Lincolnshire
Integrated Care Board

Learning from Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) in Lincolnshire Annual Report 2025

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Integrated Care Board

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1.1 Foreword

I am proud to present the 2025 Learning from Lives and Deaths (LeDeR) report for Lincolnshire. This report reflects our shared commitment to learning from the lives and deaths of people with a learning disability and autistic people, ensuring that every insight drives meaningful change.

Over the past year, we have strengthened collaboration across our local system. Our work has been supported by:

- **NHS Lincolnshire Integrated Care Board (ICB)**, leading the LeDeR programme and embedding learning into commissioning and quality improvement.
- **Lincolnshire Partnership NHS Foundation Trust**, **United Lincolnshire Teaching Hospitals NHS Trust**, and **Lincolnshire Community Health Services**, who have worked tirelessly to implement recommendations and improve care.
- **Lincolnshire County Council**, through adult social care and public health teams, ensuring integration across health and social care.
- **East Midlands Ambulance Service**, palliative and end-of-life care providers, and voluntary sector partners, all contributing to better outcomes.
- **Experts by Experience**, whose voices remain central to shaping our approach and priorities.

Foreword continued

This year’s report highlights key themes, including the importance of early detection of physical health conditions, timely reasonable adjustments, and inclusive end-of-life planning.

It also demonstrates how partnership working has led to improvements in training, communication, and care pathways.

Our governance remains robust, with oversight from the LeDeR Governance Board, Learning Disability Partnership Board, Lincolnshire Autism Partnership Board and the Transforming Care Partnership Board, ensuring accountability and transparency.

Looking ahead, our focus for 2026 will be on reducing health inequalities, embedding personalised care, and ensuring that learning translates into action across all settings.

Together, we will continue to champion dignity, equity, and inclusion for every person in Lincolnshire.
Thank you to all partners, families, and carers for your dedication and collaboration in this vital work.

Claire Frances
Senior Commissioning Manger for NHS Lincolnshire ICB
Local Area Contact for the LeDeR programme in Lincolnshire

1.2 Introduction and Background

The LeDeR programme is a vital part of our commitment to improving health and care for people with a learning disability and autistic people. It provides a structured way to review the lived experience, deaths, informing thematic analysis, and ensuring that learning leads to real system change.
This 2025 report summarises the findings from reviews completed in Lincolnshire over the past year. It highlights key themes, examples of good practice, and areas where improvements are needed. Our aim is to share learning openly and use it to drive strategic action across health and social care.

LeDeR is not just about reviewing deaths—it is about valuing lives. Every review represents a person who mattered to their family, friends, and community. We approach this work holistically with respect and a determination to reduce health inequalities, improve access to care, and promote inclusion.

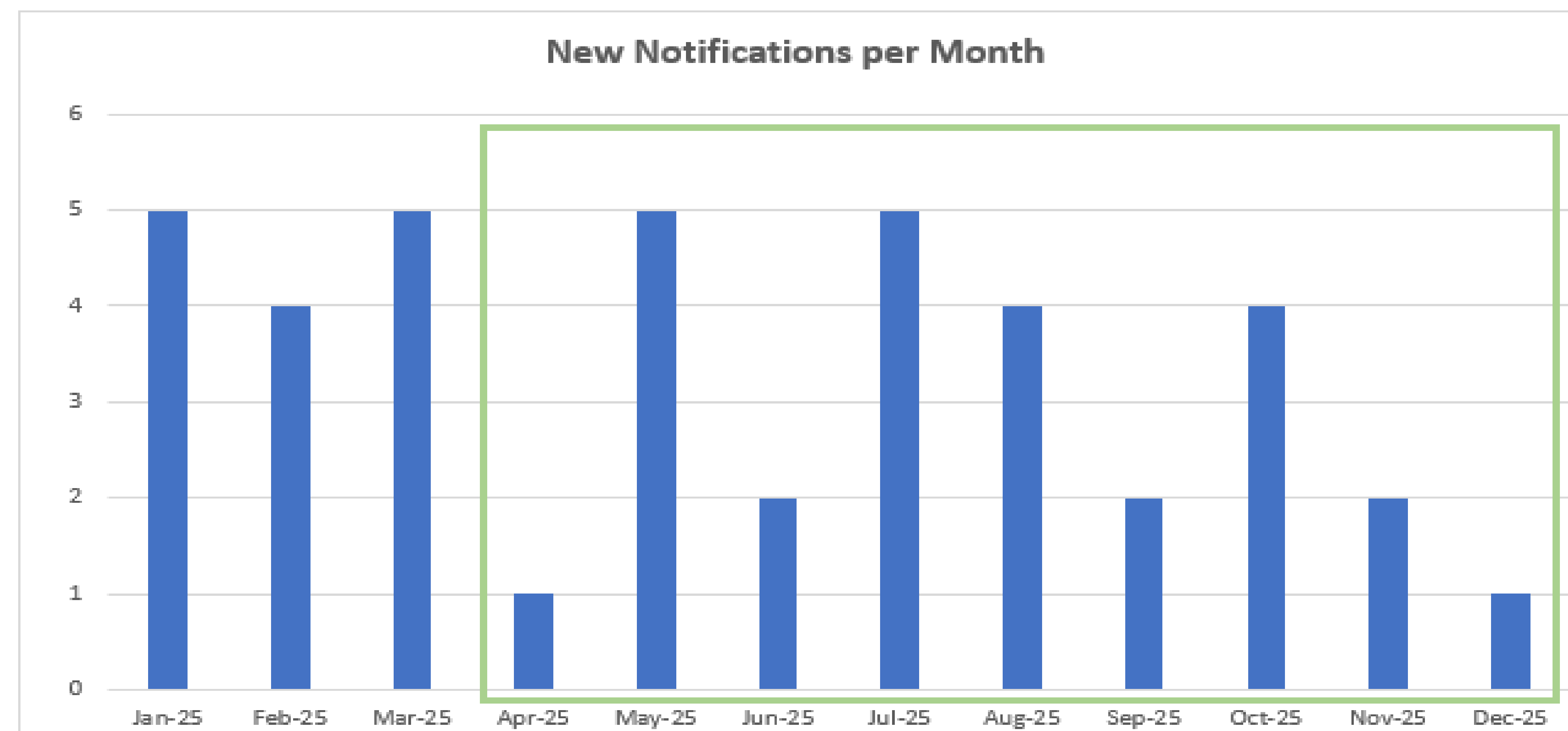
Our report reflects the strength of partnership working in Lincolnshire. Our Integrated Care System brings together NHS Lincolnshire ICB, Lincolnshire Partnership NHS Foundation Trust, United Lincolnshire Hospitals NHS Trust, Lincolnshire Community Health Services, Lincolnshire County Council, East Midlands Ambulance Service, voluntary sector organisations, and Experts by Experience. Together, we are committed to learning and acting on what matters most. As you read this report, we encourage you to consider how these findings can inform your practice, your organisation, and our shared ambition: to ensure that people with a learning disability and autistic people live longer, healthier lives with dignity and equality.

2. Summary of findings Lincolnshire 2025

The 2025 LeDeR findings for Lincolnshire highlight key patterns in health inequalities, areas of improvement in care delivery, and priority actions to enhance outcomes for people with a learning disability and autistic people across the county.

Month	Jan-25	Feb-25	Mar-25	Apr-25	May-25	Jun-25	Jul-25	Aug-25	Sep-25	Oct-25	Nov-25	Dec-25
New Notifications	5	4	5	1	5	2	5	4	2	4	2	1

Reviews Currently Allocated	15
Reviews on Hold	4
Reviews Signed Off this Month	2
Unallocated Reviews	6
Ongoing Focussed Reviews	5



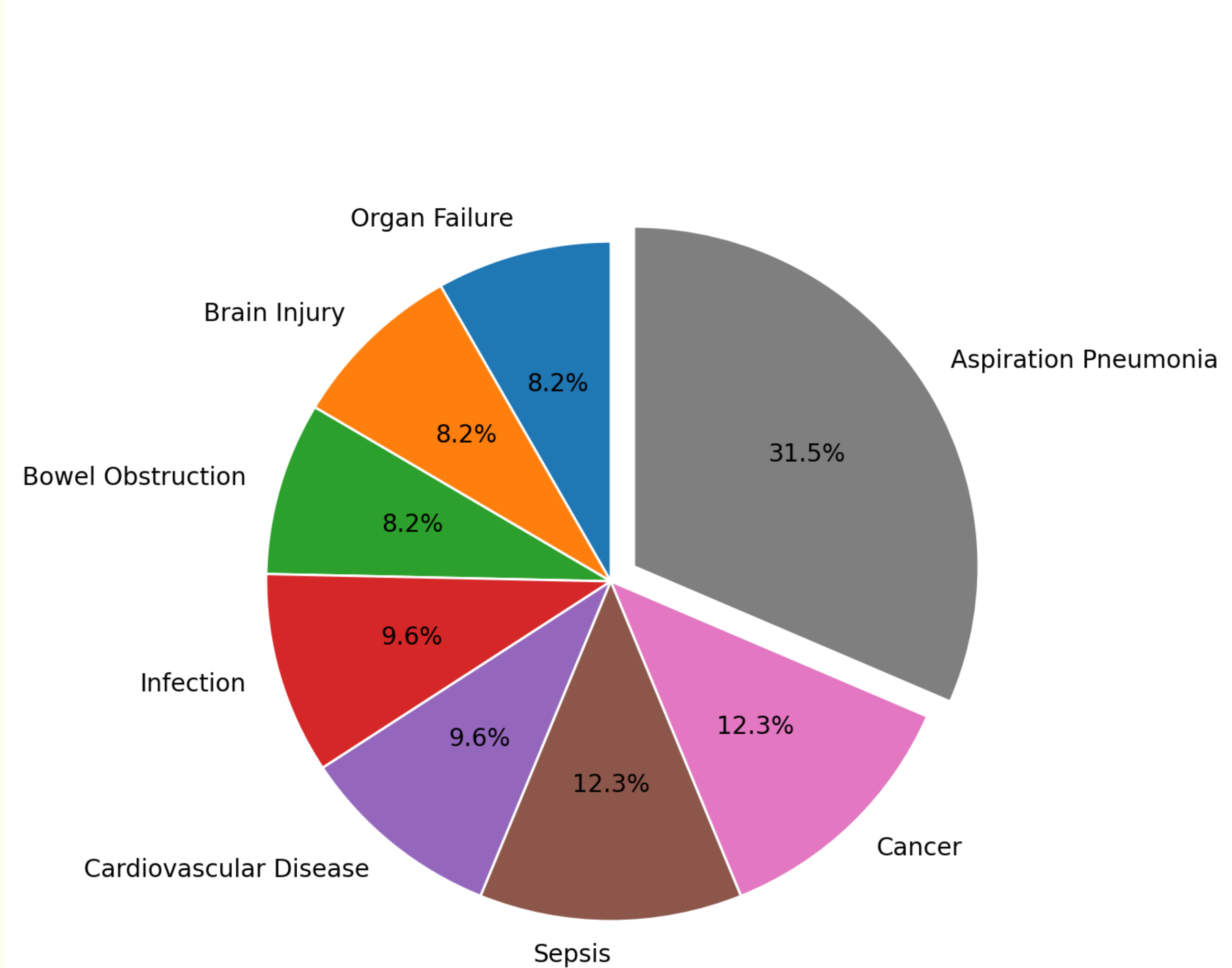
2.1 Summary of Findings 2025

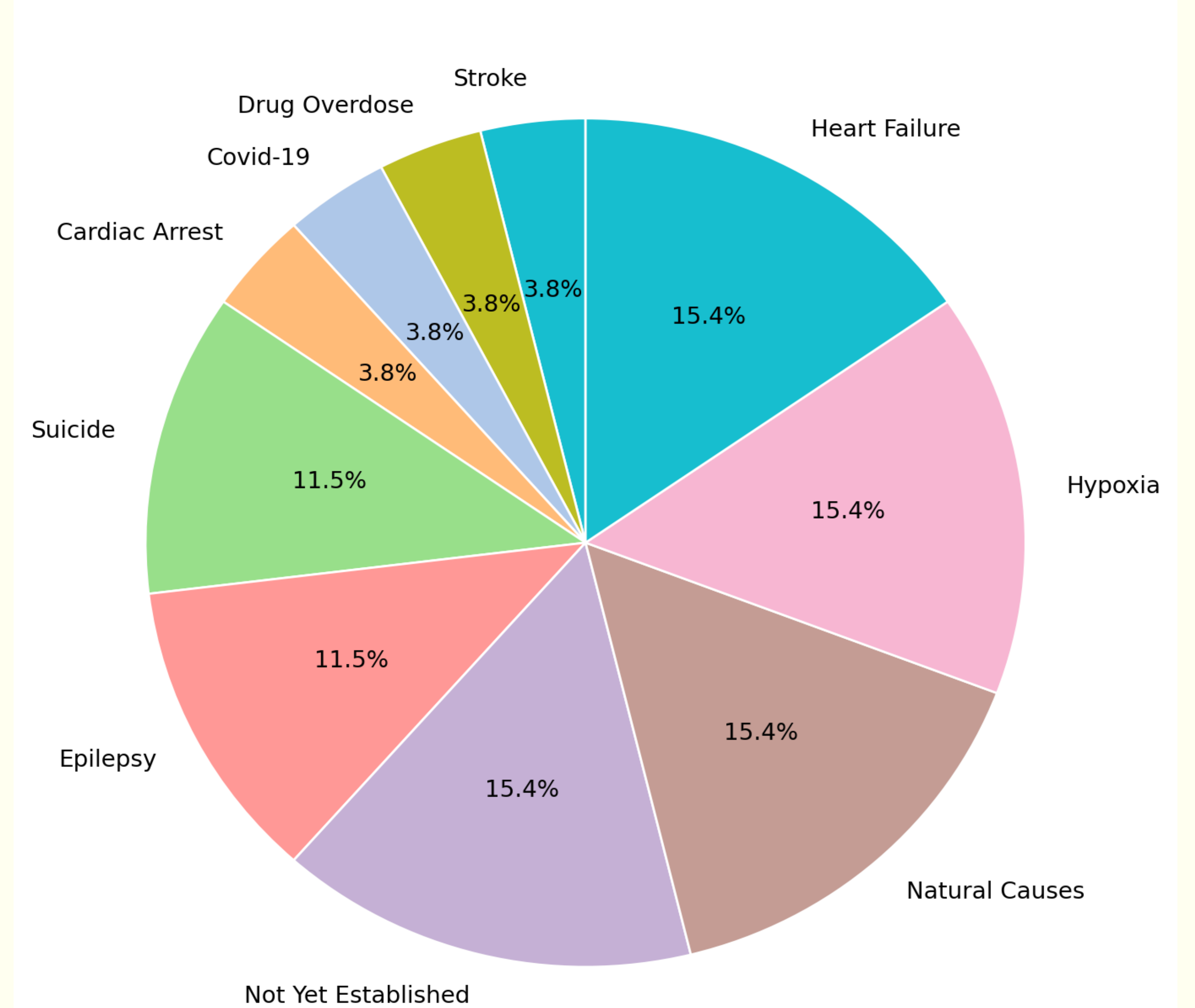
Summary of 2025 Data

- 39 notifications; 46 reviews allocated; 71 reviews signed off.
- **Age:** Median age at death is 55; 33 early deaths (<75), indicating a high proportion of early mortality.
- **Demographics:** 49% Male, 51% Female; ethnicity recorded entirely as White British (100%).
- **Causes of death for reviews signed of in 2025:** Aspiration pneumonia dominates (41%). Cancer (15%) and cardiovascular disease (14%) follow. Covid-19 accounts for 12%.
- **Place of death:** Hospitals (ULHT Boston and Lincoln) feature prominently.
- **Timeliness:** Only 29% of reviews completed within six months; workload-driven allocation
- delays (1–3 months) are the primary reason for breach.
- **Diagnosis:** 90% recorded with LD; 8% autism; 2% LD/A.

