NHS Nottingham and Nottinghamshire

LeDeR Programme Annual Report 2024–2025

Contents

Introduction and Foreword

Welcome to the NHS Nottingham and Nottinghamshire Integrated Care Board (NNICB) LeDeR Programme Annual Report for 2024–2025.

This year, the LeDeR programme has continued to grow in both maturity and impact. We have built on previous years' success by embedding systemic improvements, learning from reviews, and further personalising care for people with a learning disability and autistic people.

The LeDeR team, now fully established with permanent staff, has demonstrated our commitment to sustained quality improvement and timely learning. We have maintained strong performance against NHS England Key Performance Indicators and ensured that our SMART actions are increasingly specific, meaningful and responsive to the needs of local people.

We remain dedicated to partnership working to sharing learning widely across the system, and to acting as advocates for equitable care. The insights from bereaved families and carers remain invaluable in shaping our response and direction. Together, we will continue to drive change that saves lives and improves quality of life.

We thank every family, professional, and partner organisation who has contributed to this essential work.

Rosa Waddingham
Learning Disability & Autism Senior Responsible Officer
NHS Nottingham and Nottinghamshire ICB

Progress against 2024–2025 Objectives

Objective	Actions Undertaken	Outcome	Next Steps
Complete all reviews within the NHS England 6-month KPI timeline	Regular debriefs and proactive review allocation. Improved access to GP/hospital records. Increased use of internal QA processes.	Achieved an improved quarterly KPI performance.	Continue balancing initial and focused reviews to maintain completion rates without sacrificing quality.
Increase autism-only case notifications	Targeted outreach, publicising need for ASD notifications. Coordination with Equality, Diversity and Inclusion (EDI) teams.	ASD only notifications increased to 3 in 2024–25 (vs. 1 in 2023–24).	Continue public awareness campaigns and stakeholder engagement on autism-focused reviews.
Improve SMART action feedback to care providers	Redacted reviews shared with providers alongside new feedback assurance forms.	Positive engagement from providers. Evidence of policy changes and professional development in response to feedback.	Increase responses from acute trusts. Maintain high-quality feedback and monitor implementation.
Support system-wide learning around SUDEP, suicide and serious incidents.	Initiated collaboration with SUDEP Action. Agreed suicide prevention data sharing between LeDeR, safeguarding, and police teams.	Two reviews led to Serious Adult Reviews (SARs). Learning from incidents fed into system-level panels.	Continue information exchange. Maintain SAR triggers within review QA panels and share learning.
Enhance review quality with interdisciplinary governance input	Panel now includes pharmacy, safeguarding, physical and mental health and Learning Disability nurses.	Quality of SMART actions improved. Broader, more precise learning themes recorded.	Maintain reviewer training and governance diversity. Continue embedding feedback into provider development plans.

Key Achievements

During 2024–25, the NHS Nottingham and Nottinghamshire LeDeR Programme achieved several important milestones:

• Permanently appointed LeDeR reviewers, adding stability and continuity to the programme.

• Increased the proportion of reviews completed as focused reviews, ensuring deeper learning and actionable insights.

• Implemented assurance feedback forms to ensure providers acknowledge and respond to recommendations.

• Launched a multi-agency suicide prevention process, facilitating information sharing and early intervention.

• Supported two Serious Adult Reviews (SARs) based on concerns identified through LeDeR reviews.

• Continued robust engagement with SUDEP Action to improve awareness and system response to epilepsy-related deaths.

• All members of the LeDeR Team completed Oliver McGowan Mandatory Training.

• Maintained strong governance over the quality of LeDeR reviews utilizing the experience and knowledge of a multidisciplinary panel which includes pharmacy, safeguarding, and specialist nursing.

• Continued to embed SMART actions and learning across the system via partnerships and structured dissemination.

The LeDeR Team

The LeDeR Programme in Nottingham and Nottinghamshire has grown significantly during 2024–25. We now have a dedicated team consisting of the following individuals:

- Jonathan Sansome RN – Quality and LeDeR Programme Manager / Local Area Contact
- Kirstie Charlesworth – LeDeR Programme Administrator
- Jo Johnson RN – LeDeR Reviewer
- Sarah Edwards RMN – LeDeR Reviewer

Our LeDeR Reviewers are permanently employed, and both have made a substantial contribution to the LeDeR Team by improving the quality, consistency and insightfulness of reviews. Their membership in wider system groups — including the Physical Health Steering Group, helps ensure that learning is shared effectively and embedded across the system.

Our ICB LeDeR reviewers regularly liaise with health and social care services to raise awareness of the LeDeR programme and ensure learning reaches front-line practice. Through collaborative working, review feedback and co-production with people with lived experience, the team continues to influence improvements that reduce inequalities and improve the care of people with a learning disability and autistic people.

LeDeR Governance Arrangements

The governance of the LeDeR programme in Nottingham and Nottinghamshire is overseen by the Physical Health Steering Group (PHSG), which is part of the LDA Ageing Well workstream. The PHSG meets bi-monthly and includes representation from the ICB, NHS organisations (primary care, community and acute), local authorities, GPs, and Experts by Experience.

The LeDeR Governance Panel is a dedicated multi-professional group that reviews completed LeDeR reviews. It includes specialist nurses (learning disabilities, mental health, physical health), pharmacists, and safeguarding professionals. This ensures the review process benefits from a broad clinical and professional perspective.

The Governance Panel plays a key role in:

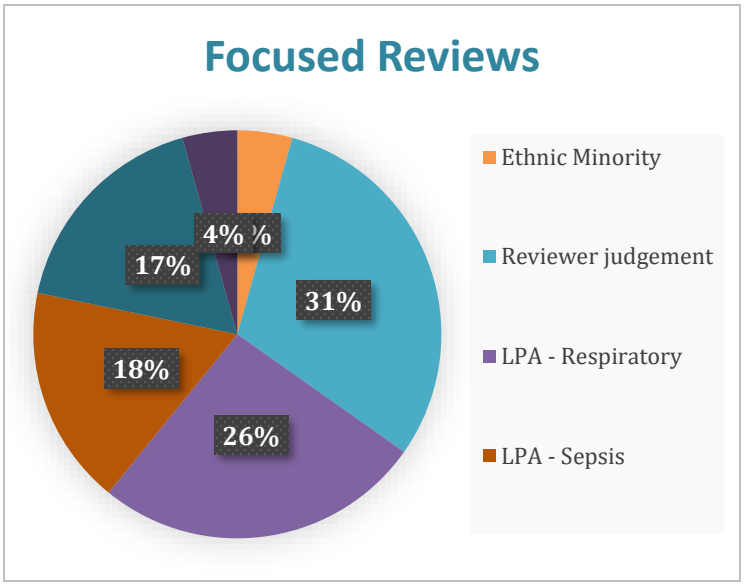
- Quality assuring reviews
- Identifying learning themes and good practice
- Recommending SMART actions
- Informing system-wide improvement initiatives

Themes and actions identified are then shared through the Physical Health Steering Group and other system governance forums including the ‘Learning From Deaths Forum’, the ‘Realtime Suicide Surveillance Working Group’.

