Joined Up Care Derbyshire

NHS
Derby and Derbyshire
Integrated Care Board

Derbyshire Learning from Deaths of those with a Learning Disability and Autistic People

The LeDeR Programme

Annual Report

1st April 2023 to 31st March 2024

Derbyshire LeDeR Learning from Lives & Deaths Annual Report 2023-2024

Responsible Committee	Derby & Derbyshire LeDeR Steering Group
Target Audience:	Report for agencies involved in the programme across the Derbyshire system and for sharing across the public domain:- LeDeR Steering Group Mental Health, Learning Disabilities, Autism & Children's System Delivery Board Neurodevelopmental Programme Delivery Group Joined Up Care Derbyshire National LeDeR Programme NHS England
Date of Approval:	23rd September 2024
Document Type	Annual Report (Quality)

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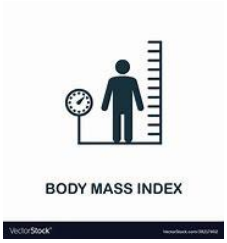
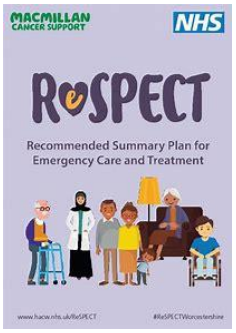
List of Abbreviations

Abbreviation	Explanation	Symbol
AHC	Annual Health Check	
BMI	Body Mass Index	
CDOP	Child Death Overview Panel	
CLDT	Community Learning Disability Team	
CQC	Care Quality Commission	Care Quality commission
DCHS	Derbyshire Community Health Services	NHS Derbyshire Community Health Services NHS Foundation Trust

DHcFT	Derbyshire Healthcare NHS Foundation Trust	
DNACPR	Do not attempt resuscitation	
GP	General Practitioner	
IAPT	NHS Talking Therapies	
JUCD	Joined Up Care Derbyshire	
LAC	Local Area Contact	

ICS	Integrated Care System	
LD	Learning Disability	
LeDeR	Learning from lives and deaths of people with learning disabilities and autistic people	
MCA	Mental Capacity Act	
NCMD	National Child Mortality Database	

NHSE	NHS England	
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment	
T2	**Transition 2** in Derby is a college for young adults aged 18 to 25 with learning disabilities and/or autism	

Executive Summary

The people whose deaths are reported in this report are people who were known and loved by many and whose loss will have had and continue to have a profound impact on those around them. The LeDeR Programme in Derbyshire wishes to thank all those who provided information when requested, especially considering the additional pressures faced during the last year. These include families and carers, GP Practices, NHS Trusts, Local Authorities, Managers, and staff working in Residential and Social Care Homes, Supported Living, Domiciliary, Day Care and other health and social care settings. Further thanks go to the reviewers for their compassion when completing the reviews, keeping the person at the centre of the process, to identify learning and share good practice.

This report is the fifth annual report for Derbyshire on the learning from deaths of those with learning disabilities and autistic people. The report uses data collated from 1st April 2023 up until 31st March 2024. Thanks to those with lived experience who have been involved in producing this report and the Derby & Derbyshire Integrated Care Board LeDeR Team.

The purpose of the report is to share the findings and the learning with those involved in the LeDeR programme and those working with individuals with learning disabilities and autistic people, to demonstrate how Joined Up Care Derbyshire (JUCD) is delivering on local actions as identified in LeDeR reviews. It is signed off through the LeDeR Steering Group and shared with the JUCD System Quality Group, the Neurodevelopmental Delivery Group and the Mental Health/Learning Disability & Autism Board for information. The report, including an accessible version, is published each year and available on the JUCD website. The report is shared with NHSE regional teams by 30th September 2024.

Summary of local data and findings

Since the programme began there have been 425 (adult i.e. age 18+) deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2024, of which 374 of these deaths have had a review undertaken and completed.

From 1st April 2023 to 31st March 2024 there were 83 notifications and 65 completed reviews in that year period. Some of those 65 completed will have been notifications received in the previous year and some will be part of the 83 notifications received in 23/24.

Of the 65 completed reviews 2 were for autistic people but with no learning disabilities. These 2 reviews have been separated out within the report and a separate section relates to their learning. The remainder of the information throughout this annual report is based on the 63 reviews that were **completed** during 2023/24.

Of the 63 completed reviews for people with learning disabilities,30 of the reviews were male, 33 of the reviews were female.

Average age at death for females was 61 years and 60 years for males. In the national LeDeR report for 2022 the average age at death was 62.9 for both female and male.

58 of the completed reviews were for the population identifying as White British. Five reviews were completed reviews for those identifying from a minority ethnic community (2 Pakistani, 2 "Any Other White Background" and 1 "Any Other Mixed or Multiple Ethnic Background"). This is the same number as the previous year. Note that the minority ethnic backgrounds/descriptions used are as requested through the LeDeR programme.

Hospital was the most common place of death, with 36 of the 63 completed reviews showing hospital as the place of death.

During 2023/24 there have been three reviews completed as confirmed Covid-19 deaths. There have been three additional completed reviews where the individual had Covid-19 at death although Covid-19 was not listed as their main reason for death. There have been no notifications made in the year where Covid-19 is mentioned on the notification.

The top reason for death was Pneumonia for 19% of our Derbyshire population. Aspiration Pneumonia (not included in the more generic Pneumonia as reason for death) was separated out and was the third top reason for death with 11% (alongside heart conditions which also had 11%). Cancer was the second reason for death at 13%. Three out of the 8 cancer deaths in 2023/24 (37.5%) were caused by bowel cancer/colorectal carcinoma (1a on the person's death certificate).

Of the 83 notifications received in the year, 5 were notifications for individuals with autism (no learning disability). Only one of these was completed in the year and details are included in the section relating to the 2 completed reviews for autistic people but no learning disabilities. In total there have only been 7 notifications since January 2022 of autistic people but had no learning disabilities. Five of these reviews are on hold as they are awaiting coroner investigation.

Local learning and making changes

Our priority is to use the learning from LeDeR to make service improvements for people with learning disability and autistic people in our local community and lots of work is happening in this area and detailed later in this report. Focus has particularly been on deaths from aspiration pneumonia and looking at learning in relation to ReSPECT/DNACPR.

Constipation has been a priority area in Derbyshire for a number of years now and it is good to see that the percentage is remaining low compared to earlier years, this year showing at 37% in health conditions. However, we will be continuing to monitor this closely as this is a slight increase on last year which was 34%.

In last year's report epilepsy was seen in 38% of the completed reviews in health conditions, this year it has

increased to 48% and we will continue to raise the importance of prioritising this area of work.

Priority areas for 2024/25

The report highlights a number of local priority areas for work across the system as identified through the LeDeR learning seen throughout 2023/24:-

Aspiration Pneumonia – A review of the 6 month project using learning from LeDeR reviews in relation to aspiration pneumonia deaths will be completed during August/September 2024. The information will be reviewed and themes/learning identified along with next steps to be considered based on this learning.

Care Coordination - We will continue to use LeDeR to evidence the need for care coordination of individuals, particularly those with a mild learning disability who do not have the support they need to manage and understand their health appointments.

Epilepsy – We will continue to identify issues found in relation to those individuals with epilepsy and highlight the importance of an Epilepsy Lead across the system.

Managing Deterioration – Based on learning through LeDeR in 2023/24 we will be considering where the information and learning can be shared across the System to encourage better understanding of managing deterioration.

Mental Capacity Act - An emerging theme is that of mental capacity for people with a learning disability and autistic people. LeDeR has found some evidence to suggest that capacity is assumed, and the individual is making an unwise decision but without the necessary professional curiosity. We will continue to monitor this through LeDeR.

Minority Ethnic Communities – We will continue to work with the Minority Ethnic leads for LeDeR to increase awareness across all agencies and communities of the role of LeDeR and why notifying LeDeR of deaths is a first important step. To further raise awareness of the even poorer health outcomes for some members of minority ethnic communities who have learning disabilities, sharing the learning from LeDeR.

ReSPECT/DNACPR – the information included in this report in relation to ReSPECT and DNACPR will be shared as detailed and used as appropriate to promote learning.

Introduction to the LeDeR Programme

LeDeR is a service improvement programme for people with a learning disability and autistic people.

The programme was established in 2017 by NHS England. LeDeR aims to:

- improve care for people with a learning disability and autistic people
- reduce health inequalities for people with a learning disability and autistic people
- help stop people with a learning disability and autistic people dying early.

Nationally, annual reports have been produced for the past 7 years and previous reports are available to view here.

It is important to note when looking at any findings in relation to LeDeR that notification to the LeDeR programme is not mandatory, so does not have complete coverage of all deaths of people with learning disabilities and that numbers in some sub-categories are small so must be interpreted with caution.

The "Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) policy" was introduced in March 2021 to serve as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR. The policy includes NHS England's (NHSE) delivery expectations of local areas, which includes a local LeDeR annual report demonstrating how the ICS is delivering on local actions addressing those areas identified in LeDeR reviews and asking that it demonstrates effective delivery of actions from learning from LeDeR reviews.

The *LeDeR Policy* [1] informed of the inclusion of LeDeR reviews for autistic people with no learning disability. This took affect from 1st January 2022.

As per requirements of the LeDeR Policy a *Derbyshire LeDeR 3-year strategy* [2] was produced using the learning that has been found and reported in Derbyshire and submitted to NHSE in March 2022.

A new LeDeR platform was introduced in 2021/22 which altered the review process from previously including new formats to the reviews. In February 2023 a LeDeR23 form was introduced which made changes to some of the information that is gathered to complete the review process.

All notifications of death for individuals age 18+ follow the LeDeR process. Anyone under the age of 18 is referred through the separate Child Death Review process. In Derbyshire, referrals to the LeDeR programme are accepted for those registered with a Derbyshire GP practice. For autistic people with no learning disability a clinical diagnosis of autism must be visible.

Depending on the complexity of the person's life and death a decision is made to complete as an Initial Review or Focused Review. However, all LeDeR reviews are automatically Focused if:-

[1] See References section
[2] See References section

- the person is from a Black, Asian or minority ethnic background
- an autistic person with no learning disability
- the person had been under mental health or criminal justice restrictions at the time of death or 5 years previously
- where there is likely to be learning from the life of the person to inform service improvements
- local priorities for focused reviews
- where the family have requested a focused review
- where there are any concerns about the care the person received

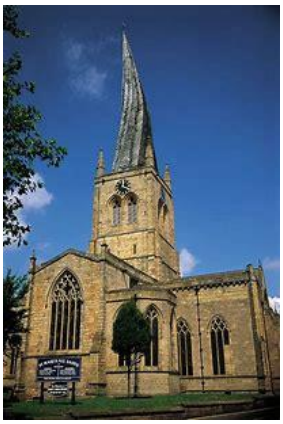
As a service improvement programme locally in Derbyshire, we are working as Joined Up Care Derbyshire ICS to use the learning found through LeDeR to improve our local services for people with a learning disability. As LeDeR also develops into a service improvement programme for people with autism the strategy will adapt and evolve to show how we aim to collect information and hope to also improve services for people with autism.

The LeDeR Programme in Derbyshire

Estimates of people with a learning disability for Derby and Derbyshire are slightly more than 2% of the population, which is approximately four times the proportion of the population who are known to services. It is estimated that there are 15,250 people in Derbyshire and 4,950 people in Derby with a learning disability (people with mild to severe learning disability). (*Reference: JUCD website*[3])

It is estimated that 1% of the population have autism. Research has identified between 44% and 52% of people with autism may have a learning disability and between 48% and 56% do not have a learning disability. Data from GPs in Derby and Derbyshire show there are 3,358 people with autism (who have no learning disability). (*Reference: JUCD website*[4])[5]

Work started on the LeDeR programme in Derbyshire early 2017. The first LeDeR Steering Group ran in February 2017 and the first reviews started in April 2017. Since that date we have received 425 notifications for those age 18+, of which 374 have had a review undertaken and completed (local collated data as of 31st March 2024). The information in this report is taken from LeDeR reviews completed between 1st April 2023 to 31st March 2024.



Learning from individual reviews is collated through an action tracker. Good practice is acknowledged and shared with organisations and individual actions are agreed and discussed at the Derbyshire LeDeR Governance Panel and fed back up to organisations through their members that attend the meetings.

Themes are also collated from each review and the theme form is evaluated alongside the review as part of the quality review process. Our reviewers have been collecting themes since 2020/21 that also identify the responsible care provider. Themes are collated and reviewed to identify areas where commissioning concerns may need to be identified. These themes are shared with organisations via the Derbyshire LeDeR Steering Group to enable them to see themed areas of work that are relevant to them for potential review and for discussion as a wider Derbyshire system.

[3] See References section for link to JUCD website
[4] See References section for link to JUCD website
[5] Note that there may be different figures available in relation to local populations within learning disability and autistic people, which reflects some of the uncertainty about prevalence & how many people are known to services.

The Derbyshire Vision for LeDeR

As Joined Up Care Derbyshire we continue to aim and work towards our Derbyshire LeDeR Vision in everything we do as part of the LeDeR programme.

Derbyshire LeDeR Vision

By 2024, we will have significantly improved the lives of people with learning disabilities and autism to work towards preventing them from dying sooner than the general population. We will do this by improving the quality of person-centred care they receive in their daily lives and making all services accessible to them; making sure they have knowledge and understanding of the services that are available for them to use and helping them to understand how to improve their own physical health.

Co-production and Engagement

Dan attends our LeDeR Steering Group Meetings as our person with lived experience. Dan has also been involved with producing the Annual Report and worked with us to make it more user friendly. This is what Dan produced to tell you a bit about what his role is and how he supports the LeDeR programme.

	Hello My name is Dan Walmsley, I am an assistant Health Facilitator in the Neurodevelopment Team .
	I have been attending the LeDeR Steering Group Meetings.
	I like to attend the meetings to share my views.
	The meetings are important, to help stop people with Learning Disabilities passing away too soon from illness.
	In the meetings we talk about people's lives and the care they had received.
	We talk about things like epilepsy, illness and other things, and about how we can improve.
	I like to give my advice on easy read.
	I like to talk about Annual Health Checks because it is important for people to go to them to try to keep healthy.

Denise co-produced the LeDeR annual report last year. This year she's been involved by reviewing the annual report and providing her feedback on the format and way the report is written and she's helped with the easy read version of this report. Here's a bit about Denise:-

Hello, my name is Denise. I am a Director on the Board of Inclusion North who are a group of people who raise awareness of the barriers to inclusion for people with a learning disability, autistic people and their families, and work to remove them. In April of 2024 I won an award at the 2024 Learning Disability and Autism Leaders List awards through Dimensions, in the award category of advocacy policy and media.

My Experience

I have a mild learning disability, but only got diagnosed at the age of 21.

I have lots of experience as part of a Care and Treatment Review panel where we work to try to help to sort out any problems which can keep people in hospital longer than necessary and try to help them stay living safely in the community.

I am an Enter and View authorised representative for Healthwatch Derbyshire where I visit health and social care settings to see how they are working and make suggestions for improvement.

My Skills and Knowledge

I am able to ask the right questions at the right time.
A good communicator.
Approachable.
A good team player.

What is important to me

Listening to people.
Being understanding.
Being kind and caring.
My family and friends.
That people are given a chance.

What people say about me

I like a bit of banter.
I am confident in myself.
A friendly person.
Kind and caring.

I Enjoy

Singing and song writing.
Going to gigs and concerts.
Socialising.
Holidays abroad.
Being a voice for people with disabilities.
Reading the news for Inclusion North.

Partnership working across the Integrated Care System

Work has continued throughout the year to ensure good partnership working across the LeDeR programme and sharing of information. This has included:-

- Quarterly LeDeR Steering Group meetings attended by people with lived experience and partners across Joined Up Care Derbyshire.
- Regular LeDeR Governance Panel meetings (approximately once a month depending on number of focused reviews for quality checking and sign off) attended by partners across Joined Up Care Derbyshire.
- Working with DCHS Mortality Review Group to ensure learning from LeDeR is incorporated into their reports and fed back to their Mortality Review Group meetings, to enable a robust look at LeDeR themes within Derbyshire to improve sharing and quality improvements.
- The LeDeR team working together with the Strategic Learning Disability Health Facilitation Team to deliver workshops across health and social care providers, promoting learning from LeDeR and the work of the Health Facilitators with particular emphasis on promotion of learning disabilities annual health checks, health action planning and making reasonable adjustments.
- Meetings between LeDeR and Safeguarding to ensure we are working together on any appropriate reviews and attending Safeguarding Adult Board meetings to share LeDeR learning. LeDeR reviewers work closely with Safeguarding Adult Board for any reviews that have been progressed as a Safeguarding Adult Review (SAR), including meeting families together with the SAR reviewer and attending the SAR meetings.
- Working with adult social care both to improve LeDeR processes and to ensure themes and learning are appropriately shared.
- Working with Royal Derby Hospital to deliver learning from LeDeR as part of the end of life study days
- Delivering learning from LeDeR at Derbyshire County Care Home Forum
- Regular meetings with managers of learning disability community care providers to share learning from LeDeR and discuss and agree next steps and how the learning can be used across Derbyshire to improve services.
- Sharing quarterly reports and updates with System Quality groups.
- Sharing LeDeR learning with the Good Health Group and Learning Disability Partnership Boards – meetings attended by people with lived experience and their carers.
- Sharing LeDeR learning at Mental Health, Learning Disability and Autism Delivery Board meetings

Child Deaths

A national report has been produced by the National Child Mortality Database (NCMD) which is available here in full and easy read and aims to identify trends in child mortality among children and young people with a learning disability and autistic children.

Locally, LeDeR no longer captures information in relation to child deaths. All child deaths are reviewed through the CDOP (Child Death Overview Panel) process and information and themes captured separately through this process.

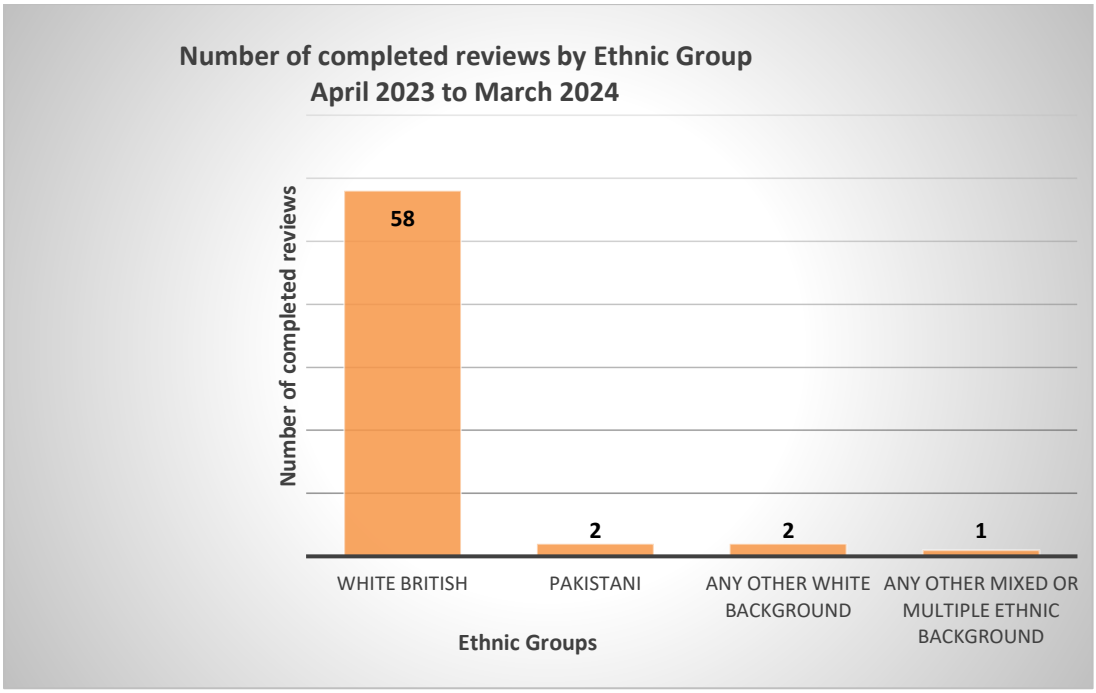
Staffing and Governance Arrangements

The LeDeR programme is part of the Nursing and Quality team within the Derby and Derbyshire Integrated Care Board (ICB). The LeDeR team are made up of the LeDeR Administrator, Local Area Contact (LAC), Senior Reviewer and 1.0 wte Reviewers. Any issues and risks are supported within the wider Nursing and Quality directorate and reported via the LeDeR Governance Panel and LeDeR Steering Group and fed into the system wide Neurodevelopmental Programme Delivery Group, and ultimately to the JUCD Mental Health/Learning Disability & Autism Delivery Board.

