where it is felt improvements could be made. Some areas of learning are evidenced through case studies to identify local priorities and agree actions. Case studies from LeDeR reviews completed in Derbyshire during 2024/25 are shared throughout this report to evidence this.

A national target set by NHSE is that 35% of reviews are completed as focused reviews.

## Grading of Care

In the current version of the LeDeR platform, the functionality to grade the quality of care is restricted solely to reviews completed as Focused. As such, the data presented below pertains exclusively to Focused reviews completed during the reporting year.

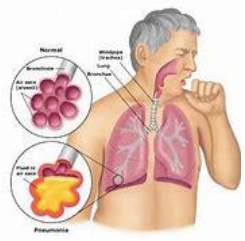
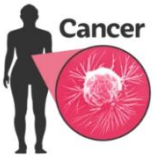
It is important to acknowledge that Focused reviews are typically initiated where concerns or issues have been identified. Consequently, it is reasonable to assume that the grading of care within these reviews is less likely to reflect high-quality care outcomes. In contrast, Initial reviews, which are not currently subject to care grading within the platform, may have yielded higher care scores had grading been available.

Note: Any comparative analysis of care grading must be limited to annual reports from 2021/22 onwards, as earlier versions of the LeDeR platform captured care grading across all review types, not just Focused reviews.

| Grade | Description of grading | Percentage against the 12 focused reviews 2024/25 | Percentage against the 15 focused reviews 2023/2024 | Percentage against the 13 focused reviews 2022/23 | Percentages for focused reviews in 2021/22 |
|---|---|---|---|---|---|
| **6** | This was excellent care (it exceeded expected good practice | **0%** | **13%** | **0%** | **0%** |
| **5** | This was good care (it met expected good practice) | **8%** | **27%** | **23%** | **30%** |
| **4** | This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing) | **17%** | **20%** | **38%** | **20%** |
| **3** | Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death | **42%** | **33%** | **31%** | **20%** |
| **2** | Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death | **25%** | **7%** | **8%** | **30%** |
| **1** | Care fell far short of expected good practice and this contributed to the cause of death | **8%** | **0%** | **0%** | **0%** |

## Reasons for Death in Derbyshire for people with learning disabilities

Of the completed reviews during the period 1st April 2024 to 31st March 2025 the reasons for death are categorised and separated out below.

| For Reviews completed 2024/2025 | | |
|---|---|---|
| **Death category** | | **Percentage with this death category at 1a on death certificate** |
| **Respiratory Infections** | Respiratory infections such as **pneumonia, bronchopneumonia, Community Acquired Pneumonias and Hospital Acquired pneumonias, along with chest infections.** A respiratory tract infection can affect the airways, such as with bronchitis, or the air sacs at the end of the airways, as in the case of pneumonia  | **31%** |
| **Aspiration Pneumonia** | **Aspiration pneumonia is pneumonia that is caused by something other than air being inhaled (aspirated) into your respiratory tract.** These non-air substances can be **food, liquid, saliva, stomach contents, toxins** or even a small foreign **object.**  | **25%** |
| **Cancers** | Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body   | **8%** |
| **Heart Conditions** | When blood flow becomes limited or stopped, the body shuts down and - without intervention - can lead to death.  | **6%** |

| | | |
|---|---|---|
| **Frailty** | Increased vulnerability to poor health outcomes due to underlying conditions  | **6%** |
| **Others** | | **24%** |

For the top 5 death categories for 2024/25 a comparison of the 2023/24 percentage is shown below.

| Death category | 2024/25<br>Percentage with this death category at 1a on death certificate | Previous year 2023/24<br>Percentage with this death category at 1a on death certificate |
|---|---|---|
| **Respiratory Infections** | **31%** | **24%** |
| **Aspiration Pneumonia** | **25%** | **11%** |
| **Cancers** | **8%** | **13%** |
| **Heart Conditions** | **6%** | **11%** |
| **Frailty** | **6%** | **3%** |

The data reveals notable shifts in the primary causes of death recorded on death certificates (section 1a) across the two years. Respiratory infections remain the most prevalent cause, increasing from 24% in 2023/24 to 31% in 2024/25. Aspiration pneumonia saw a significant rise, more than doubling from 11% to 25%, indicating a growing concern in this area.

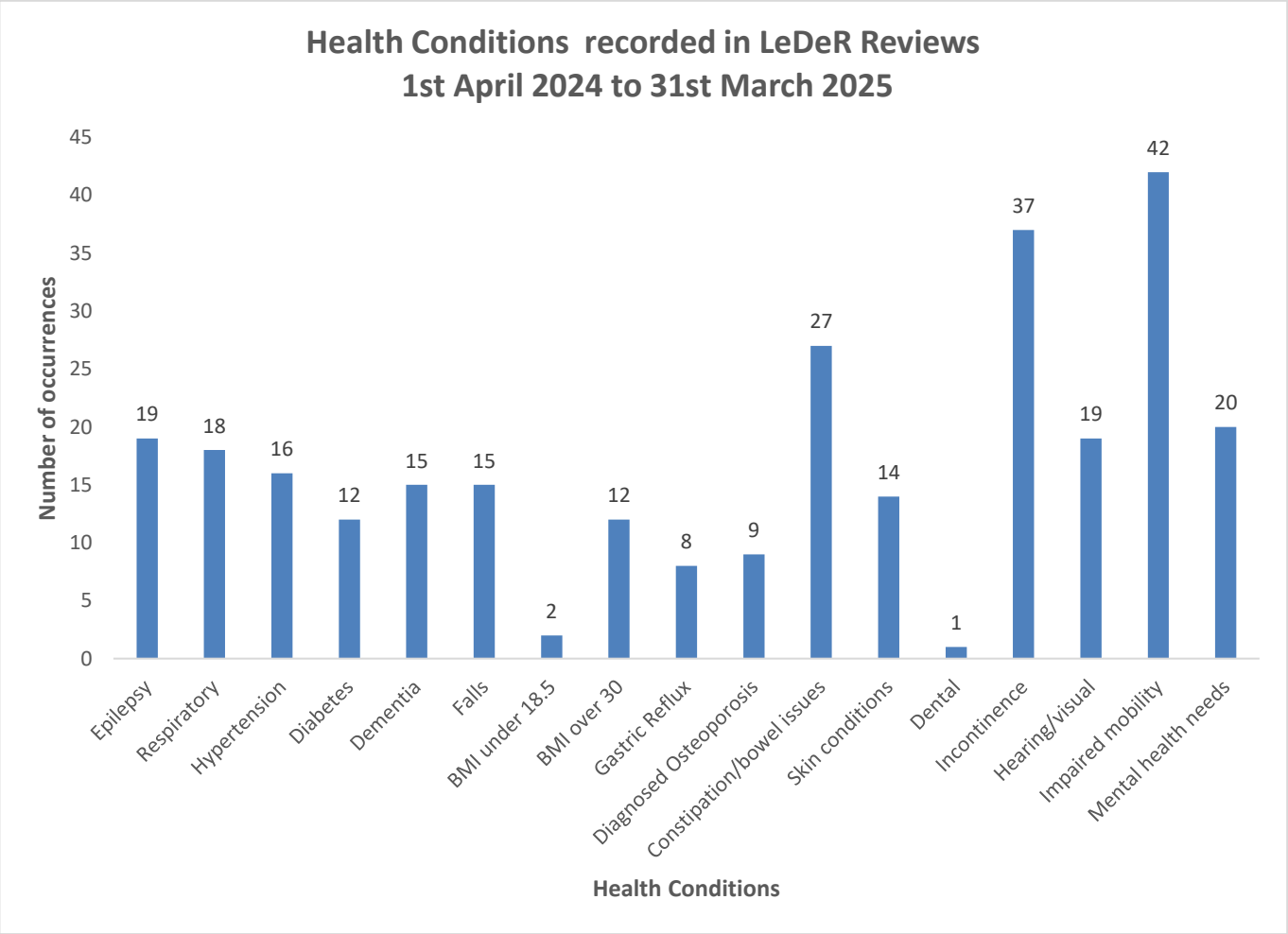
Conversely, deaths attributed to cancers and heart conditions declined, dropping from 13% to 8% and 11% to 6% respectively. Frailty showed a modest increase from 3% to 6%, suggesting a potential trend in age-related vulnerabilities.

These changes highlight evolving health challenges and may inform future priorities in care planning and preventative strategies.

## Health Conditions for people with learning disabilities

This graph presents the frequency of various health conditions identified in the 52 completed LeDeR Reviews for those with learning disabilities conducted between April 2024 and March 2025.

The most commonly recorded condition was Impaired Mobility with 42 cases, followed by Incontinence (37) and Constipation/Bowel Conditions (27). Other prevalent conditions included Mental Health Needs (20), Hearing/Visual (19), Respiratory Issues (18), Hypertension (16), Dementia (15), and Diabetes (15). Less frequent conditions included Diagnosed Osteoporosis (9), Gastric Reflux (8), and Dental, which was the least reported with just 1 case.




Unfortunately, constipation has risen again this year and was recorded as a health condition in 52% of the completed reviews.

In last year's report epilepsy was seen in 48% of the completed reviews, this year it has decreased to 37%.

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## Themes from reviews

Themes are collated for every completed review.  This information is collated and used to highlight local priorities.  Themes collated for the 2024/25 year are included in Appendix 3 of this report.

The theme analysis reveals recurring themes in addressing health inequities and improving care for individuals with learning disabilities. Significant findings include disparities in access to health services, communication barriers, and the need for enhanced training among healthcare professionals.

Disparities in access to health services remain a pervasive challenge. Individuals with learning disabilities frequently encounter unequal treatment, delayed interventions, and reduced availability of specialist care. Addressing these issues requires targeted policies and an expansion of resource allocation.

