Leicester, Leicestershire and Rutland LeDeR Annual Report 2023

Leicester, Leicestershire and Rutland
Health and Wellbeing Partnership

Contents

Foreword

This LeDeR Report would not have been possible without the dedications, commitment and passion of many people and organisations across Leicester, Leicestershire and Rutland (LLR), who have notified deaths of people with a learning disability and autistic people, conducted reviews, and coded and analysed the information. Most importantly though, we wish to acknowledge the people for whom who this report is created: people with a learning disability and autistic people, their families, their friends, their colleagues, carers, and all staff and service providers whose lives are affected by this report. Also, our LeDeR Reviewers as without their expertise, experience and passion we would not be where we are today. Whilst many people can no longer be with us today, we hope that this report honours their legacy.

We must not rest upon the contents of this report. Instead, all partners across the Leicester, Leicestershire and Rutland health and social care sector must embrace the findings of this report; everyone has a role to play. Only then will we ensure that every person with a learning disability and autistic people receive the high quality of care that they deserve. Only then will we address health inequality and inequity.

Caroline Trevithick, Chief Nurse & Executive Director, Leicester, Leicestershire and Rutland Integrated Care Board

Heather Pick, Assistant Director (Adults & Communities), Leicestershire County Council

David Williams, Director of Strategy and Business Development, Leicestershire Partnership NHS Trust

Acknowledgements

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

NHS England National Team (NHSE)

NHS England Regional Team

LLR LeDeR Team

LLR LeDeR Experts by Experience

LPT Talk and Listen Group

All family members' contributions

Leicestershire Partnership Trust

University Hospitals of Leicester

Primary Care Services

Leicester City Council

Leicestershire County Council

Rutland County Council

Leicester, Leicestershire and Rutland Child Death Overview Panel (CDOP)

LDA Collaborative

DeMontfort University

Executive Summary

The 2023 LeDeR Annual report for Leicester, Leicestershire and Rutland takes us through changes to how the LeDeR process works, including changes to the process since last year and more to come in the new working year.

The 'Reviews of Deaths' section explains how data is presented and breaks down some of the demographics by which comparisons were made. The report then looks at causes of death by demographic group, further examining the leading causes of death in LLR.

Quality of care is measured for the first time by six themes set out nationally and further examined by sub-theme.

Preventative healthcare has featured heavily in 2022/23 and LLR LeDeR has been actively involved in supporting working groups to which the programme contributes learning into action.

Thematic analysis carried out throughout the year is described, and has also been shared with national teams, notably the authors of the new 'Right Care' report.

CDOP cases and changes to policy are explained, followed by some achievements and LeDeR contributions made in the local system.

Learning into Action detail is followed by top ten learning into action, which is also highlighted below. Followed by plans for the forthcoming year, with appendices containing more detail in relation to various sections of the report.

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

Throughout the report, there are direct quotes from friends and family, shown in coloured bands across the pages. The first is shown on the next page.

Top Ten Learning into Action Points

1. Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.
2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
3. There is an emerging theme around the widespread misuse of the Mental Capacity Act. All services should review their practices to ensure compliance with this important legislation.
4. The practice of estimating someone's weight is a significant risk for people. People should be weighed using appropriate weighing equipment and the weight should be recorded accurately.

5. Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with learning disabilities as physical health and nursing care needs increase particularly towards the end of their life.

6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.

7. Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.

8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.

9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. The changing of pathway at discharge to LD MDT is imperative.

10. There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy, which is not always accessed appropriately. Intervention by these teams does not guarantee successful outcomes but the availability should be widely known.

Having a direct payment and personal assistants ensured that every day she was well enough, she had the opportunity to go out and live her life to the max. Her car has been the only Motability car returned with 100,000 on the clock which is the maximum allowance allowed!

Introduction

The LeDeR Programme was changed from a National perspective in June 2021, when the University of Bristol's involvement came to an end and the King's College London became the new lead academic partner. The LeDeR web-based platform was launched by South Central and West Commissioning Support Unit and remains the responsibility of this team. The changes to the LeDeR web-based platform from a national level means that we continue to complete initial or focused reviews for people. This has changed the amount and type of data available at different stages of data collection. Where possible we have drawn comparisons over time but have also highlighted where, due to the transition in the system of data collection, this was not possible. For the first time since its expansion, this report will include LeDeR reviews of autistic people. As this is the first time, there is no comparable data. Notifying a death to LeDeR is not mandatory and, therefore we would not expect LeDeR to have data on all people with a learning disability 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.

National context[1]

Learning from Lives and Deaths - people with a learning disability 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 learning disability and autistic people.
2. reduce health inequalities for people with a learning disability and autistic people and
3. prevent people with a learning disability and autistic people dying prematurely.

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

[1] *National LeDeR Report 2021*

Glossary of abbreviations

ALN	–	Acute Liaison Nurse
ASC	–	Adult Social Care
ASD	–	Autistic Spectrum Disorder
CDOP	–	Child Death Overview Panel
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
ReSPECT	–	Recommended Summary Plan for Emergency Care and Treatment
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
WTE	–	Whole Time Equivalent
WHO	–	World Health Organisation

Reviews of deaths

Deaths notified to the LLR LeDeR programme

A total of 83 deaths of people with a LD and Autistic people were notified to the LLR LeDeR Programme from 1st April 2022 – 31st March 2023. Of those people:

- 3 people were autistic.
- 6 were children with a learning disability.
- 2 were out of scope for a LeDeR review.
- 72 were adults with a learning disability.

Referrals received in-year

Figure 1*1* below shows a total of 83 deaths referred to LLR LeDeR in 2022/23, broken down into initial and focused categories. At end of year, 22 cases remained in progress and 55 had been completed.

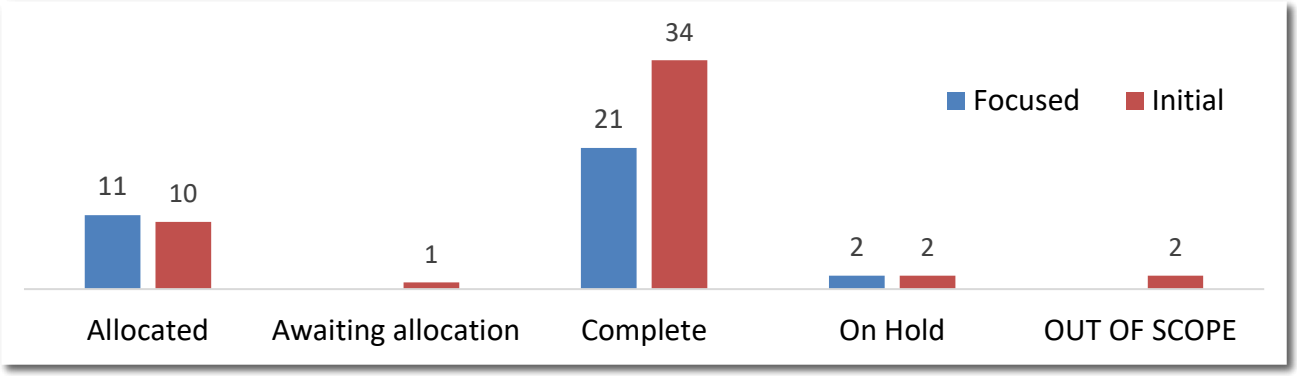


Figure 1. Referrals received by type, 2022/23

Age at death in 2022/23

Median age at death for those who passed away and their deaths notified to LeDeR in 2022/23, the median age at death was 62.

The median age at death in 2022/23, was 62.

Month of death

The 83 deaths referred to LeDeR in this time-period as shown in **Figure 2. Month of death,** with more deaths occurring in December than any other month. This is broken down in **Figure 3. Month of death by gender**

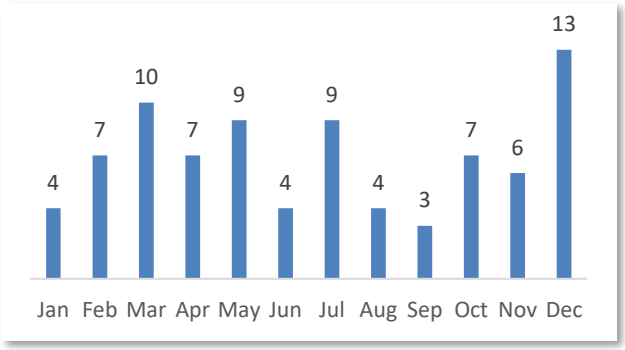


Figure 2. Month of death

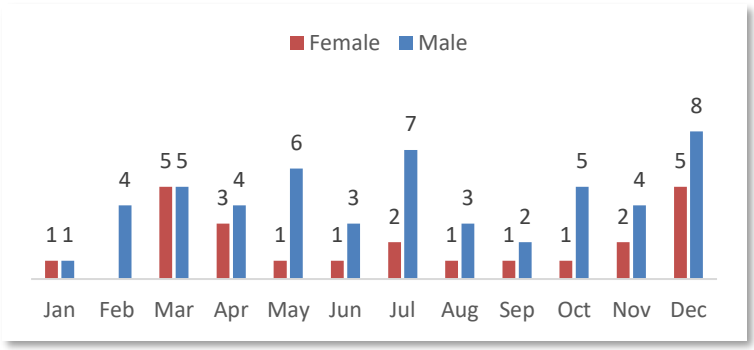


Figure 3. Month of death by gender

Reviews completed in-year

Analysis from this point covers all reviews that were completed within the 12 months from April 2022 to March 2023, rather than those received in that period.

This is because previous reports did the same, and it is possible only to report accurately on cases that were completed at the time of writing.

In 2022/23, the LLR LeDeR programme completed 94 reviews, 50 of which were initial, 44 focused (*Figure 4. Reviews completed in 2022/23*.)

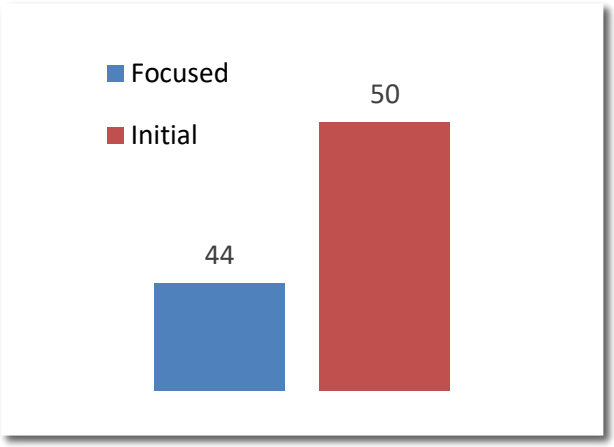


Figure 4. Reviews completed in 2022/23

It is worth noting that a number of those had been on hold for a significant period as they awaited statutory processes including Coroner's Inquests and Child Death Overview Panel (CDOP). Historically, such cases were placed 'on' hold for long periods before LeDeR was able to review them. In recent months, LLR LeDeR worked closely with LLR CDOP on 11 cases and was able finally to complete those CDOP reviews.