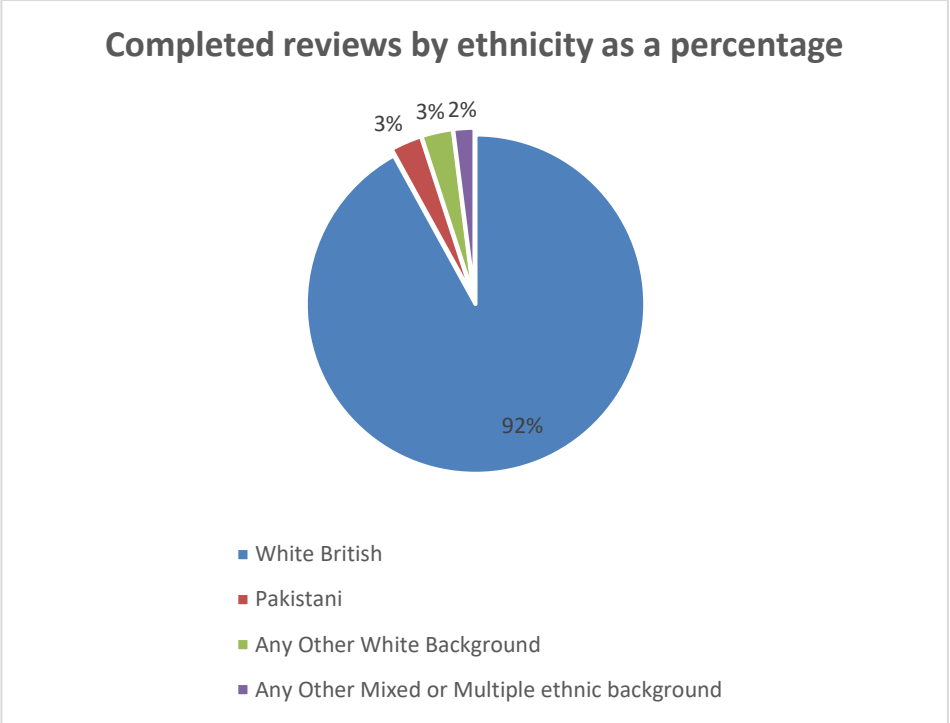
Equality Impact

Addressing Inequalities across Black Asian & Minority Ethnicity communities

During 2023/2024 five reviews (8%) were completed for those identifying from a minority ethnic community. This is the same number of reviews completed for people identifying from a minority ethnic community as last year.



**Note that the minority ethnic backgrounds/descriptions used are as requested through the LeDeR programme.*



In Derbyshire County our minority ethnic population is estimated to be about 3.9% (although this varies across the County and is separated out as Derbyshire Dales, North East Derbyshire and South Derbyshire by the Office of National Statistics) and in Derby City the minority ethnic population is estimated to be about 26.2% (taken from the Office of National Statistics, Census 2021 data[6]).

Therefore, if we break this down further to compare completed reviews separately across the City and County:-

- 16 of the overall completed reviews were individuals from the City. 4 of these individuals were from minority ethnic communities i.e., 25%.
- 47 of the overall completed reviews were individuals from the County. 1 of these individuals was from a minority ethnic community i.e., 2%.

These are encouraging as the number of notifications are closer aligned to those expected from minority ethnic communities than in previous years, however we aim to continue to promote LeDeR and the programme aims in these communities and to further raise awareness of the even poorer health outcomes for some members of minority ethnic communities who have learning disabilities.

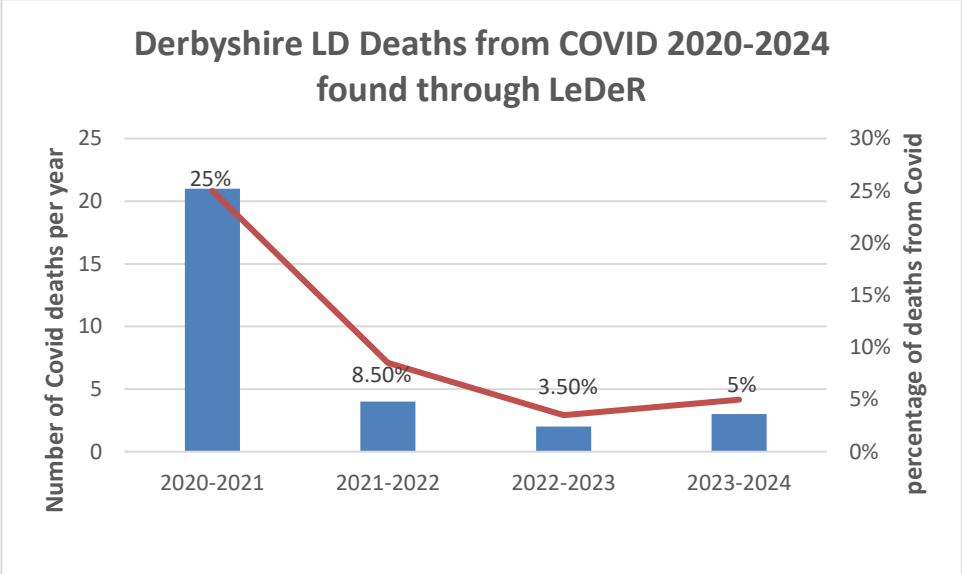
[6] See References

Covid-19

During 2023/24 there have been 3 reviews completed as confirmed Covid-19 deaths. Two of these individuals died in hospital and one in the Care Home.

There have been an additional 3 completed reviews where the individual had Covid-19 at death although Covid-19 was not listed as their main reason for death.

The table below shows the percentage of deaths from COVID (Covid cause of death as per 1a of the Death Certificate) seen in completed LeDeR reviews from 2020 to 2024.



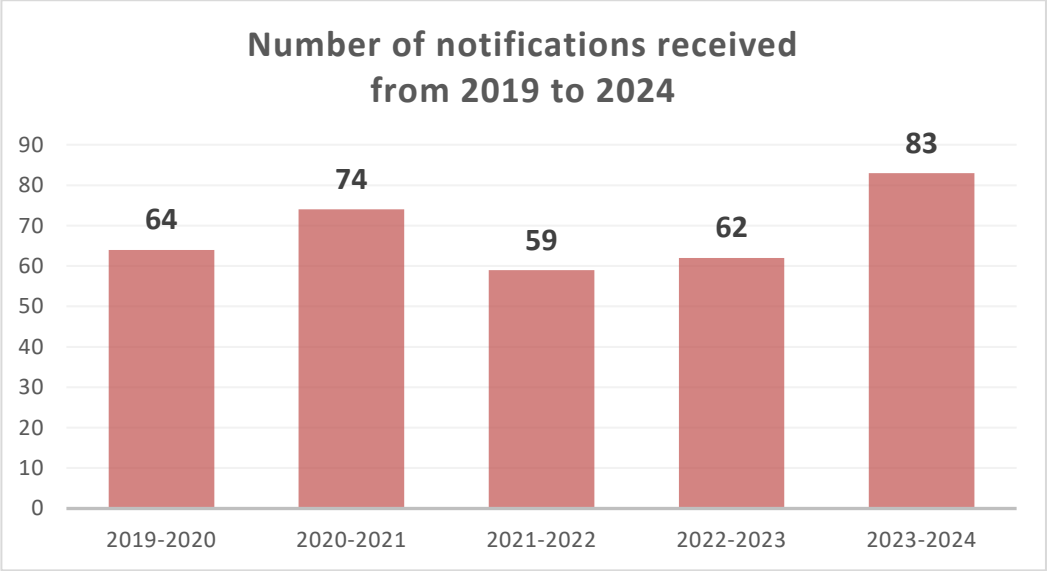
In 2020-2021 the number of LD deaths totalled 21 (25% of notified deaths) which has decreased significantly to 3 deaths (5%) in 2023-2024.

Local Demographic Data & Findings

Since the programme began there have been 425 deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2024 of which 374 of these deaths have had a review undertaken and completed. [NB. As mentioned previously all notifications referred to are for 18+ only]

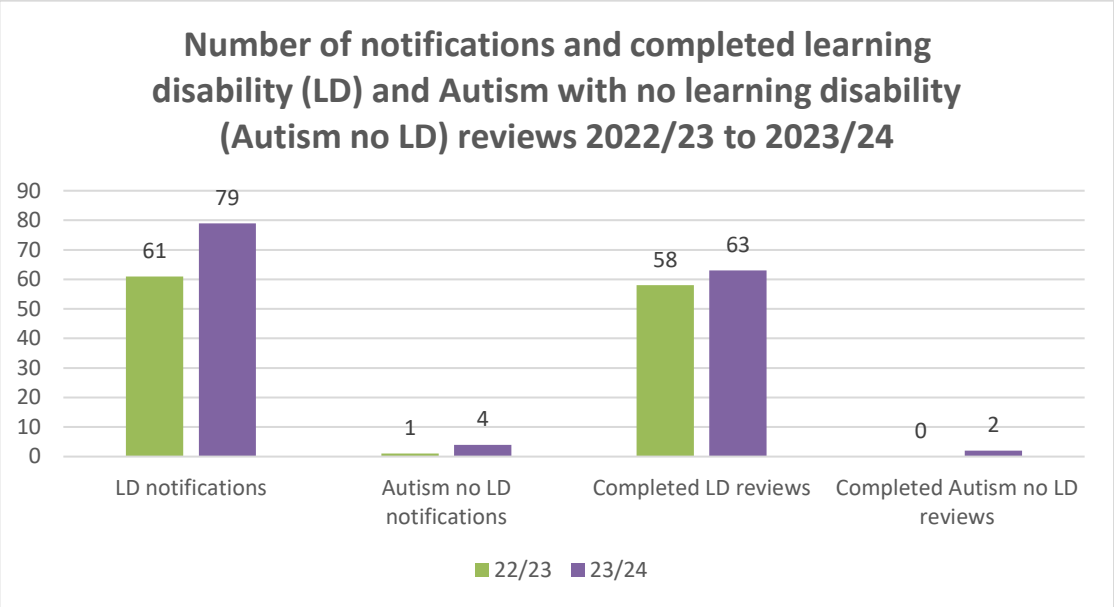
For the year 1st April 2023 to 31st March 2024 there were 83 notifications and 65 completed reviews in the year. Some of those 65 completed are from notifications received in the previous year and some will be part of the 83 notifications received in 2023/24. Information throughout the annual report is based on the reviews that were completed during 2023/24.

The table below illustrates the number of notifications to the LeDeR programme in Derbyshire from 2019 to 2024. There has recently been a significant increase in the notification rate which has increased by 34% between 2022/2023 and 2023/2024.



Autism (no learning disability) deaths

There were 2 reviews completed in 2023/24 for deaths of autistic people but did not have a learning disability. There were 4 notifications of deaths for individuals who had Autism but no Learning Disability in 2023/2024.



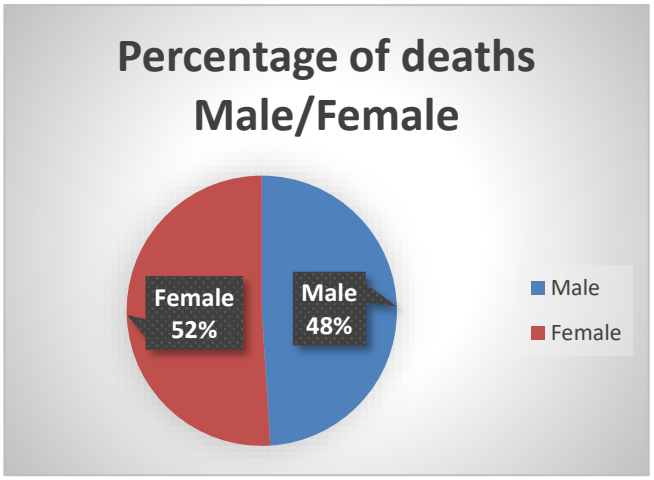
As there have only been 2 completed LeDeR reviews for individuals with autism but no learning disability we are not yet in a position to start to capture any themes. However, we can report that both these completed reviews were males in their mid 30s, both died at home, and had mental health issues. Both deaths were investigated by the Coroner, one was found to be suicide and the other was given a reason for death as "Unascertainable" by the Coroner.

For the additional autism (no learning disability) reviews that have been notified between 2022 and 2024 all were also male, age ranging from 18 to 45.

In total, there have been 7 notifications to Derbyshire for individuals with autism but no learning disability. The seventh review not yet mentioned was notified to us in 2021/22. This is the only female notification we have received, and this review is still not completed as is still being investigated by the Coroner.

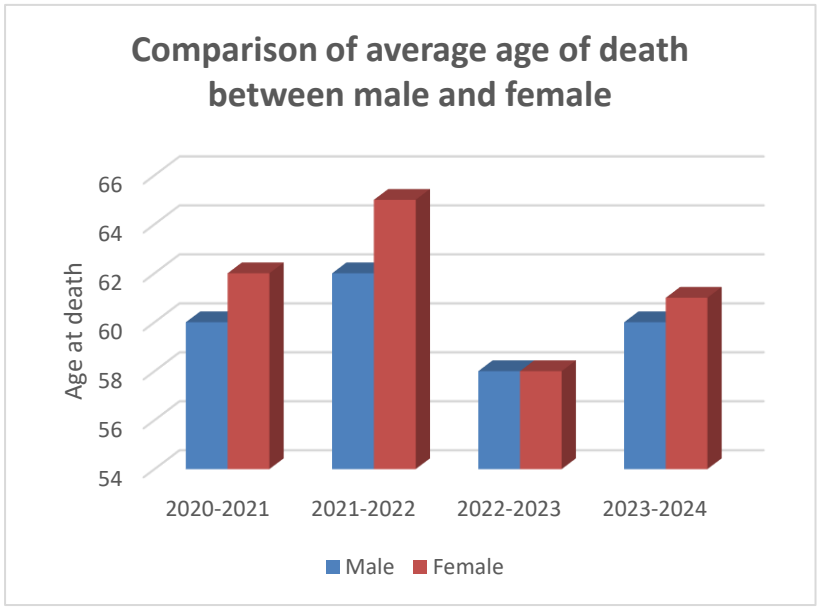
The remainder of this report will refer to the 63 reviews that were completed during 2023/24 for individuals who had a learning disability (NB some of those people will have been an autistic person as well as having a learning disability).

The following graphs represent data taken from the 63 completed reviews for 2023/24:-

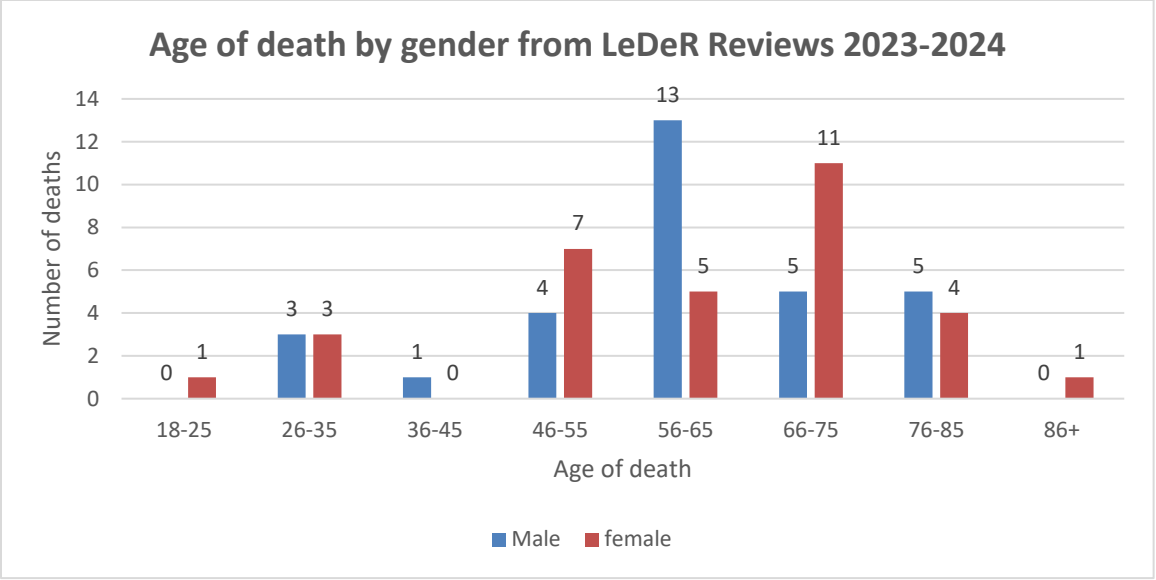


30 of the deaths reviewed were male (48%)
33 of the deaths reviewed were female (52%)

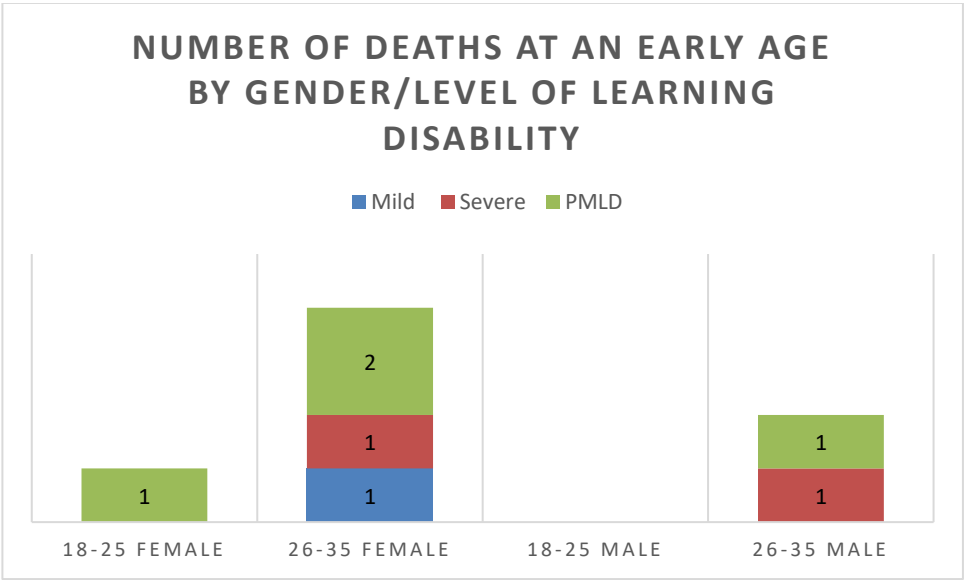
Learning from LeDeR showed that the average age of death in Derbyshire was 60 for males and 61 for females from reviews completed in 2023 to 2024.



This represents an improvement from last year as the average age was 58 for both male and females.

