Leicester, Leicestershire and Rutland LeDeR Annual Report 2025

Leicester, Leicestershire and Rutland
Health and Wellbeing Partnership

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Foreword

Leicester, Leicestershire and Rutland (LLR) remain deeply committed to the LeDeR programme and to improving care for people with a learning disability (LD) and autistic people. This ongoing dedication is what makes the production of the LeDeR Annual Report possible.

We extend our heartfelt thanks to the many individuals and organisations across the LLR system whose passion and commitment have driven this work, those who have reported deaths, carried out reviews, and analysed the data. Most importantly, we honour the people at the heart of this report: individuals with a learning disability and autistic people, along with their families, friends, carers, colleagues, and all those whose lives are touched by this work.

We also wish to recognise our LeDeR Reviewers. Their expertise, experience, and unwavering dedication have been instrumental in getting us to where we are today. While some of those we remember are no longer with us, we hope this report serves as a tribute to their lives.

This report must not be seen as an endpoint. It is a call to action. Every partner across the LLR health and social care system has a role to play in embracing its findings. Only through collective effort can we ensure that every person with a learning disability and every autistic person receives the high-quality care they deserve. Only then can we achieve true health equality and equity.

Prof. Nil Sanganee, Chief Medical Officer Director, Leicester, Leicestershire and Rutland Integrated Care Board.

Santokh Dulai, Assistant Director (Adults & Communities), Leicestershire County Council.

David Williams, Group Director of Strategy and Business Development, Leicestershire Partnership NHS Trust and Northamptonshire Healthcare NHS Foundation Trust.

Acknowledgements

Leicester, Leicestershire and Rutland Integrated Care Partnership would like to acknowledge the support provided to the LeDeR programme by the following organisations, groups and individuals:

- NHS England National Team (NHSE)
- NHS England Regional Team
- LLR LeDeR Team
- LLR LeDeR Experts by Experience
- LPT Talk and Listen Group
- All family members' contributions
- Leicestershire Partnership Trust
- University Hospitals of Leicester
- Primary Care Services
- Leicester City Council
- Leicestershire County Council
- Rutland County Council
- Leicester, Leicestershire and Rutland Child Death Overview Panel (CDOP)
- LDA Collaborative
- DeMontfort University

Executive Summary

The 2025 LeDeR Annual report for LLR outlines the learning from the deaths of those people with a learning disability and autistic people notified to the LeDeR programme.

This year saw the introduction of the '6 High Impact Actions' set out by NHS England, focusing on the top areas of avoidable mortality in respiratory, cardiovascular disease and cancer.

Following changes to the government in Spring 2024 the new 10-year plan was outlined, including the expectation for the LeDeR programme to continue to highlight and make recommendation in the systemic learning identified locally, regionally and nationally.

As per previous years a revised LLR LeDeR Top 10 is available concluding findings and highlighting the areas requiring attention from the past year.

The report delves into the findings from LLR LeDeR over the past year in comparison to previous years and highlights areas of positive practice and areas of learning. There has been a decrease in the number of people receiving cervical screening, which is a concern. The overall number of people with a LD and autistic people accessing screening programmes remain very low in comparison with the general population.

There has been an increase in the deaths from cancer with diagnosis most often at stage 4, therefore LLR has agreed for the LeDeR focused priority review area for 2025-26 to be 'all cancer diagnoses' to allow for further understanding in this area.

The local focused priority review area for 2023-24 'deaths of those under the age of 50yrs, who had a congenital condition or syndrome, through the lens of intersectionality', was completed and the analysis and findings can be found detailed in this report.

The LLR LD annual health checks remain high and LLR have been selected as a pilot site for both the DAPPLE research project (DAPPLE stands for Developing effective service models for Adult Palliative and end of life care for People with a Learning disability) and the Combined LD, SMI (severe mental illness) and autism health check.

LLR has seen the healthy weight toolkit completion supporting cardiovascular health in people with a LD and autistic people. There has also been great success with the LD Community Phlebotomy Team pilot improving venepuncture in those with the most complex needs, a trail blazing initiative for LLR.

Respiratory remains the leading cause of death in people with a LD in LLR, the development of the Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) is at pilot stage and has been selected for oral presentation at the RCN International Nursing Research Conference in Autumn of 2025.

Locally agreed action plans conclude the report along with accompanying appendices.

In all, it has been a very challenging and positive year for the LLR LeDeR programme.

At the time of writing the National LeDeR Report 2023 has just been published and it is recommended that this report be read and reflected on in conjunction with the National report.

Throughout this report, there are direct quotes from friends and family, taken from the pen portraits of local reviews that are thoughtfully shared. These are shown in coloured bands across the pages, the first is shown at the bottom of this page.

"He enjoyed interacting with others especially when staff sang or talked to him. He loved Peppa Pig the animated television character and liked to copy the sounds that she made. He also enjoyed staff blowing raspberries at him!"

Insights from the Author

This year, the author has included personal insights to offer additional local context and reflection for consideration.

Over the past 7 years, cancer was rarely recorded as a cause of death in the LLR LeDeR reviews. However, this year has seen a noticeable increase in reported cancer-related deaths—most diagnosed at stage 4. This shift suggests a positive change in the healthcare system's ability to recognise and diagnose cancer in people with LD, where previously it may have gone undetected. As a result, more individuals with LD are now receiving treatment and pain management, which marks a significant improvement in care. Notably, most of the cancers diagnosed were not part of national screening programmes, highlighting the need to improve symptom recognition and ensure routine health checks are used effectively to detect cancer earlier.

The LD phlebotomy clinic now available in LLR is a truly trail blazing initiative, and the first of its kind nationally offering support for 12 people per year with the most complex needs. The dedication to health equity in venepuncture and people with a LD should be commended, it is anticipated that the outcomes will be seen through the LeDeR programme in the coming years. This is likely to come as a relief to many people who have LD and those who care for them knowing that venepuncture should no longer be a barrier for those most in need.

In the current reporting period, the median age of death has declined by five years compared to the previous year. This shift is primarily attributable to an increase in mortality among younger individuals with life-limiting conditions, some of whom had prognoses indicating a low likelihood of surviving into adulthood. Following a comprehensive review, it was noted that many of these individuals had exceeded their anticipated life expectancy. Furthermore, the reviews highlighted that they experienced lives and deaths characterised by quality, dignity, and meaningful engagement.

Siouxie Nelson – LLR LeDeR Clinical Lead

Introduction

National context[1]

Learning from Lives and Deaths of people with a LD and autistic people (LeDeR), previously known as The English Learning Disabilities Mortality Review (LeDeR) programme, was established as a pilot in 2015 and rolled out nationally in 2017. The aims are to:

1. Improve care for people with a LD and autistic people.
2. Reduce health inequalities for people with a LD and autistic people and
3. Prevent people with a LD and autistic people dying prematurely.

Since being established, deaths of people with a LD, and from January 2022 deaths of autistic people, have been reviewed with the findings presented in the LeDeR annual reports, where the action from learning has been captured.

The LeDeR Programme continues to complete initial or focused reviews for people. A focused review includes the initial review as well as detailed learning into action which is completed when a review meets the criteria and is presented at the LLR LeDeR governance panel.

Where possible comparisons have been drawn over time but have also highlighted where, due to the transition in the system of data collection, this was not possible. The LeDeR Programme has for the third year running, included LeDeR reviews of autistic people. As this is the third year, it was hoped there would be some data to draw upon, however the notifications of the deaths of autistic people remain low, both locally and nationally, and therefore, it is important to maintain confidentiality. Notifying a death to LeDeR is not mandatory and, therefore we would not expect LeDeR to have data on all people with a LD and autistic people who have died in LLR. Some data contains relatively small numbers of cases, so some findings must be interpreted with a degree of caution.

"Things that mattered most to him included looking smart and he particularly loved the colour red and his red shirt!"

[1] *National LeDeR Report 2021*

10 Year Plan[2]

The Government changed in May 2024, as a result of this, changes were set out for NHS England, resulting in a 10 Year Plan.

The LeDeR programme, focused on Learning from Deaths of people with LD and autistic people, is integrated into the NHS 10 Year Plan through its commitment to reducing health inequalities and improving care for this population. The plan emphasises shifting from hospital-based care to community-based and preventative care, aligning with LeDeR's goal of identifying areas for improvement in local and national services. LeDeR reviews are not mortality reviews.

LeDeR is relevant to the NHS 10 Year Plan as follows:

Focus on Health Inequalities:

The 10 Year Plan aims to address health inequalities and ensure equitable access to care for all, which is a core principle of the LeDeR programme.

Shift to Community and Preventative Care:

The plan prioritises delivering more care in the community and focusing on prevention, which aligns with LeDeR's aim to improve health outcomes and reduce preventable deaths among people with learning disabilities and autistic individuals.

Data-Driven Improvement

Both the 10 Year Plan and the LeDeR programme rely on data analysis to identify areas for improvement. LeDeR reviews provide insights into the causes of death and areas where care can be enhanced, while the 10 Year Plan uses data to track progress and measure impact.

Systemic Change:

The 10 Year Plan aims for large-scale. Transformational change, and LeDeR contributes to this by identifying systemic issues in service delivery that need to be addressed at local, regional and national levels.

"A particular memory as children was, he and his sister could never walk past a house with a gargoyle on it without walking all the way around the block to avoid it!"

[2] *10 Year Health Plan for England: Fit for the future – Gov.uk*

Top Ten Learning into Action Points 2024-2025

From the findings detailed in this report the top 10 learning into action points are shown below.

1. Reporting the deaths of those people with LD and autistic people to the LeDeR Programme is essential, particularly those from Leicester city and from diverse backgrounds.

2. Improve the application of the Mental Capacity Act (2005). All services should undertake a review of their practices to ensure compliance with this important legislation.

3. The practice of estimating someone's weight is a significant risk for people with LDs. Wheelchair scales are located across LLR and hoisting scales (available via LD community teams) are locally available to use.

4. People with behaviours that challenge require clear plans including advanced care plans and anticipatory nursing care needs, highlighting the support they require and anticipating the support they are likely to need in the years ahead.

5. Talking about end-of-life matters and having these meaningful conversations at the right time is important. Instigate Advanced Care Plans and ReSPECT forms early enough.

6. National cancer screening uptake remains low for people with LD and autistic people. How cancer screening is communicated to people is important, and so are the reasonable adjustments required. The Reasonable Adjustment Digital Flag (RADF) should be fully implemented.

7. Pain in people with a LD and autistic people can be misinterpreted or missed altogether. There are communication passports and a DISDAT (Disability Distress Assessment Tool) that are readily available.

8. Aspiration pneumonia happens as a consequence of an earlier event. Identification of risk factors and root cause analysis are important. The Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) is being piloted across LLR.

9. Cardiovascular disease is the second leading cause of death among people with a LD in LLR. A healthy lifestyle, which includes a healthy diet, physical activity, and a healthy weight are important preventative factors the 'Healthy Living Toolkits' are available.

10. Funding is secured to run a small number of specialist LD phlebotomy clinics for up to 12 people per year who have been unable to have bloods taken. This service will be implemented in the next 12 months.

High Impact Actions 2024/25

During 2024, NHS England set 6 High Impact Actions for all systems to prioritise as a consequence of the national learning from LeDeR. These actions are outlined below and the LLR High Impact Action Plan can be found towards the end of this report.

1. **Reduce <u>avoidable</u> mortality** in the 3 clinical priority areas for **Learning Disability and Autism:**
   - Respiratory
   - Cardiovascular Disease
   - Cancer

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

3. **Assure and Sustain Performance:**

4. **Improve the quality of LeDeR reviews and actions from learning.**

5. **Improve access and understanding of the importance of LeDeR reviews:**

6. **Improve accuracy of Learning Disability Registers & Increase the quality and uptake of Annual Health Checks (AHC)**

"His mother fondly shared that prior to him becoming unwell he had asked "Mummy can I go out in the car". His dad drove him to a local funfair and then to his favourite charity shop where everyone knew him which he really enjoyed."

Glossary of abbreviations

ALN	–	Acute Liaison Nurse
ASC	–	Adult Social Care
ASD	–	Autistic Spectrum Disorder
BMI	–	Body Mass Index
CDOP	–	Child Death Overview Panel
CoP	–	Court of Protection
DoLS	–	Deprivation of Liberty Safeguards
DNACPR	–	Do Not Attempt Cardio-Pulmonary Resuscitation
DVT	–	Deep Vein Thrombosis
EBE	–	Expert by Experience
ECG	–	Electrocardiogram
GP	–	General Practitioner
ICS	–	Integrated Care System
IMCA	–	Independent Mental Capacity Advocate
LTC	–	Long Term Health Conditions
LeDeR	–	Learning from Lives and Deaths Review Programme
LD	–	Learning Disability
MCA	–	Mental Capacity Act
MDT	–	Multi Disciplinary Team
MHA	–	Mental Health Act
MCCD	–	Medical Certificate of Cause of Death
NHS	–	National Health Service
NICE	–	National Institute for Health and Care Excellence
ONS	–	Office for National Statistics
PBS	–	Positive Behaviour Support
PEG	–	Percutaneous Endoscopic Gastrostomy
PCLN	–	Primary Care Liaison Nurse
RCN	–	Royal College of Nursing
ReSPECT	–	Recommended Summary Plan for Emergency Care and Treatment
SALT	–	Speech and Language Therapy
SJR	–	Structured Judgement Review
SMART	–	Specific Measurable Actionable Realistic Timebound
STAMP	–	Supporting Treatment and Appropriate Medication Treatment in Paediatrics
STOMP	–	Stopping the Over Medication of People with LD and Autistic People
SUDEP	–	Sudden Unexplained Death in Epilepsy
WTE	–	Whole Time Equivalent
WHO	–	World Health Organisation

Reviews of deaths

Deaths notified to the LLR LeDeR programme.

A total of 90 deaths of people with a LD and autistic people were notified to the LLR LeDeR Programme from 1st April 2024 – 31st March 2025, of those people:

- 4 people were autistic.
- 13 were out of scope as they did not meet the criteria.
- 15 were adults with a LD and autism.
- 58 were adults with a LD.

Referrals received in year.

shows a total of 90 deaths referred to LLR LeDeR in 2024/25, broken down into initial and focused categories. At end of year, 20 cases remained in progress and 52 had been completed.

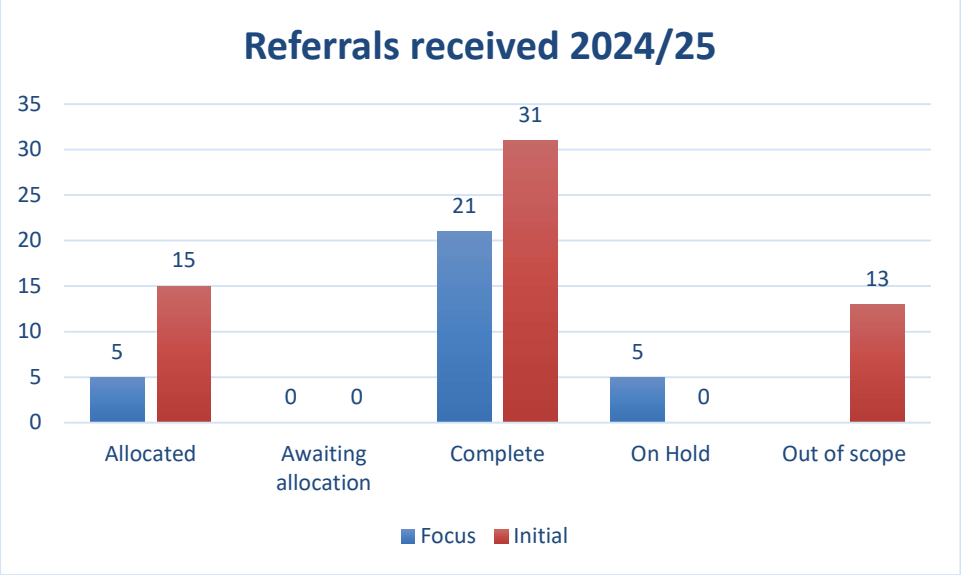


Figure 1. Referrals received by type, 2024/25

Age at death in 2024/25

Median age at death for those who passed away and their deaths notified to LeDeR in 2024/25 was 61yrs. This has fallen since last year which was 66yrs. National LeDeR data (2023), shows the median age at death at 62.5yrs.

The median age of death was 47yrs for those from a diverse ethnic background and 62yrs for those from a White British background. Only 11% (n=7) of reviews notified to LeDeR were people from a diverse ethnic background, over half of those people were under 50yrs, and had a congenital condition or syndrome, reducing the median age. It is important to understand that some congenital conditions and syndromes can unfortunately be life limiting, in LLR it is generally observed that people with a LD and autistic people do survive to the average life expectancy for their condition. Although, it is difficult to know whether underlying genetic predisposition due to known conditions, or other external factors, contributed more towards early demise.