Equality Impact & Demographic Data

Age Group

Deaths were broken down by age group (see *Figure 5. LLR LeDeR Deaths by* age group) and is clear to see that 12% were under 18 years of age. Again, this is due to a number of referrals received pre-2022/23 that had been on hold and were completed in year, as explained in the previous

paragraph. Comparison between Figure 5 and 6 is shown for comparing deaths by age with the general population, highlighting the level of disparity. With age at death for people with a LD is 51-60yrs and for the general population this is 85-89yrs.

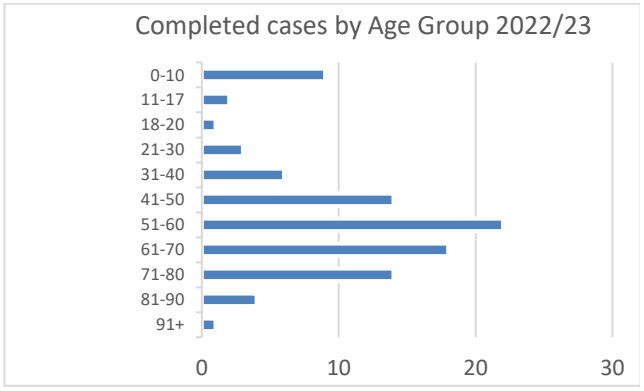


Figure 5. LLR LeDeR Deaths by age group

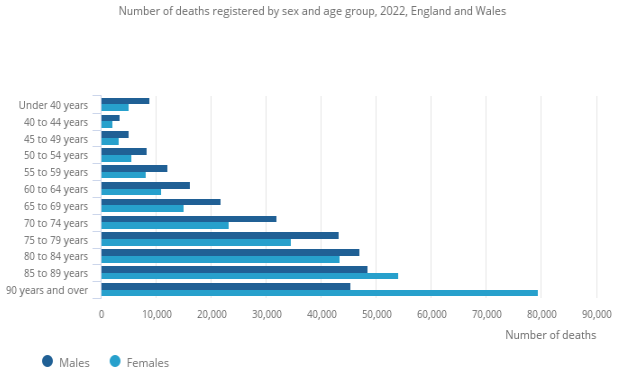


Figure 6. Death registration summary by age ONS

Median age at death in completed reviews

Due to the number of outstanding CDOP cases completed after being on hold (see previous paragraph), the mean age at death for reviews completed in 2022/23 is disproportionately affected. Taking all completed cases into account, median age at death in LLR was 54 years. Only one CDOP death was notified in this year and so the remaining 10 are skewing the median age at death. If the 10 CDOP cases that had been on hold are removed from pre-March 2022, the median age at death for reviews completed in 2022/23 completed reviews was therefore 58.

It is important to note that From July 2023, CDOP deaths will no longer be referred to LeDeR and so LeDeR will report only on deaths of people aged 18 or over.

Ethnicity

The vast majority of deaths were of 'White' people (82%), with 'Asian or Asian British' comprising 12% and 'Black, African, Caribbean or Black British' 1%. The remaining 5% had preferred not to state Ethnic Group. (*see Figure 7. Cases completed 2022/23 by Ethnic* Group)

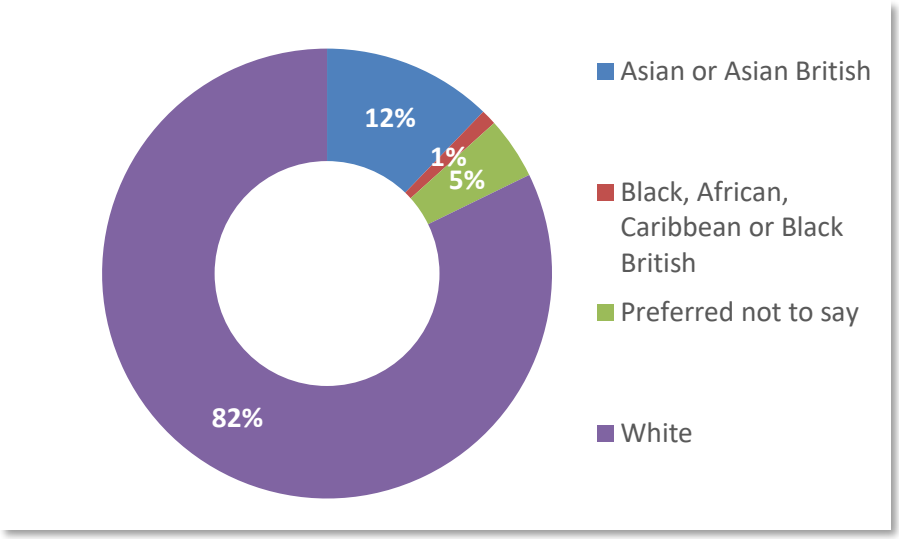


Figure 7. Cases completed 2022/23 by Ethnic Group

Breaking this down further and omitting the 'White' ethnic group allows us to see a clearer picture within different ethnicities, as shown in *Figure 8. Cases completed 2022/23 by*

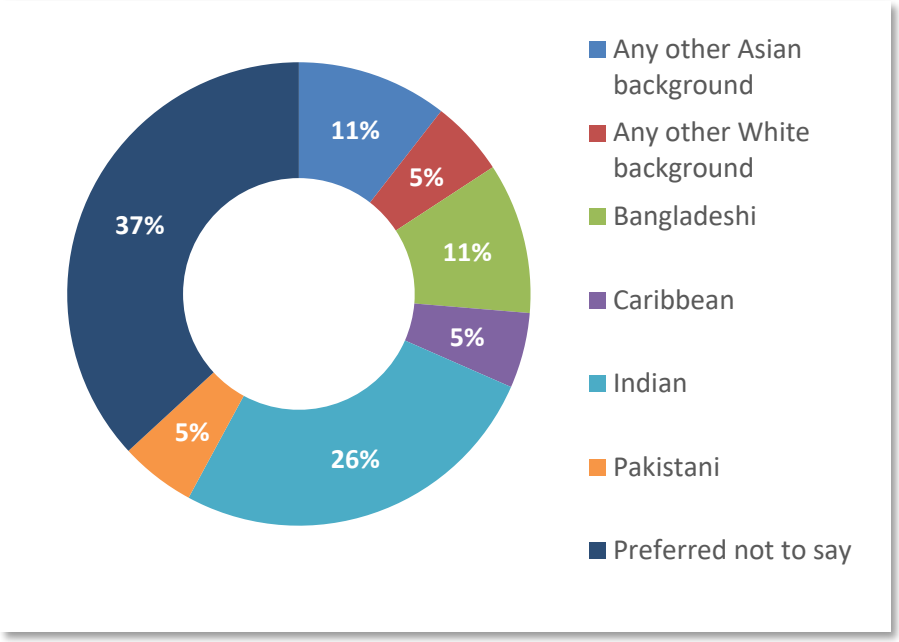


Figure 8. Cases completed 2022/23 by Ethnicity.

Gender and ICS Place

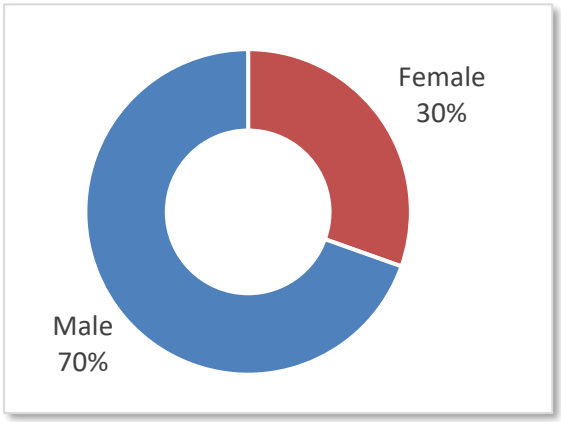


Figure 9. Deaths by Gender

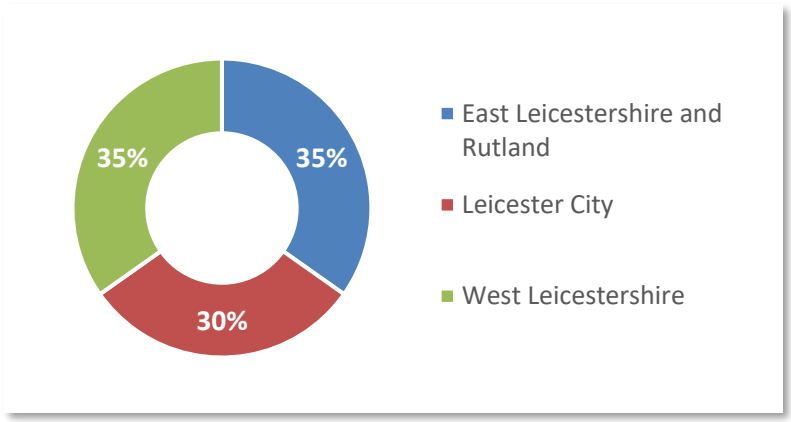


Figure 1. Deaths by ICS Place

As shown in *Figure 9. Deaths by Gender*, 70% of reviews completed in 2022/234 were of males, ad 30% of females. Those people were resident across all three ICS places, almost evenly, as illustrated in *Figure 1. Deaths by ICS Place.*

Intersectionality

The LLR LeDeR team engaged in the pilot LeDeR Intersectionality train the trainer programme run by the National LeDeR Team. This was to train the remaining LeDeR workforce in culture, race and religion sufficiently to enable the reviewers to consider these factors when carrying out LeDeR reviews and make suggestions to improve services to reduce premature mortality for people with a LD and Autistic people from minority ethnic communities.

Important Statements from LeDeR

Although a lot of positive, encouraging and at times courageous work and breakthroughs have been seen in the past year for the LLR LeDeR Programme and LLR Health and Social Care System, there are two areas that require serious attention.

1. *There remains a systemic culture of acceptance with the misuse of the Mental Capacity Act (2005) for People with a Learning Disability and Autistic people. LLR LeDeR urges our local system to act now and enforce the MCA and ensure it becomes intrinsic to our everyday care and support to people with a LD and Autistic people.*

2. *Secondly, there is no doubt that some people with a Learning Disability receive inconsistent care regarding some of the basic healthcare observations. LLR LeDeR has seen the cases of a number of people who died as a consequence of malnutrition, all of whom were not weighed when they should have been. LLR LeDeR urges the seriousness of rectifying this failure.*

"The Home had two 55-inch TVs delivered and staff saw him trying to take one and put it in his room and he insisted he wanted one, so the Home contacted his Social Worker to get authorisation to get one for him. He also wanted one of the office chairs from the staff office so he helped himself to it and would sit on his swivel chair watching Family Guy and Mrs Browns Boys on his 55-inch TV to his heart's content!"

Causes and Circumstances of Death

In this section, we summarise the circumstances and most common causes of death of people with a LD and autistic people.