Each review is also shared in a redacted format, directly with all care providers that were involved in the person’s care.

This helps ensure that lessons learned from LeDeR reviews are embedded into practice and aligned with safeguarding, serious incident reviews, and wider system priorities.

Focused Reviews



Focused reviews offer a deeper examination of cases, enabling the capture of richer data and more detailed learning. They are undertaken based on national criteria or local priority areas.

This chart illustrates the proportion of reviews completed as 'initial' versus 'focused'. Over half of the reviews were focused, exceeding the NHS England target.
National criteria for a focused review include:
• Autism-only cases
• Ethnic minority background
• Family request
• Reviewer judgement of significant learning potential

Local Priority Areas for 2024–25 were:
• Respiratory
• Epilepsy
• Cardiac
• Diabetes
• Sepsis

During 2024–25:
• 50 reviews were completed
• 29 of these (56%) were focused reviews
• This exceeded the NHSE minimum requirement of 35%

Of these, 21 deaths were caused by respiratory issues, with community-acquired pneumonia being the most prevalent. A decrease in aspiration pneumonia deaths from 29% to 14% over the past 2.5 years was observed, highlighting improvement in clinical management and early intervention.

The system continues to promote the use of focused reviews where warranted, ensuring that complex cases are examined with appropriate depth and that themes from focused reviews inform local service improvement.

Statistics and Data

The following section presents a summary of LeDeR notifications and reviews conducted between April 1st 2024 and March 31st 2025.

- Total notifications received and allocated: 113
- Out-of-scope notifications: 2
- Reviews completed by year-end: 50
- Reviews on hold (e.g., due to coroner or safeguarding): 21

7 ASD only notifications were received, however reviewers found on investigation only 3 had an autism only diagnosis and should have been focused ASD only reviews. 4 incorrectly notified as they had both LD and ASD and have been amended to LD and ASD in the below.

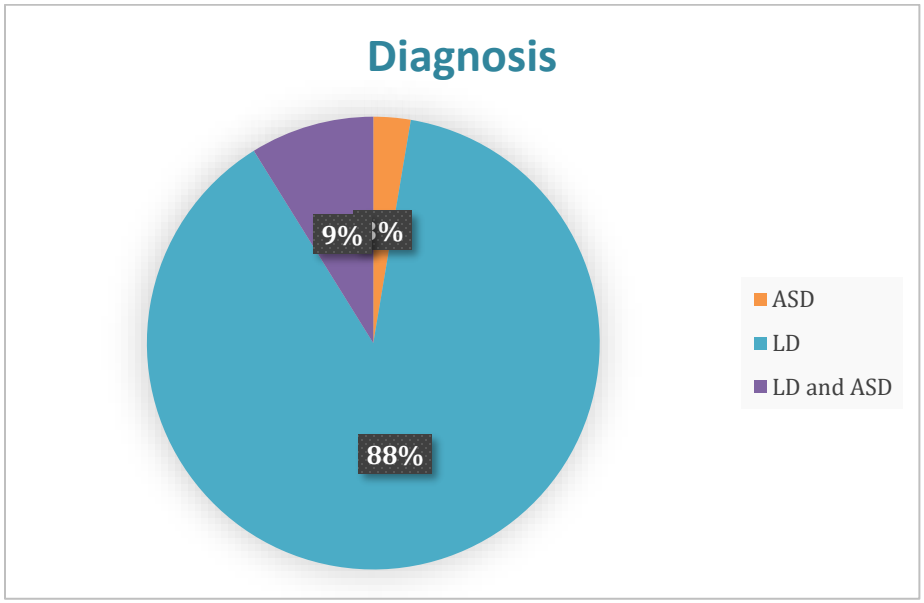
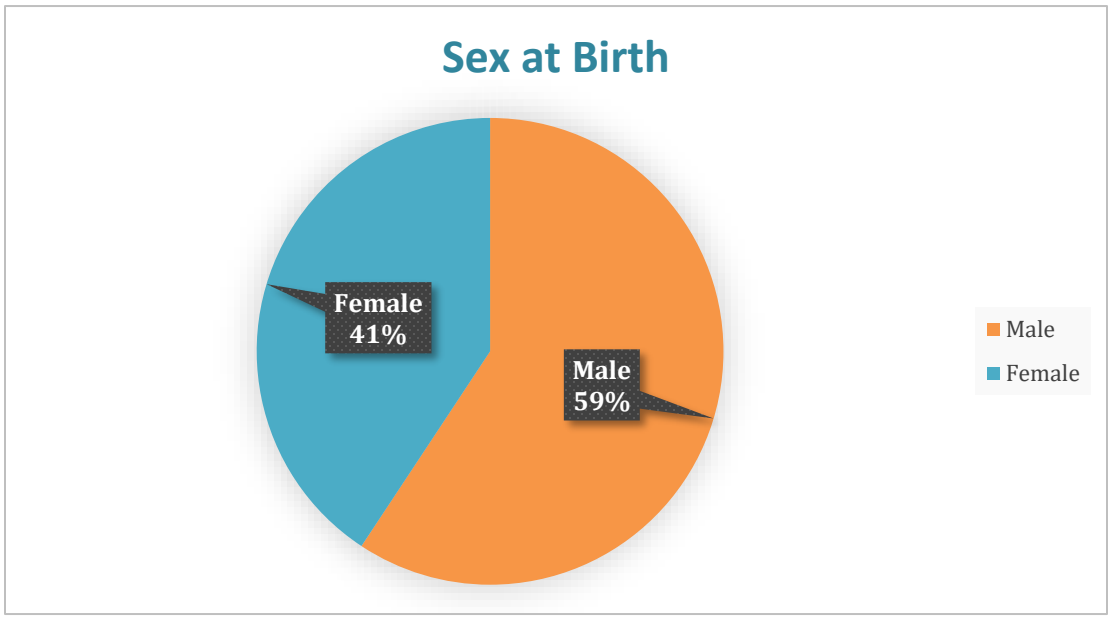
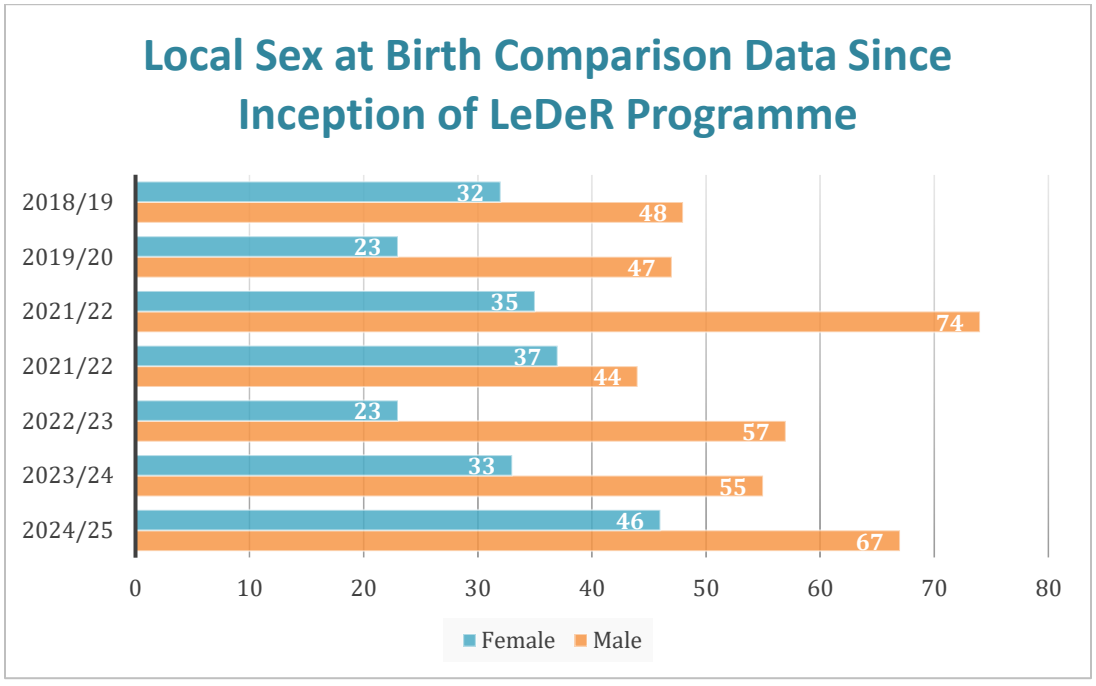