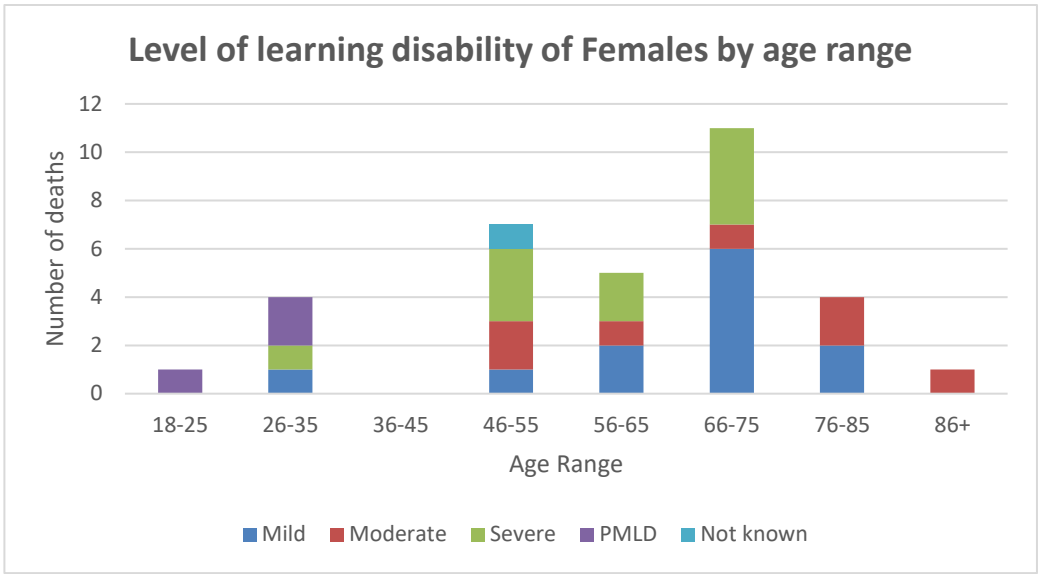


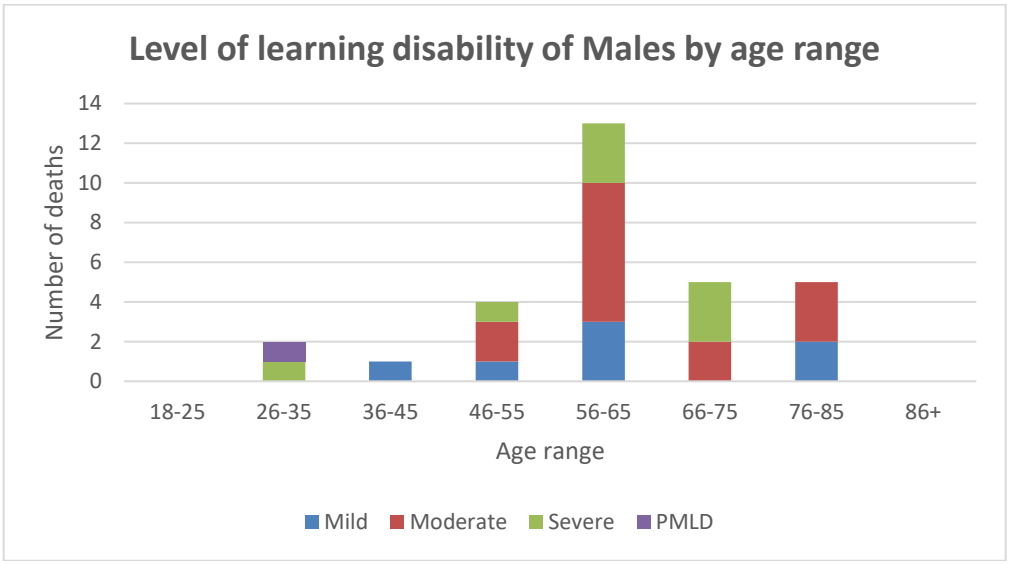
For 2023/2024, more males died in the age category 56 to 65, while more females died in the higher age category of 66 to 75.

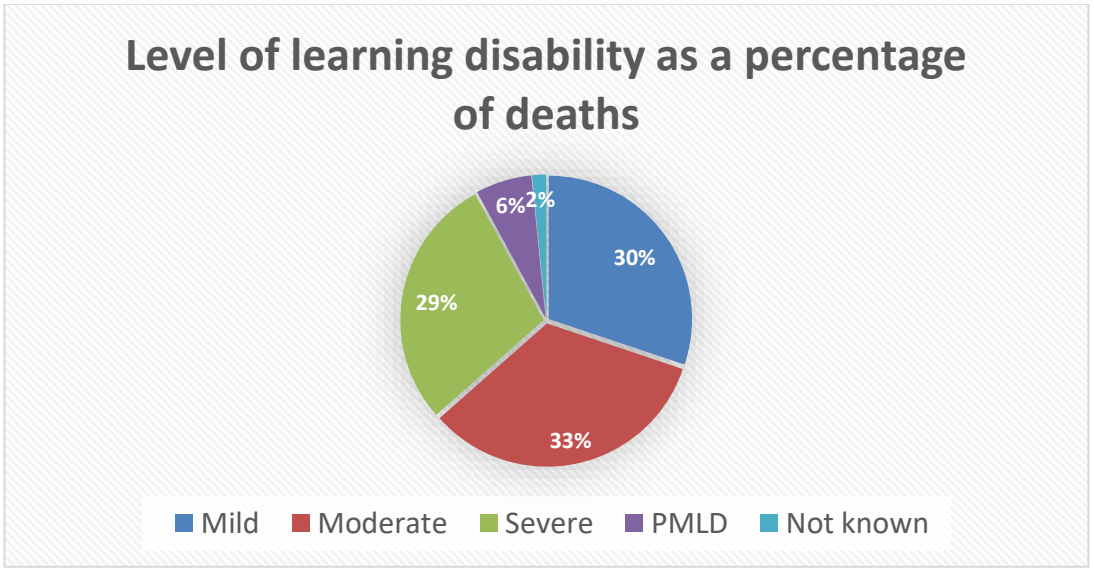


The youngest female to have died at an early age (under 35) was 18 years old and she had a profound and multiple learning disability. The cause of death was Respiratory Failure. This review was completed as a focused review.

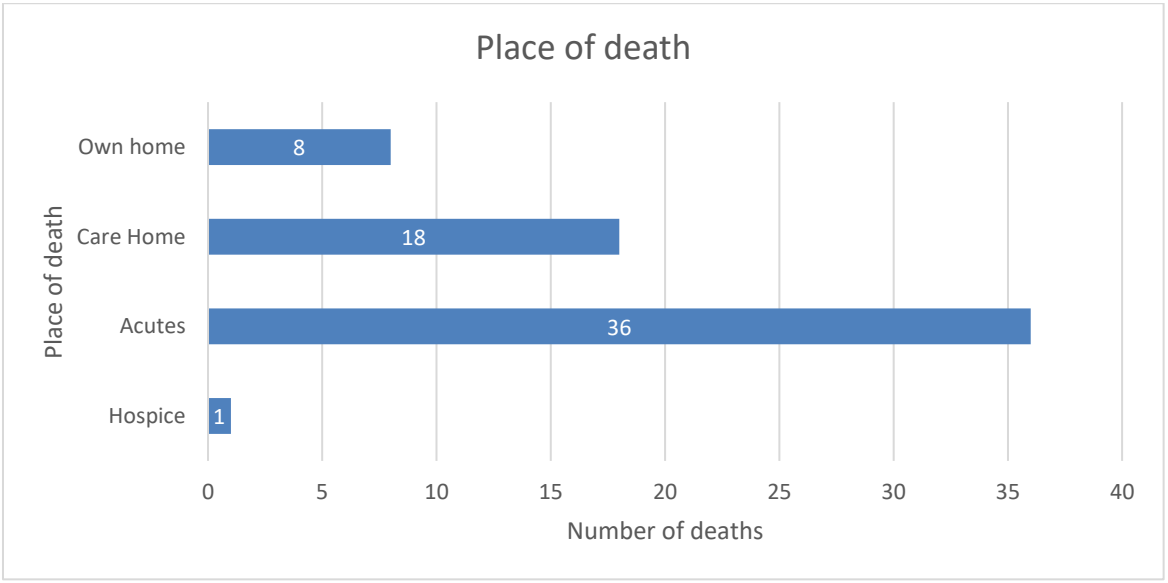
The youngest male to have died at an early age (under 35) was 30 years old and had a severe learning disability. The cause of death was Aspiration Pneumonia. This review was also completed as a focused review.


Level of learning disability of Females by age range
Number of deaths
12
10
8
6
4
2
0
18-25
26-35
36-45
46-55
56-65
66-75
76-85
86+
Age Range
Mild
Moderate
Severe
PMLD
Not known

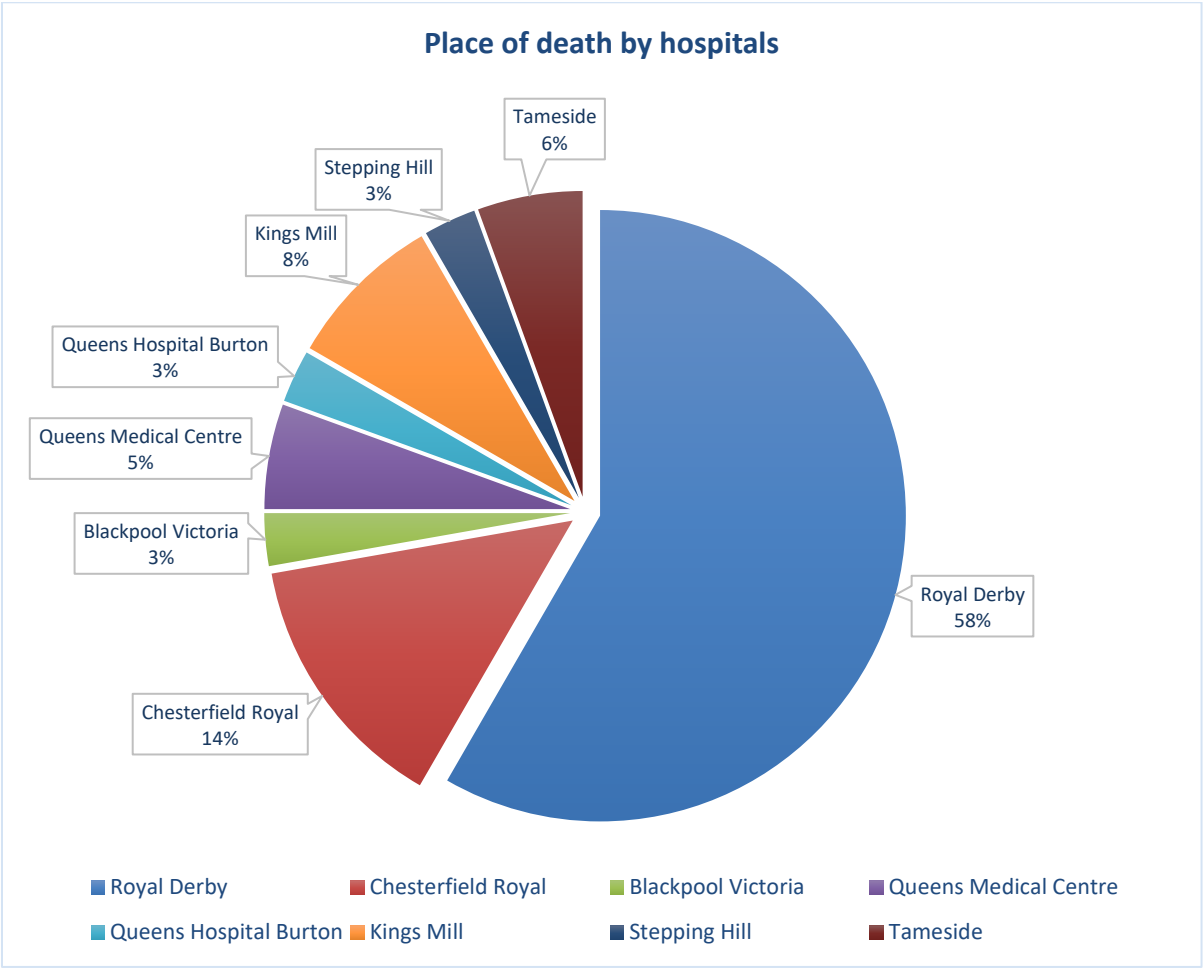

Level of learning disability of Males by age range
Number of deaths
14
12
10
8
6
4
2
0
18-25
26-35
36-45
46-55
56-65
66-75
76-85
86+
Age range
Mild
Moderate
Severe
PMLD


Level of learning disability as a percentage of deaths
30%
33%
29%
6%
2%
Mild
Moderate
Severe
PMLD
Not known

Hospital was the most common place of death, with 57% or 36 of the 63 completed reviews showing hospital as the place of death.



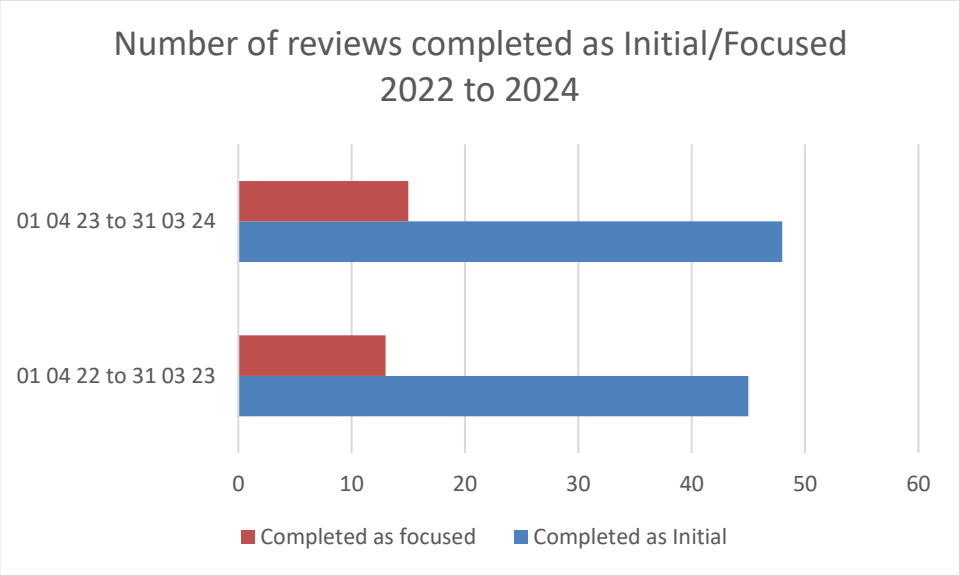
Of the 36 deaths which occurred in hospital, 28% of these took place in hospitals out of Derbyshire.

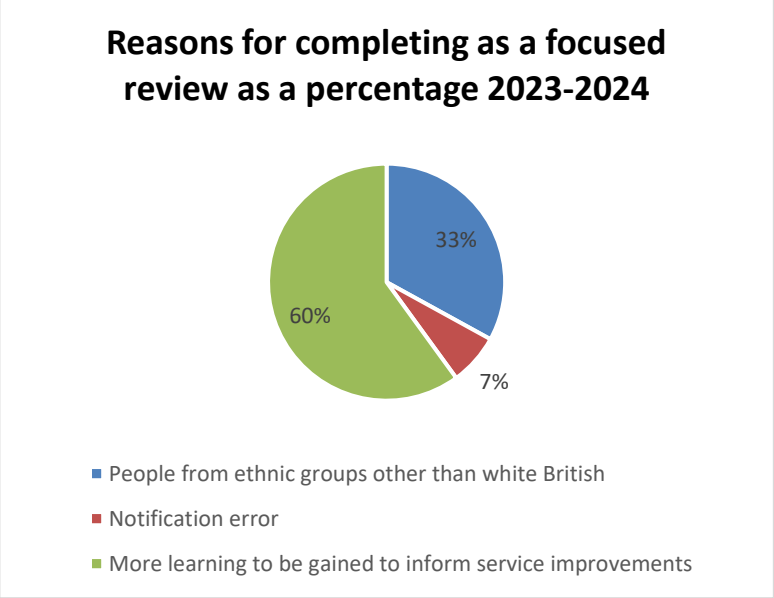


Focused and Initial Reviews

All reviews are completed either as Initial or Focused as per the national LeDeR policy. During 2023/24 there were 48 reviews (76%) completed as initial reviews and 15 (24%) completed as the more detailed focused review.

There is a slight increase in the number of both initial and focused reviews completed this year compared to the previous year. The graph below shows the number of focused and initial reviews over the last 2 years.





Of the 15 reviews completed as focused 60% of them (9) were moved to a focused review from an initial review in order to gather more learnings for service improvement.

33% were automatically completed as focused due to being individuals from a minority ethnic background.

Individual actions are identified from each review, this may show good practice and/or areas where it is felt improvements could be made. Some areas of learning are evidenced through case studies to identify local priorities and agree actions. Case studies from LeDeR reviews completed in Derbyshire during 2023/24 are shared throughout this report to evidence this.

A national target set by NHSE is that 35% of reviews are completed as focused reviews.

Grading of Care

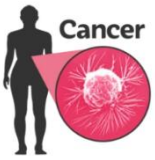
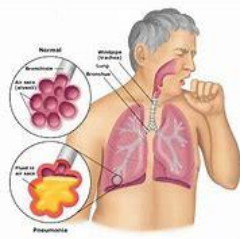
In the current version of the LeDeR platform there is only an option to grade care in reviews that are completed as Focused, and therefore the information below only relates to 15 completed Focused reviews. It is appropriate to note that Focused reviews in the majority are completed where issues have been identified and a fair assumption is that it is unlikely that grading of care would be scored at a high level. It is likely that an Initial review would have potentially been scored at a higher level.

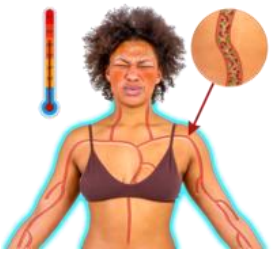
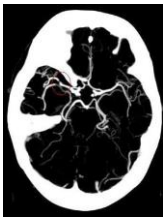
NB. If a comparison is to be looked at this can only be compared to annual reports since 2021/22 as in earlier years (when using the earlier LeDeR platform) grading of care was captured for all reviews.

Grade		Percentage against the 15 focused reviews 2023/2024	Percentage for the focused reviews 2022/23	Percentages for focused reviews in 2021/22
6	This was excellent care (it exceeded expected good practice	**13%**	**0%**	**0%**
5	This was good care (it met expected good practice)	**27%**	**23%**	**30%**
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)	**20%**	**38%**	**20%**
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	**33%**	**31%**	**20%**
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	**7%**	**8%**	**30%**
1	Care fell far short of expected good practice and this contributed to the cause of death	**0%**	**0%**	**0%**

Reasons for Death in Derbyshire

Of the completed reviews during the period 1st April 2023 to 31st March 2024 the reasons for death are categorised and separated out below.

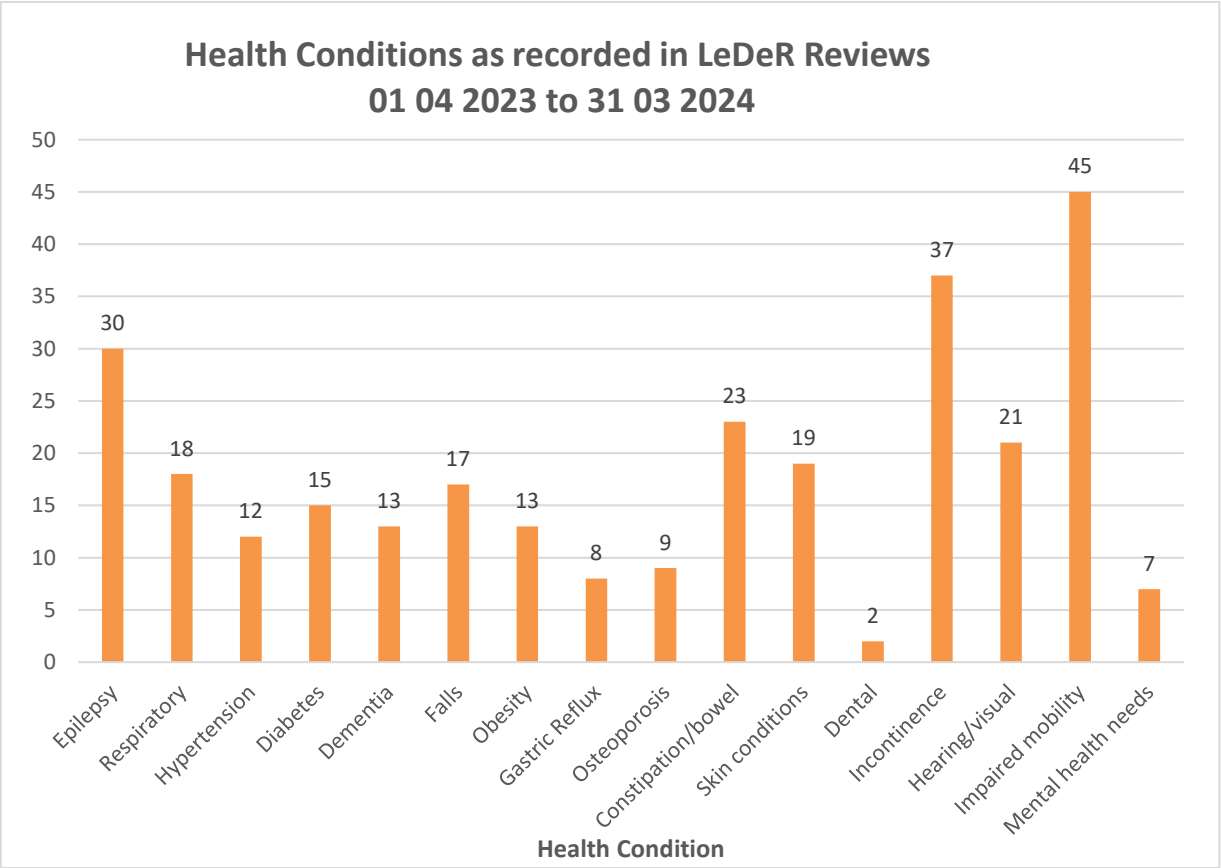
For Reviews completed 2023/2024		
Death category		**Percentage with this death category at 1a of death certificate**
Respiratory Infections	Respiratory infections such as **pneumonia, bronchopneumonia, Community Acquired Pneumonias and Hospital Acquired pneumonias, along with chest infections.** A respiratory tract infection can affect the airways, such as with bronchitis, or the air sacs at the end of the airways, as in the case of pneumonia 	**24%**
Cancers	Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body 	**13%**
Aspiration Pneumonia	**Aspiration pneumonia is pneumonia that is caused by something other than air being inhaled (aspirated) into your respiratory tract.** These non-air substances can be **food, liquid, saliva, stomach contents, toxins** or even a small foreign **object.** 	**11%**
Heart Conditions	When blood flow becomes limited or stopped, the body shuts down and - without intervention - can lead to death. 	**11%**

Sepsis/Septic shock	Happens when your body overreacts to an infection you already have and starts to damage your body's own tissues and organs 	**5%**
Covid-19	An infectious disease caused by a virus characterised mainly by fever and cough and can progress to more severe symptoms 	**5%**
Frailty	Increased vulnerability to poor health outcomes due to underlying conditions 	**3%**
Multi Organ Failure	When the inflammation from a severe infection or injury causes dysfunction in two or more organ systems 	**3%**
Stroke	A stroke can occur when blood flow to the brain is blocked or there is sudden bleeding in the brain. 	**3%**
Others		**22%**

Health Conditions

Data is collected locally of the health conditions of everyone who receives a LeDeR review. This information is used to enable us to identify possible areas of work.