Cause of death by demographic group

Age Group

It is clearly shown in Figure 2. Cause of Death by Age *that the most frequent Cause of Death (CoD) was respiratory illness and that this affected most age groups, notably prominent in people aged between 41 and 70.*

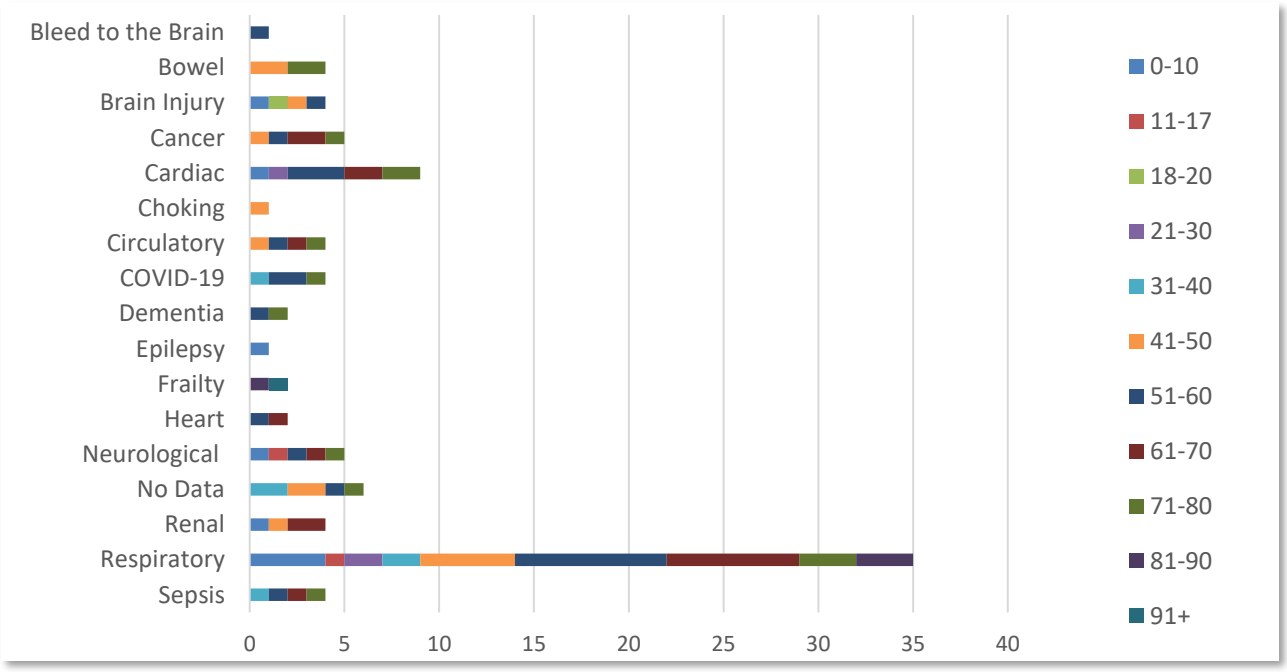


Figure 2. Cause of Death by Age

Breaking down of CoD by Ethnicity is also shown in *Figure 3. Cause of Death by Ethnicity*

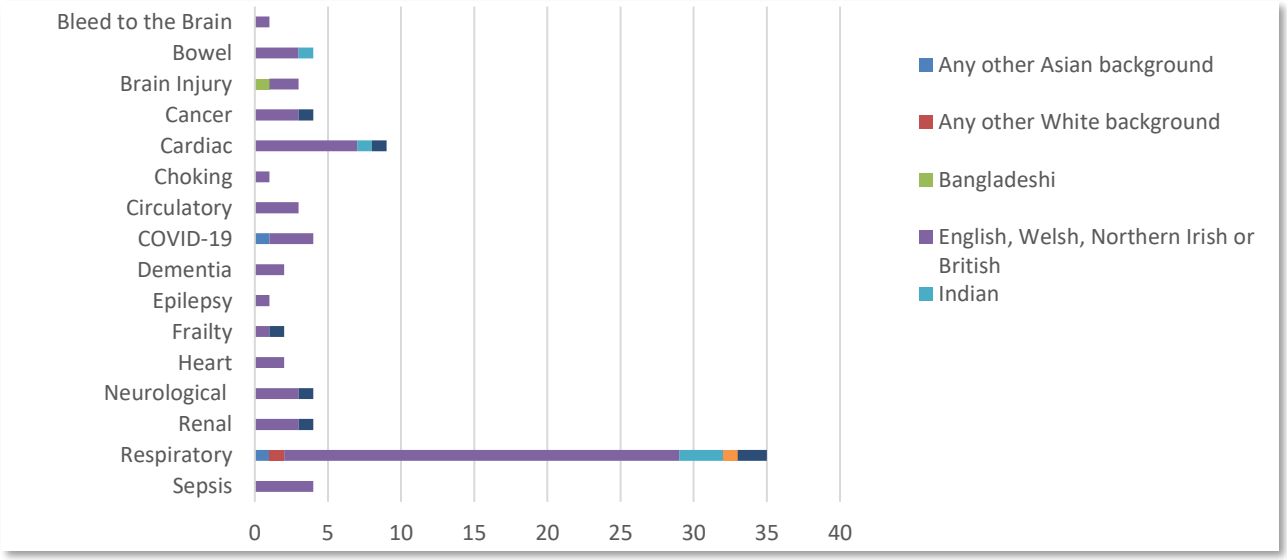


Figure 3. Cause of Death by Ethnicity

Leading Causes of Death

Causes of death in reviews competed in 2022/23 are laid out effectively in Figure 43. Causes of Death, shown below. Respiratory remains the leading cause of death, followed by Cardiac and Cancer.

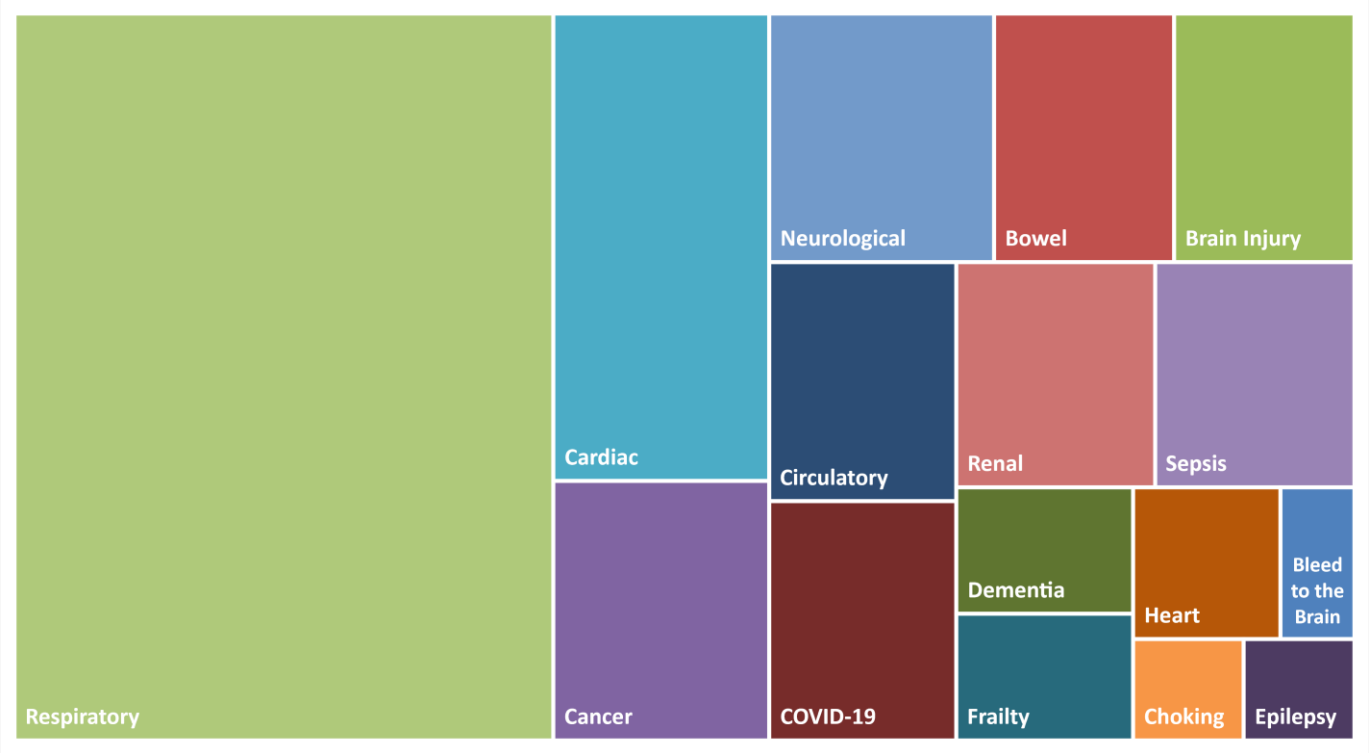


Figure 43. Causes of Death

Respiratory Deaths

Deaths from respiratory causes remains the leading cause of death for those in LLR reported to LeDeR. The Respiratory themed analysis can be found in the LeDeR 2021 – 2022 annual report. This year we were able to concentrate the Respiratory themed analysis further by analysing the deaths of those from Aspiration Pneumonia.

Cancer

Although deaths from cancer remain relatively low LLR LeDeR made the decision to revisit all the deaths from cancer reported into the LLR LeDeR Programme since 2017 up to the end of March 2023. This was to identify any inequity and offer assurance and safety in our local population. Analysis identified there were even numbers of males and females who sadly died from cancer or as a contributory factor. Since 2016, the total number of deaths from cancer is 3%, rising to 4% when including cancer listed as a contributory cause of death. There are no trends observed in the type of cancer causing the deaths of those people who have sadly died and received a LeDeR Review. Cancer screening information can be found in the section on Preventative Healthcare.

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 the case and sadly, the impact on this has the potential to contribute to early or avoidable mortality. Focused LeDeR Reviews are graded in two areas, the overall quality of care the person received and the availability and effectiveness of services. 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. This is the first year that grading of care has been implemented by the LLR LeDeR Programme in line with the LeDeR Policy (2021).

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

Context for grading of care 2022/23

Scoring of 1 for Quality of Care: This is related to a case that was on hold for several years following a police investigation, safeguarding enquiry and patient safety review. The actions taken from this were addressed by the relevant authorities and LLR LeDeR was satisfied by those reports and actions to redress the findings locally which reflected the grading of care at the time.

Scoring of 2 for Quality of Care: Those reviews were reflected with onward referrals and investigations to the necessary safeguarding, patient liaison and complaints boards required.