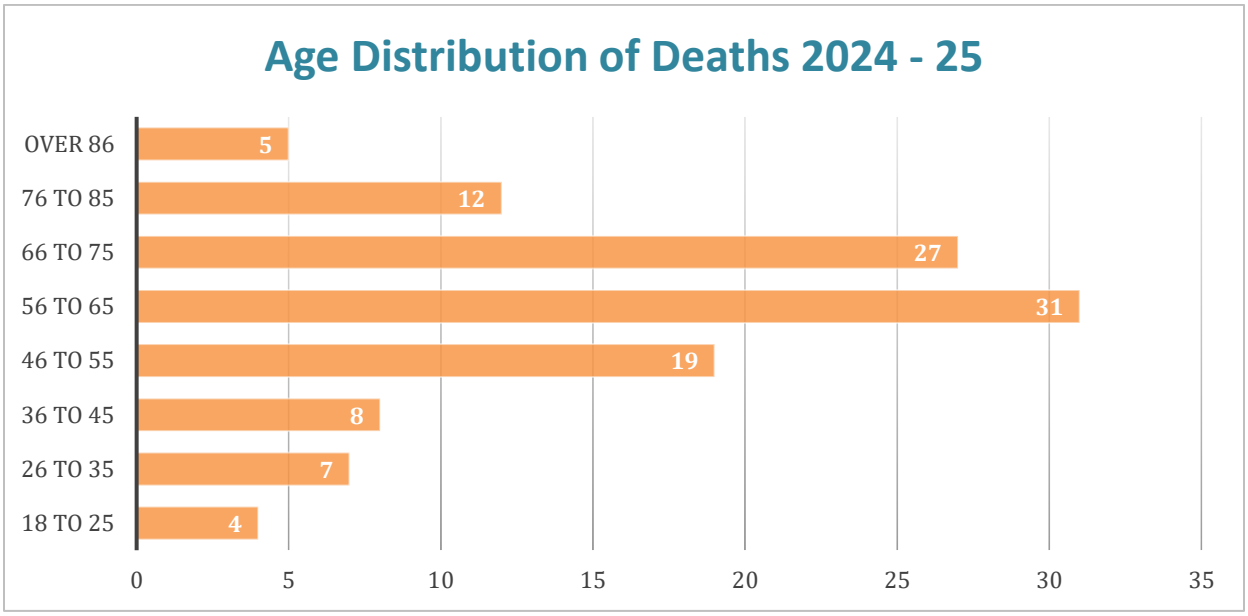
Chart shows diagnosis information from the 113 notifications received during 2024-45 with 100 LD only diagnosis, 10 LD and ASD diagnosis and 3 ASD only notifications received.

Gender and Age

Out of the 113 LeDeR notifications received the average age at death was 60 years. Gender distribution remained consistent with local population demographics: 67 male and 46 female notifications.





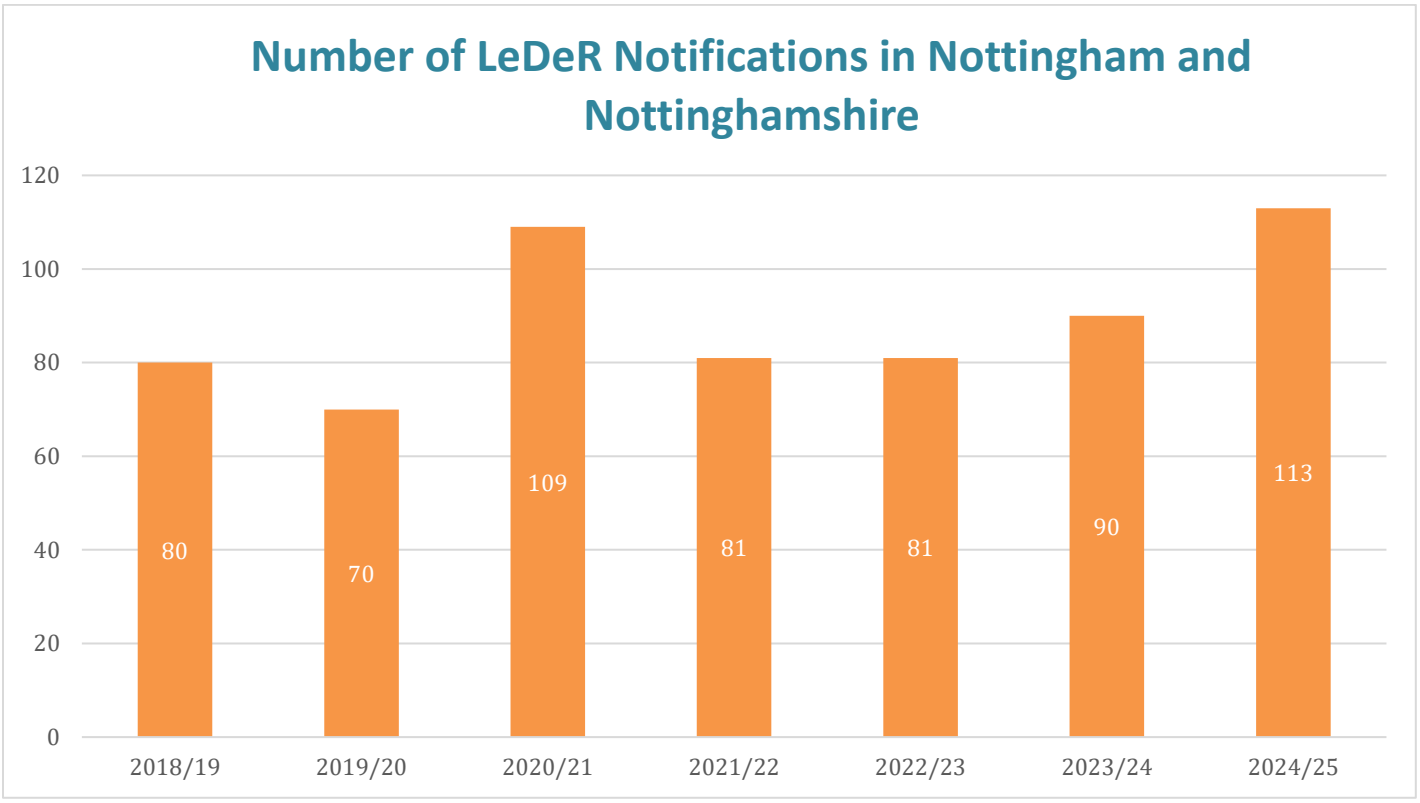


Above chart shows the age range of the notifications received. The most prevalent remains deaths between the ages of 56 to 75. The average age of death for 2024-25 is 60 years old.