It is important to understand the reason for the lower median age of death in those from a diverse ethnic background and therefore analysis was carried out to check the cause of death, the grading of care and if the death was felt to be avoidable at the governance panel:

- Causes of death included syndrome and congenital condition, cancer, status epilepticus, Covid-19, aspiration pneumonia and gastrointestinal.
- Grading of care, 71% (n=5) of reviews were graded 3 or higher and 29% (n=2) of reviews were graded 2. This indicates that concerns around quality of care and the right support was identified in 29% (n=2) of the reviews.
- 14% (n=1) of the deaths were considered to be avoidable due to reasons related to the deteriorating patient.
- It is important to note that the number of people mentioned within the analysis are on a statistical note, small and therefore, it is expected that this can have bigger changes year upon year. Therefore, this year LLR LeDeR has included 3 year rolling data sets for median age at death and mean age at death, which endeavours to give a more accurate picture. This can be found in the Equality Impact & Demographic Data section.

The median age at death in 2024/25, was 61yrs.

"He went everywhere with his penny whistle; he would play it on the bus home from school as a child. After he developed dementia, the only tune he could remember was 'Happy Birthday', but it still meant the world to him".

Mean age at death. As the annual report commenced in 2021, it felt an appropriate time to statistically consider previous years with regards to the mean age at death. To ensure this was comparable two sets of data are shown, the first includes the deaths of children (CDOP) and the second excludes CDOP. This is because CDOP was taken out of the LeDeR programme in 2023.

Mean Age of Death - Notifications received by LLR in Financial year including CDOP		Mean Age of Death - Notifications received by LLR in Financial year excluding CDOP
2021/2022	56 years	59
2022/2023	58 years	62
2023/2024	59 years	59
2024/2025	56 years	56

The mean age at death in 2024/25, was 56yrs.

"Mum described her as a massive character with red hair and green eyes, a young woman proud of her Celtic heritage and expressed her creativity through music and poetry."

Mean age at death in completed reviews

The mean age of deaths in completed reviews in 2024/25 is 56yrs, this is lower than 2023/24 which was 65yrs. Due to the statistically small number of data, this year LLR LeDeR has included for the first time 3 year rolling averages have been used from 2023-2024 onwards for the mean age at death (this 3 year rolling average includes data from 2021/2022 to 2023/2024), which endeavours to give a more accurate picture and it allows for any annual variations and extreme anomalies.

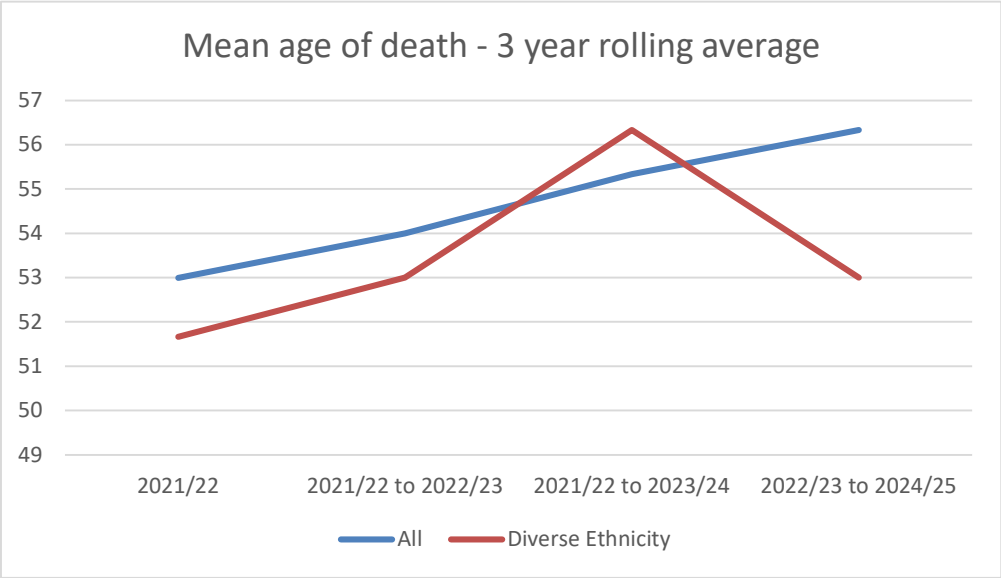


Figure 2. Mean age of death 3 year rolling average

Month of death

The 77 deaths referred to LeDeR in this time-period as shown in Figure 3. *Month of death*, with more deaths occurring in November than any other month. This is broken down in *Figure 4. Month of death by gender* This excludes 8 notifications received in 2024/25, who died prior to this reporting year. It is usually expected in the United Kingdom (UK) to see seasonal differences as sadly more deaths generally occur during the winter period.

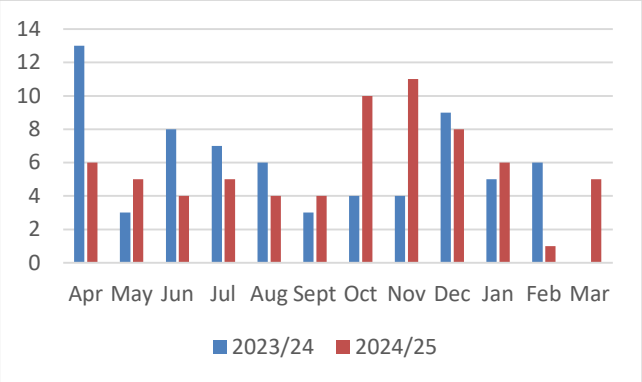


Figure 3. Month of death

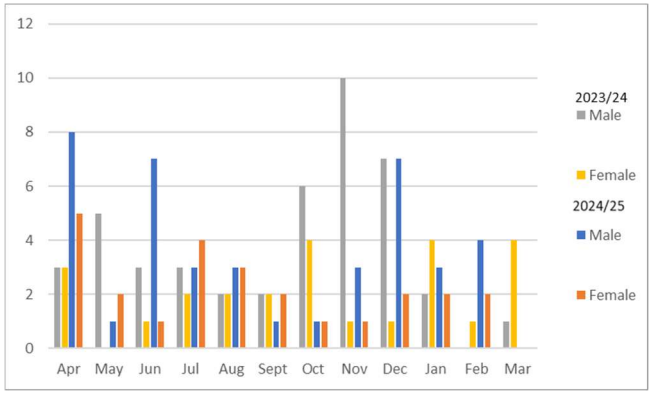


Figure 4. Month of death by gender

Reviews completed in year.

Analysis from this point covers all reviews that were completed within the 12 months from 1st April 2024 to 31st March 2025, rather than those received in that period.

This enables comparison with previous reports, and it is possible only to report accurately on cases that were completed at the time of writing.

In 2024/25, the LLR LeDeR programme completed 63 reviews, 36 of which were initial, 27 focused (*Figure 5. Reviews completed in 2024/25*.) The key performance indicator set nationally is that 35% of LeDeR Reviews are to be focused.

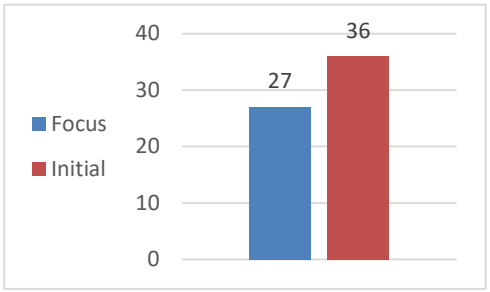


Figure 5. Reviews completed in 2024/25

For LLR LeDeR 42% of reviews were focused during 2024/25.

Equality Impact & Demographic Data

Age Group

Deaths were broken down by age group (see *2023/24, 2024/25*), 52% of people who died were aged 61yrs or older, which is an increase since the past year of 1%. By comparison, deaths by age group in 2023/24 in LLR LeDeR shows 51% of people who died were aged 61yrs or older. For wider comparison, an average age at death for people with a LD is 62.9yrs (National LeDeR Report 2023), for autistic people is 75.7yrs (National Autistic Society 2025) and for the general population this was 81.77yrs (UK Population Data 2023).

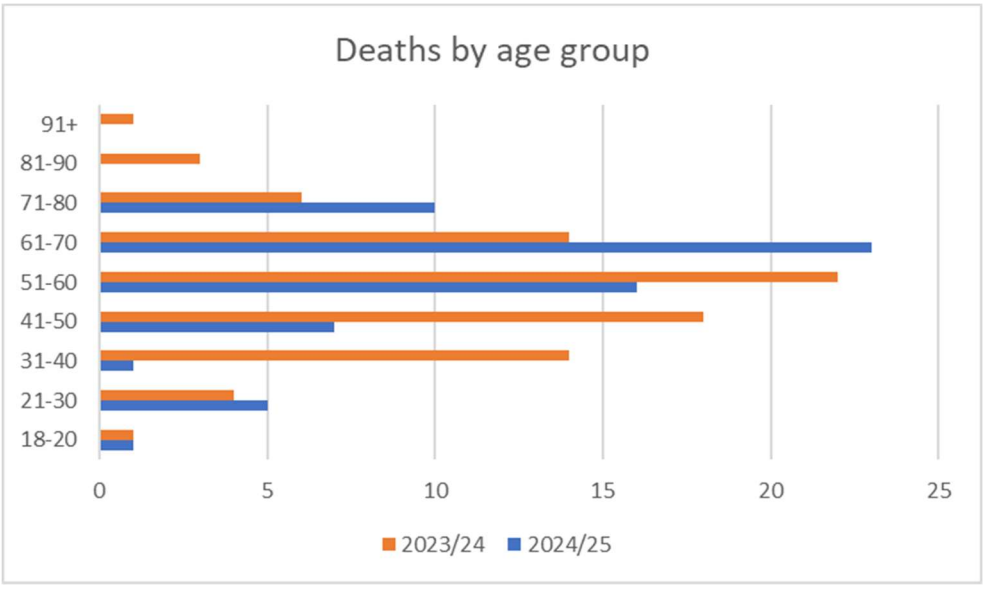


Figure 6. LLR LeDeR Deaths by age group 2023/24, 2024/25

Age of death in completed reviews by group.

Due to the statistically small number of data, this year LLR LeDeR has included for the first time 3 year rolling averages which have been used from 2023-2024 onwards for the age at death (this 3-year rolling average includes data from 2021/2022 to 2023/2024), which endeavours to give a more accurate picture and it allows for any annual variations and extreme anomalies, shown in figure 7.

ONS data is show in figure 8 for comparison for age at death for England and Wales in 2022.

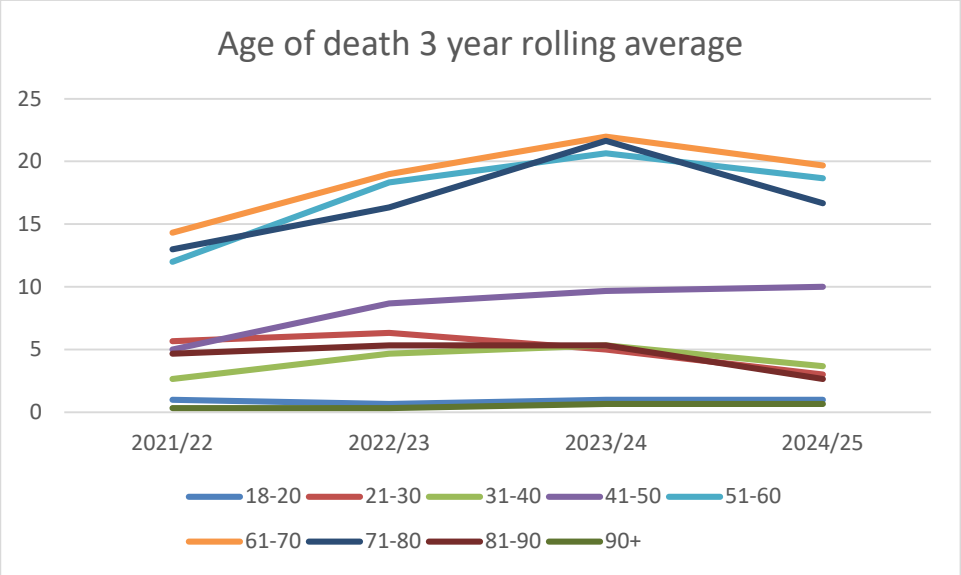


Figure 7. Deaths by age group 3 year rolling average

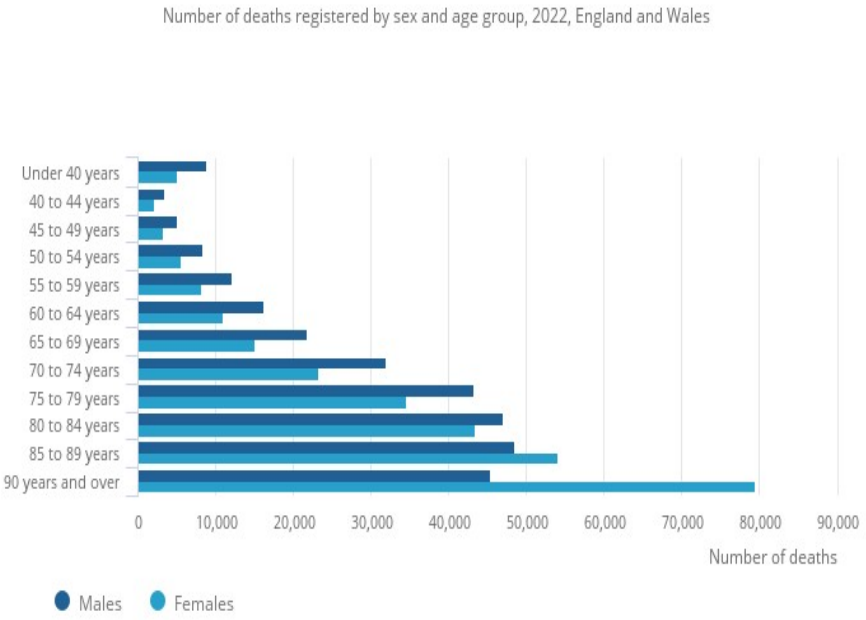


Figure 8. Death registration summary by ONS

Median age at death in completed reviews.

The median age of deaths in completed reviews in 2024/25 is 62yrs, this is lower than 2023/24 which was 65yrs. Due to the statistically small number of data, this year LLR LeDeR has included for the first time 3 year rolling averages which have been used from 2023-2024 onwards for the median age at death (this 3-year rolling average includes data from 2021/2022 to 2023/2024), which endeavours to give a more accurate picture and it allows for any annual variations and extreme anomalies.

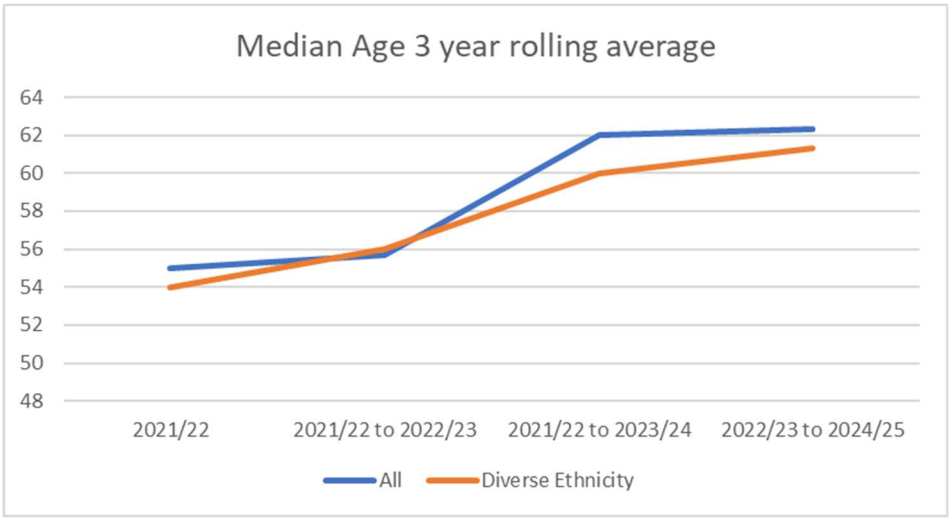


Figure 9. Median age 3 year rolling average.

Ethnicity

Most of deaths were of 'White British' people (89%), with 6% of people 'Asian or Asian British' and 3% of people 'Black, African, Caribbean or Black British'. The remaining 2% of people is 'Other ethnic groups' shown in

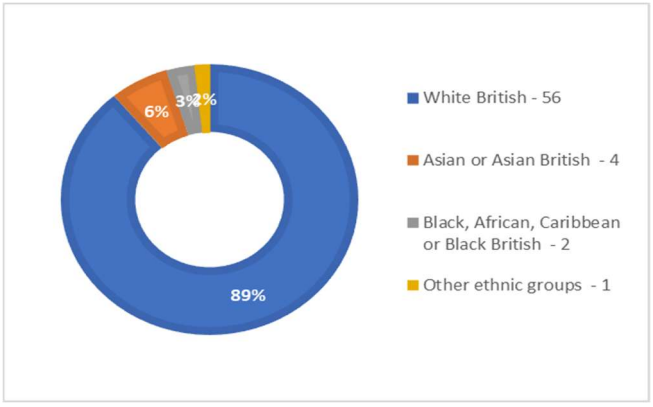


Figure10. Cases completed 2024/25 by ethnic group.

Breaking this down further and omitting the 'White' ethnic group allows us to see a clearer picture within different ethnicities, as shown in

The median age of death was 47yrs for those from a diverse ethnic background and 61yrs for those from a White British background.

