APPENDIX A

Leicester, Leicestershire and Rutland LeDeR Annual Report June 2022

This report covers the period from 1 April 2021 to 31 March 2022

Leicester City Council

NHS
Leicester City Clinical Commissioning Group
West Leicestershire Clinical Commissioning Group
East Leicestershire and Rutland Clinical Commissioning Group

Leicestershire County Council

NHS
Leicestershire Partnership NHS Trust

Rutland County Council

NHS
University Hospitals of Leicester NHS Trust

Contents

"He loved being with his family and would often enjoy family trips to the theatre, cultural music events, shopping and trips to Blackpool which he particularly enjoyed"

Executive Summary

The primary purpose of the Learning from Deaths of people with Learning Disability (LD) and autistic people review programme (LeDeR) is to review the care each person has received leading up to their death and make recommendations that could help improve the care for other people and reduce premature deaths. Recommendations from each review are intended to highlight best practice and thereby support health and social care professionals and policy makers to implement positive change for people to have better experience of their care.

The core principles and values of the LeDeR programme are as follows:

- The programme overall must effect change and make an identifiable difference to the lives of people with learning disabilities and autistic people and their families.
- We value the on-going contribution of people with learning disabilities and autistic people and their families to all aspects of our work and see this as central to the development and delivery of everything we do.
- We take a holistic approach, looking at the circumstances leading to deaths of people with learning disabilities and autistic people and don't prioritise any one source of information over any other.
- The key principles of communication, cooperation and independence are upheld when working alongside other investigation or review processes.
- The programme overall strives to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.

Therefore, the LeDeR programme is so important. It represents a real opportunity to improve the lives of people with learning disabilities and autistic people. Implementation in Leicester, Leicestershire and Rutland has been difficult, but much progress has been made; we are now able to make evidence-based SMART recommendations as to how the quality of health and social care services for people with learning disabilities can be improved.

There are two sets of people that deserve special recognition.

- Our LeDeR reviewers. Without their expertise, experience and passion we would not be where we are.
- The families, friends, carers and health and social care professionals who have provided critical contributions to each LeDeR review. Their support has been invaluable.

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 initial 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.

Caroline Trevithick, Chief Nurse & Executive Director, West Leicestershire CCG.

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

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

Good practice checklist

We can make a real difference to people in the following ways;

Listen to people with learning disabilities and autistic people and their families and carers	✓
Ensure everyone is fully up to date with training	✓
Everyone having a clear understanding of the difference between learning disability and learning difficulties	✓
Carry out Mental Capacity Assessments in every relevant case	✓
Ensure patient records are fully accurate and changes are recorded correctly	✓
Communicate more effectively, in particular • with people with LD and autistic people • across providers about Care Plans • discharge planning • advocacy • decision making • end of life • DNACPR	✓
Make no assumptions, particularly about LD or autism being related to cause of death	✓
Check procedures to ensure nothing is missed in any process	✓
Ensure annual health checks are provided for every eligible person	✓
Support people to attend appointments, especially for annual health checks and screening programmes	✓
Ensure the correct versions of documents are used and completed accurately, including death certificates	✓

Acknowledgements

Leicester, Leicestershire and Rutland Clinical Commissioning Groups would like to acknowledge the support provided to the LeDeR programme by the following organisations, groups and individuals:

NHS England and Improvement National Team (NHSE/I)

NHS England and Improvement Regional Team

All our Reviewers and Clinical Leads

All family members' contributions

Leicestershire Partnership Trust

North-East Commissioning Support (NECS)

University Hospitals of Leicester

Primary Care

Insight Training and Consultancy

Leicester City Council

Leicestershire County Council

Rutland County Council

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

LPT Talk and Listen Group

LLR LeDeR Expert by Experience

Introduction

This is the third Annual Report for Leicester, Leicestershire and Rutland (LLR) Learning from Deaths Review Programme and describes progress from the previous year's report.

The aims of the LeDeR programme are:

- **To support improvements in the quality of health and social care service delivery for people with learning disabilities and people with autism**
- **To help reduce premature mortality and health inequalities for people with learning disabilities and people with autism**

The programme is funded by NHS England at a national level with responsibility devolved to Clinical Commissioning Groups. However, the programme is delivered through local partnerships across health and social care organisations in LLR.

The LeDeR process is summarised below

Anyone with a diagnosed learning disability who has died over the age of 4 years old since 1 October 2017 can and should be referred to the programme. The more people who are referred the stronger an evidence base for change can be developed.

Since 1 January 2022, people diagnosed with autism and no diagnosis of a learning disability have been included in the notification of deaths to enable a review to be carried out.

Each LeDeR referral is allocated to a LeDeR reviewer. In LLR these are trained health and social care professionals experienced in working with people with learning disabilities and autism. Allocation of reviews ensures that a review is not allocated to someone that has previously cared for the person who has died.

The purpose of the 'Initial Review' is to identify key learnings and recommendations to improve local health and social care services. To do this the LeDeR reviewer will consider relevant case records and speak to family, friends and carers to form a 'pen portrait' of the individual and a coherent narrative of their care in the lead up to their death.

Where there were significant concerns about the person's health and social care service delivery further information can be gathered to undertake a 'focused review'. A family can request a focus review if they have concerns about the care delivery.

Focused reviews have also been undertaken if the death has been caused by a priority area. Respiratory related deaths have been an area of focus in LLR during 2021/22.

Before each review is approved and submitted, it undergoes a quality assurance process. LLR has set high standards that every review must meet.

Areas to explore are identified in every review. Initial reviews are locally analysed by clinical leads. Focused reviews are taken to governance panel for multi professionals to identify actions and recommendations required. In both circumstances thematic review is undertaken.

LLR have trialled governance panel ahead of the policy requirement and have been using this process during quarters 3 and 4.

Deaths for children with a learning disability are reviewed as part of the Child Death Overview Panel (CDOP) process. In LLR this is achieved through 'themed' panels where the exclusive focus is on learning disability or autism related deaths. The learnings and recommendations are then fed into LLR LeDeR Programme and implementation of 'Learning into Action'.

Statement of Purpose

The LLR Learning Disability and Autism Partnership is committed to the ongoing delivery of the LeDeR Programme. This means that:

- LeDeR reviews are allocated and completed to a high standard within the stipulated programme timescales.
- Identified learnings and recommendations become 'Learning into Action'.
- 'Learning into Action' improves the quality of health and social care services and reduces the health inequality faced by people with learning disabilities and autistic people.
- All stakeholders, including people with learning disabilities and their family, friends and carers, feel an equal partner in the LeDeR programme.

These ambitions sit within the broader LLR system-wide Person-Centred Leadership Framework.

"How lucky we are to have someone that made saying goodbye so hard.

Thursday was bright and beautiful, just like you"

Local Progress and Performance

The LeDeR Programme was initially led by the University of Bristol including policy, direction of reviews, the operation of the web based platform and data analysis. However, the contract ended in May 2021. This resulted in the closure to the web platform and notifications for reviews were held centrally by NHS England during this time. As per the LeDeR Policy (2021) there was an acknowledgement that the main focus so far has been on the completion of reviews. We must now improve our reporting and recording of issues and concerns and act upon those findings. Therefore the LLR LeDeR team have spent the past year synthesizing the evidence from reviews already conducted, creating a sophisticated model of analysis. Whilst also committing to meeting the timescales and quality of reviews on an ongoing basis.

Thematic analysis has been a priority for LLR LeDeR team during the past year. 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 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 team have committed to a Quality Improvement model, supported by LPT's WeImproveQ. LLR LeDeR is working with research colleagues and following a nationally recognised Plan, Do, Study, Act (PDSA) cycle of quality, service improvement and redesign. LLR LeDeR strives to ensure the programme is well-governed, produces high standards and ensures patient involvement and engagement. The PDSA cycle highlighted some areas to focus the programme which are outlined below.

Following its launch in June 2021, the web based LeDeR platform remains in beta format. NHS England has been clear in the expectation for local areas to use it, however this means there are limitations to the programme's ability to produce sophisticated reporting.

To overcome these barriers early on LLR LeDeR Team proactively engaged in all offered LeDeR web platform feedback sessions and actively participated in user groups.

