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 2022 to 31st March 2023

Derbyshire LeDeR Learning from Lives & Deaths Annual Report 2022-2023

Responsible Committee	Derby & Derbyshire LeDeR Steering Group
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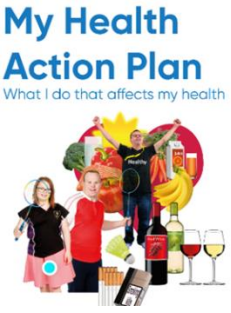
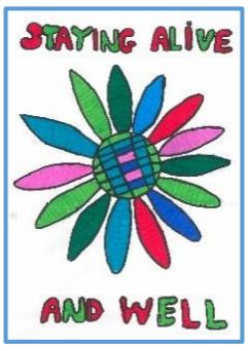
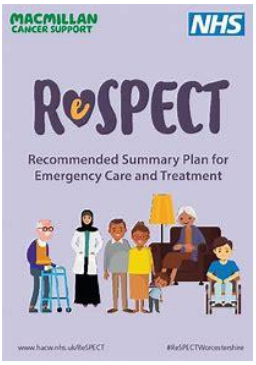
List of Abbreviations

Abbreviation	Explanation	Symbol
AHC	Annual Health Check	
CDOP	Child Death Overview Panel	
CLDT	Community Learning Disability Team	
CYP	Children and Young People	
DDICB	Derby & Derbyshire Integrated Care Board	NHS Derby and Derbyshire Integrated Care Board

DCHS	Derbyshire Community Health Services	
DHcFT	Derbyshire Healthcare NHS Foundation Trust	
DNACPR	Do not attempt resuscitation	
DSAB	Derbyshire Safeguarding Adults Board	
GP	General Practitioner	
HAP	Health Action Plan	

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	
NHSE/I	NHS England	

ReSPECT	Recommended Summary Plan for Emergency Care and Treatment	
SALT	Speech and Language Therapy	

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 fourth 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 2022 up until 31st March 2023. Thanks to those with lived experience who have been involved in co-producing this report and the ICB 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/LDA Board for information. The report, including an accessible version, is published in June each year and available on the JUCD website. The report is shared with NHSE/I regional teams by 30th June 2023.

Summary of local data and findings

Since the programme began there have been 344 (adult i.e. age 18+) deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2023, of which 309 of these deaths have had a review undertaken and completed.

From 1st April 2022 to 31st March 2023 there were 62 notifications and 58 completed reviews in that year period. Some of those 58 completed will have been notifications received in the previous year and some will be part of the 62 notifications received in 22/23.

Information throughout the annual report is based on the 58 reviews that were **completed** during 2022/23.

30 of the reviews were male, 28 of the reviews were female.

Average age at death for females was 58 years and 58 years for males. This could represent a concern as is a younger average age of death for both genders than was found in the previous year. The LeDeR Annual Report in 2021/22 showed the average age at death for females was 65 and 62 years for males.

53 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, 1 Caribbean, 1 Indian and 1 "Any Other White Background"). This is an increase since the previous year when only two were received. Note that the minority ethnic backgrounds/descriptions used are as requested through the LeDeR programme.

Hospital was the most common place of death, with 31 of the 58 completed reviews showing hospital as the place of death.

There were no completed reviews for individuals with autism (no learning disability). There was one notification for an autism only review, but this has not yet been completed. In total there have only been two notifications since January 2022 of individuals with autism but no LD. Both of these reviews are on hold as they are waiting coroner investigation.

During 2022/23 there have been two 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 has been one other notification made in the year where Covid-19 is mentioned on the notification, although this review is not yet completed.

The top reason for death was Pneumonia for 15% of our Derbyshire population. Aspiration Pneumonia (not included in the more generic Pneumonia as reason for death) was separated out and was the second top reason for death with 12%.

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.