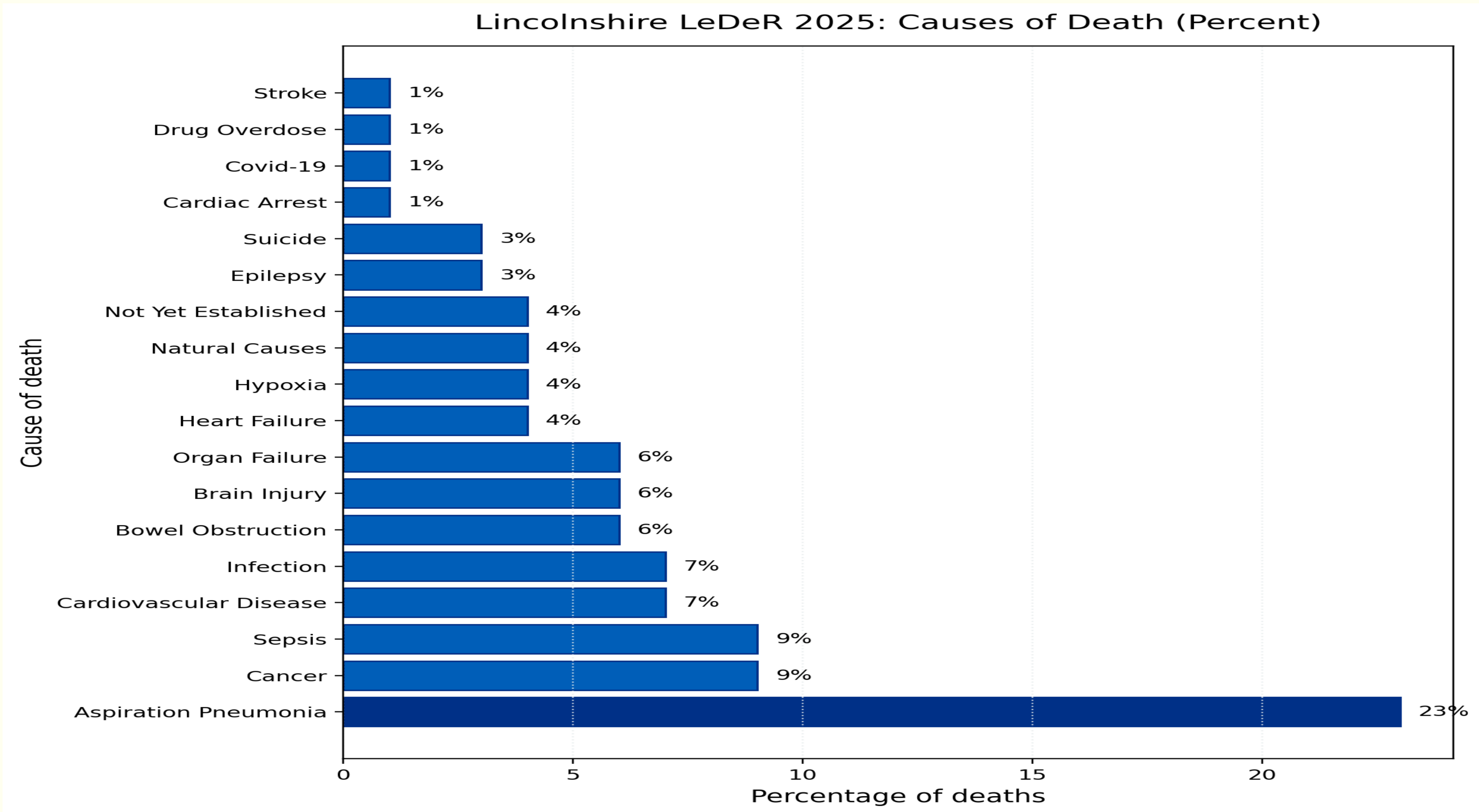
Adult Notifications Recieved this Year	39
Reviews Allocated this Year	46
Reviews Signed Off this Year	71
Median Age of Death	55
Early Deaths (<75)	84%

2.1 Summary of Findings 2025





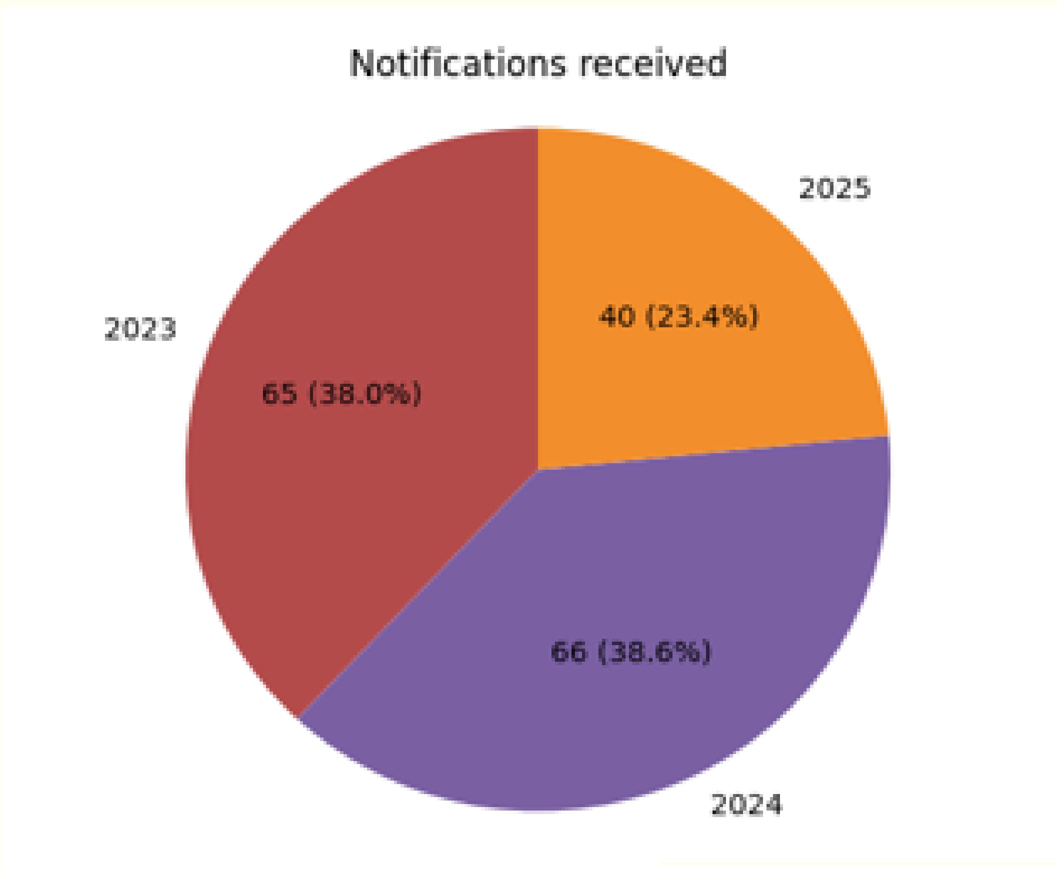
2.1 Summary of Findings 2025

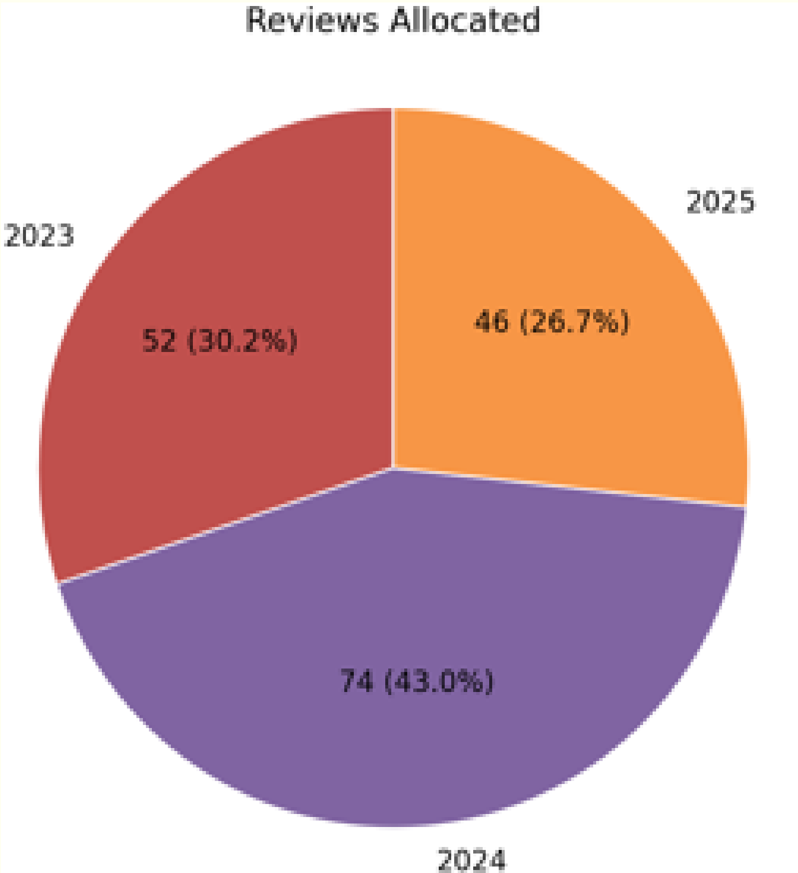


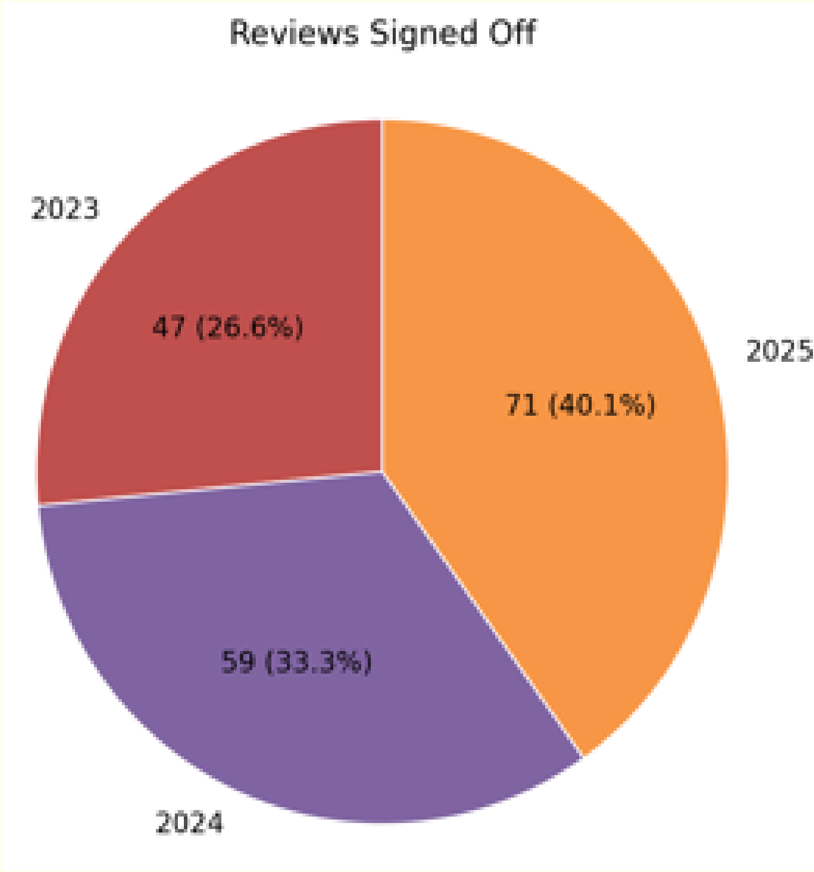
3.Summary of Findings - Thematic Analysis Lincolnshire 2023 - 2025

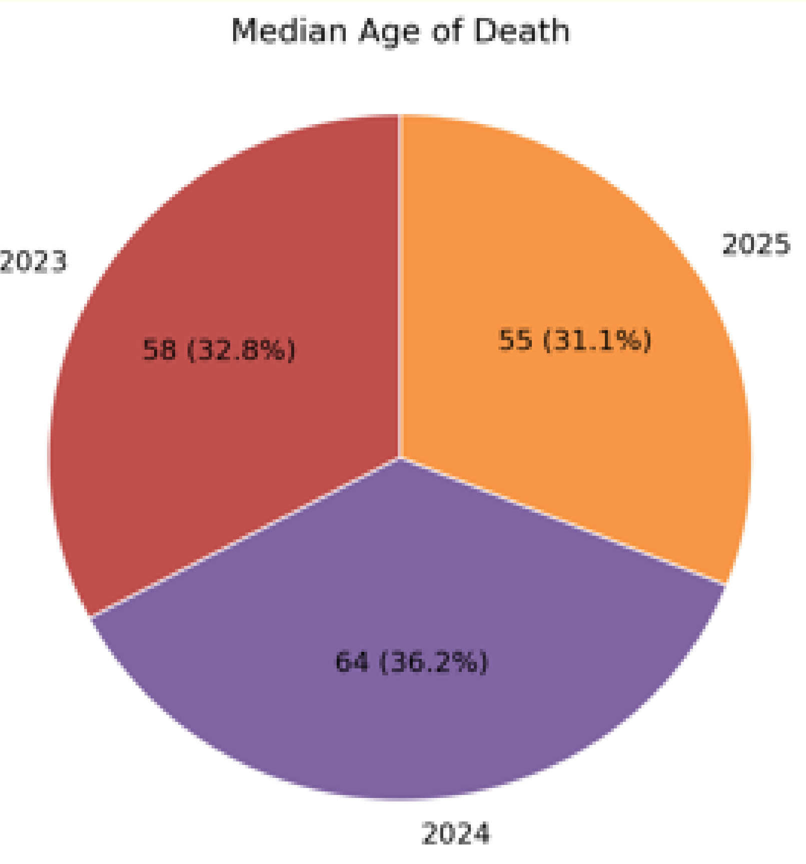
This section provides an overview of the key patterns, emerging themes, and notable changes identified across the 2023–2025 period, highlighting areas of improvement and ongoing challenges.