LLR LeDeR team took the opportunity to develop local reporting systems, therefore ensuring LLR can give assurance and reporting of the LeDeR programme. For 2022/23 these locally developed methodologies will be shared with the LeDeR User Research Group and the LeDeR system design team.

It is worth noting that the new reporting platform can only receive the reviews and does not include a facility to generate reports from the reviews. Any datasets and subsequent reports have been created from a central dashboard created and maintained by the LLR LeDeR

team[1]. Therefore, data presented in this report may not be comparable with that presented by other LeDeR programmes.

There was an additional problem between 21st December and 8th February when the LLR LeDeR programme received no notifications of death thereby causing a cumulation of unallocated reviews; no allowance regarding the completion deadline has been made for this. Consequently, 15 cases were outsourced from the CCG to achieve the six month completion date.

The ongoing pandemic outbreak of COVID-19 has continued to have a significant impact on reviewers, especially those working within the University Hospitals of Leicester NHS Trust, Leicestershire Partnership Trust and local authorities due to the redeployment of the clinical lead and some reviewers' activity to focus on clinical roles.

An addition to the LeDeR programme has been the inclusion of reviews of the death of people aged 18 years and over with a confirmed diagnosis of autism with no LD. This was delayed by the national programme and the academic partner from September 2021 to January 2022. This was further hampered because, unlike people with a learning disability, there exists no formal register of people with a diagnosis of autism. During 2021-22, one such death was referred to LLR LeDeR, the review is ongoing at the time of writing.

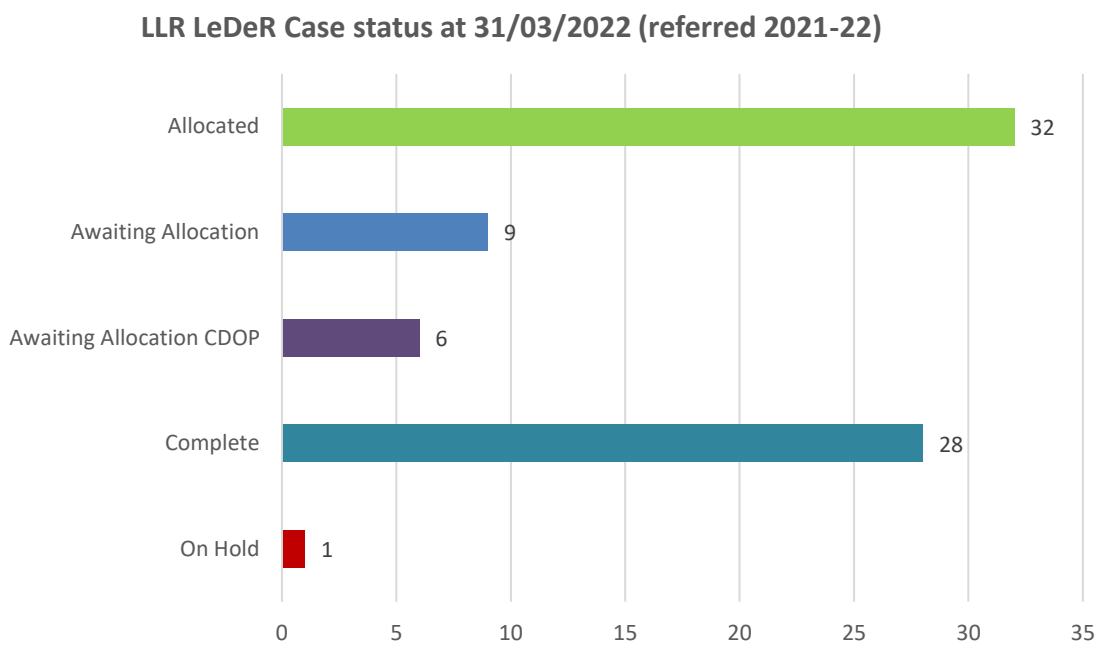
The number of cases on hold has been greatly reduced during the last twelve months, with only one case remaining on hold at end of year. This is largely due to the Team's active participation in and sharing of reports from Safeguarding and CDOP Panels. Additionally, no further CDOP cases were placed on hold, in compliance with new guidance.

All deaths of children are reviewed by the Child Death Oversight Panel (CDOP) that operates to its own timeframes. The LLR LeDeR clinical team have forged links with the CDOP team to ensure that all required reports are included in the LeDeR programme.

The chart in Figure 1 shows the status on 31 March 2022 of all cases referred to LLR LeDeR in 2021/22.

[1] It should be noted that all cases received during LeDeR system shutdown (1 March 2021 to 1 June 2021) were outsourced by NHSE/I to NECS for completion. Data on these cases was therefore not recorded in the same amount of detail as cases managed locally, as the new LeDeR system does not yet allow download of any data.

Figure 1



N.B. In 2021-22, LLR received 77 referrals and completed 65 reviews. Unless specified, all charts in this report refer to reviews *completed* within the 2021-22 year.

Quality

The LLR LeDeR team's PDSA has enabled quality improvements to the programme. These are detailed in Table 1 below.

Table 1

Area to explore	What could we do better	Where are we now	Cycle 2 of PDSA
As soon as a safeguarding concern is raised from a LeDeR Review it is being placed on hold.	Work in conjunction with local authority safeguarding teams and the safeguarding adults board (SAB) to share relevant information to allow reviews to be conducted simultaneously instead of waiting for outcomes of safeguarding reviews. This will also reduce reviews being placed on hold and support more timely outcomes.	Working relationships are much stronger with local authority safeguarding and the SAB. A lead practitioner for safeguarding has taken up a local area contact role for LLR LeDeR. The SAB invite LeDeR to all Safeguarding adult reviews associated with LeDeR.	
Families and loved ones being contacted repeated times from different services who are undertaking a review on the death of their loved one.	Work together with all partner agencies to ensure family are contacted once and informed of all the reviews that are being undertaken by one identified main contact on behalf of all reviews.	LeDeR works closely with the SAB and a single point of contact is identified for family liaison. As the SAB already have family liaison well established, this person now centralises all questions from SAB and LeDeR in one conversation and gives detail should family wish to contact LeDeR separately.	

Area to explore	What could we do better	Where are we now	Cycle 2 of PDSA
NHS England are only allowing 6 x reviewers to be able to conduct reviews at any one time. LLR LeDeR Programme uses bank staff.	Work towards employed reviewers and in the interim contract out reviews to individuals who have capacity to undertake multiple reviews at a time.	Recruitment completed in May 2022.	
Inconsistent and time-consuming retrieval of records made by individual reviewers.	Centralise record retrieval and work with other agencies to ensure where information has already been retrieved so it can be shared with the LeDeR Team, for example coroner's report.	LLR LeDeR has set up a flowchart of record retrieval which is led by LeDeR Senior Administrator. This includes all partner agencies, with regular review and checks to ensure this process remains efficient. This has also increased productivity of reviewers due to less time spent retrieving records and improved the integrity of the programme by professional, consistent record request working in collaboration with partners.	
Supporting multiple reviewers through a change process and new web platform.	Regular peer support and formalised clear process of working through a LeDeR Review.	LeDeR Clinical leads and senior administrator hold a weekly LeDeR Reviewer peer support drop-in session. A Reviewer toolkit has been developed, this has been shared with NHS England and disseminated to other regions for them to adapt and use. (See appendix)	
LeDeR Policy (2021) requires Governance Panels to be established. Plan by 30th Sept 2021 and operational by 1st April 2022.	Implement multiagency professionals to form LLR LeDeR Governance Panel, with the function of developing SMART actions for LeDeR Steering Group.	Governance panels were trialled between Sept 2021 and March 2022. The LLR LeDeR Team have a fully operational multiagency governance panel as of 1st April 2022.	
No engagement of experts by experience.	Involvement of people with a learning disability, people with autism and family and carers.	LLR LeDeR has been successful in recruiting on a voluntary basis an expert by experience to represent people with a learning disability in March 2022. A family carer has been identified and keen to work with the team, formalities to recruit on a voluntary basis into the team are being undertaken.	Recruit further experts by experience and ensure autism is included and representation of ethnic minority is included.