Communication barriers emerge as another critical theme. Healthcare professionals often struggle to adequately engage with individuals who have learning disabilities, resulting in misdiagnoses and unmet healthcare needs. Better communication training, the use of accessible formats, and inclusion of advocates can help bridge this gap.

The need for enhanced training among healthcare professionals is also highlighted. Many professionals lack the specific skills required to deliver person-centred care to individuals with learning disabilities. Comprehensive training programmes focused on empathy, understanding, and tailored care approaches are essential for fostering equitable healthcare outcomes.

The data underscores the importance of timely diagnosis and person-centred care to reduce preventable mortality. These insights guide strategic initiatives aimed at fostering inclusivity and ensuring equitable healthcare outcomes.

A recurring theme identified across LeDeR reviews completed during the 2024/25 period has been the prevalence of deaths resulting from aspiration pneumonia, alongside concerns regarding the management of clinical deterioration.

To illustrate these findings, the following case study—drawn from a LeDeR review conducted within the same timeframe—is presented below. It highlights key learning points and reinforces the importance of early recognition and appropriate response to deterioration, particularly in individuals with complex health needs.

# Case Study 2: Barry's Experience of Healthcare and Support

**The following case study recounts the experiences of an individual referred to here as Barry. The name has been changed to protect his identity.**

## Background

Barry, a 64-year-old gentleman, had a mild learning disability and schizophrenia. He lived in a supported living flat with low-level support needs, enjoying independence in many aspects of daily life. Barry often visited shops, libraries, and book fairs, and enjoyed cigarettes, beer, and fish and chips.
During lockdown, Barry experienced increased anxiety, developed nighttime incontinence, and became more dependent on care workers for support. He was subsequently referred to the continence advisory service and to community learning disability psychology services for dementia screening, which ultimately ruled out dementia. After lockdown, Barry initially showed signs of improvement, but by January 2023, his physical health had declined, marked by choking episodes, weight loss, changes in voice quality, and increasing difficulty with speech.

## Diagnosis and Management of MND Symptoms and Associated Complications

### 1.Dysphagia: a direct symptom of MND

Barry was admitted to hospital in April 2023 following choking episodes and significant weight loss.
In April 2023, Barry was admitted to hospital after two choking episodes and significant weight loss. Diagnostic investigations, including endoscopy and CT head scan, did not identify the cause of dysphagia. Referral to neurology was considered but not actioned (2). Barry was assessed by Speech and language therapy who modified Barry's diet and recommended supervision at mealtimes to reduce risk of aspiration. Discharge planning failed to trigger a social work referral for a "change in need" assessment and as a result additional hours of support weren't in place when Barry was discharged home. (1)
On 6 June 2023, Barry was taken to Chesterfield Royal Hospital with suspected sepsis and later diagnosed with aspiration pneumonia caused by inhalation of food and drink. Although initially considered fit for discharge, concerns from care staff and the late disclosure of recent "vacant episodes" led to his admission (3).
The social care practitioner notified the acute LD liaison nurse that Barry was on the ward and would require support. A referral to neurology was made, leading to an MRI scan and nerve conduction tests which confirmed Oropharyngeal Dysphagia and Motor Neurone Disease (MND) as the underlying cause.
Barrywas also assessed by Speech and Language Therapy (SLT) and dietetics, who modified his diet and prescribed oral nutritional supplements.
A referral to social work for a “Change in Needs” assessment triggered a best interest meeting. Barry was assessed as lacking capacity to manage his health, and due to the progressive nature of Motor Neurone Disease (MND), it was agreed that a 24-hour care home environment would be in his best interest. SLT supported Barry to participate in the meeting, and he was subsequently discharged to the care home.
Despite these arrangements, Barry was unable to meet his nutritional needs through eating and drinking alone. This led to a mental capacity assessment and a best interest meeting on 1st September to determine whether Barry had the capacity to consider a feeding tube. He was supported to understand the medical reasoning behind the recommendation and agreed to the surgery, which took place on 18th September.
Barry was referred to the Home Enteral Feeding Dietetic Team and continued taking oral nutritional supplements (ONS), in line with his wishes. PEG was agreed upon as a backup option should ONS become insufficient. Although a feeding regime was documented, there was no evidence of a formal “feed at risk” assessment, typically recommended for individuals with dysphagia who continue oral intake alongside PEG feeding (5).

## 2.Constipation: a complication associated with MND

Barry developed constipation secondary to reduced mobility caused by MND. In September 2023, his care team discussed increasing his laxative dosage with the GP, but there was no record of follow-up (4).

## 3. Aspiration Pneumonia and Death: associated with unmanaged constipation

On 28th October, Barry declined his bolus PEG feed in the evening and appeared unwell, prompting a nurse to contact NHS 111. Following assessment, no immediate intervention was advised due to his medical history, and instead continued monitoring was recommended. However, in the early hours of 29th October, Barry vomited and aspirated, leading to an emergency hospital admission.
It is unclear whether NHS 111 and out-of-hours services are trained to recognise "soft signs" of deterioration in people with learning disabilities, but if deterioration had been acknowledged and acted upon during the initial 111 call, his deterioration might have been prevented (6).
Barry was dehydrated upon admission, and a CT scan showed significant faecal loading and gas build-up, despite a high-fibre diet and laxatives. During his hospital stay, he developed aspiration pneumonia. Tragically, he aspirated again while in hospital, leading to his death.

# Safeguarding

A safeguarding concern was raised as part of the LeDeR process as Barry was dehydrated on admission to hospital from the care home. Following review, the safeguarding team concluded that the nursing team had provided appropriate care, and the case was closed.

# Cause of Death

Cause of death is documented as Aspiration Pneumonia citing MND as a contributory factor.
The hospital review of the death (Structured Judgement Review or SJR) documents poor hospital care citing death as "probably" avoidable if doctors had released abdominal pressure by venting the feeding tube. These concerns were dealt with through hospital incident reporting.

# Key LeDeR Issues and Learning

1. **Unsafe discharge:** Discharge planning failed to trigger a social work referral for "change in need assessment" and as a result additional hours for mealtime support hadn't been organised leading to heightened aspiration risk upon discharge.
2. **Delayed neurology referral:** Earlier referral during Barry's first hospital admission could have resulted in timely diagnosis and intervention.
3. **Communication gaps:** Incomplete sharing of symptoms (vacant episodes) in the emergency department delayed appropriate treatment planning.
4. **Constipation management:** Lack of follow-up on laxative adjustments potentially contributed to faecal impaction and subsequent complications.
5. **Feeding at risk decisions:** Continued to feed orally without formal "feed at risk" assessment and best interest decisions.
6. **Delayed action following initial 111 call:** managing deterioration in PWLD involves awareness and effective recognition of soft signs of deterioration (e.g. "not himself" / "not wanting bolus feed through PEG" plus effective escalation and sharing of information to trigger a timely response".

**Additional note**
**CHC for MND is not well understood**: A third of people with MND die within a year, yet the NHS Continuing Healthcare (CHC) system often fails to meet their urgent needs due to delays and complexity. A new booklet aims to help professionals better support timely CHC access for those with MND at their most critical time

# Positive Practices

Barry benefited from excellent inter-agency collaboration involving adult social care practitioners, acute

LD liaison nurses, SLT teams, neurologists, and gastroenterology experts. Diagnosis and care plans in place within seven weeks of hospital admission, ensuring Barry's safe transition to a care home. Barry was consistently supported to participate in best interest meetings and to understand his diagnosis.

## Conclusion

Barry's care was compromised by multiple systemic failings. Hospital discharge planning overlooked a social work referral, increasing his aspiration risk due to lack of mealtime support. A delayed neurology referral and incomplete communication of symptoms hindered timely diagnosis and treatment, and constipation management was inadequate. Barry continued oral feeding (nutritional supplements) without a formal "feed at risk" assessment. Delays in recognising early signs of deterioration, combined with limited understanding of NHS Continuing Healthcare (CHC) eligibility for individuals with MND, impacted the quality and timeliness of Barry's care.

# Learning from LeDeR and what work has been happening in Derbyshire in 2024/25

This section outlines key areas of work undertaken across Derbyshire during the 2024/25 reporting period. Several initiatives have been directly informed by learning identified through the LeDeR programme, while others represent broader efforts to address health inequalities. These activities have been regularly shared with and promoted through the LeDeR Steering Group, ensuring alignment with system-wide priorities and collaborative improvement. These collaborative efforts reflect a system-wide commitment to learning, transparency, and the continuous improvement of services for people with learning disabilities and autistic people.

Learning from LeDeR continues to be actively disseminated across the Derbyshire system. Regular discussions take place within the LeDeR Steering Group, ensuring that insights from reviews inform strategic planning and service development.

In addition, the Local Area Contact (LAC) plays a key role in strengthening LeDeR processes and fostering collaboration with partner organisations across Derbyshire. This includes:

**Joint Reporting**: The LAC is working closely with the Mortality Review Facilitator at Derbyshire Community Health Services (DCHS) to produce regular reports that incorporate LeDeR learning. These reports are shared with the Mortality Group to support continuous improvement in care delivery.

**Safeguarding Collaboration:** Engagement with Safeguarding Leads at Derbyshire County Council and Derby City Council is ongoing to explore specific themes arising from LeDeR review actions and recommendations and to work in conjunction with the Safeguarding Adult Review process.

**Adult Social Care Integration:** The LAC is working in partnership with Adult Care colleagues to ensure that LeDeR processes are appropriately aligned with social care workflows. This includes efforts to gather information in a timely manner for reviews and to ensure that key themes and learning are fed back to social care teams for practical application.

## Acute Trusts

### Chesterfield Royal Hospital

Chesterfield Royal Hospital (CRH) has undertaken several initiatives aimed at improving care for patients with complex needs, including those with learning disabilities and safeguarding concerns.