A graph for 2023/24 is shown below identifying the health conditions and the number of times each condition was identified. This information is taken from the 63 completed LeDeR reviews during that period.



Constipation has been a priority area for us for a number of years now and it is good to see that the percentage is remaining low compared to earlier years, here showing at 37% (23 of the 63 completed reviews). We will be continuing to monitor this closely as this is a slight increase on last year which was 34%.

In last year's report epilepsy was seen in 38% of the completed reviews, this year it has increased to 48% and we will continue to raise the importance of prioritising this area of work.

Impaired mobility is associated with osteoporosis and yet impaired mobility is recorded 45 times in the health conditions graph above compared to 9 for osteoporosis. It is known that FRAX, a diagnostic tool used to evaluate the 10-year probability of bone fracture risk developed by the University of Sheffield, is not sufficiently sensitive enough to identify osteoporosis in people with learning disabilities, and therefore likely to be undiagnosed in many cases. For this reason, the title *Diagnosed Osteoporosis* will be used moving forward rather than just osteoporosis. It is likely that if more people with learning disability were diagnosed with osteoporosis then impaired mobility and osteoporosis would possibly show more similar numbers.

Themes from reviews

Themes are collated for every completed review. This information is collated and used to highlight local priorities. Themes collated for the 2023/24 year are included in Appendix 3 of this report.

The two joint highest themes mentioned in **35%** of the 63 reviews completed in 2023/2024 are:

"No/poor evidence of reasonable adjustments being made"

"No GP Health Action Plan"

Followed by:

"No evidence that Mental Capacity Act has been followed in relation to best interest decisions" - **32%**

"Poor sharing of information from one organisation to another" - **29%**

"No evidence that Mental Capacity Act has been followed in relation to consent" - **26%**

Mental capacity

An emerging theme is that of mental capacity for people with a learning disability and autistic people. LeDeR has found some evidence to suggest that capacity is assumed, and the individual is making an unwise decision but without the necessary professional curiosity.

The correct application of the presumption of capacity in Section 1(2) of the Mental Capacity Act (MCA) is a difficult question and often misunderstood by those involved in care. It is sometimes used to support non-intervention, lack of engagement or non-concordance with treatment but this can leave people with care and support needs exposed to risk of harm.

One example seen in our Derbyshire reviews showed a lady in her 40's with a mild learning disability and autistic traits (awaiting an autism assessment) who went for her annual health check and had a significantly high BMI, the GP explained that she needed to lose weight to improve her respiratory condition however, it was documented that "this fell on deaf ears". This is an example of presumed capacity and the assumption of her making a poor decision. Mental Capacity is important in this example when there is a risk of harm.

What work has been happening in Derbyshire in 2023/24

This section of the report details areas of work that have been happening across Derbyshire during 2023/24. Some of this work is as a direct result of learning seen through the LeDeR programme and others are areas of work that are happening to reduce health inequalities and have been shared with and promoted through the LeDeR Steering Group throughout the year.

LeDeR Steering Group

Learning from LeDeR is shared across the System and is discussed at the quarterly LeDeR Steering Group. Specific learning is also shared across certain members of the System where it is appropriate for work they are involved in. This includes working with the Mortality Review Facilitator at DCHS to produce regular reports which includes LeDeR learning that is then fed back to the Mortality Group, and working with Safeguarding Leads at Derbyshire County Council to look at specific themes that are raised as part of actions and recommendations from the LeDeR reviews. As a result of this where there were concerns that mental capacity assessments and best interest decisions were not always considered or actioned, Derbyshire County Council have completed mental capacity briefings to further educate colleagues. Case studies in this report show real experience of the importance of correct mental capacity assessments.

Addressing Inequalities across minority ethnic communities

As part of the LeDeR programme we now have two Minority Ethnic Leads who will share the role in Derbyshire. Both individuals attended their first LeDeR Steering group in July 2023.

A system-wide meeting has been held to complete a mapping exercise, the focus of this was to determine what each service is currently doing to address health inequalities across minority ethnic communities and what are the key priority areas as a System we need to think about. There has been a particular focus on ethnic minority groups as a result of the 'We Deserve Better' Report which was fed into this meeting.

The Health Facilitation Team have given presentations about the "We Deserve Better Report" at the Good Health Group and Learning Disability Partnership Boards and the Interim Lead Health Facilitator has met with the DCC BME forum lead and hoping to present to them soon and/or further develop links.

Ageing Well Team

The team, which cover the Chesterfield and Dronfield area of the County, provide primary care for a number of care home for residents with learning disability and autism. They also visit patients who are permanently or temporarily housebound on behalf of their GPs. This includes people for whom a home visit would be a reasonable adjustment due to their diagnoses. They have employed a Care Coordinator

to specifically manage work with this cohort of patients.

They continue to have regular MDTs regarding complex patients, working with the specialist learning disability team from Ash Green in Chesterfield.

As they prepare for a CQC (Care Quality Commission) visit they have been doing some work around audits, one of which includes assessment and documentation of mental capacity.

The team are also trying to build on early work that has been done with teams in secondary care to avoid admission for those for whom this is appropriate, but also to improve access to treatment and investigations for patients who need this.

The team also work on Respect forms, which they do on behalf of the GP.

Autism Services

A number of autism services have been commissioned:-

- **Derbyshire Autism 1-1 Empowerment and Support service** – offers free short term 1-1 support to autistic people (including those who self ID and those awaiting a diagnosis)
- **Living Well with Autism service** – offers 3 free different autism education/knowledge/training courses (1x for professionals / 1x for IAPT practitioners / 1x for autistic people (including those who self ID and those awaiting a diagnosis) and their support networks)
- **Derbyshire Autism Information and Advice service** – offers free autism digital and telephone signposting for professionals and general public. Includes an autism awareness course which is free to statutory services.

Bowel Screening

Three out of the 8 cancer deaths in 2023/24 (37.5%) were caused by bowel cancer/colorectal carcinoma (1a on the person's death certificate). It is important that individuals are supported to participate in bowel cancer screening which can detect these types of cancer.

At Chesterfield Royal Hospital a quality improvement programme has been set up that aims to increase

screening participation for people with a learning disability by identifying obstacles caused by health inequalities. They are part of a task and finish group, Cancer Prevention Workstream Group, and their first study is looking at people with a learning disability.

The model for the programme has been agreed, providing additional support to people with learning disabilities when they are invited for bowel screening. Six weeks after the invite has been sent out the team will offer the individual extra support to help them make the right decision regarding whether to be part of the bowel screening. Should a colonoscopy be required following the initial bowel screening the team will also check to make sure the individual is fully supported and has all the information they need to attend, ensuring the information that is provided to the individual is appropriate to their needs. The team aim to pilot this work with patients/data from a number of GP practices in Derbyshire.
It is planned that any learning the Trust gather as part of this programme will then be shared across other screening services to allow them to adopt some of the ways to better support people with learning disabilities.

Cervical screening

Reasons for non-attendance of cervical screening (as identified by Derbyshire LeDeR programme) include assumptions that screening is unnecessary when a woman is (thought to be) sexually inactive and / or acceptance that women with learning disabilities are likely to be non-compliant with screening. In fact, support is available and should be sought to enable all women of eligible age to access cervical screening.

Following the learning from LeDeR in relation to poor uptake of cervical screening for women with learning disabilities of eligible age a summary of information was gathered from integrated sexual health services, North South community learning disability teams and Strategic Health Facilitation Team, as follows:

- Integrated sexual health services are divided into clinical, health promotion and system wide development and engagement (sexual health alliance). Easy read information is available but may require further adjustment according to need. Health promotion can offer bespoke education sessions, but the team are not able to lead on mental capacity assessments.
- The Strategic Health Facilitation Team have accessible screening resources; they include cancer screening as part of GP training and advise that it would not usually be in a woman's best interest to pursue screening where she lacks capacity to consent. Those who have capacity but do not consent to screening should be kept on recall.
- Primary care should be the first port of call for support with mental capacity assessment for cervical screening and reasonable adjustments to enable access. A specialist learning disability referral is needed for support from the community learning disability team (CLDT) who can offer education, desensitisation, reasonable adjustment, and will lead on mental capacity assessment. Although CLDTs

have good links with sexual health services, they receive few referrals for cervical screening support for women with learning disabilities.

On the back of this information gathering, representatives from the Strategic Health Facilitation Team and Community Learning Disability Teams attended the Sexual Health Alliance meeting as part of System wide development and engagement.

Another upcoming agenda is women's health hub development, led in the ICB and in liaison with the Public Health Lead in Sexual Health via the Sexual Health Alliance. The Public Health Lead planned to engage with the Health Facilitation Team and learning disability services to support ongoing development specific to needs of women with learning disabilities and in particular cervical screening.

Clinical Care Pathways

ND adult aligned health services are implementing new clinical care pathways across Derbyshire including complex physical health, functional independent and social inclusion, eating and drinking, dementia, distress and dysregulation, relationships and trauma.

Epilepsy

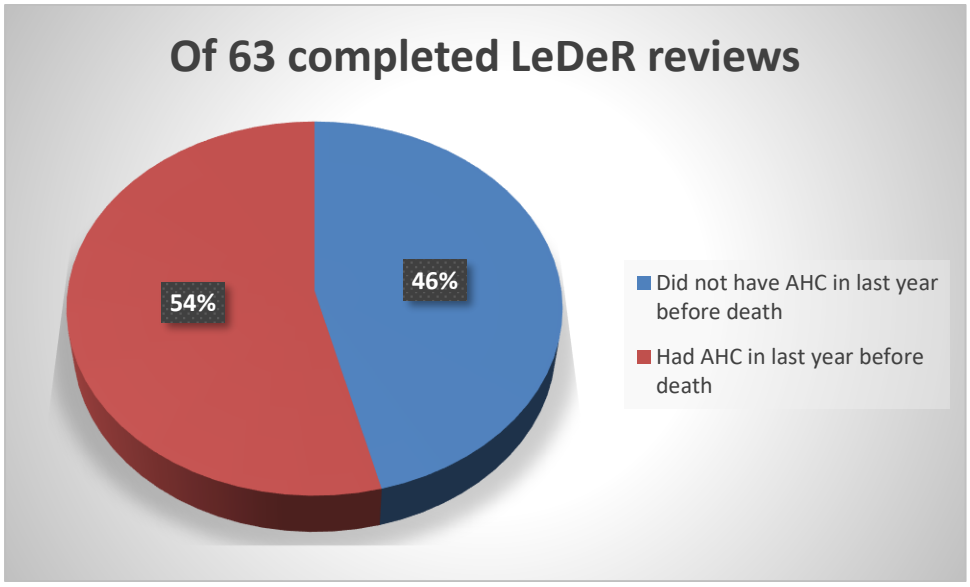
It has been escalated across the System that there is a need for an Epilepsy Lead/Commissioner as there is currently a gap here for adults. Throughout the year we have chased the possibility of this or any alternative solutions. Unfortunately, this has not progressed during the year but continues to be something we will continue to prioritise as epilepsy is still one of the highest health conditions we see in our learning from LeDeR. Work to be done was also evidenced through the NHS England Midlands Epilepsy Benchmarking exercise.

Learning Disability Annual Health Checks and the Strategic Health Facilitation Team

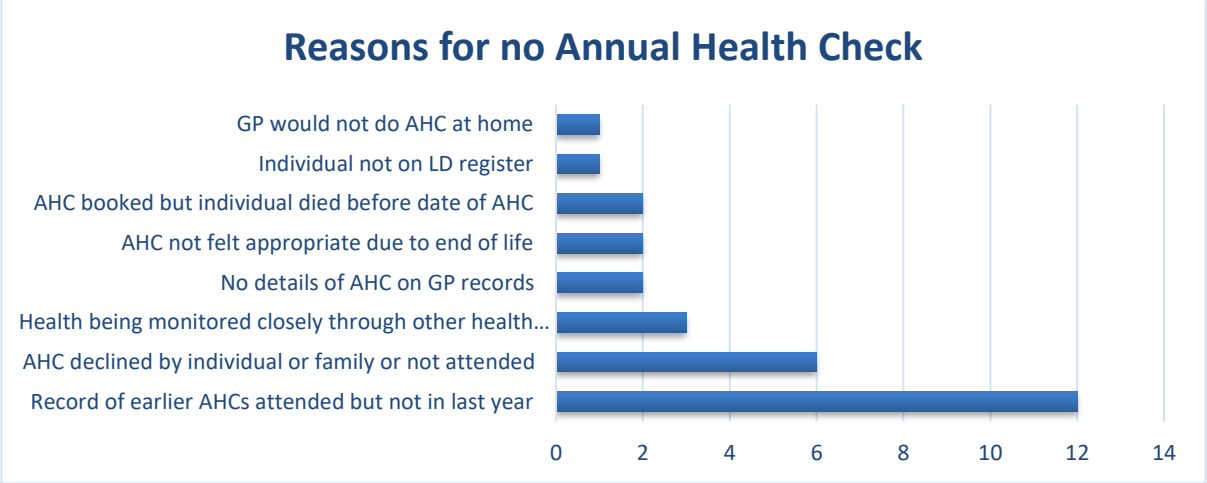
People with a learning disability often have poorer physical and mental health than other people. It is important that everyone over the age of 14 who is on their doctor's learning disability register has an annual health check (AHC).

An annual health check can help the individual stay well by talking to a doctor or nurse about their health and finding any problems early, so they can be sorted out.

We have been capturing data through LeDeR to monitor information in relation to annual health checks. Out of the 63 completed reviews, there were 29 individuals who did not have a health check in the last year before they died, and 34 individuals that did.



Reasons for no annual health check are shown in the graph below:-



Examples of good practice seen are shown below:-

- Annual health check carried out as telephone review as individual was housebound. As soon as the individual was able to travel to GP practice another appointment was made to see them in person.
- Use of accessible letters.
- Invite shared with individual to visit the breast clinic routinely to familiarise herself with the equipment and staff after the breast screening appointment had to be stopped due to distress of patient.
- Individual seen by specific GP who they had a good relationship with - the only doctor they allowed to take bloods.
- The annual health check was a holistic and person-centred review.

- Easy read health action plan with pictures was provided to aid the individual's understanding.
- Although declined by mum the referral was shared with learning disability team to see if they could support and make reasonable adjustments to support the individual to attend cervical screening.
- The annual health check template was filled out thoroughly along with a thorough physical examination.
- Reasonable adjustments were recorded that appointment reminders were sent to family members and appointment times should be based on carer availability, easy read letter should be sent and more time made available for telephone calls.
- Evidence of annual health checks carried out at individuals' homes.
- Link for easy read information on cervical screening was sent by text to parents following discussion at annual health check.

There were some areas where it was thought improvements could have been made to the health check. In a number of cases where it was stated the individual had an annual health check there was no health action plan visible to the reviewer in the GP notes. Some notes were very detailed about the annual health check, but others were not.

What work have the Strategic Health Facilitation been doing?

The team have produced a survey to find out more from individuals and their carers as to why people have not been attending their annual health checks. The survey was codesigned with experts by experience and was sent out to a range of major stakeholders in Derbyshire including partnership boards, advocacy organisations and carer representatives. The survey report was also sent to all Neurodevelopmental Teams to complete with service users and was also take to T2 in Derby (Transition 2 in Derby is a college for young adults aged 18 to 25 with learning disabilities and/or autism).

The results from the survey found:-

- 50% of people with a learning disability didn't know what the Annual Health Check was.
- 25% of carers didn't know what the check was.
- 64% of people with a learning disability and 71% of carers identified that help was needed to get them to the appointment.
- 93% of people with a learning disability said they needed help to understand during an appointment.
- 57% of people with a learning disability needed help to contact their doctors if they were poorly.
- The majority of people with a learning disability and their carers think that the Annual Health Check is important.
- Those who felt the check was not important said they were already seeing consultants and some said they thought it was a "tick box exercise".

The survey also found the following in relation to problems that stop people going to the health check:-

- Person with a learning disability doesn't like the physical examination.
- The surgery is bright and noisy and busy.
- "Transition" from child to adult services can be difficult.

The survey results were taken to the Learning Disability Derby City Partnership Board to ask for ideas of solutions. Some of the options discussed were:-

- Look at rolling out a learning disability champion system.
- Help with roll out of reasonable adjustment flag.
- Look at how the annual health check can be offered in community settings.
- Transition role to improve transition process within Derbyshire.
- Offer reasonable adjustment training to doctors' surgeries.
- Look at how health passports, health action plans can be improved.

These options are being considered.

In addition to the survey work the Health Facilitation team continue to promote annual health checks and support GP practices to ensure their Learning Disability registers are up to date. This year the team have also offered quality checks to GP practices which have been further adapted to include lifestyle factors and health promotion with a focus of including these in health action plans. Following the launch of Pharmacy First in January 2024 they are also looking at how to work with pharmacies around raising awareness of the annual health check.

Additional work the team are involved in includes:-

- They have started to offer bitesize training sessions to social care and voluntary sector staff - one has been delivered on lifestyle issues, one is due on constipation.
- Attending learning disability partnership boards and have presented on lifestyle, increasing awareness of annual health checks amongst people from an ethnic minority and other issues.
- They have started to look at improving links with Live Life better Derbyshire and Public Health and hope to continue further work in this area.

Public Health

The Mental Health and Suicide Prevention Team (Derbyshire County Council Public Health) are working on a number of pieces of work to raise awareness and decrease stigma and change culture. Work includes posts and articles on social media, podcasts, networks and producing hard copy information. This is being delivered at population level and targeted groups. They are also working in partnership with Derbyshire Autism Service to develop a training session on neurodiversity and suicide, planned for Spring/Summer 2024. The Team is also developing an easy read poster and making amendments to wellbeing booklets co-produced with Derbyshire Reps on Board Learning Disability Partnership Forum.

The Community Support and Resilience team (Derbyshire County Council Public Health) have relaunched the Derbyshire Safe Place Scheme post-pandemic to increase the number of Safe Place venues across the County and to raise public awareness of the Keep Safe Card. The scheme is now part of the Safe Places National Network, meaning venues can be located on a smart phone app as well as being identifiable by a nationally recognised window sticker. Whilst the scheme is open to anyone it is particularly pertinent for people with learning disabilities and/or autistic people as a tool to increase confidence when accessing the community independently. A video is currently being co-produced with representatives from these communities to improve understanding of how the scheme works.

Reasonable Adjustments

Under the Equality Act 2010, health and social care organisations must make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. Here's some work that has been done during 2023/24 in Derbyshire related to reasonable adjustments:-

- A **Reasonable Adjustment Group** has been set up that aims to bring together people across Derbyshire who experience, are involved in projects, or lead on reasonable adjustments for people who are neurodiverse (this includes people with Learning Disabilities, autistic people and those with ADHD).
- At DHcFT easy read training has been rolled out to improve consistency and high-quality production of accessible written information across ND adult health services.
- The Head of Practice at DHcFT has been working with the Adult In Reach Team to work through a reasonable adjustment template for admissions.
- Following involvement with LeDeR the Learning Disability Social Care Team at Derby City Council have been focussing on reasonable adjustments and ensuring all learning disability health checks, hospital passports, health action plans are in place when they undertake care reviews. The team have been analysing how many individuals they support have these in place and have highlighted the areas in their electronic social care records to highlight any reasonable adjustments required. This also means that they will then be automatically populated in individuals social care assessments. It was found through this scoping exercise that individuals living with family carers at home were the least likely to have a hospital passport and this was to be an area of focus at future reviews.
- The Learning Disability Liaison Nurse at Chesterfield Royal Hospital, who already works with the Imaging department to support patients with learning disabilities, has been doing additional working with the department to look at pathways and where reasonable adjustments can be made for patients with learning disabilities.