Area to explore	What could we do better	Where are we now	Cycle 2 of PDSA
Is LLR LeDeR programme clearly representative of its population, including the population of people from ethnic minority background.	Understand if our local population is clearly represented by the LLR LeDeR programme to demonstrate if any further work is needed in this area, based on locally understanding Leicester City, County and Rutland's diverse populations.	Collaborative work with De Montfort University has been agreed. The demographic population reporting has been requested through Leicestershire Health Informatics Service.	Population reporting to be undertaken as a clinical audit. De Montfort University research colleagues to analyse the data and feedback to LeDeR Clinical leads for synthesis.
Thematic Analysis: • **Respiratory Deaths**	Set up and define thematic analysis process for LLR LeDeR and conduct on respiratory deaths based on past reviews undertaken where the individual died from a respiratory death.	Respiratory Death Thematic Analysis conducted on deaths from LLR LeDeR pre-2021, presented to governance panel and SMART actions created.	Clearer and more structured reporting functions would support easier thematic analysis for future. In the absence of the LeDeR web platform holding a reporting function this will need to be developed locally.

The LLR LeDeR team has an agreement with local authorities that cases reported as safeguarding can share any relevant information and reviews conducted simultaneously instead of waiting for the outcome of the safeguarding review. This should enable a reduction of cases 'on hold'. Other cases currently 'on hold' are either undergoing a police investigation or are waiting for the outcome of a coroner's report.

The LLR LeDeR programme has worked closely with the regional and national teams to embrace the changes whilst continuing to undertake the reviews. During this time, the LLR LeDeR team has laid the foundations for identifying and implementing learning.

The achievements made by the LLR LeDeR programme include the profile of the LeDeR programme being raised using effective communication tools resulting in more consistent notification of deaths and strengthening across all partners, including Primary Care, to obtain and upload patient records for reviewers to access.

All reviews allocated to reviewers (79.53%) were completed within the timeframe. There remained 23 reviews that could not be completed because they had been referred into statutory processes e.g., coroner's inquest, CDOP, police or safeguarding investigations and waiting for the outcomes from those. These, along with reviews referred to LeDeR between 1 March and 1 June 2021 (LeDeR online system shutdown), comprised the remaining 20.47%.

"She enjoyed having some pamper sessions and would often relax when her hair was being washed or her nails were being painted. She always took pride in her appearance."

Governance Arrangements

Clinical Lead

The LeDeR programme leadership team in LLR consists of 1.8 WTE senior Clinical Leads who support the reviewers, undertake quality assurance of reviews and carry out thematic analysis of completed reviews. The Clinical Lead roles incorporate the Senior Reviewer role as specified in the 2021 LeDeR Policy. They lead a governance panel of representatives from a full range of providers to identify the SMART actions.

Local Area Contact

The Local Area Contact role (LAC) is shared between four people, who provide expertise from both the health and social care sectors. They approve and submit the reviews and are a direct link to the Regional NHSE/I LeDeR team.

Administration

The LeDeR Team is supported by the LeDeR Senior Assistant, who manages all meetings and performs administrative duties, including recording case information, progress and data input and analysis the LLR LeDeR 'Masterbook', a secure file with controlled access. Several requests for data from the programme are requested regularly, facilitated by the Senior Assistant and LACs, with regular verbal updates at various meetings.

Steering Group

The Steering group meets on a monthly basis. A LAC has stood in as Chair of the group, which has oversight of the activity taking place within the programme, since April 2021. This was due to the original Chair, CCG Head of Mental Health and Learning Disability, going on secondment and not being replaced for the duration of that secondment. This should be rectified in 2022/23 with a new appointment.

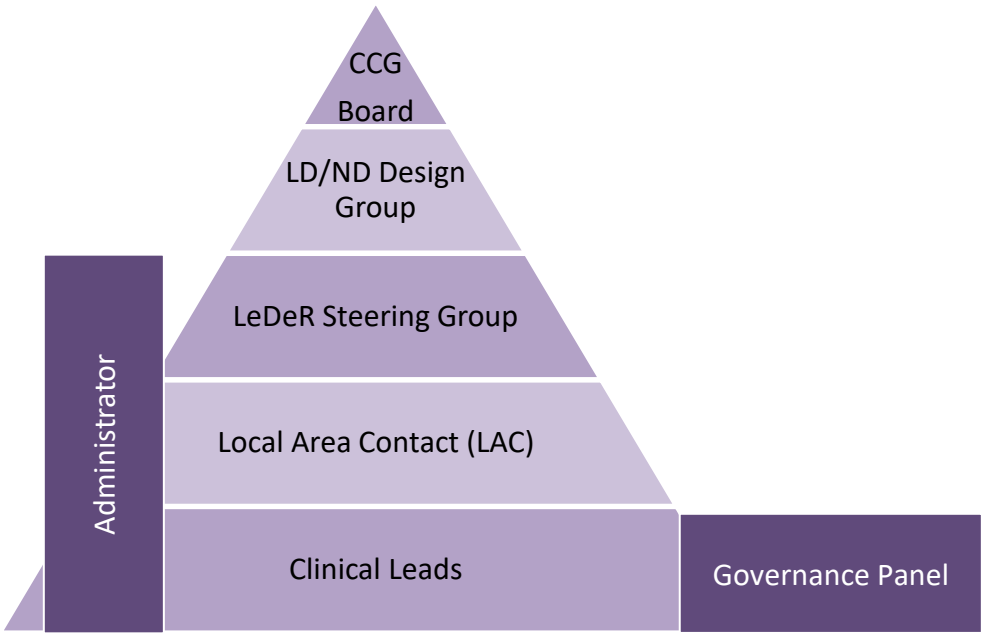
Membership of this group consists of senior managers from partner organisations including local authorities and both acute Trusts. The Steering Group has had representation from Primary Care/ethnic minority community.

Information from the Steering Group is shared monthly with the Learning Disability and Neurodevelopmental Design Group to either escalate concerns or promote achievements, which informs the CCG Board. Additionally periodic updates are provided for LLR Safeguarding Boards, CDOP and other stakeholders.

To ensure the LLR LeDeR programme has met its responsibilities under the Equalities Act, the Steering Group has endeavoured to engage with people with Learning Disability, their families and carers as well as voluntary groups, community and faith organisations to ensure views from a range of ages, demographic groups and cultures are captured. The Leicester City Council LD Partnership Board has a representative on the LeDeR Steering Group, who has lived experience and another person with lived experience began with the LeDeR leadership team on a regular basis as LeDeR EBE.

Governance arrangements are illustrated in Figure 2.

Figure 2



Equality Impact & Demographic Data

Age

Analysis of data from the local LeDeR system shows the mean age of death for people, both male and female with LD in LLR who died in 2019-20 was 58 years.

For adults only (18+) in that year the median age (used in NHSE National LeDeR Report) was 59. In 2020-21 this remained unchanged.

Median age of death for adults has increased by five years to 64

For cases completed in 2021-22, the median age at death of adults was 64, a significant improvement. This includes case that were referred before April 2021 and comprises 27% of deaths due to COVID-19. Many cases referred during 2021-22 are still ongoing and therefore the mean age for those people could not be confirmed at the time of writing.

Disability

The national data reports that of people with a disability 9.3% reported that their day-to-day activities were limited a little, and a further 8.3% reported that their day-to-day activities were limited significantly. LLR data showed that the activities of 9.1% of people with a disability were only a little limited whilst a further 7.1% of people with a disability were restricted a lot.