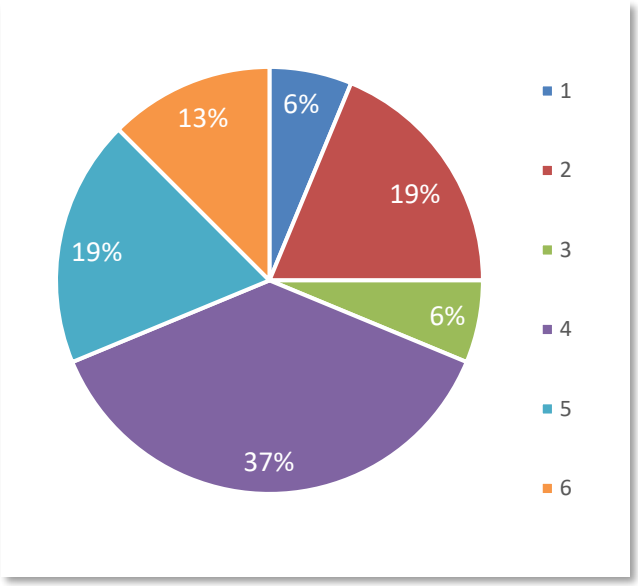


Figure 54. Grading of care

Scoring of 6 is outstanding and care we wish to celebrate and learn from; this can be demonstrated by the following: Outstanding Positive Behaviour Support and Functional Analysis assessments from the Outreach (now known as Crisis Response Intensive Support Team - CRIST) and Community LD Teams reviewed as and when required and re-referrals picked up quickly. The outcome here was that acute hospital admission was completely avoided due to the high standards of community care delivered.

Some examples of positive learning related to availability and effectiveness of services:

- Regarding the communication between the lady's carers and her GP practice there was clear evidence of good communication between the care provider and GP calls were responded to very promptly and requests for home visits were always met positively.
- The LD Annual Health Check was started via telephone call and finalised with a second appointment that was face-to-face to conduct the physical health and wellbeing checks The GP and Nurse worked together to carry out a high-quality LD Health Checks.

It is important to recognise a level of bias, as initial reviews are not graded and generally do not alert or amount to lives and deaths that have caused concern. Therefore, focused reviews are more likely to lean towards care that requires a higher level of learning into action.

Overall, the Quality of Care was favourable to higher standards, two thirds of people had satisfactory or good quality care. Although this leaves one third of people in receipt of care falling short of expected good practice.

Six Key Themes

Nationally it was requested for the first time, that all systems theme each of the learning into action into the one of six themes. As this was the first year, there is no comparable data.

In LLR, *Table 1. 6 Key Themes - learning points* shows the number of actions (learning points) related to the 6 key themes.

Theme	No. of learning points
Equality and Disability Issues including reasonable adjustments	97
All statutory duties related issues including Mental Capacity Act including end of life planning issues and DNACPR.	87
Quality of care issues in care delivery, serious incidents, and multi-agency investigations	140
Care Coordination issues including pathway issues and transition	145
Information Sharing including family involvement and documentation issues	170
Skills, knowledge and competency issues including training requirements, carers training and education.	85
Grand Total	**724**

Table 1. 6 Key Themes - learning points

The area of highest concentration is with regards to information sharing, including family involvement and documentation issues. 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
End of Life Care	67
Care coordination	67
Communication	59
Care Planning	57
Reasonable adjustments	53
Deteriorating Patient	47
Family Involvement	47
MCA	45
Diagnostic Overshadowing	33
Person Centred Care	28

Table 2. Sub-themes - learning points

Top areas of learning

End of Life Care, Care Co-Ordination, and Communication.

End of Life Care

Learning

"Updating of records was not completed when decisions had been made about End-of-Life Care and no hospital admissions. This prevented them from remaining in a familiar environment with familiar people supporting them. They died in hospital when they could have died at home."

"The provider felt that they had to advocate for them to receive end of life care with them at home rather than in a hospital setting."

"Conversations around end-of-life planning and respect form prior to last episode of care: Opportunities were missed to listen to them and gather their wishes as to how they wanted to be treated at EoL. They did not have a ReSPECT form completed until they were admitted into hospital at their last episode of care. Their family member stated that this is something that they would have liked to have been involved in creating."

Positive Practice

"They died a dignified death at home as planned for by those closest to them. They had an advanced care plan RESPECT form and DNACPR. All professionals involved in their life were aware their health was deteriorating and was for comfort care at home. They were actively treated wherever required and the multidisciplinary team (LD Team, family and GP) worked in co-ordination with care and compassion for them."

"It was acknowledged that they were coming to the end of their life, and they were supported to die at home. They had an advanced care plan describing their wants and wishes for the end of their life and this was explained in an easy read manner by the care home and GP. Their RESPECT form and DNACPR were all explained to them, and they were able to be in control and supported in a personalised and dignified manner with the necessary reasonable adjustments provided."

"They died surrounded by the people they loved the most."

Care Co-ordination

Learning

"They were losing weight, demonstrated in regular weight records and a referral was made to dieticians. They were eating and drinking as normal. The referral was declined, presumably due to the primary care options not being exhausted prior to the referral. Build up drinks were prescribed, the weight loss continued, and a cancer diagnosis was suspected by the GP. The GP requested a blood test due to concerns of cancer and wanting to instigate the 2-week wait pathway however there were delays in taking the bloods. During this time, they had laboured breathing and were taken to hospital where they sadly passed away. The cancer was looked at and suspected after they passed away."

Positive Practice

"The Acute Liaison Team supported them in hospital. Providing valuable information and raising best interests concerns with the ward consultant and suggesting a need for an IMCA."

"Good evidence of care co-ordination from the GP liaising with their family and carers and implementing the end-of-life care pathway in a timely and appropriate manner following their initial Alzheimer's diagnosis."

Communication

Learning

"There was no clear communication or discussion with their family or the care provider as to what was causing the urinary retention. They were discharged back to the care provider with a medical procedure in situ with no clear plan in place in relation to the presenting complaint and management of it. The care provider did not feel equipped or informed as to how to manage the rapid change in care needs."

Positive Practice

"Regarding the communication between the carers and GP practice there was clear evidence of good communication between the care provider and GP. Calls were responded to very promptly and requests for home visits were always met positively."

The decision has been made nationally to end the 6 key themes for this year only and as we enter into the new financial year 2023 – 2024, 10 key themes have been identified for LeDeR to map against instead, this will not be comparable for next year.

STOMP/STAMP

LLR LeDeR continues to see people with a LD and autistic people prescribed psychotropic medication, without the recommended STOMP or STAMP reviews.

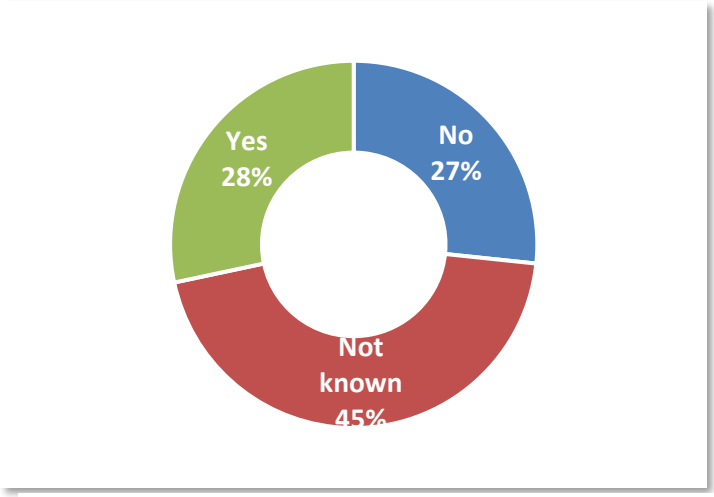


Figure 15. STOMP/STAMP review carried out for people on psychotropic medication at time of death.

Learning

- Some people were under Mental Health Psychiatry services, as opposed to LD Psychiatry, there needs to be more awareness across other directorates regarding the LDA agenda.
- Some people were prescribed Antiepileptic medication with no evidence of an epilepsy diagnosis nor prescription for behavioural management. On record analysis there were historical diagnosis of childhood epilepsy but never a review of the epilepsy or medication into adulthood. People are then living potentially unnecessarily with the side effects of antiepileptic medication.

- When a person's activities of daily living change, the impact of the psychotropic medication should be reviewed in line with STOMP. Often people with a LD communicate with their behaviour and this can be a sign of something underlying.
- Awareness in Primary Healthcare services that there are alternative options when prescribing psychotropic medication to people with a LD and a referral to Community LD Team should be considered, particularly in relation to PBS.

Positive Practice

- Some people had their medication reviewed in line with STOMP, this included clear rationale and decision making documented.
- There is evidence this year that some people had their STOMP medication with good effect, that reduced the medication they took to optimise their mental health and side effects.
- Psychiatry led MDT's when the person's presentation felt likely to be dementia avoided the need to for psychotropic medication and the care pathway implemented.
- Evidence of ongoing alternative management of behaviours that challenge for some people who experienced this their entire life and were never prescribed psychotropic medication. The stable and consistent support team were paramount in those circumstances.

An audit was conducted in 2021-22, data was collected by LPT, on local LLR prescribing practices in line with PBS guidance. Findings highlighted the need to improve physical and psychosocial health and ECG monitoring, as well improving review of medication within the 6 weeks of initiation, consent and MCA practice. Therefore, the past year has seen a benchmarking exercise against the NICE guidance NG11 (2015), and STOMP and the learning has been added to the STOMP trust wide action plan. The audit findings are comparable to what the findings are in LLR LeDeR.

For the next several years:

- LPT have delivered a new model service delivery to offer Intensive Support underpinned by PBS principles, the service is called CRIST as previously mentioned.
- The STOMP forum is led by the Clinical Director to lead improvements around polypharmacy and pharmacological interventions.
- Sponsorship of the implementation of the role of the Advanced Clinical Practitioner, in line with building the right support and STOMP. The intention is to recruit to in the next financial year.

Behaviours that Challenge

LLR LeDeR analysis highlights that more people did not have a PBS plan where behaviours that challenge were present than did. When considering this it would be anticipated that more people would have a PBS plan in place than would not. However, it should also be noted that not all behaviours that challenge presents risks and support needs that require PBS input.

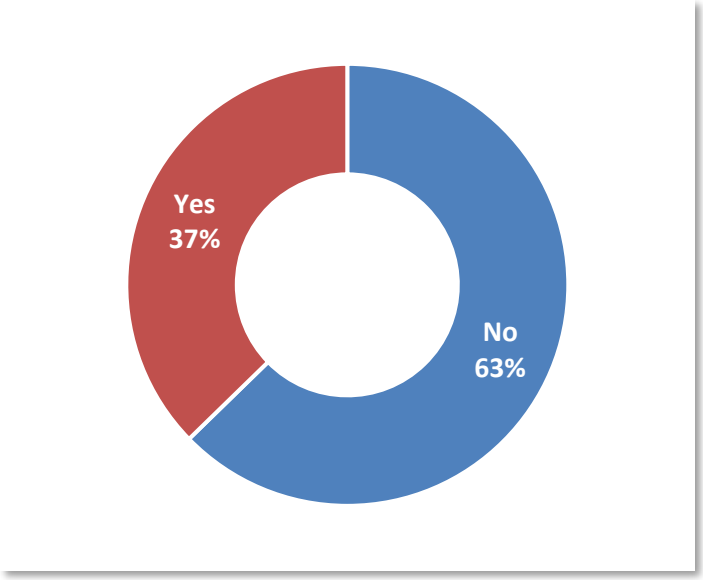


Figure 6. People with challenging behaviour who had a PBS plan in place.