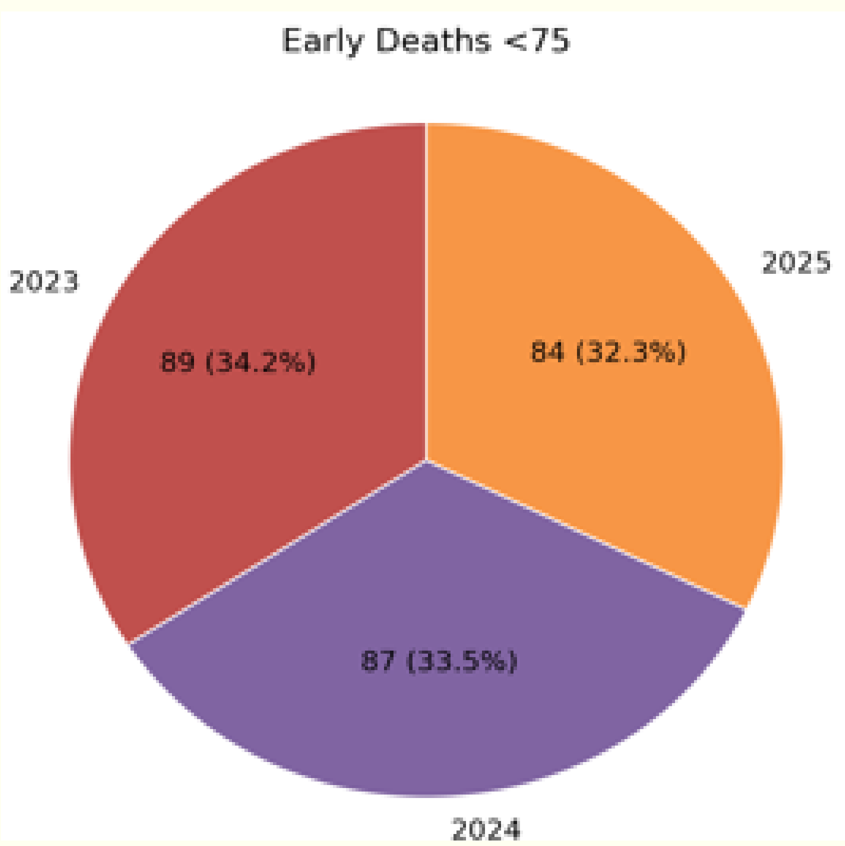
3.1 Thematic Analysis Lincolnshire 2023 - 2025











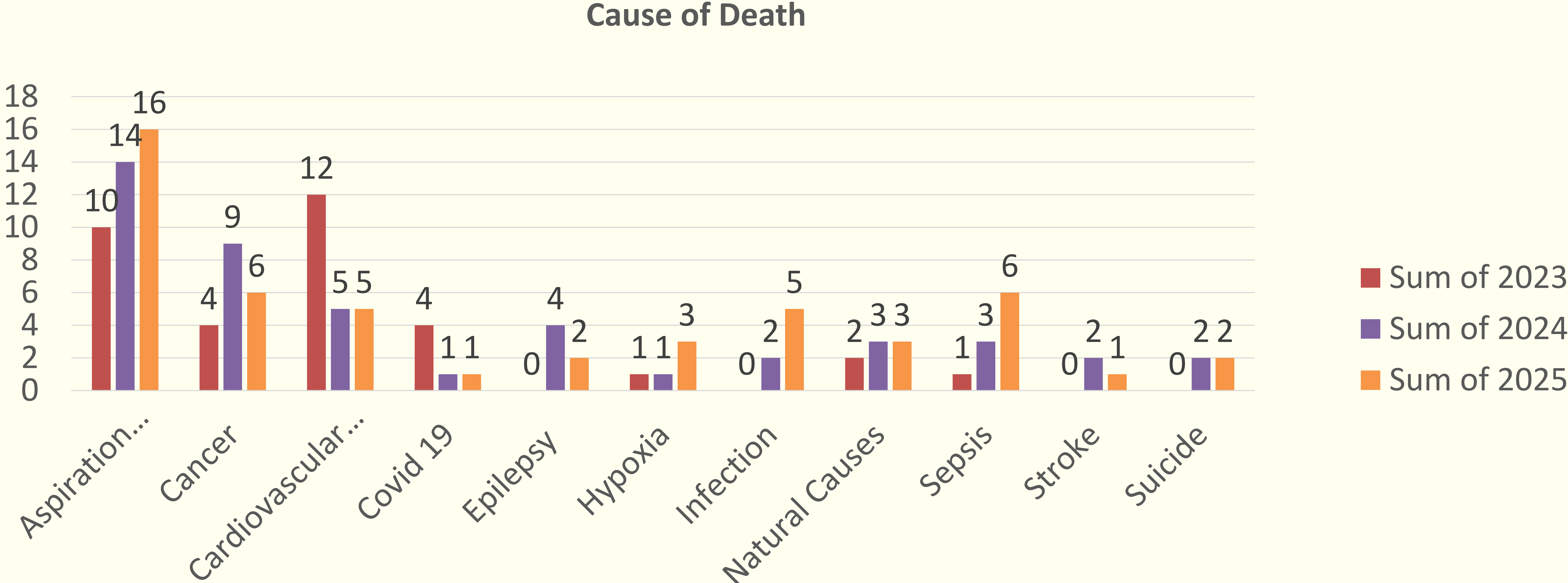
3.1 Thematic Analysis Lincolnshire 2023 - 2025

Cause of Death

Largest increases (2025 vs 2024): Infection **+3**, Sepsis **+3**, Aspiration Pneumonia **+2**, Hypoxia **+2**.

Largest decreases (2025 vs 2024): Cancer **−3**, Epilepsy **−2**, Stroke **−1**.

Since 2023: Aspiration Pneumonia **+6**, Sepsis **+5**, Infection **+5** stand out as sustained rises; cardiovascular disease **−7** and Covid-19 **−3** have fallen.



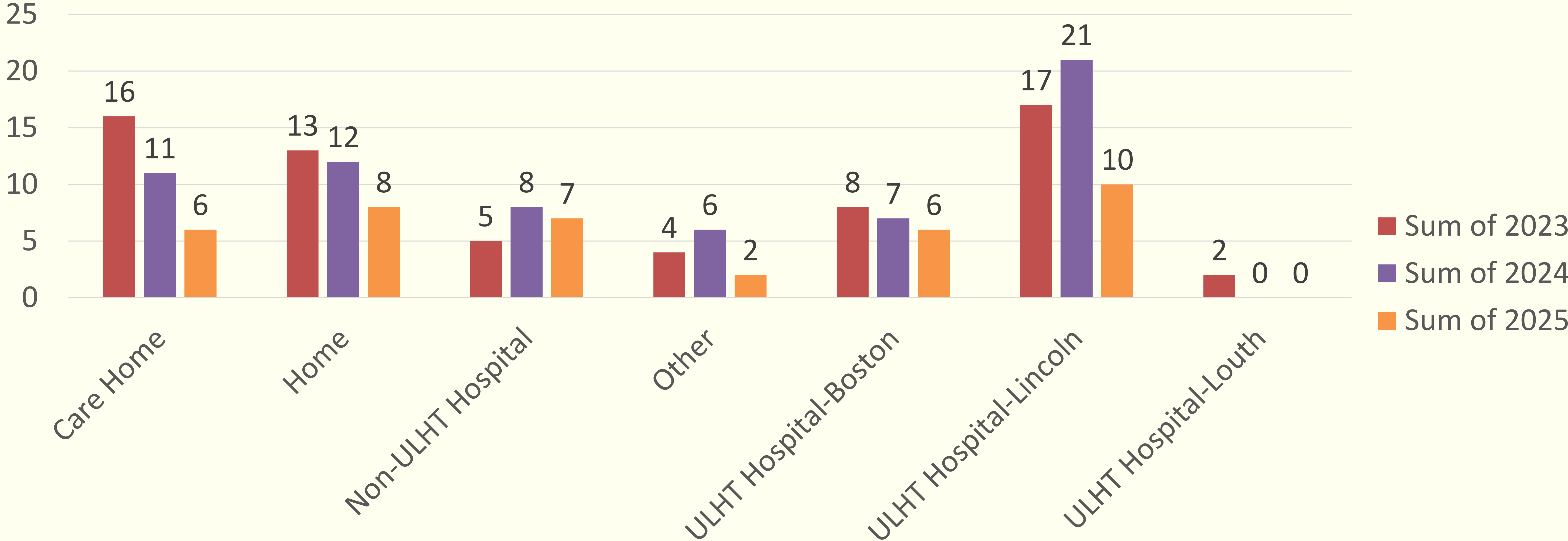
3.1 Thematic Analysis Lincolnshire 2023 - 2025

Location of Death

ULHT hospitals (Boston + Lincoln + Louth): 41.5% → 43.1%

Care Home share fell from 24.6% → 16.9%

Non-ULHT Hospital rose 7.7% → 12.3%.



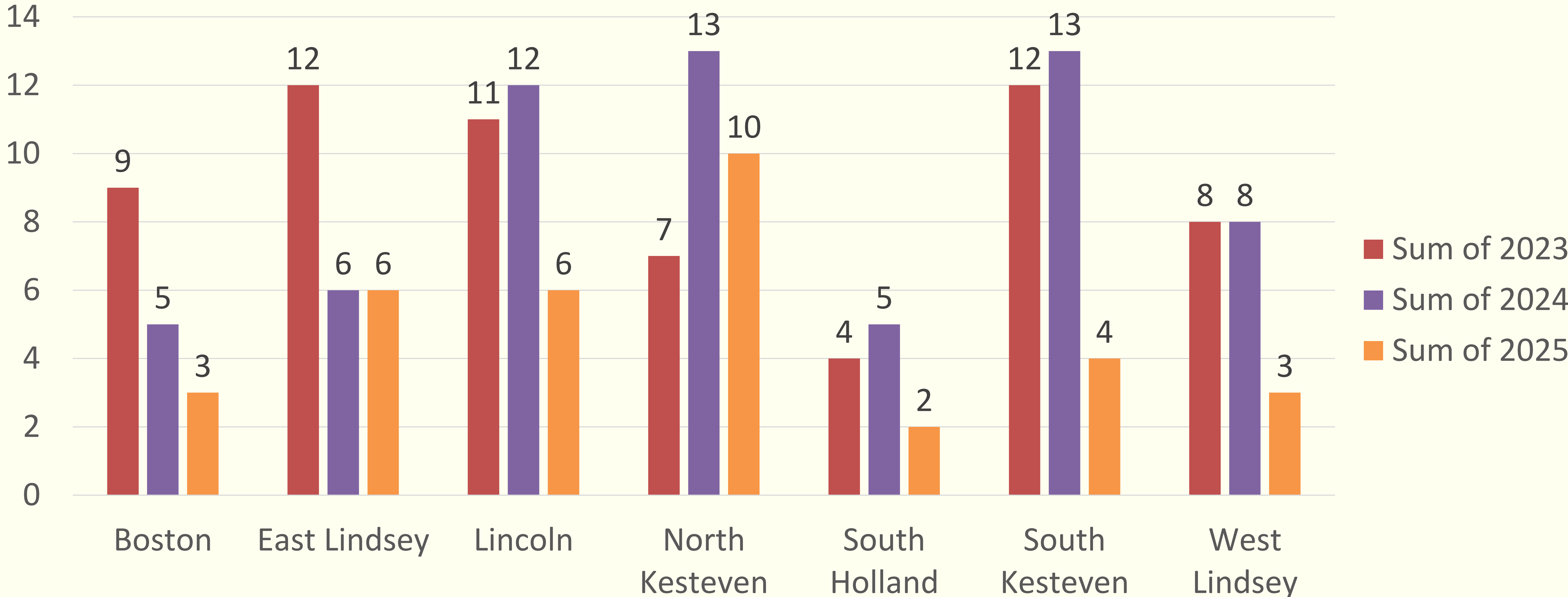
3.1 Thematic Analysis Lincolnshire 2023 - 2025

Deaths in Districts

2023: Joint highest South Kesteven & East Lindsey (12 each).

2024: Joint highest South Kesteven & North Kesteven (13 each).

2025: Highest North Kesteven (10).

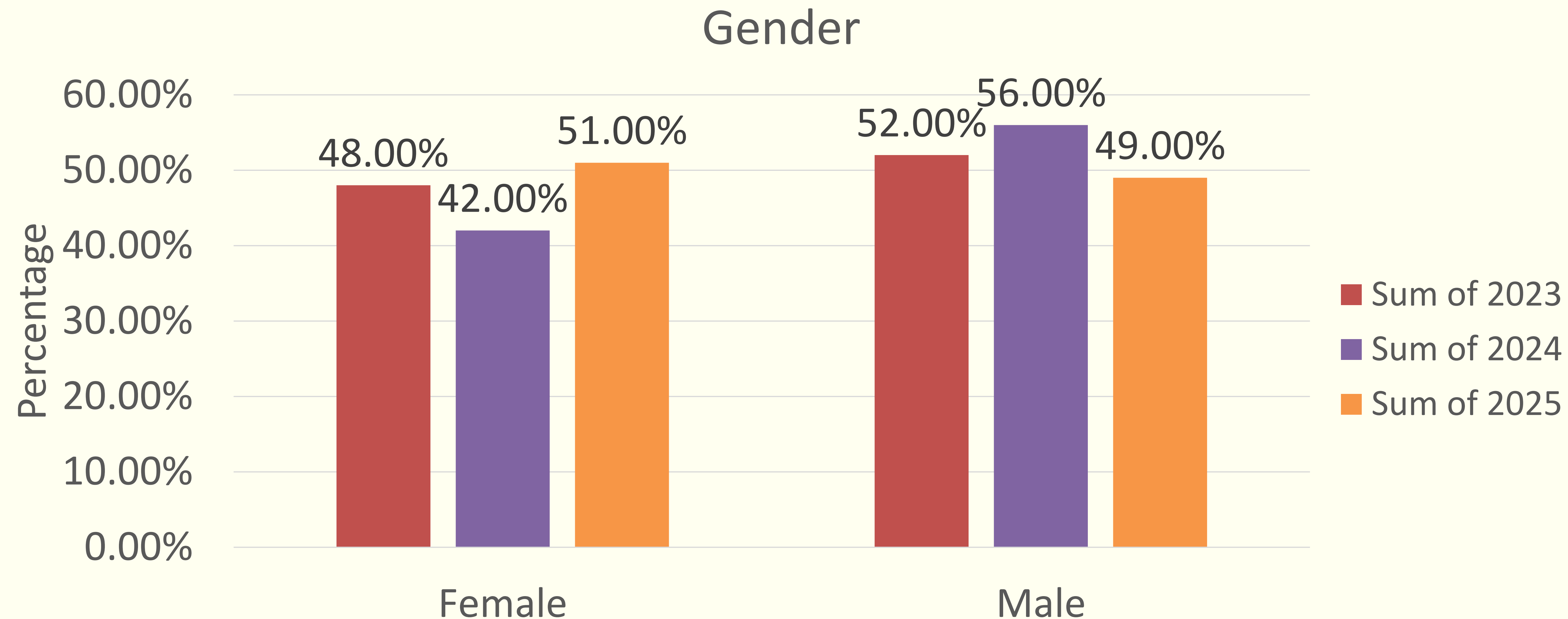


3.1 Thematic Analysis Lincolnshire 2023 - 2025

Gender

2023 → 2024: Increase in Male deaths by 4% and a decrease in female deaths by 6%.