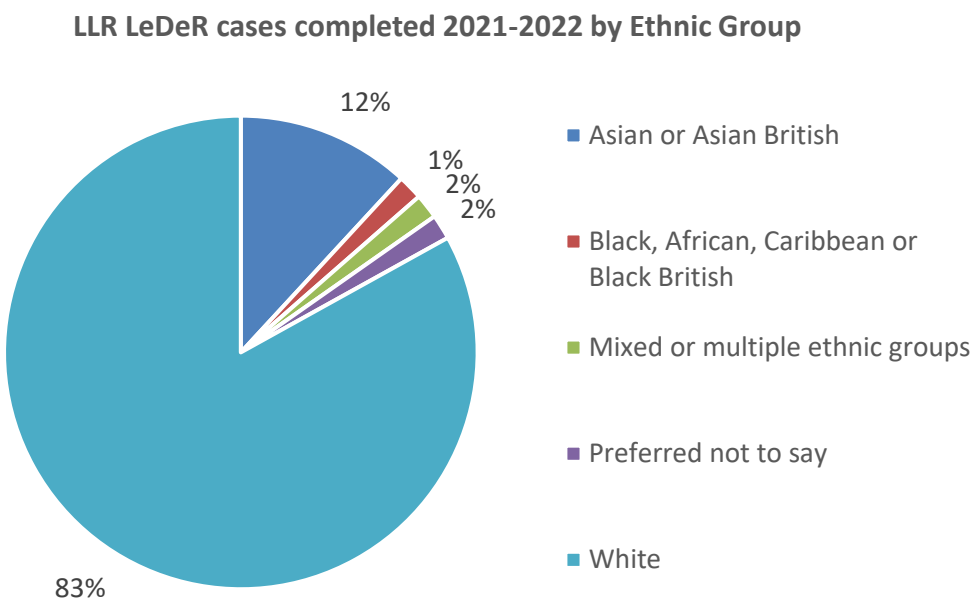
First Language

Compared to the England benchmark, Leicester, Leicestershire, and Rutland had a lower proportion of people who spoke English as their first language. In Leicester, Leicestershire, and Rutland the most widely spoken first language was English (88.7%), followed by Gujarati (4.3%), Punjabi (1.0%), Polish (1.0%), and Urdu (0.4%). These languages covered over 95% of the population of Leicester, Leicestershire, and Rutland.

Ethnicity

Compared to the England benchmark, LLR has a higher proportion of people from an Asian or other ethnic group background. However, this is more focused within the boundaries of Leicester city as Leicestershire and Rutland counties had a lower proportion of people from an Asian or other ethnic group than Leicester city or the England benchmark. Figure 3 shows 83% of cases were 'White' and 12% 'Asian or Asian British'. 'Mixed or multiple ethnic groups' comprised 2% and 'Black, African, Caribbean or Black British' at 1%. 2% had no ethnicity recorded.

Figure 3

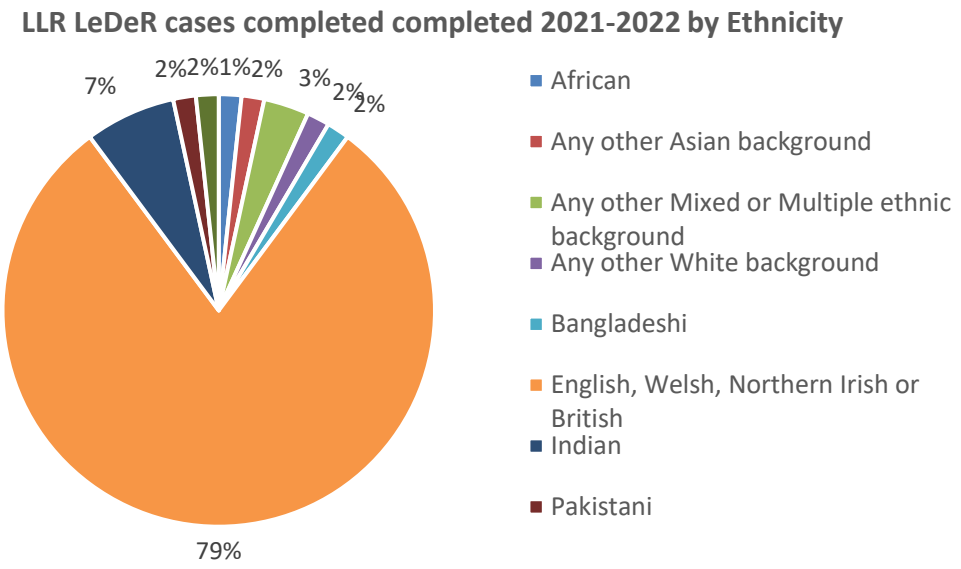


Looking at those wider groups broken down into individual ethnicities, Figure 4 shows that of all deaths referred to LLR in 2021-22, the majority, 79% were 'British' (White) 7% were 'Indian', 3% were 'Any other Mixed or Multiple Ethnic background''.

"Staff still regularly talk about him very fondly and he is greatly missed.

They were glad to be able to support him during the end of his life at home."

Figure 4



Ethnic Minorities

Looking at ethnic minorities only, with the 'English, Welsh, Northern Irish or British' group removed, it is easier to see distribution of deaths within those communities. These correlate with the overall composition of the LLR population.

Cases by Ethnicity

Figure 5

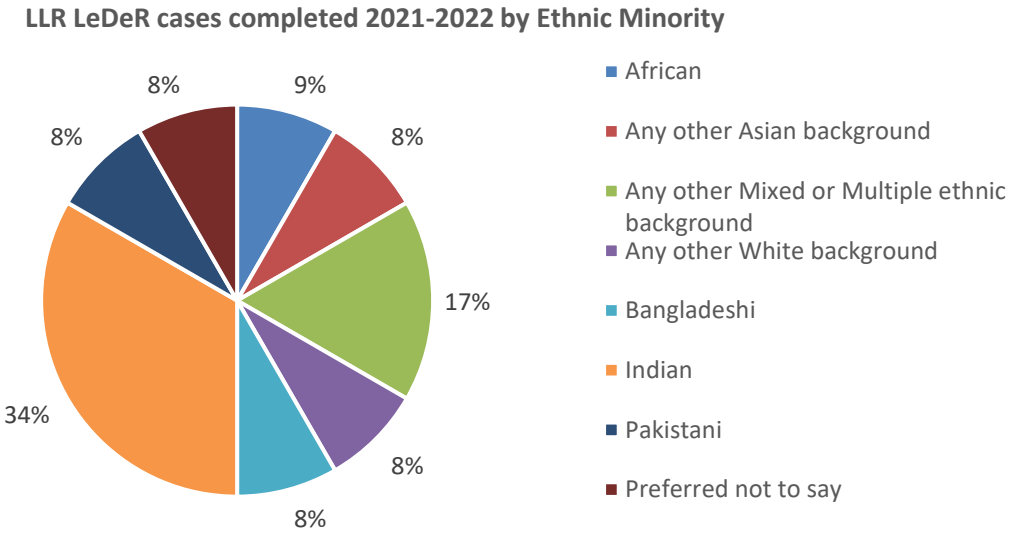


Figure 5 shows that the largest ethnic minority groups were 'Indian' at 34% and 'Any other Mixed or Multiple Ethnic background' at 17%. The remainder were fairly evenly distributed; 9% 'African', 8% 'Any other Asian background', 8% 'Any other White background', 8% 'Bangladeshi and 8% 'Pakistani'. 8% had no ethnicity stated.

Leicester, Leicestershire and Rutland has a very diverse population of mixed ethnic groups, especially within the boundaries of Leicester city. However, it has been a concern that the notifications of deaths amongst the LD/A population does not reflect this. As highlighted in the PDSA plan a clinical audit between LLR LeDeR and De Montfort University colleagues is being undertaken to determine reasons for this.