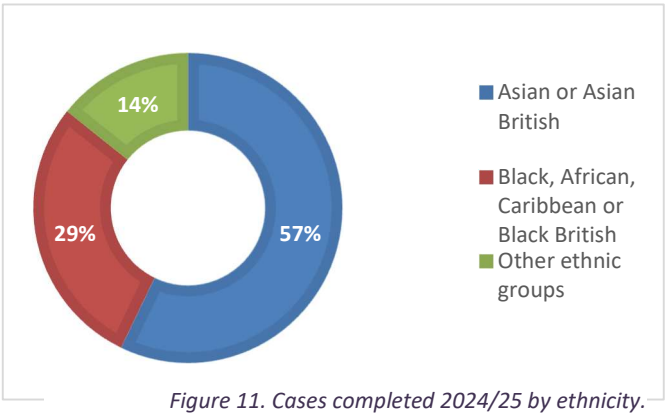


Figure 11. Cases completed 2024/25 by ethnicity.

As shown in *Figure 12. Deaths by gender*, 60% of reviews completed in 2024/25 were male, 38% female, and 2% transgender, which is in line with national and local gender demographics. Those people were resident across all three ICS places, lower for East Leicestershire and Rutland and West Leicestershire but higher in Leicester City as illustrated in *Figure 13. Deaths by ICS place.*

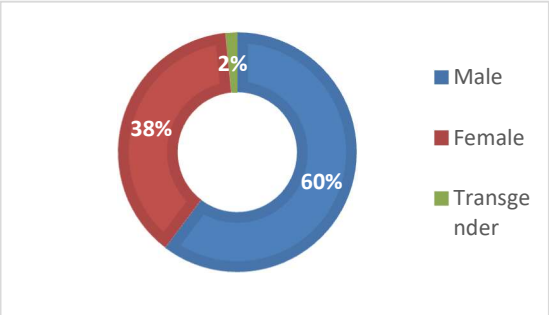


Figure 12. Deaths by gender

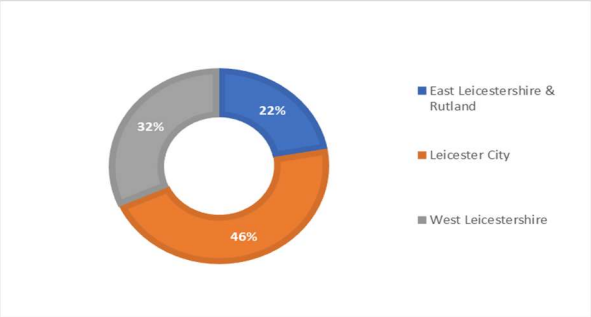


Figure 13. Deaths by ICS place

Reason for focused review

Focused reviews are completed for various reasons, as shown in *Figure 14 Focus by category*.
It is a priority set by the National LeDeR programme to conduct focused reviews for the following reasons:

- Autistic people.
- People who are from a diverse ethnic background.
- Being open to the criminal justice system as an offender in the previous 5yrs.
- Being under section of the Mental Health Act (1983) in the previous 5yrs.
- Family request.
- Local priority focused review area.
- Due to safeguarding or concerns in care.

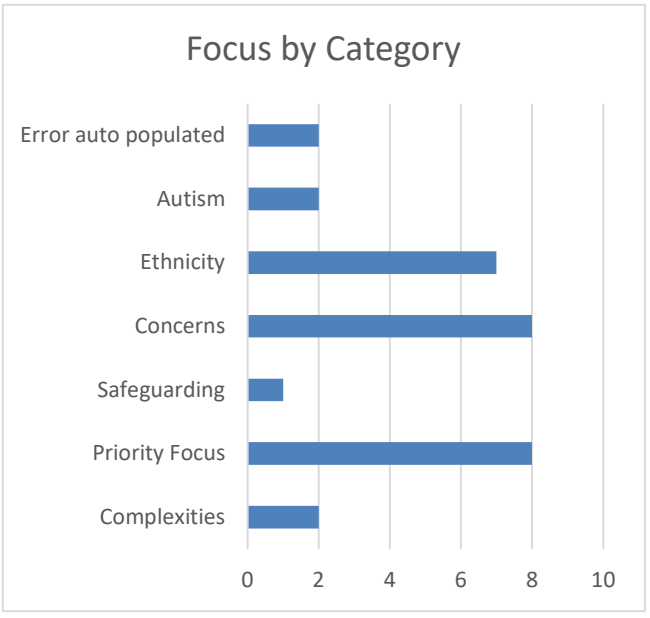


Figure 14. Focus by category

Most focused reviews are carried out due to diverse ethnicity. There were no focused reviews carried out due to being open to the criminal justice system as an offender, nor due to being under the section. There were more reviews carried out in 2024/25 due to concerns in care the person received. This year there was 1 death reviewed under an extraordinary governance panel, where those involved in the person's care were brought together to extract detailed learning from the review due to significant concerns in the person's care. This process was used as the review

did not meet the criteria for a safeguarding adults review, however it was felt significant learning would be better understood by listening to a group collectively of those directly involved in the care of this person. The LeDeR Governance Panel is usually anonymous which is what made this panel extraordinary.

Intersectionality

Intersectionality continues to be promoted in the LeDeR Governance Panels and reviews. LeDeR is striving to increase learning into action in this area and aims to ensure that the Governance Panels are diverse.

Important Statements from LeDeR

Although a lot of positive, encouraging and at times courageous work has been seen in the past year for the LLR LeDeR Programme and LLR Health and Social Care System, there are two areas that require immediate action to resolve. As a system we must be mindful that reasonable adjustments by mainstream services of all types is not optional; it is a requirement under the Equality Act (2010). This year the issues with the Mental Capacity Act (2005) are sustained issues from previous years.

1. Although improvements have been made with regards to the Mental Capacity Act (MCA) (2005) during the past year. The same problems persist.
   The learning demonstrates that the system in LLR continues to be challenged in the correct and complete application of the Mental Capacity Act (MCA) (2005) for all people with a LD and autistic people. This is problematic for impending investigations and treatment, creating unnecessary delays and consequently unlawful restrictive interventions. Many professionals have legal obligations under the MCA, but LeDeR consistently finds evidence that these are not fulfilled. This leaves people with a LD and autistic people at increased risk of poorer health outcomes and does not uphold their rights under the MCA. LLR LeDeR urges local organisations to take action that will improve the application of the MCA.

2. LLR LeDeR have seen a rise in people with a LD dying from cancer particularly in the past year. It is a concern that most of those people had a stage 4 cancer diagnosis, which means the cancer was at the most advanced stage. LLR LeDeR urges local health and social care organisations to act accordingly to improve earlier cancer diagnosis in line with the standards experienced by the general population; through improvement of access to local screening programmes and through more vigilant assessment of individuals presenting with nonspecific symptoms. It is important to note many of those cancers were not those identified through the national cancer screening programmes.

Causes and Circumstances of Death

In this section, the circumstances and most common causes of death are summarised.

Cause of death by demographic group

Age Group

It is shown in *Figure 15. Cause of death by Age Group* that the most frequent cause of death (CoD) was respiratory illness and that this affected most age groups, notably prominent in people aged between 51yrs and 70yrs.

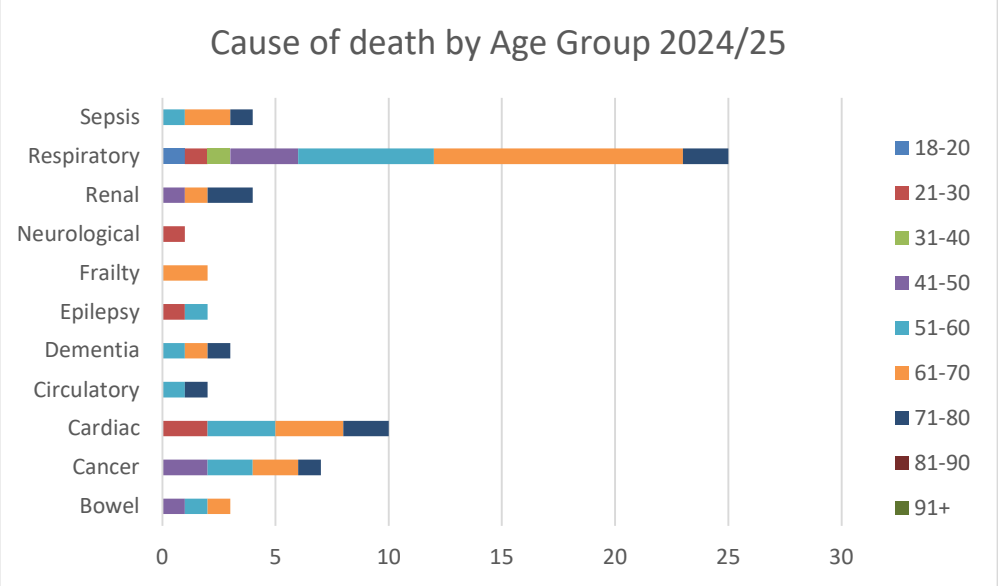


Figure 15. Cause of death by age

Breaking down of CoD by Ethnicity is shown in *Figure 16. Cause of death by Ethnicity.* It should be further noted that only 11% (n=7) of notifications received were those from a diverse ethnic background, therefore implicating statistical generalisation.

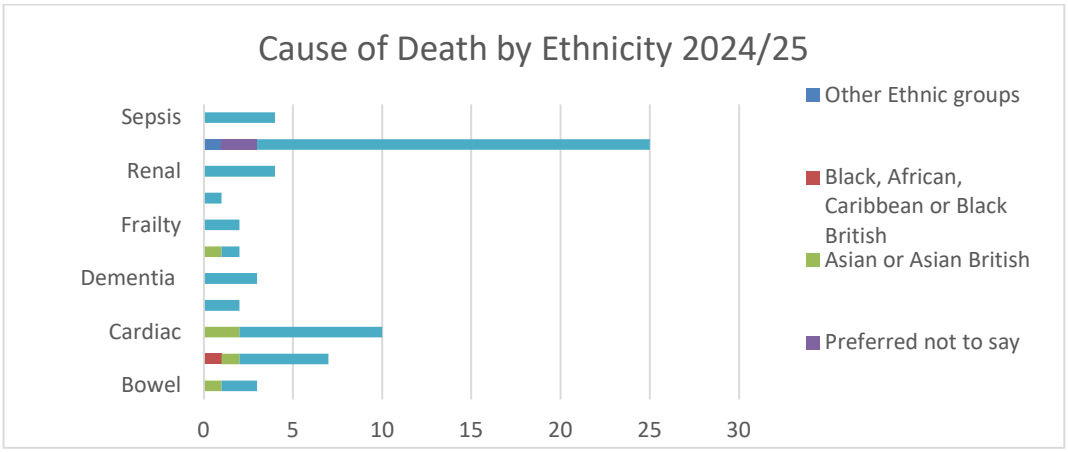


Figure 16. Cause of death by ethnicity

Leading Causes of Death

Causes of death in reviews competed in 2024/25 are shown in *Figure 17. Causes of death* below. Respiratory remains the leading cause of death, followed by Cardiac and Cancer. Respiratory accounts for 40% of deaths in completed reviews in 2024/25.

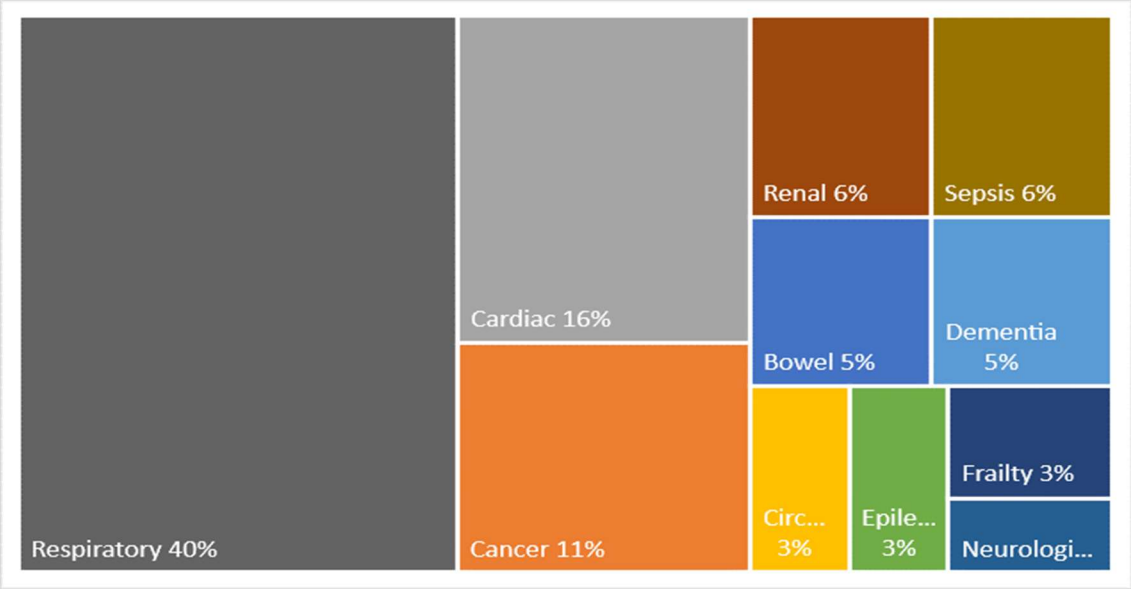


Figure 17. Causes of death

Respiratory Deaths

Deaths from respiratory causes remains the leading cause of death for those in LLR reported to LeDeR, this is the same as last year. There was cause for concern that 2 deaths reported were related to Covid 19, the first since March 2022. The 2 individuals although unrelated had both had vaccination up until 2023 and then no further vaccinations since. The respiratory thematic analysis can be found in the LeDeR 2022 annual report. The aspiration pneumonia thematic analysis can be found in the LeDeR 2023 report. Respiratory deaths remain an area of focus for LLR LeDeR particularly with regards to deaths where there were avoidable factors highlighted. The SMART actions continue to progress as learning into action with a dedicated workstream.

"She was known to have a bubbly and smiley personality, who liked to be pampered and was very well known for her bright red curly hair!"

What do we want to achieve?

Aspiration Pneumonia

The aim for 2024/25 is to reduce preventable aspiration pneumonia deaths in people with LD in LLR by adjusting already existing care pathways to include a multi-agency response and address the precipitating factors linked to increased risks to aspiration pneumonia.

A comprehensive plan has been created, called the 'Leicestershire Aspiration Pneumonia Protection Plan (LAPPP)' based on the findings and is currently being piloted as part of the testing phase prior to implementation. This work has been written up as a journal article to enable ongoing learning and research in this area and is due to be published next year. This work has also been accepted for oral presentation at The RCN International Nursing Research Conference in Exeter in September 2025. LLR LeDeR are also working with some other Midlands LeDeR programmes on progressing further collective analysis around aspiration pneumonia.

NHS England produced the 'Right Care Scenario' relating to aspiration pneumonia, which is an excellent resource and can be found here:

20241402-Learning-disability-and-aspiration-pneumonia-FINAL.pdf (gettingitrightfirsttime.co.uk)

Cardiac

Deaths from cardiac causes have decreased since last year but remain the 2nd highest leading cause of death. 9 out of 10 (90%) of people who died from a cardiac related deaths had recorded in their clinical records overweight, or obesity for their BMI category, which is known to increase the risk of heart and circulatory diseases. It would be beneficial to increase awareness for people with a LD of healthy hearts and what measures can be taken to optimise cardiac health. The types of cardiac issues included: coronary atherosclerosis, myocardial infarction, hypertensive heart disease, cardiac arrest.

The prevalence of both underweight and obesity is disproportionately higher among people with a LD than in the general population. Data was extracted from general practice registers across LLR and analysed in August 2025. The analysis indicated that between 22–27% of individuals with a LD were of a healthy weight, 27–34% were living with obesity, 22–25% were living with overweight, and 14–29% were underweight.

Both underweight and excess weight are closely linked to a range of health conditions. Obesity, in particular, is associated with increased risk of certain cancers (for example colorectal), cardiovascular disease, type 2 diabetes, and chronic kidney disease. Many of these conditions feature prominently among the leading causes of death reported in LeDeR.

Underweight is also a significant health concern, yet it is often less emphasised in public health discourse. Being underweight is linked to malnutrition, increased susceptibility to infections, and reduced muscle mass and strength. It may also be associated with underlying health conditions,

difficulties with food access or preparation, and mental health challenges. In people with a LD, underweight can exacerbate existing health inequalities and contribute to poorer outcomes, including increased hospital admissions and reduced life expectancy.

Early identification of weight-related concerns, and appropriate support is essential for a shift towards a preventive healthcare approach. This not only mitigates risks to health and quality of life but also carries significant economic implications. Recent analysis (Aristotle, July 2025) estimates that the annual healthcare costs for an individual with a learning disability living with obesity are £2,729.40 higher than for an individual living without obesity.

