

Leicester, Leicestershire and Rutland LeDeR Annual Report 2026



**Leicester, Leicestershire
and Rutland**
Health and Wellbeing Partnership

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Foreword

Leicester, Leicestershire and Rutland (LLR) continue to demonstrate a strong and unwavering commitment to the LeDeR programme and to improving the care and outcomes for people with a learning disability and autistic people. It is this sustained commitment across the system that has enabled the development of this Annual Report.

We would like to express our sincere appreciation to the many individuals and organisations across LLR whose dedication, professionalism, and compassion have underpinned this work. This includes those who have reported deaths, undertaken reviews, and contributed to the analysis of learning. Most importantly, we acknowledge the individuals at the heart of this report—people with a learning disability and autistic people—as well as their families, friends, carers, colleagues, and everyone whose lives are affected by this work.

We also wish to recognise the vital contribution of our LeDeR Reviewers. Their knowledge, compassion, and commitment have been central to the progress achieved to date. We remember with respect those whose lives are reflected in this report and those who are no longer with us, and we hope this report honours their memory.

This report is not an endpoint, but a catalyst for continued improvement. It calls on every partner within the LLR health and social care system to reflect on the findings and take meaningful action. Only through shared responsibility and collective action can we ensure that people with a learning disability and autistic people receive consistently high-quality care, and that true health equality and equity are achieved.

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

Executive Summary

The Leicester, Leicestershire and Rutland (LLR) LeDeR Programme reviewed the lives and deaths of people with a learning disability and autistic people to identify learning that can improve care, reduce health inequalities and prevent avoidable deaths. During 2025/26, 97 deaths were notified to the programme and 82 reviews were completed, exceeding the national target for focused reviews.

Respiratory disease remained the leading cause of death, followed by cardiovascular disease and cancer. This year saw a significant increase in cancer-related deaths, with many people diagnosed at Stage 4 disease. A thematic review highlighted delays in diagnosis, barriers to investigations and missed opportunities for reasonable adjustments, leading cancer to become a key area for system-wide improvement.

The report identifies two continuing priorities for action: improving compliance with the Mental Capacity Act (2005) and ensuring earlier recognition of cancer and deteriorating health. Reasonable adjustments also remained the most common learning theme, reinforcing the need for all services to provide equitable and accessible care.

There were many positive achievements across LLR during the year, including continued high uptake of Learning Disability Annual Health Checks, the development of the specialist Learning Disability Phlebotomy Pathway, progress with the Leicestershire Aspiration Pneumonia Protection Plan (LAPPP), and ongoing success of the STOMP/STAMP programme. These initiatives demonstrate a continued commitment to improving health outcomes and reducing inequalities.

The report concludes with a renewed focus on preventive healthcare, early diagnosis, end-of-life planning, reasonable adjustments, Mental Capacity Act compliance and reducing health inequalities. Through partnership working and shared responsibility, LLR remains committed to ensuring people with a learning disability and autistic people receive high-quality, equitable care throughout their lives. 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.

"To those who knew her, she will always be remembered for her sweetness, her vibrant joy, her laughter, her dancing, and above all, her unwavering affection."

Insights from the Author

This year has been one of reflection, challenge and optimism.

Over the past several years, the LeDeR programme in LLR has repeatedly highlighted the same themes: reasonable adjustments, the Mental Capacity Act (2005), communication, preventative healthcare and end-of-life planning. Whilst it can be frustrating to continue reporting similar findings, it is important to recognise that meaningful change across a large health and social care system takes time. This year we have again seen evidence of excellent practice, but also clear reminders that there is still more work to do.

One of the most striking findings from this year's reviews was the increase in cancer-related deaths, although being mindful that we focused on all cancer diagnosis and saw people survive the disease too. Historically, cancer has not featured prominently within our local LeDeR data. This year, however, there was a noticeable rise in cancer diagnoses, often at Stage 4. Although concerning, this may also represent some positive progress in recognising and diagnosing cancer in people with a learning disability who may previously have remained undiagnosed. The challenge now is, ensuring that people are diagnosed earlier through improved recognition of symptoms, equitable access to investigations, and effective use of reasonable adjustments throughout diagnostic pathways.

The Mental Capacity Act (2005) remains a recurring area of concern. Whilst there were examples of excellent, person-centred and legally compliant practice, the same issues were repeatedly identified across reviews. Capacity assessments, best-interest decision making and documentation continue to be inconsistent. It remains my view that the principles of the MCA are generally well understood; however, translating that understanding into everyday practice continues to be challenging across all sectors.

This year has also provided considerable encouragement. The Learning Disability Phlebotomy Pathway and sedation clinic pilot have been genuinely innovative developments for LLR. For many people, access to blood tests has been a long-standing barrier to healthcare. Seeing individuals successfully undergo investigations that were previously not possible has been both rewarding and humbling. The dedication of commissioners and staff involved in the development of this pathway demonstrates what can be achieved when health inequalities are approached creatively and collaboratively.

One of the most inspiring pieces of work undertaken this year was the thematic review of people with learning disabilities who lived into older age. Spending time reviewing the stories of individuals who lived into their 80s was a privilege and a reminder of why the LeDeR programme exists. These were stories of resilience, strong relationships, person-centred support and lives well lived. The review challenged many assumptions about ageing with a learning disability and reinforced the importance of preventative healthcare, stable support networks and maintaining meaningful lives throughout the life course. It also had a profound impact on those involved in the review process, reminding us to celebrate success as well as learn from difficulty.

This year marked a significant achievement for the LLR LeDeR Team, who were honoured with the LPT Celebrating Excellence Team of the Year Award, in recognition of their dedication, hard work, and impact throughout the year.

Finally, I would like to acknowledge the families, carers, professionals, reviewers and experts by experience who continue to contribute to the LeDeR programme. Their honesty, compassion and commitment ensure that every review becomes an opportunity for learning and improvement. Behind every statistic is a person, a family and a story. It is our responsibility to ensure that those stories continue to drive meaningful change across Leicester, Leicestershire and Rutland.

Siouxie Nelson – LLR LeDeR Clinical Lead

Introduction

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 fourth year running, included LeDeR reviews of autistic people. As this is the fourth 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.

"His sister shared that he had a really lovely childhood. He was the youngest of three children and was very much "Peter Pan" for their mum."

National context¹

The final National 2024 LeDeR Annual Report has been published in July 2026 and, whilst it has confirmed that this is the final national academic report, this does not signal an end to LeDeR, the collection of mortality data, or the focus on reducing health inequalities experienced by people with a learning disability and autistic people. The accompanying written Ministerial Statement confirms the Government's ongoing commitment to learning from deaths and improving outcomes for these populations.

The Minister highlighted concerns regarding the high proportion of adults with Down syndrome who die before the age of 65 and reiterated the Government's commitment to improving outcomes through implementation of the Down Syndrome Act 2022. The statement also recognised that suicide, misadventure and accidental death remain the most common causes of death among autistic adults without a learning disability. The Government committed to addressing these inequalities through the Suicide Prevention Strategy for England and the development of a new Mental Health Strategy that considers the specific needs of autistic people and the provision of reasonable adjustments. NHS England has revised the LeDeR review process to strengthen its focus on service improvement, including greater consideration of modifiable factors, barriers to good health, safeguarding concerns and quality-of-care issues. The Minister confirmed that the 2024 report will be the final national academic LeDeR report. Future national learning will be supported through a new patient-level dataset bringing together information on health outcomes for people with learning disabilities, Down syndrome, autism and ADHD, enabling improved understanding of inequalities and supporting local and national service improvement.

The 2024 National LeDeR Report continues to demonstrate significant health inequalities experienced by people with a learning disability. Nationally, adults with a learning disability died at a median age of 62.8 years compared with 81.8 years in the general population. People with profound learning disabilities died at a median age of 40.7 years, more than 20 years younger than those with mild learning disabilities. Treatable mortality was particularly high in this group. Although avoidable mortality has reduced over recent years, 39% of deaths remained avoidable, almost double the rate seen in the general population. Pneumonia, epilepsy and cardiovascular disease continue to be leading causes of avoidable death. Recurring themes include delays in recognising deterioration, barriers to accessing healthcare, diagnostic overshadowing, inadequate reasonable adjustments and challenges in care co-ordination. These findings reinforce the importance of annual health checks, effective implementation of the Mental Capacity Act, proactive management of long-term conditions, and ensuring equitable access to high-quality healthcare for people with a learning disability.

"She was special- not only to her mum, who held a deep and singular bond with her, but to everyone who's life she touched. Her story is one of love, resilience, and the pure, uncomplicated happiness she brought into the world."

Top Ten Learning into Action Points 2025-2026

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. Incomplete or estimated height and weight measurements remain a risk for people with LD. Wheelchair scales are available across LLR and hoist scales can be accessed via Learning Disability Community Teams to support accurate measurement.
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 which include this information in various formats.
10. Funding has been secured and the referral pathway is now being implemented for the specialist Learning Disability Phlebotomy Sedation Clinic. This innovative service will support people who have previously been unable to access blood tests, helping to reduce health inequalities and improve access to preventative healthcare.

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 97 deaths of people with a LD and autistic people were notified to the LLR LeDeR Programme from 1st April 2025 – 31st March 2026, of those people:

- 12 people were autistic.
- 15 people were out of scope as they did not meet the criteria for a LeDeR review.
- 15 people were adults with a LD and autism.
- 55 people were adults with a LD.

Referrals received in year.

shows a total of 97 deaths referred to LLR LeDeR in 2025/26, broken down into initial and focused categories. At end of year, 36 cases remained in progress and 46 had been completed.

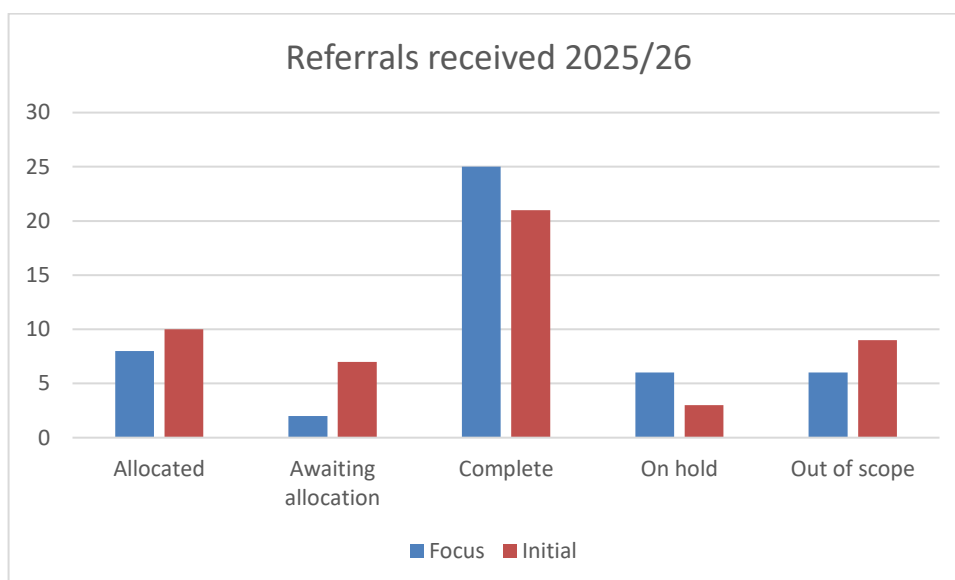


Figure 1. Referrals received by type, 2025/26

Age at death in 2025/26

Median age at death for those who passed away and their deaths notified to LeDeR in 2025/26 was 63yrs. This is a slight improvement on last year which was 61yrs. National LeDeR data (2024),

"He said the compassionate way the LeDeR letter was sent, along with the follow-up phone messages, showed genuine concern and encouraged him to take part in the review to help others who may face similar issues."

shows the median age at death at 62.8yrs.

The median age of death was 50yrs for those from a diverse ethnic background and 63yrs for those from a White British background. 14% (n=10) of those from a White British background were under 30yrs, and half of those (n=5) were deaths by suicide. Only 13% (n=11) of reviews notified to LeDeR were people from a diverse ethnic background, and over half of those were over 60yrs.

The median age at death in 2025/26, was 63yrs.

"He was described as always having sweets in his pocket. He would at times offer a sweet to someone in his hand, then, in a joking way, he would shut his hand and put the sweet away, sometimes he would go on to give the sweet and other times he wouldn't. This was a longstanding joke that he liked to do."

Mean age at death

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
2025/2026	59 years	59

*CDOP was removed from LeDeR reviews from 2023 onwards.

The mean age at death in 2025/26, was 59yrs.

Mean age at death in completed reviews

The mean age of deaths in completed reviews in 2025/26 is 59yrs, this is higher than 2024/25 which was 56yrs. Due to the statistically small number of data, this year LLR LeDeR continues to include 3 year rolling averages from 2023-2024 onwards for the mean age at death (this 3-year rolling average includes data from 2021/2022 to 2025/2026), which endeavours to give a more accurate picture and it allows for any annual variations and extreme anomalies.

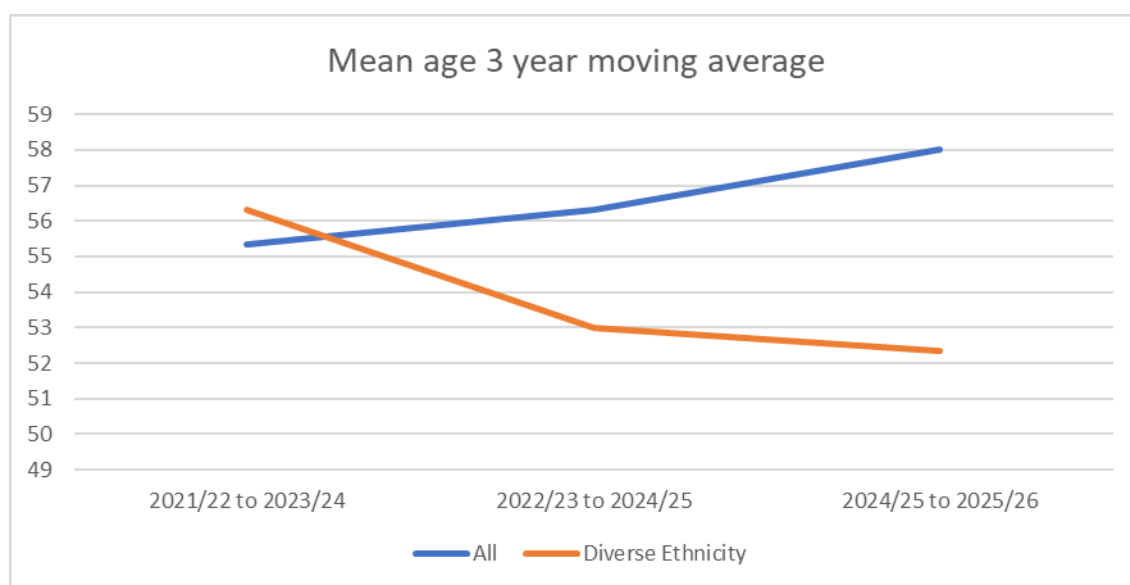


Figure 2. Mean age of death 3 year rolling average

Month of death

The 82 deaths notified to LeDeR in this time-period as shown in [Figure 3. Month of death](#), with more deaths occurring in August than any other month. This is broken down in [Figure 4. Month of death by gender](#). This excludes 10 notifications received in 2025/26, 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.