One area of success is in relation to the work that has been happening to promote awareness of constipation and bowel issues. In our 2020/21 LeDeR Annual report 60% of LeDeR reviews reported that the individual had constipation/bowel issues as a health condition. Lots of work across the system followed that year to increase awareness of constipation and bowel issues. The following year (2021/22) we saw 42% of LeDeR reviews showing constipation/bowel issues as a health condition and then this year (2022/23) the LeDeR reviews have shown a further reduction to 34%. This is a great achievement and is due to the work that continues across the system in promoting the awareness of constipation and bowel conditions across such teams as the LD Health Facilitation team and the Community Learning Disability Teams.

Another priority area in 2021/22 was in relation to a lack of reasonable adjustments being made as it was our top theme that year. During 2022/23 Reasonable Adjustments has only been identified as a theme in 15.5% of the completed LeDeR reviews for 2022/23 compared to 50% of LeDeR reviews in 2021/22 which is possibly due to the work across the system detailed further in this report in the past year. This will be monitored further over the coming year.

Priority areas for 2023/24

The report highlights a number of local priority areas for work across the system as identified through the LeDeR programme: -

1. Increasing the number of focused reviews to reach the national target of 35%
2. Improving the number of (and quality of) GP Health Action Plans
3. Reduce the number of LD annual health checks not attended
4. Ensuring that services are made aware where the LeDeR review has evidenced poor sharing of information
5. To 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
6. To promote LeDeR and the notifying of deaths, both for autism only reviews and those with a learning disability.
7. Working 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.
8. To continue to identify issues found in relation to those individuals with epilepsy and highlight the importance of an Epilepsy Lead across the system.
9. To set up a DNACPR working group and share learning across the system, identifying any gaps or training issues and improve the completion and following of DNACPR ReSPECT forms where identified.

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 6 years and previous reports are available to view here. The latest report (2021) highlighted that since the LeDeR programme was established more than 10,000 deaths of people with a learning disability have been reviewed.

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 but there are close links with the Child Death Review process and some data is captured through LeDeR for individuals under the age of 18. Therefore, the majority of the information shown in this report is for individuals age 18+ with a separate section to show information from child deaths.

Depending on the complexity of the person's life and death a decision is made to complete as an Initial

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

Review or Focused Review. However, all LeDeR reviews are automatically Focused if:-

- the person is from a Black, Asian or minority ethnic background
- the person was autistic with no learning disability
- the person had been under mental health or criminal justice restrictions at the time of death or 5 years previously

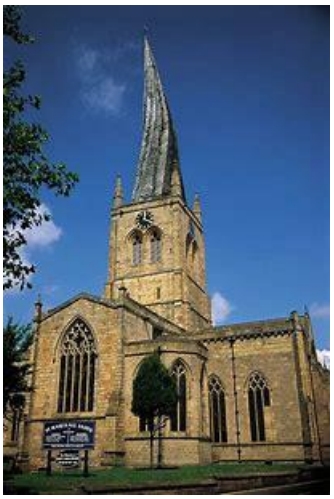
As a service improvement programme locally in Derbyshire, we are working as Joined Up Care Derbyshire ICS to use the learning found through LeDeR to improve our local services for people with a learning disability. As LeDeR also develops into a service improvement programme for people with autism the 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])

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 344 notifications for those age 18+, of which 309 have had a review undertaken and completed (local collated data as of 30th March 2023). The information in this report is taken from LeDeR reviews completed between 1st April 2022 to 31st March 2023.



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

Co-production and Engagement

This year's LeDeR Annual Report has been co-produced with Denise. Here's a bit about Denise:-

"Hello I'm Denise and I'm an expert by experience with Inclusion North

I've been doing care and treatment reviews now for about 5 years

I also have a mild learning disability

My hobbies are
Singing and songwriting
A comedian

I'm also an author as I have a book out on Amazon called I WANNA TELL YOU MY STORY

What's important to me regarding health is making sure I'm updated with my annual health check. The last one I had one was in January 2022.

I've tried ringing up my doctors for an appointment, it is like waiting for Christmas. Since the pandemic it has been very difficult to get an appointment with any GP and this could do with changing.