ReSPECT/DNACPR

The aim of the ReSPECT process is to create personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices.

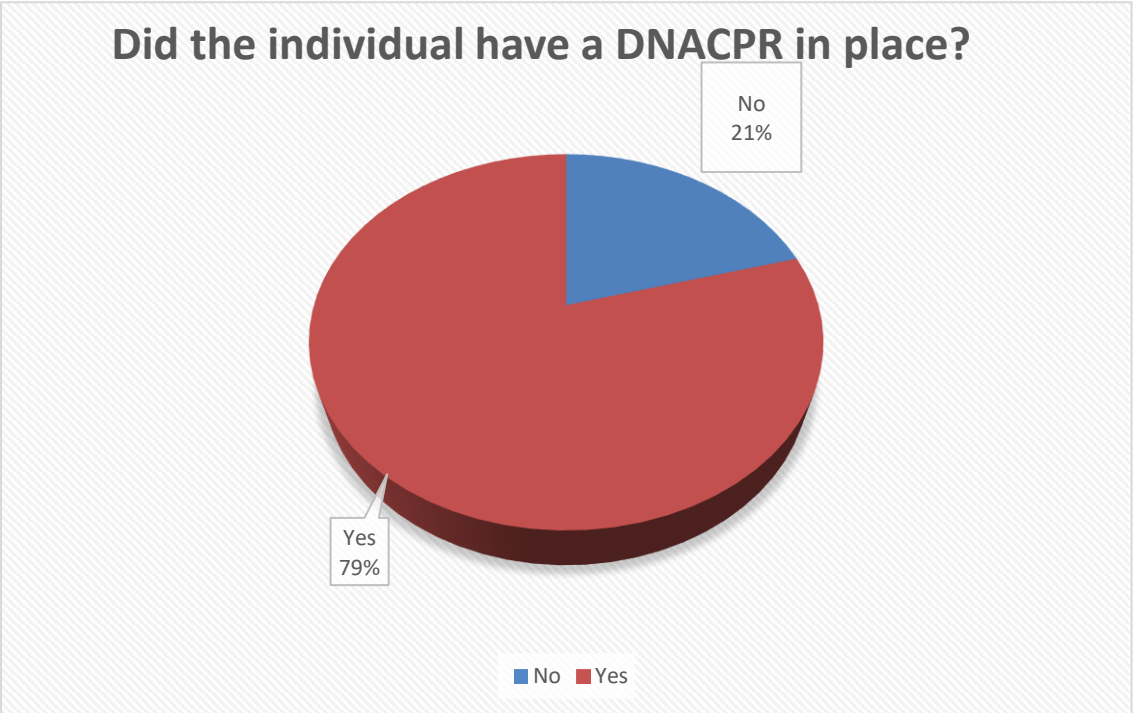
These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment. The ReSPECT process can be for anyone but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest. Some people will want to record their care and treatment preferences for other reasons.

As part of the LeDeR review, information is gathered with regards to the conversations that are held around DNACPR and how this information was recorded on the individual's ReSPECT form and in their health records. DNACPR stands for do not attempt cardiopulmonary resuscitation. It is sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate) but they all refer to the same thing. DNACPR means if your heart or breathing stops your healthcare team will not try to restart it.

Learning found through LeDeR

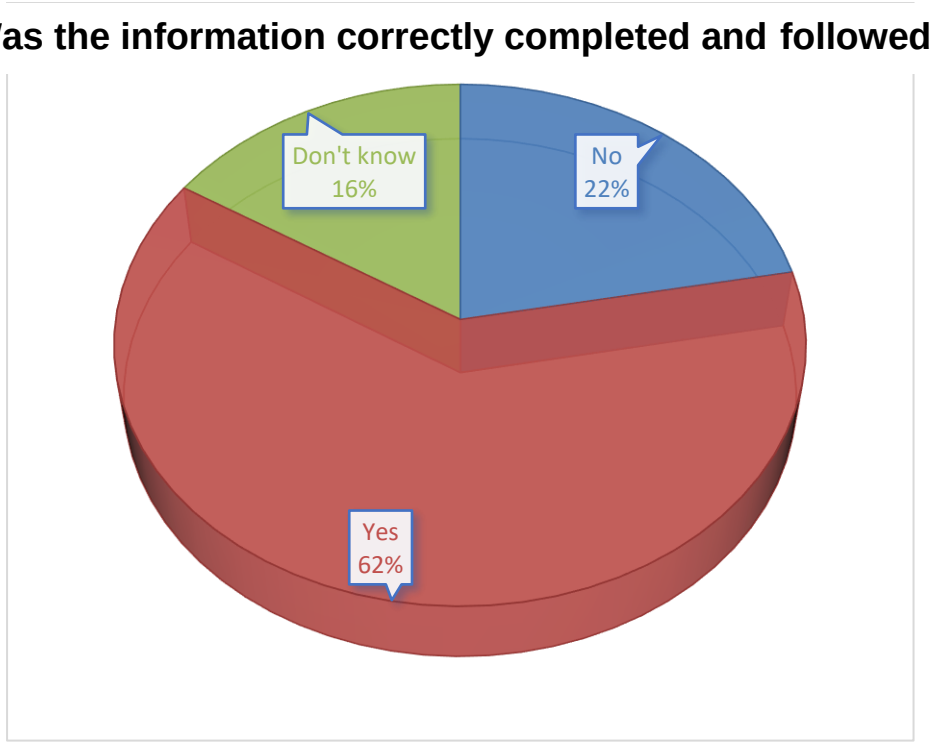
For the 2023/24 period, of the 63 completed LeDeR reviews for people with learning disabilities, the information captured shows:-

50 individuals had a DNACPR in place, 13 did not have a DNACPR in place.



Of the 50 individual who had a DNACPR in place:-

For 31 of the individuals it was reported in the LeDeR review that the information had been completed and followed correctly, for 11 of the individuals it had not, and in 8 cases it was not known.



Where the answers were recorded as not known this is due to the ReSPECT/DNACPR form not being available for the reviewer to see.

Evidence provided as to why the answers were recorded as no against "*Was the information correctly completed and followed*":-

Documentation was only partially complete and indicated a required capacity assessment, which had not taken place

Section 2 relating to having a legal welfare proxy in place is not completed despite mother having health and welfare lasting power of attorney.

DNACPR form states discussed with patient but no narrative and no indication given on the form that a capacity assessment was considered.

Does not contain any evidence pertaining to individual's wishes (either at the time or previously). Individual had a regular care team involved and the DNACPR should have involved them.

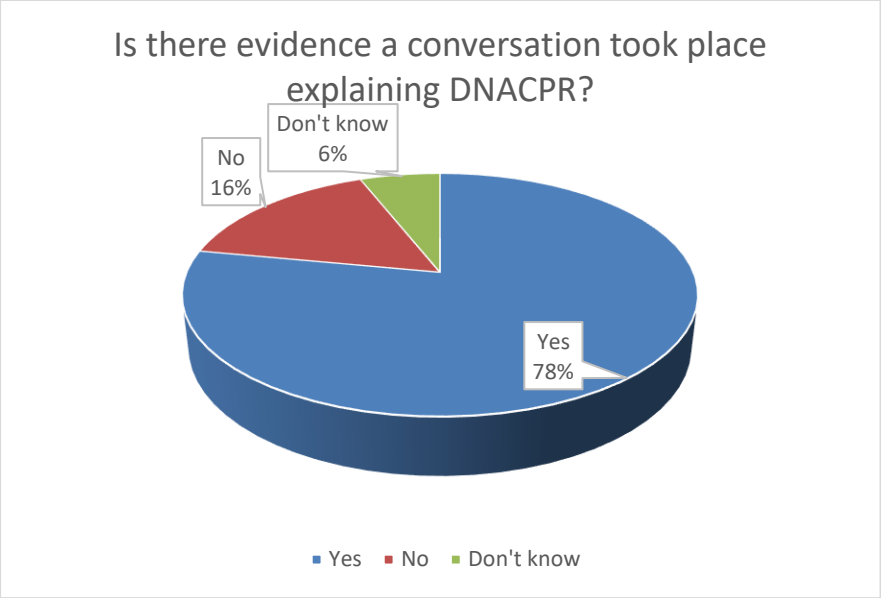
Sections were left blank or incomplete on the ReSPECT form. Shared understanding of health and current condition section states that individual was "bed bound ...since August 2022" which was inaccurate as she was mobile in her wheelchair. The mental capacity assessment of the ReSPECT form had been left blank.

The section relating to the lawful decision maker was not completed and it was recorded that Best Interest discussions had taken place with the family, but detail of that discussion was not documented on the form

It was documented in hospital record that a conversation was had with family but this was not on the ReSPECT form

Although there was a best interest decision agreed with family and carer involvement this section was incomplete on the ReSPECT form

The reviewer could see in the electronic records that the DNACPR was updated on 18th August 2020, but the date was not added to the ReSPECT form

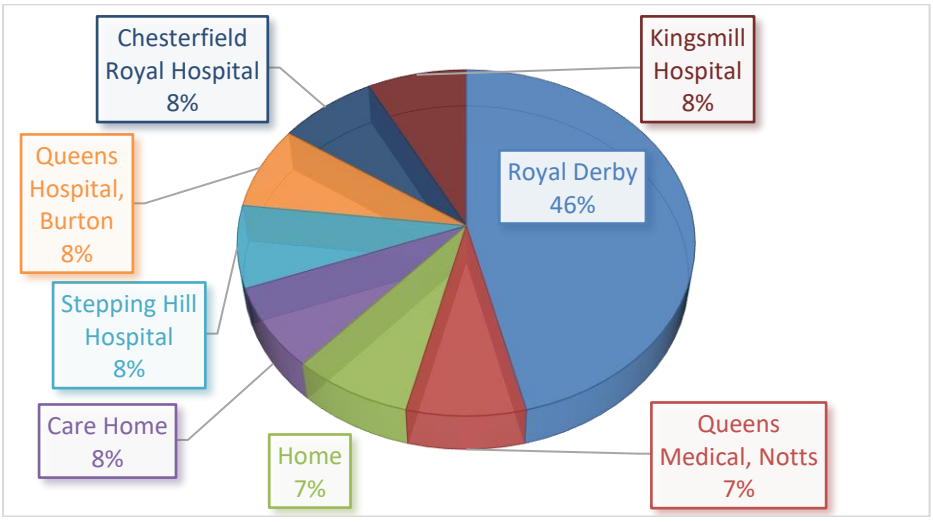


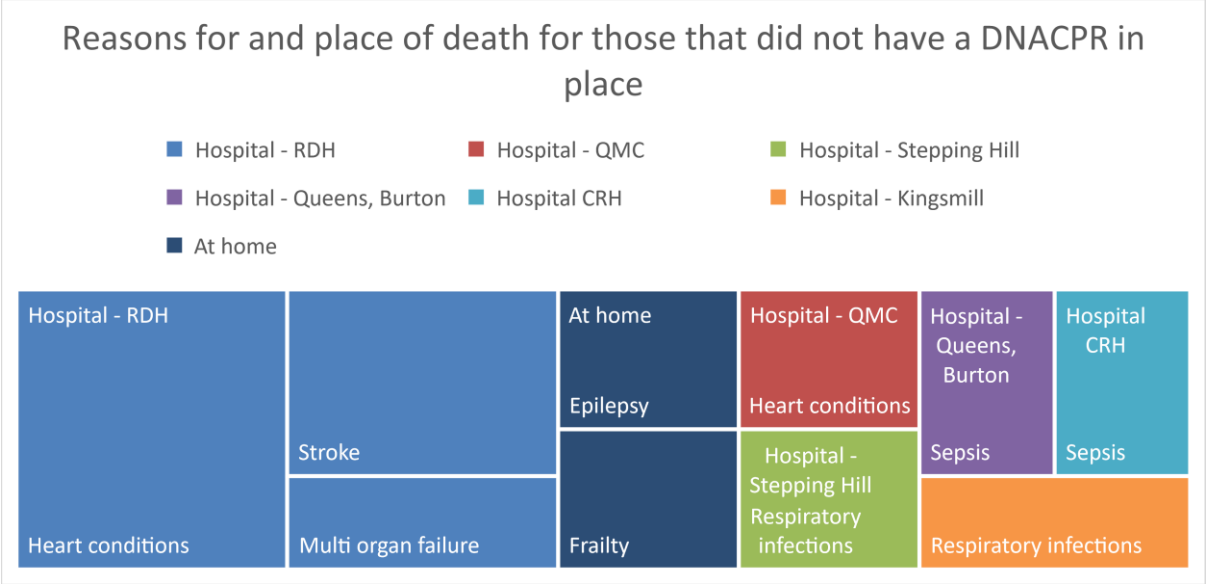
Out of the 50 who had a DNACPR in place there was evidence to show a conversation took place to explain DNACPR in 39 of the reviews, there was no evidence in 8 of the reviews, and for 3 of the reviews this could not be answered as the ReSPECT form was not reviewed and no information provided during any conversations the reviewer had.

29 (or 58%) of the reviews showed evidence that this conversation was recorded in records and on the ReSPECT form. The figure is lower than the 39 as in some cases the conversation was not actually recorded on the ReSPECT form, but the LeDeR reviewer saw evidence that the conversation was recorded in medical records or the reviewer was told by family/carers that they had been involved in a conversation. There were only 6 reviews that showed evidence of the individual having capacity and being engaged in this discussion and decision making. Often the person was too unwell to be involved in these conversations particularly for those in a hospital setting.

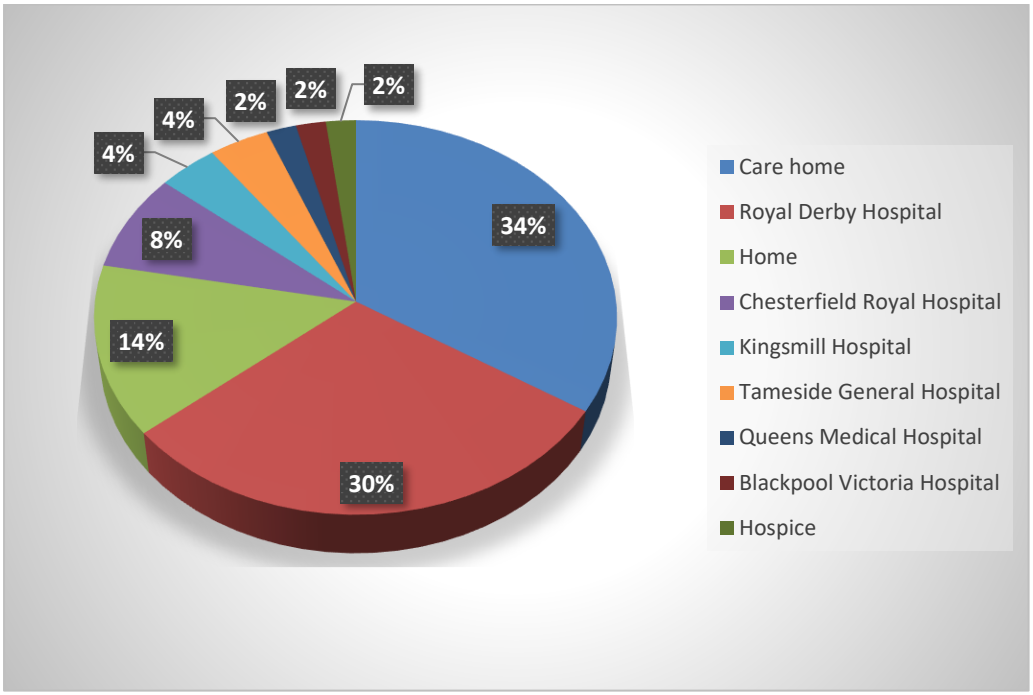
Hospital deaths

Of the 13 that did not have a DNACPR in place at the time of their death, 11 died in hospital, with the majority being at Royal Derby Hospital at the time of their death.





For those that had a DNACPR in place at the time of their death the most common place of death was the care home with 17 deaths, followed by Royal Derby Hospital with 15 deaths. Seven individuals died at home and 4 individuals died at Chesterfield Royal Hospital.



Good practice seen

It's important to share that evidence of some good practice has been seen in the learning from LeDeR in relation to DNACPR. Evidence of this is shown below taken directly from the LeDeR reviews:-

Cousin informed that the original DNACPR was completed in hospital when xx had his PEG inserted and that this was regularly reviewed during subsequent hospital admissions. She was always contacted as next of kin and involved in the decision making process. She reports that xx did not have capacity to understand this and that's why best interest decisions were made.

It was not appropriate to provide accessible communication to aid understanding due to the individual's level of learning disability. Mum was involved in all of the discussions and part of decisions made in individual's best interests.

An MCA was completed as part of this and xx did not have capacity due to delirium and learning disability. The decisions were made in her best interests and fully considered her health status each time as well as what would be considered her wishes for treatment and dislike of hospitals. The most recent form stated that a community ReSPECT form was in place and that this had been discussed with her brother.

DNACPR was discussed at length and agreed in a meeting with palliative care nurse, sister, and a member of the care home nursing team. The discussion was documented in the notes and on the ReSPECT form, which was correctly dated and signed.

Documented on ReSPECT form that individual does not have the mental capacity, even with support, to participate in making these recommendations. Best Interests professionals meeting held 21/4/2023 attended by Learning Disability team, Gastroenterology Consultant, GP, Social Worker and Care Workers from supported living.

What work has been done in 2023/24?

Earlier learning from LeDeR evidenced that 69% of DNACPRs (where in place) were correctly completed and followed, (note that the later learning collated in this report across the whole of the year now shows this percentage to be lower at 62%) and based on this earlier evidence a ReSPECT/DNACPR meeting was held at the end of Quarter 2. The aim of the group was to bring colleagues together across the System to hear about what is happening across care providers in relation to understanding what learning is already available with regards to ReSPECT/DNACPR, are the issues already known and what training is available to support the ReSPECT process.

The meeting was well attended with colleagues from both Derbyshire acute hospitals, general practice, a local hospice, community care providers and ICB.

Some key points taken from the meeting were:-

- This meeting wasn't about changing the ReSPECT forms in any way but was to open a discussion about whether they are completed and followed correctly
- Audits are completed within the acute hospitals
- CQC will audit some ReSPECT forms as part of their inspections of GP practices
- There are already lots of pieces of work happening individually across the system
- Although the meeting had been set up to talk about ReSPECT across the whole population (not just people with learning disabilities and autistic people) it was widely acknowledged in the meeting that it was such things as the mental capacity section and the making of reasonable adjustments for individuals where appropriate that were key areas where work was still needed to make improvements
- Education and training were acknowledged to be key and the need to build the confidence of people to have the conversations around ReSPECT and for it to be clear whose responsibility it is.

Some areas of work that are already happening:-

- The Derbyshire Alliance End of Life Care toolkit that exists in Derbyshire. This is a very valuable resource that shares information and knowledge, it has been around for a number of years and supports the whole delivery of education and knowledge and information around every aspect of end of life care, including ReSPECT information. There's also lots of information that supports the encouragement of ReSPECT being used correctly and education and training. Derbyshire is currently part of a programme of work that is a collaboration between three ICBs (Derbyshire, Notts and Birmingham/Solihull), funded by NHSE, to improve the toolkit. Project delivery is planned for this year and will include an education and training portal as part of the toolkit. Part of the ambition across the three ICBs is that this could be shared across the Midlands.
- GP working with NHSE looking at ReSPECT/Advance Care Planning and how to roll out ReSPECT on a Midlands footprint. Aim for how each system can put training packages together but there are loads of resources on the site already so there is no need to reinvent the wheel. Hoping if one area has an educational programme then this could be shared across the whole of the Midlands.