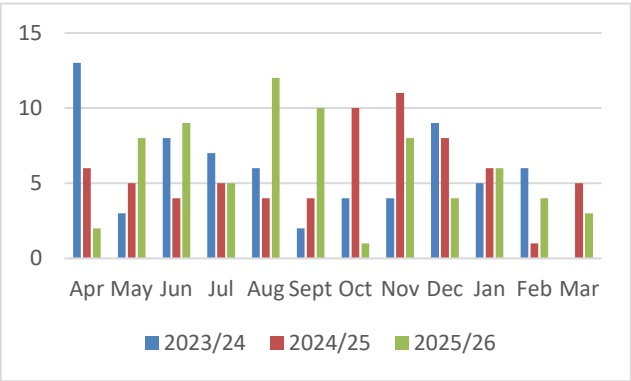


Figure 3. Month of death

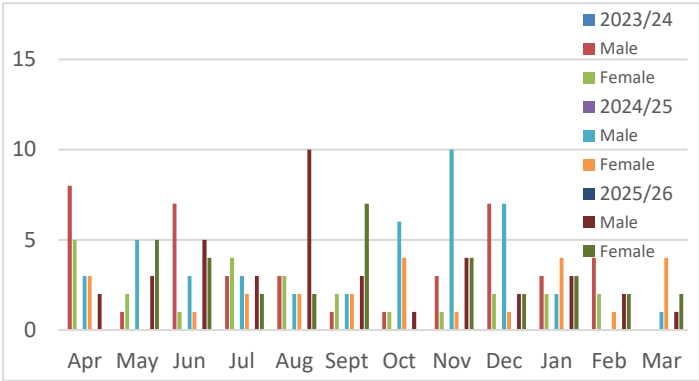


Figure 4. Month of death by gender

"She engaged in a range of sensory activities that she thoroughly enjoyed. These included playing with her belongings—particularly her tambourine, which was her favourite."

Reviews completed in year.

Analysis from this point covers all reviews that were completed within the 12 months from 1st April 2025 to 31st March 2026, 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 2025/26, the LLR LeDeR programme completed 82 reviews, 44 of which were initial, 38 focused (*Figure 5. Reviews completed in 2025/26.*) The key performance indicator set nationally is that 35% of LeDeR Reviews are to be focused.

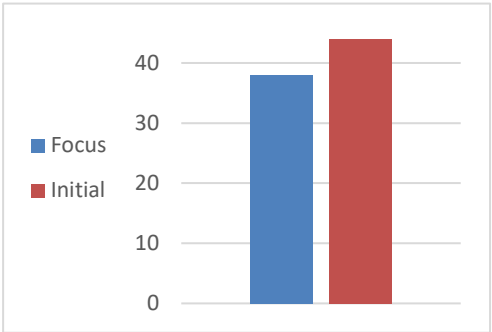


Figure 5. Reviews completed in 2025/26

For LLR LeDeR 46% of reviews were focused during 2025/26.

Equality Impact & Demographic Data

Age Group

Deaths were broken down by age group (see 2024/25, 2025/26), 56% of people who died were aged 61yrs or older, which is an increase since the past year of 4%. By comparison, deaths by age group in 2024/25 in LLR LeDeR shows 52% of people who died were aged 61yrs or older. For wider comparison, the national average age at death for people with a LD is 62.8yrs (National LeDeR Report 2024), for autistic people is 75.7yrs (National Autistic Society 2025) and for the general population this was 81yrs (UK Population Data 2023).

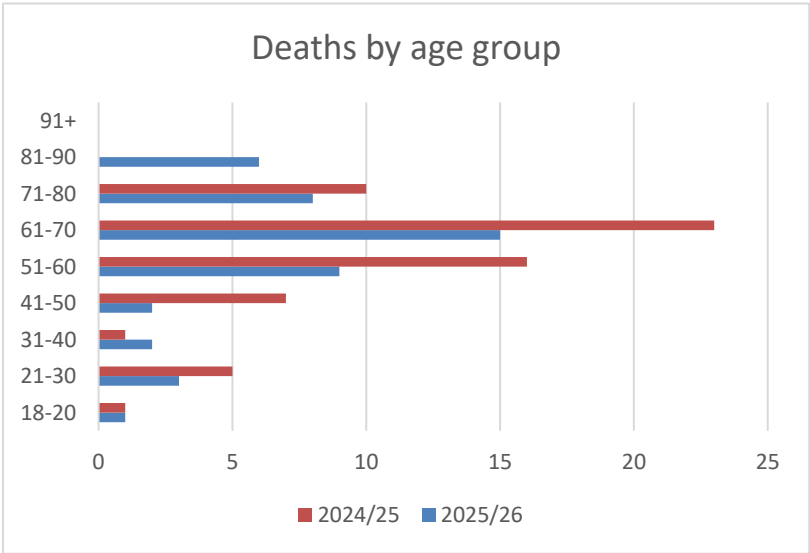


Figure 6. LLR LeDeR Deaths by age group 2024/25, 2025/26

Age of death in completed reviews by group

Due to the statistically small number of data, 3 year rolling averages have been used from 2023-2024 onwards for the age at death (this 3 year rolling average includes data from 2021/2022 to 2025/2026), this endeavours to give a more accurate picture and it allows for any annual variations and extreme anomalies, shown in figure 7.

ONS data is shown in figure 8 for comparison for age at death for England and Wales in 2023

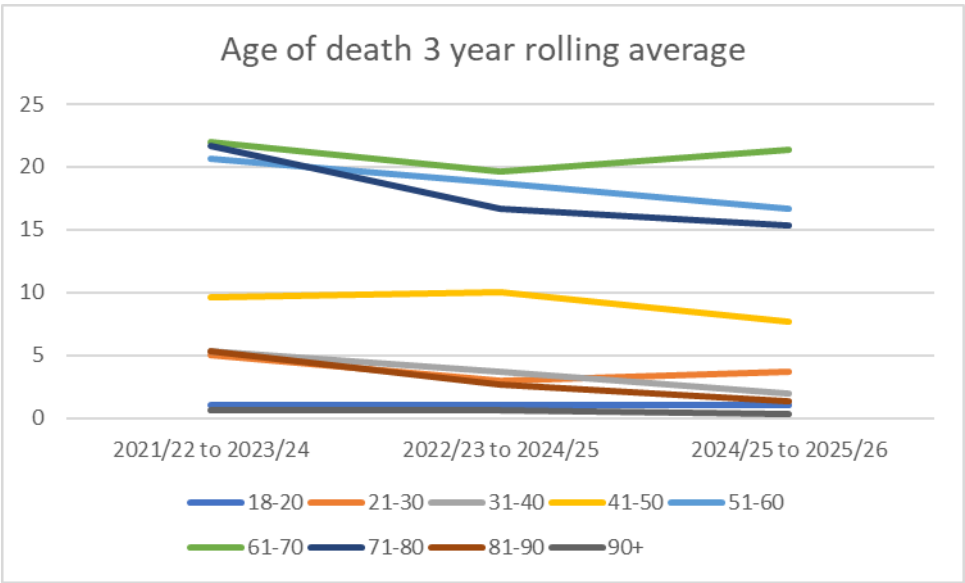


Figure 7. Deaths by age group 3 year rolling average

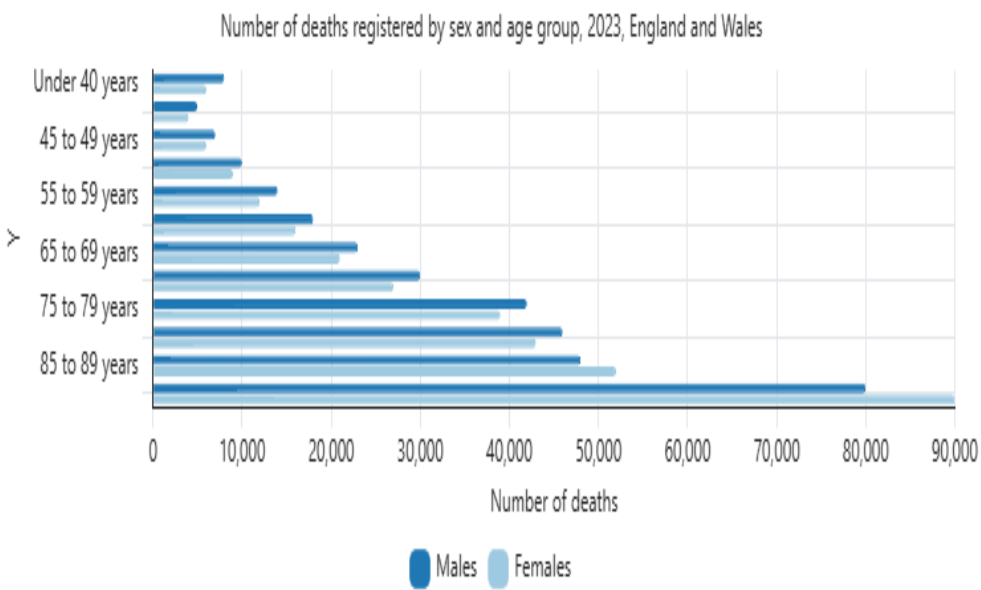


Figure 8. Death registration summary by ONS

Median age at death in completed reviews.

The median age of deaths in completed reviews in 2025/26 is 63yrs, this is only a year higher than 2024/25 which was 62yrs. Due to the statistically small number of data, LLR LeDeR has included 3 year rolling averages. These have been used from 2023-2024 onwards for the median age at death (this 3 year rolling average includes data from 2021/2022 to 2025/2026), which endeavours to give a more accurate picture and it allows for any annual variations and extreme anomalies.

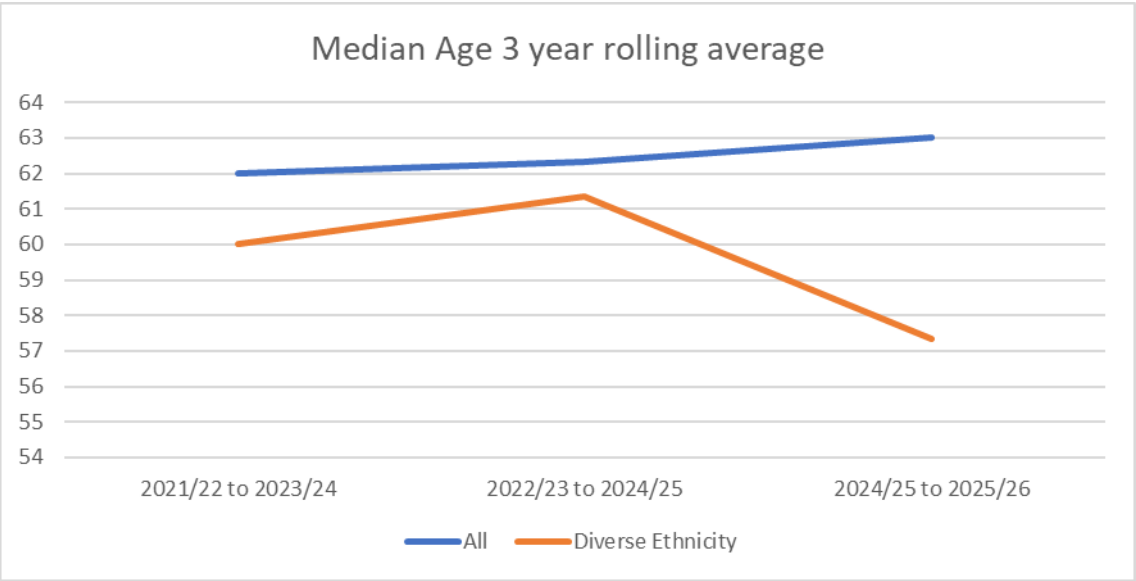


Figure 9. Median age 3 year rolling average.

“She was known to enjoy conversation and was affectionately described as a “lovely gossip” by those close to her.”

Ethnicity

Most of deaths were of 'White British' people (87%), with 9% of people 'Asian or Asian British' and 2% of people 'Black, African, Caribbean or Black British' ethnicity. The remaining 2% of people is 'Other ethnic groups' shown in

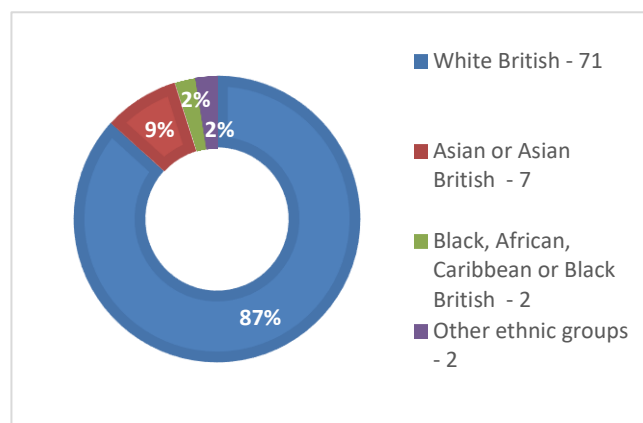


Figure 10. Cases completed 2025/26 by ethnic group.

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 50yrs for those from a diverse ethnic background and 63yrs for those from a White British background.

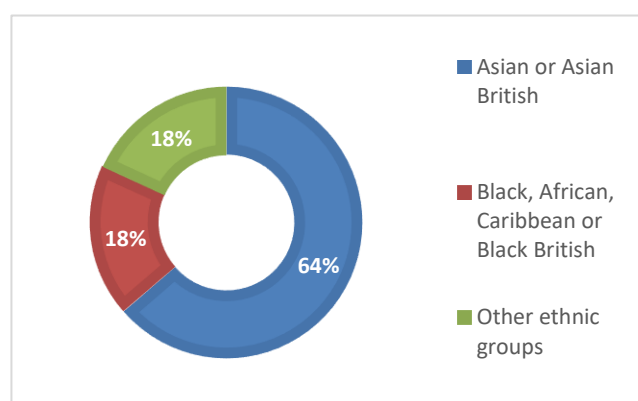


Figure 11. Cases completed 2025/26 by ethnicity.

As shown in *Figure 12. Deaths by gender*, 59% of reviews completed in 2025/26 were male and 41% female, which is in line with national and local gender demographics. Those people were resident across all three ICS places, and deaths were lower in East Leicestershire and Rutland and Leicester City but higher in West Leicestershire as illustrated in *Figure 13. Deaths by ICS place*.