I'm being a voice for the vulnerable as I was on the Jo Whiley campaign which was about raising awareness that people with a learning disability needed to have the Covid jab as a priority.

Trying to make a difference in society is challenging but I always say, what we got to lose let's do this"

Dan has been working with us as part of the LeDeR Programme this year. He 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. Here's a bit about Dan:-

"Hi I Am Dan

I am an Assistant Strategic Health Facilitator.

What I Do in My Role

I help out with the GP training, talking to Doctors and Nurses about how they can help people with a Learning Disability go for Annual Health

Checks.

I help out with interviewing and promotion for people who apply for jobs and get asked to help out with the panel and be part of it.

I come to the Inequalities Meetings and listen to people's views and I talk about my views as well.

I come to the LeDeR meetings and listen to people's views and I speak up about what I think should change and I always want more easy read information to come into force because people with a Learning Disability should have more easy read letters than just a normal letter."

All about Our Vision Our Future

We also met with Our Vision Our Future, a self-advocacy group for adults with learning disabilities based in Chesterfield. We talked to them about their experiences in Derbyshire in the last year and shared some of the areas of the annual report with them for their feedback. Some of the members talked about their recent experiences with their Annual Health Checks which included being called by the practice a few days before the appointment to check the individual was still ok to attend and seeing the same nurse each time they visited the GP practice. One member talked about her epilepsy but said she had not had any face-to-face appointments recently. Another member talked about their experience of living in a house as part of the Shared Lives in Derby and how he felt it was a good experience and worked well for him as he was quite independent.

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.

We are also committed to a number of statements we have made as part of the Derbyshire LeDeR strategy:

Statement	How are we achieving this
1. We will ensure all LeDeR reviews are completed within 6 months of notification	• All reviewers are made aware of relevant deadlines when they undertake a review including latest dates they will need to submit the review. Our LeDeR Administrator works closely with reviewers to ensure they meet the deadline, sending out reminders and assisting them by chasing contacts if needed • The LeDeR Performance report (*see Appendix 1*) is used to monitor numbers of reviews in progress and if there are any "hold ups" in the LeDeR quality process • Information is collated and reviewed where there are any "hold ups" across the system to capture any trends.
2. We will ensure processes are in place to include the review of deaths of autistic people when this becomes part of the LeDeR programme/policy	• Our reviewers have all undertaken the necessary training in order to complete an autism only review.
3. We will ensure that reviews are completed and quality assured to an acceptable standard	• We continue to update and revise our quality processes to ensure we produce good

that ensures the programme can share and use learning to make meaningful changes to the lives of individuals with learning disabilities	standard LeDeR reviews. This has included a review following the 2023 LeDeR Handbook and the NHSE Quality Audit of reviews.
4. We will continue to work as Joined Up Care Derbyshire ICS in relation to the LeDeR programme and acknowledge the importance of making service improvements across the whole system as we further develop as an ICS	• We have re-visited our Steering Group and Governance Panel membership to ensure we have individuals involved who understand the LeDeR agenda and are involved in relevant areas to work on improvements. Guest members are also invited where relevant depending on the meeting agenda.
5. We will follow the new guidance of the LeDeR policy and ensure there is clear and effective governance in place	• LeDeR sits within a governance structure at the ICB feeding into System Quality Group, ND Programme Delivery Group and MH/LDA/CYP Board (*See Appendix 2*)
6. We will use learning from the LeDeR programme and work with the Minority Ethnic lead to reduce the health inequalities faced by people from minority ethnic communities who live locally and who have a learning disability	• Promotion of LeDeR and the importance of notifying deaths has been presented to various networks across the year. There has been an increase in the number of notifications this year to 5 (in 2021/22 there were only 2 notifications) • We have recently "recruited" a new Minority Ethnic Lead and hope to build on this work.
7. We will ensure we have meaningful involvement of people with learning disabilities and their families in the LeDeR programme	• We now have an individual with lived experience attending our LeDeR Steering Group • This report has been produced with an individual with lived experience
8. We will promote LeDeR and share learning from LeDeR across Derbyshire learning disability forums and with learning disability services and care providers	• LeDeR learning and updates are fed into our Derbyshire LD forums and Partnership Boards, parent carer networks and Autism Board.
9. We will have a clear plan in place for the new quality assurance structures and processes	• We have set pathways and processes that are followed for our quality assurance structures