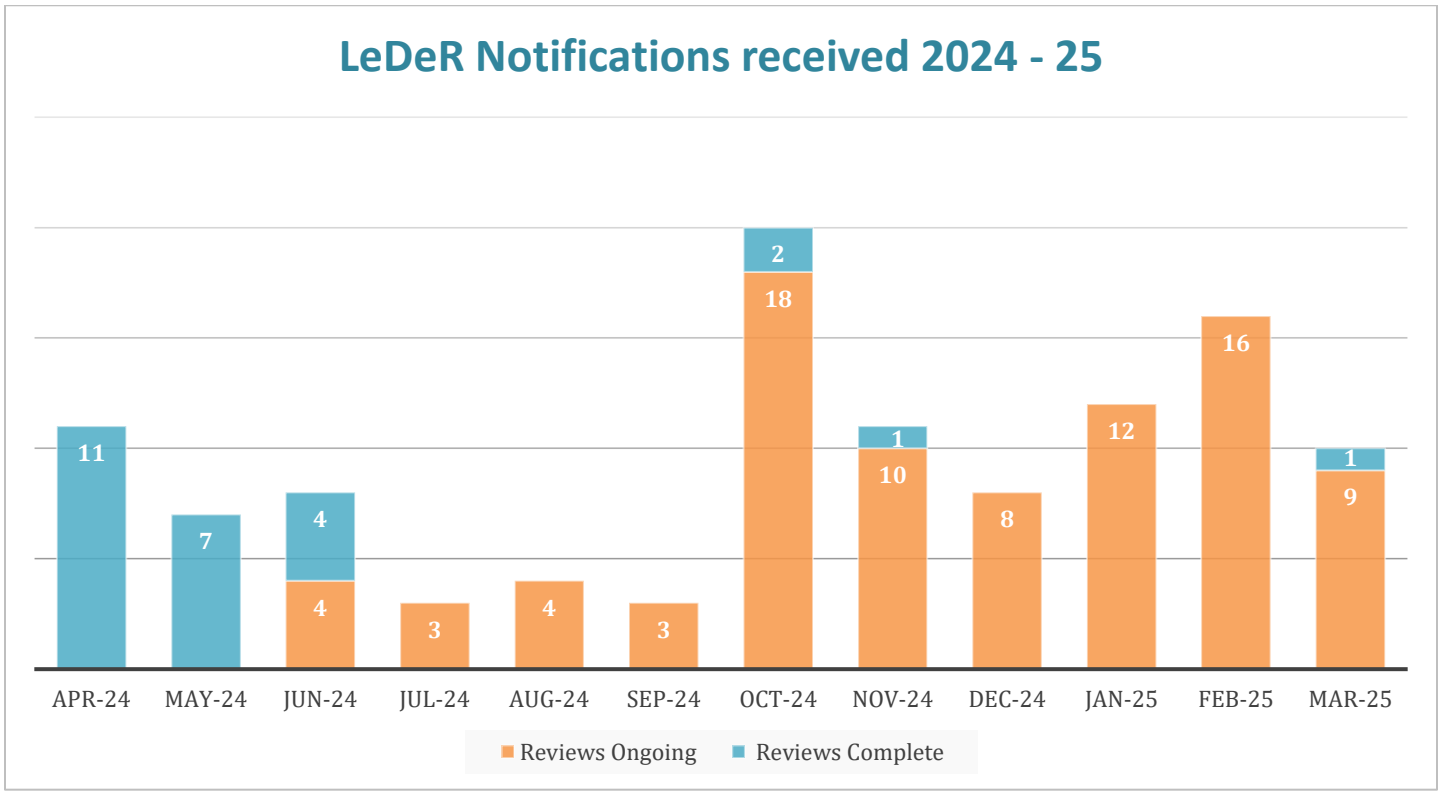
Average at death

Reporting Period	Average age of adults (over 18) at death
2024/25	60
2023/24	60
2022/23	59
2021/22	57

The average age of death of adults with learning disabilities and autistic people is increasing, showing an incremental improvement in longevity.



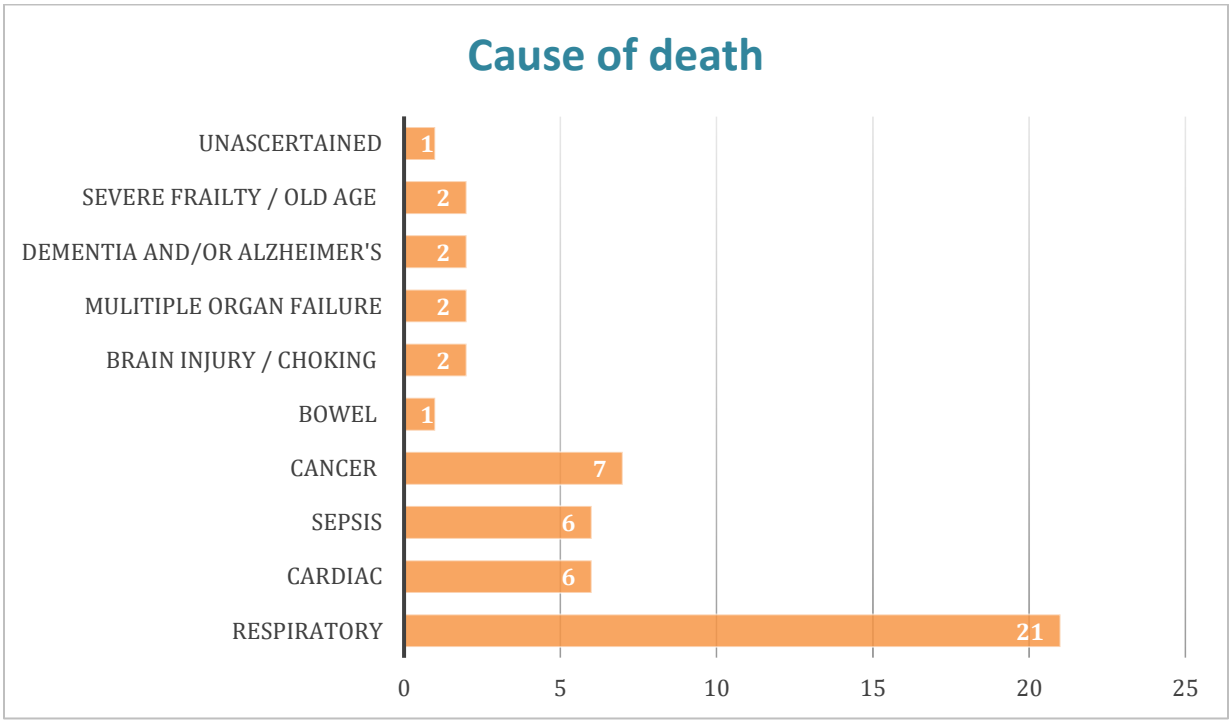
Above chart shows number of LeDeR notifications for Nottingham and Nottinghamshire over the last 7 years.