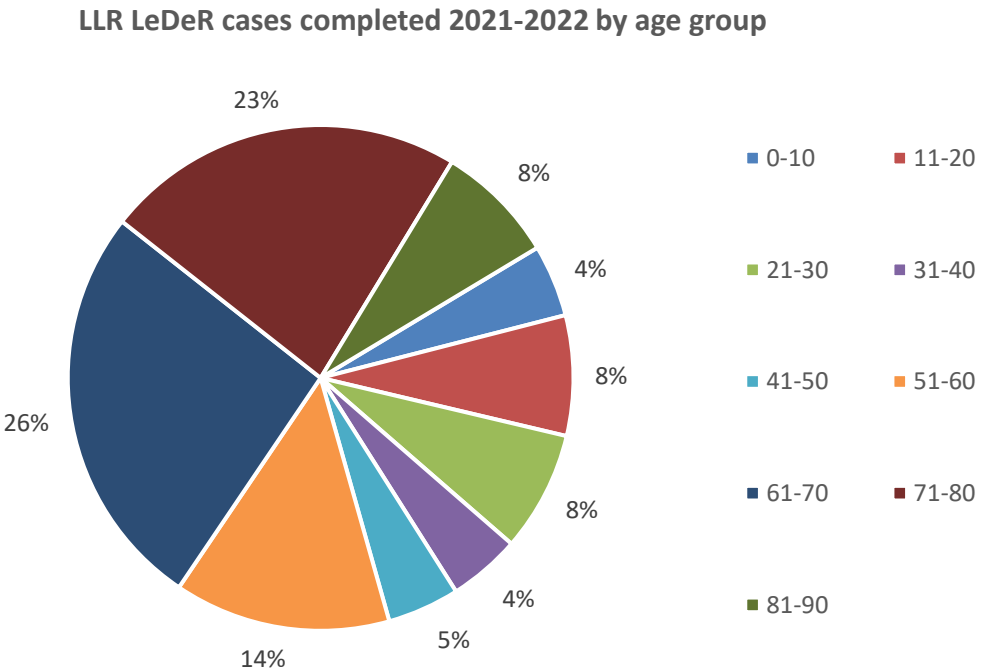
Cases by age group

Cases completed in 2021-22 are broken down into age groups in Figure 6. A total of 57% of cases were aged 61 or older (26% 61-70, 23% 71-80 and 8% aged 81 or older). 14% were aged 51-60. 41-50 and 31-40 age groups comprised 5% and 4% respectively, while 11-20 year olds were 8% and under 0-10 4%.

It is worth noting that 12% of all reviews completed within 2021-22 were of CDOP cases (Child Death Overview Panel). Some of these had been on hold for a significant amount of time and as a result, the average age at death for the year was artificially lowered (56).

Looking at adults only (18 and older), the mean age at death was 62. LeDeR nationally however has traditionally reported the median age. In 2020-21 in LLR, the median age was 59. In 2021-22, it has risen to 64.

Figure 6



Cause of Death

Of all case reviews completed in 2021-22, the two most prevalent causes of death were COVID-19 and Respiratory illness (each at 27%). Taken together, these represent 54% of all LLR LD deaths reviewed within the year.

54% of deaths were from COVID-19 or Respiratory causes

Respiratory deaths

A thematic analysis of Respiratory Deaths was conducted on earlier deaths to the programme (Deaths notified to LeDeR on or before 31st March 2021).

The top two areas of focus around the quality of the lives and deaths of those dying from Respiratory related deaths were:

1. Advanced care planning is not happening early enough; or in a multiagency manner and plans of how to support avoidance of hospital admissions for those with known readmissions are not being instigated.
2. The Mental Capacity Act (MCA) is not being applied and the decision making framework is not being operated. This is in relation to both preventative healthcare and ongoing treatment decisions related to respiratory illness [such as a requirement for a Percutaneous Endoscopic Gastrostomy (PEG)]. Consensus in the reviews found that there appears to be a general lack of instigation and enquiry regarding the MCA in the health and social care of the person during their life and death.

Positive experiences highlighted compassionate, person centred care and collaborative working to be of a particularly high standard within both health and social care. The support from the Learning Disability Acute Liaison Nurses during hospital admissions demonstrated noticeable improvements in the care and treatment people received. Timely support from GP practices and individuals were supported to die at home, supporting their wishes, signifying dignity and respect at the end of life.

This analysis has prompted a deep dive into those deaths from Aspiration Pneumonia, early findings indicate:

- Aspiration Pneumonia appears to be being used as an overarching cause of death for people with a learning disability, even though reviews do not demonstrate this to be the case.
- Aspiration Pneumonia diagnosis during treatment appears to also be used as an overarching diagnosis for repeated chest infections.
- Identification of the deteriorating patient requires improvements, where aspiration pneumonia is present.

- An aspiration pneumonia workstream to be convened.

Two actions have been developed

Aim:

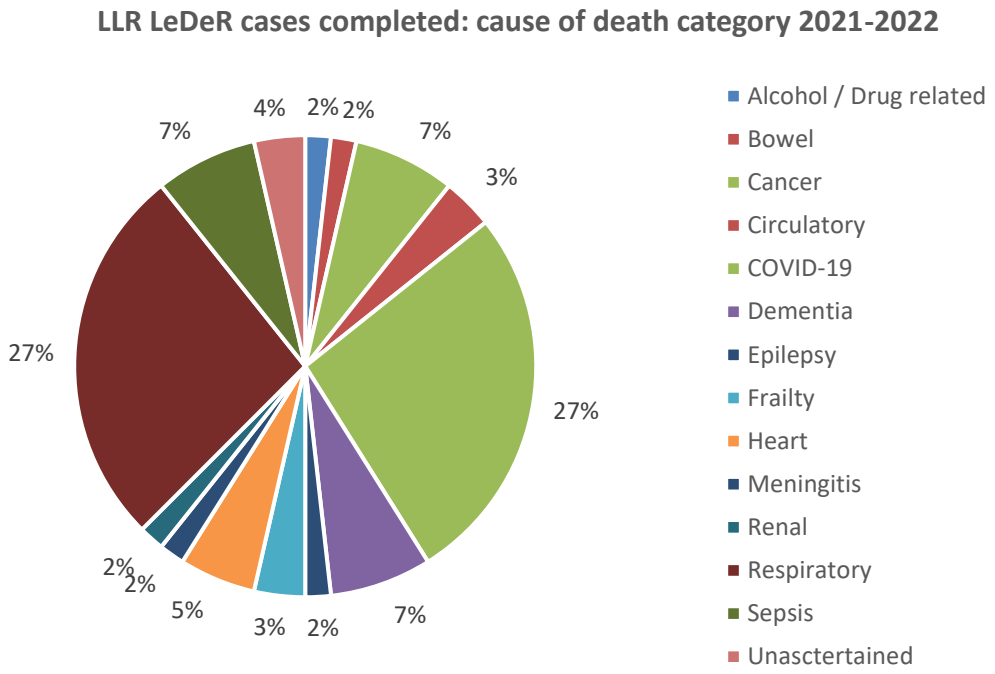
1) To improve the holistic care of people with a learning disability when diagnosed with aspiration pneumonia.

2) To ensure National policy and recommendations are followed locally in LLR in the care and management of Aspiration Pneumonia diagnosis in people with a learning disability.

Other deaths

Other Causes of death from completed cases were 'Cancer' 'Dementia' and 'Sepsis' (each at 8%), followed by 'Heart' conditions 'Alcohol/drug related', 'Circulatory', 'Frailty' and 'Meningitis'. 2 Causes of death were unascertained (see Figure 7).

Figure 7



The percentage of deaths related to respiratory causes has reduced from 46% in 2020/21 to 27% in 2021/22, which is closer to national averages. However, this in part due to COVID-19 related deaths not being separated from other respiratory deaths in 2020/21. The combination of respiratory and COVID-19 related deaths in 2021/22 is 54%.

Thematic analysis was undertaken of all reviews completed before 1 April 2021. Only respiratory deaths were analysed, this included but was not limited to:

- Aspiration Pneumonia
- Respiratory Failure
- Pneumonia
- Bronchiectasis
- Community Acquired Pneumonia
- Lower Respiratory Tract Infection

Areas of positive practice found:

- Many people died at home, which was their wish
- Compassion and honesty (UHL)
- Successful personal health budgets (LA)
- Health and social care services working in a person-centred way and listening to families
- Best interest decisions conducted well
- Collaborative working (GP UHL and LPT)
- GP's visiting in a proactive and timely manner on several occasions.
- Support from the LD Acute Liaison Nursing team was evidently consistently beneficial for high quality care

Top two themes to explore further:

- Advanced Care Planning
- Mental Capacity Act

"They had been best friends for around 18 years and social services recognised this, moving them to different care agencies together when needed allowing their friendships to continue."

Specific actions (objectives) resulting from this analysis are shown in Table 2.

Table 2

Aim	Objective

Respiratory Deaths Thematic Analysis 1) End of Life Care Aim: To improve the end of life care of people with a learning disability (LD) in line with national policy and recommendation	• Launch and embed Accessible Advance Care Plan
	• Establish a working group to
	  ○ identify systemic barriers for people with a LD in end of life care
	  ○ create an action plan for presentation at LeDeR Steering Group
	Achievement will be demonstrated when the Reduction in the number of Recommendation on improving EoL are noted from LeDeR Deaths.