2024 → 2025 There was a large increase in Male deaths in 2024 followed by a steep fall of 7% in 2025. There was a large increase of 9% for female deaths in 2025.

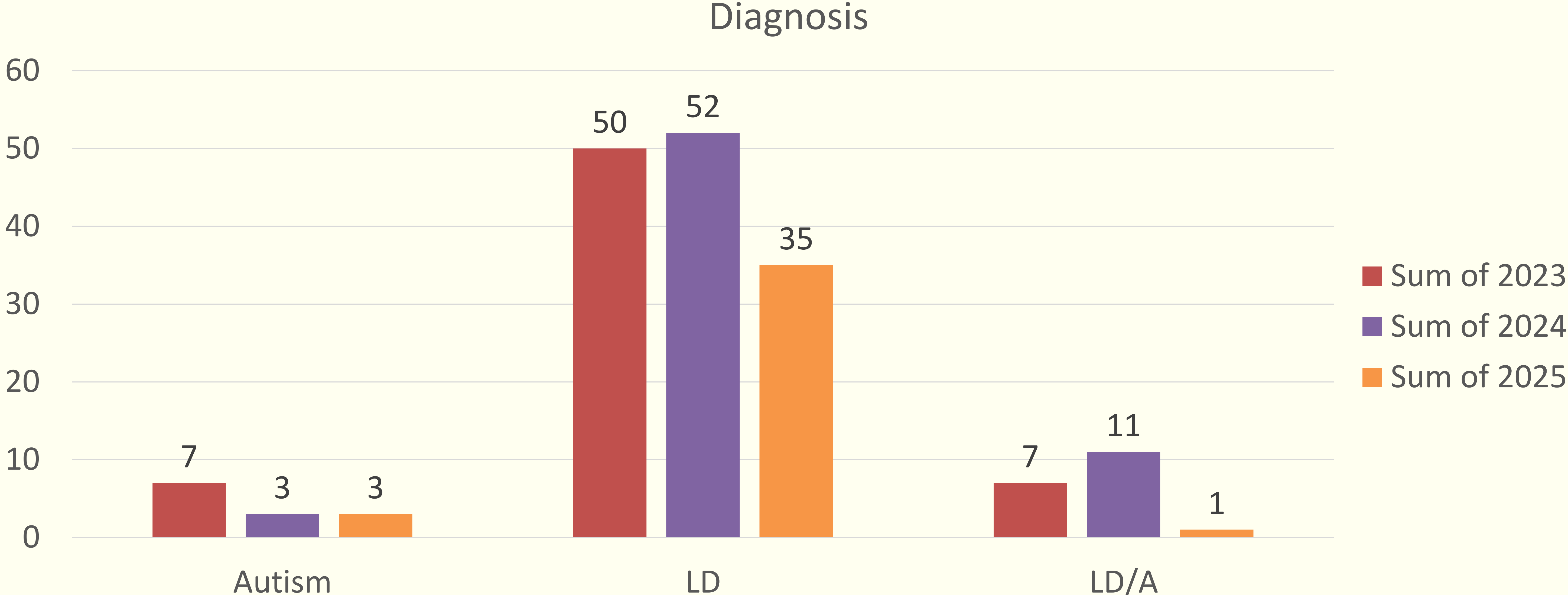


3.1 Thematic Analysis Lincolnshire 2023 - 2025

Diagnosis

Total up slightly +3.1% (64→66) in 2024; down −40.9% (66→39) in 2025 (*likely partial-year*).

2025 mix skews more to LD (≈90%), with LD/A notably lower



4. Governance and Oversight Priority Actions & Next Steps

The Role of the LeDeR Governance Panel

The LeDeR Governance Board process reviews learning from cases to drive improvements in care for people with learning disabilities and autism.

By examining themes, patterns and findings, we identify priorities, actions and next steps that help reduce health inequalities and improve safety and quality.

Priorities and actions identified at Governance Panel throughout 2025 have been aimed at making meaningful changes across services and ensuring better outcomes for individuals and families.

4.1 Priority Actions and Next Steps

Aspiration Pneumonia, Cancer & Sepsis:

Reduce aspiration-related deaths

Dysphagia protocols

Care training

Acute response

Strengthen hospital pathways for LD

Reasonable adjustments

Discharge safety

Cancer & CVD care

Improve timeliness

Capacity planning

Prioritization rules

Process targets

Suicide Prevention: Priority Actions & Next Steps

Early Identification & Risk Assessment

Routine mental health screening

Suicide risk tools adapted for LD/Autism

Flagging systems for previous self-harm

Crisis Response & Safety Planning

Personalized crisis plans

Rapid access to crisis teams

Safe discharge protocols

Workforce & System Support

Staff training in suicide prevention

Promote awareness across the ICS

Multi-agency coordination

Family/carer support resources

4.1 Priority Actions & Next Steps

Acute Causes: Priority Actions & Next Steps

Early Detection & Monitoring

Routine abdominal and neurological assessments

Use of early warning scores adapted for LD

Rapid escalation for acute symptoms

Emergency Response & Care Pathways

Clear protocols for suspected obstruction or organ failure

Fast-track imaging and surgical review

ICU access planning for high-risk cases

Prevention & System Improvements

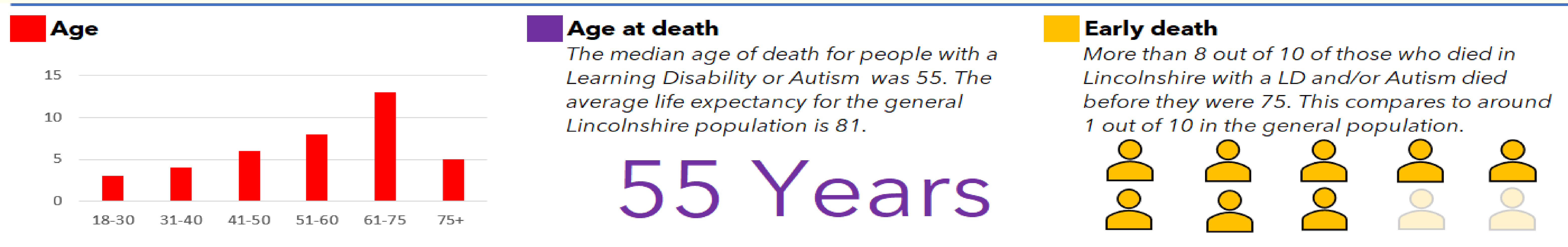
Regular medication reviews to reduce obstruction risk

Training for staff on acute deterioration signs

Strengthen hospital-LD liaison for emergency admissions

5. Governance and Oversight: Early Deaths

Early Deaths Summary January 2025 to December 2025



LeDeR Notifications Overview

In 2025, 39 death notifications were recorded for individuals with learning disabilities and/or autistic people in Lincolnshire.

Early Death Prevalence

84% of deaths occurred before age 75, below the official early death threshold, highlighting a major health disparity.

Life Expectancy Gap

There is a 21-year life expectancy gap compared to the general population, emphasizing persistent health inequalities.

Need for Intervention

Early deaths require urgent intervention to reduce preventable deaths and improve health outcomes.

5.1 Governance and Oversight: Early Deaths – Recommendations & Actions

To reduce early deaths, a multi-pronged approach is essential.

Priority actions should include improving access to annual health checks and proactive management of long-term conditions, particularly cardiovascular and respiratory health.

Strengthening reasonable adjustments in primary and secondary care, alongside better coordination between health and social care, can help prevent avoidable hospital admissions.

Enhanced training for professionals on recognising early signs of deterioration and embedding personalised care planning will also be critical.

Finally, learning from local reviews and sharing best practice across the ICS can drive system-wide improvements in health equity.

6. Case Study Summaries

The case studies in this Annual LeDeR Report are based on completed focused reviews, with system quality improvement actions identified and agreed by the LeDeR Governance Board.

6.1 Case Study: Learning from the Life and Death of Mr A

Complex Health Needs and End-of-Life Care

Background:

Mr A was a man with a moderate learning disability and schizophrenia, living in a care home under a DoLS authorisation. He had multiple long-term health conditions, including Type 2 diabetes, rheumatoid arthritis, and urological issues requiring a supra-pubic catheter. He attended a day centre regularly, enjoyed social activities, and maintained strong family and community connections.

Key Issues Identified:

- Complex health needs and end-of-life care challenges
- Communication gaps between hospital and care home
- Delay in surgery due to ICU bed availability
- Lack of clarity on decision-making when no legal next of kin was available

6.1 Case Study: Learning from the Life and Death of Mr A

System Quality Improvement Actions Taken:

- Re-launch of 'All About Me' hospital passport across Lincolnshire
- Development of emergency 'Grab Bag' initiative for LD patients
- Review and rollout of A&E LD grab sheet
- Training for medical staff on alternative communication methods

Positive Practice:

- Care home-maintained family connections and advocated during hospital stay
- GP practice delivered high-quality annual health checks and medication reviews

Full details of this case study are provided in Appendix A.

6.2 Case Study: Learning from the Life and Death of Mr X

Missed Opportunities for Early Intervention

Background:

Mr X was a 63-year-old man with a moderate learning disability and multiple physical health conditions, including Type 2 diabetes, hypertension, DVT in the left leg, esophageal varices, previous stroke, gangrene leading to toe amputation, and chronic leg ulcers. He grew up in rural Lincolnshire and lived with his brother in the community for many years. He could not read or write and relied on face-to-face support for managing correspondence and bills. Both brothers were well known locally and lived independently with minimal formal support, using mobility scooters and eating mainly ready meals and takeaway food.

Key Issues Identified:

- Missed opportunities for early intervention despite repeated GP referrals
- Inconsistent capacity assessments between 2020 and 2024
- Poor engagement with LD community team influenced by family dynamics
- Late admission to residential care when health deteriorated

6.2 Case Study: Learning from the Life and Death of Mr X

System Quality Improvement Actions Taken:

- LD Physical Health Liaison Lead to review training for care home staff on recognising deterioration, including Restore2 pilot project
- LD Student Nurse placement at the care home to develop a project based on this case
- Panel agreed to explore an ICB Led webinar in 2026 with LPFT Acute Liaison Nurses and LD Physical Health Lead to strengthen system-wide learning

Positive Practice:

- Social worker and neighbourhood team demonstrated persistence and creativity in engaging Mr X and supporting family involvement
- Care home facilitated family visits and continuity of relationships during his final months

Full details of this case study are provided in Appendix B.

6.3 Case Study: Learning from the Life and Death of Miss L

Cardiovascular Disease and Early Mortality

Background:

Miss L was a 29-year-old woman with a diagnosis of moderate to severe learning disability, autism, and significant communication difficulties.

She lived in a residential care home in Lincoln, having been placed there by another local authority. Miss L enjoyed sensory activities, watching videos on YouTube, and attending social events such as a weekly 80s disco.

She had no verbal communication and used limited Makaton, with staff anticipating most of her needs. Miss L had no diagnosed physical health conditions and was not prescribed regular medication.

Key Issues Identified:

- Heightened anxiety around physical health appointments leading to remote health checks
- Cross-border placement limiting local service engagement and reasonable adjustments
- Severe obesity increasing cardiac risk
- Lack of proactive management of cardiovascular risk

6.3 Case Study: Learning from the Life and Death of Miss L

System Quality Improvement Actions Taken:

- Notification protocols for Local Area Contact (LAC) to liaise with placing authority
- GP education on accurate patient location and cross-border collaboration
- Health screening standards to ensure physical assessments during annual checks
- System learning: Lincolnshire ICB webinar to raise awareness of cardiovascular risk and preventative strategies

Positive Practice:

- Use of LeDeR reviews to identify systemic gaps and drive improvements
- Multi-agency governance panel engagement to agree actions and share learning
- Commitment to education and awareness initiatives aimed at reducing preventable deaths from cardiovascular disease

Full details of this case study are provided in Appendix C.

7. Learning Events and Engagement

2025 has been a year of meaningful progress and shared learning for the Lincolnshire LeDeR Programme. Our commitment to improving health outcomes for people with learning disabilities and autistic individuals has remained at the heart of everything we do.

This progress has only been possible thanks to the dedication and collaboration of services and teams across the Integrated Care System (ICS). Together, we have worked to reduce health inequalities, embed learning into everyday practice, and ensure that every person receives care that is equitable, safe, and responsive to their needs.