which will be implemented for LeDeR and fully operational from 1 April 2022	and processes which are reviewed and updated where necessary
10. We will work as an ICS to use the learning from the Derbyshire LeDeR programme to make service improvements across areas identified throughout the whole health and social care system in Derbyshire, aiming to narrow the gap in health inequalities and premature mortality for those who have a learning disability in Derbyshire and for those with autism from 2022.	• We meet as a system on a regular basis to discuss learning and themes from the LeDeR reviews and share learning through the LeDeR Steering Group and LeDeR Governance Panel

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 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 LD Health Facilitation team to deliver workshops across health and social care providers, promoting learning from LeDeR and the work of the LD Health Facilitators with particular emphasis on promotion of LD 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.
- Regular meetings with managers of LD 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.
- Working with Acute Trusts to review the Structured Judgement Review which is completed for deaths in hospitals with an aim to improve the information collated to support the reviews of deaths for individuals with learning disabilities.

- Sharing quarterly reports and updates with System Quality groups.
- Sharing LeDeR learning with the Good Health Group and LD 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 in Derbyshire

Please note that all other information (other than in this section) in this report relates to individuals aged 18+ years. Some data for those under 18 years is captured through LeDeR where a notification has been made into LeDeR. However, these reviews are not taken through the LeDeR process, but through a separate Child Death Review process where reviews and actions are agreed at a Child Death Overview Panel (CDOP). In Derbyshire one of our LeDeR reviewers attends this panel in order to offer LD expertise and knowledge and to capture any themes.

There were five notifications of deaths of individuals under the age of 18 which are in progress or have been completed through the CDOP process during 2022/23.

Nine child deaths have been completed through the CDOP process in 2022/23 and a breakdown of these nine deaths is shown below:-

Total		Total split by Gender		Total split by Ethnicity				Diagnosis		Average age of death		Place of death	
		Male	Female	White (A)	Any other ethnic (S)	Multiple Ethnic Group (G)	Pakistani (J)	LD	ASD only	Male	Female	Hospital	Family home
Number of reviews completed from 1/04/22 to 31/3/23	9	5	4	4	2	1	2	9	0	10	10	7	2

Reasons for death for the 9 completed reviews:
Acute bronchopneumonia (2 deaths)
Chronic Respiratory Failure
Acute Chest Infection
Respiratory infection
Sigmoid Volvulus
Necrotising enterocolitis of unknown cause with perforation
Hypoxic brain injury
Multi organ/system failure

Individual actions are collated as part of the CDOP process in relation to these deaths but we do not capture our local themes through LeDeR for CDOP deaths. One area that has been noted by our LeDeR reviewers who attend the CDOP panel meetings is that these are all children with complex health (underlying respiratory problems/non mobile) with a paediatrician who has oversight and a coordinating role whereas when these children become adults the complex health is no longer coordinated which we start to see as an issue.

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 2022/2023 five reviews (9%) were completed for those identifying from a minority ethnic community. Their ethnicities were listed as:

2 were Pakistani
1 Caribbean
1 Indian
1 Any Other White Background

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

This is an increase since the previous year when only two reviews (4%) completed were from minority ethnic communities.

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, NE 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[5]).