- Standardised resus training is held locally and has been shared by resus leads across the system at UHDB and Chesterfield. There have been lots of audits completed around Respect forms and how they are completed. When delivering training they are aware there has been the need to build on the confidence of people to have the conversations around ReSPECT and be clear whose responsibility it is. A working group has been set up about how to reframe and support some of those conversations and communication skills.
- Specific Tier 2 ReSPECT communication skills training has been developed and being delivered by both Advanced Communication Skills Facilitators at Treetops Hospice and by the acute End of Life Facilitators education offer at UHDB as a pilot . There has been a small amount of money to pilot this training across Derbyshire community clinical services (100 places, 2023/24 Treetops Hospice). Both have been using RealTalk direct evidence base and CRH hope to deliver some Tier 2 also. The confidence building and increasing number of clinicians able to have these conversations are in line with the recommendations of the PHSO report (2024) but there are gaps as no further funding at present.
- Work with Shared Care Record – The Derbyshire Electronic Palliative Care Coordination System (EPaCCS) records people's care preferences and important details about their care at the end of life. The aim is that this will be rolled out in Autumn 2024 alongside a new education package for the new form. This will ensure there will be one place where we can document conversations and preferences about end of life care that everybody can access and read and write to, so everyone will have access to the latest information.

Conclusion and Next steps

Learning from LeDeR has shown us:-

Better recording needs to be included in the ReSPECT form. We have seen evidence that the conversation did take place in some cases to explain DNACPR and/or to involve families or carers in decision making, but this was not always recorded on the ReSPECT form.

In some reviews we have seen that conversations about ReSPECT could have been held earlier when the individual was in the community, rather than waiting until they are in hospital where the individual is more ill and often does not have the capacity to be involved in the conversations.

The figure of 22% for the number of ReSPECT/DNACPR forms that are in place and not completed and/or followed correctly is obviously concerning and we want to improve on this figure.

We will be sharing the information captured in this section across a number of sources as shown below:-

- With training leads in order that learning can be used to identify where training is needed and work with staff who are involved in the ReSPECT conversations.
- With LeDeR contacts in Derbyshire acute settings and community to encourage the learning to be shared and used as feedback with staff involved in the ReSPECT conversations.
- With care home leads to encourage the ReSPECT/DNACPR conversations to be held in the community with care staff and the individuals involvement in the discussions.

- With GP practices – in some cases the report has shown that a record of the DNACPR decision and/or the ReSPECT process form cannot be located. GP Practices to ensure that they have a copy of the form in all cases appropriately filed on electronic systems. CQC state that "*The presence of a ReSPECT or DNACPR form should be clearly highlighted in the patient's clinical record for all who access it*" (CQC GP Mythbuster 105)

In addition, from a LeDeR perspective we need to continue to work to improve on the number of "Don't knows" to ensure we have a clearer picture of what is being recorded on the ReSPECT/DNACPR forms.

This learning will also be shared with the JUCD End of Life Operational Group.

Healthy Lifestyle

People with a learning disability are more likely to have problems with their weight. Some people may be underweight because their disability means they have difficulties with eating or swallowing, for example. Others may be overweight because they have a condition that increases their risk of obesity, such as Down's syndrome and Prader-Willi syndrome.
It has been recognised for many years that people with learning disabilities are at increased risk of being overweight or obese compared to the general population, with poorly balanced diets and very low levels of physical activity.
Being obese puts people at much greater risk of many important health problems including - heart disease, high blood pressure, strokes, diabetes, several types of cancer, mobility difficulties.

As noted in the PHE 2020 to 2025 strategy, poor diets and excess body weight deprive people in England of more than 2.4 million life years through premature mortality, illness and disability each year. There are close links to broader social disadvantage, such as poverty, poor housing and social isolation, which is experienced disproportionately by people with learning disabilities.
The most recent data on the prevalence of excess weight in people aged 18 and older with learning disabilities is based on analysis of data from GPs across the whole of England. This showed that, in comparison to the general population, a smaller proportion of people with learning disabilities are in the milder category termed 'overweight' (27% of people with learning disabilities compared to 31.8% of people without a learning disability). However, there are higher proportions in the more severe category of obese (37% of people with learning disabilities compared to 30.1% of people without learning disabilities).

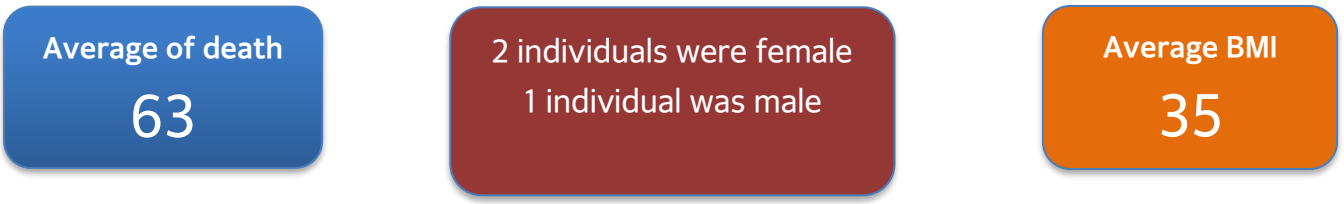
Autistic women are much more likely to develop anorexia than non-autistic women. According to Autistica, more than 2 in 10 women with anorexia are autistic. Research suggests between 4% to 23% of people with an eating disorder are also autistic.

*NHS Digital **Autistica

The above information is taken from the Learning Disability, Autism and SEND Interactive Data Source Repository

In Derbyshire we have started to collate information through LeDeR in relation to healthy lifestyles. There is only a limited amount of information currently available as the collection of this did not start until February 2024. The information shown below relates to only 3 reviews that were completed between February 2024 and 31st March 2024 where a high BMI was documented and therefore further information captured in relation to lifestyle. We have since started to capture information for those with a low BMI, as quoted there are issues with individuals who are underweight, not just overweight.

Learning showed us (taken from the 3 completed reviews):-



Data being captured includes whether there is a record that the individual was referred to the Derbyshire Live Life Better Derbyshire (county) or Live Well (city) services. In one of the 3 cases a referral had been made to the weight management service, although this was declined by the individual. In the other 2 cases there was no evidence that discussions had been held with the individual about diet or exercise.

What more can we do?

This information is shared with our Learning Disability Health Facilitation teams who are working with GP practices to promote the use of the Live Life Better and Live Well services in Derbyshire.

Through LeDeR we will continue to capture this information to share where we are identifying positive practice or gaps in services.

The following case study, details taken from a LeDeR review that we have received in Derbyshire, highlights the importance of a healthy lifestyle and also links to the next section: weight management.

Case Study

Background

J was a 54-year-old man with mild learning disabilities and multimorbidities (including insulin dependent type 2 diabetes and morbid obesity) and lived independently with minimum support. J communicated verbally and needed reasonable adjustments to optimise his understanding and engagement.

J enjoyed going into town on his mobility scooter and often treated himself to fish and chips, sugary drinks, and cakes. J relied on district nursing team to administer insulin every morning but was admitted to hospital on numerous occasions due to hypoglycaemia (blood glucose levels too low) or hyperglycaemia (blood glucose levels too high).

Issues

1.Person-centred goals

When J's placement broke down he wanted to move to Hertfordshire to be close to his brother. He was moved to a care home in Derbyshire for a period of six weeks respite until appropriate accommodation in Hertfordshire was found. Despite efforts to find alternative accommodation J remained in the Derbyshire care home for eighteen months which affected his mental and physical health.

2.Diabetes Management

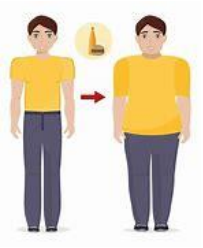
A community diabetes nurse showed the care home nursing team how to safely administer J's insulin injections prior to each meal.

J was given a blood glucose monitor and could read and record his blood glucose levels and knew when the levels were too high, but his capacity to manage his diabetes was not assessed specifically. It was the responsibility of the nursing team to manage his diabetes with support from specialist community diabetes team.

3.Mental capacity assessments/best interest decisions:

J was "assumed" to have capacity in relation to his eating habits and was "assessed" to have capacity to go to town on his mobility scooter whenever he pleased BUT would indulge in eating whatever he liked without insulin. As a result J continued to present with hyperglycaemia, with increased risks to his health. DoLS (Deprivation of Liberty Safeguarding) mental capacity assessment found J lacked capacity to make decisions concerning his "health needs" including type of accommodation to meet his needs, but that he had capacity to decide where he wanted to live in terms of location.

4.Weight Gain



The care home nursing team were concerned that J had gained nearly two stones in one month and asked the GP if dietetic referral could be considered. The GP agreed to the referral but due to J's "assumed" capacity doubted it would be effective.

Dietician found that J was "unmotivated" and was discharged after two appointments as he continued to indulge in unhealthy eating habits. Staff were issued with healthy eating guidance to try and encourage J towards a healthy diet. Specialist community diabetes team worked with care home nursing team as did the community dietician, but services worked in silo and didn't implement reasonable adjustments for communication needs (information given in small chunks, familiar language, and time to process).

J gained eight stone in weight during his eighteen months at the care home and before he died weighed twenty-four stones and one pound, and his body mass index was 51.89kg/m2 indicating morbid obesity.

Death

The death certificate shows that J died of acute left ventricular (heart) failure, caused by obesity-associated cardiomyopathy (weight related heart disease).

The case was referred to the coroner and safeguarding but there was no postmortem or inquest and there was no evidence to suggest that J's death was due to neglect or acts of omission.

Learning was identified through LeDeR

Communication is key to all decision making and reasonable adjustments must be made when considering capacity.

Person centred care; J's care was heavily biased towards his health needs compared to his person-centred needs and although placements in Hertfordshire were being addressed J's mental health and physical health suffered the longer he remained in the care home away from his family.

A Personalised Integrated Package of Care could potentially have been explored to support a personalised approach to care.

Mental Capacity & Diabetes Management

J had capacity to go out independently, but critically his capacity in relation to eating his favourite foods without insulin in the community was not questioned. Had the capacity question been more specific to include the matter of eating out whilst accessing the community independently, it is likely that a best interest decision would have been agreed and consideration of least restrictive safe community access.

Mental Capacity & Weight Management

J was assumed to have capacity to eat and drink what he liked but gained eight stones in weight and died from heart failure due to obesity associated heart disease. Where capacity is "assumed", but doubt exists or high risk is identified as in J's case, mental capacity assessment is justified and should be completed.

Weight management

Obesity and Weight Management guidelines for People with learning disabilities (2020) recommends a multidisciplinary approach to weight management. This was lacking in J's case despite a specialist (multidisciplinary team) weight management service being available within DCHS. There was a lack of awareness about the service and although currently under review, the service will need to be promoted well across the System.

Weight Management

Based on LeDeR learning such as seen in the case study above and there seems to be a lack of awareness of what services are available, this prompted an exploration of what is available in Derbyshire in relation to weight management services.

Background

There is an increased risk of severe obesity in people with a learning disability and a higher incidence of associated serious health conditions compared to people without a learning disability. Whilst lifestyle factors such as low activity levels and poor diet contribute to the risk of obesity for people with and without learning disability, additional factors such as family and carer knowledge and attitude, inconsistent nutrition and difficulty in understanding change behaviour strategies for people with learning disabilities add to the complexity of *managing* obesity in this population.

Services in Derbyshire

Derbyshire Adult Social Care commission a Health Tier 2 weight management programme which forms part of the Live Life Better Derbyshire www.livelifebetterderbyshire.org.uk. scheme. This programme provides a personalised approach to weight loss programmes and considers emotional and psychological elements of weight management as well as food and activity.

There is a self-assessment which can be completed online and if the outcome meets the Tier 2 referral criteria below individuals can self-refer.

- Aged 18 years or over
- Live in Derbyshire
- Body Mass Index* of 25+ and 23+ for people of Asian and black ethnicity

It is possible people with learning disabilities would need reasonable adjustments and support with a self-referral and face to face attendance or remote access to the sessions. Support workers, carers and family are all are encouraged to attend to improve knowledge and consistency across the system and improve individual outcomes.

Bespoke group sessions can be discussed and accessed by contacting the service development officers directly. The team have recently worked in partnership with Fairplay Day Services for young adults. The team are passionate about their programmes and are happy to talk to different organisations about what they do and are very keen to work with other learning disability day services, supported living environments and care homes.

All individuals with a BMI in between 25 and 49 with or without comorbidity must have attended the Tier 2 weight Management programme before they can be considered by the GP for referral to DCHS Tier 3 weight management service.

The current DCHS Tier 3 weight management service provides specialist multiagency support to individuals presenting with a BMI of 35-49 with comorbidity, or a BMI of more than 50 (with or without comorbidity). The team consists of psychology, psychotherapy, nutrition and dietetics, doctors, and Tier3 weight management advisors.

The service is accessed through GP referrals only and the focus is on managing weight through long-term behavioural/ lifestyle changes, exploring the relationship with food and how it features in the patients' lives. This reflects NICE weight management guidelines (2022).

The Tier 3 service was granted funding in 2021 to do some research around health inequality and weight management and learning disabilities was one of the areas they explored. The project has been submitted and is awaiting approval but there is a potential opportunity to become involved in the Tier 3 project following an update in October 2023 and with Tier 2 who are also keen to include people with learning disabilities. During 2023/24 the DCHS Tier 3 weight management service completed an inequalities audit and have been doing improvement work in response to this which has included training all of the staff around working effectively with people with learning disabilities.

However, there have been issues with regards to the high numbers of people on the waiting list although work to improve the current service model, waiting list management and clarify the prescribing pathway, is in progress.

There is an equivalent weight management service available to Derby City residents through Livewell | Derby City Council's wellbeing service (livewellderby.co.uk).

References:

https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-

disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance

Obesity: identification, assessment and management

Clinical guideline Published: 27 November 2014 Last updated: 26 July 2023

Footnote * BMI of 25 to 29.9 is classed as overweight, 30 to 39.9 as obese, and a BMI of 40 or more as severely obese.

Managing Deterioration

Managing Deterioration refers to spotting that a person's physical condition is worsening and responding appropriately, to get them the best support and keep them safe.

The following case study, taken from one of Derbyshire's LeDeR reviews in 2023/24 shows the importance of managing deterioration.

Case Study

Background

D was a 64-year-old man with learning disability moderate frailty and chronic constipation. He lived in 24- hour supported living accommodation with ten 1:1 hours for support with communication and going out. He was independent with personal activities of daily living and some domestic activities of daily living. With support he enjoyed doing his own shopping and liked to go to the pub for a beer.

He had a history of chronic constipation and acid reflux and was prescribed laxatives to prevent constipation and medication to prevent reflux. D could communicate verbally but he could be difficult to understand for people who were not familiar with him. For optimal communication with D, reasonable adjustments were essential, which included speaking slowly and clearly and allowing time for D to process information.

On 7th August 2023, D presented with subtle changes in his behaviour which staff thought was due to constipation and attempted to treat it in the usual way with laxatives and diet, but the following day D was struggling to breathe, and his stomach was distended.

Emergency services were called, and whilst in the ambulance D vomited and aspirated faecal matter. On arrival in the emergency department a CT scan showed a twisted bowel, which was conservatively treated, a chest x-ray was taken and this was clear. He was treated with intravenous (IV) antibiotics and IV fluid. Support staff were unable to provide details of when D last opened his bowels as they did not monitor or document his bowel movements.

That evening D vomited and aspirated again which caused a chest infection and aspiration pneumonia. D

sadly died four days after admission.

Family were shocked by the death of D as they were under the impression he was improving after successful treatment for twisted bowel. Their experience of D's patient journey was poor, and it was their perception that there was lack of learning disability awareness amongst staff on the hospital ward.

Family learnt that a Do Not Attempt Resuscitate (DNAR) order had been instigated without discussion with them.

Cause of Death

Aspiration pneumonia, caused by bowel obstruction, caused by twisted bowel.

LeDeR Issues and Learning Identified

1. Managing Deterioration

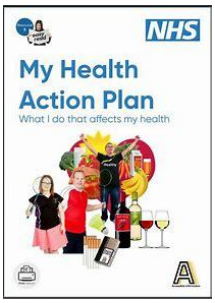
No health action plan was provided with guidance around bowel management, including guidance for staff to monitor bowel movements, or when to escalate concerns

Staff weren't monitoring bowel movements so weren't aware that preventative management of constipation wasn't effective

Staff identified D was constipated but said they were treating his constipation in "the usual way"

Staff did not recognise subtle changes in behaviour as Soft Signs (proxy measures for physiological deterioration including observed changes in person's normal behaviour, such as sleep, eating, drinking and mood, which present up to five days before physiological signs).

Learning



- Health action plans should be provided to identify health needs, what will happen about those needs (including what the patient needs to do), who will help and when this will be reviewed.
- Monitoring bowel movements is essential to identify when to escalate concerns to review and adjust management plan.

National Patient Safety Improvement Programmes
Managing Deterioration

- Training in Management of deterioration in people with learning disability which includes recognition and escalation of soft signs using deterioration / escalation tools such as Restore2 Mini and SBARD (Situation, Background, Assessment, Recommendation, Decision).

Action

Feedback sent to GP about accessible health action plans. Response received to say the GP will take this on board for future and ensure they document accurately the advice given.

To consider managing deterioration as a priority area of work for LeDeR.

LeDeR Issues and Learning Identified

2. Good Care for people with learning disabilities in hospital settings

Sister and family experienced a lack of dignity and respect, care and compassion and communication and a lack of awareness and skill amongst some of the staff caring for people with learning disability in the hospital setting, creating a barrier to good care.

No discussion about DNAR was held with family prior to D's death.

Learning

Shared; "Who I am Matters" **Report: Who I am matters – Experiences of being in hospital for people with a learning disability and autistic people** for the attention of Acute Learning Disability Liaison Team at the hospital, for the team to meet with ward staff and share document and family feedback. The document describes 6 NHS values that constitute good care, including Dignity and Respect, Compassion and Everyone counts and more.

CPR doesn't work for everyone, and the consultant informed the family that D was too frail for CPR. Useful sources of information for patients and families are the Do Not Attempt Cardiopulmonary Resuscitation (DNAR) patient leaflets which explain how decisions are made and can be helpful for families to see in advance.

Action

DNAR is a local theme/priority, and this is captured as part of local LeDeR themes and the priority work in progress. This was an action also taken back to hospital ward staff by the hospital LeDeR Governance Panel members.

Reducing Health Inequalities Working Group

A Neurodevelopmental Reducing Health Inequalities working group, chaired by the LAC for LeDeR in Derbyshire, and closely supported by the Area Service Manager for the Community Support Team, meets on a monthly basis and aims to ensure local and national priorities are being met in relation to learning disabilities and autism. This has included promoting the STOMP STAMP framework, looking at services that promote Health Lifestyle and how to take forward the "We Deserve Better" report in relation to the minority ethnic population as well as continuing to pull information together to ensure assurance of our System processes that relate to learning from the Clive Treacey report. The group is attended by individuals across Joined Up Care Derbyshire including an expert by experience. Daniel H, our expert by experience has written a few words about his involvement with the group:-

"It's been interesting getting to know what different organisations and job roles do and good for people to get together. We talk about policies and important work like; LeDeR, Epilepsy, Autism, STOMP and STAMP. We talk about Inequalities that affect people with learning disabilities and autism and about Physical health and mental health.
I follow up and put pressure on the group about not having an Epilepsy lead in Derbyshire, reminding the group.