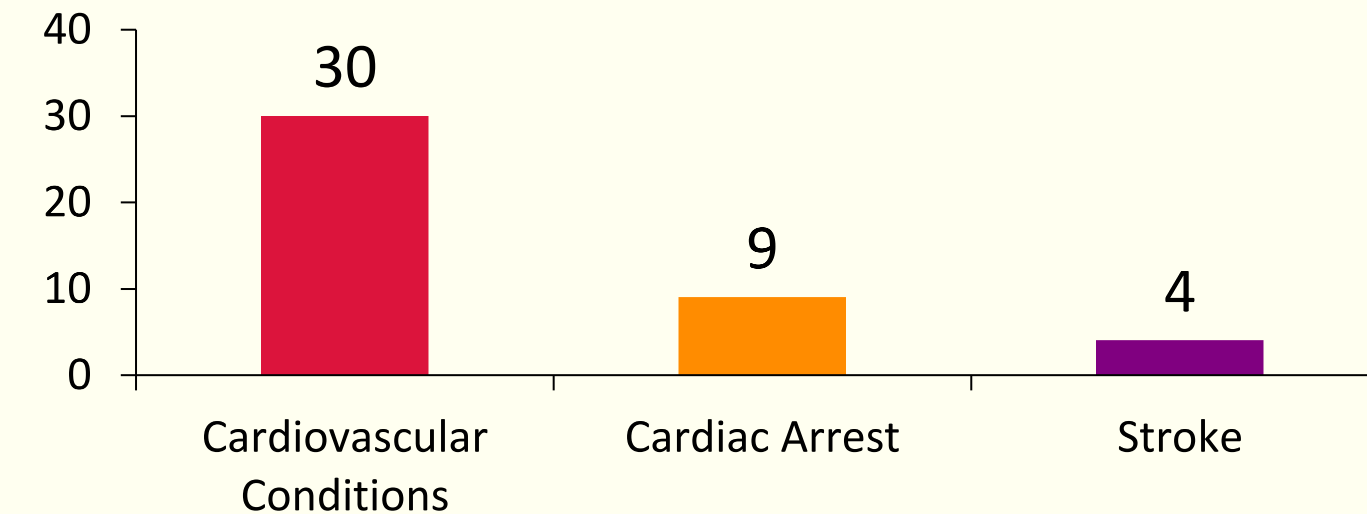
In this section, we celebrate some of the outstanding work and initiatives that have taken place across Lincolnshire during 2025—work that reflects our shared ambition to make a real difference in people's lives.

7.1 Learning Events & Engagement: Cardiovascular Disease Webinar

Cardiovascular Disease (CVD) – LeDeR Lincolnshire (2021–2024)

Summary of Findings:

- Total deaths attributed to cardiovascular conditions: 43
- Median age: 59.7 years



Context and Action:

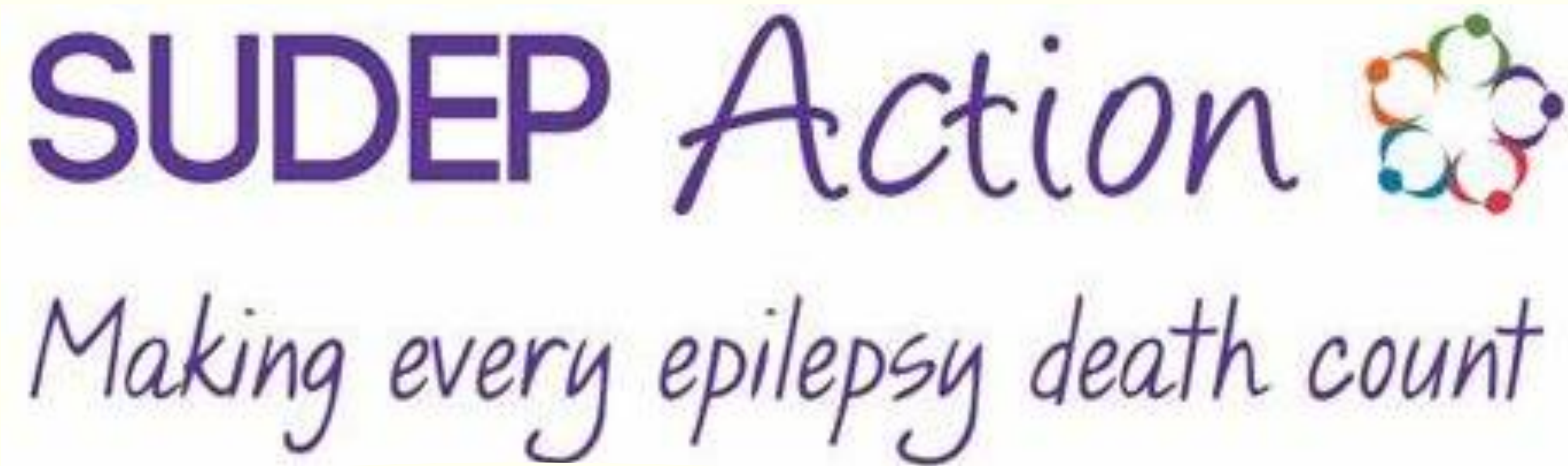
Cardiovascular disease remains one of the top three causes of death for people with a learning disability, both nationally and locally. In response to this, NHS Lincolnshire ICB collaborated with Lincolnshire Partnership NHS Foundation Trust to host and co-produce a webinar on 5th June 2025. The session aimed to:

- Raise awareness of the LeDeR Programme findings
- Highlight cardiovascular disease as a significant health risk
- Promote preventative strategies and early intervention across health and social care sectors
- Reflect on Rebecca's Story a fictional case study developed from the findings of two local focused LeDeR reviews.

See Appendix D for full details of the Webinar

7. Learning Events & Engagement: SUDEP Action Conference

NHS Lincolnshire



<u>Epilepsy and learning disability – a tribute to the life of Clive Treacey</u>

NHS Lincolnshire ICB hosted an all-day event took place in Sleaford on International epilepsy Day, Monday 10th February 2025, with 71 attendees from across health and social care professionals in Lincolnshire.

See Appendix E for full details of the event.

8. Service Innovation & Good Practice

This section highlights the developments, creative approaches, and examples of effective practice that have improved outcomes, strengthened system working, and enhanced the experience of people with a learning disability and autistic people across Lincolnshire.

8.1 Service Innovation & Good Practice: Healthy Lifestyle Project

One You Lincolnshire planned and delivered a 12-week healthy lifestyle pilot programme in 2025 in two of the learning disability hubs in Lincoln and Boston.

The programme consisted of weekly, adaptive physical activity sessions that were designed to be inclusive, engaging and fun for participants to attend.

See Appendix F for full details of the project.

8.2 Service Innovation & Good Practice: Bowel Cancer Screening Project

The NHS Lincolnshire ICB Health Inequalities Programme, supported by the Cancer Team and Dr Nicholas Bigwood (GP Fellow in Deprivation), led a Bowel Cancer Screening Project in Gainsborough, Mablethorpe, and Skegness.

Key Finding:
People with a learning disability—particularly those in care homes and supported living—are significantly less likely to complete bowel cancer screening compared to the general population.

Action Taken:
Cath Koutna (Cancer Project Manager) and Dr Nick Bigwood, with input from a clinical sub-group, developed a practical resource titled: "Improving the Uptake of Bowel Cancer Screening for People with Learning Disabilities." This guide supports carers in encouraging and assisting individuals to complete the screening process.

See Appendix G for full details of the project.

8.3 Service Innovation & Good Practice: Lincolnshire Rapid Response Service

NHS
Lincolnshire Community and Hospitals NHS Group

Pilot scheme for children with complex respiratory needs

Lincolnshire Rapid Response Respiratory Service

Featured in the LeDeR Action Learning Report for England 2023/2024, this initiative was inspired by reflections following the death of a child with complex needs in 2018.

Clinicians recognised that children with cerebral palsy—over 80% of whom have a learning disability—often experience recurrent chest infections or require long-term ventilation, particularly those with limited mobility.

The service focuses on preventing, diagnosing, and managing respiratory health at home, aiming to reduce hospital admissions and improve care for children with complex needs.

See Appendix H for full details of the project.

8.4 Service Innovation & Good Practice: TEPac

Technology Enabled Prevention and Care (TEPaC)
Lincolnshire County Council Adult Care is exploring how technology can improve outcomes while ensuring support remains available for those who need it.

A **TEPaC pilot** ran from **February 2024 to June 2025** in partnership with the University of Lincoln and a specialist technology provider. The project tested a range of solutions with individuals across Lincolnshire to identify what works best and for whom.

The pilot focused on:
People living at home
Individuals supported by family and friend carers
People in Community Supported Living

See Appendix I for full details of the project.

8.5 Service Innovation & Good Practice: HIU Service

High Intensity Use (HIU) Service – Trent Care PCN Pilot

Launched in June 2023, this pilot supports people who frequently attend A&E or Urgent Treatment Centres due to complex life challenges.

Although these individuals represent less than 1% of the population, they account for a disproportionate number of emergency visits, ambulance journeys, and hospital admissions—costing the NHS an estimated £2.5 billion annually (British Red Cross, 2021).

Common underlying issues include:

- Poor mental health
- Housing insecurity or homelessness
- Substance misuse
- Loneliness and isolation
- Past trauma or grief
- Difficulty accessing appropriate support
- **See Appendix J for full details of the project.**

Trent Care Network

8.6 Service Innovation & Good Practice: LD Friendly GP Practice

Learning Disability Friendly GP Practice Quality Mark

In **April 2025**, Lincolnshire refreshed the **Learning Disability Friendly GP Practice Quality Mark** to help improve health outcomes for people with a learning disability by supporting GP practices to deliver accessible, high-quality care.

The Quality Mark:

- Recognises good practice in providing equitable healthcare
- Encourages continuous improvement in patient experience

Awarding Process:

- Practices apply and submit evidence of meeting standards
- Applications are reviewed by a panel including experts-by-experience
- Successful practices receive **Bronze, Silver, or Gold** status
- NHS Lincolnshire ICB maintains a register of LD Friendly Practices
- **See Appendix K for full details of the project.**

8.7 Service Innovation & Good Practice: VoiceAbility

VoiceAbility

The Speak Out Leaders.

The Speak Out Leaders act as a voice for people of all ages who have a learning disability, their families and carers, and support people to get involved in all aspects of the running and delivery of Lincolnshire County Council's Learning Disability Partnership board, including Board Meetings and working groups, such as Staying Safe and Healthy Living.

By running events to give people, their family and carers a say on all sorts of issues, and working with professionals and organisations as active partners, their aim is to improve health and social care services across Lincolnshire for people with learning disabilities

The Speak Out Leaders presented their Journey with the MHDLDA Co-production Network to the Learning Disability and Autism Joint Delivery Group.

See Appendix L for full details.

9. Looking ahead to 2026

Looking ahead, our focus for 2026 will be on reducing health inequalities, embedding personalised care, and ensuring that learning translates into action across all settings. Together, we will continue to champion dignity, equity, and inclusion for every person in Lincolnshire.

We extend our deepest gratitude to Experts by Experience, partners, families, and carers for your dedication and collaboration in this vital work. Your commitment makes a difference.

10. End Note

As we conclude the 2025 Learning from Lives and Deaths (LeDeR) report for Lincolnshire, we reflect on the collective effort that has driven progress in improving care for people with a learning disability and autistic people. This report is not just a record of learning—it is a commitment to action.

The insights gained this year highlight the importance of early detection of physical health conditions, timely reasonable adjustments, and inclusive end-of-life planning. They also demonstrate how partnership working has strengthened training, communication, and care pathways across our system.

Our governance remains robust, with oversight from the LeDeR Governance Board, Learning Disability Partnership Board, Lincolnshire Autism Partnership Board, Learning Disability and Autism Joint Delivery Group and the Transforming Care Partnership Board, ensuring accountability and transparency at every stage.

Claire Frances

11. Special Thanks

On behalf of the LeDeR Governance Board, I would like to offer special thanks to the following individuals, whose contributions were essential to the completion of this report:

- **Skye Cooper**, Commissioning Officer, NHS Lincolnshire ICB – for providing excellent oversight in the management of data and ensuring its accuracy and consistency, which was invaluable to the success of this report.

- **Jodie Goodman and Katrina Brown**, Senior LeDeR Reviewers, NHS Lincolnshire ICB – for their expertise, diligence, and commitment in reviewing cases and maintaining the highest standards of accuracy and quality. Their contribution has been instrumental in the development of this report.

- **Suse Kilburn**, LeDeR Co-ordinator – for invaluable support and coordination throughout this process.

11. Special Thanks

It has been a privilege to chair our LeDeR Governance Panel for another year. I would like to take this opportunity to sincerely thank all system leaders and professionals with a special interest in learning disabilities and autism for supporting the work of our Governance Panel.

I feel so supported in this role by colleagues whose commitment to our Quality Improvement has been unwavering, during what has been an exceptionally difficult year. Colleagues on the Governance Board have no protected time for this role and I am so appreciative of how dedicated everyone is, regularly supporting additional Governance actions and dissemination outside of Panel.

I am always so moved at how sensitively and compassionately our LeDeR Reviewers represent the life of a person at Governance Panel and then how Panel colleagues respond with appreciative enquiry and when required hold their own services to account.

The lives and deaths of Lincolnshire citizens and the highly personal stories of our citizens and their family carers inspire and inform our strategic work. As this annual report highlights, those actions are making such a difference for Lincolnshire people with a learning disability and autistic people.

Catherine Keay
Chief Commissioning Manager Mental Health, Learning Disabilities & Autism

12. Acknowledgements

We would like to express our sincere thanks to all those who contributed to the development of this report. We acknowledge the invaluable input from:

- To all the LeDeR Reviewers who have contributed to the LeDeR Programme throughout 2025
- SUDEP Action and Elaine Clarke
- Lincolnshire County Council for sharing Projects and Case Studies
- One You Lincolnshire
- The Health Inequalities Team - NHS Lincolnshire ICB
- Rapid Response Respiratory Service - Lincolnshire Community Health Services NHS Trust
- PCN Transformation & Integrated Communities Team NHS Lincolnshire ICB, Trent Care Network and The Lincolnshire Primary Care Network Alliance.
- The Learning & Development Centre – Lincolnshire Partnership NHS Foundation Trust
- Tina Auger, LD Physical Health Liaison Nurse, and the Acute Liaison Nursing Team LPFT
- VoiceAbility, Lincolnshire and the Speak Out Leaders

Appendices

Appendix A: Case Study Mr A – Complex Health Needs and End-of-Life Care

Appendix B: Case Study Mr X – Missed Opportunities for Early Intervention

Appendix C: Case Study Miss L – Cardiovascular Disease and Early Mortality

Appendix D:Cardiovascular Disease Webinar

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Appendix K: LD Friendly GP Service

Appendix L: The Speak Out Leaders VoiceAbility

Appendix A: Case Study Mr A – Complex Health Needs and End-of-Life Care

Background:

Mr A was a man with a moderate learning disability and schizophrenia, living in a care home under a DoLS authorisation. He had multiple long-term health conditions, including Type 2 diabetes, rheumatoid arthritis, and urological issues requiring a supra-pubic catheter. He attended a day centre five days a week, enjoyed gardening, music, dancing, and outings to theatres, zoos, and the seaside. He was well known in his local community and maintained meaningful relationships, including with his sister and friends. His care home supported him to visit family and maintain social connections throughout his life.

Health Monitoring:

Mr A received annual health checks (July 2022 and April 2023) and regular medication reviews in line with STOMP guidance. His GP practice provided high-quality care and health action planning.

Appendix A: Case Study Mr A – Complex Health Needs and End-of-Life Care

Events Leading to Death:

29/11/23: Care home requested urgent support due to abdominal distension and dark urine. Paramedics suspected bowel obstruction; admitted to hospital.
11/12/23: Large bowel obstruction confirmed.
12/12/23: Underwent laparotomy and sigmoid colectomy with stoma formation.
15/12/23: Vomiting noted; patient continued eating despite suspected ileus.
16/12/23: Rapid deterioration; resuscitation attempted but unsuccessful.