Respiratory Deaths Thematic Analysis 2) Mental Capacity Act (MCA) Aim: To improve the use of the MCA including knowing when to instigate, in health and social care professionals when working with people with a LD.	All members of LeDeR Steering Group to • escalate to their organisational MCA lead (or individual responsible for MCA such as safeguarding lead or principle social worker) the lack of undertaking of the MCA in the health and social care treatment of people with a LD in LLR • bring to the LeDeR Steering Group an action plan as to how to address this to enable a wider cross organisational action plan to be produced and shared plans There is a specific gap to be highlighted which is professionals knowing about MCA but not instigating it in practice.
1) To improve the holistic care of people with a learning disability when diagnosed with aspiration pneumonia. 2) To ensure National policy and recommendations are followed locally in LLR in the care and management of Aspiration Pneumonia diagnosis in people with a learning disability.	• Clear understanding from the literature on the evidence base of reflux and aspiration pneumonia diagnosis. • SALT to undertake a Literature review on the evidence base of reflux specific to people with a learning disability on 18th Feb 2022. • To ensure the responsibility to manage aspiration pneumonia is a multi-disciplinary responsibility • Define who's role is it to manage secretions (excess or poor control) and reflux • Patients being referred to UHL in a timely manner • LD Physio to undertake a literature review to establish requirement for specialist LD Chest physio in adults with LD. If not required, specify where adults with a learning disability can access chest physio after childhood. • Plans of care to evidence consideration of aspiration pneumonia when the patient has this diagnosis (all professionals) and where ceiling of care has been reached. • Consideration of differential diagnosis to be recorded. Potential aspiration pneumonia management flow chart.

This thematic analysis requires further scrutiny and LLR LeDeR intends to understand the death from aspiration pneumonia in further detail to understand why this cause of death remains so high.

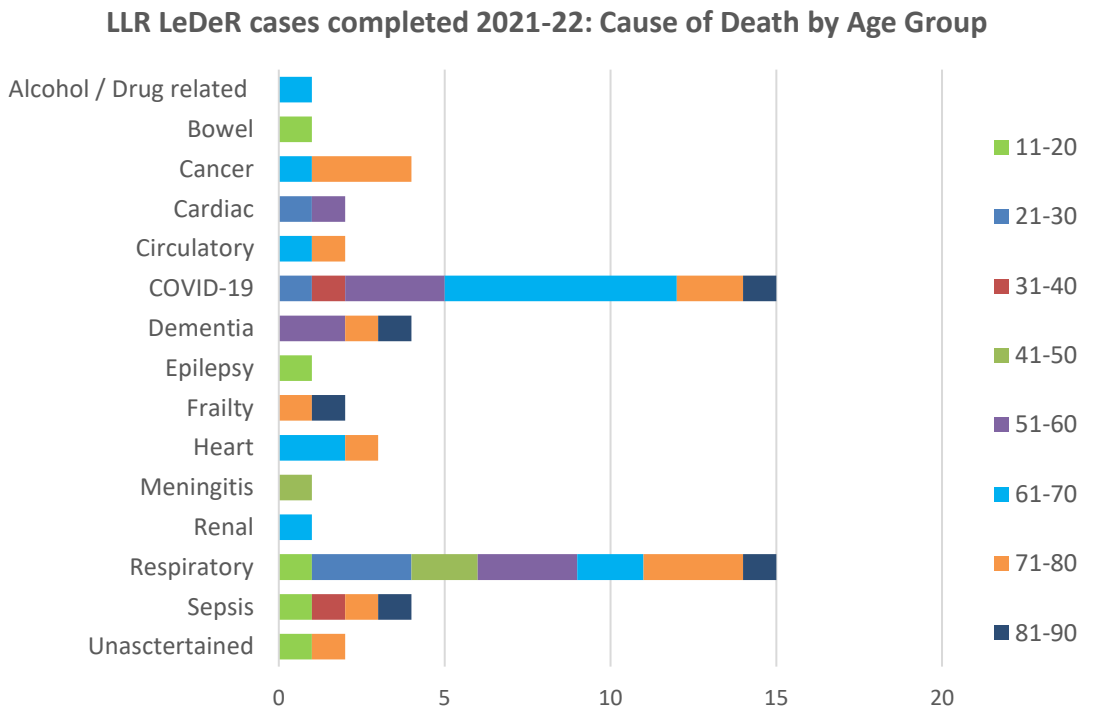
The respiratory deaths thematic analysis has prompted a deep dive into those who have died from aspiration pneumonia, this will be commenced in the coming year as part 2 of respiratory deaths thematic analysis is formulated. Early findings into those who have died from aspiration pneumonia is indicating there may be a potential for people with a learning disability to be experiencing diagnostic overshadowing at the end of their life, with aspiration pneumonia being used as a universal diagnosis at death in some instances.

This has implications for the recommendations that LeDeR can make therefore, it is imperative to further evaluate those deaths. LeDeR will be leading a multi-agency work stream focusing on aspiration pneumonia and people with a learning disability. The workstream will be evaluating the evidence base, research and NICE Guidelines around the diagnosis and care of people with dysphagia and aspiration pneumonia and deliberate local practice for improved care and outcomes for people with a learning disability in LLR.

Cause of death by age group

Cause of death is broken down by age group in Figure 8. It is clear that the main causes of death, COVID-19 and Respiratory, were most prevalent in the 61-70 and 51-60 age groups respectively. COVID-19 was in fact the most common cause of death in the 61-70 age group. Respiratory illness was more prevalent in the younger age groups than COVID-19.

Figure 8

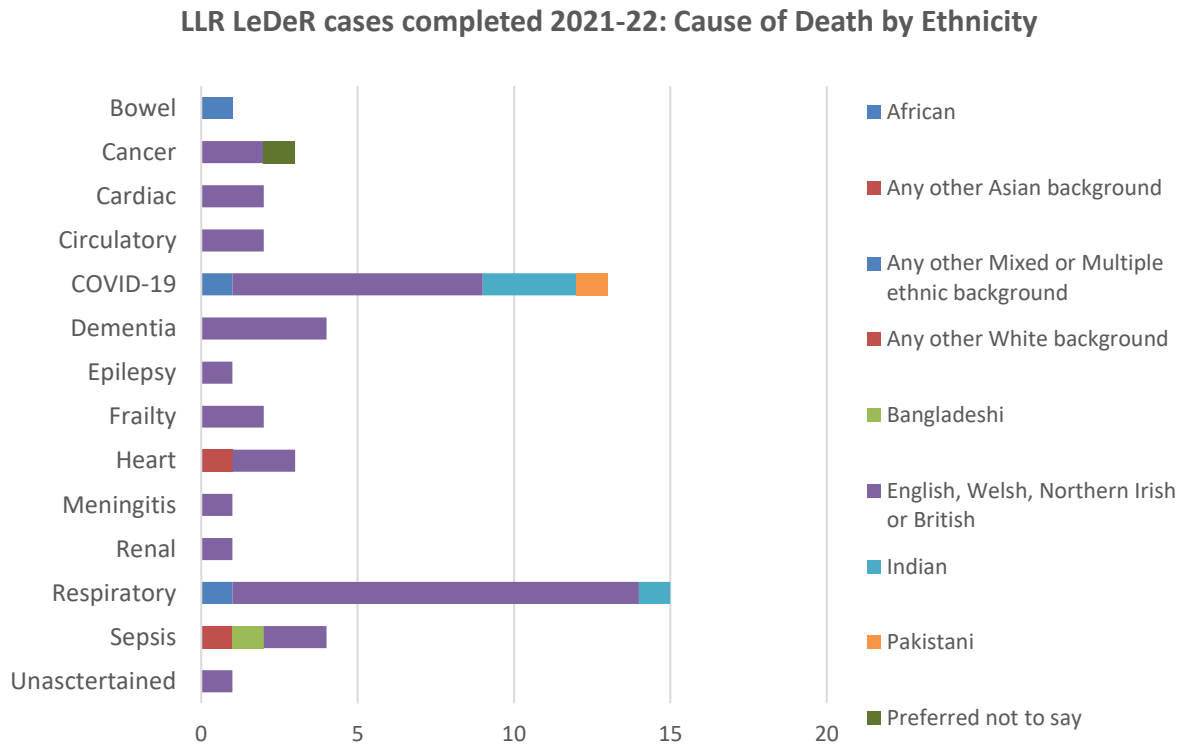


"She loved animals and thoroughly enjoyed when the care home would have the animal interactions, cats were her favourite!"