Due to the ongoing evidence of Winterbourne View and Whorlton Hall enquiries and lengthy admissions to assessment and treatment hospitals for people with a LD and Autistic people with behaviours that challenge, the LLR LeDeR Programme advise that this is an area for consideration and review. The more that is understood by the behaviours that challenge and the communication needs that are being presented can only increase community care and avoidable hospital admissions.

Learning

"They received extensive support from Specialist LD and Autism services having displayed challenging behaviour for some time refusing to leave their bedroom. Although behaviours were common, they had escalated in frequency. Advice and recommendations were provided to supporting staff at their care setting; however, the care staff did not follow the suggested reasonable adjustments and the behaviour continued, he did not leave his bedroom until admission to hospital."

Positive Practice

"When their personality was understood and they were listened to and cared for in a personalised way, their challenging behaviour reduced. Community LD team particularly Outreach prevented a mental health hospital admission for them. The care from the LD team was paramount and resulted in them finally having a settled and happy life (despite years of moving from placement to placement)."

Repeated hospital admission at End of Life

It is evident to see that the EOL care of people with a LD and Autistic people in LLR is not where it needs to be yet. There are more people having repeated hospital admissions during their EOL care, than not. People with a LD and Autistic people can find hospital admissions particularly stressful and challenging, which should be avoided when it is unnecessary, in order to provide the appropriate care to the person in the community, as would be expected for all.

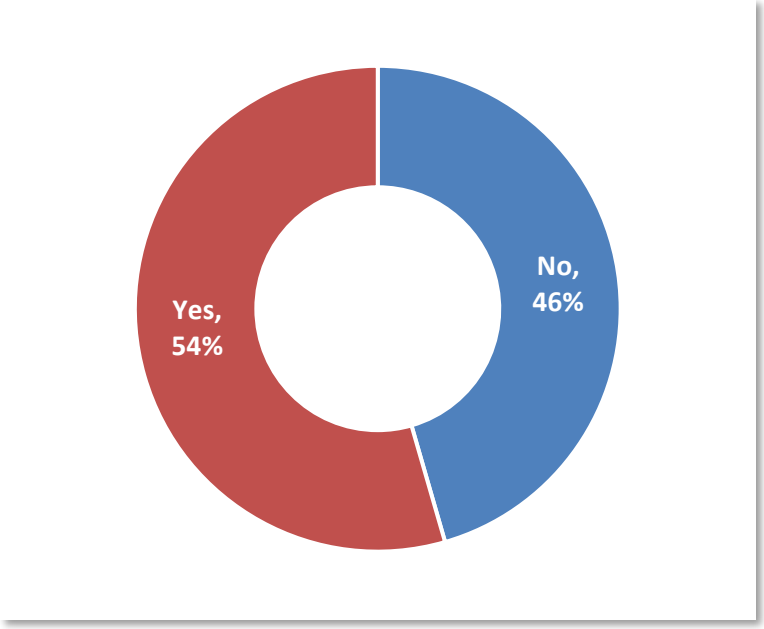


Figure 17. People on EoL pathway who had repeat hospital admissions.

It has been observed through the LeDeR governance panels that the lack of 'specialised nursing care provision for people with a LD' is showing an impact. The programme has heard the care of some people with a LD who experience behaviours that challenge and have physical healthcare needs requiring nursing care. Some people are having either their behavioural and LD needs met, or their nursing care needs met. Whereas they require both, behavioural care and management and nursing care.

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

This should be balanced with some outstanding care that has also been seen:

- Panel members describe this particular care home as brave and as a standout service. They were not a nursing care home and were not equipped to manage those needs alone (all other residents were mobile and independent). They wanted to meet the person's needs in a person-centred way, which ultimately meant they were reliant and trusting on community services supporting them all through the EOL care for them. This is not an ordinary position to take and should be commended. The person died peacefully at their care home.

LLR LeDeR is committed to a deeper understanding of the deteriorating patient and EOL care, particularly where there are concerns in those areas. This has been recognised by the LACs and LeDeR Steering Group and an agreement has been made to commit the local priority focused

review area to be "e*ither concerns around the deteriorating patient OR concerns around the EOL care the person received."*

In the past year the LDA collaborative in LLR has introduced the LDA Health Inequalities group and a subgroup focusing on learning around the deteriorating person. LeDeR has been influential and a focal point in steering these groups with the learning into action. The LeDeR themes influence the future of these working groups across the system to implement the learning into action and improvements.

An example: this year has seen successful sign off and implementation of the local accessible end of life care plan.

The LDA Collaborative focus on the deteriorating patient for this year has been:

- Weight management/nutrition and hydration.
- Improving the outcomes for people with LD and epilepsy benchmarking.
- The role out of LD specific training to care homes on recognising the deteriorating person, RESTORE2 mini and SBARD.
- Venepuncture care and provision.
- Health Equity Lead Nurse post established.

Safeguarding

LLR LeDeR continue to work closely with the LLR safeguarding teams. Where a LeDeR review and Safeguarding Adults review is being conducted at the same time, the Safeguarding Adults team lead and carry out necessary communications specifically to family members, this is also on behalf of the LeDeR Team. This enables collaborative approaches, reducing stress and inconvenience to families already under stress and upset. A memorandum of understanding is being drawn up to establish this process formally during the coming year.

"A gentle person who had a good sense of humour and someone who enjoyed being sociable."

Preventative Healthcare

Venepuncture

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

Learning

"They did not have a blood test throughout their life at the GP surgery there is no evidence of a referral to the Community LD Team for desensitisation work especially after concerns were raised back in 2017 and up to the time they passed away."

"This person who had severe LDs, autism and displayed behaviours that challenge. Attempts to provide blood desensitisation support had been made over the years, but with little effect, and there were MDT discussions but there appears to have been a delayed response to best interest discussions and action around blood taking intervention. There were difficulties with the use of the Mental Capacity Act and the level of restriction that was required for successful venepuncture in the community. This person sadly died from the cancer that was in question."

"LD Team completed desensitisation work, but blood taking attempts were unsuccessful. It was decided not to do any blood tests. This was despite conventional antipsychotic medication prescribed (known to carry more side effects) most of their life. There is evidence that indicates the lack of provision available for people with a LD and behaviours that challenge with regards to blood taking when more restrictive practice under the MCA is required in community care."

"It was clearly difficult to progress through for the required blood tests and medical investigation when the person did not respond as hoped from the desensitisation."

Positive Practice

"District Nursing services would do home visits to obtain blood even though they would have been able to access the surgery. This was because it was so difficult to do a blood test and they would always have several blood vials taken to test for everything to minimise the number of times a blood test would be required. This was planned for and instigated by the GP."

"They were supported to attend all health appointments including ECG's and blood tests for metabolic monitoring."

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 occurrences that can affect engagement and opportunities for vaccinations for people with a LD and autistic people and therefore, reasonable adjustments are often required.

The LLR LeDeR programme, as mentioned earlier, is able to utilise only local data, manually recorded as opposed to reporting direct from the LeDeR web-based platform and the information below is reflective of this for 2022-2023.

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 consent is important. Respiratory illness remains 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 are 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 it is encouraging that 70% of people had their flu vaccine in the last year of life (*Figure 18. Flu jabs*), this should continue to be encouraged and increased. People should also be encouraged to attend their LD Annual Health Checks where further reasonable adjustments and opportunities can be discussed.

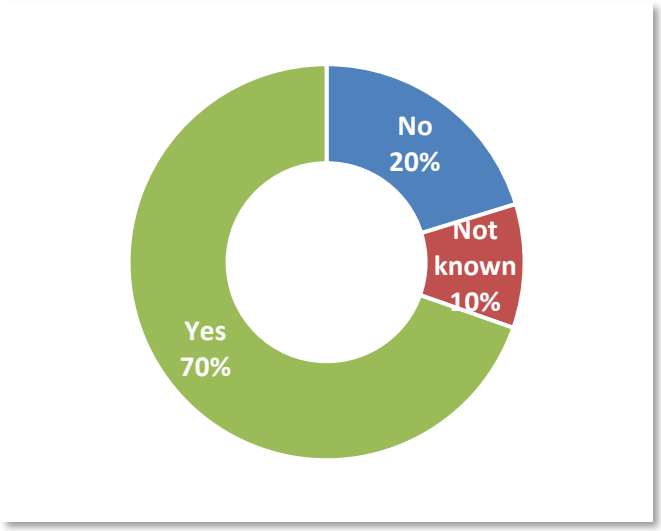
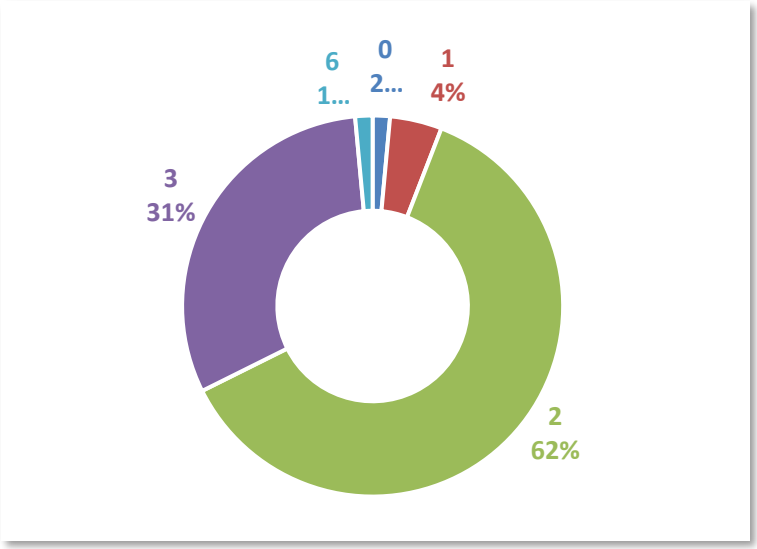


Figure 18. Flu jabs received.

Covid Vaccine

The Covid-19 pandemic struck the world in 2020 and the years that followed remained challenging for the entire population. For people with a LD and autistic people these challenges were particularly heightened and difficult; the social isolation masks, absence from families and loved ones. The change of routine and testing were demanding, tiring and for some sadly, catastrophic. The Covid vaccination programme offered some relief and protection as well as new challenges to overcome. This year has seen a decline on the number of deaths from COVID-19..



shows only 2% of people who died and not had a COVID vaccine at all. 4% had received a single vaccine, 62% had received two, 31% had received three vaccines and 1% had even received six.