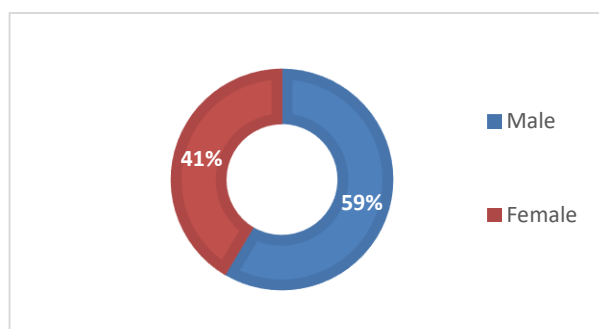


Figure 12. Deaths by gender

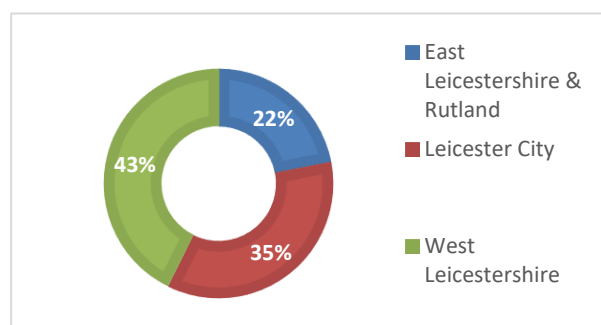


Figure 13. Deaths by ICS place

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.

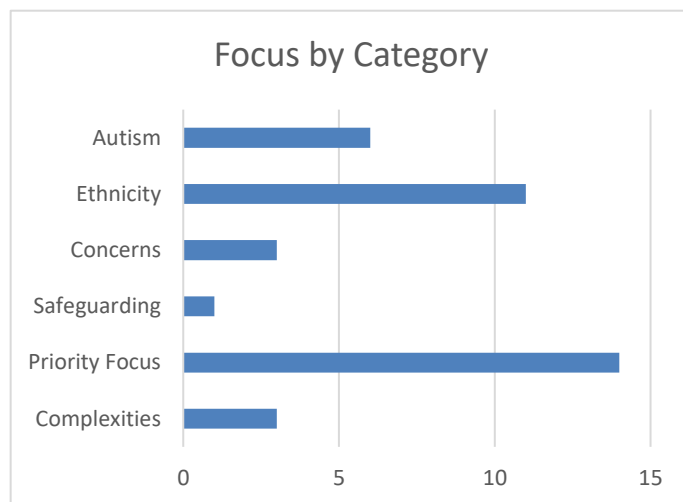


Figure 24. Focus by category

Most focused reviews were carried out due to Priority Focus area. 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.

Important Statements from LeDeR

Although a great deal of positive, innovative and compassionate work has been evident across LLR during the past year, there remain two areas requiring urgent and sustained system-wide attention. These issues continue to be identified consistently through LeDeR reviews and have the potential to significantly impact health outcomes, individual rights and access to equitable healthcare.

1. Mental Capacity Act (2005): From Awareness to Compliance

Despite increased awareness and examples of good practice, the application of the Mental Capacity Act (2005) remains one of the most significant and recurring concerns identified through LeDeR reviews. Inconsistent completion of capacity assessments, best-interest decision-making, documentation and understanding of legal responsibilities continue to be found across preventative healthcare, investigations, treatment decisions and end-of-life care. LLR LeDeR urges all partner organisations to move beyond awareness and demonstrate consistent legal compliance, audit assurance and workforce competence in MCA practice to ensure the rights of people with a learning disability and autistic people are upheld.

2. Earlier Identification of Cancer and Deterioration

There is increasing concern regarding the number of people with a learning disability and autistic people who are being diagnosed with cancer at a late stage, often Stage 4 disease. LeDeR reviews identified delays in recognition, referral, investigation and access to diagnostic procedures, with additional barriers relating to communication, diagnostic overshadowing and insufficient reasonable adjustments. Alongside cancer, deterioration was frequently not recognised early enough. LLR LeDeR urges the system to strengthen early identification, improve access to investigations through reasonable adjustments, enhance annual health checks and screening uptake, and ensure people receive equitable opportunities for diagnosis, treatment and care.

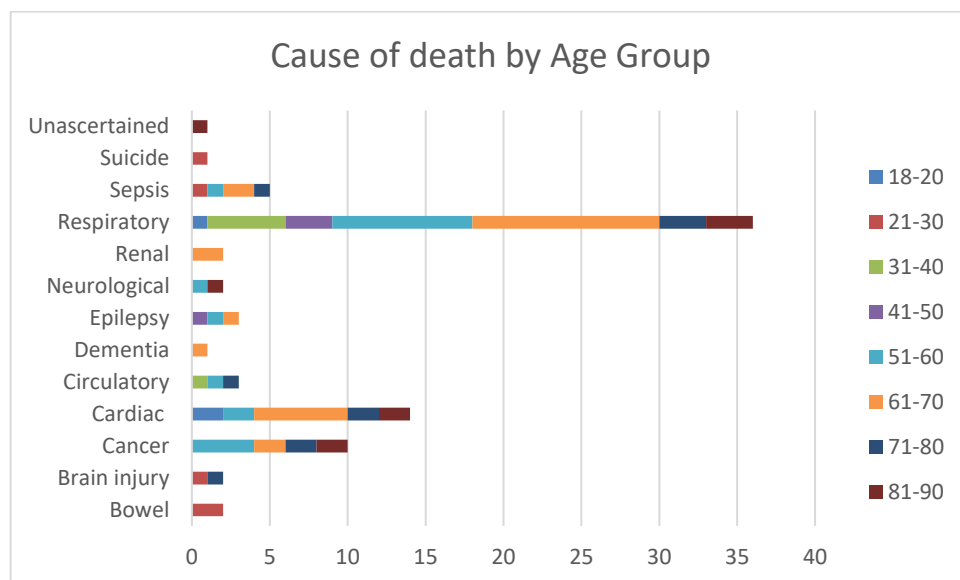
Causes and Circumstances of Death

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



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.

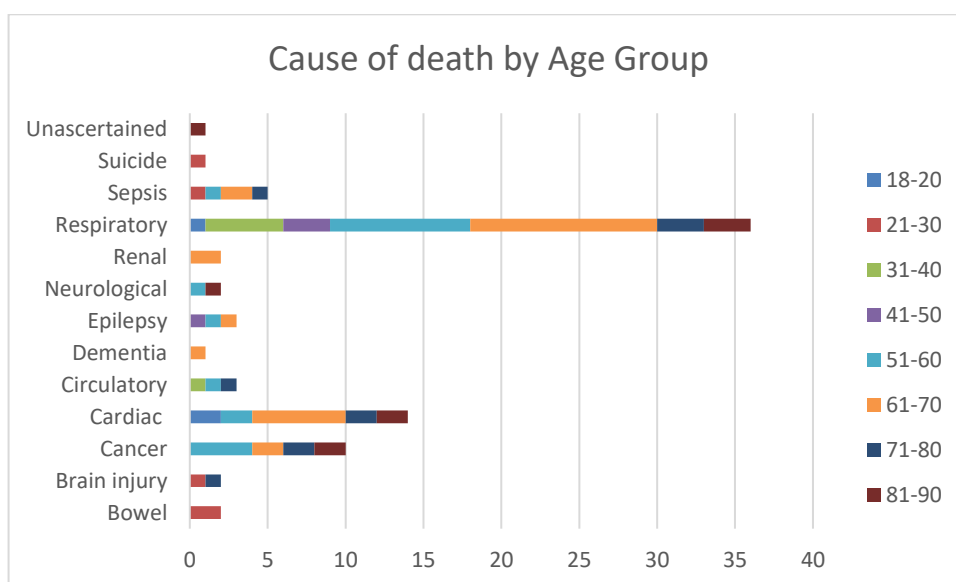


Figure 35. Cause of death by age

Breaking down of cause of death by Ethnicity is shown in

. It should be further noted that only 13% (n=11) of notifications received were those from a diverse ethnic background, implicating generalisation.

therefore statistical

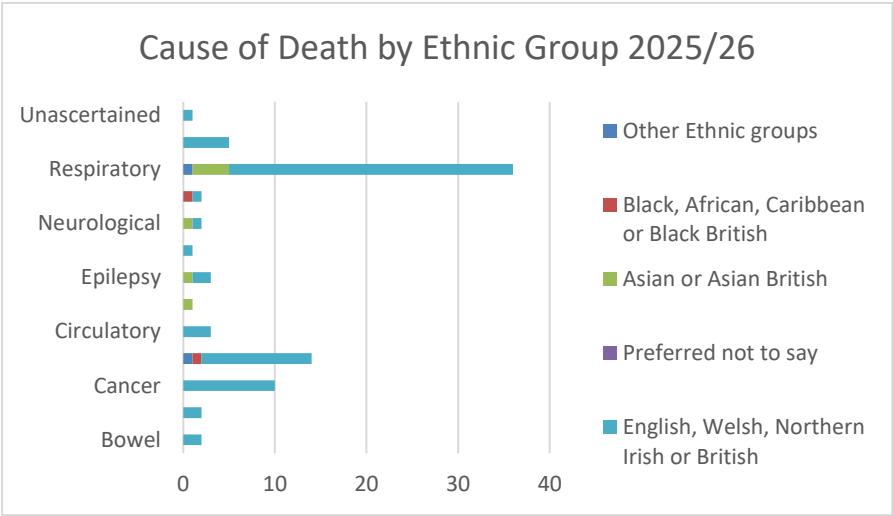


Figure 46. Cause of death by ethnicity

Leading Causes of Death

Causes of death in reviews completed in 2025/26 are shown in *Figure 17. Causes of death* below. Respiratory remains the leading cause of death, followed by Cardiac and Cancer. Respiratory accounts for 44% of deaths in completed reviews in 2025/26.

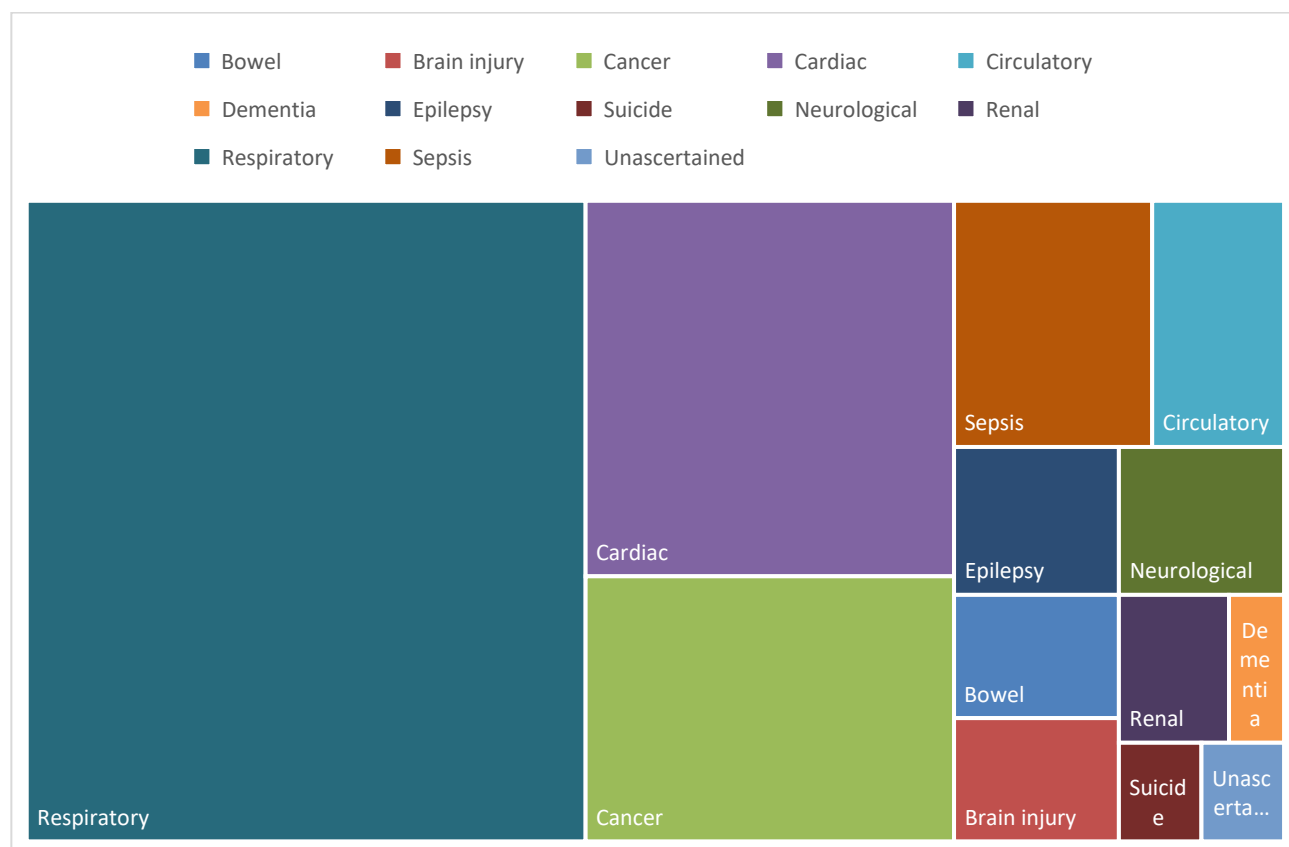


Figure 17. Causes of death

Respiratory Deaths

Deaths from respiratory causes continues to remain the leading cause of death for those in LLR reported to LeDeR. 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. This year a breakdown of the respiratory deaths has been included.	- Aspiration pneumonia - Recurrent aspiration pneumonia - Bronchopneumonia - Cardiorespiratory arrest - Cardiorespiratory failure - Chest infection - Pneumonia of unspecified origin
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Regional Thematic Analysis: Aspiration Pneumonia

Aspiration pneumonia	5
Recurrent aspiration pneumonia	1
Bronchopneumonia	7
Cardiorespiratory arrest	1
Cardiorespiratory failure	1
Chest infection	3
Recurrent chest infection	1
Infective exacerbation of asthma	1
Lower respiratory tract infection	4
Pneumonia	10
Respiratory failure	2

During 2025/26, the LLR LeDeR Programme collaborated with three other Midlands LeDeR programmes to undertake a regional review of aspiration pneumonia deaths in people with a learning disability. The review analysed 47 deaths between April 2023 and January 2025 where aspiration pneumonia was recorded as the immediate cause of death. The purpose was to better understand common risk factors and identify opportunities for prevention and earlier intervention.

The analysis demonstrated that aspiration pneumonia is rarely an isolated condition and is more commonly the culmination of a series of complex health and care factors. The most frequently identified contributory factors were uncontrolled epilepsy (27.5%), congenital conditions (27.5%), constipation (20%), reduced mobility, frailty and dependency on others for activities of daily living. Almost all individuals required support with daily living activities, indicating that dependency and complexity of need may increase vulnerability to aspiration-related mortality.

Most people who died had a moderate or severe learning disability, although aspiration pneumonia deaths occurred across all levels of learning disability. This highlights the importance of considering aspiration risks contributing to aspiration pneumonia for all people with a learning disability rather than focusing solely on those with profound disabilities. The review also found that whilst many individuals had received an annual health check and had end-of-life documentation in place, opportunities remained to identify aspiration pneumonia risk factors earlier and strengthen preventative care planning.