The above chart shows the number of LeDeR notifications received by month and the completed reviews shown in blue from 24-25 as of the end of March 2025.

Cause of Death

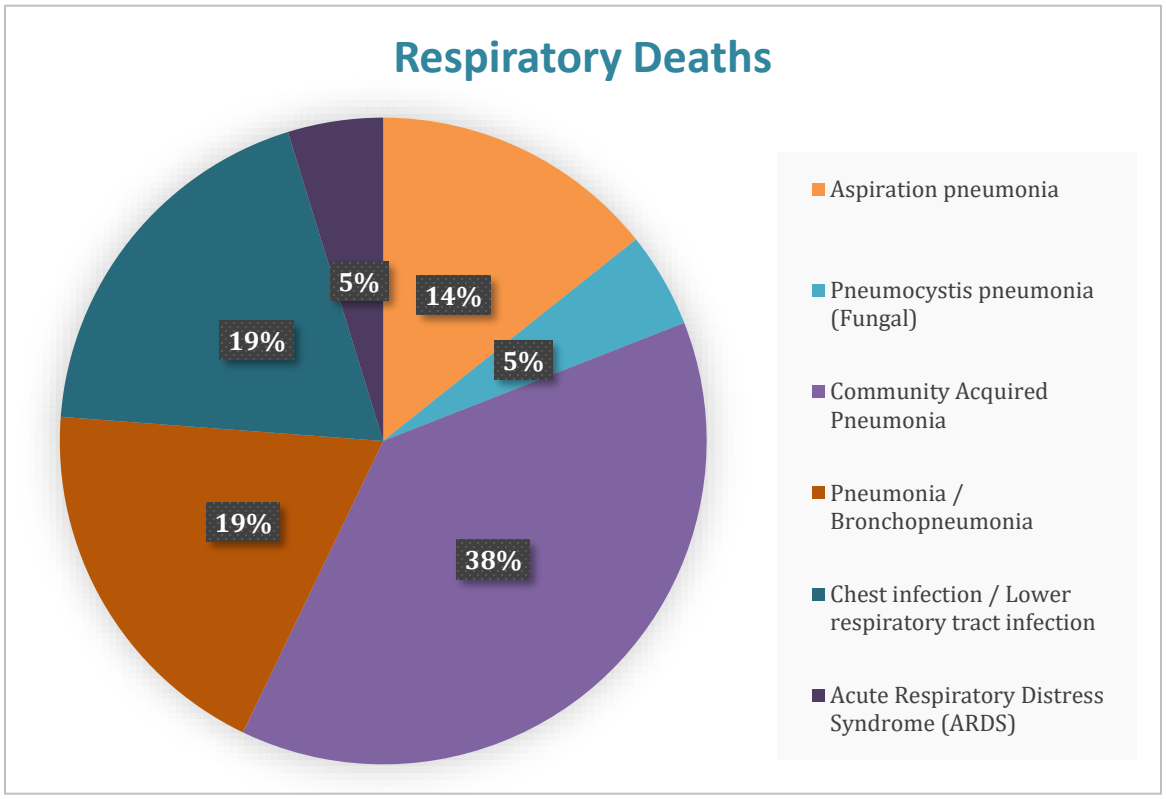
The primary causes of death among completed reviews continue to be led by respiratory issues, followed by cardiac conditions, sepsis, epilepsy, and other causes.



Data taken from 50 reviews completed between April 1st 2024 and March 31st 2025 This chart shows the primary cause of death found in these reviews. The data shows the primary cause of death, but it should be noted that many of these people had multiple comorbidities which often contributed to the cause of death.

Respiratory issues remain the highest cause of death in the cohort of people with a learning disability. There were 3 confirmed ASD notifications this year, these reviews are still ongoing.

Primary Cause of Death



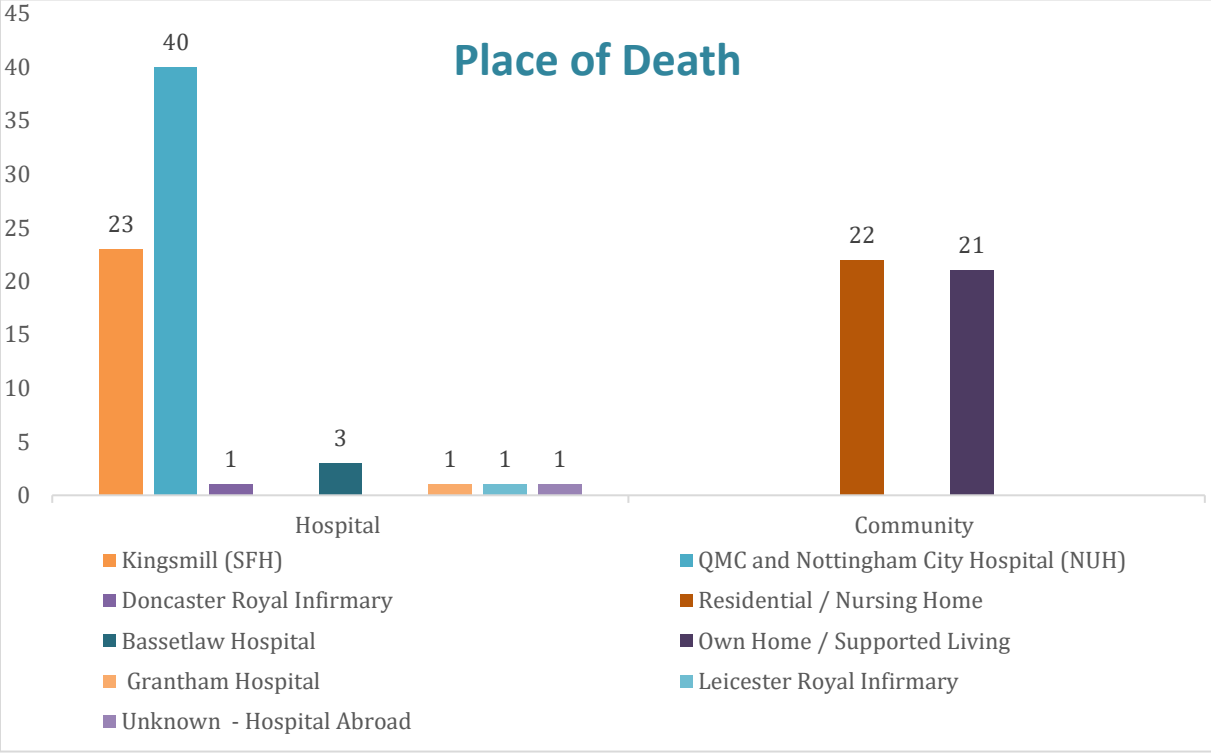
This chart shows the confirmed cause of death in 50 completed reviews in 24-25, as in previous years deaths caused by respiratory illness remain the most prevalent. However, it should be noted that many had contributing co morbidities within the cause of death.