#### Discharge Coordination and Safeguarding Collaboration

A training package has been proposed for Discharge Coordinators to enhance discharge planning for

patients with complex needs and/or safeguarding issues. As part of this initiative, Discharge Coordinators have been spending time with the Safeguarding Team to deepen their understanding of safeguarding processes and improve multidisciplinary collaboration during discharge planning.

### ReSPECT Audit for Patients with Learning Disabilities

CRH is also conducting a ReSPECT Audit, specifically focused on monitoring the use and quality of ReSPECT forms for patients with learning disabilities. The audit aims to evaluate compliance, documentation standards, and the appropriateness of care planning.

#### CRH-Ageing Well Collaborative Group

CRH has set up the CRH-Ageing Well Collaborative Group aimed at improving care for patients with complex needs, including those with learning disabilities. This group is chaired by the Deputy Medical Director with representation from the Ageing Well Team and from key areas at CRH such as the Emergency Department.

## Royal Derby Hospital

A number of targeted initiatives have been underway at Royal Derby Hospital aimed at enhancing the quality of care for individuals with learning disabilities and autistic people. These developments reflect a commitment to inclusive, person-centred care and are outlined below:

**Accessible Information:** A suite of easy-read information leaflets has been developed to support understanding of diagnostic procedures. These include:

- Having an X-ray
- Having an Ultrasound
- Having a CT Scan
- Having an MRI

**Audit and Evaluation**: A bespoke Learning from Death Audit Tool has been created to support reflective practice and identify areas for improvement in care delivery.

The hospital has undertaken two audits aimed at improving care for individuals with learning disabilities and autistic people:

#### Retrospective Audit of Deaths

A retrospective, generic audit is being conducted to review deaths of individuals with autism and learning disabilities that occurred during Quarter 1 and Quarter 2 of 2025/26. The findings from this audit will be compiled into a formal report to identify key themes and areas for improvement.

#### ReSPECT Process Audit

A second audit is focused on evaluating the ReSPECT process, with particular attention to its application

for patients with learning disabilities. This audit aims to assess the quality and consistency of ReSPECT documentation and decision-making.

**Pathway Development:** Work to establish clear referral pathways for both maternity and cancer services, ensuring timely and appropriate support for individuals with learning disabilities and autism.

**Annual Blood Tests**: Discussions regarding service development and desensitisation approaches to support individuals undergoing annual blood tests, with a focus on reducing anxiety and improving experience.

**Staff Training:** The Learning Disability (LD) team actively delivering training to hospital staff on effective communication strategies and the use of hospital passports to support personalised care.

**Community Engagement:** The LD team strengthening links with community providers and patient-led groups to enhance knowledge sharing and continuity of care across settings.

**Transition Planning:** A pathway being developed within the acute setting to support smooth transitions from paediatric to adult services, ensuring continuity and reducing disruption during this critical period.

# Ageing Well Team

The Ageing Well Team serving the Chesterfield and Dronfield area within Derbyshire have shared several ongoing initiatives aimed at improving care for individuals with learning disabilities. These efforts reflect a proactive and collaborative approach to enhancing service delivery and clinical understanding across care settings.

**Key Developments**

Partnership Work on Consent and Capacity

A Lead Community GP within the team has engaged in a collaborative project with colleagues at Chesterfield Royal Hospital (CRH). This initiative focuses on strengthening partnership working around the themes of informed consent and mental capacity, specifically for care home residents with learning disabilities in the local area.

**Advanced Clinical Practitioner (ACP) Placement**

The team will be hosting a trainee Advanced Clinical Practitioner (ACP) who brings a background in Speech and Language Therapy (SaLT). The placement will support the development of her physical assessment skills and contribute to a service improvement project focused on care home residents with learning disabilities.

**Specialist Training in Learning Disability Care**

The Lead ACP is commencing a Postgraduate Certificate in Medical Needs of Adults with a Learning Disability. The team currently supports 30 care homes, approximately one-third of which cater specifically to adults with learning disabilities. A gap in specialist knowledge has been identified, as none of the team members have formal training in learning disability care. To address this, the team plans to disseminate course content internally to build capacity and improve practice.

## Diabetes - Collaboration with Healthier You: Enhancing Diabetes Prevention for People with Learning Disabilities and Autism

The Local Area Contact (LAC) has engaged with Healthier You, the provider of the Diabetes Prevention Programme in Derbyshire, to explore opportunities for improving accessibility and inclusivity for people with learning disabilities and autistic individuals.

As part of this collaboration, the LAC shared key learning from LeDeR reviews, particularly regarding the prevalence of diabetes as a health condition among individuals with learning disabilities. Discussions focused on how Healthier You is implementing reasonable adjustments to tailor their programme to better meet the needs of this population.

To further strengthen this partnership, Healthier You attended a LeDeR Steering Group meeting, where they presented their current approach and gathered additional insights and advice on working effectively with autistic people and those with learning disabilities.

## Engagement with ICB Primary Care Quality Leads: Strengthening LeDeR Integration in Primary Care

The Local Area Contact (LAC) has met with Integrated Care Board (ICB) Quality Leads for Primary Care to explore opportunities for improving the integration of LeDeR learning within general practice. The discussion focused on mechanisms for sharing insights from LeDeR reviews and establishing feedback loops to assess whether practices have implemented changes based on previously shared learning.

As a result of this collaboration, LeDeR is now being incorporated into quality visit checks conducted by ICB Quality Leads with general practices and Primary Care Networks (PCNs). This enhanced approach includes:

- Promoting notifications to LeDeR from general practice teams.
- Sharing learning materials developed by the LeDeR team with practices and PCNs.
- Facilitating discussions with general practice staff on how previously shared LeDeR learning has been applied in their settings.

# Local Authorities (Derby City Council and Derbyshire County Council)

## Derbyshire County Council

Derbyshire County Council **are providing** essential training programmes for colleagues, which have recently undergone review. These programmes include:

- Autism Awareness
- Supporting People with a Learning Disability

These courses are also made available to colleagues working within the private and independent sector, supporting wider system learning and consistency in care delivery.

In addition, the Council is reviewing the Oliver McGowan Mandatory Training to assess its suitability for Adult Care staff. Consideration is also being given to offering this training to private and independent providers as part of future Board sessions.

Learning and insights gained through LeDeR forums are regularly shared with internal colleagues and external partners/providers, ensuring that emerging themes and recommendations inform practice across the system.

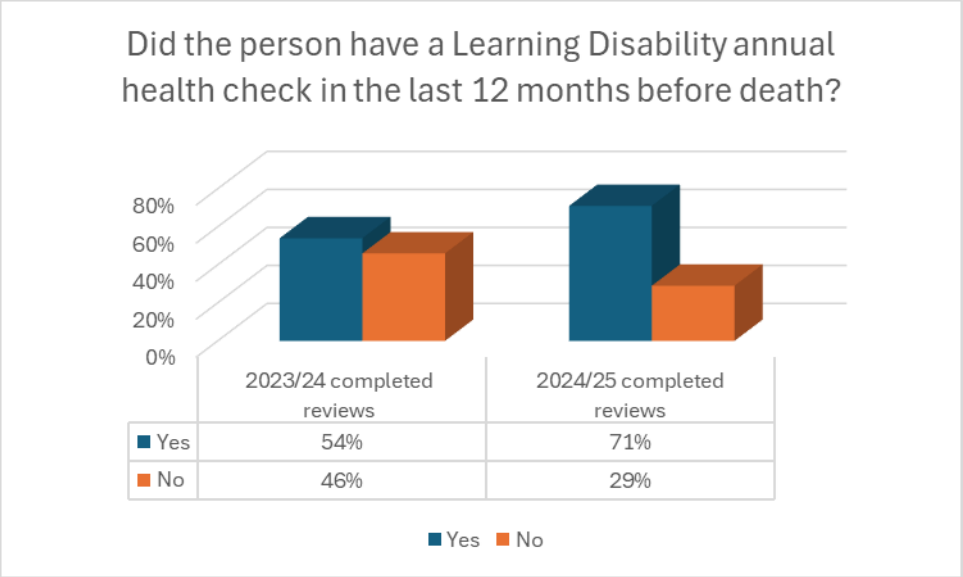
Ongoing support is also provided through briefings on mental capacity, which are shared with both internal teams and external partners to strengthen understanding and application of the Mental Capacity Act in practice.

# Learning Disability Annual Health Checks and the Strategic Health Facilitation Team

### Learning Disability Annual Health Checks

People with learning disabilities often experience worse physical and mental health than others. Everyone over 14 on a doctor's learning disability register should have an annual health check to help identify and address health issues early. We use LeDeR data to monitor information about annual health checks. The following information is taken from LeDeR learning over 2024/25.

Of 52 completed reviews, 29% of individuals missed a health check in their last year, while 71% received one. This marks an improvement from the previous year's data, when only 54% had an annual health check. This is shown in the graph below.




GP records cited various reasons for missed annual health checks:

- End-of-life or palliative care made reviews unnecessary.
- Hospitalisation at recall time.
- Longstanding fear of healthcare settings.
- Reminders not understood.
- No recent invites, but regular frailty team reviews occurred.
- Individual or parent declined.
- Regular GP reviews, but no formal health check.
- Housebound status prevented attendance.
- Reason not documented.

Examples of best practice observed include:

- Comprehensive Annual Health Checks were conducted, complemented by regular multi-disciplinary meetings to address complex needs.
- Individual needs were clearly identified, with all pertinent plans in place and detailed within the Action Plan to ensure appropriate support.
- Thorough assessments and meticulous documentation processes were maintained.
- Reviews were comprehensive, offering clear explanations of individual needs and noting any deterioration over time.