In response to these findings, a collection of healthy living toolkits was co-produced with lived experience partners, family carers, and professionals from across the health and social care sectors. These toolkits address weight monitoring, early warning signs, and appropriate interventions, while emphasising the role of physical activity, a factor often neglected in weight management strategies. The toolkits are freely accessible online and developed for different audiences, including general practice teams, family carers, healthcare professionals, care providers, adult social care workers, and an easy-read version for people with a learning disability.

https://leicesterleicestershireandrutlandhwp.uk/about/collaboratives/lda-collaborative/new-healthy-living-toolkits/

Cancer

Deaths from cancer have risen again and remain the 3rd leading cause of death. As reported last year, although this could be due to improved cancer diagnosis for people with a LD and autistic people and more people receiving diagnostic tests than seen previously. The area of concern is still the number of people who received a late cancer diagnosis, which was 71% of people with a cancer diagnosis. Other areas of concern included issues around the use of the MCA, and lack of comprehensive clinical assessment. It is clear to see that much work is to be done with earlier cancer diagnosis in people with a LD and autistic people, it is recommended that health and social care professionals work together to ensure equality of outcome for cancer care for this population. It was noted that one review of the death of a person with cancer revealed only positive practice with their care, identifying good use of MCA and MDT working.

The types of cancer included prostate, colorectal, cholangiocarcinoma, ovarian, vulval, penile and pancreatic, these are not cancers identified through the national screening programmes.

Quality of Care

High quality health and social care is of paramount importance for people with a LD and autistic people. However, evidence has demonstrated that this is sometimes not achieved and sadly, the impact of this can contribute to early or avoidable mortality. Focused LeDeR reviews are graded in two areas, in line with the LeDeR Policy (2021), the overall quality of care the person received and the right support. The score is an overall judgement on the care the person received, it is not reflective of one service but of all the services who worked with the person as an entirety.

The breakdown of the grading can be found in *Appendix* .

Context for grading of care 2024/25 shown in figure 18.

Scoring of 2 for Quality of Care: This relates to concerns of a late cancer diagnosis, MCA omissions and suboptimal end of life care.

Scoring of 3 for Quality of Care: This relates to concerns of reasonable adjustments, MCA and concerns around communication.

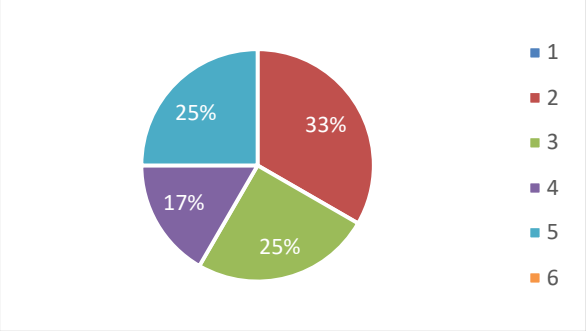


Figure 18. Grading of care

Scoring of 4 for Quality of Care: This relates to concerns the about deteriorating patient and MCA.

Scoring of 5 for Quality of Care: This relates to positive end of life care planning, appropriate use of MCA, deteriorating patient, communication, and care co-ordination.

There were no gradings of 1 or 6 in 2024/25.

Grading of the Right Support.

Overall, almost 50% of care was found to be satisfactory or good, a further 25% were above average, which is an improvement on last year; however, this still presents LLR with opportunity for improvement.

Some examples of the positive learning found related to **the right support**:

- Care planning, MDT working, compassion, proactive care, consistent preventative healthcare including LD Annual Health Checks, vaccinations, screening and early diagnosis and intervention, professional curiosity.
- Carers seeking advice and further support from specialist services; GP providing consistent care and treatment; person-centred care; providing correct equipment efficiently; support for medical staff to access information about a person with a LD at the time it was needed, non-judgemental approaches.

As only focused reviews are graded and by nature many cases that require the initial review have fewer areas of concern, a level of caution in the interpretation is required. Although this information has been approved and supported through the LeDeR governance panels.

Ten Key Themes

All learning from LeDeR nationally requires theming.

In LLR, *Table 1. 10 Key Themes - learning points* shows the number of actions (learning points) related to the 10 key themes.

Theme	No. of learning points 23-24	No. of learning points 24-25
Professional practice and provision of care	162	200
DNACPR recommendations and end of life care	64	65
Learning Disability Awareness	24	47
Care Pathways	60	38
Safeguarding	24	22
Family and carer awareness of available support	48	19
Training on specific conditions	12	9
Transition	10	3
Involving the Coroner	1	2
Grand Total	**427**	**431**

Table 1. 10 Key Themes - learning points

The area of highest concentration 2024/25 remains the same as 2023/24 and is with regards to professional practice and provision of care. This is broken down again in *Table 2. Sub-themes - learning points*. *(Please note only top 10 sub themes included.)*

Sub theme	No. of learning points
Reasonable adjustments	44
End of Life	42
MCA	40
Person Centred Care	38
Communication	28
Care Planning	25
Deteriorating Patient	23
ReSPECT	21
Cancer screening	21
Annual Health Check	21

Table 2. Sub-themes - learning points

Priority areas of learning

This section outlines the priority areas of learning from the LLR LeDeR reviews for the past year. The top 3 priority areas are Reasonable adjustments, End of Life, and MCA, which are all different from the previous year's priorities for learning [*Person Centred Care, Deteriorating Patient and Care Planning*]. Some anonymised information reviews have been included to aid learning and context shown below.

Reasonable Adjustments

Learning [22]

"It was recommended by health care professionals that he be weighed every two weeks. However, he would often decline being weighed. As a result, this presented challenges for health care professionals and care staff to monitor any weight loss or progress with weight gain."

"Progress was halted for the gentleman in getting his prosthetic leg. He was choosing to sleep in a chair, and this was impacting on the healing of his leg and foot ulcers. Therapy was limited for him as he did not get up until 16:00 hours and did not engage with therapists, preventing them from assessing his ability to transfer." [Autism]

"He died suddenly from heart disease, he had known high blood pressure and an unhealthy diet (excess Lucozade and sugary diet), he had a BMI in the overweight category. He did not respond to cancer screening letters. Although he did attend for GP appointments, he would decline any form of examination / blood test and not attend follow up appointments / would not wait at A&E. This gentleman had lived most of his life with his parents, when they were sadly no longer able to support him, little was known re: reasonable adjustments." [Autism]

Positive Practice [22]

"SAT (Specialist Autism Team) had placed an alert on the electronic patient record stating that he had a hospital booklet and a PBS reflecting his needs and how support could be offered."

"He was seen by Neurology services after experiencing a first epileptic seizure and diagnosed with late onset myoclonic epilepsy in Down syndrome. Following discharge, he was allocated to a patient initiated follow up, so that in the next 3 years carers could request an appointment through the booking system and advice was available from the epilepsy specialist nurse in line with NICE guideline NG217 Epilepsies in children, young people and adults."

"A 73yr old with a genetic condition, epilepsy, and selective mutism. The LD psychiatrist was keen to ensure reasonable adjustments and displayed professional curiosity to ensure consideration of existing conditions alongside dementia investigation, this reduced the risks of diagnostic overshadowing."

End of Life

Learning [11]

"He deteriorated and required hospital admission, where he was placed on a palliative care pathway. The family felt his needs on discharge would be better met within in a home with nursing care. This went to the CoP (Court of Protection) and it was ruled that he should be discharged to the placement the family had identified. Sadly, he passed away in hospital prior to his discharge."

"She had been diagnosed with advanced colorectal cancer stage 4 with metastasis. When she became unwell and was felt to be in the end days of life family were not informed by carers of the situation and were only informed when LD SALT contacted them."

Positive Practice [31]

"A 77-year-old gentleman with a moderate LD and autism. When his health began to deteriorate, he was placed on an end-of-life pathway and during his last hours, the duty GP attended his home to discuss his care with his carers. This is not usual practice or protocol and demonstrates exceptional care, going above and beyond for patients with a LD for the GP practice."

"Throughout his life he resided in 10 different homes and had been placed under a section of the Mental Health Act (1983) on 3 separate occasions. His final placement, although a long distance from home, had the skills to provide end of life care for him. The impact of this was that he had a home for life and death, he had no further moves. He required nursing care and was supported to remain at home with his care staff who knew him and additional district nurse support."

Mental Capacity Act (2005)

Learning [30]

"A 59-year-old male from a diverse ethnic background. He lived at home with his father in the downstairs area of the house. He required moving and handling equipment, however this was declined by his father. The bathroom for him to access was cluttered with belongings and therefore not in use. There was no consideration of the use of the MCA with regards to his decision making for where he lived and received his care and support. Communication was had with his father, leaving his voice and wishes unknown."

MCA was not followed with regards to a gentleman being non concordant with his anti-epilepsy medication. He was at high risk of SUDEP. An MCA assessment was required with regards to the decision of taking antiepileptic medication. He was deemed to lack capacity. However, due to the risks involved with the frequency of not taking his antiepileptic medication a multi-professionals meeting should have been convened to address those areas placing him at risk. There is also a LD epilepsy clinic that this gentleman was a candidate for consideration, MDT working with the LD psychiatrist would be recommended to aid access to the clinic.

Positive Practice [10]

"She had been diagnosed with cataracts and following IMCA involvement and guided support she underwent successful surgery."

STOMP/STAMP

(Stopping Over Medication in People with a LD and Autistic People/Supporting Treatment and Appropriate Medication in Paediatrics)

LLR LeDeR has again seen a reduction in the prescribing of psychotropic medication without a STOMP/STAMP review. This is extremely positive and encouraging. There were 32 people prescribed psychotropic medicine at the time of death, 82% had a STOMP/STAMP review, 10% did not and no data was available for 8%. This is a significant improvement on the previous year as only 72% of people had a STOMP/STAMP review and 16% did not, and no data was available for 14%. Due to more accurate data being available *figure 19* shows a significant increase in the numbers having a STOMP/STAMP review. This improvement reflects the hard work of our GP and Psychiatry colleagues and the STOMP/STAMP workstream.

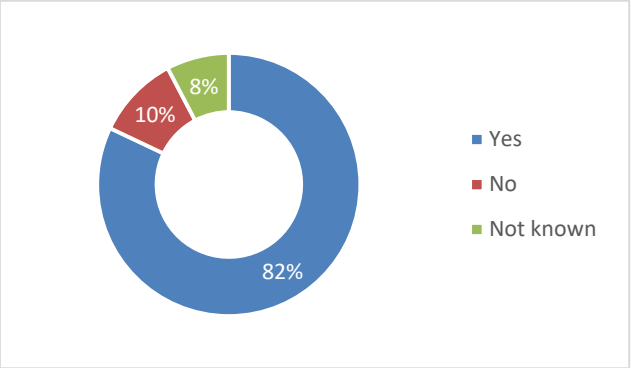


Figure 19. STOMP/STAMP review carried out for people on psychotropic medication at time of death.

Learning

- A male with LD and autism experienced a deterioration in his mental health, he was required to be sectioned and admitted into an inpatient assessment and treatment unit. While an inpatient, family reported he became very disturbed and being there was a traumatic experience for him. There were ongoing issues and disputes and issues between the family and the doctors there, regarding his ongoing care. It was later concluded that his presentation was a side effect from the large doses of Clopixol medication administered, further aggravated by his anxieties and stress.

Positive Practice

- A male, in his late 70's, at his last mental health review, the LD consultant psychiatrist reduced his prescribed antipsychotic medication as the gentleman's mental health was settled. This is in line with STOMP and the NHS Long Term Plan. He also received health checks including heart and blood monitoring as part of a thorough review.
- A male with a severe learning disability and autism, he experienced behaviours that challenge when unwell, frustrated or upset and was prescribed antipsychotic medication. Following a review of medication by LD psychiatry it was felt medication could be reduced in dosage, as behaviours had reduced in intensity and frequency, and the reduction was successfully achieved.
- A female with severe LD and Down syndrome. A STOMP review completed by the LD psychiatrist was successful in weaning off the prescribed antipsychotic, Haloperidol. This demonstrates good practice in the unnecessary prescribing of psychotropic medication and demonstrated that she had regular, person-centred, holistic and structured medication reviews from professionals who understand people with a LD and autistic people.

- A male with LD and autism and complex physical health conditions, following review of his mental health and medication the LD consultant psychiatrist stopped prescribing antipsychotic medication as it was no longer required.

Health Inequalities Group STOMP/STAMP Annual Report 2024/25

The LLR STOMP/STAMP Working Group project aims for 24/25 were:

- Implementation of the Midlands STOMP/STAMP Framework (published in January 2024)
- Training and Education in relation to STOMP/STAMP
- Supporting the introduction of Sleep Clinics (to reduce melatonin prescribing levels)
- Rationalisation of medication prescribing

Our Impact & outcomes:

There has been a significant increase in the number of people with a LD and autistic people receiving an annual review of their psychotropic medication, increasing from 735 during 22/23 to a YTD total of 2355 for 24/25. The outcome data received also confirms that an increasing percentage of people are having ineffective, or inappropriate, medication stopped because of their annual review.

The quarterly prescribing data received from LHIS confirms that we have maintained our progress in relation to prescribing rates for people with a LD, prescribing below national rates and against the trend of increasing antidepressant prescribing and have particularly low benzodiazepine prescribing in children.

Our Lived Experience Partner has worked with the Autism Space Team to create accessible information and further raise awareness regarding STOMP/STAMP: STOMP and STAMP - making sure medication is safe for autistic people | Autism Space | Leicestershire Partnership NHS Trust. This includes a video and a guidance document with visuals.

A guidance document was created for GPs and practice staff regarding medication reviews – this was circulated in the GP newsletter and LPT's e-news. The document outlined the importance of making all reasonable adjustments to support people to attend their medication review.

A STOMP/STAMP Case Study was created with clinicians at the Agnes Unit; this was shared with the LDA Collaborative Board and subsequently at the NHSE Regional Health Inequalities Group.

NHSE's lead for STOMP/STAMP attended a meeting during the year and provided positive feedback.

Summary and next steps:

The prescribing data we've received throughout 24/25 indicates that our workplans for 25/26 should focus on:

- Prescribing rates of Melatonin in autistic children or children with a learning disability (prescribing above the national average and at a significant cost)
- Polypharmacy (5 or more different types of antipsychotic/psychotropic medications) for people with a learning disability and autism diagnosis

A scenario of a STOMP outcome is shown in Appendix 3.

Behaviours that challenge.

LLR LeDeR has again seen an increase in the number of people who had a PBS plan where behaviours that challenge were present. Last year 81% of people had a PBS plan and 19% did not. The previous year showed only 37% had a PBS plan and 63% did not. This is extremely positive and demonstrates the enormous amount of work from the PBS practitioners and LD services. It should also be noted that not all behaviours that challenge present risks and support needs that require PBS input.

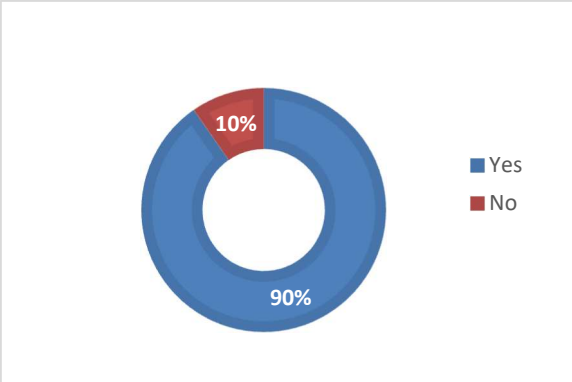


Figure 20. People with behaviours that challenge who had a PBS plan in place.

Behaviours that challenge, the LLR LeDeR Programme recommends further commitment to PBS work and increasing the knowledge across LLR of behaviours that challenge, and the importance of meeting people's communication needs on improving care experiences and reducing admission to hospital. It is also important to consider how people with behaviours that challenge will be supported into older age and the potential of nursing care needs and how these will be addressed, including place of residence.

Learning

“A male with LD and Down syndrome, he began exhibiting behaviours that challenge, which was discussed with the GP practice. Within the electronic records a GP practice staff member recorded this as having ‘bad behaviour’ a number of times. This is unsuitable language and does not evidence that the function of his behaviour has been considered. This is not in line with NICE Guidelines NG11- Challenging behaviour and LD: prevention and interventions for people with LD whose behaviour challenges. People working with or who are likely to work with people who have LD should be aware of this guidance.”

Positive Practice

“A female with LD and autism and behaviours that challenge, the PBS practitioner became involved and promptly made clear recommendations and visited the care home to offer support in developing and updating the PBS.”

Repeated hospital admission at End of Life

Last year the number of people who experienced repeated hospital admissions at the end of their life was 23%, this has increased to 31% this year. Through the LDA Collaborative and SHaW, (Safe, Healthy and Well) LLR have been determinedly working to improve end of life care and respond to identified concerns about the care provided to people with a LD and autistic people when their health is deteriorating. The impact in this area is difficult to measure. It is recognised that there may often be some requirement for hospital admission, however repeated admissions should be avoided.