A key finding was that aspiration pneumonia frequently occurred following a period of deteriorating health, rather than as a sudden isolated event. Constipation and epilepsy emerged as potentially modifiable risk factors. Constipation was associated with increased risks of reflux, vomiting and aspiration, which if aspirated can lead to an aspirational pneumonia, whilst poorly controlled epilepsy increased aspiration pneumonia risk through seizures, reduced consciousness and impaired airway protection.

The review concluded that aspiration pneumonia should be viewed as the consequence of earlier health events and multiple vulnerabilities rather than solely a respiratory diagnosis. The findings support the need for proactive management of epilepsy and constipation, early identification of deterioration, improved annual health check processes, robust advanced care planning and integrated multi-agency approaches to aspiration pneumonia prevention and management. These findings support the ongoing development and implementation of the Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) across LLR.

The 'Leicestershire Aspiration Pneumonia Protection Plan (LAPPP)' based on the findings from LeDeR was tested during the pilot year. This work has been written up as a journal article to enable ongoing learning and research in this area and is at peer review stage for publication. This work was presented for oral presentation at the RCN International Nursing Research Conference in Exeter in September 2025. The LAPPP is being considered for a wider grant funding opportunity in order to progress this invaluable work.

Cardiac

Deaths from cardiac causes have decreased since last year but remain the 2nd highest cause of death. This year a breakdown of the cardiovascular deaths has been included:

Acute cardiac dysrhythmia	1
Acute Myocardial Infarction	1
Cardiac failure	1
cardiorespiratory arrest	1
cardiorespiratory failure	1
Congestive Cardiac Failure	1
Exacerbation of Cardiac Failure	1
Heart failure	1
Hypoxic Brain Damage Secondary to Cardiac Arrest due to Multiple Organ Failure	1
Ischaemic Heart Disease	1
Myocardial infarction	1
Obesity related and diabetic heart disease	1

LLR LeDeR are undertaking a thematic analysis of the effects of underweight BMI recordings in people with a learning disability in Summer 2026 using retrospective analysis. The analysis will support the identification of contributing factors and commonalities that may be contributing to low weight and the consequences of underweight.

The healthy living toolkits were produced last year, but this remains an important reminder of this freely accessible online resource:

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

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 2025/26 shown in figure 18.

Scoring of 1 for Quality of Care

This relates to concerns raised may have contributed to death.

Scoring of 2 for Quality of Care:

This relates to concerns of a deteriorating patient, lack of good practice and missed opportunities.

Scoring of 3 for Quality of Care:

This relates to concerns of reasonable adjustments, MCA and concerns around communication.

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.

Scoring of 6 for Quality of Care: This relates to escalation of care, MDT working and nursing care for people with a learning disability.

There were no gradings of 1 in 2025/26.

If the grading is 2 or lower for quality of care and the right support a referral to safeguarding will be considered.

Grading of the Right Support.

Overall, over 50% of care was found to be satisfactory or good, a further 34% 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**:

- Reasonable adjustments, family involvement, care coordination, person centred care, MDT working, compassion, proactive care, consistent preventative healthcare including LD Annual Health Checks, vaccinations, screening and early diagnosis and intervention, joint funded care, supported to remain living at home.
- Use of interpreter services, collaborative working, easy read documentation, medication and psychiatry review, timely investigation, metabolic monitoring reminders on electronic

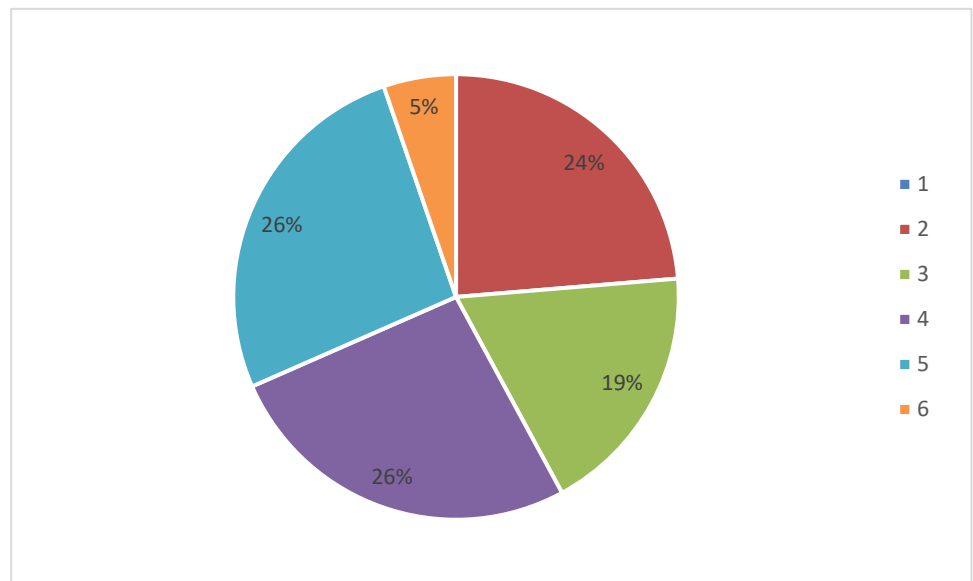


Figure 18. Grading of care

patient record, ALN support, preventing hospital readmission, responding to care needs, person centred care.

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 24-25	No. of learning points 25-26
Professional practice and provision of care	200	304
DNACPR recommendations and end of life care	65	57
Care Pathways	38	56
Deterioration	26	46
Learning Disability Awareness	47	45
Family and carer awareness of available support	19	28
Training on specific conditions	9	20
Transition	3	12
Safeguarding	22	9
Involving the Coroner	2	1
Grand Total	431	578

Table 1. 10 Key Themes - learning points

The area of highest concentration 2025/26 remains the same as the last 2 years 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	60
Person Centred Care	52
Deteriorating Patient	47
Communication	41
Cancer screening	38
End of Life	33
Care Planning	32

MCA	28
ReSPECT	28
Annual Health Check	18

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 [35]

"She had a consultation with a nurse at the practice due to post-menopausal bleeding. She declined a blood test, and the nurse recorded that they were unable to obtain a weight due to the lady being in her wheelchair. There was no evidence found of reasonable adjustments being made to enable her to have her weight measured."

"There was no alert on the electronic patient health records informing health care professionals of his autism diagnosis so they would not have been aware that he may have required reasonable adjustments to engage with health care services." [Autism]

"He was assessed and diagnosed with autism in November 2012, aged 13. There was no alert or flag on his GP record, and the diagnosis was not listed as an active problem. Health professionals accessing his record would not have been aware of his autism diagnosis. As a result, communication needs, sensory needs, anxiety, and barriers to attending appointments may have been overlooked." [Autism]

"There were transport challenges for the ambulance service and care provider when considering hospital admission and safe transportation. His moulded wheelchair could not be accommodated in the ambulance, and care staff were unavailable to assist with transfer in his Motability vehicle due to staffing shortages. Although a hospital admission was ultimately avoided, this may have delayed medical assessment. Planning ahead for specialist transport arrangements is important."

"A male under 20 years, despite a rheumatology consultant highlighting he had an immunocompromised state and was eligible for a one off dose of the pneumococcal vaccine as well as the flu and covid vaccinations, this does not appear to have been actioned by the GP. Discussions happened at his AHC, but no plans were made for him to receive the vaccinations, or follow ups made with regards to him being clinically vulnerable and unvaccinated."

Positive Practice [25]

"As his dementia progressed, he would get more agitated, making it difficult for him to get to and from his dialysis sessions (3 times a week). The ambulance transport escorts were said to have gone above and beyond to make his journeys comfortable and enjoyable e.g. play music, sing his favourite songs with and to him, being patient with him and providing a lot of reassurances. This allowed for his dialysis sessions to continue."

“During his annual health check, the practitioner noted that he required a double time slot for having any vaccinations as well as consideration to be made to offer the Flu vaccination as the spray due to his needle phobia. This was recorded in his electronic records, reasonable adjustment digital flag, so others could see.”

“During the hospital admission prior to her death the LD acute liaison nurse was informed of her admission. They visited her on the ward and were able to give advice around MCA and best interest as well as helping her to understand procedures required, reducing anxiety. This demonstrates good practice in making reasonable adjustments for people with LD receiving care and treatment in hospital in line with the Equality Act (2010).”

“Due to her level of understanding and communication needs, it was recognised that she was unlikely to engage effectively in one-to-one psychology therapy sessions. Instead, psychological input was provided indirectly through the MDT, with a focus on consultation and staff training. This good practice demonstrates how psychological interventions and MDT working were adapted and focused on indirect work, including consultation and training for staff in line with the British Psychological Society Best Practice Guidelines (2015).”

End of Life

Learning [15]

“She was coming to the end of her life and had anticipatory medications prescribed. Governance panel members felt that the medication should have been started a week earlier as she was communicating pain. It is important the district nurses visiting patients with a learning disability at end of life understand how to look for signs and symptoms of pain.”

“His family expressed concerns about his discomfort on the day that he died due to a delay in the district nurse arriving to administer pain relief and staff not being experienced in providing end of life care.”

“He had been accessing short breaks services on a regular basis for the past 20 years, he was also in regular receipt of Community LD Services over a similar time period. He did not have an advanced care plan or DISDAT in place. He had lived at home with parents all of his life.”

“He was prescribed anticipatory EoL medications, but it does not appear that a plan was made for seizure management in EoL. This resulted in him not receiving medication for a seizure in a timely manner and resulted in an ambulance being called and paramedics also not being able to administer any medication. Although he was prescribed rescue medication it was not clear if this could be administered once he was commenced on EoL.”

“His advanced care plan stated that his preferred place of care was his home, but he could not return home after his second admission because his care team felt that this would upset his housemates. However, this contradicts information provided by his sister who stated that the care provider was willing to have him discharged home. These decisions were based on an assumed negative impact on his housemates and not in line with the advanced care plan wishes. He was on

end of life for some time in hospital and there would have been many opportunities for him to be discharged home.”

Positive Practice [18]

“The pharmacist and palliative care nurse completed regular medication reviews towards the end of his life. They also liaised with the palliative care consultant for additional guidance when required. The outcome of this was effective control of his symptoms which included nausea and vomiting and ensured that his symptoms were managed as comfortably as possible during this stage of care in line with NICE guideline NG31 Care of dying adults in the last days of life.” [Autism]

“Diagnosed with rectal cancer in 2023, he was supported and cared for by a consistent staff team who knew him well and had provided person-centred care for many years. His end-of-life care was delivered in the comfort of his own home by his familiar staff team, with support from the community palliative care service, GP, and district nursing team. This ensured he was surrounded by people he knew and trusted. This quality of care reflects NICE guideline NG96 Care and support of people growing older with learning disabilities (2018).”

“As part of her advanced care plan, her family had wished for her to remain at the home she had resided at for 32 years of her life when the time came to die. These wishes were adhered to.”

Mental Capacity Act (2005)

Learning [18]

“Her health had been deteriorating and she was seen on separate occasions by a colorectal consultant and a consultant for her gallstones. Neither professional documented the use of the mental capacity act/best interest within the records they made even though they both deemed her to lack capacity to consent to any treatment options.”

“He received the yearly flu vaccination from 2015 until 2021. Despite being offered the flu vaccination and several reminder text messages being sent to his main carers he was not taken to have any more flu vaccinations. Covid vaccinations were also offered but declined on his behalf by family. There was no rationale for the reason why the flu and Covid vaccinations were being declined and no documentation around MCA or best interest for these decisions.”

“She had covert administration of medication implemented due to concerns regarding missed doses of sodium valproate and increased seizure activity. While there was clear clinical rationale for this approach, documentation did not consistently evidence that covert administration was authorised and reviewed within the framework of the MCA. In particular, there was limited evidence of a documented capacity assessment, best-interests decision-making process, formal treatment plan, and regular review over time, as required by NICE guidance and the Leicestershire Partnership NHS Trust Covert Administration of Medicines Policy.”

Positive Practice [10]

“Capacity assessments were completed, documented, and used to inform decisions about care, residency, finances, and treatment. Risk related behaviours in 2021 and 2022 were escalated, and safeguarding processes were initiated appropriately. DoLS was correctly applied during the 2022 mental health admission and throughout a prolonged 2022-2023 hospital stay. An IMCA was

involved when he was assessed to lack capacity for residence/finances. MDT best interest decision making supported proportionate, lawful planning and resulted in a least restrictive specialist placement that was approved by the courts.”

“During her prolonged hospital admission, multiple teams were involved in her care, working collaboratively to promote her best interests. The MCA and DoLS were applied to support decision-making, protect her and work towards the best possible outcomes.”

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 30 people prescribed psychotropic medicine at the time of death, 87% had a STOMP/STAMP review, 13% did not. This is a further improvement on the previous year 82% of people had a STOMP/STAMP review and 10% did not, and no data was available for 8%. Due to more accurate data being available *figure 19* shows an 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.

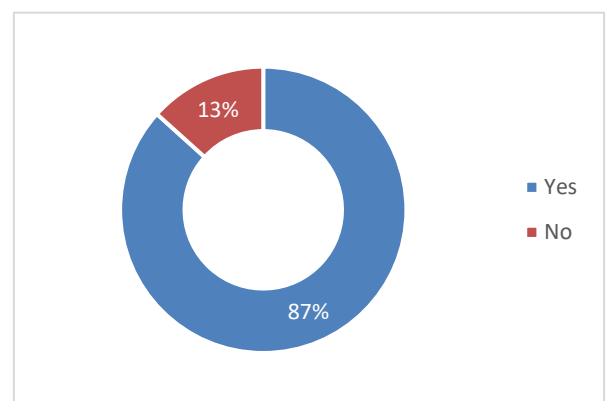


Figure 19. STOMP/STAMP review carried out for people on psychotropic medication at time of death.

Learning

- A young female with a diagnosis of multiple and profound LD, during a hospital admission, she was seen by the respiratory consultant who advised that care must be taken with regards to changes to the prescribed Benzodiazepine due to their sedative effect, small increases in doses over a number of days was recommended. However, this advice was not continually followed contributing to avoidable negative outcomes.

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 2025/26

The LLR STOMP/STAMP Working Group project aims for 25/26 were:

- Increasing STOMP/STAMP reviews in secondary care (linked to STOMP/STAMP framework)
- Training and Education in relation to STOMP/STAMP
- Rationalisation of medication prescribing- polypharmacy for people with a learning disability and autism, focusing on those taking 5 different psychotropic medications
- Reducing melatonin prescribing levels for young people across LLR, linked to the introduction of Sleep Clinics as alternatives to medication

The project is a continuation and development of the work that has been taking place, over several years, to implement best practice in relation to STOMP/STAMP to support individuals in LLR, so they take less psychotropic medications, or none at all.