Structured Judgement Review:

Patient should have been nil by mouth (NBM) and had an NG tube inserted on 15/12 when vomiting began.
Delay in surgery due to ICU bed availability.
Grade 3 – Probable avoidable death: Suboptimal care; different care could reasonably have affected the outcome.

Appendix A: Case Study Mr A – Complex Health Needs and End-of-Life Care

Coroner's Narrative Conclusion:
Death resulted from known complications of necessary medical intervention for a natural disease process.

Learning Identified:
Communication gaps between hospital and care home regarding RESPECT documentation
Lack of clarity on decision-making when no legal next of kin was available
Missed opportunity to escalate earlier when vomiting occurred post-surgery
Need for better emergency planning and reasonable adjustments in acute settings

Appendix A: Case Study Mr A – Complex Health Needs and End-of-Life Care

System Quality Improvement Actions Taken:

Re-launch of 'All About Me' hospital passport across Lincolnshire
Development of emergency 'Grab Bag' initiative for LD patients
Review and rollout of A&E LD grab sheet for quick patient overview
Working group established to review LD care bundle and embed reasonable adjustments in EPR systems
Support for expanding Acute Liaison Nurse service in ED
Training for medical staff on alternative communication methods and reasonable adjustments

Positive Practice:

Care home maintained family connections, advocated during hospital stay, and planned a meaningful funeral and memorial
GP practice delivered high-quality annual health checks and medication reviews

Appendix B: Case Study Mr X – Missed Opportunities for Early Intervention

Background:

Mr X was a 63-year-old man with a moderate learning disability and multiple physical health conditions, including Type 2 diabetes, hypertension, DVT in the left leg, esophageal varices, previous stroke, gangrene leading to toe amputation, and chronic leg ulcers.

He grew up in rural Lincolnshire and lived with his brother in the community for many years. He could not read or write and relied on face-to-face support for managing correspondence and bills. Both brothers were well known locally and lived independently with minimal formal support, using mobility scooters and eating mainly ready meals and takeaway food.

Appendix B: Case Study Mr X – Missed Opportunities for Early Intervention

Health Monitoring:
Annual health checks were completed in 2020 (community) and later in 2023 and 2024 (in care)
Despite repeated GP referrals to the LD community team, engagement was poor, influenced by family dynamics.

Capacity assessments were inconsistent, with significant gaps between 2020 and 2024
In later years, the Wellbeing team and a social worker successfully engaged X, leading to admission to residential care when his health deteriorated

Appendix B: Case Study Mr X – Missed Opportunities for Early Intervention

Events Leading to Death:

Mr X was admitted to hospital in early January 2025 with bowel obstruction and pneumonia, following a two-week history of being unwell, lethargy, and abdominal pain.
He had multiple infections treated with antibiotics prior to admission and was receiving daily insulin support from district nurses.

On admission, he was catheterised, commenced on fluids and antibiotics, and underwent a CT scan under anesthetic due to agitation
During the scan, he stopped breathing; CPR was deemed not in his best interests

Structured Judgement Review:

Primary diagnosis: Ischemic bowel with contributing factors of atrial fibrillation and diabetes
Grade 2 – Possible avoidable death: Failure to admit under the appropriate surgical team may have delayed care.
Missed opportunity for urgent surgical review when patient was in a critical state.

Appendix B: Case Study Mr X – Missed Opportunities for Early Intervention

Learning Identified:

Capacity assessments were not consistently applied, despite repeated concerns about engagement and safeguarding.

Care coordination gaps between community services and LD teams led to missed opportunities for earlier intervention.

Recognition of soft signs of deterioration in care settings needs improvement.

Delays in sharing notes between LPFT and other providers impacted continuity of care.

System Quality Improvement Actions Taken:

LD Physical Health Liaison Lead to review training for care home staff on recognising deterioration, including Restore2 pilot project.

LD Student Nurse placement at the care home to develop a project based on this case.

Agreed at Governance Panel that the ICB will deliver a webinar in 2026 in co-production with LPFT Acute Liaison Nurses and LD Physical Health Liaison Lead to strengthen system-wide learning.

Appendix B: Case Study Mr X – Missed Opportunities for Early Intervention

Positive Practice:

Social worker and neighbourhood team demonstrated persistence and creativity in engaging Mr X and supporting family involvement.

Care home facilitated family visits and continuity of relationships during his final months.

Local System Learning:

Need for earlier MCA assessments when engagement with health care is poor.

Review of referral pathways and shared care agreements between LD Hub and community teams.

Strengthen face-to-face physical health training for care home staff and agency workers.

Appendix C: Case Study Miss L – Cardiovascular Disease and Early Mortality

Background:

Miss L was a 29-year-old woman with a diagnosis of moderate to severe learning disability, autism, and significant communication difficulties. She lived in a residential care home in Lincoln, having been placed there by another local authority.

Miss L enjoyed sensory activities, watching videos on YouTube, and attending social events such as a weekly 80s disco. She had no verbal communication and used limited Makaton, with staff anticipating most of her needs. Miss L had no diagnosed physical health conditions and was not prescribed regular medication.

Health Monitoring:

Miss L demonstrated heightened anxiety around physical health appointments, which triggered behaviours of concern. As a result, all annual health checks were completed remotely. Miss L was registered with a GP practice in a neighbouring county, limiting opportunities for local services to provide reasonable adjustments and proactive health interventions. Miss L's weight increased steadily from childhood into adulthood, and by age 27, her BMI was 50.4, indicating severe obesity.

Appendix C: Case Study Miss L – Cardiovascular Disease and Early Mortality

Events Leading to Death:

- The evening before her death, Miss L communicated feeling unwell. Staff believed her distress was related to anxiety about a possible GP review.
- The following morning, Miss L collapsed. Staff initiated CPR and called an ambulance, but sadly, Miss L died at the age of 29.
- The medical certificate recorded the cause of death as: 1a: Acute Myocardial Ischemia; 1b: Ischemic Heart Disease; 1c: Severe Coronary Artery Atheroma

Learning Identified:

- Cardiovascular disease is a leading cause of death for people with learning disabilities, both nationally and locally
- Remote health checks can limit opportunities for physical examination and early detection of risk factors
- Anxiety and behaviours of concern around health appointments require tailored strategies to ensure engagement
- Cross-border placements can lead to gaps in communication and coordination between services
- Severe obesity significantly increases cardiac risk and requires proactive management

Appendix C: Case Study Miss L – Cardiovascular Disease and Early Mortality

System Quality Improvement Actions Taken:

- Notification protocols for Local Area Contact (LAC) to liaise with placing authority
- GP education on accurate patient location and cross-border collaboration
- Health screening standards to ensure physical assessments during annual checks
- System learning: Lincolnshire ICB webinar to raise awareness of cardiovascular risk and preventative strategies

Positive Practice:

- Use of LeDeR reviews to identify systemic gaps and drive improvements
- Multi-agency governance panel engagement to agree actions and share learning
- Commitment to education and awareness initiatives aimed at reducing preventable deaths from cardiovascular disease

Cardiovascular Disease Webinar

NHS Lincolnshire ICB hosted and co-produced a webinar with Lincolnshire Partnership NHS Foundation Trust on 5th June 2025 to promote awareness of the LeDeR Programme and highlight Cardiovascular Disease as one of the top three causes of death of people with a learning disability both nationally and locally.

- *Guest Speaker Tina Auger, LD Physical Health Liaison Nurse, LPFT* promoted Learning Disability Annual Health Checks, discussing how diseases can be detected early and ways in which the LD Physical Health Liaison Nurses can support with bloods, screenings and onward referrals.

- *Guest Speaker Gareth Elwick Clinical & Practice Education Lead, LPFT* Provided insight into the relationship between mental capacity and choice and discussed how to support carers to make best interest decisions to influence lifestyle choices of the people they support.

- *Guest Speaker Joseph King Practice Educator & Professional Nurse Advocate LPFT* provided an overview of Positive Behaviour Support and discussed how understanding behaviours can assist in the promoting of healthy lifestyle choices.

Cardiovascular Disease Webinar

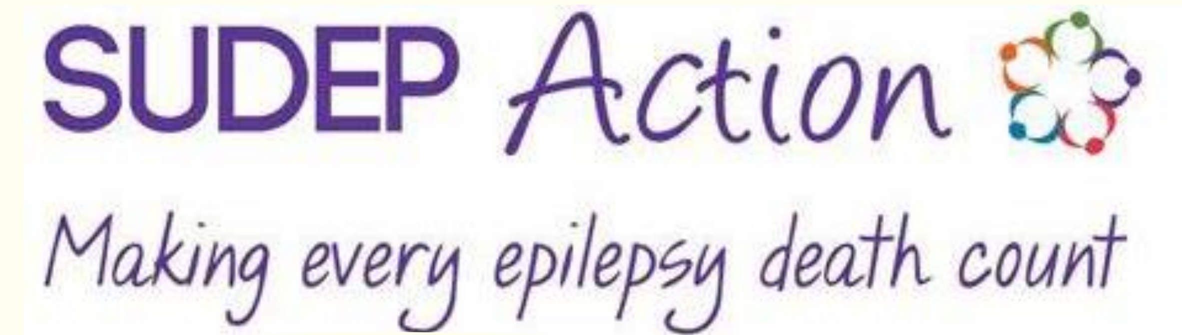
Reflective Session – Rebecca's Story

Attendees viewed a recording of *Rebecca's story;* a fictional case study developed from the findings of two local focused LeDeR reviews.

These reviews highlighted deaths caused by undiagnosed cardiac disease in young adult females, and the learning was presented to the Lincolnshire LeDeR Governance Panel.

Following the viewing, participants engaged in breakout discussions to reflect on the key themes and learning points.

The session concluded with a group discussion to share reflections and insights, reinforcing the importance of early recognition and proactive management of cardiac risk in this population.



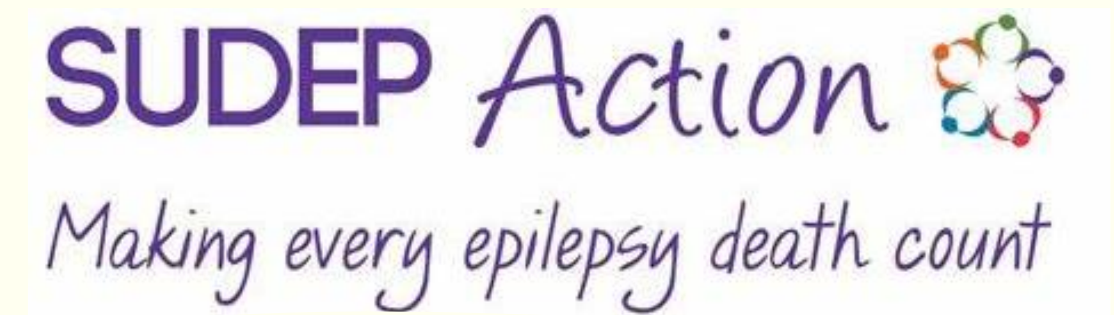
Epilepsy and learning disability – a tribute to the life of Clive Treacey

NHS Lincolnshire ICB hosted an all-day event took place in Sleaford on International epilepsy Day, Monday 10th February 2025, with 71 attendees from across health and social care professionals in Lincolnshire.

The day was led by Robert Ferris- Deputy Director for Learning Disabilities, Autism & SEND Region – Midlands and Jane Hanna OBE- Director of Policy and Influencing, SUDEP Action.

We heard from UK and international expert guest speakers on SUDEP and epilepsy risk, epilepsy and learning disability and health checks including Elaine Clarke UK patient safety advocate and sister of Clive Treacey.

Appendix E: SUDEP Action Conference



Attendees accessed a choice of workshops during the afternoon;

1. **Learning from lives and deaths - People with a learning disability and autistic people (LeDeR).** This workshop was aimed at raising awareness and understanding of the LeDeR programme.

2. **SUDEP and Seizure safety checklist Paediatric and adult resources** – The session explored how community settings have used the adult tool to improve patient outcomes and learn about the recently launched paediatric version

3. **Supporting patients with learning disability in the acute Hospital -** this session explored the reasonable adjustments of patients with learning disabilities when attending hospital.

4. **CPAP/ Commissioning guidance –** the workshop highlighted NHSE Midlands & ADDAS's - Clive's Way: A Conscience Manual and NHSE's NHSE CPAP resources [for people with Learning Disabilities, carers & healthcare professionals]. Obstructive sleep apnoea can be life-threatening for people with a learning disability.

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

Appendix F: Healthy Lifestyle Project

Lincolnshire COUNTY COUNCIL Working for a better future

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

One You Lincolnshire planned and delivered a 12-week healthy lifestyle pilot programme in 2025 in two of the learning disability hubs in Lincoln and Boston.

The programme consisted of weekly, adaptive physical activity sessions that were designed to be inclusive, engaging and fun for participants to attend.

The instructor led activity sessions also included a short 15-minute educational element that we bolted on to the end of each session, where we were able to discuss important lifestyle elements like healthy eating, physical activity, alcohol, water, sleep, stress.

Participants were encouraged to set themselves a lifestyle goal and report back the following week how they got on with their set goal.

Appendix F: Healthy Lifestyle Project

Lincolnshire COUNTY COUNCIL Working for a better future

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

“To help ensure sustainability we involved the support staff in the weekly sessions.”

“To inspire participants, we introduced a ‘move more’ Champion Trophy that was handed out to a different person each week and introduced a 21.4-minute leaderboard to help keep participants motivated to track how much movement they were doing each week.”

“We provided easy read healthy lifestyle resources and pinned this to the notice board for everyone to see.”

“We also offered both LD centres access to Gloji Gym, our online physical activity platform.”

Appendix F: Healthy Lifestyle Project

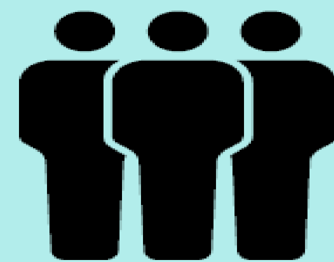
Lincolnshire COUNTY COUNCIL Working for a better future

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

HOW MANY PEOPLE TOOK PART?

Lincoln: 11 participants

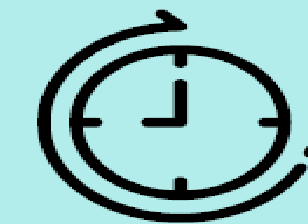
Boston: 14 participants



100% of participants reported that they felt more confident to participate in physical activity at the end of the programme

The average overall feeling of health went from 7.4 (out of 10) at the start, to 9.2 (out of 10) at the end.