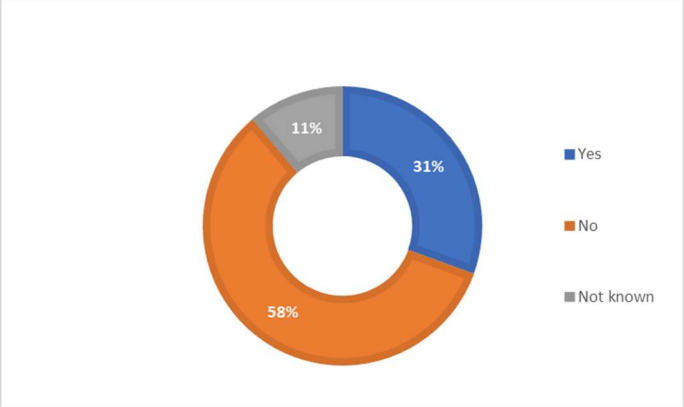


Figure 21. People on EoL pathway who had repeat hospital admissions.

An issue that was observed last year, is a sustained issue and still raises concerns from the LeDeR governance panels that the lack of 'specialised nursing' care provision for people with a LD is showing an impact. The programme has heard about the care of some people with a LD who experience behaviours that challenge and have physical healthcare needs not receiving sufficient specialist nursing care that includes both behavioural care and management, and nursing care. Some people are having either their behavioural and LD needs met, or their nursing care needs met. This is consistent with the findings from the previous year.

Without care provision skilled in both areas, we will continue to see people with a LD having avoidable and repeated hospital admissions, becoming 'stuck' in hospital care having had notice issued on their placement, and frustrated care providers unable to provide the home for life and death that people with a LD and autistic people deserve.

LeDeR continues to be influential and a focal point in steering the LDA Health Inequalities group and the SHAW subgroups agendas. The LeDeR themes influence the future of these working groups across the system to implement the learning into action and improvements. These are listed throughout this report.

Safeguarding

LLR LeDeR continue to work closely with the LLR safeguarding teams. Where a LeDeR review and Safeguarding Adults review is being conducted at the same time, the Safeguarding Adults team lead and carry out necessary communications specifically to family members, this is also on behalf of the LeDeR Team. This enables collaborative approaches, reducing stress, upset and inconvenience to families. A memorandum of understanding has been agreed to formalise this process. During the coming year there will be further progress as the safeguarding elements in LeDeR are strengthened through this partnership and direction of a LLR LeDeR programme standard operation procedure is being produced.

Preventative Healthcare

Venepuncture

Venepuncture is one of easiest and the most widely used medical tests to diagnose and manage people's health. However, this can be extremely challenging if a person is not compliant with the blood taking procedure. Learning from the LLR LeDeR programme is listed below.

Learning

"A gentleman with LD and autism diagnosed with cancer. He was needle phobic and had been for many years. There was discussion around making a referral to the CLDT, for blood desensitisation, but it does not appear this had happened. As part of LPT's referral process for blood desensitisation work, the Access team would have sent out a desensitisation pack, for carers to start some work with him prior to him being allocated and/or provided any further advice/guidance."

Positive Practice

*"*A female with LD and Down syndrome. A protocol was written for administration of sedation prior to a blood test, following unsuccessful attempts to obtain blood specimens. This was successful and a blood specimen was obtained indicating raised blood sugars which would benefit from increasing her metformin dose. This good practice evidences that reasonable adjustments were made in line with the Equality Act 2010 to support the person to have a successful blood test."

Health Inequalities Group LD Phlebotomy Team Annual Report 2024/25

Project aim:

- To reduce health inequalities faced by people with a LD accessing venepuncture services.
- The LD Community Phlebotomy Service, was set up to instigate safe use of safety interventions, phlebotomy, legal frameworks and desensitising techniques for people with a LD in LLR to successfully have their blood tests completed. The target patient group was people with a LD, in LLR, who have not been able to access existing phlebotomy services due to, but not limited to: behaviours that challenge; none compliance with venepuncture; issues regarding legal framework, namely the MCA; fears/phobia and accessibility issues.

Approach:

1) Recruited a LD phlebotomy nurse associate and a LD phlebotomy team lead 0.2 WTE.

2) Produce a Standard Operating Procedure.

3) Set up the 3 restrictive practice options conducive to preparing for a blood test:

   1) Chemical restraint 2) Transient restraint 3) Outpatient Sedation pathway.

Impact and Outcomes:

- 52 patients with a LD were referred into the service.
- 5 patients successfully had blood tests completed.
- 3 patients discharged as no longer required.
- 7 patients ready for outpatient sedation pathway.
- 37 patients are awaiting triage.

Of the blood tests successfully completed health condition(s) have been identified as well as enabled ruling out of suspected conditions and therefore, progression to other diagnostic testing.

Summary and Next Step:

Funding has been secured for the Outpatient Sedation Clinic recurrently, which is the first of its kind nationally, to support up to 12 patients per year with complex support needs for venepuncture.

Health Inequalities Group LD Deteriorating Patient Update 2024/25

Diabetes

Diabetes mellitus, encompassing both type 1 and type 2, is more prevalent among people with a LD than in the general population. For individuals with a LD living with type 2 diabetes, prevalence in Leicester City ranged from 50-63%, in East Leicestershire and Rutland from 18-21%, and in West Leicestershire from 19-29%. Variation was also observed in sex-specific estimates, with 33-47% of females and 53-67% of males living with type 2 diabetes.

Earlier onset is a consistent finding. Among those aged 18–34, males with a LD were 8.1 times more likely, and females 5.6 times more likely, to be living with diabetes than their people without a LD. Increased prevalence was observed across all age categories, suggesting that diabetes (specifically type 2) develops at a younger age in this population.

There is evidence of gaps in prevention and management opportunities for people with a LD, including limited adaptation of mainstream programmes. Co-produced, accessible resources and reasonable adjustments across service are required to improve uptake, adherence, and outcomes. The findings demonstrated a need for prevention, consistent delivery of the nine care processes alongside AHC's, and targeted intervention for those with combined risks such as obesity.

LD Physical Health Pathway

An ambitious project to create a LD physical health pathway within the LPT FYPCLDA directorate was launched in response to concerns around the deteriorating patient (analysis in LeDeR 2024 annual report). A physical health lead matron was appointed on secondment to deliver on this project, the key aims are listed below.

- Physical Health Competency framework:

    - Develop a set of core competencies for LD Community Services which are specific to individual service disciplines and represent the skills required for our clinical workforce.
    - Development of a clinical self-assessment framework
- Training Needs Analysis & Programme Development:
    - Scope the current training offers available for the LD Community and identify gaps in line with agreed competencies.
    - Develop training programmes to align with training gaps/needs.
- Strengthen processes to support the identification of the deteriorating patient:
    - Ensuring that operating procedures and systems supports the capture of baseline data on how the patient presents at their best & worst and enables clinicians to promptly identify if a patient is deteriorating and have a clear process for escalating their concerns.

Vaccinations

There are preventative healthcare measures that are available on rolling NHS programmes, the aim is to prevent avoidable mortality through vaccinations and screening for early detection of changes. Everyone should be given the opportunity to partake in and be aware of the available programmes. There are a number of factors that can affect engagement and reduce opportunities for vaccinations for people with a LD and autistic people and therefore, reasonable adjustments are often required.

Flu Vaccine

People with a LD, their family carers and paid supporters are entitled to a free flu vaccination. The person's choice, history and informed consent are important. Respiratory illness continues to remain the leading cause of death for people with a LD in LLR. It is also known that if those around the person are vaccinated against flu, then the person is less likely to contract it. Reasonable adjustments are pivotal in increasing the uptake of the flu vaccination for people, where required the nasal vaccine can be considered as an alternative with the planning and agreement of the GP practice and the person and support network. In LLR 70% of people with LD had their flu vaccine in the last year of life, which is lower than in the previous year [77%], this should continue to be encouraged and increased. People should also be encouraged to attend their LD AHCs where further reasonable adjustments and opportunities can be agreed, recorded, and shared with other care providers.

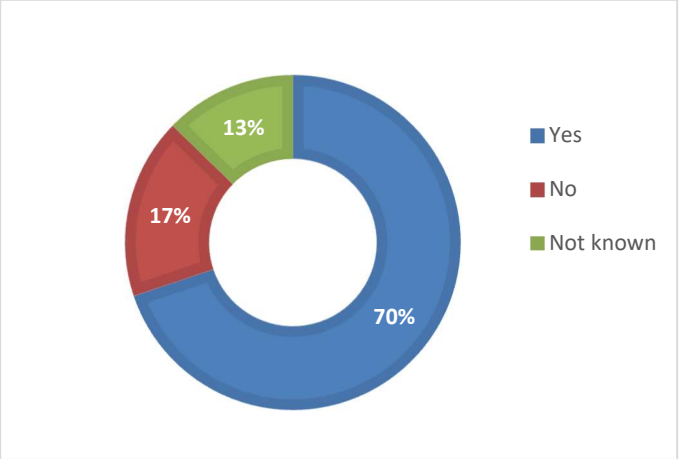


Figure 22. Flu jabs received.

Pneumococcal Vaccine

This year 11% of people who died had received the pneumococcal vaccine. The pneumococcal vaccine helps protect against serious illnesses like pneumonia and meningitis. It's recommended for people at higher risk of these illnesses, such as babies and adults aged 65 and over. Respiratory is the leading cause of death for people with a LD in LLR and it is therefore recommended to encourage vaccination in those who are at risk of serious illness related to respiratory.

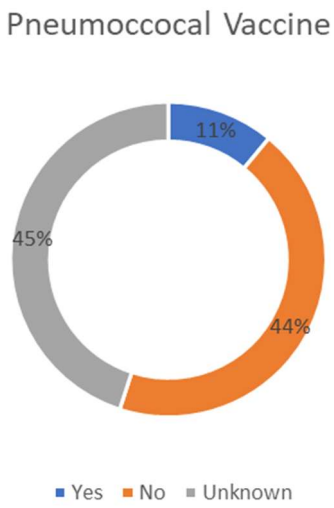


Figure 23. Pneumococcal vaccine

COVID-19 Vaccine

This year there has been 1 death from COVID-19 and 1 death with COVID-19 secondary to cardiovascular causes

The chart shows that most people have had either 5 or 6 COVID-19 vaccines, with 1 person having had zero vaccines. It is noted that there is a group of people for who this information is unknown. It is encouraging that more people this year have had 5 or 6 COVID-19 vaccines and fewer people have had 1, 2 or 3.

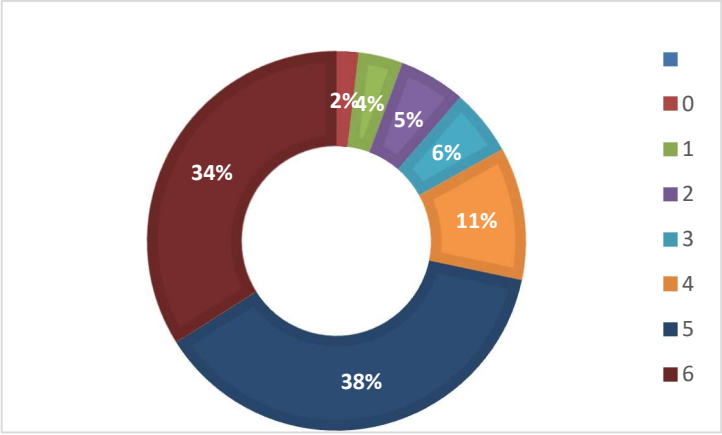


Figure 24. Covid 19 vaccine jabs received.

Health Inequalities Group LD Vaccinations Annual Report 2024/25

Project aim:

Lessons learnt from the COVID-19 pandemic shone a spotlight on the access issues faced by people with a LD.

The ICB Immunisation Programme has worked closely with LPT to provide a bespoke COVID-19 vaccination offer to people with a learning disability; this has included providing:

- Dedicated vaccination clinics resourced by professionals experienced in working with people with a LD.
- Variable vaccination offers e.g. drive-through vaccination, in-clinic vaccination, home-based vaccinations, extended vaccination appointment times, weekend vaccination clinics, family/friends vaccination clinics.

- Proactive phone calls to individuals to make them aware of their vaccination offer and facilitate an appointment booking.
- Provision of suitable easy-read materials.
- Liaising with community and voluntary groups with work with or support people with LD to promote awareness of essential vaccinations and provision.

Our impact & outcomes:

Between 24 October and 17 November 2024, the following vaccinations were delivered via the dedicated vaccination clinics geared to suit the needs to people with LD, as part of the autumn/winter 2024/25 seasonal vaccination campaign:

- 376 x COVID-19 vaccinations
- 168 x flu vaccinations.
- 544 x vaccinations in total

Many more people with LD may have obtained their seasonal vaccinations via their GP, however these numbers cannot be extracted from GP patient records for the purposes of this report.

A small vaccination team visited individuals with complex LD conditions in their own homes and provided them with their vaccinations.

Summary and next steps:

A LLR roving healthcare unit is moving around the city and county, providing walk-in vaccinations to anyone who is eligible.

During Spring/Summer 2025, the unit is offering vaccinations for RSV (Respiratory Syncytial Virus), MMR (Measle, Mumps, Rubella), and pertussis (whooping cough), as well as blood pressure checks. During the transition into autumn, the unit will also start carrying flu and COVID-19 vaccinations.

The roving healthcare unit can visit groups to offer vaccinations. Below is a list of the cohorts in scope for the flu and COVID-19 vaccinations this time, which at the current time people with a LD is not specifically mentioned within the criteria (see below):

Eligible Cohorts	COVID-19 Vaccination	Flu Vaccination
Pregnant women	No, unless immunosuppressed	Yes
Children aged under 18 years	6 months to 17 years with a weakened immune system	• 2 & 3-year-olds • 5 to 16-year-olds (reception to school year 11) • 6 months to 18 years in clinical risk groups
Adults aged 18 years and over	• 75 years & over • Older adult care home residents • Over 18s with a weakened immune system	• 65 years & over • In clinical risk groups • Long-stay care home residents
Carers of disabled & elderly people	No	Yes
Close contacts of immunosuppressed people	No	Yes
Frontline healthcare workers	No	Yes
Frontline workers in social care settings	No	Yes
Social care workers working with clinically vulnerable people	No	Yes

"Her appearance matched her personality – just fabulous! She enjoyed wearing make-up, getting her nails done and to be colour co-ordinated. She wore bright coloured and patterned clothing and 'blink' (bling) jewellery. She had once volunteered at a clothes shop as she wanted the discount!"

Screening

Cancer screening is an extremely valuable and important preventative healthcare measure. However, there remain some barriers to access and even more so for people with a LD and autistic people.

Cervical Screening

In 2024-25 of all the LeDeR Reviews, 5% of people eligible for cervical screening attended regularly over their life course.

Cervical screening is known to be one of the more challenging of the screening services offered in terms of uptake, due to the intimate nature. Nevertheless, people should always be offered the appointment, never be removed from the screening register due to having a LD or autism, and if required should be offered alternative checks such as, abdominal checks and menstrual tracking. This is unless people are making an informed choice to be removed from the register.

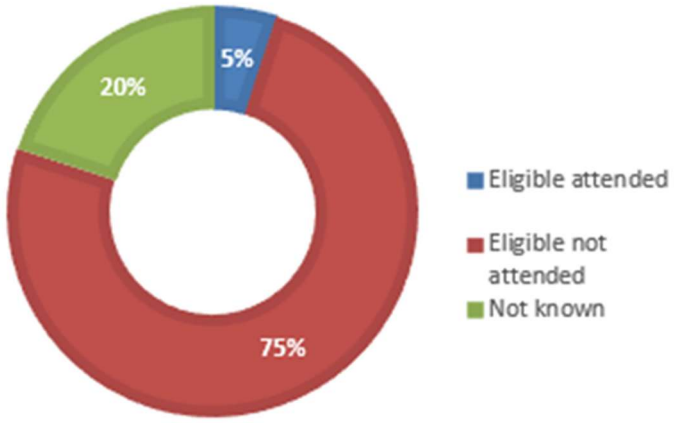


Figure 25. Cervical cancer screening attended (Where eligible)

It was noted that 'not sexually active' has historically been recorded in notes for people with LD and carers are declining on behalf of the person, without any consideration of best interest under the MCA. It should also be considered that some people would need to be taken to their appointments, and 'was not brought' safeguards are important.

It is recommended by the LLR LeDeR programme that exploration of the contractual services for cervical screening are reconsidered to reduce the inequalities seen here.

It should be noted that from 1st July 2025 changes are being made to cervical screening; for Ages 25-49 the screening interval will move from every 3 years to every 5 years due to more advanced testing.

System updates:

- Success in purchasing two specialist colposcopy chairs that are within primary care settings.
- PCLN team appear to have had an increase in the number of requests from primary care, to support/advise on cervical screening for individuals with a LD. This work is undertaken through advice and guidance and is individually specific. It is felt that this perceived increase may be due to PCLN team continuing to provide training and updates including through the GP ambassador network.
- Training offered within the last 12 months has included providing LD awareness sessions to NEPSEC (new sample taker training) and the plan for this to continue for rolling new staff.

- PCLN attending working group for cervical screening project group. Part of discussion around self-sampling and planning how this can be utilised or implemented within the LD population in future.
- The cervical screening videos (myth busting and Calli's story) are now imbedded into the AHC template.
- Working at PCN level to deliver specialist clinics when needed, PCLN's take a lead role in the preparation of these patients.