In 2022 LPT was one of the lead organisations in rolling out mass Covid vaccination programmes which enabled the LD and autism leaders to influence the mobilisation of the LD and autism vaccine programme. This offer was extended until March 2023. The LD and autism vaccine programme consisted of hubs that were identified to be more accessible to the LD and autism population, that were staffed and supported by health professionals who had the skills and knowledge to overcome barriers and provide reasonable adjustments.

The teams identified a proportion of people with LD and autism who could not access the LD vaccine clinics and were able to organise a roving programme where health professionals went out to people's homes with great success.

It is important to acknowledge that there remains a portion of the population of people who did not achieve all 3 of their vaccines and some who were not successfully vaccinated. The themes for this were the complexity of restrictive practice that would have been required and would have necessitated the involvement of the Court of Protection. For some people, it was deemed not to be in their best interest by the MDT and family/carers.

There was media interest and press release which can be found in *Appendix II*.

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 2022-23 for those eligible for cervical screening only 19% of people attended, with 70% of people not attending. 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 ceased from the screening register due to having a LD or autism and alternative checks can be offered such as, abdominal checks and menstrual tracking.

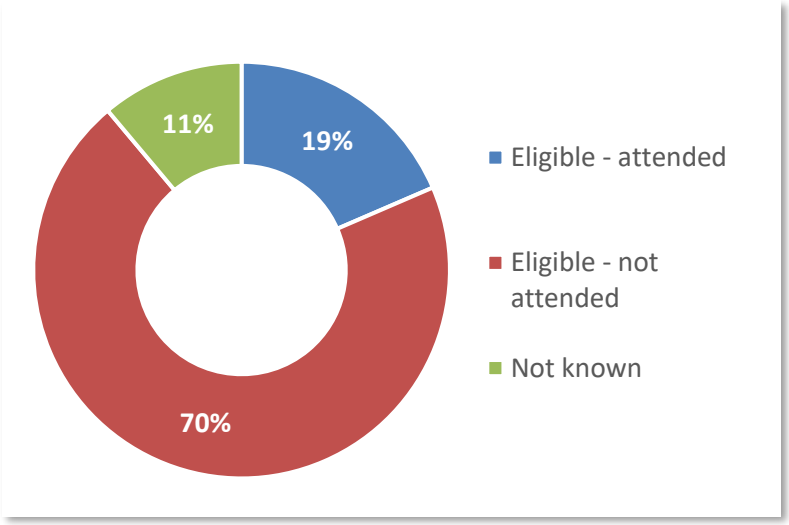


Figure 7. Cervical cancer screening attended (Where eligible)

The LD PCLN team planned and co-ordinated a specialist project on cervical screening to increase the uptake for people with a LD in LLR.

The team were successful in securing funding for the project from the LLR Cancer Screening Network. The initial project was due to run in March 2020, however due to the Covid-19 pandemic the work was suspended for two years.

The collaborative work between LPT and UHL was a complete success, yielding 100% success rate for every person on the day. The nurses have since reflected upon this session, the tilt chair was of exceptional benefit for all who attended for cervical screening, and it is hoped that this chair can be purchased and used for primary care next year. The detail of person-centred care and reasonable adjustments, including transport was found to be of most benefit.

The team are considering locations nearer to the individuals as well as plans to run regular clinics for non-attenders. The LD PCLN team have also worked collaboratively with one Primary Care Network in LLR who have put forward a proposal to run an enhanced service for LD specialist cervical screening clinics into 2023-2024. The team are considering local data analysis and impact going forward into the next financial year.

Breast Screening

In 2022-23, 33% of people eligible for breast screening attended, with 53% of people not attending. 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 is still available to support people with LD and autism on breast screening, on the internet, that was developed by LLR and should be used and promoted.

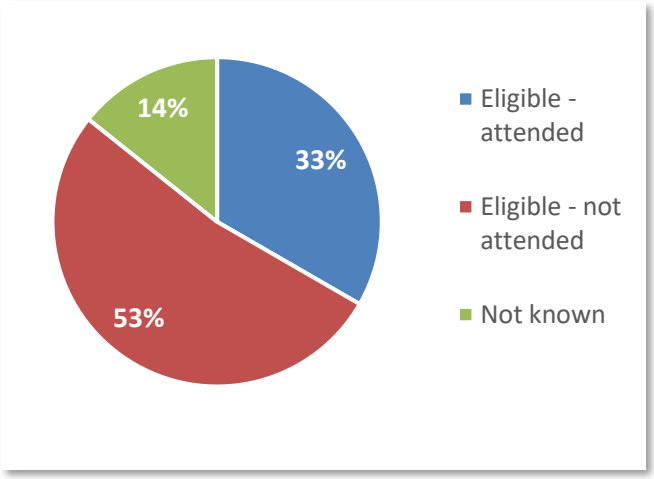


Figure 8. Breast screening attended (where eligible)

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

Bowel Screening

This year has seen 58% of people eligible, attend for their bowel screening appointment, leaving 32% of people not attending. Bowel screening usually yields one of the highest attendance rates due to its less invasive nature and we would be expecting this figure to rise. There has been some encouraging positive practice seen 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. This will be continued into the next financial year.

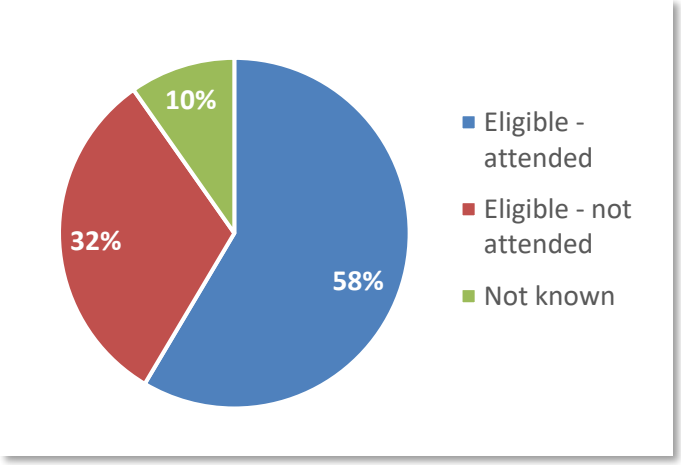


Figure 9. Bowel screening attended (where eligible)

Abdominal Aortic Aneurysm (AAA) Screening

AAA screening demonstrates that approximately half of the eligible people through the LeDeR programme are attending but half are not, further work is required to understand this better.

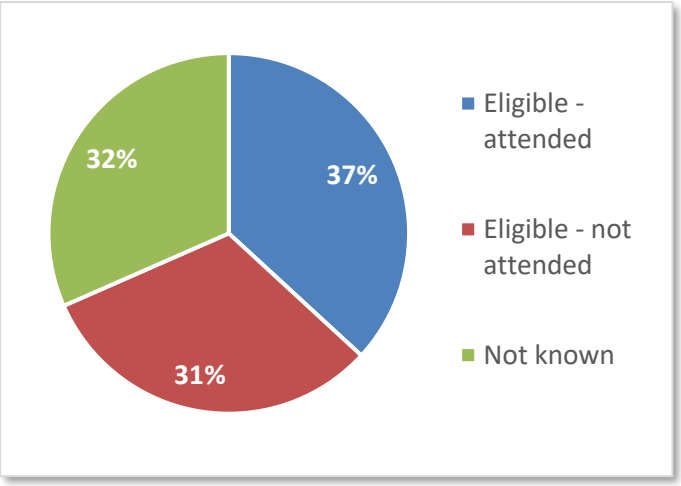


Figure 10. AAA screening attended (where eligible)

LD Annual Health Check

The past year has seen the highest achievement in LD AHCs, achieving in LLR just over 80%, which is reflected in LeDeR too. The GP practices and LD PCLN team as well as others including people with a LD and their family, friends and carers should be commended on the success in driving forward this agenda.

LLR is now second in the whole of the Midlands (and in the top ten in England) in terms of the number of annual health checks completed. Two years ago, LLR was one of the lowest performing areas in the country.

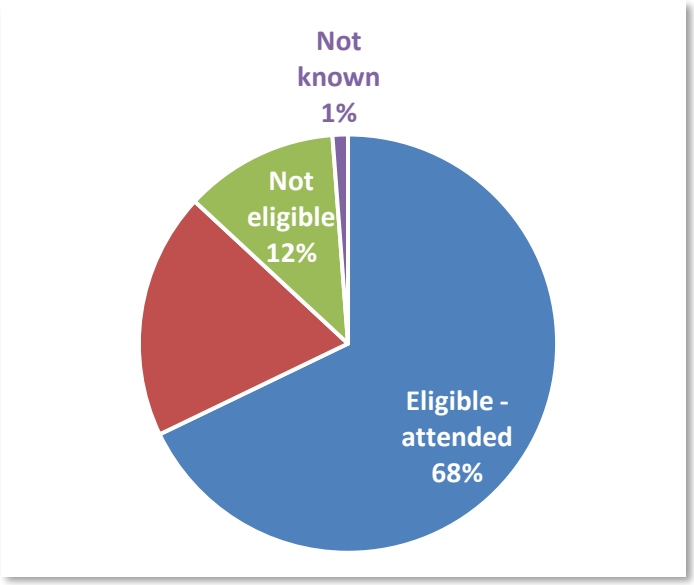


Figure 11. LD Annual Health check attendance

LD PCLNs, offer regular support and training on AHCs for primary care and social care partners – including GP practices – to improve access to health care and reduce health inequalities for people with a learning disability. The team are currently running a pilot project to increase the AHC uptake for those hard-to-reach communities and people who may find accessing the AHC challenging. See *Appendix III* for further information.

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.

There were five areas of focus for LLR LeDeR during 2022 – 2023, which were:

- Aspiration Pneumonia - *priority focused review area agreed at Steering Group.*
- Covid-19 – *Requested from Steering Group.*
- Weight - *[this was carried out but is still underway and will be explored further with completion in 2023-2024]*.
- MCA - *[this work will also continue be being explored and finalised through into 2023-2024].*
- Ethnic Minority – *Mandated focused review area and agreed at Steering Group.*

Aspiration Pneumonia

Aspiration pneumonia is categorised by the Office for National Statistics (ONS86) as a preventable medical cause of death. Aspiration pneumonia results from accidental infiltration of food or other substances from the mouth or stomach into the lungs that leads to a chemical pneumonitis, lung injury, and resultant bacterial infection. **NHS website 2022**

It is diagnosed through a series of medical history, signs and symptoms along with clinical investigation. One of the challenges with aspiration pneumonia in people with a LD is that often no one actually sees the person breathe in an object or food or saliva. People are sometimes unable to communicate what and how the event occurred, putting them at greater risk.

29 LLR LeDeR reviews of people who died from aspiration pneumonia were identified for analysis, time period not restricted, this only included adults with a LD. A workstream was convened which included Consultant in Respiratory Medicine, Acute LD Liaison Nurse, Specialist Respiratory Physiotherapist and Occupational Therapist and Professional Lead for LD Speech and Language Therapy. It was found that the deaths **could not be attributed to aspiration pneumonia alone**, this is because something must have precipitated the aspiration for the incident(s) to occur. The summary can be seen below.