- General Practitioners (GPs) conducted home visits when required and engaged with family members regarding DNACPR (Do Not Attempt Resuscitation), hospital admissions, and levels of care.
- Health Action Plans were reviewed, and reasonable adjustments were recorded—such as recommending that individuals be seen at home and accompanied by staff familiar to them.

- Easy-read questionnaires were distributed beforehand, requesting the inclusion of medication lists, prior health action plans, and urine samples.
- The Annual Health Check incorporated information about available and required support, as well as the individual's level of independence.
- An accessible Health Action Plan (HAP) template was utilised to facilitate communication among the staff team.
- Health checks systematically addressed communication and accessibility requirements.
- It was agreed that annual health checks and blood sample collections should be performed at home, rather than at the surgery, as a reasonable adjustment for optimal assessment.
- Comprehensive question lists were used to assess communication methods, additional support needs, and the necessity for interpreters.
- Easy-read Health Action Plans were observed to be uploaded into individual records.

Although at times health action plans were formulated and discussed with patients, some records either did not mention a health action plan at all or it was noted in the LeDeR review that no accessible health action plan was provided.

Additional observations regarding health action plan records included:-

- In several instances, it was noted that a health action plan was given or completed ; however, there was no evidence of its presence within the patient record system.
- There were entries indicating that advice intended for the home care team had been written, but without supporting evidence of a completed health action plan in the records.
- Health action plans included key information such as cancer screening and vaccinations.
- In some records, an easy-read health action plan was seen as uploaded.
- Reasonable adjustments documented in health action plans included recommendations for home visits with familiar staff.

The learning highlights variation in the completion, accessibility, and visibility of health action plans within patient records. Improved documentation and consistent use of accessible templates are recommended to facilitate better communication and continuity of care.

### Overview of Recent Initiatives by the Strategic Health Facilitation team

The Strategic Health Facilitation Team has undertaken a range of initiatives aimed at enhancing the health and wellbeing of individuals with learning disabilities. These efforts focus on improving the uptake and

quality of annual health checks, increasing staff awareness of key health risks, and supporting continuous professional development for those working within neurodevelopmental and supported living services.

### Promotion of Annual Health Checks

A central priority for the team has been to promote the uptake of annual health checks. The team is working alongside Neurodevelopmental Services to ensure that all staff routinely ask, “Have you had your annual health check?” as part of initial assessments and ongoing casework. This systematic approach is intended to increase the visibility and importance of health checks, thereby supporting early identification and management of health needs.

### Development of Targeted Training

To address key risks identified through the LeDeR programme, the team has begun developing a series of bitesize training sessions targeted at paid workers in care and supported living environments. Planned topics for 2025 include aspiration pneumonia, frailty, cardiovascular disease, and cancer screening. These sessions aim to provide practical knowledge and promote best practices for supporting the health of individuals with learning disabilities.

### Constipation Awareness and Evaluation

Constipation awareness has been a particular focus, with dedicated sessions delivered to approximately 35 participants to date. Feedback on these sessions has been highly positive, with attendees noting the relevance and usefulness of the information provided. A follow-up survey has been distributed to assess the impact of the sessions, specifically looking at any changes in practice related to diet, monitoring, and escalation of medical concerns.

### Upcoming Training and Events

Building on the success of recent sessions, the team is preparing to deliver further training on cancer screening. Additionally, further bitesize training for supported living staff is in development. The team is also collaborating with colleagues from DHcFT to deliver health workshops during Learning Disability Week, reinforcing their commitment to ongoing education and support.

In summary, the Strategic Health Facilitation Team continues to play a vital role in promoting best practices, supporting continuous learning, and enhancing the health outcomes of individuals with learning disabilities through targeted, practical interventions.

## Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

*Overview and Local Implementation*

The ReSPECT process (Recommended Summary Plan for Emergency Care and Treatment) is a nationally recognised approach designed to support personalised emergency care planning. It enables individuals to record their preferences and clinical recommendations for treatment in situations where they may be unable to make or communicate decisions. The process is particularly relevant for individuals with complex health needs, those approaching end-of-life, or those at risk of sudden deterioration or cardiac arrest.

### *Core Components of the ReSPECT Process*

**Person-Centred Planning:** The ReSPECT plan is developed through structured conversations between the individual and their healthcare professionals. These discussions may also involve family members or carers, ensuring that the plan reflects both personal values and clinical judgement.

**Documentation:** The agreed recommendations are recorded on a ReSPECT plan, which is accessible across care settings including hospitals, hospices, care homes, and community services. The plan is designed to be available during emergencies to guide rapid decision-making.

**Dynamic and Reviewable:** The ReSPECT plan is not static. It can be updated as the individual's condition or preferences change, ensuring ongoing relevance and accuracy.

### *Derbyshire System Implementation*

Within Derbyshire, the ReSPECT process has been actively embedded across services, with several initiatives supporting its rollout and quality assurance:

**Digital Integration**: Although still available as a paper plan, the ReSPECT plan is now available in digital format via the Derbyshire Shared Care Record (DSCR), enhancing accessibility for clinicians and LeDeR reviewers.

**Education and Training:** Tier 1 and Tier 2 communication skills training have been developed and delivered by Treetops Hospice and University Hospitals of Derby and Burton (UHDB) and Ashgate Hospice. These sessions utilise evidence-based approaches such as RealTalk and are aligned with recommendations from the Parliamentary and Health Service Ombudsman (PHSO).

**Audit and Quality Monitoring:** Local audits are conducted to assess the use and quality of ReSPECT documentation. These audits include reviews of mental capacity assessments, patient experience, and documentation standards across community and acute settings.

**LeDeR Integration:** The ReSPECT process is closely linked to the LeDeR programme. Reviewers are encouraged to assess the presence, quality, and appropriateness of ReSPECT plans during case reviews. Case studies and statistical analyses are being used to highlight good practice and identify areas for improvement.

**System-Wide Collaboration:** The Derbyshire Alliance for End of Life Care and other stakeholders are involved in developing resources and toolkits to support ReSPECT education and implementation, including easy-read guides and webinars.

### *Challenges and Considerations*

**Documentation Gaps:** Issues have been identified through LeDeR where ReSPECT plans are incomplete or not retrievable, prompting actions to improve electronic filing systems and coding practices.

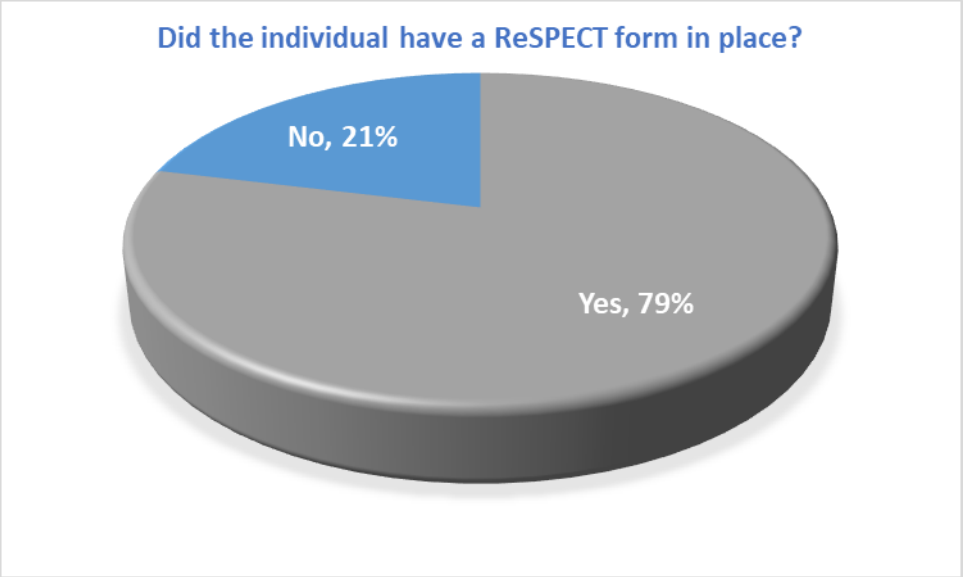
**Consistency in Practice:** There is variation in how ReSPECT is used across settings, with some acute admissions treating it primarily as a DNACPR form. Efforts are underway to promote its use in outpatient and community settings where patient involvement is more feasible.

**Funding and Sustainability**: While pilot funding supported initial training efforts, there are concerns about the sustainability of Tier 2 training due to lack of ongoing financial support.

*Learning found through LeDeR*

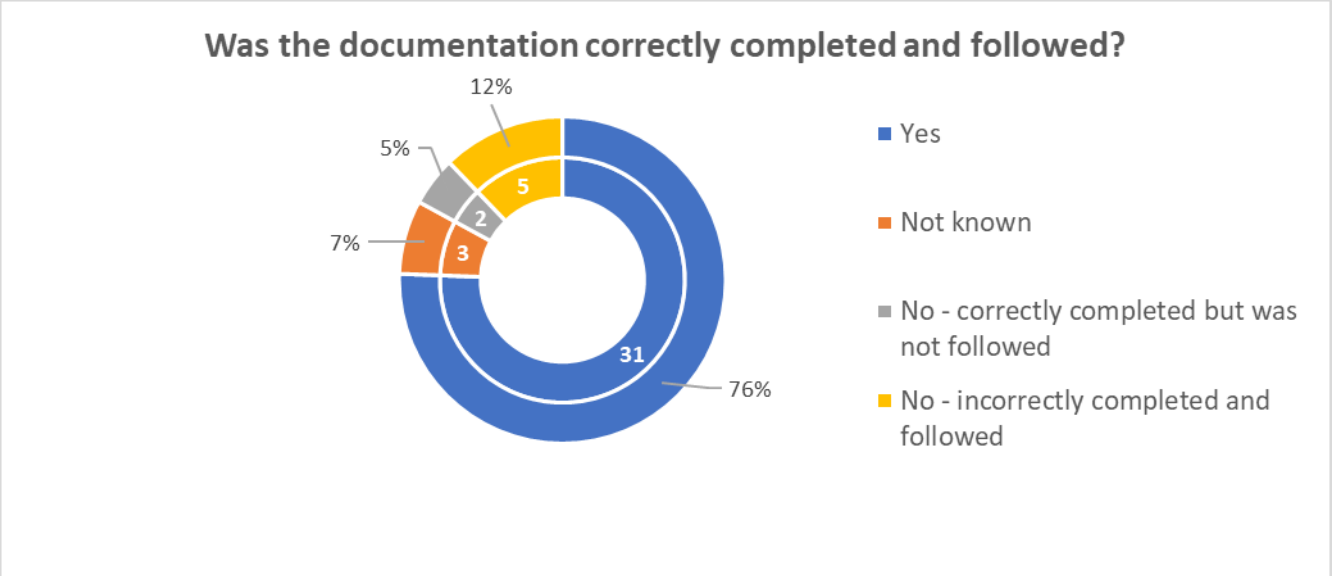
For the 2024/25 period, of the 52 completed LeDeR reviews for people with learning disabilities, the information captured shows:-

41 individuals had a DNACPR in place, 11 did not have a DNACPR in place.