Cervical screening myth busting: Question and answer (youtube.com)

Cervical screening myth busting: Cali's story (youtube.com)

Press release can be found here:

leicspart.nhs.uk/wp-content/uploads/2024/07/BBC-Radio-Leic-090724-Cervical-screening.m4a

Breast Screening

In 2024-25 of all the LeDeR Reviews, 35% of people eligible for breast screening attended regularly over their life course.

Breast screening along with breast checking are imperative for preventative healthcare and people should be adequately supported with relevant reasonable adjustments, reminders and prompts where required. The easy read video on checking your breasts and breast screening developed by LPT is still available on the website and should be used and promoted.

https://www.youtube.com/watch?v=HphkoUbfNQQ

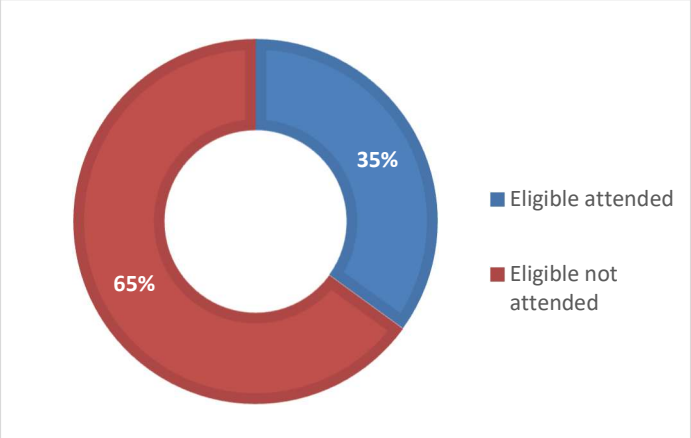


Figure 26. Breast screening attended (where eligible)

As part of the drive to increase equality for people with a LD, the LD PCLN team are working with the Breast Screening Service in LLR. The aim is to improve access by ensuring that the breast screening service are aware of individuals that have a LD and can offer them appointments at their Equality Access Clinic by using accessible letters that are more easily understood. The AHC template has also been revised and now alongside all screening questions are the links for the easy read information which can be printed and given during the check. LLR LeDeR recommend that contractual mechanisms are put into place to support real drive in changing and increasing how people with a LD and autistic people are accessing and supported with breast screening.

Bowel Screening

In 2024-25 of all the LeDeR Reviews, 31% of people eligible for bowel screening attended regularly over their life course.

Bowel screening usually yields one of the highest attendance rates due to its less invasive nature and it would be expected this figure continue to rise. There has been some encouraging positive practice seen again this year in LLR LeDeR with regards to supporting people with a LD to respond to the bowel screening invitation and on occasions work has been undertaken to support people in their best interests where this has been deemed necessary and appropriate.

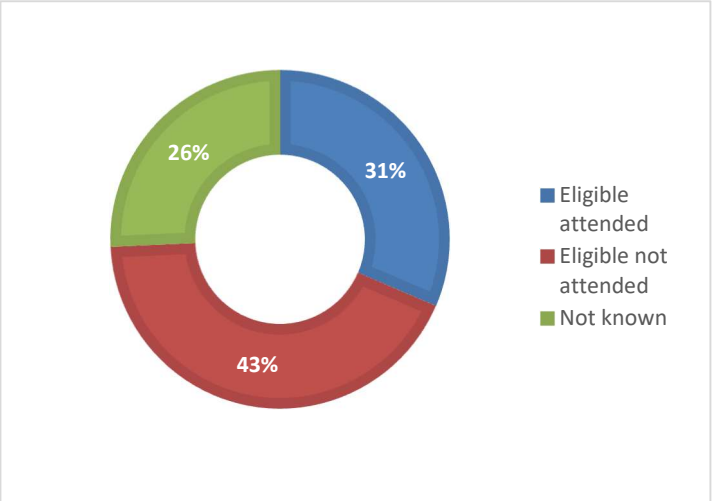


Figure 27. Bowel screening attended (where eligible)

PCLN team are undertaking a pilot project that commenced in the East area of LLR and has now been rolled out across West and City. Working with the Eastern Bowel screening hub to identify eligible cohort of patients on the LD register in order for the hub to add additional care notes so that reasonable adjustments can be offered at point of invitation for FIT test. PCLN team are notified by the screening hub of any non-responders to the FIT, and a brief intervention is offered from the PCLN team to support the person to complete their FIT test. Early data suggests an 11% increase in FIT's being returned.

Abdominal Aortic Aneurysm (AAA) Screening

AAA screening shows that that only 5% of the eligible people through the LeDeR programme are attending compared to 81.9% of the general population of LLR. This is down from 32% last year. Further work is required to address this significant difference.

UHL LD team identifies and notifies the AAA screening team on a yearly basis of those held on their database who become eligible for screening.

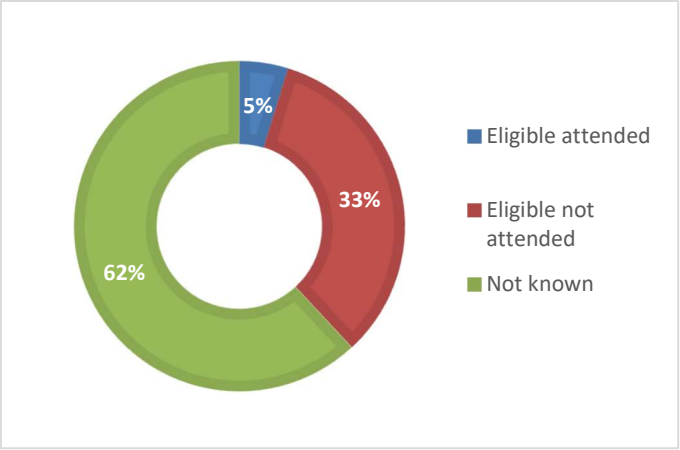


Figure 28. AAA screening attended (where eligible)

"His friendly nature made him a joy to be around."

LD Annual Health Check

The past year has seen the highest amount of LD AHCs within LeDeR at 86%.

The GP practices, LD PCLN team and the Health Equity Lead this year, as well as others including people with a LD and their families, friends and carers should be commended on the success in driving forward this agenda.

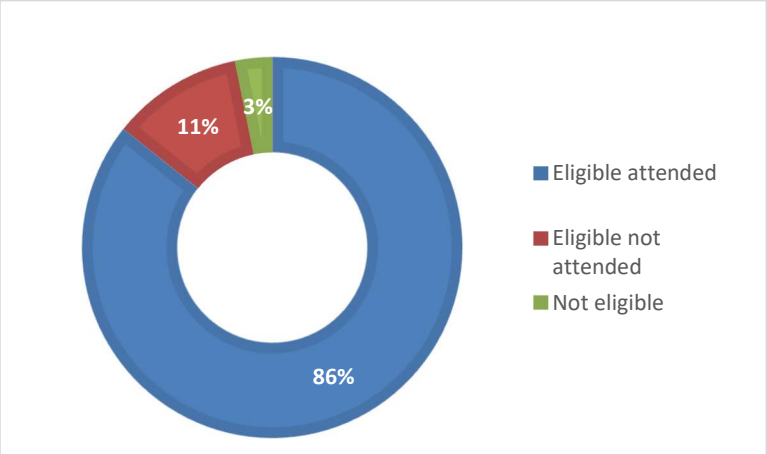


Figure 29. LD Annual Health check attendance

Seasonally it is observed there are more deaths during winter months and therefore, it is worth considering the timing of the LD AHC and winter planning for people with a LD.

Overall, LLR continue to perform very well in this area.

Local data provided shows that the LD register size increased across LLR and also that the total number of checks completed in 2024-25 was higher than 2023-24 and a record achievement.

23/24 – 80.9% (4215 checks out of 5208 people on the LD register)

24/25 – 82.1% (4403 checks out of 5415 people on the LD register)

LD PCLNs, offer regular support and training on AHCs for primary care, social care partners and care providers – including GP practices – to improve access to health care and reduce health inequalities for people with a LD.

In addition, for 2025-26 PCLN team have established the Primary Care LD Ambassador Network which aims to:

Work together to improve access to primary care for people with LD and promote health equity for this patient group.

They will:

- Bring together GP ambassadors, PCLN's and people with specialist knowledge about LD.
- Work together to understand how better to support people with a LD to live happy healthier lives.
- Consider ways to improve the accuracy of the LD register to ensure that the correct support can be offered.
- Share good practice and challenges and disseminate this back to your area of work.
- Opportunity to meet CPD requirements.

So far this year three meetings (quarterly) have been held and there is a network of approximately 180 ambassadors.

The team ran a pilot project to increase the AHC uptake for those people who haven't had a health check in 2 years or who have complex needs requiring reasonable adjustment over and above what the GP practice can offer. This project ended in March 2025.

In addition to raising awareness of screening in primary care, PCLN team have worked with LLR partnership boards, LLR local offer events, specialist education providers, healthy living groups and self-advocacy groups to promote the uptake of all screening programmes, typically this would involve utilising the anatomically correct models and other adapted resources.

"When visiting Scotland, she loved listening to the bagpipes being played live. On one occasion, as she was enjoying dancing along to the music, the bagpiper had put his hat on her, which she loved!"

Thematic Analysis

Thematic analysis is a qualitative research method that can be widely used across a range of epistemologies and research questions. Lincoln and Guba's (1985) criteria for trustworthiness during each phase of thematic analysis is widely used and often viewed as the "gold standard" for qualitative research. This ensures reliability, credibility and trustworthiness in our analysis process. This framework has been adopted in LLR for the purposes of the LeDeR Learning into Action and demonstrates the systematic structure of thematic analysis undertaken for the LeDeR reviews in LLR.

LLR LeDeR Focused Priority Review Area 2024-2025

Deaths of those under the age of 50yrs, with congenital conditions and/or syndromes, through the lens of intersectionality

As per national guidelines and recommendations, LeDeR programmes always select an area for local focused priority review area on an annual basis.

The LLR LeDeR programme ensures that the focused priority review area for the financial year is cognisant with the wider LLR System plans to enhance, compliment and feed into learning into action for LLR with regards to people with LD and autistic people.

The notifications remain very low for the deaths of autistic people, and therefore, it was agreed that the focus would be on people with a LD to ensure enough information could be gathered for analysis.

In agreement with the LLR LDA Collaborative the following was agreed upon as the focused priority review area for 1st April 2024 – 31st March 2025:

"Deaths of those under the age of 50yrs, with congenital conditions and/or syndromes, through the lens of intersectionality."

It was identified by the LLR system a priority to understand what the demographics, care needs and intersectionality nuances were of the people who died in the past year under the age of 50yrs who also have congenital conditions and/or syndromes. The following analysis summarises the key findings and recommendations.

Demographic Analysis of Priority Review Area

This section presents key demographic insights from the priority review area, based on completed reviews. The data highlights patterns in gender, age, disability level, living arrangements, ethnicity, and congenital conditions.

As shown in *Figure 30. Death by Gender,* 78% of reviews completed were of males and 22% of females.

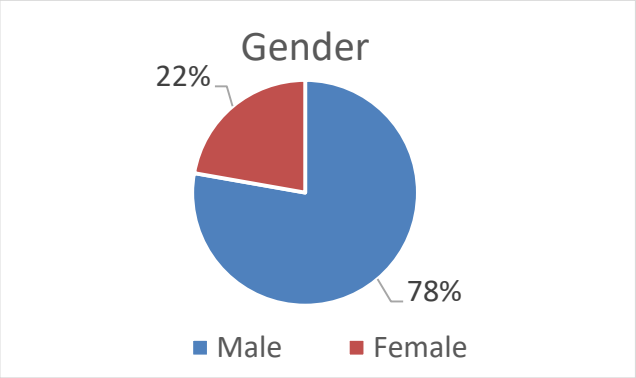


Figure 30. Deaths by gender

Figure 31. Level of Learning Disability, shows that most people had severe or profound LD, there were no people with a moderate LD.

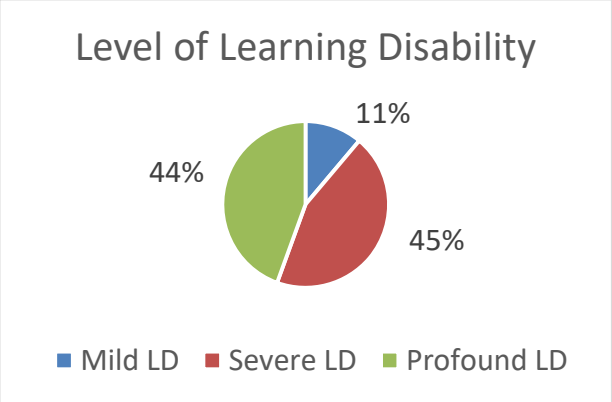


Figure 31. Level of Learning Disability

Figure 32. Congenital conditions or syndrome, outlines the congenital conditions or syndromes present among the reviewed population. It is generally observed that people do survive to the average life expectancy for their condition. Although, it is difficult to know whether underlying genetic predisposition due to known conditions, or other external factors, contributed more towards early demise. The complications from the conditions brought about the most significant risks i.e. seizure control, lung capacity, constipation, location of tumours, CVD risks. Therefore, it is especially important for optimal care planning and preventative healthcare for this group.

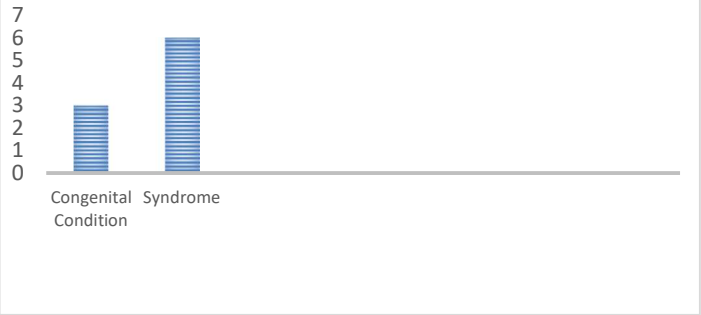


Figure 32. Congenital condition or syndrome

The analysis looked at a very specific young population group in this priority review area, with the median age 28yrs and the mean age 30yrs, when compared with the LLR LeDeR Median age. As shown in *Figure 33. Age at death.* Where the death was expected/anticipated (44%) the person died from the congenital condition/syndrome, with good, advanced care plans and end of life planning observed. Where the person's death was unexpected (56%) the deaths were all Respiratory related and last-minute ReSPECT was observed, 4 or more infections in the community requiring antibiotics indicated requirement for secondary care earlier and there were issues with recognition of the deteriorating patient and recognising the dying patient and the difference between the two.

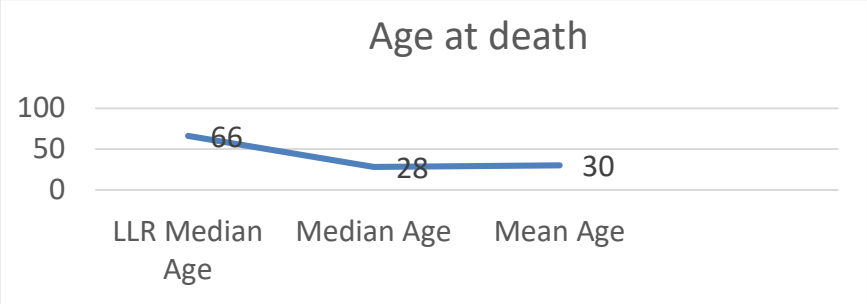


Figure 33. Age at death

The review considered whether people lived at home with parents/family or were in a care home setting and found that the majority lived with parents/family.

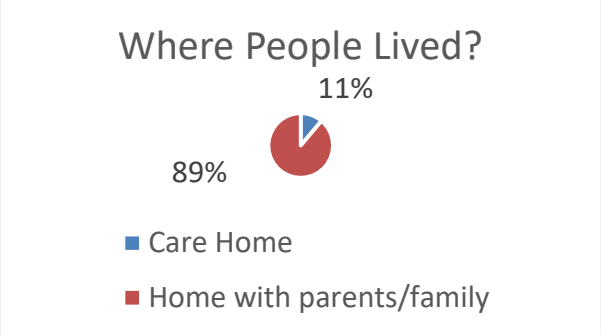


Figure 34. Where people lived

The ethnicity of the people in the priority review area were predominantly White British (67%) and 33% being from a diverse ethnic background.

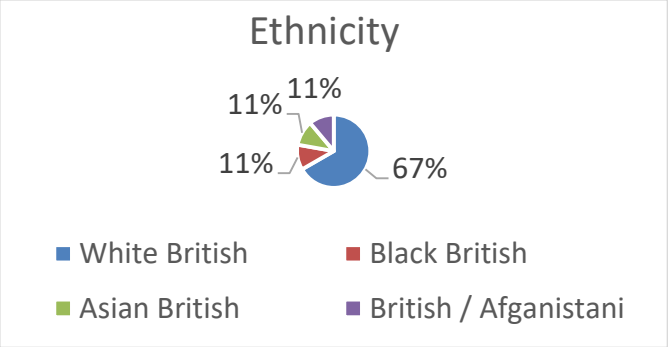


Figure 35. Ethnicity

Intersectionality considerations and findings

It did not appear from the reviews that intersectionality, particularly with regards to the person's LD, directly disadvantaged the person and there were many reasonable adjustments in place to enhance the equal opportunities required. However, an interesting finding was that the intersectionality of the care giver for the person (direct carer) did seem to have the potential to impact on and influence the person's experiences, known as vicarious intersectionality.