WHAT INCREASE IN PHYSICAL ACTIVITY LEVELS DID WE SEE?



Lincoln:

- Average number of minutes of moderate intensity physical activity per week at the start: 45 minutes p/w
- Average number of minutes of moderate intensity physical activity per week at the end: 126 minutes p/w

Boston:

- Average number of minutes of moderate intensity physical activity per week at the start: 26 minutes p/w
- Average number of minutes of moderate intensity physical activity per week at the end: 58 minutes p/w

Appendix F: Healthy Lifestyle Project

Lincolnshire COUNTY COUNCIL Working for a better future

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

FEEDBACK FROM SUPPORT STAFF:

"I liked the activity session itself for getting the people we support exercising in a way they enjoyed it and the move more trophy as it motivated everyone to participate more in and outside of the sessions"

"The sessions delivered were of a high standard and I felt they were adapted to suit the individual needs of the people. I work with a young lad who has limited movement in the chair and was able to join in and engage with his peers. Thankyou!"

"It was a great program to take part in which the staff and people we support enjoyed. The individuals taking part were excited every week for the session and enjoyed tracking their progress on the 21.4 minutes, it helped them get motivated to exercise more and built their confidence being able to exercise whilst having fun"

Appendix F: Healthy Lifestyle Project

Lincolnshire COUNTY COUNCIL Working for a better future

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

CLIENT FEEDBACK

- Made me feel stronger week by week and more coordinated in each session
- Made me feel happy and healthy when learning new exercises, liked learning about healthy eating.
- Trudy liked running and learning new exercise routines.
- I liked joining in the exercise sessions and learning new ways to do exercise.
- Joining in with friends and learning new exercise with dave.

STAFF FEEDBACK

"The education on healthy eating helped them and the goal to win a trophy helped them continue to learn."

"Just wanted to say how much positive feedback there was from all the guys who joined in the exercise class, they had such a wonderful time, and everyone has said how much they would like to continue the journey of healthy eating and exercise, please let us know if any more sessions are planned or if we could join future pilot schemes, a big thankyou to everyone for letting us join in the sessions and we had a wonderful time!"

Appendix F: Healthy Lifestyle Project

Lincolnshire COUNTY COUNCIL Working for a better future

LEARNING DISABILITY – HEALTHY LIFESTYLE PROJECT

WHAT DID THE PARTICIPANTS ENJOY MOST ABOUT THE SESSIONS?

- Its helped her to get out her chair and been able to walk across the hall
- Exercising - swimming
- Trying new exercises
- The instructor and joining in
- Leg exercises
- Kicking with the feet and rowing
- Being happy in the session
- Shadow Boxing
- Marching exercises
- Had fun doing the exercises
- All of the exercises

NHS Lincolnshire Integrated Care Board

Bowel Cancer Screening Project

In the 2024 Lincolnshire Annual LeDeR Report, we highlighted that the The NHS Lincolnshire ICB Health Inequalities Programme was leading on a Bowel Cancer Screening Project with the support of the NHS Lincolnshire ICB Cancer Team and Dr Nicholas Bigwood who completed a GP fellowship on Deprivation.

As part of the Bowel Cancer Screening Project in Gainsborough, Mablethorpe and Skegness, it was identified that individuals with a learning disability living in Lincolnshire—particularly those in care homes and supported living settings—are significantly less likely to complete bowel cancer screening than the general population.

To help address these inequalities, Cath Koutna (Cancer Project Manager) and Dr Nick Bigwood (GP, The Glebe Practice), with strong support from a clinical sub-group, developed a practical resource titled "***Improving the Uptake of Bowel Cancer Screening for People with Learning Disabilities***". This document is designed to assist carers in encouraging and supporting those they care for to complete the screening process.

NHS Lincolnshire Integrated Care Board

Bowel Cancer Screening Project

Work is ongoing to implement support for people with learning disabilities at two stages of the bowel screening pathway: during the invitation stage (to encourage uptake when people are first invited), and at the non-responder stage (to follow up with those who have not completed screening).

The document is available here: https://lincolnshire-pacef.nhs.uk/download_file/1619/0

Lincolnshire ICB's Expert by Experience, Lorraine Abbott kindly appeared in an educational video to support people with learning disabilities to complete their bowel screening, which can be watched at the following link: https://www.youtube.com/watch?v=30KM4GYGcag

Appendix H: Lincolnshire Rapid Response Service

NHS
Lincolnshire Community and Hospitals NHS Group

Pilot scheme for children with complex respiratory needs

The Lincolnshire Rapid Response Respiratory Service featured in the LeDeR Action Learning Report for England 2023/2024.

The children's physiotherapist at Lincolnshire Community Health Services NHS Trust was profoundly affected by the death in 2018 of a child with complex needs they had treated during repeated admissions to hospital with chest infections.

The physiotherapist reflected that preventing, diagnosing and managing poor respiratory health at home would be a better way to care for the children they see in hospital, many of whom have cerebral palsy and over 80% a learning disability.

Clinicians observed that the young people under their care who were not mobile or who needed support for movement experienced recurrent chest infections or long-term ventilation.

NHS
Lincolnshire Community and Hospitals NHS Group

The response

In 2019 the physiotherapist and a colleague established a pilot scheme of support for parents and carers of children with complex respiratory needs to do some physiotherapy, as well as a visit when any child or young person at home became ill, for example, at the start of a cough – to deliver treatment.

Without this visit the child or young person would likely have seen a GP or attended hospital and potentially been admitted.

They piloted a scheme for children with complex respiratory needs to have physiotherapy and a visit for treatment as soon as they show signs of respiratory illness instead of visiting their GP or hospital.
The pilot was successful in avoiding admissions or reducing length of stay, achieving an estimated £1million saving in costs in 2023.

Appendix H: Lincolnshire Rapid Response Service

NHS
Lincolnshire Community and Hospitals NHS Group

Based on the success of the pilot in reducing hospital admissions and with recurrent funding for an expanded physiotherapy team, in February 2020 the team established the 5-day Lincolnshire Complex Needs Rapid Response Respiratory Service – a new pathway to avoid hospital admissions/readmissions for children and young people aged 19 and under with complex respiratory needs.

Since 2023, this has been an all age, 7-day service.

A physiotherapist visits the person within 48 hours of being notified by a parent or carer that they are unwell, but in practice this is usually on the same day.

People are seen at home, in school, in care homes and even at holiday sites. The physiotherapists provide treatments to keep the person well: for example, airway suction, chest percussion and use of cough assist machines.

Appendix H: Lincolnshire Rapid Response Service

Lincolnshire Community and Hospitals NHS Group

Some can prescribe antibiotics and others are training to qualify as prescribers. The physiotherapists also assess the child's chest using a risk identification matrix to identify the risk of recurrent chest infections.

Where the person needs further support, the team can contact the local district general hospital, nearby tertiary centres and other community services to request advice from consultants, nurses or palliative care teams.

If a person does need to be admitted to hospital, the physiotherapy team can assist the paramedics – for example, by sharing information about the person's specific needs, including use of the correct chair and reasonable adjustments.

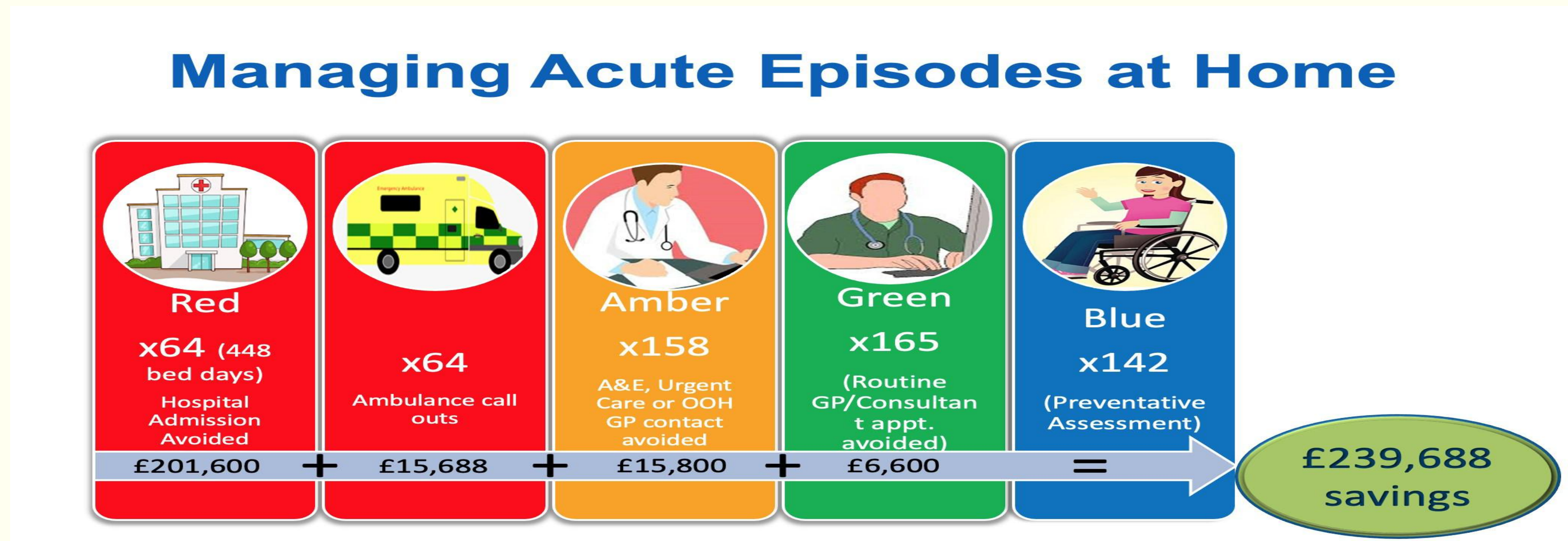
In hospital, the physiotherapists can discuss the patient's care with the consultant or other staff and train staff on using specialist kit such as a cough assist machine or oscillating vest. In one case, a physiotherapist supported a person while in A&E who had a tracheotomy and was on a ventilator.

Lincolnshire Community and Hospitals NHS Group

The outcome

From avoiding hospital admissions or reducing length of stay, the team, which now has the equivalent of 6 full time staff, estimates that in 2023 they saved £1 million in cost: a hospital admission due to asthma can cost £1,516 to £2,473 a night and an intensive care bed for a patient with a tracheotomy can exceed £3,000 a night.

Home: Lincolnshire Children's Therapy Services



Lincolnshire
COUNTY COUNCIL
Working for a better future

Technology Enabled Prevention and Care TEPaC

Lincolnshire County Council Adult Care are exploring how technology can improve outcomes for people while ensuring care and support remain available for those who need it.

As part of this work, we ran a TEPaC pilot from February 2024 to June 2025 in partnership with the University of Lincoln.

We partnered with a specialist technology provider to test a range of solutions with individuals across Lincolnshire, aiming to understand what works best and for whom.

We focussed on people who live at home, people who have family and friend carers and people who live in Community Supported Living.

UNIVERSITY OF
LINCOLN

Appendix I: TEPac

Technology Enabled Prevention and Care TEPaC

We explored whether technology from the TEPaC pilot could enable people to be more independent—both in their homes and when accessing the community.

We also looked at how technology could help people remain at home for longer, reduce or prevent the need for additional more intrusive support, and avoid long-term residential care.

We looked at how technology might help providers address some of the challenges they face when working with people who live in Community Supported Living.

The University of Lincoln carried out an independent evaluation of the pilot and provided recommendations for future service development and are now considering next steps, with a focus on helping people stay independent and at home for longer and supporting practitioners to provide the right information and advice.

LeDeR have been given permission to showcase a Case Study of a person with learning disabilities who trialled the use of TEPaC.

Appendix I: TEPac

Background

Katy is a person with Learning Disabilities lives in supported housing. Her Support Worker, Janice works with Katy very regularly and knows them well and supported with the interview. (Names have been changed to protect identities).

How Katy was referred to the TEPaC pilot was not clear but when they first moved to the house, they found it difficult to settle and manage a big transition.

Katy was offered a Robotic Companion Cat as a potential support or means of accessing comforting care during times of uncertainty.

"Because I believe Katy always lived with her relative….. And they've got a very busy household and obviously coming here, it's very much, it's quiet most days. And you are in the house more often than you probably should be."

But Katy didn't settle very well, so I think that's where the cat idea came from. To make her feel more comfortable and just have something that's hers. Because I don't think she came to terms that this was her new place now."

Appendix I: TEPac

USE

Katy loves animals and enjoys taking care of animals and people. The robotic cat was quickly adopted by Katy, and it was used all day. The cat goes everywhere in the house with Katy, and it is switched on all the time to enable the cat to be responsive to Katy attention and care. At night, the cat sleeps with Katy in her bedroom.

"Until the batteries obviously went off, she was having it every day. It was the first thing she used to turn on every morning as soon as she woke up. And you used to know when she's awake before the door was open, because you could hear the cat miaowing. So, yes, she loves her. I do think it was a really good idea."

Janice commented that Katy enjoyed tending to the cat (brushing it, stroking it and having it on her lap). Her tending of the robotic animal seemed to reflect her enjoyment and appreciation of animals and opportunities to tend to and care for animals. In the supported housing, live pets were not allowed.

IMPACT

The cat has, according to Janice, helped Katy to settle into her new home which she initially found difficult.

"I think so, personally. I do think it has helped her a lot. Yes, I would say so, because, like I said, when she first moved in, she did used to get overwhelmed, and she used to throw things and get really a bit agitated. But as soon as the cat came in, I've not noticed that behaviour has gone on my shifts anyway."

On average, batteries for the Robotic cat last for three months. Katy's cat was quite quickly low on batteries as she used it all day and every day.

Appendix I: TEPac

"They said the batteries should last three months, but they haven't. I believe it is probably because she has had it on all the time. Because they did say when not using it, obviously, turn it off. But on the days where we're in the house, it's on all day, because, obviously, she was holding it all day, and she wanted it. She used to bring it to the table, as well, when she had her dinner. It just sat in front of you while you were eating your lunch, didn't it?"

Katy was initially frustrated that the cat was not working as usual because the batteries were expiring. However, she understood what had happened to the cat and was happy to wait for replacement batteries.

"I think when she first turned it on and it wasn't working, she'd get bit mad with it because it wasn't doing what she'd known it to do. But we explained that it needed new batteries and that it'll soon be fixed and be working again."

Appendix I: TEPac

Apart from providing opportunities for Katy to realise her strengths and interests in animals and caring for them, Janice felt that the robotic cat played a big role in helping Katy to settle into her new home. Providing a source of sensory and comforting care seems to have been important to Katy during times of uncertainty and change. Perhaps the cat gave Katy a role in an environment where she did not know or understand how or where she fitted in.