Place of Death

The data below was compiled from the 113 notifications taken to review

From the 113 notifications received in 2024-25, Deaths occurring in hospital remains most prevalent. With 70 notifications received,

-40 deaths Queens Medical Centre and Nottingham city hospital (NUH)



-23 Deaths at Kingsmill Hospital.

-1 Death at Doncaster Royal Infirmary.

-3 Death at Bassetlaw Hospital.

-1 Death at Grantham Hospital

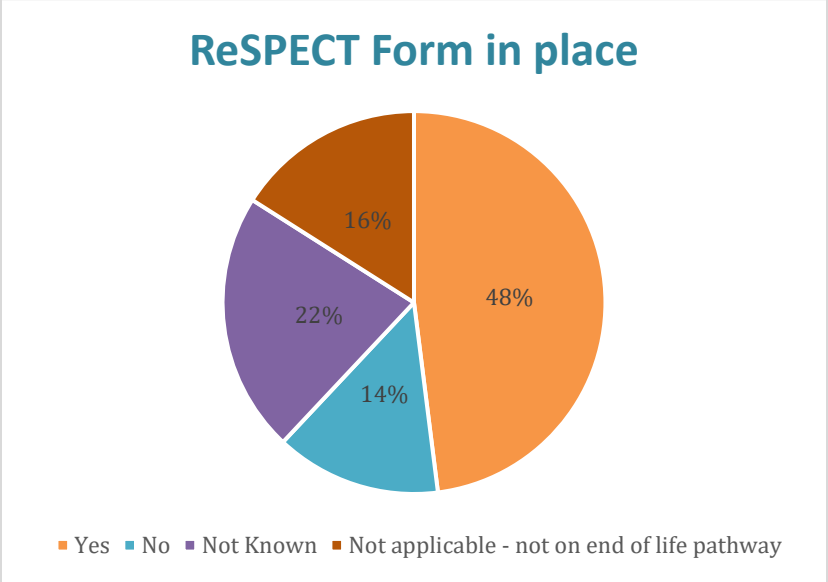
-1 Death at Leicester Royal Infirmary

-1 Death in a hospital abroad.

43 notifications have been received where deaths have occurred in the usual place of residence such as residential and nursing homes, own home/ supported living. To note the precise place of death in the community setting is often unclear until the review is complete.

Respect Forms

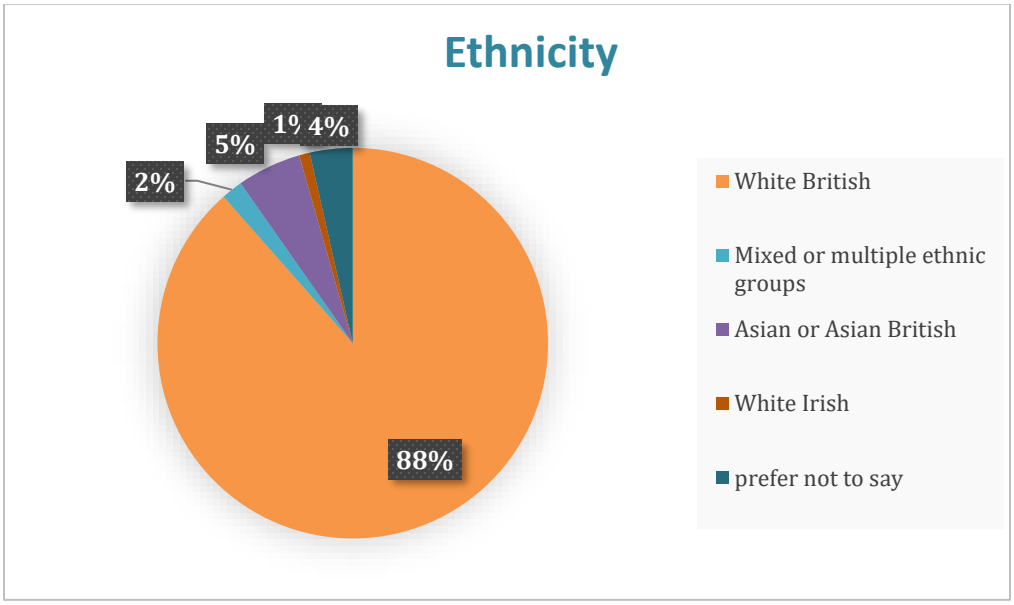
ReSPECT forms (Recommended Summary Plan for Emergency Care and Treatment) as used to show the preferred place of death - the detail of preferred place of death is not recorded in LeDeR reviews as such, the below chart shows where the individual had a respect form in place. in the sample of 50 reviews taken 48% had a respect form. There are fewer cases where there was evidence to the reviewer that palliative wishes and preferences were discussed with these being recorded in patient records.

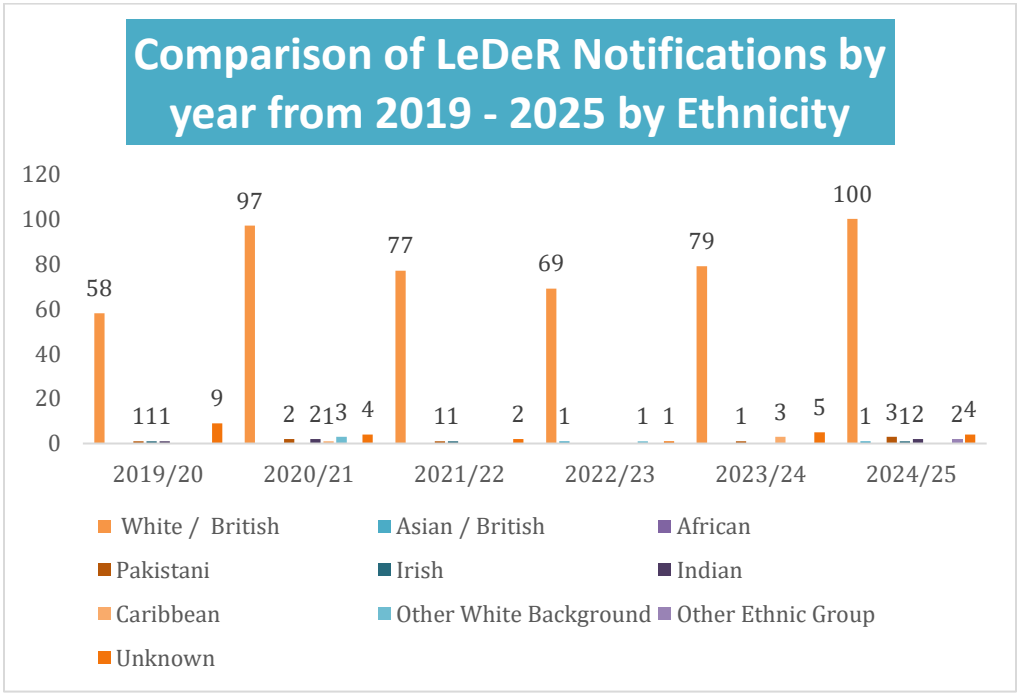


From the sample of 50 completed reviews 48% had a completed ReSPECT form in place, as identified in the LeDeR learning there were inconsistencies in the recording of respect forms. 14% were found to have no respect form in place and 22% of reviews were not known to have a respect form due to inconsistencies in recording.