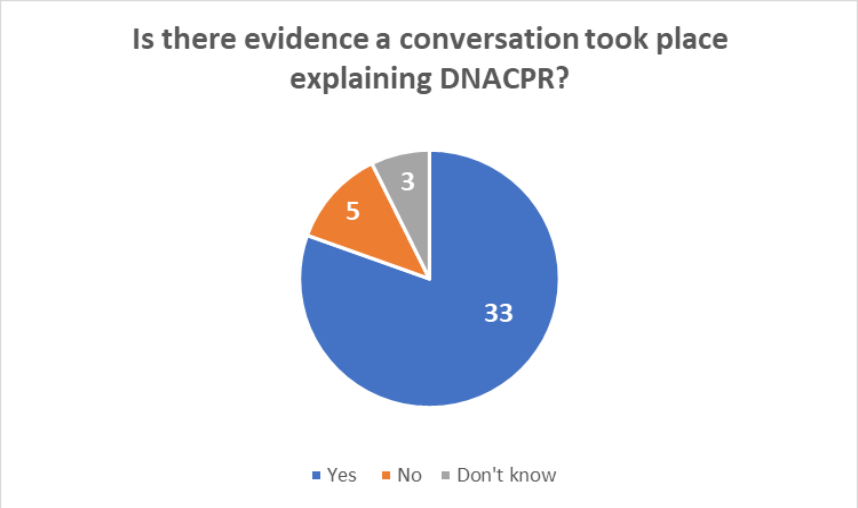



**Review of DNACPR Conversations and Documentation**

Of the 41 individuals who had a DNACPR in place:-



Out of the 41 cases reviewed where a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision was in place, evidence of a conversation explaining the DNACPR was found in 33 cases, representing 80% of the total. In contrast, 5 cases (12%) showed no evidence of such a conversation, while 3 cases (7%) could not be assessed due to the ReSPECT plan not being reviewed and no relevant information being provided during discussions with the reviewer.



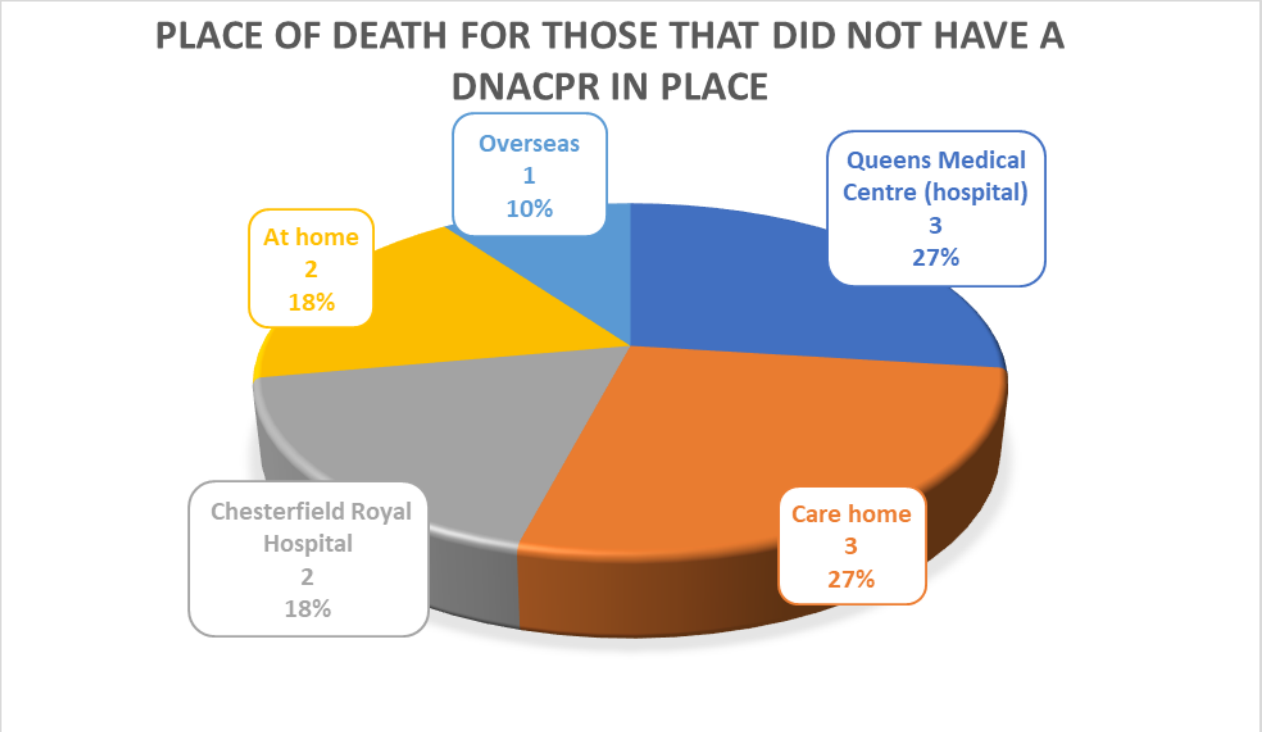

Further analysis revealed that 27 reviews (82%) included documentation of the DNACPR conversation both in the clinical records and on the ReSPECT plan. This marks a significant improvement from the previous year's figure of 58%, likely attributable to the extensive training initiatives conducted across Derbyshire. These efforts have aimed to enhance understanding of the ReSPECT process and the importance of accurately recording DNACPR-related discussions.

Additionally, 9 reviews provided evidence that the individual had capacity and was actively engaged in the DNACPR discussion and decision-making process. However, in many cases—particularly those involving hospitalised individuals—patients were either too unwell or lacked the capacity to participate in these conversations.

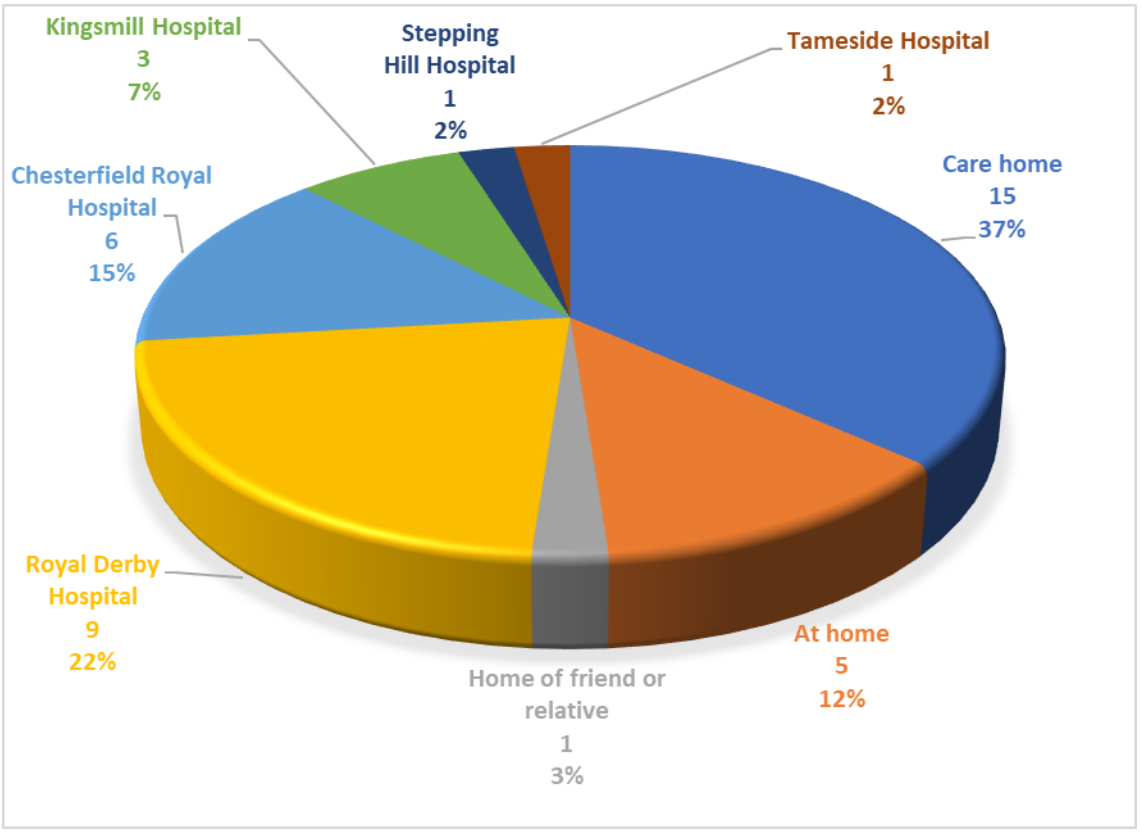
**Places of death**

Among the 11 individuals who did not have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place at the time of their death, 5 died in hospital settings. Of these, only 2 deaths occurred at Derbyshire hospitals, specifically at Chesterfield Royal Hospital. Notably, no deaths without a DNACPR order were recorded at Royal Derby Hospital.