Impact and outcomes:

There has been a further increase in the number of people with a learning disability and autistic people receiving an annual review of their psychotropic medication. During 2024/25, a total of 3097 reviews were completed, and the year-to-date data indicates that 2241 people have had a review during 2025/26. The outcome data indicates that during 2024/25, 103 people had psychotropic medication stopped because it was ineffective/inappropriate, compared to 49 during 2025/26 to date. During 2025/26 a total of 42 people have had a dosage reduced for their psychotropic medications, positively impacting the quality of life for these individuals.

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

Work has taken place nationally, through the Action Learning Set events, to share LLR's work in relation to STOMP/STAMP and were highly commended at the PrescQIPP Awards during 2025/26 for the work in implementing the regional STOMP/STAMP Framework and increasing the number of medication reviews taking place.

Through the MedSIP programme mapping the existing LD pathways went ahead and have held a system wide action planning session to inform the groups plans for 2026/27. A summary report has been produced which recognises the work of the STOMP/STAMP group in driving forward this important area of work.

A Sleep Hygiene working group has been established and a sleep pathway for CAMHS/Community Paediatrics has been developed. CPD sessions with Sleep Practitioners have been established.

Our Lived Experience Partner worked with the Autism Space Team as mentioned last year and this sets as a reminder for this useful resource: [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 scenario of a STOMP outcome is shown in Appendix 3.

Behaviours that challenge.

This year LLR LeDeR has seen a decrease in the number of people notified with behaviours that challenge. In 2025/26 78% had a PBS plan where behaviours that challenge were present and 22% did not. Last year 90% of people had a PBS plan and 10% did not. The previous year 81% of people had a PBS plan and 19% did not. This is still a significant increase from 2022/23 where only 37% had a PBS plan for behaviours that challenge and 63% did not.

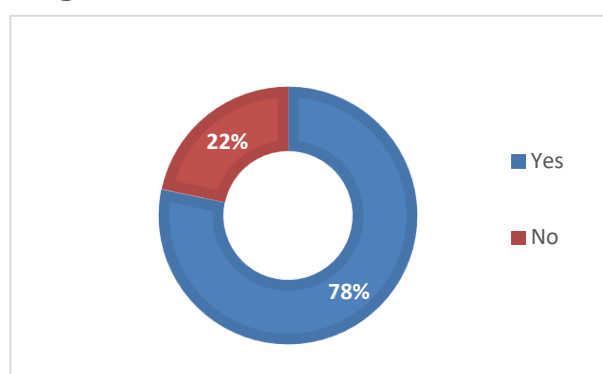


Figure 20. People with behaviours that challenge who had a PBS plan in place.

This remains 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

The LLR LeDeR Programme recommends continued 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 gentleman of Caribbean descent with a severe LD and complex health needs. As his health deteriorated, his anxieties and frustrations increased, resulting in him displaying behaviours that challenged. He had involvement from his family and many services who knew and supported him

well, but there was no positive behavioural support (PBS) plan in place to ensure there was consistency in place.”

Positive Practice

“A gentleman diagnosed with autism and dementia. PBS strategies led to improved emotional stability and reduced behavioural challenges. Removing 1:1 supervision, guided by PBS principles, helped him feel more at ease and improved his engagement with staff. This positive practice highlights how specialist placements significantly improve outcomes for individuals with complex needs.”

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 31%. This has decreased to 26% this year. Through the LDA Collaborative and LDA Health Inequalities group, 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.

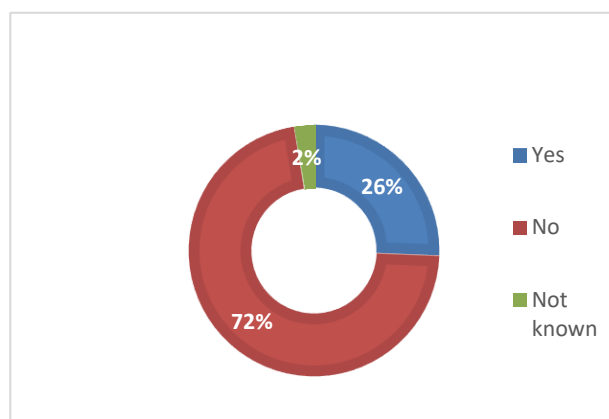


Figure 21. People on EoL pathway who had repeat hospital admissions.

Specialised nursing care provision for people with a LD remains an ongoing gap in service provision. 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.

Safeguarding in LeDeR Reviews

LeDeR is supported through safeguarding supervision from the Designated Safeguarding Adults Lead for LLR. This external supervision helps maintain the independence and integrity of the LeDeR programme, ensuring objective oversight and challenge where required. Reviews that are graded 1 or 2 are discussed at safeguarding supervision, and it is then agreed if further escalation, if not already considered, is processed. In line with this process 2 letters to the safeguarding team have been sent regarding 2 x LeDeR reviews graded between 1 and 2 for quality of care and right support. It has since been agreed that letters are no longer required and the safeguarding supervision is sufficient.

The threshold for safeguarding are used and considered within LeDeR reviews and at LeDeR governance panel.

Across the LeDeR reviews where safeguarding was identified in the learning into action, the findings are listed below. Safeguarding practice shows both effective multi-agency responses alongside some opportunities for improvement at a system level. Four safeguarding themes emerged:

1. Neglect and Poor Care Environments:

- Early signs of neglect in care settings
- Patient placed in unsuitable environment (wheelchair facing away from TV, overstimulating setting)
- Inadequate engagement and person-centred care
- lack of dignity
- poor environmental adaptation
- unmet sensory and communication needs

Positive aspect:

- OT recognised “early indicators of concern” and escalated appropriately.

Learning identified the importance of:

- early identification
- professional curiosity
- acting on “low-level concerns” before harm occurs.

2. Social Isolation and Insufficient Support for Independent Living:

- Individuals living alone with insufficient care packages and monitoring
- 70-year-old man with epilepsy:
 - only 1 hour support/week
 - died alone after 2 weeks of non-attendance
- Lack of escalation after missed contact
- Underestimation of risk in:
 - epilepsy
 - LD/autism
 - social isolation
- No robust escalation pathway for:
 - missed visits
 - disengagement
- “Invisible vulnerability”
- increased risk of:
 - unattended death

- untreated deterioration

Learning identified:

- risk-based care planning especially as people grow older and/or needs are changing
- clear escalation procedures for:
 - missed visits
 - loss of contact

3. Failure in Communication and Accessibility

- Barriers to accessing care due to:
 - language
 - unclear communication
 - family reliance
- Referral follow-up unclear and possibly not in preferred language
- Written information (leaflets) may not have been accessible

When communication is not accessible:

- people cannot engage with care
- risks are not understood
- appointments are missed
- This is a failure of reasonable adjustments
- Working in accordance with equality and safeguarding duties is essential

Learning identified that services must ensure:

- accessible information (easy read, translated materials)
- active follow-up, not passive reliance on families

4. Missed Opportunities for Escalation and Safeguarding Intervention.

- Concerns identified but not escalated early enough
- Missed appointments not followed up promptly
- Lack of proactive welfare checks
- Inconsistent response to disengagement
- Reactive rather than proactive safeguarding
- Delayed identification of:
 - deterioration
 - crisis situations

Learning identified that safeguarding requires:

- proactive risk management
- structured escalation pathways
- curiosity about “why” someone disengages

Positive Practice

Effective Safeguarding Practice and Multi-Agency Working with strong examples of safeguarding done well are outlined below

1. Coercive control case:

- Risks identified early
- Safeguarding enquiry initiated
- Multi-agency collaboration (police, social care, advocate)
- Person supported to remain safely at home

2 . Medication risk:

- GP and pharmacy:
 - identified overdose risk
 - implemented safe prescribing controls
 - maintained access to essential meds

3. Police safeguarding referral:

- Mental health risk identified
- Shared with GP → led to intervention

4. Financial abuse:

- Concerns escalated
- Police involvement
- Legal safeguards (deputyship)

These cases demonstrate high-quality safeguarding aligned with Care Act principles:

- Protection → preventing harm
- Partnership → agencies working together
- Accountability → clear action taken

Learning identified effective safeguarding requires:

- professional curiosity
- information sharing
- coordinated multi-agency action

Preventative Healthcare

Venepuncture

Venepuncture is one of the 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. This is reflective of both the local and national findings. Learning from the LLR LeDeR programme is listed below.

Learning

"A British Asian male diagnosed with severe learning disability and autism. He also experienced behavioural problems that challenge and obsessive-compulsive disorder. He had been displaying weight loss and found it very distressing to have any medical intervention including having bloods taken or receiving a vaccination. This identified that there should be further discussion/pathways on applying restrictive practice in relation to taking bloods and other healthcare procedures when a least restrictive approach has been unsuccessful."

Positive Practice

"A British Indian male diagnosed with moderate to severe learning disability. The GP practice was always responsive when family requested advice or for him to be seen. Reasonable adjustments around health appointments were adhered to. Bloods were taken regularly and at home due to his mobility issues and family feeling he accepted blood tests better in a familiar environment. The appropriate referrals were made on several occasions to the community phlebotomist by the GP. This evidences good practice in the application of reasonable adjustments in line with the Equality Act (2010)."

Health Inequalities Group LD Phlebotomy Team Annual Report 2025/26

Project aim:

- Improve access to venepuncture for people with a learning disability across LLR.
- Create a sustainable and equitable pathway that meets individual needs.
- Reduce failed attempts and improve patient experience.
- Ensure clear legal and clinical processes, including capacity assessments, best-interest decisions and appropriate use of restrictive interventions.
- Strengthen system collaboration between primary care, community services, CHS, UHL and the ICB.

Approach:

A structured pathway was designed across primary care, CHS Phlebotomy, Community LD Teams, PCLNs and acute services. This includes roles, responsibilities, triage criteria, and escalation routes. Introduced a tiered model of support:

- Tier 1: Reasonable adjustments and support within primary care.
- Tier 2: Community LD nursing input (blood test preparation, communication planning, sensory regulation, MCA support).

- Tier 3: Specialist intervention including the Midazolam sedation clinic for individuals where more restrictive intervention is indicated.

Multi-agency collaboration.

Extensive engagement took place with CHS, UHL anaesthetics, Community LD MDTs, PCLNs, psychology, OT, SALT, psychiatry, and the ICB to ensure alignment and shared responsibility. Process mapping and system design.

A full mapping exercise described the journey from referral to discharge, identifying gaps, pressures and opportunities for improvement across the system.

Sedation clinic development

A specialist sedation pathway was created at Loughborough Hospital to provide a last-resort option for people requiring blood tests who were unable to tolerate standard or community approaches.

Impact and Outcomes:

Successful blood tests for people previously unable to access them

- Nine successful blood tests completed across the system.
- Community preparation and reasonable adjustments enabled several patients to avoid escalation to sedation.
- Six patients have already successfully used the Midazolam sedation clinic, with additional clinics planned.
- Five additional patients have been identified for future clinics and are awaiting scheduling.

Positive patient and family experience

Families reported relief after years of unsuccessful attempts, improved trust in services, and reduced distress for the individuals involved.

Improved system coordination

The pilot strengthened relationships between CHS, LD services, UHL and primary care, helping clarify roles and reduce duplication.

Early identification of health risks

Successful blood tests allowed identification of previously unknown health needs, such as pre-diabetes or clarification of suspected clinical conditions.

Summary and Next Step:

Significant progress has been made this year to improve access to blood tests for people with a learning disability. The two sedation clinics successfully supported four patients, and further clinics are scheduled. The pathway has demonstrated that equitable and safe venepuncture is achievable when the right support is in place.

Priorities for 2026/27

- Embed the system-wide venepuncture pathway into routine practice.
- Secure sustainable staffing as the long-term funding for the sedation clinic is now secured.
- Strengthen reasonable adjustments and support within primary care.
- Expand preparation support to reduce reliance on sedation.
- Continue evaluating outcomes, patient experience and equity.
- Ensure the model evolves into a sustainable, long term LLR offer.

Health Inequalities Group LD Deteriorating Patient Update 2025/26

Diabetes

Project aim:

People with a learning disability are at a higher risk of developing type 2 diabetes, as they are more likely to experience a sedentary lifestyle, higher rates of excess weight, and the use of medications (e.g., second generation antipsychotics) that can contribute to weight gain. This increases their susceptibility to obesity related health conditions, including diabetes.

The project aimed to establish the current diabetes care provision for people with a learning disability and identify the prevalence of diabetes within this group.

Approach:

- Diabetes and prediabetes data requested to identify prevalence and higher prevalence areas.
- Establish uptake of people with diabetes attending their learning disability annual health check, and diabetes annual health check.
- Scope existing services and gaps.

Impact and Outcomes:

The primary outcome of this project was to scope out the current prevalence and services offered. The data found:

- 11% of people with a learning disability in LLR are living with diabetes.
- Age % of people living with type 2 diabetes ~ 3-4% 18-25yrs, 8% 26-35yrs, 18% 36-45yrs, 19% 46-55yrs, 27% 56-65yrs, 25% 66yrs +.
- Adults with a learning disability more likely to be living with type 2 diabetes at a younger age compared to people without a learning disability.
- 12.9% of people with LD + diabetes have not had their learning disability annual health check
- Leicester City and West higher prevalence of diabetes type 2.
- Services available/offered were identified as part of a mapping process.

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 themselves 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 72% of people with LD had their flu vaccine in the last year of life, which is slightly higher than in the previous year [70%], 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.

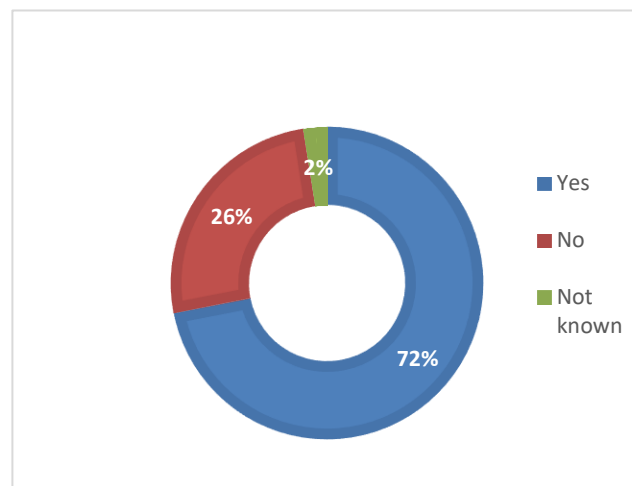


Figure 22. Flu jabs received.

Pneumococcal Vaccine

This year 17% 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.