"And she did have a massive difference when that cat came. Because at first, I didn't know how she would deal with it, just because I knew how overwhelmed she gets with new things. And she loved it. She had it all that day. She didn't leave its side."

Lincolnshire Primary Care Network Alliance

NHS

Trent Care Network

High Intensity Use (HIU) Service- Trent Care PCN Pilot Summary

Trent Care PCN launched a new service in June 2023 to support people who frequently attend A&E/UTC's — often because they're facing complex challenges in their lives.

These individuals make up less than 1% of the population, but account for a large number of emergency visits, ambulance journeys, and hospital admissions. The cost to the NHS is estimated at £2.5 billion a year (British Red Cross, 2021).

Why This Matters

. People who use emergency services more than expected often face:
. Poor mental health
. Housing insecurity or homelessness
. Drug and alcohol issues
. Loneliness and social isolation
. Past trauma or grief
. Difficulty accessing the right support

Appendix J: HIU Service

Trent Care PCN was chosen to pilot this service because of high levels of need in the area. Data showed a clear pattern of frequent A&E use, and the local team recognised the opportunity to offer better support.

What the Service Offers

Since June 2023, two dedicated HIU (High Intensity Use) Leads worked with individuals who attend A&E/UTC's frequently. They offer:

- A flexible, person-led approach
- Time to listen without judgement
- Help accessing mental health, GP, and community services
- Advocacy and emotional support
- Trust-building over time — often taking months

The service is non-clinical and holistic, working closely with GPs, neighbourhood teams, safeguarding, mental health services, and the police.

Appendix J: HIU Service

What We're Learning

Many people supported by the service have experienced:

- Undiagnosed or unsupported ADHD or autism
- Functional Neurological Disorder (FND) with no clear pathway
- Difficulty communicating their needs in GP appointments
- A lack of suitable local support groups

The HIU Leads have helped individuals feel heard, supported, and better connected to services — often for the first time.

LeDeR has been given permission to showcase a local case study of a young autistic man called Ben and his High Intensity Support Worker Sue (names have been changed to protect identities).

Appendix J: HIU Service

The following account is written by the High Intensity Worker who worked with Ben.

“The case that I would like to tell you about was my very first client, he had attended A&E 11 times within a period of 12 months.

I met this young man7 months ago now, he was 21 at the time, I visited him at home, and his Mum and girlfriend were there too, I sat for almost 3 hours listening to his story. They all feel let down by the system and are struggling to get any help and he summed up our conversation with he didn’t want to be here anymore!

This young man has severe ADHD and is an Autistic person and he had been taken off his medications 18 months ago, due to a heart issue and needing an ECG. His life and home are chaotic, he also suffers with anxiety and depression, which ultimately led him to The Bridge, carrying a knife, wanting to end his life, this happened on several occasions, he says has a mental health monster in his head often telling him to do bad things and to hurt people, he carries the knife as he said he would rather hurt himself than anyone else.

Appendix J: HIU Service

This young man has the kindest heart and is so keen to try anything to start feeling better, he is full of enthusiasm and ideas and wants to be able to achieve his dreams.

The first day I was there, he told me that he had had an appointment with LPFT but as his house is in chaos he couldn't find the letter and hadn't been able do anything about it. I called them and they had a conversation that evening, from this the doctors were contacted and an appointment had been made with the ADHD consultant within another 8 weeks he was back on his medication and said he felt like he was getting his life back.

We then started to tackle his finances as this young man manages his very low moods by shopping and then he doesn't have any money to pay for his bills or food, so we made an appointment at the CAB Citizens Advice Bureau).

This caused a lot of anxiety in the build up the week before, but we went and it was very productive, as there was so much to tackle, we needed to make another appointment, which was due a few weeks later.

Again, throughout the week before, the anxiety had built up as we had been having conversations with UC and DWP which he found very stressful, so the night before our next appointment came around unfortunately it all got too much, and this young man was battling with his mental health monster and took himself off to Lincoln on the train with a kitchen knife.

He said his intention was going to present himself at the police station or A&E to ask for help with his mental health, but he got arrested at the station and charged.

Then a court case was pending, this was an awful time of worry and anxiety, and he got so wound up he didn’t know how to express his feelings.

I attended court to show that he had support from his surgery alongside his Mum. Luckily, they could see that he was getting support and how much he struggled with his mental health and had no previous convictions he didn’t get charged.

Appendix J: HIU Service

So, with that behind him he we are back on track and have spent time filling out forms to write of his debts, all utility services have been contacted, and payment plans, and vulnerability packages have been put in place. Universal credit has also now been applied for.

He has also now been accepted to start on an electrician's course at college in September something he has always wanted to do, which gives him a focus for the future.

There is still a long way to go as this is also working on a whole lifestyle change, as when this young man and his girlfriend get low, they eat takeaways a few times a week, they both have diabetes and use money that should be meant for bills, they lack motivation, to tidy the house and cook or even get in the shower.

We have sat and done a very basic rota that covers everything from cleaning the house, taking medication, having a shower and cooking tea.

It is a struggle for them to follow the rota so I have now referred them to our Health and Wellbeing Coach for some professional sessions to see if this will help. They are also due to start up at the local gym for the free 12-week sessions, through One You Lincolnshire to kick start a healthier regime for themselves.

Appendix J: HIU Service

This young man's girlfriend also has her own struggles, so she has been involved in a lot of the work, and I have helped her fill in her PIP form and she has also been referred to the health and wellbeing coach and for the gym, they are each others rock, and they help each other getting out and about with their anxiety.

We don’t say sorry you aren’t on our list or fit our criteria, we know that these changes will benefit the life of our client so we do what we can to make the family life better all round.

Talking therapies have been involved but this young man is too complex, so they have referred him to Trent Locality Mental Health Services, we are now waiting on an assessment.

Appendix J: HIU Service

I have made a referral for a mental health social worker so that they can see what long term support could be provided as he does need constant reminders to take his medication and self care.

Since this intervention this young man has visited A & E once within the first 3 months and as our work has progressed there have been ups and downs, with it being stressful for him these visits have increased to 6 visits to A&E within the first 6 months, I am hopeful that these visits will now start to reduce.

This isn't by any means going to be a quick fix, but I am pleased to say that this young man's Mum is already seeing changes and is very grateful to our service and our patience, so we are getting there.

In the words of Ben " I cannot picture a life without Sam, but I know she just a phone call away".

Appendix K: LD Friendly GP Service

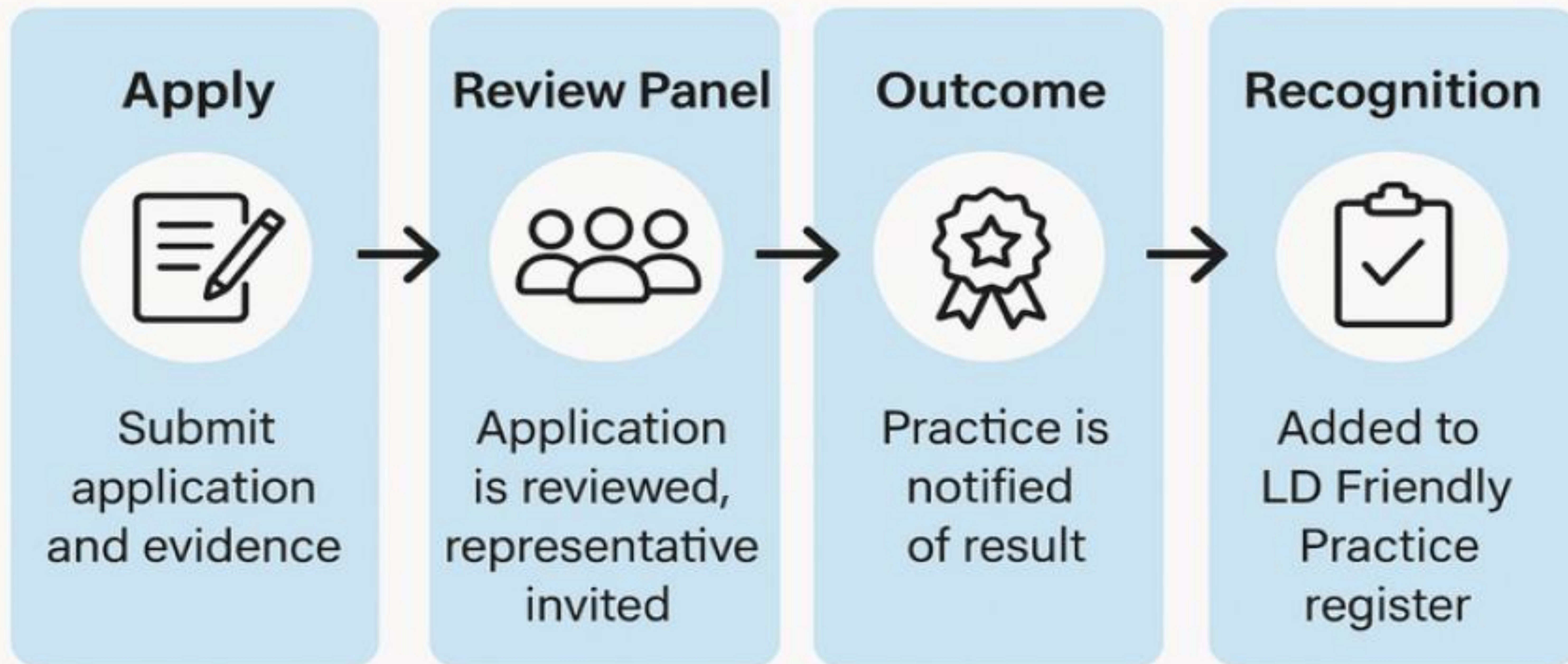
In April 2025, Lincolnshire refreshed the 'Learning Disability Friendly GP Practice Quality Mark' forms and processes. The aim of the Lincolnshire Learning Disability Friendly GP Practice Quality Mark is to improve health outcomes for people with a learning disability living in Lincolnshire by supporting GP practices to improve care quality and patient experience.

Everyone is entitled to good health care, and it is vital that LD patients have equal access also. The Quality Mark aims to recognise good practice in providing accessible health care to people with a learning disability and encourage continuous quality improvement.

Awarding the Quality Mark follows a process:

- Practices apply and need to provide the required evidence that they meet the standard;
- A LD panel, including experts-by-experience, reviews applications, a practice representative is invited to attend the panel (via Microsoft Teams);
- Applicants will be notified of their outcome, and successful applications will go through the new awarding system of Bronze, Silver, Gold;
- A register of LD Friendly Practices will be maintained by NHS Lincolnshire Integrated Care Board (ICB).

Appendix K: LD Friendly GP Service



Appendix K: LD Friendly GP Service

GP practices are critically important in supporting people with a Learning Disability (LD) to manage their health and obtain access to the health care they need.

Those with a Learning Disability may have poorer physical and mental health than the general population which means providing excellent health care includes identifying undetected and underlying health conditions, providing personalised care, and working collaboratively with families, carers, and other professionals.

Long Bennington Medical Practice were the first GP Practice since the refresh to gain accreditation, with the GOLD award!

VoiceAbility

The Speak Out Leaders: Our Journey with MHDLDA Co-production Network

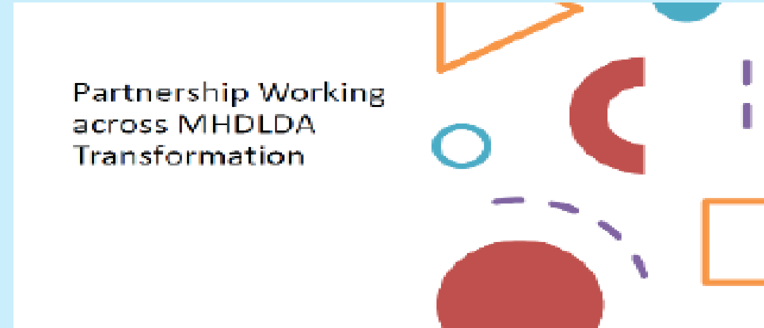
The Speak Out Leaders act as a voice for people of all ages who have a learning disability, their families and carers, and support people to get involved in all aspects of the running and delivery of Lincolnshire County Council's Learning Disability Partnership board, including Board Meetings and working groups, such as Staying Safe and Healthy Living.

By running events to give people, their family and carers a say on all sorts of issues, and working with professionals and organisations as active partners, their aim is to improve health and social care services across Lincolnshire for people with learning disabilities

The Speak Out Leaders presented their Journey with the Mental Health, Dementia, Learning Disability & Autism Co-production Network to the Learning Disability and Autism Joint Delivery Group at a face to face meeting in November 2025.

Appendix L: The Speak Out Leaders VoiceAbility

Our Journey with MHDLDA Co-production Network



- The Speak Out Leaders were invited to attend the 'No Wrong Door' Event at Sleaford in December 2024.
- The Speak Out Leaders were not involved in the preparation for the meeting.
- A presentation was given and in that presentation was a photograph of the Speak Out Leaders from the LDP website.
- This left everyone confused. We had not had any discussions about the event with anyone.

Appendix L: The Speak Out Leaders VoiceAbility

- The Speak Out Leaders did not feel very involved in the meeting.
- Making meetings accessible is not just about the venue.
- It is about time, planning, communicating with the individuals accessing.
- Our voice is valuable!
- The Speak Out Leaders fed back to the LDP board about the meeting.

Appendix L: The Speak Out Leaders VoiceAbility

- Victoria Sleight, Head of MHDLDA transformation was at the board meeting and listened to the feedback from the Speak Out Leaders.

- Victoria set a meeting up with members of the MHDLDA coproduction network and the Speak Out Leaders for them to work together.

- At our first meeting everybody was able to talk about work projects and what they would like to achieve.

Appendix L: The Speak Out Leaders VoiceAbility

- At the second meeting we all had a good look at the leaflet that had been produced promoting the coproduction network.
- The Speak Out Leaders expressed what made reading difficult, such as:
- Pictures in the background of the writing.
- Black ink on a white background.
- Fonts and sizes.
- How using photosymbols helps.

Appendix L: The Speak Out Leaders VoiceAbility

- What makes them want to look further and not be distracted by other things on the page.

- Everybody listened to each other and talked about what was said to show everyone understood.

- We have since had four meetings working together on making information accessible for all.

- A final guide to the network is now available. The information leaflet will be used across the board.

Appendix L: The Speak Out Leaders VoiceAbility

- The meetings went at a steady pace and reflected true coproduction with the Speak Out Leaders feeling involved in a meaningful way.

- Everyone felt comfortable to share their feedback.

- Everyone felt like an equally important member of the team.

- We have built trusting relationships.

Appendix L: The Speak Out Leaders VoiceAbility

- We also gained self confidence from the experience of working together.

- Through mutual respect we learnt a lot from each other.

- The whole experience was empowering for everyone involved.
- It has been a very positive journey.

End of Report