Cause of Death by Ethnicity

Looking at Figure 9, cause of death prevalence is proportionately spread across the ethnicities, though the proportion of 'Indian' deaths due to COVID-19 appears more significant than other ethnicities.

Figure 9



COVID-19

The continued absence of any reporting or analysis facility in the LeDeR online system meant that all data management and analysis was carried out externally to that system, and this was true for COVID-19 cases.

Thematic Analysis on Covid-19 deaths is a priority for LLR LeDeR. At time of writing this was in the process of being conducted with results and analysis available later in 2022.

As shown earlier in Figure 7, just over a quarter of all deaths (27%) were from COVID-19.

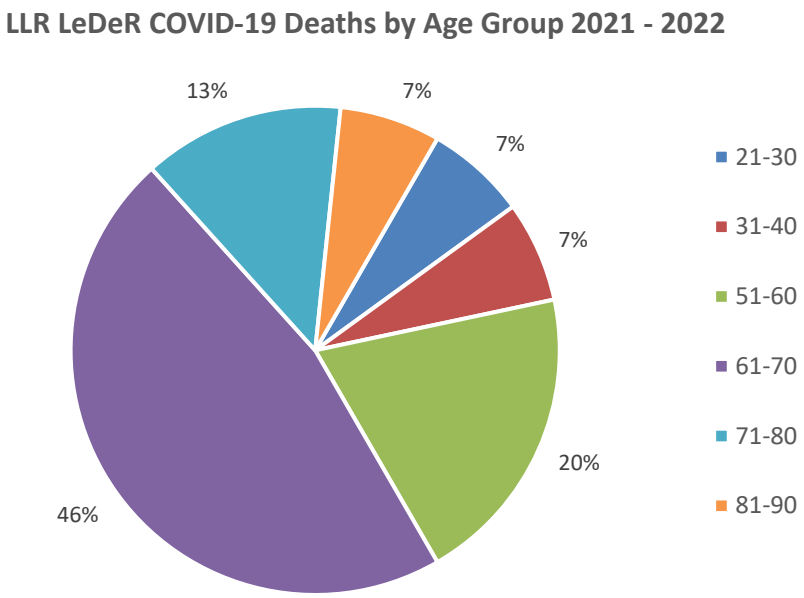
COVID-19 deaths by age group

In the UK, the average (mean) age of death due to COVID-19 in 2021/22 was 76 [ONS, 27 April 2022, www.ons.gov.uk]. In LLR LeDeR cases, the mean age of COVID-19 deaths was 62; 14 years younger than national average. However, it is interesting to note that other causes of death occurred at a younger age, a mean age of 54. Some of this is due to several CDOP

cases being completed that were outstanding and on hold from the previous year and which have biased the mean age overall downwards to 56 years.

It is clear to see from Figure 10 that almost half of all deaths from COVID-19 (46%) were of people aged 61-70. 20% were aged 71-80 13% were 51-60. The youngest COVID-19 death was in the 21-30 age group.

Figure 10



COVID-19 and ethnicity

Of the 15 cases in which COVID-19 was named the primary cause of death, ethnicity recorded in 13 of those. Figure 11 shows a contrast to deaths overall, as originally shown in Figure 3; 83% of all deaths were 'White English, Welsh, Northern Irish or British', but only 69% of COVID-19 deaths were of this ethnicity. Only 12% of all deaths were 'Asian or Asian British', but this group comprised 31%. Overall, only 15 deaths were due to COVID-19 so it is not necessarily significant statistically but is still of concern and will be examined in thematic analysis. Comparison data table is shown in Table 3.

Figure 11

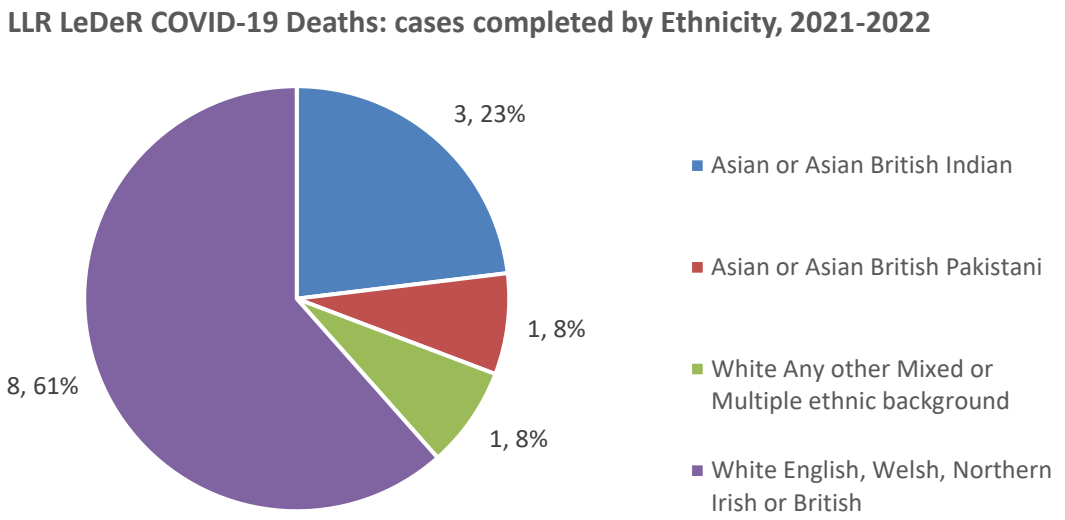


Table 3

Ethnicity	All Deaths	COVID-19 Deaths
Asian or Asian British	12%	31%
Black, African, Caribbean, or Black British	2%	0%
Mixed or Multiple Ethnic Groups	2%	0%
White	83%	69%
No ethnicity recorded	1%	0%

"They enjoyed making homemade cards and used to sell them to raise funds for charity"

Service Improvement achievements

A wide range of improvements have been achieved within the year.

LPT has introduced a range of service improvements supporting the LeDeR programme:

- The Families, Young Person and Children / Learning Disability Directorate (FYPC/LD) has implemented a learning from deaths forum which welcomes clinicians to review the care and treatment provided by LPT and identify lessons to be learnt locally in a timely manner.
- LeDeR clinical leads are engaged with LPT's governance process allowing for robust information sharing and influencing lessons learned.
- LPT LD Community have identified progression of a complex physical health pathway to incorporate deteriorating patients and end of life care.

- LPT LD services have improved access to services and mobilised a new access to service pathway and team which has improved its assessment process, responsiveness and utilised the learning from LeDeR to inform the implementation of this pathway, e.g., introduced physical health observations at core assessment, purchased accessible scales to ensure all patients accessing the community LD Team have baseline weight and ongoing monitoring if required as part of their treatment and care plan.
- The service has also employed a practice development nurse who will be given set projects across LD services to improve clinical skills in relation to physical health, recognising the deteriorating patient and end of life.
- LPT is also engaging in the Learning Disability and Autism (LD/A) Collaborative Meeting ensuring a LLR approach to learning lessons from LeDeR is embedded in the 3 year plan.

UHL has undertaken a variety of improvements to enhance the experience of people admitted to hospital. These include:

- LD Lead Nurse has liaised with the Lead for the hospital post-pandemic recovery programme to identify and prioritise those patients who have had long waits for appointments or procedures due to the pandemic.
- The team has worked with the Surgical Pathway Lead to produce easy read leaflets regarding pre-operative assessment.
- LD Liaison Nurses are attending Mortality & Morbidity meetings across different Clinical Management Groups where a structured judgement review (SJR) for a patient with a learning disability is being discussed to identify any specific learning related to their care. (There are plans for this to be further developed in 2022 with the acute liaison team supporting the completion of the LD specific slides prior to the Mortality and Morbidity meetings and jointly presenting them with the Doctors.)
- Identified LD Champions across UHL with a passion to 'get it right' for patients with learning disabilities and provided them with some online resources and training with a plan to meet in 2022 to further explore the role to enhance patient care

- Designed and produced a Traffic Light Lanyard Pin Badge to be awarded to hospital staff who consistently go the 'extra mile' to support patients with learning disabilities.
- Continued to provide direct support to the wards, departments and all areas of the hospital to identify and implement reasonable adjustments for patients despite current pressures and a reduced team.
- Produced and presented an annual report to the Mortality Review Committee regarding the deaths of patients with a learning disability.