Ethnicity and intersectionality

Below chart shows a breakdown of ethnicity in individuals notified during 2024-25, as in previous years notifications are predominantly White British.





Themes and Learning from Reviews

Several key themes emerged during the 2024–25 LeDeR reviews, reflecting patterns in care provision, risks and areas for improvement:

1. Respiratory Health:
• Community-acquired pneumonia was the leading respiratory cause of death.
• Aspiration pneumonia-related deaths have reduced from 29% to 14% in the past 2.5 years.
• Speech and Language Therapy (SLT) assessments proved effective when deployed early.
• Timely referral to SLT upon signs of swallowing difficulty was associated with better outcomes.

2. Cardiac Health:
• Medication combinations have been highlighted by pharmacists as a contributing factor.
• Lifestyle factors, such as diet and smoking, are consistently raised but rarely addressed proactively.
• Health education, alongside monitoring and reviews, remains a priority.

3. Epilepsy and SUDEP:
• Coordination with SUDEP Action has begun to enhance system-wide awareness.
• Deaths of people with epilepsy have prompted updates to care pathways and family education efforts.

4. End of Life and Palliative Care:
• End-of-life care was consistently well managed.
• However, documentation of ReSPECT forms and capacity assessments was variable.

5. Screening and Preventative Care:
• Gaps in vaccination uptake and screening follow-ups were noted.
• There was often no recorded rationale for missed appointments or failed engagement.

The LeDeR Programme continues to support system-wide conversations and interventions to address these themes. SMART actions derived from each review are fed back to providers to promote measurable change.

Governance and the Physical Health Steering Group

The LeDeR Programme in Nottingham and Nottinghamshire operates within Workstream 3 – 'Living and Ageing Well' and is governed through the Physical Health Steering Group (PHSG).

The PHSG provides cross-system oversight for the LeDeR Programme and plays a pivotal role in:

- Reviewing physical health services for people with a learning disability and autistic people
- Identifying service gaps and acting on learning from LeDeR reviews
- Informing future commissioning intentions and priorities
- Delivering on NHS Long Term Plan commitments, including Annual Health Checks and LeDeR KPIs
- Supporting workforce development and training needs
- Championing data-sharing protocols and safeguarding information governance
- Escalating system-wide risks and proposing mitigations where required

The PHSG is responsible for agreeing a work plan with clear deliverables and timescales. It includes representatives from primary care, secondary care, pharmacy, commissioning, safeguarding, and service user representation. It also liaises with related subgroups and task-and-finish initiatives.

Critically, the group includes Experts by Experience to ensure that the voices of people with learning disabilities and autistic people are heard and influence every stage of governance, service development, and quality assurance.

LeDeR reviews and learning feed directly into this group's agenda, enabling real-time escalation and service improvement proposals based on evidence, thematic findings, and community insight.

Annual Health Check Performance and Quality

The Nottingham and Nottinghamshire Integrated Care System (ICS) continued to perform strongly in delivering Annual Health Checks (AHCs) for people with a learning disability.

By 31st March 2025, a total of 5,684 AHCs had been completed, against a target of 5,694. This represents:

• 82% of the target based on the NHSE-set denominator (all-age QOF GP LD register)

• 80% against the E-Health Scope register for individuals aged 14 and over

Additionally, 95% of completed AHCs had an accompanying Health Action Plan (HAP), with a decline rate of 3.8%. This represents sustained engagement by Primary Care and excellent uptake across all Place-Based Partnerships (PBPs).

Notably:

• Bassetlaw achieved 84% performance, with 98% of those checks resulting in a HAP

• Mid Notts and South Notts both achieved over 80% completion

• Nottingham City recorded a slightly lower rate at 72%, with further support being planned

While performance remains high, there is growing recognition of the need to improve the **quality** of AHCs, not just the quantity.

A quality audit carried out by the ICB found that more than 50% of health checks failed to address long-term conditions or document referrals to specialist services. In some instances, pre-check questionnaires were not used, limiting the ability to identify early intervention opportunities.

This aligns with NHS England's decision to remove the AHC uptake target from the 2025/26 Operational Planning Guidance. The focus now shifts to effectiveness and quality, with the following intended impacts:

• Better identification of specialist referral need

• Increased confidence in personalised primary care

• More joined-up care systems for people with learning disabilities

• Reduced crisis presentations and hospital admissions

Each audit will inform an improvement plan and highlight both good practice and areas for development — supporting long-term reduction of health inequalities.

Improving Review Quality through Relationships and Practice

High-quality LeDeR reviews require accurate, detailed, and person-centred information. To support this, the Nottingham and Nottinghamshire ICB has focused on building strong and sustained relationships with key stakeholders across the system.

LeDeR reviewers gather data under the authority of Section 251 of the NHS Act 2006 (ref: 20/CAG/0067), which permits sharing identifiable information about deceased individuals for the purposes of service improvement. This legal foundation supports open access to records and transparency in reporting.

However, the quality of a review often hinges on more than clinical records. Much of the richest insight comes from dialogue with:

- GPs and practice nurses
- Community Learning Disability Teams
- Acute Liaison Nurses
- Residential and supported living providers
- Families and carers

The Nottingham and Nottinghamshire ICB LeDeR team has actively developed these connections. Reviewers regularly meet with providers, visit services, and maintain communication channels with primary and secondary care teams. This has resulted in more informed, honest and complete reviews, with stronger evidence underpinning each SMART action.

While LeDeR recommendations are not mandatory, responsive services are increasingly recognising their value. Engaging in the review process, contributing clinical and contextual insight, and discussing emerging system-wide themes has helped stakeholders adopt learning in real time.

This proactive approach enhances the credibility and relevance of LeDeR and strengthens its ability to shape policy, commissioning and frontline care improvements.

Review Clinic: Enhancing Review Quality and Oversight

A key innovation in 2024–25 has been the formalisation of a ‘Review Clinic’ process, held regularly by the LeDeR team.

The clinic provides a collaborative space where LeDeR reviewers bring forward cases nearing completion. These sessions allow for:

• Peer review and discussion of emerging findings

• Troubleshooting of barriers in information gathering

• Quality assurance prior to submission

• Real-time support from the LeDeR Programme Manager

This multidisciplinary process has enabled the team to draw on collective knowledge and experience, particularly in cases where difficulties accessing family input or structured judgement reviews arise. Examples include using liaison team records or care provider feedback when family engagement is limited, and checking hospital notes in person when electronic systems are delayed.