The rationale to explain this further from the findings and what parts of the intersectionality this related to are listed below along with the findings from this analysis:

- The first language of the care giver, if there were communication or language barriers experienced by the care giver, it was observed the same barriers were simultaneously observed for the person.
- Letters, text, correspondence being sent in the language the care giver spoke was important to prevent communication barriers and delays, where those delays occurred, they were also experienced by the person.
- Digital poverty, none or limited access to phones or computers contributed to inequality and delay in care.
- Where a care giver had multiple caring responsibilities for more than one household member the challenges that arise from practicalities of attending appointments is important and should be considered by professionals.
- Where a person lived in a multi-generational household, familial agreements on things like equipment the person required such as a ceiling track hoist, and how much space this required and/or required changes to the building or home environment to accommodate the equipment were important. Therefore, discussions should include all family members so that solutions can be found where there are disputes.
- Awareness of the screening programmes i.e., cervical screening, due to this not being available in the Country the individual and care giver had originated from. Therefore, it is recommended that people are appropriately invited and involved in those discussions.
- The application of the MCA appears to challenge professionals more when the care giver is an unpaid care giver, as opposed to a paid care giver, highlighted as learning into action by the LeDeR governance panels. On occasion it was felt that too much clinical decision making was placed on unpaid care givers, which was not observed in paid care givers. For example, decisions on when to admit to hospital, or not, with the balance of medical urgency vs causing distress to the patient.
- A ReSPECT forms and advanced care plans should be instigated early enough to involve the person and their wishes.
- There appeared to be a reliance on carers to monitor levels with no care plan in place.
- MCA decisions were not always documented.
- Decisions taking a long time because of how many professionals need to be consulted with i.e. being fitted for PEG.
- It is important to consider the needs of the care giver simultaneously to the person for optimal care.

The Mental Capacity Act (2005)

As mentioned in the statement at the beginning of this report there remains work to be done to achieve improved application of the MCA for people with a LD and autistic people. Learning from all previous years for LeDeR was carried out in 2023-2024 to identify the areas of the MCA that seem to be the most challenged in the system. The following issues persist into 2024-2025.

1. Despite the person's capacity being in question the decision maker has not instigated the legal framework.
2. Record keeping and documentation issues. This includes demonstrating the workings out and how the conclusions have been drawn through the steps of the MCA.
3. Procedural issues. This includes lack of family involvement in best interest meetings.
4. 'Was not brought' safeguards. Recording in patient record as having DNA'd (Did not attend) their appointment when they would not have been able to get to the appointment without the care of someone else. Consequently, due to incorrect documentation, 'Was Not Brought' safeguards are not being implemented.
5. Restrictive intervention. There was evidence of a lack of process and understanding of how to support someone with medical procedures when more restrictive measures are indicated under the MCA.

During 2024-2025 the programme has seen some excellent practice with regards to the MCA an example is shown below:

MCAs were repeated on many occasions, and she was deemed to have capacity in different areas of care and treatment. Some decisions she made caused her to become very unwell, significantly increasing the risk of death, resulting in high levels of anxieties within her care teams. She was deemed to have capacity in all areas following thorough MCA assessment. There was extensive and impressive use of and application of the MCA. She frequently changed her mind and made unwise decisions, which challenged professionals and her care team. The support around her was responsive to this and never made judgement on her decisions, maintaining support and objectivity, working with her at all times in the most effective ways and supporting reasonable adjustments. In line with acknowledging and respecting her wishes, care teams supported her throughout her health deterioration, ensuring she was as comfortable as possible. When staff were undertaking the MCA, it was noted by the LeDeR governance panel that professionals clearly demonstrated full compliance with the MCA, ensuring everything possible was put into place (day/time/not hungry/calm/easy read) to enable her to make decisions.

Autism

This year there were 4 deaths of autistic people notified to the LLR LeDeR Programme, 2 of which were completed within this financial year and 2 remain ongoing. Whilst in keeping with national reports of the response from other systems, this is concerning. The notifications of deaths of autistic people must be a priority and LLR LeDeR completed a quality improvement project set to increase the notifications of the deaths of autistic people in LLR to the LeDeR Programme (see appendix 2). However, the issues will likely remain with low notifications to LeDeR because there is not an autism register at this time where an electronic reporting notification can be added to the health and social care system, like there is for people with a LD. Therefore, it is much more reliant on word of mouth and individual notifications. This is reflected nationally and LLR LeDeR are in line with national notifications in this area.

In total there were reviews of 2 autistic people's deaths completed in LLR LeDeR during 2024-25, both individuals were male, there have been no notifications of females. Areas of learning are highlighted below from the LeDeR Governance Panel members.

- Improving the understanding of autism across the whole of LLR health and care and consequently the LeDeR governance panel supports in its entirety the continued roll out of the Oliver McGowan training.
- Concerns with regards to identifying the person has autism and the required reasonable adjustments.
- The importance of post diagnostic support services, with consideration of active surveillance of the health and wellbeing of autistic people post discharge.
- The mental and physical health of autistic people is paramount. There is a call for an autism register and autism health check.

LLR LeDeR universally supports the introduction of the reasonable adjustment flag. This elevates the importance of the Equality Act (2010) and will raise awareness of the needs of both autistic people and people with LD, particularly when using mainstream services.

"He was described as being full of life and a 'Cheeky Chappy'."

Learning Disability Child Death Reviews

Definition:
Individuals with a LD are those who have:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A significantly reduced ability to cope independently (impaired adaptive or social functioning), and
- Which is apparent before adulthood is reached and has a lasting effect on development.

Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) Policy 2021

LLR CDOP LeDeR Themed Review

In 2023, LeDeR stopped reviewing the deaths of children with a learning disability under 18 years of age due to duplication between LeDeR & CDOP. In LLR, it was agreed that we continue to work closely together, and this is now achieved through an annual themed review. During 2024-25, 6 case reviews were completed for children with a LD who had died. A review group was convened with representation from Public Health, Children's Social Care, UHL, LPT, ICB and the LeDeR Programme to look at these cases collectively, identify themes and learning, and to generate actions.

Update on actions from 2023/24 Review:

1. For the use of hospital passports to be fully embedded across LLR for children, young people & adults with a Learning Disability. Hospital Passports are being promoted within UHL Children's Hospital; it is recognised that a broader 'Care Passport' single document recognised by all care providers would be beneficial.
2. For LLR CDOP to meet with the ICB Pharmacy team to share learning & review mechanisms for supporting families to access timely prescriptions. A meeting took place with the ICB Head of Pharmacy, who shared processes already in place to support vulnerable patients with accessing prescriptions, with a plan to share the learning further via Medication Safety Leads training, and review of the LLR Prescribing Guidance.
3. For LLR CDOP to share with LLR LeDeR the resources & advice about how to gather mortality review information for deaths which occur overseas. Resources developed through the Association of Child Death Review Professionals were shared to the LLR LeDeR team.
4. For ongoing work to ensure all children & young people with a Learning Disability are on the GP Practice Learning Disability Register and offered annual health checks from 14 years. Quality Improvement work, led by the Learning Disability Primary Care Liaison Nurse team, is ongoing, and numbers of children and young people on the GP LD Registers is

rising. To address barriers around diagnosis, Paediatricians can now use the 'On the Learning Disability Register' read code within SystmOne electronic records.

Case characteristics of the 6 cases with reviews completed in 2024/25: -

The most common category for cause of death of children was:

- Chromosomal, genetic, or congenital anomalies (67%).
- Other categories included chronic medical condition and trauma/other external factors.

- Modifiable factors were identified in 5 cases.
- Positive aspects of service delivery were noted in 5 cases.
- Median age at death was 12 years (9-17 years)
- 83% were on the GP practice Learning Disability Register (compared to 80% in 2023/24 and none of the 10 cases in 2022/23).

Key learning themes identified during the 2024-25 review

Children & young people with a Learning Disability and their families often describe challenges with navigating and accessing health and care systems, often having to repeat their stories. Care Passports can provide a single summary of a child's health and care needs, and reasonable adjustments to enable them to access the care and support they require.

When Children & young people with a Learning Disability are included on the GP Practice Learning Disability Register, this enables reasonable adjustments to be provided, and delivers enhanced support for their long-term health & wellbeing, and for their family.

Children & young people with a Learning Disability are vulnerable to the impact of second-hand cigarette smoke inhalation, which can exacerbate existing health issues.

Aspiration pneumonia is a significant cause of ill-health and death for children, young people & adults with a Learning Disability; identification of those at risk and appropriate management can reduce the impact of aspiration pneumonia on long-term health & outcomes.

For those with a life-limiting condition, children, young people & their families benefit significantly from timely and clear advanced care planning, including being offered choice around their preferred place of death, and information about practical considerations, before and after bereavement.

Having an allocated lead medical consultant enables delivery of high-quality coordinated care across different teams and agencies, even in highly medically and socially complex cases. In line with national guidance & the recommendations of the Francis Report, every child and young person with complex healthcare needs should have an allocated lead medical consultant.

"She had her own bedroom at the residential home which she referred to as her "batcave!"

Word cloud: Learning from excellence – what good care looked like for completed reviews of children 2024/25:

Recommendations and actions:

1. For collaboration between UHL, LPT & the ICB LDA Collaborative to develop an LLR-wide Care Passport for children & young people with a Learning Disability.

2. For continuation of the ongoing work across LLR, led by the Learning Disability Primary Care Liaison Nurse team, to identify children & young people with a Learning Disability, to ensure they are included on the GP Practice Learning Disability Register, and for all agencies to promote participation in the Annual Learning Disability Health Check for young people (aged 14yrs onwards) and their families, as a key part of transition to adulthood.

3. For Public Health in Leicester City & Leicestershire to explore expanding smoking cessation in-reach services to parents and carers of children and young people with a Learning Disability.

4. For the LDA Collaborative to evaluate whether the Aspiration Pneumonia tool used for adults with a Learning Disability would be clinically appropriate for use in the paediatric population across LLR.

5. For paediatric services across UHL and LPT to continue to ensure that all children and young people with a life-limiting condition are considered for a Children & Young People's Advanced Care Plan (CYPACP), that discussions around advanced care planning with families are informed, timely, sensitive and clear, and that (wherever possible) the wishes of children, young people & their families are accommodated in end-of-life care planning.

6. In line with the recommendations of the NCMD (National Child Mortality Database) Report Learning from deaths: Children with a learning disability and autistic children aged 4-17yrs (based on the Francis Report findings & Paediatric Critical Care Society 2021 Standards), paediatric services across LPT & UHL to ensure that every child & young person with a Learning Disability & medical complexity has an allocated lead medical consultant.

Learning into Action

The learning into action for LLR LeDeR is reviewed on a quarterly basis and sent to the respective service provider in order for them to develop SMART actions. The service provider then reports back to the LeDeR steering group.

Top 3 Highlights of LLR LeDeR Learning are shown below:

GP and Primary Care:

- Annual health checks - Significant improvement in uptake across LLR – now focusing on quality of health checks with plans for quality improvement projects and continued integrated working between GP practices and LD Primary Care Liaison Nurse Team - empowering practices and utilising the appropriate staff to carry out the checks and provide them with additional training as needed. This has been enhanced by the establishment of a GP LD Ambassador Network, enabling us to have regular contact with key health professionals within primary care who are involved in caring for patients with LD.
- Blood taking in patients with LD – Launch of pilot scheme – a patient centred pathway to facilitate better attempts at blood taking in the community in patients who to date have been unable to have one. The aim being to improve disease detection and prevention and reduce morbidity and mortality. Has highlighted evidence of the poor use of MCA best interests when assessing a patient's need for having a blood test.
- End of life care – new working group being established to focus on improving appropriate and timely use of the RESPECT process in patients with a LD and autistic people and inappropriate completion of medical death certificates listing 1a for LD or learning difficulties - will be incorporated into the EOL/getting older with LD workstream led by LD transformation lead GP.

LPT FYPCLDA

- STOMP - The significant increase in the number of people with a LD and autistic people receiving an annual review of their psychotropic medication, increasing from 735 during 22/23 to 2355 for 24/25 is an incredible achievement. The outcome data received also confirms that an increasing percentage of people are having ineffective, or inappropriate, medication stopped because of their annual review. Maintenance of prescribing rates for people with a LD, prescribing below national rates and against the trend of increasing antidepressant prescribing and have particularly low benzodiazepine prescribing in children. Our Lived Experience Partner has worked with the Autism Space Team to create accessible information and further raise awareness regarding STOMP/STAMP. A guidance document created for GPs and practice staff regarding medication reviews, outlining the importance of making all reasonable adjustments to support people to attend their medication review.

- The LD Physical Health Pathway launched in response to concerns around the deteriorating patient. A Physical Health Lead Matron appointed delivering on this project, the key aims: Physical Health Competency framework; Training Needs Analysis & Programme Development; Strengthen processes to support the identification of the deteriorating patient.
- The Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) is a 1-page risk profile to support decision making around aspiration pneumonia diagnosis and treatment and enable people with this diagnosis to have personalised care, reasonable adjustments, identify higher risks and potentially identify appropriate treatment in a more holistic way. It is now in the pilot stage of the process prior to implementation and evaluation. The LAPPP has been accepted for oral presentation at the RCN International Nursing Research Conference in the Autumn of 2025.

University Hospitals Leicester

- Ongoing support for clinicians to appropriately use MCA. This has previously been escalated to Hospital Directors. LD Matron has also repeatedly raised this issue, but it is recognised that the issues around MCA and ReSPECT are not just isolated to patients with a LD. Some systems have now changed to proactively encourage clinicians to complete an MCA for example electronic surgical consenting, but further work still needs to be done to ensure MCA is fully embedded in day-to-day situations and remains a high priority.
- Training delivered to support for emergency department clinicians in the use of ReSPECT forms to ensure all urgent care clinicians have good knowledge of using ReSPECT forms.
- Implementation of the Outpatient Sedation Pathway as part of the LD Phlebotomy pathway has been successful and a nationally trail blazing initiative.

Leicestershire & Rutland County Councils

Learning Disability Week 2025

- Leicestershire ASC hosted a one-day conference for adult social care staff, which included information about LLR LeDeR programme the learning into action and priorities from the annual report.
- Adult Social Care Team Away Days, sharing the key learning from LeDeR, focusing on reasonable adjustments, MCA's and weight management. Leicestershire County Council Learning Disability Partnership Board & Locality Groups, information sharing on the LLR programme and information hosted on the website for public information.
- To share with commissioned social care providers the positive outcomes for people with LD at end of life.

Leicester City Council

- Continue to reduce professional barriers between Health and Social Care in delivering best practice to ensure that people are supported effectively in helping to support people to live healthier lives to maintain health checks and other appointments.
- Ensure that through joint working with health, care professionals and families that people have appropriate reasonable adjustments are completed in place when decisions are being made in best interest are being assessed under the MCA.
- Earlier end of life care planning between Health, Social Care and providers in understanding Cultural needs to how best to deliver care, treatment, and support.

Comprehensive learning into action plans are held within the LLR LeDeR programme and health and social care systems, including plans in relation to the areas outlined in the LLR LeDeR top 10, some highlights can be seen below.

"He was described as a friendly, caring, lovely, personable, fun and charismatic character who was always smiling and loved to talk."

Response to the Top Ten Learning into Action 2024

This section aims to give an update on the responses to the top 10 learning into action points from LLR LeDeR Annual Report 2023 – 2024:

No.	Action	Response/Update
1	Report the deaths of people with autism (with or without a learning disability) to the LeDeR Programme	Quality Improvement project completed. See Appendix 2.
2	Report the deaths of individuals from Leicester City and diverse ethnic backgrounds to the LeDeR Programme	Improvement is yet to be made in this area.
3	Improve application of the Mental Capacity Act (2005). Services should review practices to ensure compliance.	Positive practice has improved, but further progress is needed. The ICB has prioritised MCA workshops led by the Deputy Chief Nursing Officer to address legal understanding and system-wide challenges.
4	Avoid estimating weight; ensure access to suitable weighing equipment	Healthy living toolkits co-produced with lived experience, carers, and professionals. Toolkits address weight monitoring and physical activity. Wheelchair scales have been purchased and are available across LLR.
5	Develop clear plans for individuals with behaviour that challenges, anticipating future support needs	Progress is yet to be made. Future commissioning must reflect increasing physical and nursing care needs.
6	Ensure care providers are confident discussing end-of-life matters and initiating Advanced Care Plans	Workshops and training delivered across adult social care. Accessible Advanced Care Plan produced by LPT. Internal reflection sessions underway. A working group will review end-of-life care in 2025–26. Collaboration with DAPPLE research project ongoing.
7	Address screening inequalities and improve uptake, especially for non-invasive bowel screening. Implement Reasonable Adjustment Digital Flag	Despite resources and awareness efforts, screening uptake remains low and inequitable.
8	Improve understanding of STOMP/STAMP agenda across health services	Significant improvements noted. STOMP/STAMP working group remains active and committed.
9	Prevent aspiration pneumonia through risk identification and discharge pathway changes	Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) developed and in pilot phase. Collaboration with Midlands LeDeR teams to analyse avoidable deaths.
10	Promote awareness of specialist phlebotomy support for individuals unable to access standard services	LD community phlebotomy pilot launched with a 3-tiered approach. First of its kind nationally. Plans underway to establish service and introduce Midazolam Outpatient Sedation Pathway Clinic.