"He loved to watch steam trains".

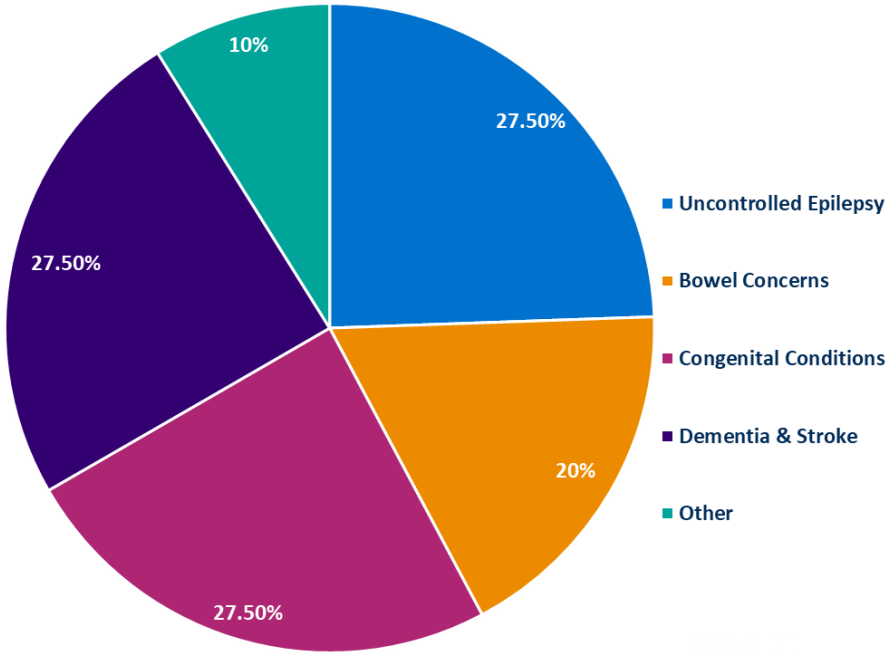


Figure 12. Percentage attributable to Aspiration Pneumonia

Sadly, 34% of the deaths were found to be potentially avoidable.

We have identified the area in the NICE Guidelines pathway that we wish to work through in LLR which is "Correct any reversible underlying problems that precipitated the aspiration". **Error! R eference source not found.**, while *Figure 27* shows the proposed pathway.

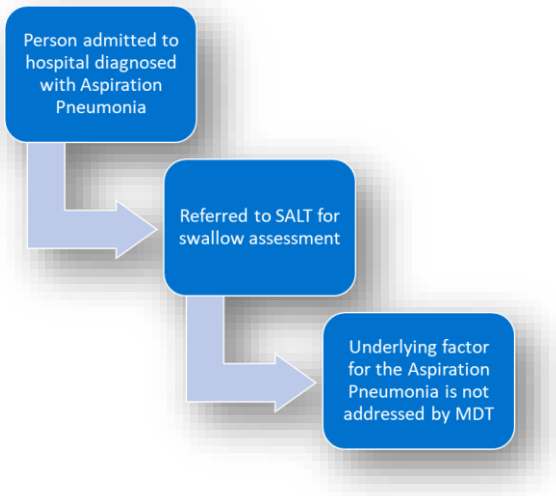


Figure 26. Current Aspiration Pneumonia pathway

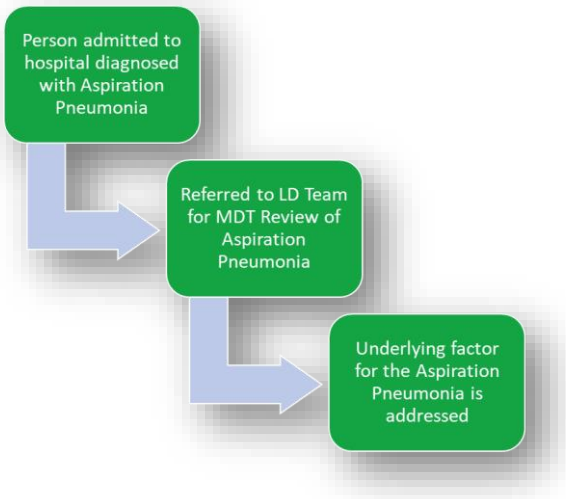


Figure 27. Proposed Aspiration Pneumonia pathway

This aims to eliminate the risk of escalation by replacing referral only to SALT with referral to LD Team for MDT review of Aspiration Pneumonia.

SMART Actions

What do we want to achieve?

To reduce preventable aspiration pneumonia deaths in people with LDs in LLR.

By creating/embedding into already existing care pathways and addressing the precipitating factors linked to increased risks to aspiration pneumonia.

A comprehensive plan has been agreed based on the findings and will be implemented with the support of the LDA Collaborative partners during 2023-24. These recommendations are ambitious and require a whole system approach. The aspiration pneumonia analysis is currently being written up as a journal article piece to enable ongoing learning and research in this area.

Covid-19

A scoping exercise was completed to review further detail to inform us on the effects of the Covid-19 pandemic. This was challenging because it is often difficult to fully understand the indiscriminate nature of Covid. However, quality of care was able to be analysed with the top 3 themes highlighted and requiring improvement in the care of people with a LD and Covid:

- The implementation of the Mental Capacity Act (MCA).
- Diagnostic overshadowing and misinterpreting signs and symptoms for behaviour and communication.
- Record keeping and clearly documenting the excellent work that is often carried out, particularly in what reasonable adjustments have been provided, the MCA and how certain decisions have been reached.

Ethnic Minority

LLR LeDeR conducted a scoping exercise on all the notifications to the LeDeR Programme since 2017 of those from a diverse ethnic background.

Due to ethnicity not currently being reliably and routinely recorded on electronic patients records (SystmOne), LLR LeDeR compared the 2020 – 2021 Census data with the LeDeR notifications for the exact same time period by way of population comparative. This information and data comparison must be used with caution as it is not without its discrepancies. Special thanks to DeMontfort University in supporting this piece.

LLR LeDeR Notifications by ethnicity

White British	85.05%
Ethnic Minority	14.94%

Census data population by ethnicity

White British	87.52%
Ethnic Minority	12.48%

The charts above show on the left the LLR LeDeR Notifications received by ethnicity during specific time period of 22/03/2020 – 21/03/2021. On the right shows the Census population by ethnicity

for the same time period. This information should be used with caution, however, demonstrates the LLR LeDeR programme are receiving the expected number of notifications of those with from a diverse ethnic background.

However, when comparing specifically LLR LeDeR Notifications from Leicester City there appears to be disparity.

Comparing the census population data of those from an ethnic minority background with the LLR LeDeR notifications received of those from an ethnic minority background, in the same time period (22/03/2020 – 21/03/2021).

Census Population - Ethnic Minority background – Leicester City	**59.11%**
LeDeR Notification - Ethnic Minority background – Leicester City	**28.20%**

We would expect to be seeing more notifications to the LLR LeDeR programme of those from an ethnic minority background from Leicester City.

The scoping exercise was then undertaken, this information includes only people with a LD whose deaths were notified to the LLR LeDeR Programme.

The top 3 main causes of death were aspiration pneumonia and covid followed by pneumonia.

Diabetes in those people from an Ethnic Minority background:

- 41% of people from an ethnic minority background had **diabetes**.
- Of those people with diabetes, 71% of people had very serious health concerns. These were concerns picked up in an emergency and had been lived with for some time, but not identified or remedied prior, including ketoacidosis (life threatening condition in diabetes).
- Almost a third of those people with diabetes had morbid obesity, this increases the risks of nephropathy, heart disease and amputation, in those with diabetes.
- 86% of people lived at home with their family and no one lived in paid care environments.
- 57% of people did not attend their LD AHC and diabetic appointments.

Covid-19 in those people from an Ethnic Minority background:

- 17.5% of people from an ethnic minority background died from Covid-19.
- Of those people who died from Covid-19 85% of people had multiple co-comorbidities.
- The average age of death was 55yrs old. The average age of death from Covid-19 in the general population is 80yrs old.
- 43% of people lived in a care home and 57% of people lived at home with family.

Conditions in those people from an Ethnic Minority background:

- 14% of people from an ethnic minority background had vitamin deficiency.
- 14% of people from an ethnic minority background had anaemia.
- 60% of people did not attend age-appropriate screening and LD Health Checks.

What else have we found out through this scoping exercise?

- There is no detail at all regarding the risk level for the person with regards to their health condition and their ethnicity in clinical records/care plans, or if they are at an increased risk to a health condition. Subsequently, there is no detail on how to reduce the risk for them.

- People were more likely to live at home with their family providing care for them.
- There were higher than expected levels of obesity observed.
- Iron deficiency and vitamin D deficiency went unnoticed, especially in care homes where risks are known to be higher, but this was not accommodated.
- Culturally appropriate health and social care to support the person's life and death, was largely not documented. Where people lived with families, they were more likely to have their cultural beliefs met during life and death.
- It is not always represented in respect forms how someone's culture should be addressed at time of death.
- Assumptions are often made about someone's cultural beliefs.
- Ethnicity is not accurately and consistently recorded. Moving forward it would be more suitable to break down the ethnic groups as opposed to grouping ethnic minorities, nobody wants to be known as "other" and this should be respectfully avoided.

Autism

This year saw the LeDeR Programme open to receiving notifications of those with a clinical diagnosis of autism, and do not have a learning disability, aged 18yrs and over. The LLR LeDeR programme has received notification of very few deaths that is not representative of the local population. This is concerning and the awareness of the LeDeR programme and the notifications of deaths of autistic people must be a priority.

In total there were 3 deaths notified to LLR LeDeR of autistic people, who were all male, there have been no notifications of females. The reviews will be completed in the coming year.

"Family was very important to him, and he enjoyed going out and socialising. On a Saturday night he and his Mum would go to the local club for a drink and a dance."

LLR CDOP LeDeR themed review

Deaths of all people with learning disabilities aged 4 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 cohort. During 2022-23, 10 case reviews were completed for children who had died, who met the criteria for LeDeR. 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.

Of the 10 cases:

- The most common category for cause of death was:
  - Chromosomal, genetic or congenital anomalies (60%)
  - Other categories included acute or chronic medical conditions, malignancy, and infection.
- Modifiable factors were identified in 2 cases.
- Positive aspects of service delivery were noted in 7 cases.
- Mean age at death was 8.3 years (4-17yrs)
- Of the two young people who were eligible for AHCs in primary care, neither were on the GP learning disability register.

LeDeR Scope & definition: Everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a diagnosis of autism is eligible for a LeDeR review.
Individuals with a learning disability 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.

"She was a lovely bubbly person and she really loved babies".