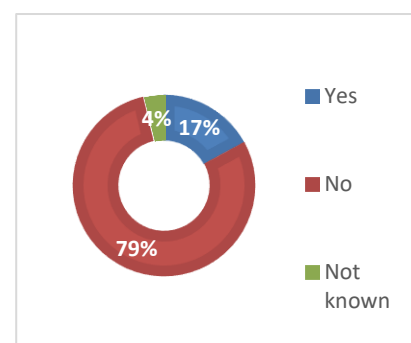
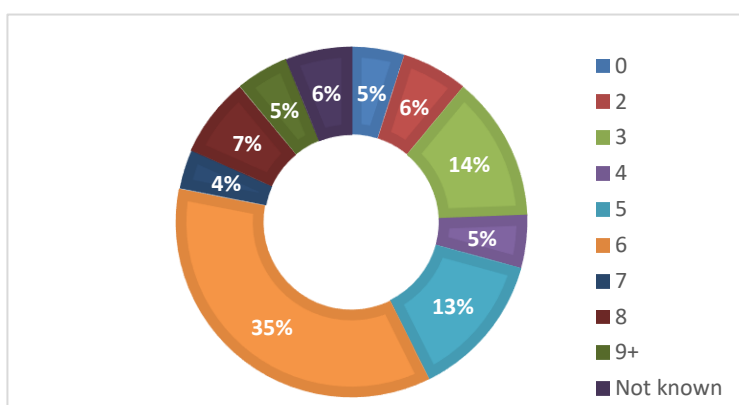


Figure 23. Pneumococcal vaccine

COVID-19 Vaccine

This year there were no deaths solely from COVID-19 and 2 deaths with COVID-19 secondary to cardiovascular and respiratory tract infection causes. The chart shows that most people have had either 5 or 6 COVID-19 vaccines, with 4 people 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 0, 2 or 3.



Health Inequalities Group LD Vaccinations Annual Report 2025/26

Project aim:

This project aims to ensure that individuals with LD and autistic people across LLR to have fair, equal and convenient access to all mainstream vaccination programmes throughout the life course. This includes flu, COVID-19, HPV and routine childhood immunisations.

It seeks to remove structural, communication and accessibility barriers by embedding reasonable adjustments - such as flexible appointment times, desensitisation visits, accessible communication formats, LD-specific clinics, and personalised support - to reduce vaccine hesitancy and improve the overall vaccination experience.

It aims to reduce health inequalities by working collaboratively across NHS England, ICB partners, Primary Care, Public Health, and VCSE organisations, ensuring that vaccination services are co-produced with people with lived experience, carers and families, and delivered in a way that is inclusive, person-centred and responsive to community needs.

Our impact & outcomes:

Seasonal Vaccine Uptake (Qualitative Improvement)

While LD-specific numerical uptake data is still being refined due to data-quality challenges, multiple reports indicate that uptake among LD cohorts increased across winter 2025/26 through targeted clinics, mobile outreach and proactive recall.

- LD vaccine uptake was actively monitored, with LPT identifying improvements following targeted actions.
- Winter targeted-work updates describe increased engagement and improved clinic attendance among LD patients following personalised outreach.

Service Accessibility Improvements

People with LD were successfully vaccinated in low-stimulus environments and at home where required—demonstrating that accessibility interventions directly removed historical barriers.

Co-Production Outcomes

Resources co-designed with people with LD (easy-read materials, animations, website updates) were shown to improve understanding and reduce anxiety.

Reduction of Missed Opportunities

Roving units in communities and at LD events captured people who would not have otherwise presented in traditional healthcare settings.

Summary and next steps:

To consolidate progress and address outstanding gaps, we will prioritise the following actions over the next reporting period:

- Strengthen LD data quality and reporting
- Expand accessible and LD-friendly vaccination models

- Complete co-produced resources and communication improvements
- Enhance workforce capability
- Strengthen multi-agency coordination
- Evaluate impact and shared learning

The roving healthcare unit can visit groups to offer vaccinations.

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 2025-26, 21% of people eligible for cervical screening attended regularly over their life course (where a LeDeR review was carried out). This is a significant increase from last year which was only 5%

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.

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 were 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:

- Two specialist cervical screening clinics have been held with great success.
- Data collection is underway.

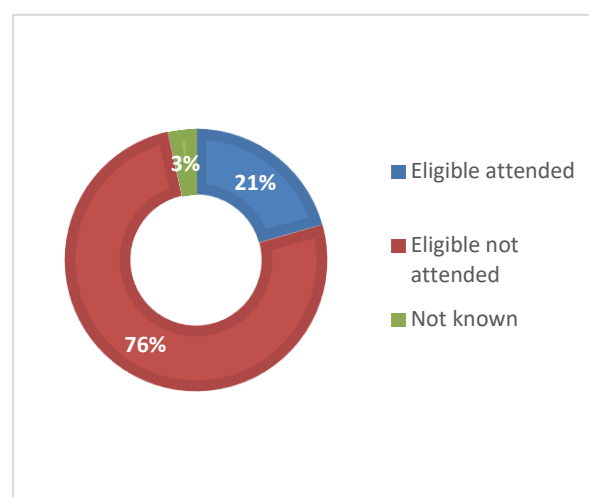


Figure 25. Cervical cancer screening attended (Where eligible)

- 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

The PCLN team has adopted a proactive and collaborative approach to improving cervical screening uptake for people with a learning disability across LLR. Our current and recent activities include:

Data collection and analysis

The team gathered cervical screening data from LHMIS for 2024/25, with the intention of tracking improvements over time and identifying individuals with a learning disability who had not yet accessed screening. This would support targeted intervention.

Ongoing partnership working with primary care

Continue to meet quarterly with the core primary care group in North West Leicestershire to plan and coordinate specialist learning disability smear clinics.

These clinics have been successful previously, and planning is now underway for delivery in summer 2026, dependent on staffing capacity.

Training and workforce development

The PCLN team provides training on the specific needs of people with a learning disability as part of the national sample taker training programme.

This ongoing contribution helps improve confidence, understanding, and reasonable adjustments within primary care.

Targeted individual interventions

Continue to support individual patients who may need additional help to access cervical screening. This includes personalised interventions, capacity-related guidance, reasonable adjustments, and liaising with primary care teams.

[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

"He was described by those who knew him as a much-loved gentleman with a warm personality and a cheeky sense of humour. Staff who had supported him for several years spoke very fondly of him and said he was well known for his funny side and gentle nature!"

Breast Screening

In 2025-26 of all the LeDeR Reviews, 46% of people eligible for breast screening attended regularly over their life course. This is an increase on the previous year which was 35%.

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>

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 2025-26 of all the LeDeR Reviews, 66% of people eligible for bowel screening attended regularly over their life course which is a more than double last year (31%).

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.

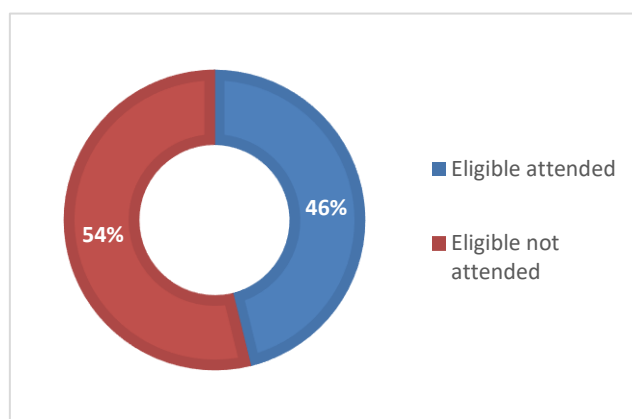


Figure 26. Breast screening attended (where eligible)

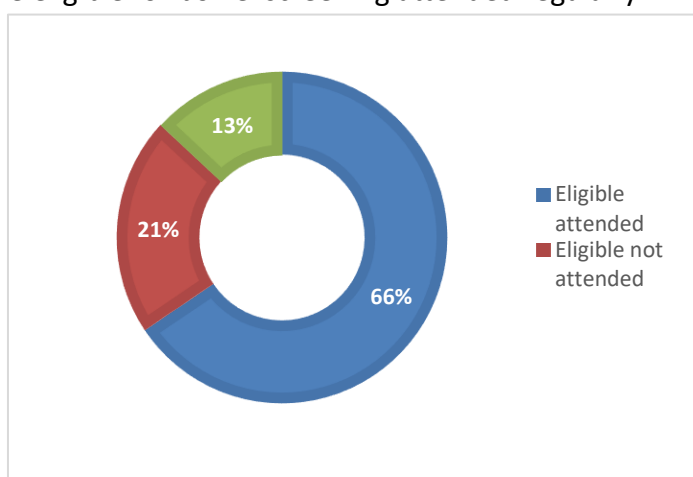


Figure 27. Bowel screening attended (where eligible)

PCLN team undertook a pilot project that commenced in the East area of LLR and was rolled out across West Leicestershire and Leicester City. Working with Eastern Bowel screening hub to identify eligible cohort of patients on the LD register to add additional care notes that reasonable adjustments were to be offered at the point of invitation for FIT test.

Initial finding show that the PCLN intervention pathway has had an impact on the uptake of bowel screening in people with a learning disability.

There has been opportunity to increase health promotion activities to include bowel screening at engagement events.

The project is planned to be rolled out to all eligible people with a learning disability across the whole of LLR and will be evaluated for the impact in terms of the number of FIT kits returned.

Abdominal Aortic Aneurysm (AAA) Screening

AAA screening shows that that only 27% of the eligible people through the LeDeR programme are attending compared to 81.9% of the general population of LLR. This is up from 5% 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.

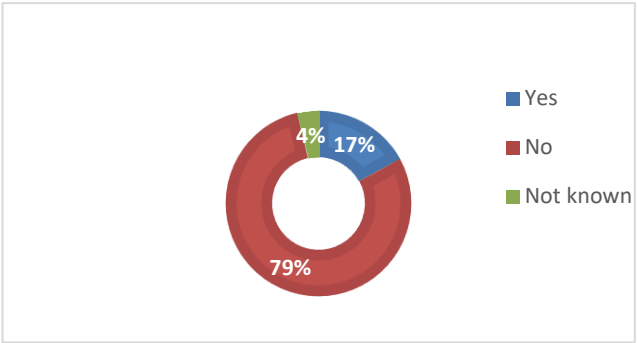


Figure 28. AAA screening attended (where eligible)

LD Annual Health Check

The past year has seen the LD AHCs within LeDeR at 86% again this year.

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.

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.

Continue to 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.

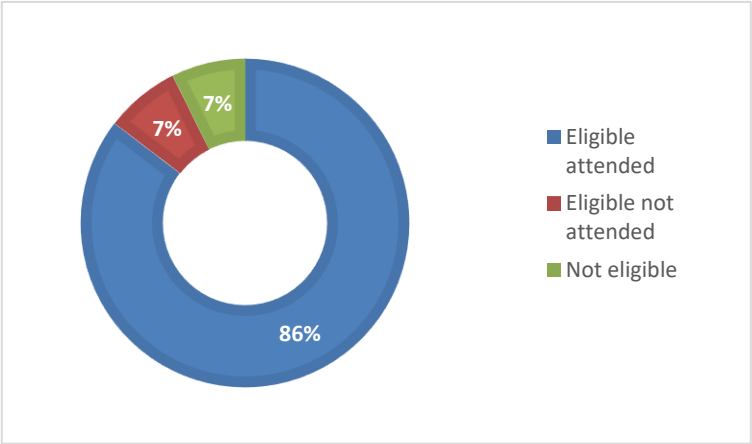


Figure 29. LD Annual Health check attendance

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.

- Brings 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.
- LD Friendly practice award continue to promote and celebrate success.
- The PCLN team are successfully working on reducing did not attend appointments and declined appointment coding.

"She liked to be 'very well turned out' wearing hair clips, enjoyed having her nails done and pamper sessions."

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 2025-2026

All diagnoses of cancer

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. Although notifications remain very low for the deaths of autistic people, we were able to include reviews of autistic people in this analysis. In agreement with the LLR LDA Collaborative the following was agreed upon as the focused priority review area for 1st April 2025 – 31st March 2026:

"All diagnoses of cancer."

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 that had received a diagnosis of cancer or a positive FIT test. 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, and ethnicity, and congenital conditions.

As shown in *Figure 12. Deaths by gender*, 64% of reviews completed were of males and 36% of females.

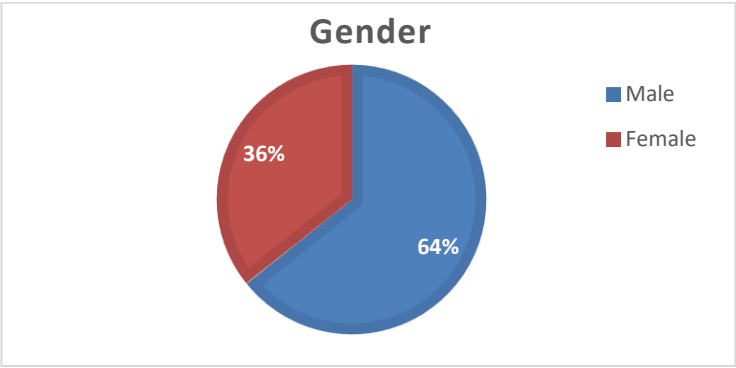


Figure 30. Deaths by gender

Figure 31, Level of learning disability shows that most people had Mild LD, there were no people with a Profound LD

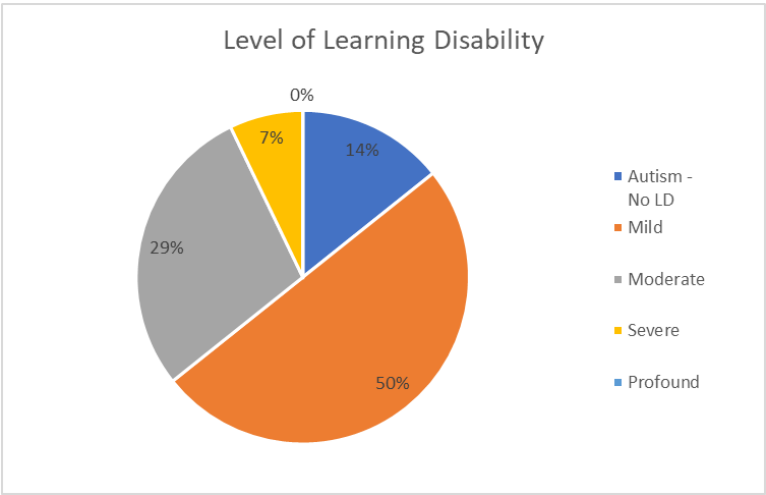


Figure 31. Level of learning disability

Figure 32. Age at death shows that 50% of deaths were age 56-70.

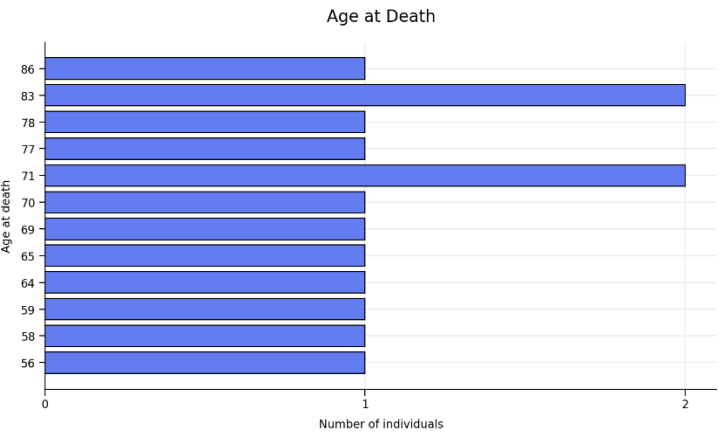


Figure 32. Age at death

Figure 33. Where did they live identified that most people were in residential care or their own home, with less in supported living or with family.