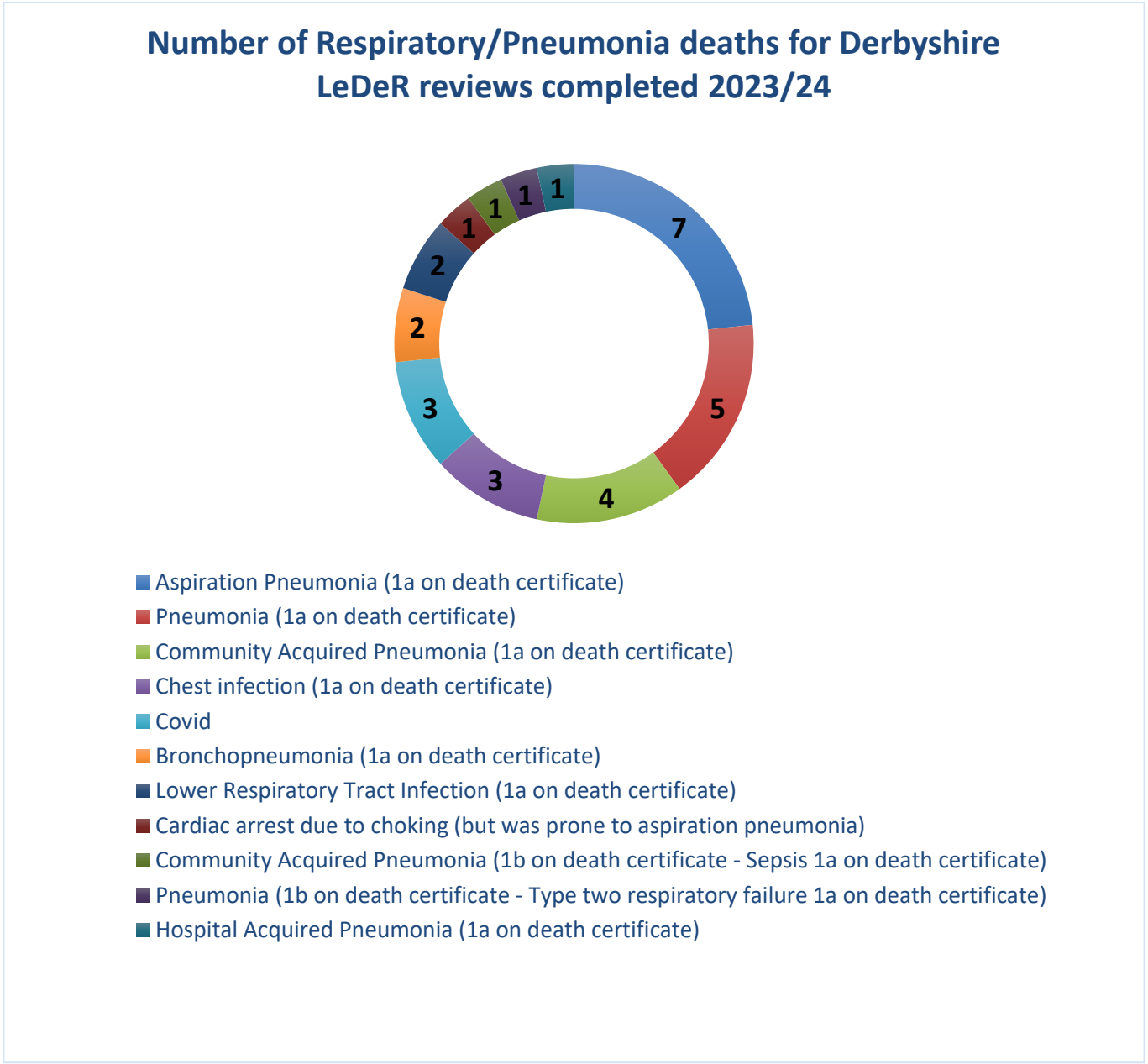
I ask the group to use simpler language and explain things clearer to make it easier to understand, which they do. I asked for a 5 minute break to be added to the meeting, which has worked well.
As a person with Down's Syndrome, I have personal experiences that help me influence the group."

Respiratory/Pneumonia Deaths

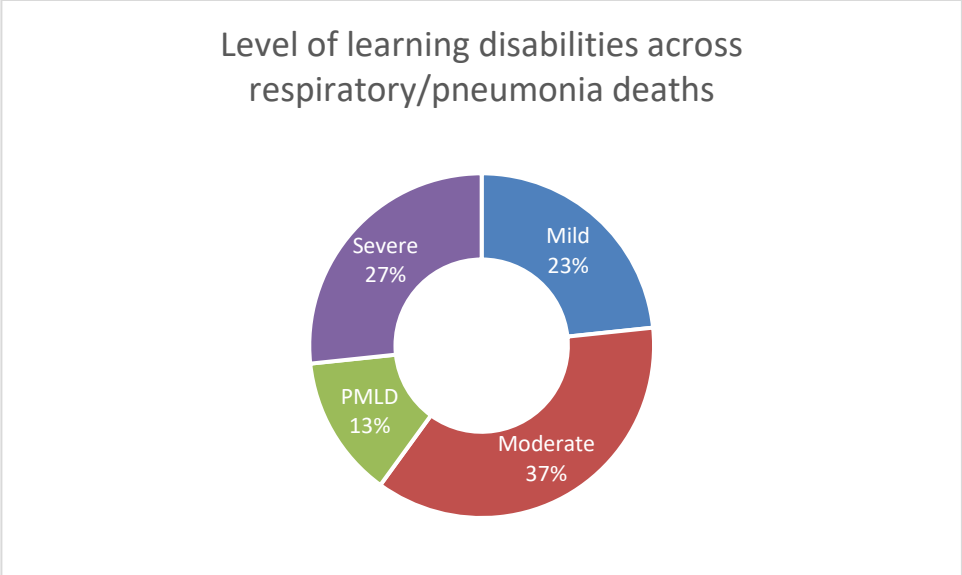
The top reason for death in Derbyshire was Pneumonia for 24% of our Derbyshire population. Aspiration Pneumonia (not included in the more generic Pneumonia as reason for death) was separated out and was the third top reason for death with 11%.

A large proportion of the deaths in Derbyshire are due to the various forms of pneumonia and this has been reviewed and broken down further.

Of the 63 completed reviews for 2023/24 in Derbyshire, 30 (or 48%) of those reviews were due to deaths directly linked to pneumonias or where there is a potential link to some form of pneumonia. A further breakdown of this is shown in the graph below:-



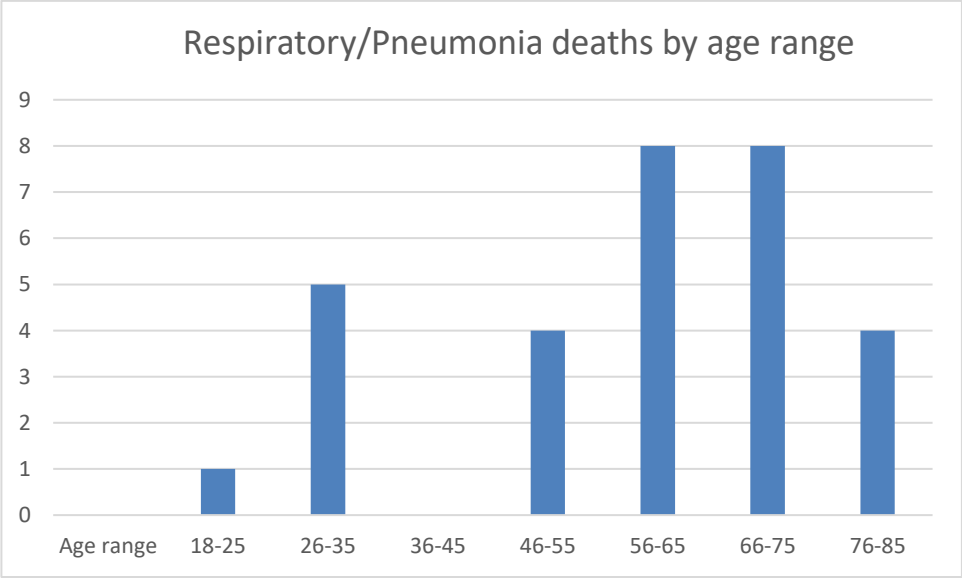
The level of learning disability ranged from mild to profound & multiple learning disabilities across the reviews.



Age of death ranged from 18 years of age to 84 years of age.

The 18 year old was female with profound multiple learning disabilities (PMLD). Type 2 respiratory failure was listed as the main reason for death (1a) with pneumonia listed as Other disease/condition leading to death (1b) on the death certificate.

The 84 year old was male with a moderate learning disability with Covid listed as the main reason for death (1a) on the death certificate.



Next Steps?

Pneumonia, and particularly aspiration pneumonia, is a prominent cause of death in people with a learning disability (NHSE). The national LeDeR annual report for 2022 (latest published) identified respiratory deaths as the third most common cause of death. In Derbyshire we are seeing respiratory deaths as the most common cause of death.

Pneumonias was also our top reason for death in our Derbyshire 2022/23 LeDeR annual report.

Aspiration Pneumonia, as the most common cause of respiratory death, has been highlighted as a priority area for Derbyshire across 2023/24 and this will continue into 2024/25.

As a result of this we have set up a 6 month project (started January 2024) where we are focusing on any deaths where aspiration pneumonia is the main cause of death or the individual has had issues with aspiration pneumonia. Members of the LeDeR team are meeting on a regular basis with the Speech and language therapy Professional Lead at DHcFT to discuss the LeDeR reviews in greater detail in relation to aspiration pneumonia findings. Through these discussions we are identifying themes. At the end of the 6 month project it is intended to review the findings to see what themes have been identified and to pull together a larger project group of people across the JUCD System where discussions will be held as to how these findings can be used to improve care.

Wheelchair services

There has been an increase in concerns seen through LeDeR in 2023/24 in relation to the provision of specialist and custom-made wheelchairs for people with learning disability and complex physical disability. In Derbyshire our wheelchairs are provided by AJM Healthcare. Issues found in Derbyshire particularly are related to delays in reviews and provision of equipment. Some short case studies are shown below which highlight the issues:-

Case 1

The initial wheelchair referral in 2019 considered anticipated seating needs based on the inevitable decline in posture and mobility associated with dementia. The individual's posture did decline to the point she could not sit safely in her transit wheelchair. A re-referral to wheelchair services was made in May 2021 and the wheelchair received in September 2022 but this no longer met her needs due to weight loss.

By the time additional parts were ordered and delivered in January 2023 the individual was being cared for in bed.

LeDeR learning identified that AJM and therapists can work more effectively towards client need if AJM accepted referral information (provided by experienced therapists) as a valuable contribution to effective wheelchair prescription.

Case 2

The LeDeR review found that interventions from wheelchair services between January and April 2023 had not been effective in addressing the individual's risk of harm.

Concerns raised with wheelchair services included increased risk of aspiration whilst seated in wheelchair due to inadequate head support. There was, however, no specialist dysphagia referral informing wheelchair services of optimal head and neck position to facilitate safe swallow.

There was lack of awareness and coordinated, multi-agency approach to postural care.

Case 3

Despite a wheelchair referral in August 2022 to request a review of current wheelchair seating to improve the individual's seating posture, there was no record of any seating interventions prior to her death in September 2023 (thirteen months).

How are we trying to make improvements to services?

- AJM Wheelchair Services asked to be part of LeDeR reviews and be given the opportunity to feed into the LeDeR reviews where any concerns have been raised in relation to wheelchair provision. This means that future LeDeR reviews will be able to address the concern within the actual review rather

than just raising the concern as an issue following completion of the review. They have subsequently also asked to be part of future LeDeR Governance Panels so they can be involved in the discussions when addressing actions and learning to help to improve future care and make further improvements.

- In February 2024 Healthwatch Derbyshire reached out to wheelchair users and their carers, to find out what they thought about the wheelchair service in Derbyshire. Following on from this they produced a report that shows the experiences of wheelchair users in Derbyshire. The report includes a series of recommendations aimed at improving wheelchair services in Derbyshire which mirrored some of the concerns found through LeDeR. These include:

    - Calls for better assessment processes
    - Better communication with people whilst they're waiting for assessments, parts, and repairs
    - More engagement with wheelchair users in their care.

    Following the survey, AJM wheelchair service have taken on board the feedback from wheelchair users and put a plan in place. The plan shows what they aim to do, or have started doing, with clear dates to be achieved by. This shows a positive reaction by the AJM wheelchair services which will provide improved future care.

Oliver McGowan training

The training is named after Oliver McGowan whose death showed the requirement for health and social care staff to have better skills, knowledge and understanding of the needs for autistic people and people with a learning disability. The training is delivered in 2 Tiers. Health and social care staff need to complete either Tier 1 or Tier 2.

Both tiers consist of 2 parts. The first part of both Tier 1 and Tier 2 is e-learning.

Everyone will need the e-learning regardless of where they work and the Tier of training they require. It is free and can be accessed here.

The second part of the training is either a live 1 hour online interactive session for those needing Tier 1, or, a 1-day face to face training for people who require Tier 2.

In Derbyshire:-

Tier 2: fortnightly sessions are being held based on trainer capacity and additional trainers are being recruited. The training is being delivered to a mixed audience across the four NHS organisations, adult social care and primary care. Performance data is monitored by NHSE.

Tier 1: Trainers who work in "trios" are currently going through the assessment and accreditation process and will commence delivery as soon as that has been completed. The aim is to run 2 training sessions a month, increasing to a session each week as trainer capacity increases. The training for Tier 1 trios is extremely complex however they have commenced a second recruitment drive.

What we said our Local Priorities would be for 2023/24 and what we have done

Priority 1: We said….

We would increase the number of focused reviews to reach the national target of 35%

We did…

- In 23/24 24% of reviews completed were focused. This is an increase since 22/23 when 22% of the completed reviews were focused.
- Processes are continually checked and updated and reviews go through a quality check to ensure reviews are progressed to focused where appropriate.

See ***Local Demographic Data & Findings*** section of this report for further details.

Priority 2: We said…..

We would improve the number of (and quality of) GP Health Action Plans

We did…..

The Strategic Health Facilitation Team have offered quality checks to GP practices which have been further adapted to include lifestyle factors and health promotion with a focus of including these in health action plans. See ***What's been done in Derbyshire in 2023/24*** section of this report for further details.

Priority 3: We said….

We would reduce the number of learning disability annual health checks not attended

We did…

The Strategic Health Facilitation team produced a survey to find out more from individuals and their carers as to why people have not been attending their annual health checks. The results from this have been shared and discussed further and solutions considered. See ***What's been done in Derbyshire in 2023/24*** section of this report for further details.

Priority 4: We said….

We would make services are made aware where the LeDeR review has evidenced poor sharing of information

We did….

This is part of LeDeR processes when issues have been identified in LeDeR reviews.

Priority 5: We said…

We would escalate the need for care coordination of individuals, particularly those with a mild learning disability who do not have the support they need to manage and understand their health appointments

We did…

This area of work has not been completed this year and will move into priorities for 2024/25

Priority 6: We said…

We would promote LeDeR and the notifying of deaths, both for autism only reviews and those with a learning disability.

We did…

The LeDeR programme has been promoted across health and social care throughout the year and we have seen an increase in number of notifications this year. See ***Local Demographic Data & Findings*** section of this report for further details.

Priority 7: We said…

We would work with the new Minority Ethnic lead for LeDeR to increase awareness across all agencies and communities of the role of LeDeR and why notifying LeDeR of deaths is a first important step. To further raise awareness of the even poorer health outcomes for some members of minority ethnic communities who have learning disabilities, sharing the learning from LeDeR.

We did…

This area of work has not been completed this year and will move into priorities for 2024/25

Priority 8: We said…

We would continue to identify issues found in relation to those individuals with epilepsy and highlight the importance of an Epilepsy Lead across the system.

We did…

Although this has continued to be highlighted across the System there is still further work to do here and this will move into priorities for 2024/25

Priority 9: We said…

We would set up a DNACPR working group and share learning across the system, identifying any gaps or training issues.

We did…

This was completed and the group met in September 2024. Further work has been completed in relation to this throughout the year. However, there is still areas of work to complete here and this will move into priorities for 2024/25.

See ***What's been done in Derbyshire in 2023/24*** section of this report for further details.

LeDeR High Impact Actions 2023/24

Across the NHS England Midlands Region there have been 6 high impact actions agreed. Here's what's been done in Derbyshire to address the 6 actions:-

1. **Reduce avoidable mortality in the 3 clinical priority areas (respiratory, cancer & heart diseases) for Learning Disability and Autism**

   Please see section *What work has been happening in Derbyshire in 2023/24* of this report for work we have done across Derbyshire priority areas, with particular reference to Aspiration Pneumonia and cancer bowel screening.

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

   In Derbyshire DNACPR/ReSPECT is one of our priority areas. We also review each death that is notified to us bearing in mind whether the death was avoidable and premature as part of our decision making as to whether the review should be completed as focused.

3. **Assure and Sustain Performance**

   a. **LeDeR review completion within 6-month KPI (Understanding, addressing and monitoring variation in performance across the region)**

   Performance of the LeDeR programme in Derbyshire is monitored and we aim to complete all reviews in a timely way where possible meeting the 6 month KPI. There are challenges to this due to capacity within the team. See Appendix 1 for the LeDeR Performance report as at 31st March 2024.

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

   a. **Facilitate peer review opportunities**

   In Derbyshire we have been involved in the peer review meetings set up across the Midlands to share feedback of completed reviews, discuss and learn from each other about how improvements could be made. This learning is being used as part of work we are doing locally in Derbyshire to discuss how we can improve reviews.

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

   a. **Communicating more with stakeholders encouraging referrals to LeDeR to better understand the experience of LeDeR for families and relevant others particularly minority ethnic groups and autistic people**

   Promoting LeDeR and working with stakeholders across the Derbyshire System is a key part of the role of the Derbyshire Local Area Contact (LAC). Throughout the year this has included working closely with health and social care colleagues to promote LeDeR and the notification of deaths, delivering presentations at partnership meetings, nurse training events, care home forums and social care team meetings.

6. **Improve accuracy of Learning Disability Registers & Increase the quality and uptake of the annual health check**
    a. **To support continued improvements in data accuracy for thematic analysis**
    b. **Improve the quality of annual health checks**

Please see section *What work has been happening in Derbyshire in 2023/24* of this report for work that has been done in relation to annual health checks.

Our Local Priorities for 2024/25

Aspiration Pneumonia – the 6 month collection of data through LeDeR reviews in relation to aspiration pneumonia deaths will be completed during August/September 2024. The information will be reviewed and themes/learning identified along with next steps to be considered based on this learning.

Care Coordination - We will continue to use LeDeR to evidence the need for care coordination of individuals, particularly those with a mild learning disability who do not have the support they need to manage and understand their health appointments.

Epilepsy – We will continue to identify issues found in relation to those individuals with epilepsy and highlight the importance of an Epilepsy Lead across the system.

Managing Deterioration – based on learning through LeDeR in 2023/24 we will be considering where the information and learning can be shared across the System to encourage better understanding of managing deterioration.

Mental Capacity Act - An emerging theme is that of mental capacity for people with a learning disability and autistic people. LeDeR has found some evidence to suggest that capacity is assumed, and the individual is making an unwise decision but without the necessary professional curiosity. We will continue to monitor this through LeDeR.

Minority ethnic communities – We will continue to work with the Minority Ethnic leads for LeDeR to increase awareness across all agencies and communities of the role of LeDeR and why notifying LeDeR of deaths is a first important step. To further raise awareness of the even poorer health outcomes for some members of minority ethnic communities who have learning disabilities, sharing the learning from LeDeR.

ReSPECT/DNACPR – the information included in this report in relation to ReSPECT and DNACPR will be shared as detailed and used as appropriate to promote learning.