This represents a significant improvement compared to the previous year, particularly for Royal Derby Hospital, which had previously reported 46% of hospital deaths without a DNACPR in place. The marked progress is likely attributable to the extensive training initiatives implemented across hospitals in Derbyshire and throughout the wider Derbyshire System. These efforts have focused on improving understanding and compliance with DNACPR protocols and ensuring appropriate documentation is in place.




Among individuals who had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place at the time of death, the most common place of death was a care home, accounting for 15 cases. This was followed by Royal Derby Hospital, where 9 individuals died in hospital. Additionally, 6 deaths occurred at Chesterfield Royal Hospital, and 5 individuals died at home.



**DNACPR and ReSPECT Process: Observations from LeDeR Reviews**

***Areas of Poor Practice Identified***

The following concerns were noted in relation to DNACPR decision-making and documentation in some the reviews:

**Lack of involvement:** No evidence was found to indicate that the individual or their family had been involved in discussions or decisions regarding DNACPR.

**Delayed communication**: Families reported that the DNACPR decision had not been explained to them until after the individual's death.

**Unclear terminology:** Terms such as "ceiling of care" and "ward-based care" were used in documentation, but these were not clearly defined and may not be easily understood by all parties involved.

**Documentation gaps**: ReSPECT forms were not consistently available at the time of review, limiting the ability to assess the decision-making process.

***Examples of Good Practice Observed***

Despite the concerns noted above, several examples of good practice were identified through the LeDeR reviews:

**Use of IMCA:** In cases where individuals had no family or next of kin, an Independent Mental Capacity Advocate (IMCA) was appropriately involved in best interest decisions regarding hospital admission and life support.

**Dynamic documentation:** ReSPECT plans were updated and reviewed in response to changes or deterioration in the individual's condition.

**Family involvement:** Evidence was found of conversations held with family members and their involvement in completing the ReSPECT documentation.

**Supportive families:** Families were seen to be actively supporting individuals through the decision-making process.

**Accessible communication:** Some reviews showed evidence of appropriate and accessible communication methods being used to aid understanding for individuals and families.

*Conclusion*

The review of ReSPECT and DNACPR processes through LeDeR across Derbyshire highlights significant progress in education, clinical practice, and documentation. Notable improvements include increased evidence of patient and family engagement in decision-making, improved completeness of documentation, and strengthened digital integration supporting real-time availability of plans. The reduction in deaths without a DNACPR order, especially within hospital settings such as Royal Derby Hospital, further reflects the positive impact of targeted training and system-wide collaboration.

However, persistent challenges (such as inconsistent terminology, occasional gaps in documentation, and

limited opportunities for individual or family involvement) underscore the need for ongoing quality assurance and continuous professional development. Addressing these areas, along with ensuring sustainable funding for education, will be essential for maintaining momentum and ensuring that ReSPECT remains a person-centered, dynamic process that adapts to patients' changing needs.

Overall, Derbyshire's commitment to embedding ReSPECT as a core component of emergency care planning is evident, with lessons learned from LeDeR informing further improvement.

# LeDeR High Impact Actions

The LeDeR High Impact Actions set across the Midlands region continue to be a priority across the Derbyshire System. These are:-

1. Reduce avoidable mortality in the 3 clinical priority areas (respiratory, cancer & heart diseases) for Learning Disability and Autism

2. Focus on co-morbidities associated with premature death and DNACPR/RESPECT

3. Assure and Sustain Performance
    a. LeDeR review completion within 6-month KPI (Understanding, addressing and monitoring variation in performance across the region)

4. Improve the quality of LeDeR reviews and actions from learning
    a. Facilitate peer review opportunities

5. Improve access and understanding of importance of LeDeR reviews
    a. Communicating more with stakeholders encouraging referrals to LeDeR to better understand the experience of LeDeR for families and relevant others particularly minority ethnic groups and autistic people

6. Improve accuracy of Learning Disability Registers & Increase the quality and uptake of the annual health check
    a. To support continued improvements in data accuracy for thematic analysis
    b. Improve the quality of annual health checks

# National work - Deep Dives and Publications that have arisen from LeDeR

The LeDeR academic partnership led by Kings College London regularly undertakes more in-depth and extensive investigations (“deep dives”) to gain insights into key areas to improve our understanding of the health needs and service improvements needed for people with a learning disability and autistic people. Working in collaboration with NHS England, the academic partnership has investigated several different topic areas that have impacted policy, guidance, and service provision across England.

Much of this work uses LeDeR data directly. Some, however, use LeDeR findings as a starting point for further investigation and may use other datasets or gather new information to explore specific questions regarding the health and care of people with a learning disability or autistic people further. The published reports, known as deep dives, can be found in full on their website at Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) | King's College London

**Special thanks** to the following people who have been involved in producing this report and the easy read version of the report:-

Our LeDeR expert by experience – Dan W

LeDeR team

LeDeR Steering Group and Governance Panel members across the Derbyshire system

# References

National LeDeR Policy 2021

Joined Up Care Derbyshire (JUCD) website

Office of National Statistics, 2021 Census

Population and Person insight data/dashboard

LeDeR national report - 2023

# Appendix 1 – Derbyshire LeDeR Performance Report (4 pages)

# LeDeR Performance Report

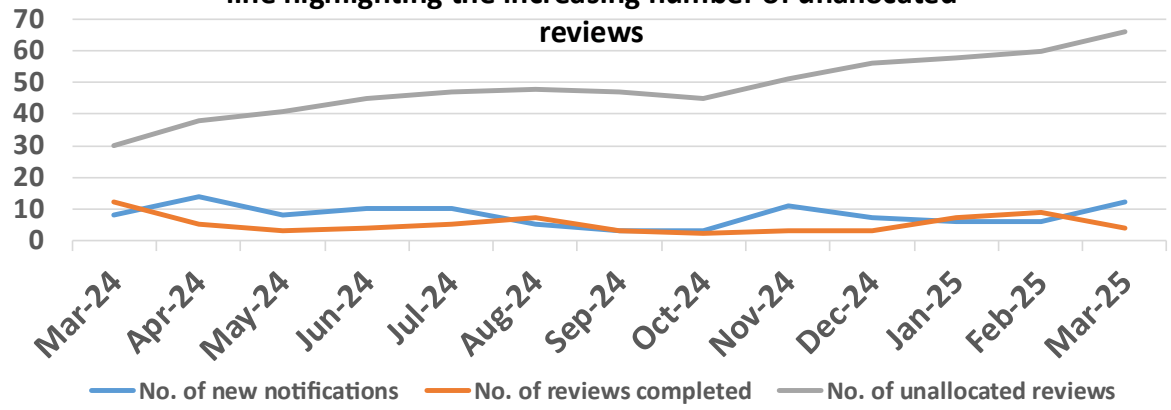
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

## Data to 31st March 2025

| Key Highlights/ Issues | Details | Mitigations |
|---|---|---|
| INCREASING NUMBER OF UNALLOCATED REVIEWS – at 31/3/25 there are 66 unallocated reviews | **NOT ENOUGH REVIEWER CAPACITY LEADING TO HIGH NUMBER OF UNALLOCATED REVIEWS** | Global shout out to ICB staff to be LeDeR Reviewers - No volunteers<br><br>Previously had some funding to use external reviewers -funding now fully spent<br><br>Escalated through LeDeR Steering Group/Governance Panel - no system solutions found<br><br>To be presented/escalated at MH/LDA Board in April 2024 |
| 35% of reviews to be completed as focused reviews (NHSE target) | Latest performance as per NHSE for Derbyshire is 32%. Latest info available as at 31/3/25. | |
| 100% of reviews to be completed in 6 months (NHSE target) – unable to meet target due to limited number of reviewers and increasing numbers of unallocated | Currently at 26% (this is taken from NHSE figures over a 6 month rolling period – latest data available at 31/3/25) | |

Number of new notifications received (blue line) compared to number of reviews completed (orange line) - top grey line highlighting the increasing number of unallocated reviews




Proportion of All reviews completed within 6 months of Notification (6 month rolling period) - Derby and Derbyshire ICB

Date of extraction

31/03/2025

# Executive Summary

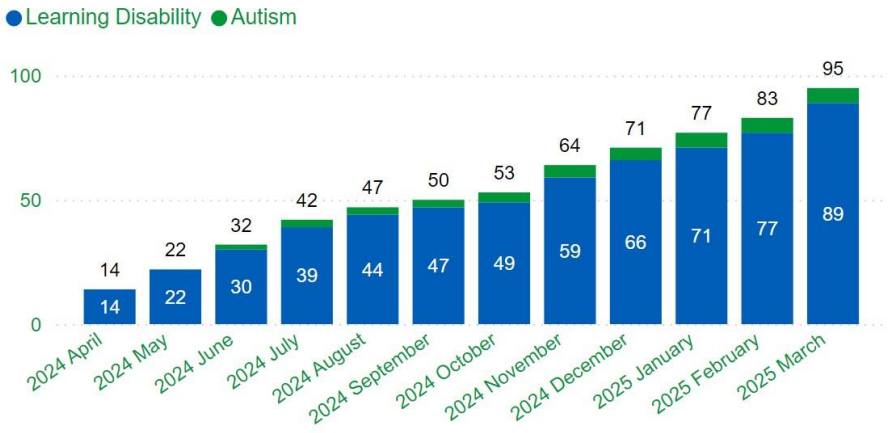
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