Leicestershire County Council has undertaken Continuous Professional Development learning sessions with all Social Workers and Occupational Therapists, this involved learning from the life and death of someone with a learning disability, who was also part of a safeguarding enquiry. This case study enabled professionals to explore the challenges faced by people with learning disabilities, in relation to health inequalities. Through the session they were able to reflect on their practice and consider how this learning transitions into their professional practice. In addition to this, all newly appointed staff that work within the Learning Disability and Autism Teams are provided with comprehensive learning development training, that explains the importance of the LeDeR programme and how learning from deaths and lives of people with learning disabilities and autism can support professional development and our work with people across Leicestershire.

Rutland County Council has maintained a monthly Continuing Professional Development session delivered to all our Adult Social Care (ASC) teams including therapy and housing. At least one of these sessions is scheduled annually to deliver a learning session on LeDeR as well as information shared at team meetings across ASC especially those with a high staff turnover.

Leicester City Council continues to develop its internal review group process and quality assurance mechanisms where learning into actions from LeDeR reviews, in relation to care and support providers or care management process, can be embedded.

In addition, representation from both contracts and assurance and care management teams

"He enjoyed slapstick humour and had a very dedicated staff team who learned how to communicate with his non-verbal signs."

steering group where action plans are approved and monitored. There have been several engagement sessions from LeDeR Clinical Leads and Local Area Coordinators at management sessions, team meetings and provider forums including the shared lives teams. This has enabled the reinforcement of the message that LeDeR is a system wide responsibility and as such we will continue to ensure that there is a process for supporting the implementation of learning into action.

Future Plans

2021-22 has been a year of significant change and development for the LeDeR programme and the LLR LeDeR team has effectively coalesced into a proactive team with some strong plans for the forthcoming year. It is important to highlight that the new reporting platform can only receive the reviews and does not include a facility to generate any reporting from the reviews. Any datasets and subsequent reports have been designed from a dashboard formulated by the LLR LeDeR team. Therefore, data presented in this report may not be comparable with information presented by other LeDeR programmes.

It is hoped that comparable information will be generated by improvements to the national reporting platform through improved liaison with NHSE/I. One member of the LLR LeDeR Senior Team has enrolled onto the national Technical User Research Group to encourage and support this work.

The role of the person with lived experience will be developed as the individual gains confidence and experience. Initially, attendance and support at the LeDeR Steering Group will be the priority with a progression to advising on the actions required to implement recommendations from the reviews.

To comply with directions in the national policy, the LLR LeDeR programme has recruited 1.6 WTE and retained 2 supplementary reviewers. Their role will be to support the programme by undertaking reviews, monitor progress of reviews, support the administrative assistant to update and cleanse data and support the implementation of recommendations from reviews.

The substantive Clinical Lead posts commenced in June 2021 and together with the administrative assistant developed an in-house data set to monitor review progression and produce reports. This will be refined on an 'as and when' basis during the coming year.

There has been a suggestion to link with another CCG/ICS to 'share' reviewers and this will be explored in more detail over the coming months. A toolkit for reviewers has been developed by the Clinical Leads that has been widely shared across the Midlands LeDeR network. This will be regularly revised as required by the clinical leads and new substantive reviewers to ensure consistency in the approach to reviews.

The regional NHSE/I, to comply with the national policy, has requested support to quality assure completed reviews. Following discussion with NHSE/I and other LeDeR programmes, a system of peer review has been suggested, which will be developed further in partnership with NHSE/I and other area programme leads.

The LLR Clinical Leads have completed an in depth thematic review of respiratory associated deaths and identified SMART actions as outcomes from the review.

The team has identified a need for further thematic reviews of:

- Second thematic analysis of respiratory deaths post April 2021
- COVID 19 related deaths
- Deaths those associated with nutritional status, particularly weight loss or gain in the months leading up to death
- Constipation and continence issues as contributing factors

The Clinical Lead roles have specific responsibility to embed learning into action and support a cycle of learning, positive change, monitoring and evaluation throughout each year. The outcomes from the reviews and the in depth thematic reviews will be periodically reported from the Governance Panel to the LeDeR Steering Group; LD and Autism Collaborative meeting; the ICS Board and NHSE/I.

The thematic reviews will take place during the forthcoming year creating links with clinical specialists outside of the LeDeR programme such as Physiotherapists, Occupational

Therapists, Speech and Language Therapists and expert nutritional clinicians. Whenever possible experts from social care and care providers will be consulted and included in developing the improvements in care provision. The intention is to raise the profile of LeDeR as a collaborative and inclusive quality improvement programme across all areas of care and that it is not a 'stand-alone' programme.

In addition to the proposed improvements in the quality of care and improved experience of people and their families, the LLR LeDeR programme is participating in the national Learning Disability week in June aimed at raising the profile of learning disability in the community as well as that of the LeDeR programme. We have liaised with three third sector organisations and individuals, their families and carers during the month of June will be invited to create video clips, audio clips, artwork, prose or poetry of their experiences, whether positive or negative, that will be shown during events held in LD week in June.

Strengthened links, formalised and streamlined partnership working with Safeguarding Adults and Child Death Overview Panels CDOP, resulting in several outstanding CDOP cases being completed in-year.

The LLR LeDeR programme senior team has identified that the cause of death is not always easily accessible at the time of notification. This has been known to be a cause of difficulty for reviewers when speaking directly with families. To overcome this, the LLR team intends to work with the city and county registrars to develop a system to access death certificates in a timelier way.

Conclusion

In conclusion, the LLR LeDeR team has worked tirelessly and in collaboration with partners and stakeholders to progress the LeDeR programme against a backdrop of significant change within the national programme and local organisational changes.

Reflecting on the principles of the LeDeR programme, the LLR team has effected change and is beginning to make differences to the lives of people with LD and autism, their families and carers who have been enabled to contribute to reviews. Together with other sources of information, a rounded approach to identifying learning has been accomplished, the outcome is the increased recognition of the programme as a force for constructive service improvements and enhanced quality of care for those people with LD and autism, their families and carers.

Appendix I: LLR LeDeR PDSA Cycle 2

1st April 2022

Area to explore	What could we do better	Where are we now	Cycle 3 of PDSA
Recruit further experts by experience and ensure autism is included and representation of ethnic minority is included.			
Population reporting to be undertaken as a clinical audit. DeMontfort University research colleagues to analyse the data and feedback to LeDeR Clinical leads for synthesis.			
Communication Plan is ad hoc.	A clear, strengthened and organised communication plan that is well structured, factual, empathetic and ignites change.		
Recruitment of LeDeR Reviewers on fixed term contract.	Permanent roles would ensure the widest range of suitable candidates and	Funding in place only for 2022/23.	
A LLR LeDeR Vision	LLR LeDeR Programme must ensure its independence whilst equally collaborating with partner agencies. A clear vision to be defined based on LPT, CCG, Local Authority, UHL and national LeDeR visions.		
Yearly planning calendar for LLR LeDeR	Understand, outline and define the input and output for LLR LeDeR to prevent duplication and improve efficiency and professionalism.		
Process for obtaining death certificates is unclear.			
Thematic Analysis: • **Respiratory Deaths** • **COVID-19** • **Weight**			
Clearer and more structured reporting functions would support easier thematic	The Masterbook of all reviews was developed and implemented in 2021/22.		

Area to explore	What could we do better	Where are we now	Cycle 3 of PDSA
analysis for future. In the absence of any data download or reporting functionality from the LeDeR web platform, this will need to be developed locally.	For 2022/23 a qualitative data analysis tool would prove beneficial.		
Sharing of LLR LeDeR Areas to Explore and actions (not Steering Group SMART Actions) are not regularly shared in a timely manner to relevant service.	Set up a quarterly communication out to share those actions with the relevant authority.		