Key learning from the Review Clinic includes:

• Ensuring medication is obtained and administered without delay, particularly for urgent prescriptions

• Challenging assumptions in provider narratives when discrepancies emerge (e.g., pharmacy opening hours verified by direct contact)

• Improving coordination with external agencies, including the CQC, when concerns cross over into regulatory territory

The Review Clinic strengthens the integrity and impact of reviews and supports reviewers in identifying SMART actions that are specific, evidence-based, and capable of influencing care improvements.

Learning Disability and Autism Deaths: Data and Trends

The Nottingham and Nottinghamshire ICB continues to enhance its understanding of mortality among people with a learning disability and autistic people through data triangulation. LeDeR notification data is now regularly compared with death registration and GP-recorded diagnoses to support a more complete picture.

Between 2021/22 and 2023/24, an average of 105 adults with a learning disability died each year. In 2024/25, this rose slightly to 119. While this increase is not statistically significant, it reflects projected demographic shifts, with more people in the 55–80 age bracket — where risk of death is naturally higher.

Forecasting based on ONS population projections suggests the number of learning disability-related deaths is likely to rise incrementally over the next 15 years, unless targeted prevention and early intervention strategies succeed in reducing modifiable risk factors.

Separately, in the last 12 months, around 20 individuals registered as having Autism only (i.e., with no diagnosed learning disability) died across the system. These deaths are not always notified to the LeDeR programme and are being prioritised for further community outreach and awareness raising.

This expanded dataset supports the LeDeR team and wider ICB to:

- Improve alignment between LeDeR reviews and actual deaths
- Target reviews in high-risk age groups and geographies
- Engage system leaders in planning for future demand
- Understand underreporting or discrepancies in ASD-only notifications

We will continue refining how learning disability and autism deaths are captured, analysed, and used to inform system-wide safeguarding, commissioning, and quality improvement activity.

STOMP & STAMP

The Nottingham and Nottinghamshire ICB continues to lead on the national STOMP (Stopping Over Medication of People with a Learning Disability, Autism or both) and STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) initiatives.

Key achievements in 2024–25:
• Pharmacists from the ICB Medicines Optimisation Team contributed to 15 LeDeR reviews.
• Their involvement enriched medication-related insights and governance.
• Regular review of prescribing practices, especially psychotropics, has helped reduce inappropriate prescribing.

Themes identified by pharmacists included:
• Lack of clarity around PRN (‘as required’) medication instructions
• Instances of polypharmacy with QT-prolonging drugs
• Use of medications with unclear indications (e.g., hay fever prescriptions in winter)
• Missed opportunities for medication reviews as part of AHCs

The Medicines Optimisation Team continues to liaise with care providers, providing support and ensuring prescribing aligns with best practice and national guidelines. LeDeR reviewers now benefit from specialist pharmacy input as part of the quality assurance process for every review — a first nationally.

This close collaboration ensures that learning from LeDeR reviews supports safer, person-centred medication use across the system.

Areas for Improvement:

While the LeDeR programme in Nottingham and Nottinghamshire has seen notable success, several areas require continued focus:

• Timeliness:
  - Some reviews exceeded the 6-month KPI due to delays from external statutory processes or volume of focused reviews.
  - Improved balance between focused and initial reviews is now being monitored.

• Capacity and Legal Frameworks:
  - Reviews noted insufficient documentation of Mental Capacity Assessments and Best Interests decisions.
  - Training and guidance are needed to reinforce legal compliance.

• ReSPECT Documentation:
  - Inconsistent use and recording of ReSPECT forms across care settings.
  - Improved awareness and integration in end-of-life care planning is a priority.

• Annual Health Checks:
  - Some lacked qualitative detail or failed to address long-term health needs.
  - Further education and system reminders are needed to improve AHC quality.

• Screening and Vaccination Uptake:
  - Little documentation around declined screenings or missed vaccinations.
  - Reasonable adjustments and follow-up practices must be better captured and acted upon.

• Provider Engagement:
  - While many providers now respond to SMART actions, engagement from acute hospital trusts is variable.
  - Further strategic follow-up is planned to ensure all provider types are accountable.

These challenges are being addressed collaboratively through system-wide governance and targeted improvement workstreams.

Objectives for 2025–26

The following objectives have been set for the 2025–26 programme year, aligning with national guidance, local insights, and findings from this year's reviews:

1. Further improve review timeliness and maintain 95%+ compliance with NHSE 6-month KPI.
2. Expand outreach into ethnic minority communities to increase ASD-only and underrepresented group notifications.
3. Deepen integration of pharmacist feedback into care improvement cycles.
4. Formalise escalation routes for concerns identified during reviews to system safeguarding and transformation groups.
5. Collaborate with Primary Care to improve the quality and consistency of Annual Health Checks.
6. Continue refining our SMART action framework and support implementation with feedback assurance tracking.
7. Work with system leads to improve hospital and residential use of ReSPECT forms and capacity assessments.
8. Monitor and respond to trends in sudden cardiac and respiratory deaths through targeted thematic reviews.
9. Embed routine inclusion of Expert by Experience reflections in governance and quality meetings.
10. Use new national LeDeR platform tools to enhance reporting, reviewer support, and data transparency.

These goals are designed to ensure that the LeDeR programme continues to drive impactful change and champion equity for people with learning disabilities and autistic people.

Summing Up and Final Thoughts

As we reflect on the progress made throughout 2024–25, it is clear that the LeDeR programme in Nottingham and Nottinghamshire is maturing into a powerful, embedded driver of system improvement. Our ability to identify trends, highlight inequalities, and influence care delivery has been enhanced through the appointment of dedicated reviewers, deeper engagement with partners, and an improved focus on review quality.

The growing use of focused reviews, cross-system governance, and analytics integration are enabling us to move beyond description into real-time action. We are increasingly confident that SMART actions resulting from LeDeR reviews are being heard, understood, and implemented by providers.

Challenges and disparities remain in annual health check quality, gaps in mental capacity assessments, and ongoing variation in ReSPECT form completion all show that we have more to do. Throughout the year, we have built and maintained strong partnerships with colleagues across health, social care and commissioning services. The introduction of structured 'Review Clinics' has improved both the timeliness and quality of our reviews, while increased engagement with primary care has helped address challenges around Annual Health Checks and care coordination.

This report highlights where care has improved, where challenges remain, and where opportunities for meaningful change continue to emerge. Most importantly, it reaffirms our shared commitment to learning from the lives and deaths of people with a learning disability and autistic people to help shape better, safer services.

In 2025–26, our efforts will focus even more on prevention, early identification, and working with underrepresented groups. We will continue to strive toward a health and care system where every person with a learning disability or autistic person receives high-quality, safe and personalised care throughout their life.

Thank you to every person, provider and partner who contributes to our work. Together, we learn. Together, we improve. Together, we make a difference.

Credits

This report was produced by the NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) LeDeR Team.

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