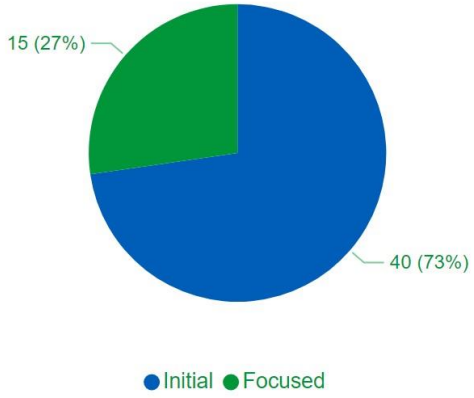
Current Totals for the 24/25 year – from April 2024

| 95 | 55 | 29 | 53% |
|---|---|---|---|
| Total Notifications 24/25 | Total Completed 24/25 | Total Completed in 6 months 24/25 | % Completed in 6 months |

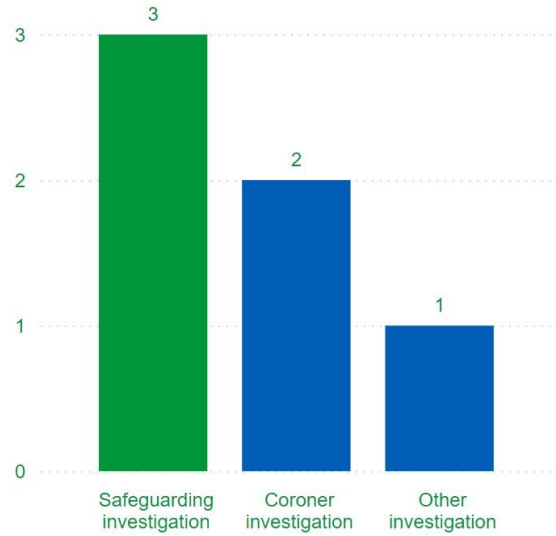
## Cumulative Total of Notifications received from April 2024 split by Autism only and LD




## Total number of completed reviews from April 2024




## Reason for on hold



Date of extraction

31/03/2025

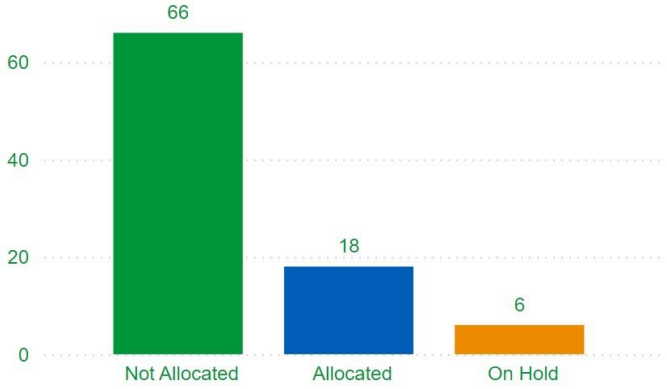
# Introduction of new LeDeR Platform since March 21

Joined Up Care Derbyshire

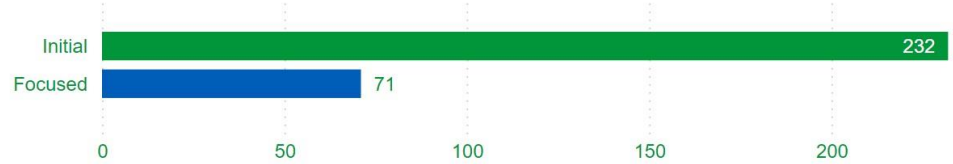
NHS Derby and Derbyshire Integrated Care Board

## Current Status of Reviews by Reviewer

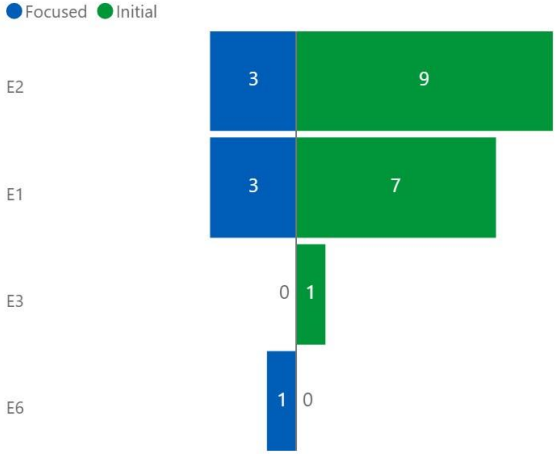

## Current reviews by status



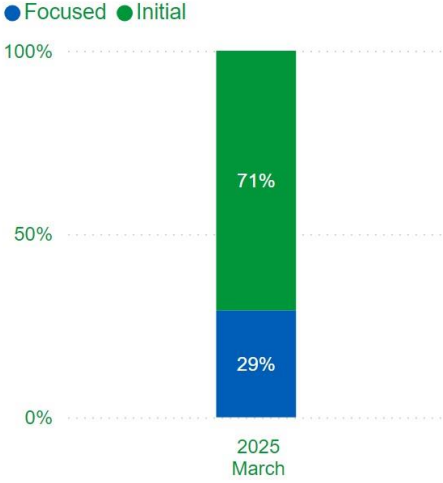

## All Reviews (completed and in progress) since March 2021



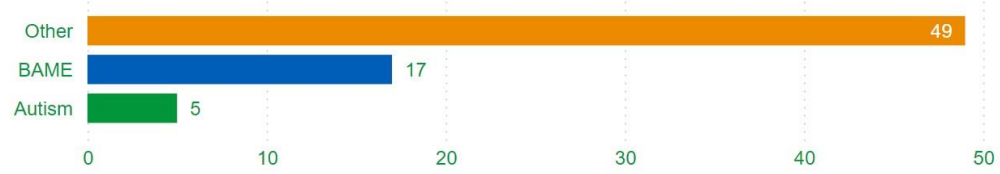

## Type of Review by Reviewer in progress




## Reviews currently in progress




## Breakdown of completed and in progress focused reviews since March 2021



Date of extraction

31/03/2025

# Overall Position

Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Since 2017 the start of the LeDeR program

**520**

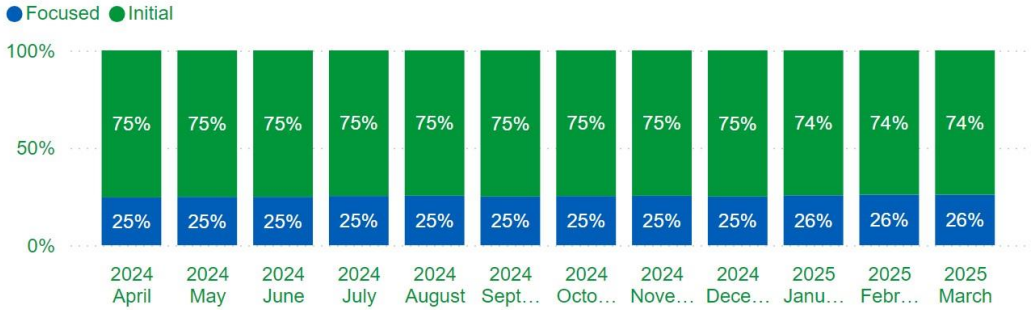
Total Number of notifications since 2017

**429**

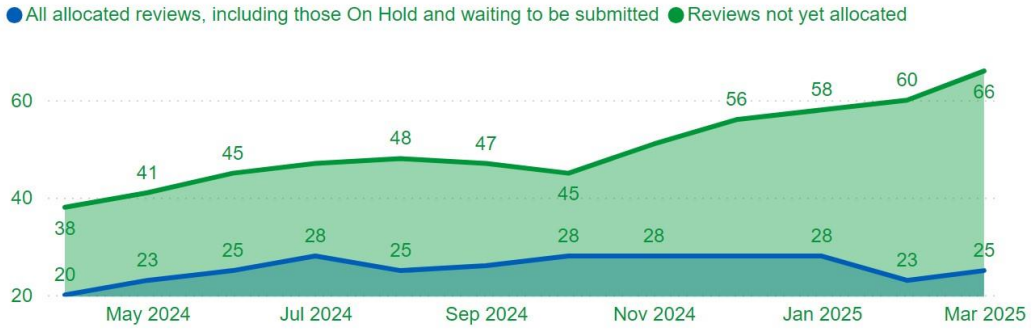
Total Completed since 2017

Graphs show a rolling 12 months but can be amended with the Date of extract filter >>