LeDeR High Impact Action Plan 2024/25

*RAG Rating = Red (Not started), Amber (in progress), Green (Complete).

Action Plan	Detail	Outcome	*RAG Rating
Reduce avoidable mortality in 3 clinical priority areas for the LD &A 1. Respiratory	Thematic analysis conducted on Respiratory deaths during 2021, found that pneumonia and particularly aspiration pneumonia were a frequenting cause of death in people with a LD. Thematic analysis conducted on Aspiration pneumonia deaths in 2022. Workstream convened under the Health Inequalities Group and framework. The aspiration pneumonia thematic analysis has been re-run for 2023/24 simultaneously with LeDeR teams from Coventry and Warwickshire, Northamptonshire and Shropshire, Telford and Wrekin. This is to analysis and observe wider conclusion into the avoidable deaths from aspiration pneumonia. A LD Community Phlebotomy Team pilot was run during 2024-25, it was evident the success being yielded for those with highly complex needs requiring timely venepuncture. This supports the diagnostic pathway, identification of early and preventable health conditions.	*The group developed the Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) which is currently in pilot stage. The LAPPP is designed to support protective factors in the care of people at risk of aspiration pneumonia. It also enables clinicians to think holistically which is known to demonstrate better outcomes for people with a LD.* *LAPPP being written for publications and work has been accepted for oral presentation at the RCN International Research Conference 2025 in Exeter.* *Analysis for the Midlands aspiration pneumonia in people with a LD analysis is currently ongoing.* *The pilot was a success and used a 3 tier model for venepuncture for those with the most complex needs. The team successfully set up a Midazolam Sedation Clinic for venepuncture use to enable those most in need to receive timely venepuncture, all within safe and legal frameworks to ensure the best interest of the patients are at the centre of their care. It is hoped that the pilot*	

		will become a service, and the Midazolam Clinic can continue, further information to follow.	
2. CVD	The prevalence of both underweight and obesity is disproportionately higher among people with a learning disability than in the general population. Data was extracted from general practice registers across Leicester, Leicestershire, and Rutland and subsequently analysed in August 2025. Both underweight and excess weight are closely linked to a range of health conditions. Obesity, in particular, is associated with increased risk of certain cancers (for example colorectal), cardiovascular disease, type 2 diabetes, and chronic kidney disease. Many of these conditions feature prominently among the leading causes of death reported in LeDeR. See above for the LD Community Phlebotomy Team.	*In response to these findings, a collection of healthy living toolkits was co-produced with individuals with lived experience, family carers, and professionals from across the health and social care sectors. These toolkits address weight monitoring, early warning signs, and appropriate interventions, while emphasising the role of physical activity, a factor often neglected in weight management strategies. The toolkits are freely accessible online and developed for different audiences, including general practice teams, family carers, healthcare professionals, care providers, adult social care workers, and an easy-read version for people with a learning disability.*	
3. Cancer	LLR LeDeR focused priority review area for 2025-26 is agreed as 'All cancer diagnoses. Analysis to follow next year. See above for the LD Community Phlebotomy Team.		
Focus on co-morbidities associated with premature death and DNACPR / ReSPECT	Following learning into action taken from LLR LeDeR in the last 2 years - we are looking to form a working group during 2025-26 around end of life care, the ReSPECT process and advanced care planning for people with learning disabilities. This is to review all our currently available resources and current processes, to establish as a system	*Focused priority review area completed and closed, analysis and conclusion available earlier in this report.*	

	are we uniform in our working, and are these resources being used effectively. We will then agree as a group what work needs to be done in terms of outputs either new or fine-tuning of what is already in place. LLR LeDeR focused priority review area for 2024-25 was 'Deaths of those under 50yrs of age who have a congenital condition or syndrome – through the lens of intersectionality'.		
Assure and sustain performance. - LeDeR Review within 6 month KPI	LLR LeDeR will work to complete reviews within 6 months (where possible) to meet KPI		
Improve the quality of LeDeR Reviews and actions from learning - Facilitate peer review opportunities	LLR LeDeR have introduced peer reviewing as part of internal process. Attendance at the regionally organised peer review for the East Midlands led by NHS England. The first of which was on those from a diverse ethnic background. The second was on autistic people.	*As a result, LLR LeDeR will be looking at the following:* - *Ensuring people's culture, religion and all parts of their intersectionality are considered and written in LeDeR reviews.* - *The wording in which is used to describe access to services is reflective of the circumstances from the individual's perspective, as opposed to putting ownership on an individual. [Learning from autism peer review NHS England 2025].* - *LLR LeDeR Governance panel is now asked to consider if there is learning into action related to intersectionality for each review.*	
Improve access and understanding of	A communication plan was developed and completed this year.	*The LLR LeDeR webpage was launched.*	

importance of LeDeR Reviews - communicating more with stakeholders, encouraging notifications to LeDeR to better understand the experience of LeDeR for families and other relevant others, particularly minority ethnic groups and autistic people	A presentation to the local LD and autism partnership boards is scheduled to be delivered by the LLR LeDeR expert by experience.		
Improve accuracy of LD Registers & increase the quality and uptake of AHC's - to support continued improvements in data accuracy for thematic analysis - improve the quality of AHC's	The PCLN team, Health Equity Lead and LD transformation lead GP are continuously working to support LLR GP practices on the improving LD registers and local QI projects. LLR are a pilot site for the Combined LD, SMI and Autism Annual Health Check.	*Additional work has been introduced to improve the accuracy of ethnicity status for those on the LD register. Annual health checks remain high in uptake at 86%.* *The GP's LD Friendly practice award has been implemented, and 2 GP practices have received a gold standard rating which is fantastic. [please note only a small number have undertaken the assessment process at this stage.]*	

LeDeR Actions 2024 – 2025

Action	Detail	Outcome	RAG Rating
Life QI Improving the notifications of the deaths of autistic people to the LeDeR Programme.	All areas of Life QI completed. Storyboard complete.	There has been an improvement in the number of notifications received but this remains minimal. The QI project identified that in the absence of an electronic source of notification alert and reminder this will likely remain low. However, this is reflected nationally, and the programme continues to work with the national team as required. The LPT data source has been identified and is now being reviewed for validity and reliability with GP practices.	
Establish LeDeR Confirm and Challenge Group.	Recruitment of lived experience partner was successful. She now chairs the LLR LeDeR Confirm and Challenge group, which they have self named, *'Stopping People Unnecessarily Dying Young – S.P.U.D.Y'.*	A successful board level group has been established with regular reporting into and out of the LeDeR Steering Group.	
Audit of Learning into Action.	The feedback loop of learning into action is required and review on the governance arrangements.	Although work has been carried out, there still remains some outstanding parts of the system to continue this work with into 2025-2026.	
High Level Action Plan created following announcement of NHS England.	The high level action plan to be created (see above) and director letter to go out to system leader.	Completed. The action plan is ongoing and a new and continued action plan will be arranged into 2025-26.	
Support the roll out of the RADF and system wide quality standards for improved LD response from all services and partnerships.		The roll out of the RADF has been successful, however further work is required on its use. Quality standards have been set however, still require further work to monitor and set improvements. RADF in place for all S1 users. UHL go live pending new EPR. Online training live. Training and use data now accessible and being refined to support performance improvement in LPT - comms strategy live. Further work required in Primary Care.	

Appendix 1

Governance Group

Grade	Quality of Care	The Right Support
6	This was the excellent care (It exceeded expected good practice). Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.	Responsiveness of ICS services to the person's needs was excellent and exceeded the expected standard.
5	This was good care (it met expected good practice). Please identify in learning and recommendations what features of care that current practice could learn from	Responsiveness of ICS services to the person's needs was good and met the expected standard.
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the persons wellbeing). Please address these issues in your recommendations for service improvement and identify in learning and recommendations any features of care that current practice could learn from.	Responsiveness of ICS services to the person's needs fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.
3	Care fell short of expected good practice and this did impact on the persons wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement and identify any features of care that current practice could learn from.	Responsiveness of ICS services to the person's needs fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death.
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	Responsiveness of ICS services to the person's needs fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
1	Care fell far short of expected good practice and this contributed to the cause of death.	Responsiveness of ICS services to the person's needs fell far short of the expected standard and this contributed to the cause of death.

Appendix 2

Improving notifications of the deaths of autistic people to the LLR LeDeR Programme

Leicestershire Partnership NHS Trust

The aim of the project

The aim of the project was to improve the notifications of the deaths of people with a diagnosis of autism to the local LeDeR Programme, as the notifications are very low locally but also nationally.

The rationale for the project

This improvement matters as the number of notifications of the deaths for people with a diagnosis of autism is very low. Nationally, since autism was added to the LeDeR Programme in Feb 2022, there have only been 406 notifications, 36 of these were for the Midlands of which 9 were for LLR.
We cannot review the deaths of autistic people if they are not notified to the LeDeR programme, and so, we cannot learn from their deaths and make improvements in the future care that autistic people receive.

What we did

LLR LeDeR met with the Midlands LeDeR Peer Support Group who are working on the rollout of the Reasonable Adjustment Digital Flag (RADF)

Our baseline was established on the number of notifications received to the LLR LeDeR Platform.
Communications published information on how to make notifications to the LeDeR platform for those with a diagnosis of autism.
By working with other professionals in the 'learning from deaths' field, and with regional LeDeR colleagues, IT technicians and the LDA Collaborative
We requested a SNOMED report for the deaths of people that had a diagnosis of autism.

How we measured change

At the start, LLR had records of only 4 deaths of people with autism notified to the LeDeR platform.

To date LLR LeDeR have now received a total of 10 notifications.

LLR LeDeR has been able to review the lives and deaths of these 10 case of autistic people and these will contribute to service level improvements and mortality review findings.

A further effect has been improved communication and working with other 'learning from deaths' groups and systems (i.e. suicide prevention group, drug and alcohol related deaths group), and presenting at health and wellbeing board (City).

Impact of the project

Due to improved communications and working with other agencies to promote the LeDeR programme via trust boards and panels, there is now a wider knowledge of the LeDeR programme.

We have recruited a lived experience partner to join and support the LLR LeDeR programme to progress change.

The learning has provided the much-needed evidence to support the roll out of the RADF and combined annual health check pilot.

Initial steps have been made to better understand the challenges faced by autistic people in managing their health and social care.

Notifications have doubled; LeDeR has a clear plan to build on this further. The QI plan has been a success.

Next steps

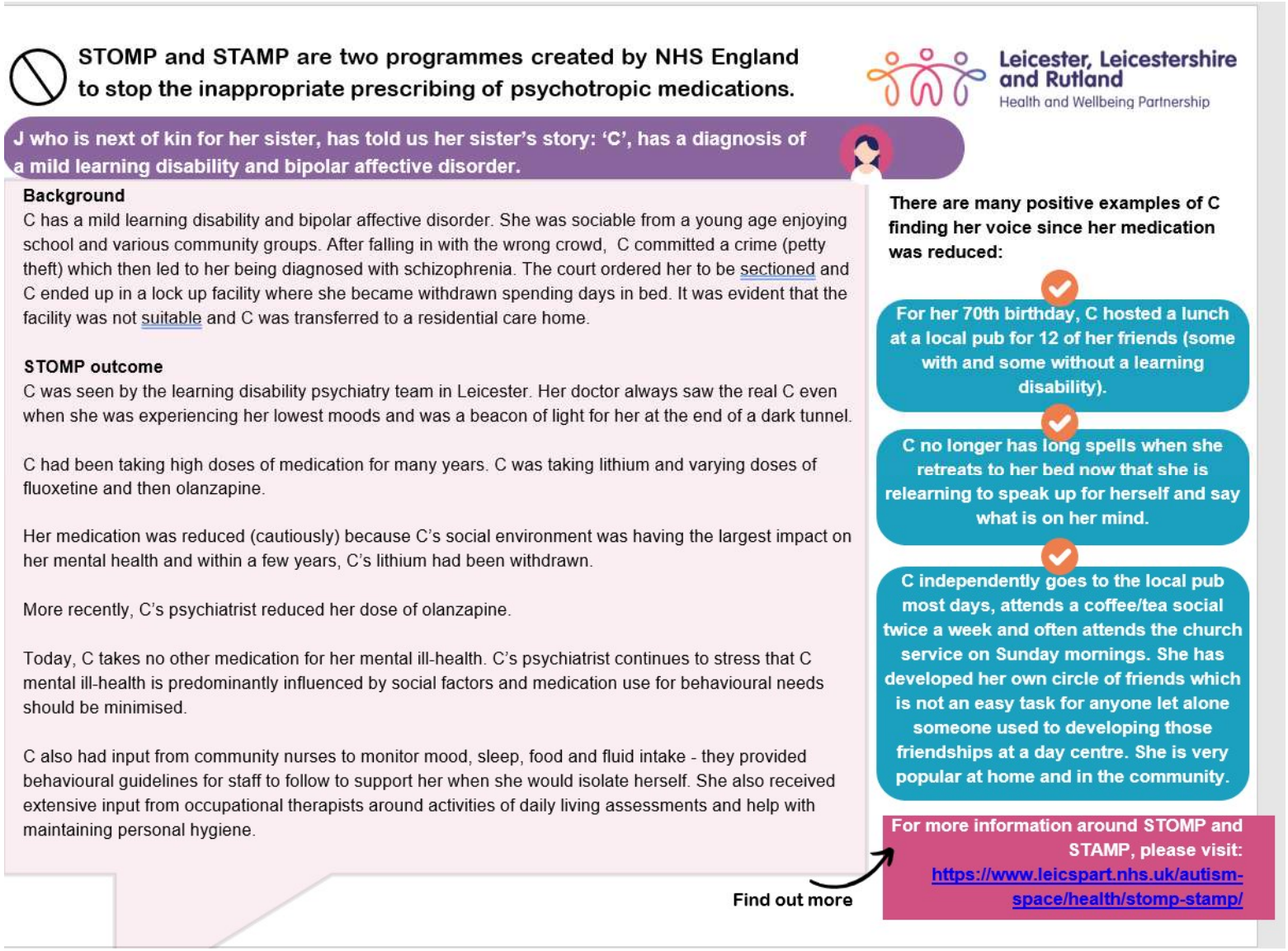
LLR LeDeR Programme work is ongoing, looking for ways of improve notifications and avoid unnecessary deaths. The Programme is working towards an online electronic alert to further improve notifications.

Continue to promote LeDeR notifications, specifically autistic notifications, through as many channels as possible.

LeDeR is a national programme and LLR routinely share positive practices with the Midlands LeDeR Peer Support Group.

Details of all findings are published in the LLR Annual Report

Appendix 3


STOMP and STAMP are two programmes created by NHS England to stop the inappropriate prescribing of psychotropic medications.
Leicester, Leicestershire and Rutland
Health and Wellbeing Partnership
J who is next of kin for her sister, has told us her sister's story: 'C', has a diagnosis of a mild learning disability and bipolar affective disorder.
Background
C has a mild learning disability and bipolar affective disorder. She was sociable from a young age enjoying school and various community groups. After falling in with the wrong crowd, C committed a crime (petty theft) which then led to her being diagnosed with schizophrenia. The court ordered her to be sectioned and C ended up in a lock up facility where she became withdrawn spending days in bed. It was evident that the facility was not suitable and C was transferred to a residential care home.
STOMP outcome
C was seen by the learning disability psychiatry team in Leicester. Her doctor always saw the real C even when she was experiencing her lowest moods and was a beacon of light for her at the end of a dark tunnel.
C had been taking high doses of medication for many years. C was taking lithium and varying doses of fluoxetine and then olanzapine.
Her medication was reduced (cautiously) because C's social environment was having the largest impact on her mental health and within a few years, C's lithium had been withdrawn.
More recently, C's psychiatrist reduced her dose of olanzapine.
Today, C takes no other medication for her mental ill-health. C's psychiatrist continues to stress that C mental ill-health is predominantly influenced by social factors and medication use for behavioural needs should be minimised.
C also had input from community nurses to monitor mood, sleep, food and fluid intake - they provided behavioural guidelines for staff to follow to support her when she would isolate herself. She also received extensive input from occupational therapists around activities of daily living assessments and help with maintaining personal hygiene.
There are many positive examples of C finding her voice since her medication was reduced:
For her 70th birthday, C hosted a lunch at a local pub for 12 of her friends (some with and some without a learning disability).
C no longer has long spells when she retreats to her bed now that she is relearning to speak up for herself and say what is on her mind.
C independently goes to the local pub most days, attends a coffee/tea social twice a week and often attends the church service on Sunday mornings. She has developed her own circle of friends which is not an easy task for anyone let alone someone used to developing those friendships at a day centre. She is very popular at home and in the community.
Find out more
For more information around STOMP and STAMP, please visit: https://www.leicspart.nhs.uk/autism-space/health/stomp-stamp/