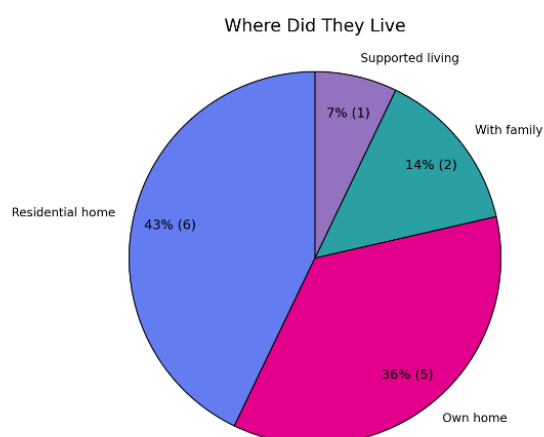


Figure 33. Where people lived

The ethnicity of the people in the priority review area were all White British with no cancer diagnoses for those from a diverse ethnic background.

Figure 34 Type of cancer shows most had bowel cancer followed by prostate cancer.

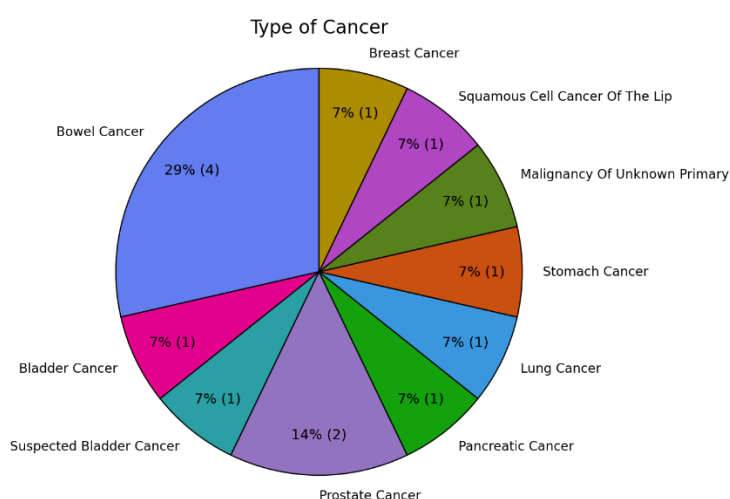


Figure 34. Type of cancer

This part of the thematic review highlights significant inequalities in cancer diagnosis and care for people with learning disabilities and autistic people within LLR. Across the cohort (aged 51–86 years), there was a high prevalence of **late-stage cancer diagnosis**, often at Stage 4 or presumed advanced disease, particularly in cancers with poorer survivability such as lung, stomach, and pancreatic.

A key finding was **delay in diagnosis and limited access to the 2-week wait (2WW) pathway**, with referrals frequently not initiated or delayed despite the presence of concerning symptoms. These delays were multifactorial and included **diagnostic overshadowing, reduced clinical suspicion of cancer, misinterpretation of behavioural changes, and system-related barriers** such as poor coordination and difficulties accessing investigations. In several cases, symptoms had been present for prolonged periods prior to referral.

Barriers to investigations were also significant, with individuals often unable to tolerate diagnostic procedures without additional support, leading to delays, incomplete staging, and reduced treatment options. The need for **anticipatory reasonable adjustments**, including sedation, longer appointments, and adapted approaches, was consistently identified.

Communication was a critical factor influencing engagement and outcomes. Where communication was adapted and person-centred, individuals were more likely to tolerate investigations and engage in care. Conversely, poor communication contributed to distress, refusal, and delay.

Carer involvement emerged as a key determinant of outcomes. Proactive and informed advocacy supported early identification, access to services, and continuity of care, while reduced engagement or limited support contributed to missed opportunities and delays.

The involvement of **specialist learning disability services (CLDT, LD PCLN, ALN teams)** was inconsistent but demonstrably beneficial when in place, particularly in facilitating reasonable adjustments and coordinated care.

Further contributing factors included **complexities surrounding mental capacity and consent**, under-recognition of important clinical indicators such as **family history**, and the **masking of symptoms** due to communication difficulties, behavioural presentation, or high levels of independence. These factors often resulted in delayed recognition of deterioration and late presentation.

Overall, the findings demonstrate that delays in cancer diagnosis for people with LD and autistic people are **systemic and multifactorial**, but also **potentially avoidable**. Where **reasonable adjustments, effective communication, carer advocacy, and specialist input** were present, outcomes and experiences improved.

This analysis highlights the need for a **coordinated, system-wide approach** to ensure equitable access to timely cancer diagnosis. Priorities include improving early recognition and referral, embedding anticipatory reasonable adjustments (including RADF), strengthening pathway coordination, enhancing clinical awareness, and ensuring consistent involvement of specialist LD services.

LeDeR Thematic Analysis Summary

Living Longer with a Learning Disability

The LDA Collaborative agreed that analysis would be beneficial to understand what contributors the LeDeR programme could identify with regards to the oldest population of people with a LD for the purposes of learning through positive case study. Therefore, this retrospective thematic review examined the deaths of 12 adults with learning disabilities who lived into older age (80–87 years), with a focus on understanding factors contributing to longevity, quality of life, and care experiences.

The findings demonstrate that **people with learning disabilities can live into later life, including their 80s**, across all levels of disability, when supported by consistent, person-centred care and access to appropriate services. High levels of **multimorbidity** were observed, reflecting typical ageing patterns, with respiratory disease identified as the most common cause of death.

Proactive healthcare was a key protective factor, with most individuals receiving regular learning disability annual health checks and vaccinations. Where preventative care and monitoring were in place, this supported early identification of health needs and better management of long-term conditions.

Stable living environments and strong support networks were strongly associated with positive outcomes. Most individuals lived in long-term placements with consistent staffing and care arrangements, often spanning many years. Support was generally described as responsive and well-coordinated, with multidisciplinary input from health and social care services. Involvement of specialist learning disability services further enhanced care through reasonable adjustments, advocacy, and support for decision-making.

Advance care planning was evident in many cases, although formal documentation (such as ReSPECT plans) was not consistently in place but it was clear that discussions were had. Where advance care planning was established, individuals were more likely to die in their preferred place, with reduced hospital admissions and a greater focus on comfort.

Importantly, **quality of life was consistently high across the cohort**. Individuals were supported to maintain meaningful lives, including social relationships, activities, routines, and personal identity. Reviewers concluded that all individuals lived lives aligned with their preferences and values, with autonomy and positive risk-taking respected.

Overall, this review highlights that **longevity for people with learning disabilities is achievable and is associated with stable, well-coordinated, and person-centred systems of care**. Key contributing factors include proactive healthcare, strong relationships and advocacy, sustained support arrangements, and respect for individual choice.

Key learning points include the need to strengthen **ageing and frailty pathways**, support **relationship based care**, improve **respiratory and dysphagia management**, ensure **end-of-life discussions are consistently formalised**, and maintain **specialist learning disability input across the life course**.

The Mental Capacity Act (2005)

As highlighted in successive LeDeR reports, further progress is needed to improve the application of the Mental Capacity Act (MCA) for people with a learning disability and autistic individuals. Key learning from this year has been identified, themed, and outlined below.

Decision Making

- Over-reliance on family members to make decisions
- Lack of clarity around legal responsibility of the decision-maker

LeDeR Reviews:

- Flu vaccination decisions left with family (58-year-old male)
- COVID/flu vaccinations declined by family without challenge or MCA process
- Clinicians not taking responsibility for best interest decisions

The MCA is outlines:

- Family opinion is important; however, family do not make decisions unless they hold Health & Welfare LPA
- The clinician is the legal decision-maker (Best Interest decision)

Pattern identified:

- Staff defer to families, especially in preventative care (vaccinations)

It is important to consider consequences of decisions:

- avoidable harm (e.g. pneumonia, COVID deaths)
- inequality in access to treatment
- on balance with how the procedure if it is to go ahead would be achieved.

Learning identified, clinicians should:

- take ownership of decision-making
- ensure informed discussions with family
- clearly document rationale

Documentation

- MCA often applied in practice but not recorded
- Lack of evidence of:
 - capacity assessments
 - reasoning
 - best interest processes

LeDeR Reviews:

- Consultants failed to document MCA despite lack of capacity
- End-of-life surgical decision not clearly recorded under MCA
- Cancer diagnostics: no formal best-interest documentation
- NICE NG108 requirement (recording reasons) not followed

This is one of the **strongest recurring themes** from the MCA analysis.

Decisions clinically appropriate but not meeting legal compliance standards because of insufficient record-keeping.

This can lead to:

- Non-compliance with the MCA
- Safeguarding concerns
- Lack of transparency and audit trail

Learning identified that documentation is not optional:

- capacity decision-specific assessment
- why the person lacks capacity
- best interest reasoning
- who was involved

Inconsistency with capacity assessment

- Failure to:
 - assess capacity for specific decisions
 - involve the person where possible

LeDeR Reviews

- Denture removal plan – no evidence of consent or MCA
- Weight monitoring declined – unclear capacity assessment
- Dental care – good example of structured assessment
- Speech & language involvement supporting decision-making (good practice).
- Capacity is often:
 - assumed rather than assessed
 - not decision-specific

Learning identified capacity assessments must always be:

- decision-specific
- time-specific
- supported with:
 - communication adjustments
 - specialist input (e.g. SALT)

Best Interest Decision

- Best interest decisions
 - Absence of best interest decisions or lack of documented evidence
 - Decision making applied inconsistently
 - Challenges were identified with regard to high risk or complex decisions
 - Lack of coordinated MDT input delays decisions

LeDeR Reviews

- Vaccination refusals not explored via best interest
- Colonoscopy declined due to lack of “consent” (incorrect legally)
- Cancer investigation not pursued without BIM
- Covert medication used without proper MCA framework and not reviewed through MDT
- PEG decision delayed due to lack of MDT involvement
- Cancer pathway unclear due to lack of formal meeting

Learning identified that best interest must include:

- risks vs benefits
- least restrictive option
- multidisciplinary input
- documented rationale

- ensuring that where capacity is lacking, care decisions are guided by best interests rather than non-provision of treatment
- MDT collaboration
- clear leadership

Legal Literacy:

- Challenges identified in demonstration of understanding of MCA legal frameworks

LeDeR Reviews:

- LPA not recorded or misunderstood (finance vs health)
- Failure to recognise no LPA → clinician decision
- Failure to involve IMCA when required
- Missed DoLS considerations in restrictive practices
- Confusion around:
 - **who legally decides**
 - when to escalate decisions

Some examples:

- Brother had LPA but not recorded → missed care opportunities
- Sister had finance LPA only → correctly clarified (good practice)

Learning identified that staff awareness on:

- The differences between Next of kin and LPA (health vs finance)
- When to involve IMCA and apply DoLS

Inequalities in Preventative Healthcare (Vaccinations and Screening)

- People with LD not receiving:
 - flu vaccines
 - COVID vaccines
 - Screening

LeDeR Reviews:

- Multiple cases of missed vaccination
- No challenge to refusal
- No MCA or best-interest assessment
- Missed screening due to communication failures

Preventative care appears to be one of the lowest areas of MCA compliance and most influenced by family/carers decisions.

Learning identified that the MCA must be applied to:

- routine and preventative care
- not just major treatments

Positive Practice

Several cases demonstrated high-quality MCA application:

- Comprehensive capacity assessments
- Formal best-interest meetings
- Family involvement (but not decision-making control)
- DoLS and IMCA use
- Person-centred approach

LeDeR Reviews

- Dental GA decision with full BIM
- Social worker-led discharge planning
- Dementia case with MCA + DoLS compliance
- Communication support enabling decision-making

These show what “gold standard MCA practice” looks like.

“She had an incredibly positive relationship with her paid support workers, who she described as her “friends” during social care reviews.”

Autism

This year there were 11 deaths of autistic people notified to the LLR LeDeR Programme, 3 of which were completed within this financial year, 4 remain ongoing and 4 on hold waiting for outcome of coroner's inquest(2) and safeguarding(2). The notifications of deaths of autistic people although has increased, it remains low and must be a priority. 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 6 reviews of autistic people's deaths completed in LLR LeDeR during 2025-26, 4 individuals were male, and 2 were females. Areas of learning are highlighted below.

The review of six deaths of autistic adults identified consistent and recurring system-level issues contributing to health inequalities and poorer outcomes. These were not isolated incidents but reflect wider patterns in service delivery.

Key themes:

1. Failure to identify and respond to autism

In all cases, autism was either not clearly recorded, not flagged, or not considered in care planning.

This resulted in reasonable adjustments not being implemented, limiting patients' ability to engage with services.

2. Barriers to engagement with healthcare

All individuals experienced difficulties engaging with services, including non-attendance and limited follow-up.

Despite repeated attempts by services, approaches were not adapted to meet individual needs, leading to continued disengagement.

3. Lack of reasonable adjustments

There was no consistent evidence that services met their duties under the Equality Act (2010).

Care delivery remained largely standardised rather than personalised, particularly in communication, appointment systems, and follow-up.

4. Missed opportunities for prevention

Across all cases, there were missed opportunities to deliver preventative care, including:

- Weight management
- Screening (e.g. bowel, cervical, AAA)
- Vaccination

Preventative interventions were often offered but not actively followed through or tailored, leading to worsening health outcomes.

5. Reactive rather than proactive care

Care was often episodic and reactive, with limited proactive monitoring or follow-up.

When patients did not engage, there was no escalation or alternative approach, increasing risk of deterioration.

6. Fragmented and poorly coordinated care

Multiple services were involved in each case, but there was no clear coordination or oversight.

The absence of a named lead professional contributed to gaps in care and missed opportunities for intervention.

7. Workforce knowledge and awareness gaps

There was limited evidence of consistent understanding of:

- Autism and neurodiversity
- Communication needs
- Co-existing conditions (e.g. ADHD, mental health, dementia)

This contributed to missed risks, delayed care, and reduced quality of engagement.

8. Over-reliance on patient self-management

Care systems relied heavily on individuals to:

- Initiate contact
- Attend appointments
- Manage complex care

This approach did not take account of autism-related differences in communication, organisation, and engagement.

Additional Findings

- **Delays in access to services** (e.g. therapy, specialist assessment) were common and not actively risk-managed.
- **Mental health needs** were often under-recognised or insufficiently addressed, including one case of suicide.
- **Social care provision** was, at times, insufficient or not aligned with complexity of need.
- **Data quality issues** (e.g. inaccurate clinical records) and inconsistent application of frameworks (e.g. STOMP, MCA) were identified.