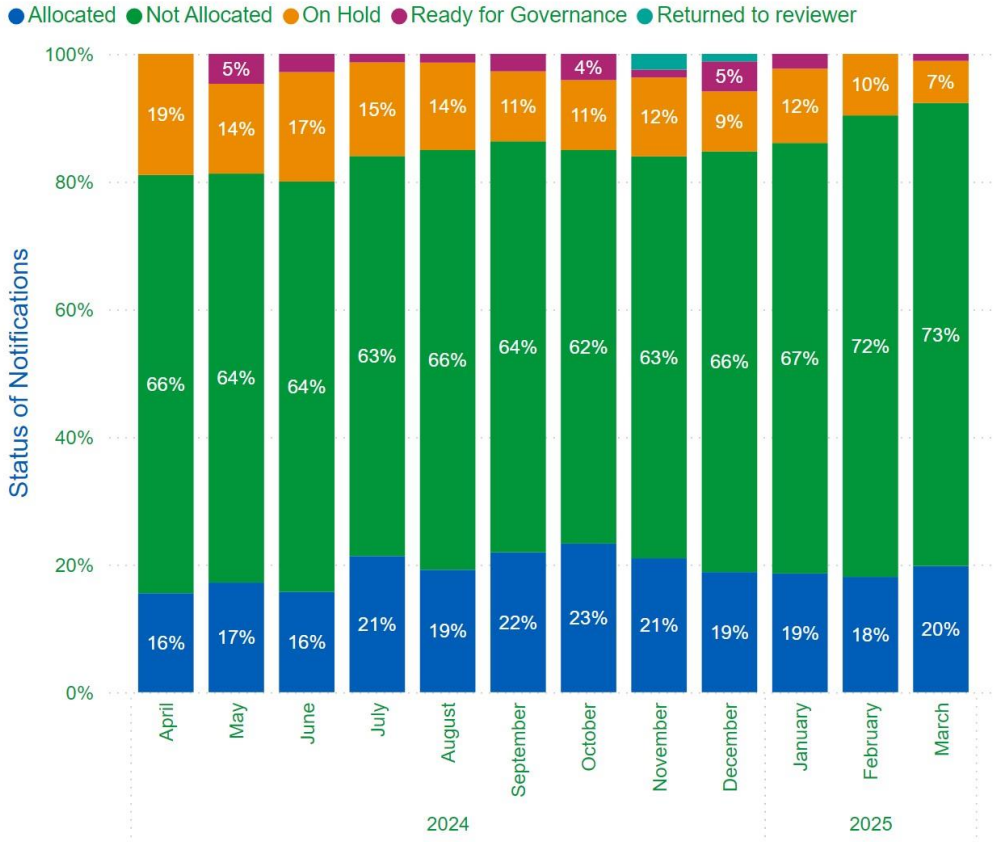
## Type of Review Completed since March 2021



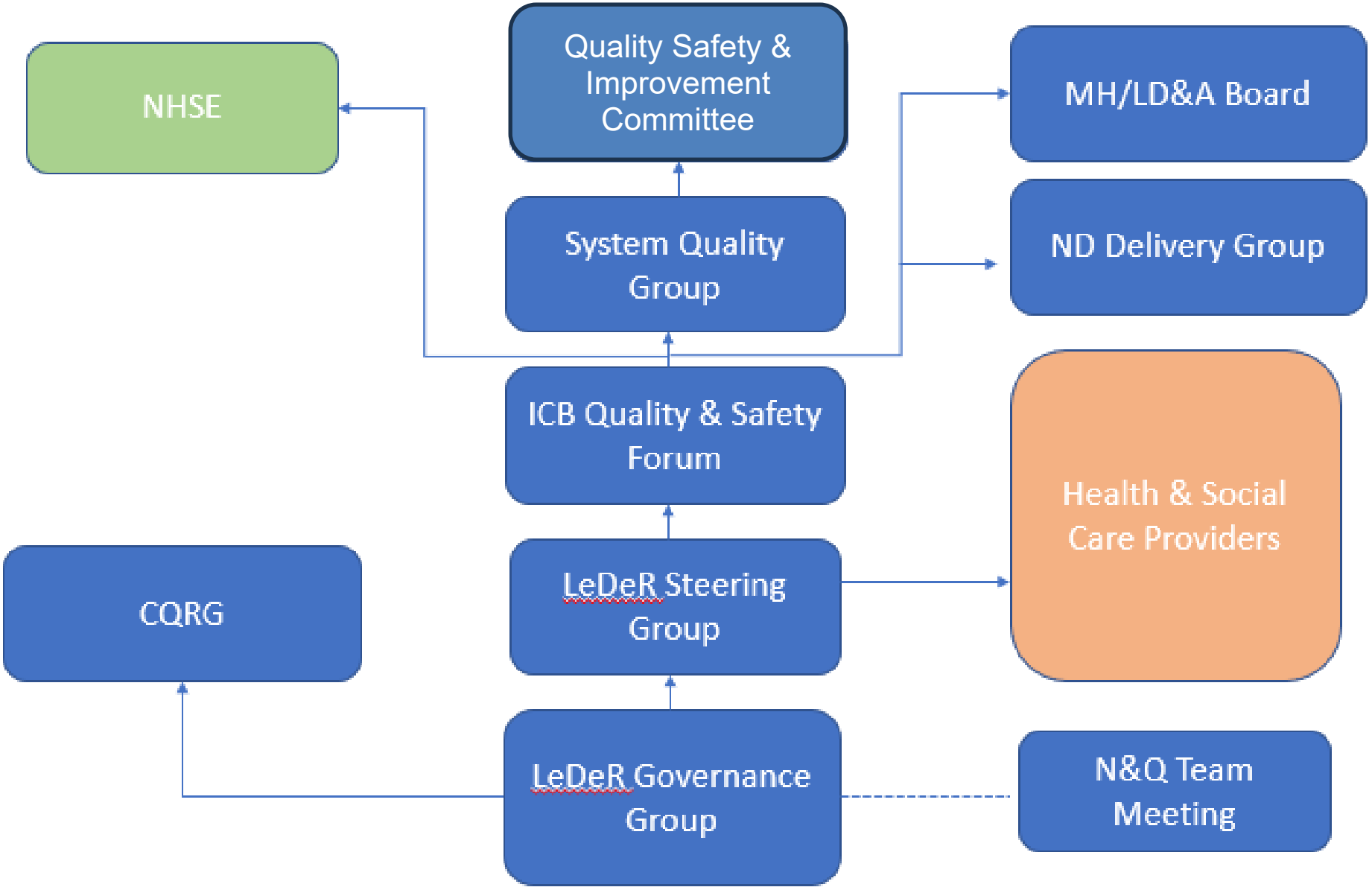

## Comparison of notifications received but not yet allocated against allocated reviews (including On Hold reviews)



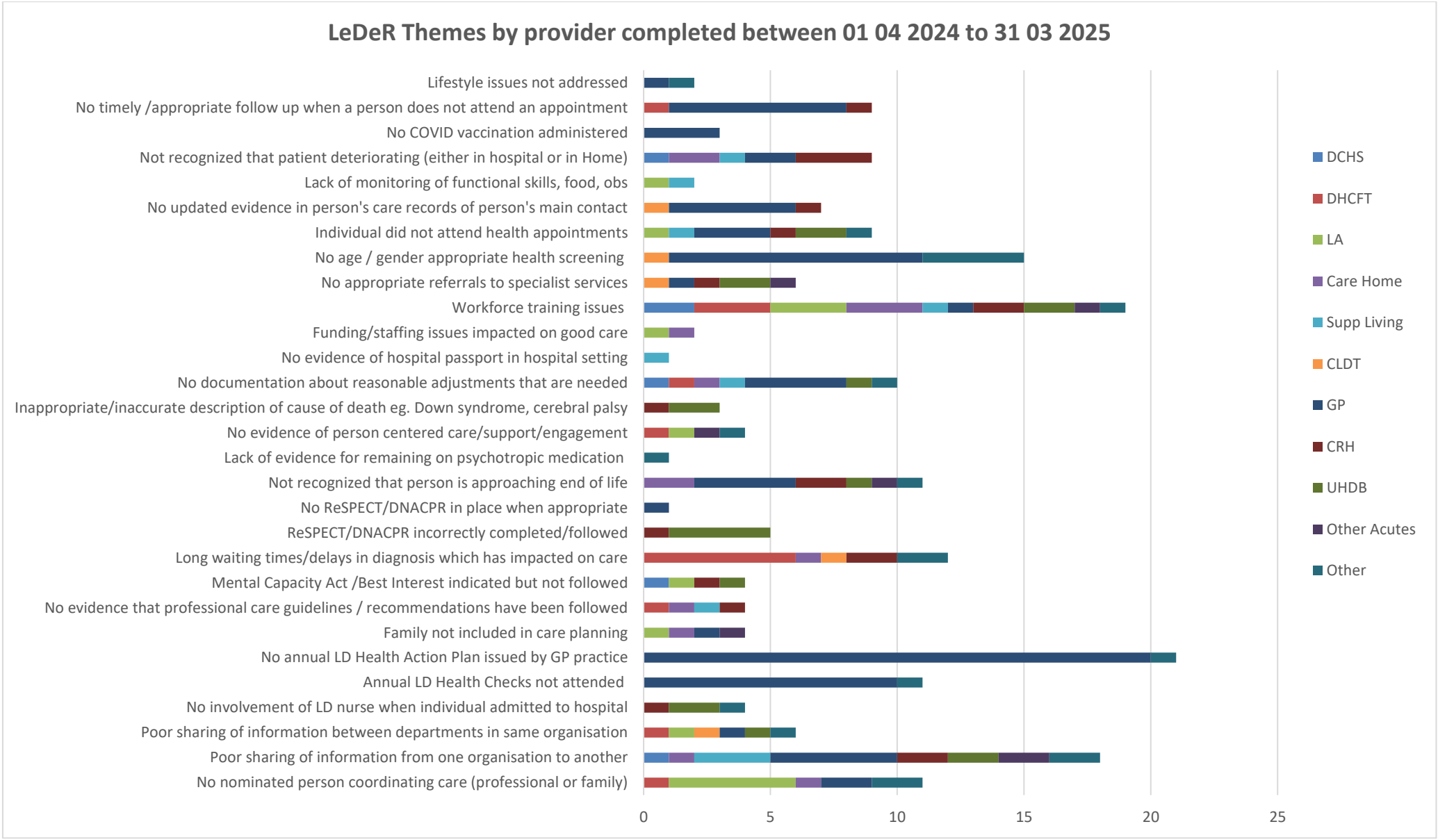

## Current Reviews by Status



# Appendix 2 – LeDeR Governance Structure



# Appendix 3 – Derbyshire LeDeR Themes Graph for learning disability reviews



# Appendix 4 – Derbyshire LeDeR Themes Graph for autistic (no learning disability) reviews