Special thanks to the following people who have been involved in producing this report and the easy read version of the report:-

Our experts by experience – particularly Denise B and Dan W and the Derbyshire Reps on Board

LeDeR team

LeDeR Steering Group and Governance Panel members across the Derbyshire system

References

National LeDeR Policy 2021

Derbyshire LeDeR Strategy 2021

Joined Up Care Derbyshire (JUCD) website

Office of National Statistics, 2021 Census

NHS – Bowel cancer screening

Population and Person insight data/dashboard

Appendix 1 – Derbyshire LeDeR Performance Report (4 pages)

LeDeR Performance Report

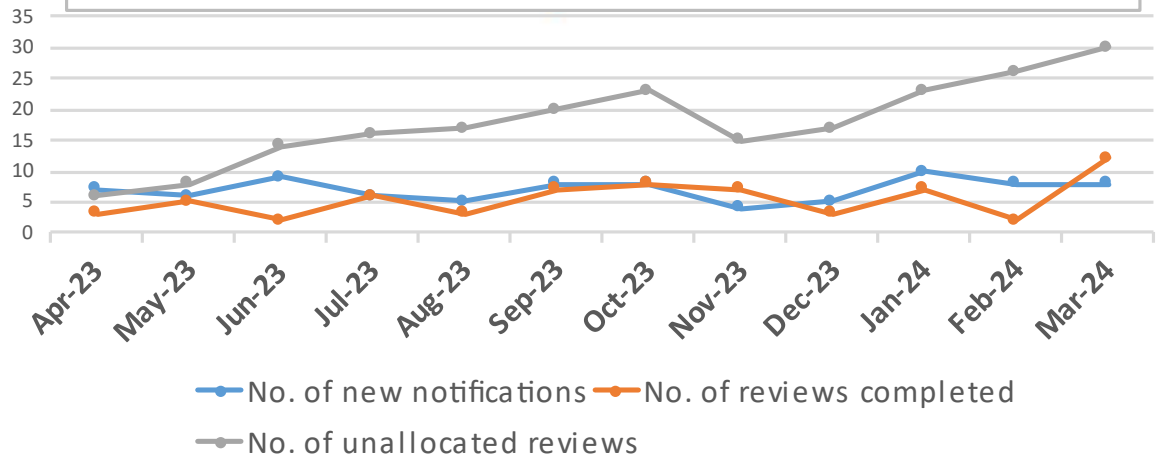
Joined Up Care Derbyshire

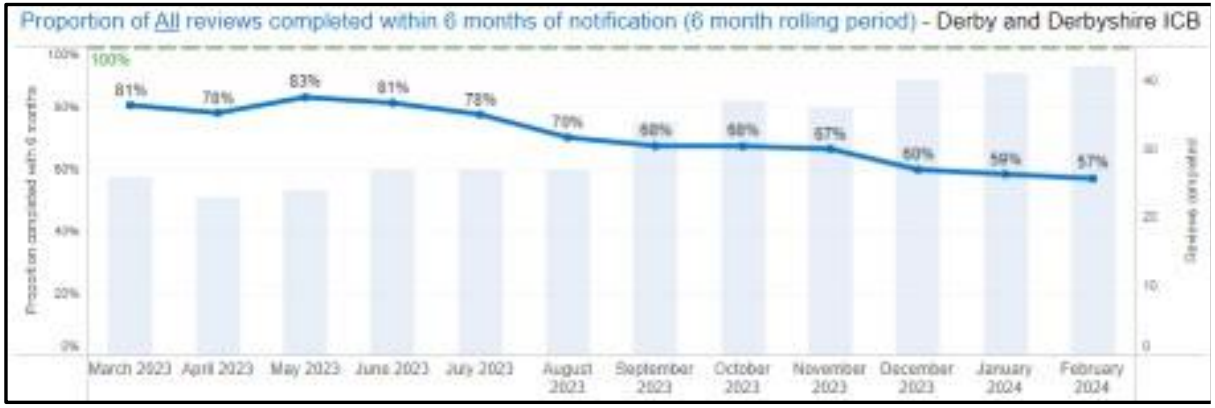
NHS Derby and Derbyshire Integrated Care Board

Data to 31st March 2024

Key Highlights/Issues	Details	Mitigations
INCREASE IN UNALLOCATED REVIEWS – NOW 30 unallocated	**NOT ENOUGH REVIEWER CAPACITY LEADING TO INCREASE IN NUMBER OF UNALLOCATED REVIEWS**	Global shout out to ICB staff to be LeDeR Reviewers - No volunteers Previously had some funding to use external reviewers -funding now fully spent Escalated through LeDeR Steering Group/Governance Panel - no system solutions found Escalated at MH/LDA Board in February 2024
35% of reviews to be completed as focused reviews (NHSE target)	Latest performance as per NHSE for Derbyshire is 21%.	
100% of reviews to be completed in 6 months (NHSE target) is decreasing due to limited number of reviewers.	Currently at 57% (this is taken from NHSE figures– latest data available at 29/2/24) there has been a gradual decline of this percentage since May 2023– see graph	

Number of new notifications received (blue line) compared to number of reviews completed (orange line) - top grey line highlighting the increasing number of unallocated reviews





Date of extraction

31/03/2024

Executive Summary

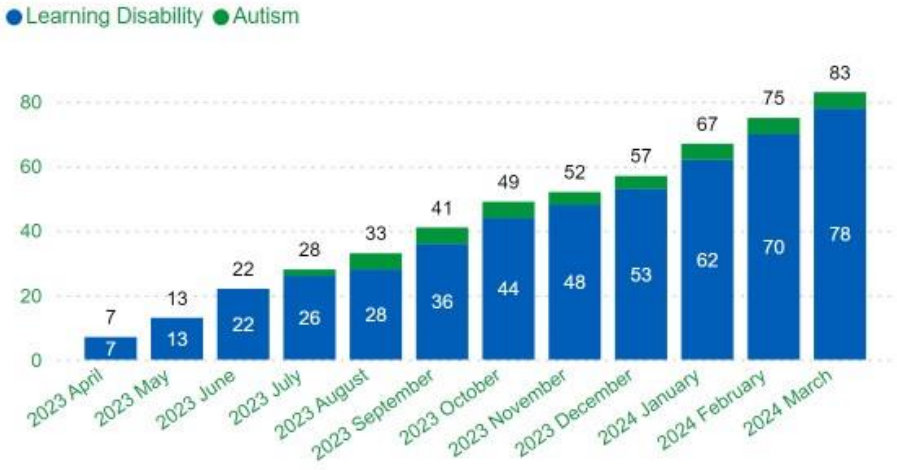
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

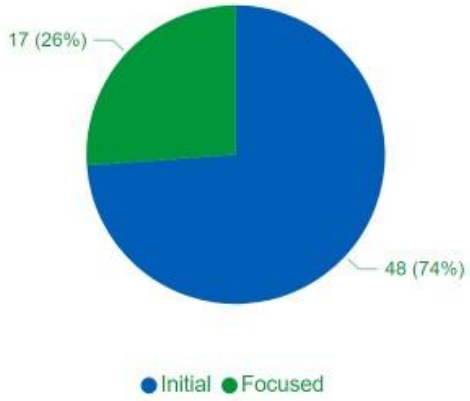
Current Totals for the 23/24 year – from April 2023

83	65	38	58%
Total Notifications 23/24	Total Completed 23/24	Total Completed in 6 months 23/24	% Completed in 6 months

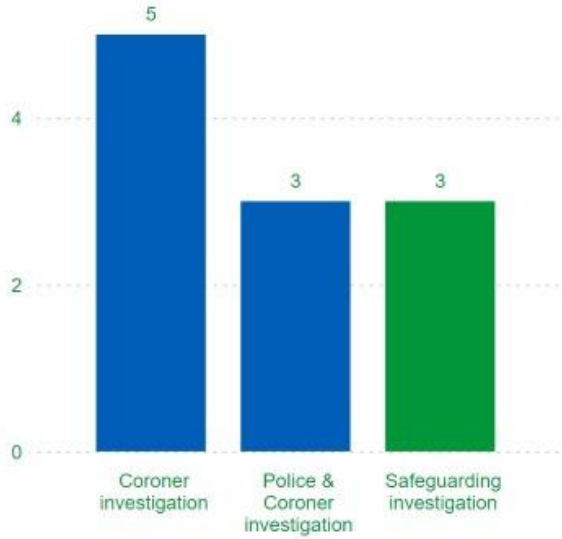
Notifications received from April 2023 split by Autism only and LD



Total number of completed reviews from April 2023



Reason for on hold



Date of extraction

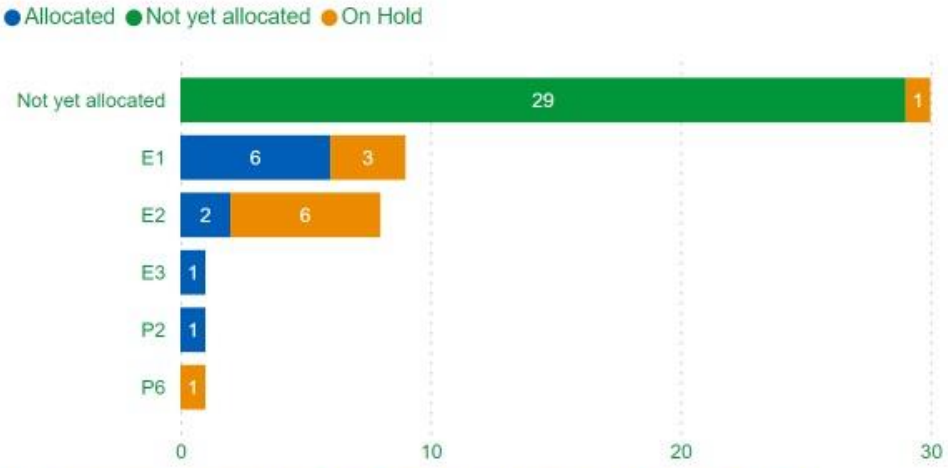
31/03/2024

Introduction of new LeDeR Platform since March 21

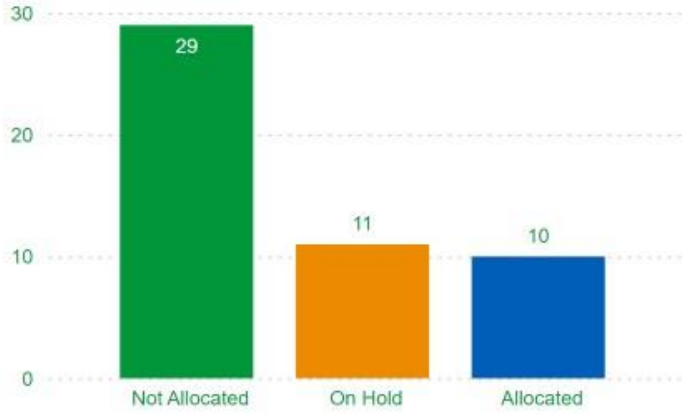
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Current Status of Reviews by Reviewer

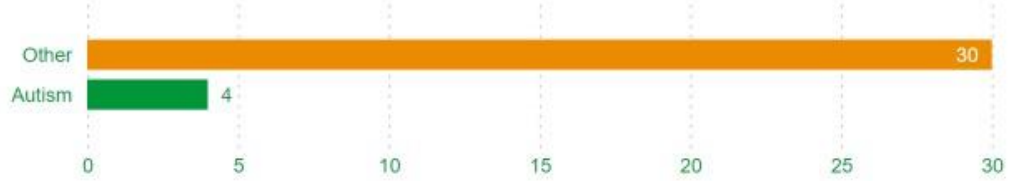


Current reviews by status

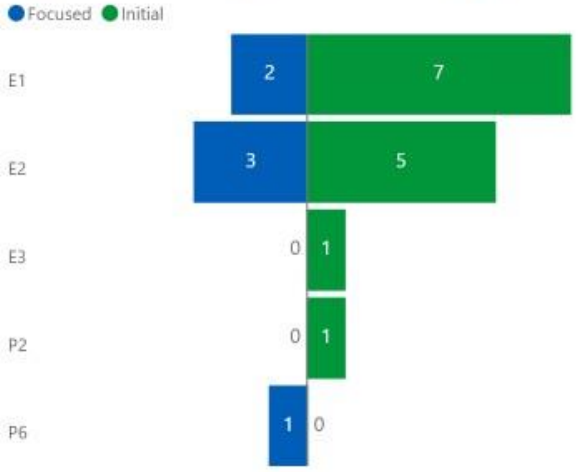


All Reviews (completed and in progress) since March 2021

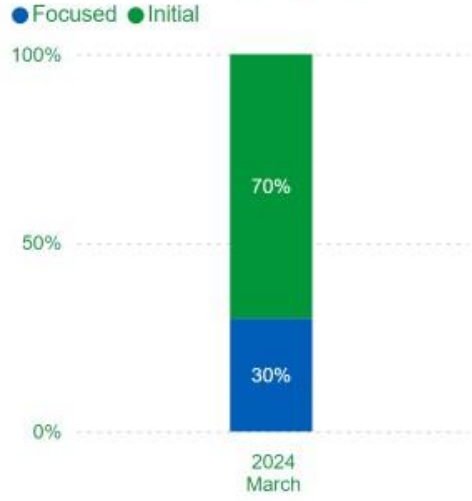
Breakdown of completed and in progress focused reviews since March 2021



Type of Review by Reviewer in progress



Reviews currently in progress



Date of extraction

31/03/2024

Overall Position

Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Since 2017 the start of the LeDeR program

425

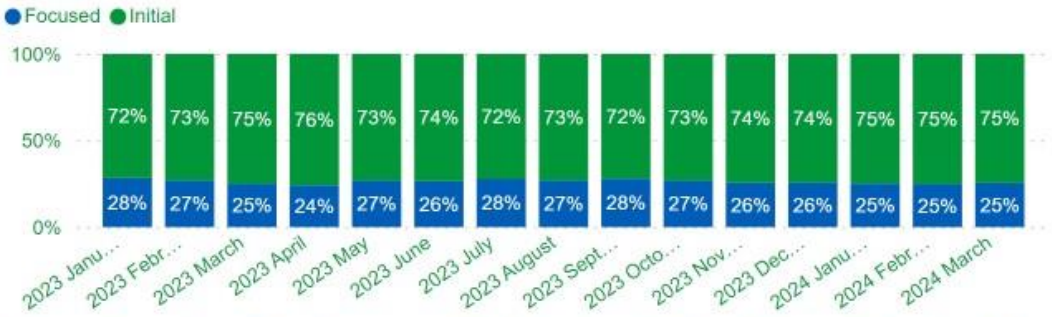
Total Number of notifications since 2017

374

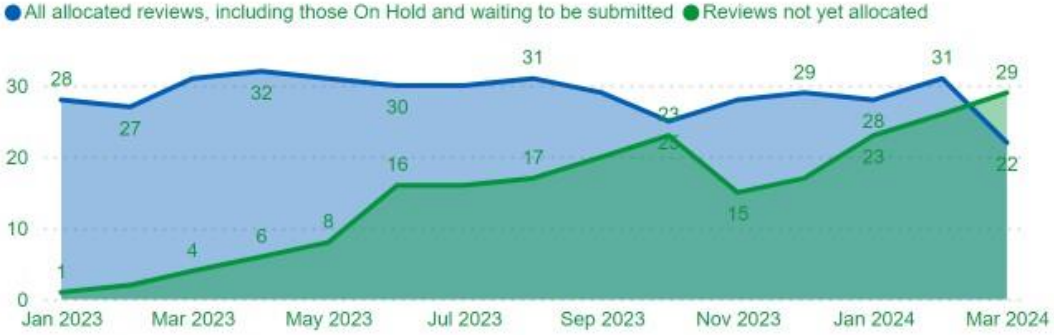
Total Completed since 2017

Graphs show a rolling 12 months but can be amended with the Date of extract filter >>

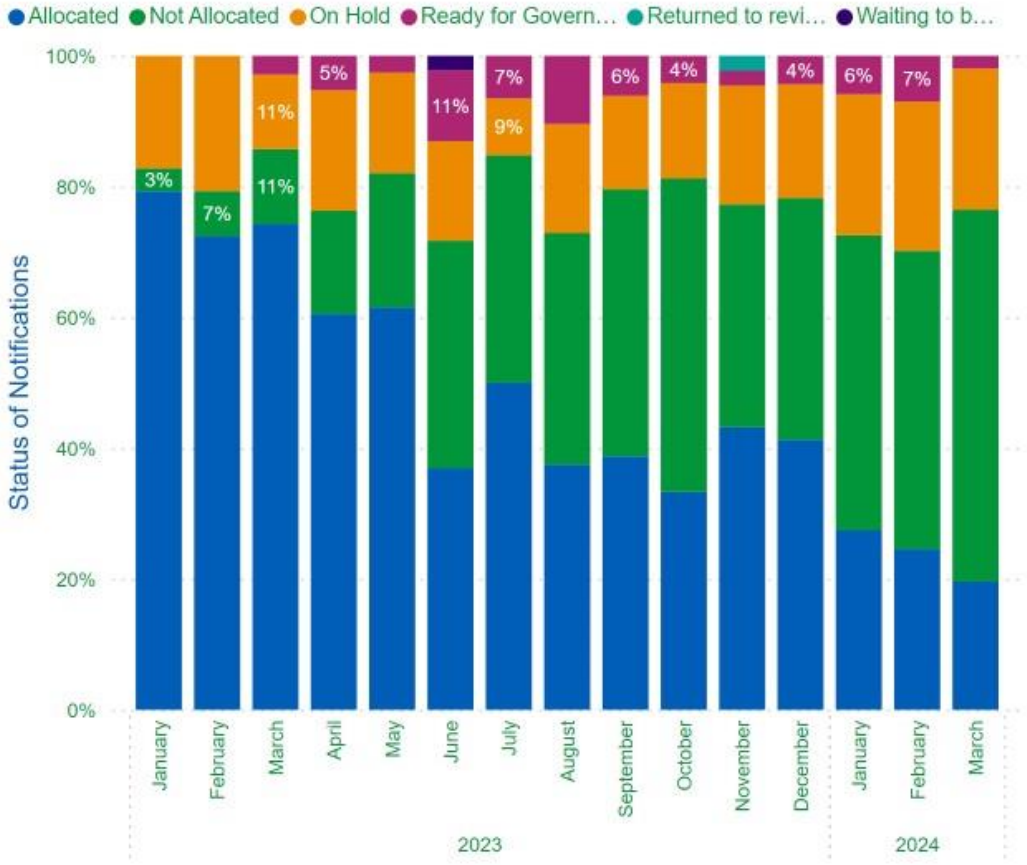
Type of Review Completed since March 2021



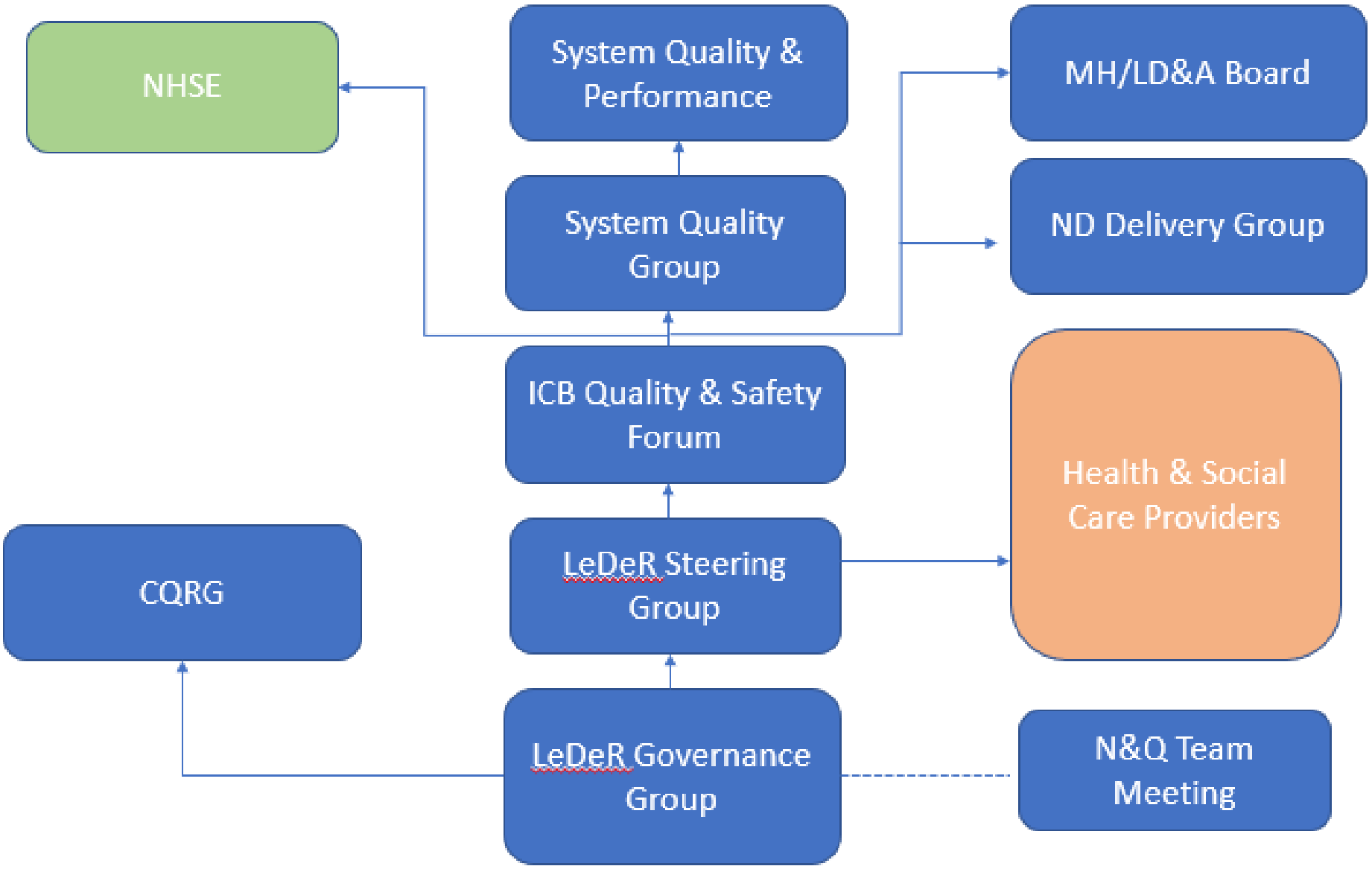
Comparison of notifications received but not yet allocated against allocated reviews (including On Hold reviews)



Current Reviews by Status



Appendix 2 – LeDeR Governance Structure



Appendix 3 – Derbyshire LeDeR Themes Graph