Recommendations

Key learning themes identified during the CDOP LeDeR reviews:

	**Children & young people being appropriately included on the GP learning disability register at the earliest opportunity.** - Ensures appropriate adjustments are made within primary care, including offer of services tailored to children and young people with a learning disability (e.g., LD vaccination clinics). - Ensures once young person is 14 years of age, they are offered an AHC. - As well as optimising overall health, can provide support with transition from child to adult services. This is also an opportunity for the GP practice to support the whole family including the needs of the parents.
	**Importance of communication with families.** - Complex care needs good coordination, families need to know who their lead professional is, effective transition to adult services for vulnerable young people is vital.
	**End of life care.** - Advanced Care Planning can be complex for children, young people and their families, whether or not they have a Learning Disability, and it is important for services to communicate and work well together to provide timely and appropriate support.

Children who have a learning disability should be on the GP Practice Learning Disability Register, to ensure that, from the age of 14 years, they are offered the opportunity for a Learning Disability Annual Health Check.

Services should ensure that:

1. At the earliest opportunity children with a learning disability are added to the GP learning disability register.

2. Inclusion in LD AHC and ensure reasonable adjustments are identified and offered at the earliest possible opportunity.

3. Individual circumstances are taken into account in terms of exceptions as it may not be appropriate for a child or young person receiving end-of-life care to be offered a LD AHC. It may be appropriate to offer a modified health check to ensure a supportive experience for the child or young person and their family.

Learning into Action

The learning into action for LLR LeDeR has a formal structured process that can be viewed in the LeDeR reporting structure at the beginning of this report. On a quarterly basis all the issues and positive practice that are highlighted from LeDeR reviews are 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. This is the first year it has been delivered in this way and LLR LeDeR intends to strengthen this in the coming year.

Top 3 Highlights of LLR LeDeR learning into action:

GP and Primary Care

- Improved integrated working between GP practices and LD PCLN team – enabling improved accuracy of LD registers and improved numbers of AHCs completed.
- Safeguarding, "Was Not Brought" code, is now actively in use and receiving 6 monthly updates from HIS data team, action plan will be developed from this.
- LD Primary Care Champions – seeking to establish a key person in each GP practice across LLR, including implementation of positive praise of practices demonstrating good care/positive changes for LD and Autism population.

LPT FYPC / LDA

- Accurate weight checking services for those who require alternative weighing than stand on scales. Accessible portable scales have been purchased, next step of how this will be rolled out across LLR and how wider GP networks can utilise is to be established.
- Venepuncture – seeking to establish a service appropriate for those requiring more restrictive intervention under the MCA in community care.
- Epilepsy pathway joint with UHL changes to the access to service, templates and assessments incorporating a more robust assessment of physical health and encouraging access to AHC's.

Acute Care

- Delays in access to treatment and ensuring that people with a LD are not adversely disadvantaged, there is now oversight of waiting lists by the LD ALN team.
- Limited capacity of the specialist LD ALN team to provide training and support for patients with autism and children. The capacity of the LD ALN team has been reviewed along with a business case to expand the service, which was successful and funding for an all-age LD ALN Team confirmed.
- To ensure that complex discharges are correctly identified, an audit of patients with a LD will be undertaken to confirm if they were correctly coded as a simple or complex discharge and action plan following results.

Leicestershire County Council

- Weights oversight - Care providers to understand and evidence in practice how they effectively support people with their weight management, know who they can refer to for concerns over weight management and how to make those referrals in a timely way, through training and awareness raising.
- Mental Capacity Act - Care providers to work within the Mental Capacity Act and the remit of their role. To have understanding about best interest decisions, contribute towards that decision where appropriate, working with the lead professional from health or social care, through awareness training and information.
- Reasonable adjustments - Care providers to understand reasonable adjustments and how to request this for people they support with LD and/or Autism. To make improvements through signposting care providers to LD and Autism LPT training to cover RESPECT, reasonable adjustments, hospital passports & STOMP, via Care Provider Bulletin and Provider Forums.

Leicester City Council

- Transitions care, ASC frontline staff are now discussing at point of contact with families the difference between Children's Act and Care Act. This is to ensure and support realistic support care and treatment as the child becomes an adult.
- To overcome language barriers, LD social care now have an agreement with Leicester City Council language services, that if interpreter required by phone in emergency, this can be provided. Family's preferred method of language is obtained prior to any meetings/visits and interpreter secured to enable person(s) to express views.
- ASC frontline staff are striving to secure culturally appropriate residential placements. When sourcing placements the individual's culture, language and communication needs are identified to match to the best available care provider.

"She had a wonderfully close relationship with her mother and sister and people would talk about how much her face lit up every time she saw them".

Top Ten Learning into Action

This section aims to give a final top 10 summary learning into action points from LLR LeDeR Annual Report 2022 – 2023:

1. Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.

2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.

3. There is an emerging theme around the widespread misuse of the Mental Capacity Act. All services should review their practices to ensure compliance with this important legislation.

4. The practice of estimating someone's weight is a significant risk for people. People should be weighed using appropriate weighing equipment and the weight should be recorded accurately.

5. Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with learning disabilities as physical health and nursing care needs increase particularly towards the end of their life.

6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.

7. Screening inequalities exist and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.

8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.

9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. The changing of pathway at discharge to LD MDT is imperative.

10. There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy, which is not always accessed appropriately. Intervention by these teams does not guarantee successful outcomes but the availability should be widely known.

Plan for 2023/24

1. LLR LeDeR projects for 2023 - 2024:
    a. LLR LeDeR – the Mental Capacity Act through story telling.
    b. Leading a safe programme – Review of deaths of those who live in care homes. Weight Management – effects of poor weight management from the perspective of LLR LeDeR.

2. Restorative Supervision:
    a. To balance the effects of compassion fatigue the LLR LeDeR Team will be engaging in 6 x restorative supervision sessions during 2023 – 2024.

3. Experts by experience:
    a. Aim to ensure all the LLR LeDeR programme, boards, panels and where possible interviews are co-chaired by an EBE. This is from a strategy and planning perspective, creating the agenda and forming the drive and commitments of the programme.

4. Intersectionality:
    a. The LLR LeDeR programme intends to embed intersectionality into each review, understanding local cultures, highlighting areas that are impactful for individuals on an individual and personable level, creating a diversity to the review, panels and discussions. This in turn will shape the steering group and LD&AAB.
    b. Accurate recording of the ethnicity of people with a LD and autistic people on electronic patient records is a priority to be addressed in LLR for next year.

5. LeDeR:
    a. To revise the membership and include more people and a wider audience i.e., registered managers of care provision for those with LDs or autistic people; mental health practitioners; Drug and Alcohol services; lay member to represent those from a diverse ethnic background etc. *[List not exhaustive].*
    b. To hold themed analysis:
        i. Ethnic Minority.
        ii. Autism only.
        iii. Local priority focused review area, which for LLR in 2023-2024 is ‘concerns around end-of-life care and/or the deteriorating patient’.

6. Steering Group:
    a. To hold themed steering groups directing the focus on learning into action and bringing all providers services together:
        iv. LD AHCs.
        v. MCA.
        vi. EOL.
        vii. Weight.
    c. To receive bimonthly highlight reports from each provider service and to include positive practice. To better understand the learning into action progress more consistently.

7. Conducting High Quality LeDeR Reviews:
    a. Receive a session on the 5 Why's is scheduled for the LLR LeDeR Team in May 2023.

8. Autism:
    a. Support the introduction of the Autism register and autism AHC.
    b. To work with the Patient Safety Team and Learning from Deaths team in LPT to look to improve notifications of autistic people and improve overall governance structure of LLR LeDeR programme.
    c. Develop an autism only data collection, including additional relevant factors in autism only governance presentations.

9. The LDA Collaborative focus on the deteriorating patient workstream for next year is:
    a. Themes from the LLR LeDeR aspiration pneumonia analysis.
    b. EOL care for people with LD.
    c. Continuation of improving the outcomes for people with LD and epilepsy benchmarking - this is a 3-year plan.
    d. Continuation of the weight management and nutrition and hydration workstream.
    e. Trialling the new plans and service delivery on for venepuncture care and provision.

10. Aristotle
    a. To work with and alongside the Aristotle data system and teams utilising this database to reflect on findings from LeDeR.

11. Health Equity and LD PCLN team Qi projects:
    a. Working with people with a LD in prisons ensuring the correct people are appropriately on the LD Register and appropriate LD AHC.
    b. To re-establish the Better Health group to work collaboratively on the health equity plan which LeDeR feeds into.
    c. Implement the transition age uptake of LD AHCs project [including CDOP analysis].
    d. To implement the mobile vaccination unit for the coming year, to offer additional reasonable adjustments to access primary care; offer health promotion; screening and access to weighing and physical health checks.
    e. Quality audit for LD AHCs.

"She loved having nice clothes and she had beautiful outfits and wore these with bracelets and necklaces. She had a great collection of them and wouldn't leave the home without a necklace and a bracelet."

Appendix I

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

Appendix II

Covid 19 Coverage for LLR LD Vaccination Programme.

- 12 Oct: LD Vaccination Clinic promo interview on BBC Radio Leicester Breakfast Programme.
- 28 Oct: LD Vaccination Clinic, coverage on East Midlands Today lunchtime bulletin.
- 28 Oct: LD Vaccination Clinic, coverage on East Midlands Today evening bulletin.

13 Jan: https://www.leicspart.nhs.uk/news/people-with-learning-disabilities-invited-to-book-in-at-specialist-covid-19-vaccination-clinics/

06 May: https://www.leicspart.nhs.uk/news/specialist-learning-disability-and-autism-covid-19-vaccination-clinics-open-doors-to-children-and-adults-this-spring/

21 June: LD Week - https://www.leicspart.nhs.uk/news/more-specialist-covid-19-vaccination-clinics-announced-this-learning-disability-awareness-week/

21 Sept: Winter preparation - https://www.leicspart.nhs.uk/news/specialist-learning-disability-covid-19-vaccination-clinics-reopen-ahead-of-winter-season/

06 Oct: https://www.leicspart.nhs.uk/news/octobers-specialist-learning-disability-covid-19-vaccination-clinic-is-announced/

08 Nov: LD Vaccination Clinic at Highcross Shopping Centre - https://www.leicspart.nhs.uk/news/highcross-shopping-centre-to-host-the-next-learning-disability-covid-19-vaccination-clinic/

05 Dec: **LD Vaccination clinics/last of 2022 -** https://www.leicspart.nhs.uk/news/leicestershire-partnership-nhs-trust-to-host-final-covid-19-vaccination-clinic-for-people-with-a-learning-disability-of-the-year/

Appendix III

LD AHCs further information

Further information can be found here Huge progress on annual health checks for people with learning disabilities across LLR - Leicestershire Partnership NHS Trust [URL: https://www.leicspart.nhs.uk/news/huge-progress-on-annual-health-checks-for-people-with-learning-disabilities-across-llr/] (Last accessed 17/07/2023)