Examples of Good Practice

- Persistent attempts to engage individuals using multiple methods
- Strong involvement of family and carers

- Effective safeguarding processes
- Positive impact of specialist placements and multidisciplinary input
- Good palliative and end-of-life care, including respect for patient wishes

Conclusion

These reviews demonstrate **systemic challenges in delivering equitable care to autistic people**.

The most significant learning is the need to move from **standardised, reactive models of care** to approaches that are:

- **Proactive**
- **Coordinated**
- **Personalised**
- **Autism-informed**

Addressing these themes is essential to reduce health inequalities and prevent avoidable deaths.

"He was described as a 'larger than life character, intelligent, funny, cheeky, and endlessly creative. He had a wonderful imagination, and talents that amazed all'."

Learning Disability Child Death Reviews

LLR CDOP LeDeR Themed Review

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

Deaths of all people with learning disabilities aged 18 years and over are reviewed as part of LeDeR Programme, aiming to identify learning to reduce the increased mortality and morbidity rates seen for this population. 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 collaborate, by carrying out a joint annual themed review. During 2025-26, 6 case reviews were completed for children with a Learning Disability who had died. A review group was convened with representation from Public Health, Childrens 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 2024/25 Review:

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

An LLR-wide Hospital Passport is in place currently; a 'Healthcare Passport' that can be used in any care setting would reduce the need for families to repeat information, and support joined-up care, ensuring reasonable adjustments can be made in all healthcare settings that a child or young person may access.

2. Ongoing work across LLR (led by the Learning Disability Primary Care Liaison Nurse team), to ensure children & young people with a Learning Disability 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.

A Quality Improvement project within LPT led by the Primary Care LD Liaison Nurses has led to successful IT system changes, to make it much easier for children & young people with a Learning Disability to be flagged to primary care.

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

Links have been shared between the Step Right Out campaign, and the Paediatric Respiratory Team.

4. 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. This has been incorporated into a larger piece of work, with a bid for NIHR funding to evaluate its use in children as well as adults.

5. Paediatric services across UHL and LPT to continue to ensure that all children and young people with a life-limiting condition are offered a Children & Young People's Advanced Care Plan (CYPACP), with informed, timely, sensitive, and clear discussions, and that (wherever possible) wishes of children, young people & families are accommodated.

Training has been delivered in both LPT & UHL settings, however, there remains no commissioned specialist Paediatric Palliative Medicine input within the East Midlands.

6. For paediatric services across LPT & UHL to ensure that every child & young person with a Learning Disability & medical complexity has an allocated lead medical consultant.

The Children with Medical Complexity team within UHL now provides oversight & supports coordinated MDT care and discharge planning for this cohort of children and young people. The NCMD have updated data collection forms to ask about Medical Leads in every case, enabling monitoring of this locally.

Case characteristics of the 6 cases with reviews completed in 2025/26: -

The most common category for cause of death was:

- Chromosomal, genetic, or congenital anomalies (67%).
 - o Other categories included chronic medical condition and perinatal/neonatal events.
- No modifiable factors were identified.
- Positive aspects of service delivery were noted in 5 cases.
- Median age at death was 11 years (5-17 years)
- 100% were on the GP Practice Learning Disability Register (compared to 83% in 2024/25, 80% in 2023/24 and none of the 10 cases in 2022/23).

Table 1. Key learning themes identified during the 2025-26 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. Healthcare 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.



All children whose cases were reviewed during 2025-26 were appropriately on the GP Learning Disability Register. This is a significant improvement from 2022/23 where none were. The Learning Disability Primary Care Liaison team have been instrumental in driving forwards quality improvement work, education, and training for both primary and secondary care, to ensure that every opportunity is taken to optimise the long-term health outcomes for both children and adults with a learning disability.



Excellent collaborative working between EMAS, Leicestershire Police, Coroners and Acute/Emergency Paediatrics meant that in two cases, the Joint Agency Response was appropriately commenced, but was then able to be rapidly stepped down as more information became available. Children & their families were able to then access the local hospice bereavement suite, for ongoing care.



For those with a life-limiting condition, children, young people & their families benefit significantly from timely, clear and sensitive advanced care planning, including being offered choice around their preferred place of death, and information about practical considerations, before and after bereavement. Discussions around advanced care planning can be complex, and family wishes should be accommodated wherever possible, whilst recognising the needs of the child remain paramount.



Due to a national workforce shortage of specialist paediatric pathologists, there are delays in postmortems being undertaken, which can increase the distress to families, particularly if it impacts on cultural mourning practices. Whilst the issue has been raised at a national level, locally the Child Bereavement Specialist Nurse and Child Death Review Nurses (in conjunction with the Coroners Offices) ensure that families are supported and kept regularly updated.

"He was described as a gentleman who would want to go out in all weather conditions, come rain or shine, snow and ice."

[illegible]

Fig 2. (Left) Family voices – family feedback received as part of reviews for 2025/26:

Ongoing recommendations & actions:

1. For CDOP Chair to write to the Chair of the LDA Collaborative, recommending the development of 'Healthcare passports' 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 continue to explore expanding smoking cessation in reach services to parents and carers of children and young people with a Learning Disability.
4. 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.
5. For LLR CDOP to routinely collect information from primary care about participation in Annual Health Checks, as part of the review of deaths of children & young people with a Learning Disability, and to include this information in future thematic reviews.

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:

- Cancer - Improved cancer diagnosis rates reflect the system's increasing ability to recognise and diagnose cancer in people with a learning disability through effective cross-organisational and multidisciplinary team (MDT) working. Work is now underway to strengthen reasonable adjustments across fast-track cancer pathways and increase primary care awareness of these adjustments, encouraging clinicians to refer people with a learning disability through mainstream cancer pathways where appropriate.
- Mental Capacity Act (MCA) - Appropriate use of the MCA is evident across many cases. The focus now is on improving the consistency of documentation for MCA assessments and Best Interests decisions within primary care, supported by education on the minimum documentation expectations.
- Advance Care Planning (ACP) and the ReSPECT process - Earlier identification of individuals who would benefit from Advance Care Planning (ACP) and the ReSPECT process is supporting more timely, person-centred conversations. Positive examples of early care planning and multidisciplinary team (MDT) involvement have demonstrated the benefits of this approach. The End-of-Life Care Working Group is developing a new ACP section within the personalised LLR Learning Disability Annual Health Check Template, with key prompts to help health professionals identify when an ACP discussion is appropriate.

LPT FYPCLDA

- A specialist Learning Disability Venepuncture Pathway has been introduced across LDA teams to improve access to safe, person-centred blood testing for adults with a learning disability. Using a multidisciplinary approach, the pathway provides specialist assessment, reasonable adjustments and personalised support to maximise successful venepuncture within mainstream healthcare settings, with escalation to the Learning Disability Phlebotomy Sedation Pathway when required. This helps reduce health inequalities, supports STOMP/STAMP and LeDeR priorities, enables effective health monitoring, and improves long-term health outcomes through timely and accessible blood testing.
- Following the introduction of the Learning Disability Physical Health Pathway and Physical Health Matron secondment, a range of improvements have been embedded across community services to address health inequalities and improve physical health outcomes for people with learning disabilities. These include a new holistic physical health assessment process, enhanced waiting list reviews to identify deterioration and enable timely intervention, a formal Physical Health Deterioration MDT process with clear escalation pathways, and a Pressure Ulcer Prevention SOP. Together, these initiatives strengthen risk identification, care coordination and prevention of avoidable harm, while

targeted training and education, improving staff confidence and competence in recognising, monitoring and responding to physical health needs.

- Early findings show that the PCLN intervention pathway is improving bowel screening uptake for people with a learning disability, with an initial 12% increase in FIT kit returns. Feedback suggests that the personalised and proactive PCLN approach is more effective than other engagement methods for this population group. Key learning highlights the importance of accessible information, practical support, and reasonable adjustments in helping people with a learning disability participate in bowel screening and reducing health inequalities.

University Hospitals Leicester

- Work is underway to look to reduce the number of falls within hospital for people with a learning disability and the associated harm and reduction in this area.
- A priority has been set to reduce the number and severity of Hospital Acquired Pressure Ulcers (HAPU) people with learning disabilities experience when in hospital.
- Work is set with the discharge planning team to ensure timely, safe and coordinated discharges for people with learning disabilities.
- A key area of focus is looking to increase the number and quality of ReSPECT forms completed for those with a learning disability, ensuring they are appropriately in place.

Leicestershire & Rutland County Councils

- One-page profile sessions were completed with staff to promote improved communication, engagement, and person-centred approaches when working with people who use our services. These sessions were identified from a learning need relating to effective communication with people we work with. The sessions were very well received, with strong levels of engagement and positive feedback from participants. As a result, the initiative has been adopted and is now being delivered within in-house services. The primary target audience is Learning Disability and Autism (LDA) teams; however, there has also been uptake from staff outside of these teams, demonstrating wider interest and recognition of the value of this tool.
- Regular Sign Along training sessions were offered to all frontline staff. The programme focused on enhancing communication skills, increasing staff confidence in the use of effective communication strategies, and supporting more accessible interactions with people who use our services. The training also promoted inclusivity and reinforced the importance of adopting communication approaches that enable meaningful engagement and participation for all individuals.
- A review identified the need to strengthen staff knowledge and application of good and legally literate practice when working with carers. The Engagement Panel and Steering Group have played a key role in the comprehensive redesign of the Carers Strategy, policies and associated staff training programme. This work has been co-produced, co-led, and co-delivered with members of the Engagement Panel, ensuring that the lived

experience and perspectives of carers are embedded throughout the development and delivery of a key area of practice.

Leicester City Council

- Continue to strive to ensure that carers are consistently offered a Carer's Assessment as part of a holistic approach to meeting the needs of the cared-for person. Recognising and supporting carers is essential in maintaining individuals safely at home or within their chosen environment, helping to sustain wellbeing and prevent unnecessary escalation of need.
- Throughout the year, there has been a strong focus on ensuring ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) forms are completed during assessments and reviews as part of ongoing care planning. Moving forward, the aim is to maintain and further improve the consistency of this practice to ensure individuals' wishes and preferences are clearly documented and reflected in their care.
- Safeguarding Assistive Technology continues to be considered and implemented where appropriate to maximise independence while ensuring that care and support needs are responded to effectively. This person-centred approach promotes dignity, choice and autonomy, enabling individuals to remain as independent as possible while feeling safe and supported within their preferred living environment.

"His sister shared that he had a really lovely childhood. He was the youngest of three children and was very much "Peter Pan" for their mum."

Response to the Top Ten Learning into Action 2025

This section aims to give an update on the responses to the top 10 learning into action points from LLR LeDeR Annual Report 2024 – 2025:

No.	Learning into Action 2025–2026	Response / Update 2026
1	Improve reporting of deaths to LeDeR, particularly autistic people and people from diverse ethnic backgrounds.	Notification numbers for autistic people have improved but remain low. Continued work is underway to increase awareness and reporting through provider engagement, primary care and partnership forums. Diverse ethnicity notifications continue to require further improvement.
2	Improve compliance with the Mental Capacity Act (2005).	MCA continues to be a system priority. ICB-led workshops, provider training, governance discussions and LeDeR learning have been shared widely. Positive practice has improved, although recurrent issues remain around documentation, best interest decision-making and legal responsibilities.
3	Ensure accurate physical health monitoring through reasonable adjustments.	Healthy Living Toolkits have been successfully launched across LLR. Wheelchair scales and hoisting scales are available, and physical health remains a key focus through the LD Physical Health Pathway and annual health checks.
4	Develop future-focused care plans for people with behaviours that challenge and increasing nursing needs.	PBS planning continues to improve and remains significantly higher than previous years. However, challenges remain regarding future specialist nursing provision and support for ageing people with learning disabilities and complex needs.
5	Start end-of-life discussions, Advance Care Planning and ReSPECT processes earlier.	End of Life remains a priority workstream. An LD-specific End of Life working group has been established and work is aligned with the DAPPLE research programme. Training and accessible resources continue to be developed across health and social care.
6	Improve access to cancer screening, investigations and early diagnosis.	Cancer was selected as the priority thematic review area for 2025–26. Learning has been shared across cancer pathways, primary care and screening programmes. Work continues to improve reasonable adjustments, early recognition and access to diagnostic investigations.
7	Recognise pain, distress and deterioration earlier.	Significant progress has been made through the LD Physical Health Pathway and deteriorating patient workstream. Competency frameworks, escalation processes and physical health initiatives are being implemented across services.
8	Reduce aspiration pneumonia through earlier identification of risk factors.	The Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) remains in pilot phase. A regional thematic review of aspiration pneumonia deaths has now been completed and findings are informing future pathway development.
9	Improve cardiovascular health through healthy	Healthy Living Toolkits have been launched and adopted across LLR. The Health Inequalities Group continues to focus

	weight, activity and preventative healthcare.	on obesity, healthy weight, diabetes and preventative healthcare interventions.
10	Fully implement and utilise the Reasonable Adjustment Digital Flag (RADF).	RADF implementation has progressed significantly across LLR. Training is available, usage is being monitored and work continues to strengthen utilisation within primary care and acute settings.

LeDeR High Impact Action Plan 2025/26

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

Priority Area	Action	Outcome Measure	*RAG Rating
Mental Capacity Act (2005)	Improve MCA compliance, documentation and best-interest decision-making across all sectors.	Reduction in MCA-related learning identified through LeDeR reviews.	
Cancer and Early Diagnosis	Increase awareness of cancer symptoms, improve screening uptake and support earlier referrals through reasonable adjustments.	Reduction in late-stage cancer diagnoses identified through LeDeR.	
Reasonable Adjustments	Strengthen implementation of RADF and improve reasonable adjustment recording and utilisation.	Increase in documented and utilised reasonable adjustments.	
Deteriorating Patient	Embed physical health competencies and deteriorating patient pathways across LD services.	Earlier recognition and escalation of deterioration.	
Aspiration Pneumonia	Implement and evaluate the Leicestershire Aspiration Pneumonia Protection Plan (LAPPP).	Reduction in avoidable aspiration pneumonia factors identified within reviews.	
Preventative Healthcare	Improve vaccination uptake, cancer screening and annual health check quality.	Improvements in uptake and compliance data.	
Cardiovascular Health	Continue roll-out of Healthy Living Toolkits, healthy weight interventions and multiagency staff training (primary focus on LD service, and carers (care home, nursing, and supported living etc).	Increased recording of healthy weight interventions and monitoring.	
End of Life Care	Improve uptake and quality of Advance Care Plans, ReSPECT forms and end-of-life discussions.	Earlier and more personalised end-of-life planning.	

Appendix 1

Governance Group

Grade of Care 1-6	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 <u>practice</u> 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 <u>practice</u> 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 <u>practice</u> 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.



Consider referral to safeguarding if grading lower than 2 in both areas

Appendix 2



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



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.

For more information around STOMP and STAMP, please visit:

<https://www.leicspart.nhs.uk/autism-space/health/stomp-stamp/>

Find out more