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

- 12 of the completed reviews were individuals from the City. Two of these individuals were from minority ethnic communities i.e., 17%
- 46 of the completed reviews were individuals from the County. 3 of these individuals were from minority ethnic communities i.e., 6.5%

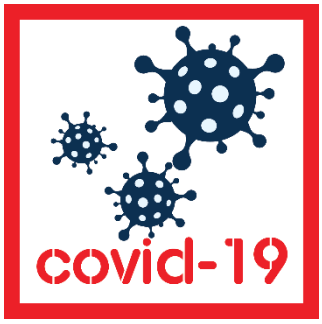
[5] See References

These are encouraging as the number of notifications are closer aligned to those expected from minority ethnic communities than in previous years. However, a new Minority Ethnic Lead for LeDeR has recently started to work with us and our aims are to increase awareness across all agencies and communities (statutory, independent, voluntary) of the role of LeDeR (reducing the health inequalities currently experienced by people with learning disabilities) and why notifying LeDeR of deaths is a first important step. We want to further raise awareness of the even poorer health outcomes for some members of minority ethnic communities who have learning disabilities.

Local Action Plan

As part of the LeDeR Policy 2021 ICBs were provided with several delivery expectations. Please see *Appendix 3* for the updated Derbyshire Local Action Plan showing delivery against these targets.

Covid-19



During 2022/23 there have been 2 reviews completed as confirmed Covid-19 deaths. Both of these individuals died in hospital.

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. There has been one other in the year where Covid-19 is mentioned on the notification, although this review is not yet completed.

Independent Reviews

Clive Treacey

Clive Treacey was an individual from Staffordshire who died in 2017 following a number of years in a variety of placement settings due to his learning disabilities. In 2020 NHSE/I commissioned an independent review into his care following concerns raised by the Treacey family. The review was undertaken in line with the principles of the Learning Disability Review from Lives & Deaths (LeDeR) methodology.

The report was published on the 9th December 2021 and identified that Clive's death was 'potentially avoidable'. There were multiple, system-wide failures in delivering his care and treatment that together placed him at a higher risk of sudden death as set out in the report. Clive should not have spent so many years of his life detained in specialist hospitals. There were extensive periods when he experienced an unacceptably poor quality of life and where he was not always kept safe from harm.

Although Clive did not receive any care and treatment in Derbyshire, the report included 10 key findings and identified a number of learnings and recommendations for consideration across health and social care providers. In Derbyshire we have produced an action plan which highlights the learning and recommendations. This action plan continues to be reviewed and monitored through the Derbyshire Neurodevelopmental Programme Delivery Group for assurance and to identify any actions needed locally.

The Oliver McGowan Training on Learning Disability and Autism

The training is named after Oliver McGowan. Oliver was a young man whose death shone a light on the need for health and social care staff to have better skills, knowledge and understanding of the needs of autistic people and people with a learning disability.

The Oliver McGowan Mandatory Training on Learning Disability and Autism is the government's preferred and recommended training for health and social care staff. The training is delivered in 2 Tiers. 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 via e-learning. Everyone will need to complete the e-learning regardless of where they work and the Tier of training they require. It is free to access.

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.

Across Joined Up Care Derbyshire we have a stakeholder group in place who are working on the roll out

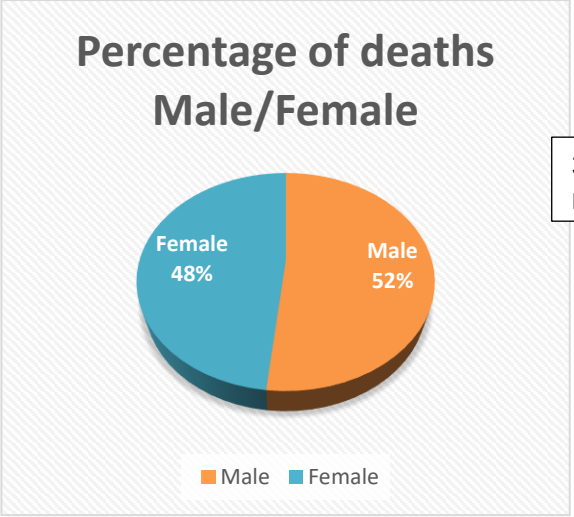
of the training including the recruitment of the trainers who will form the "Trios" who will deliver the face to face training.

Local Demographic Data & Findings

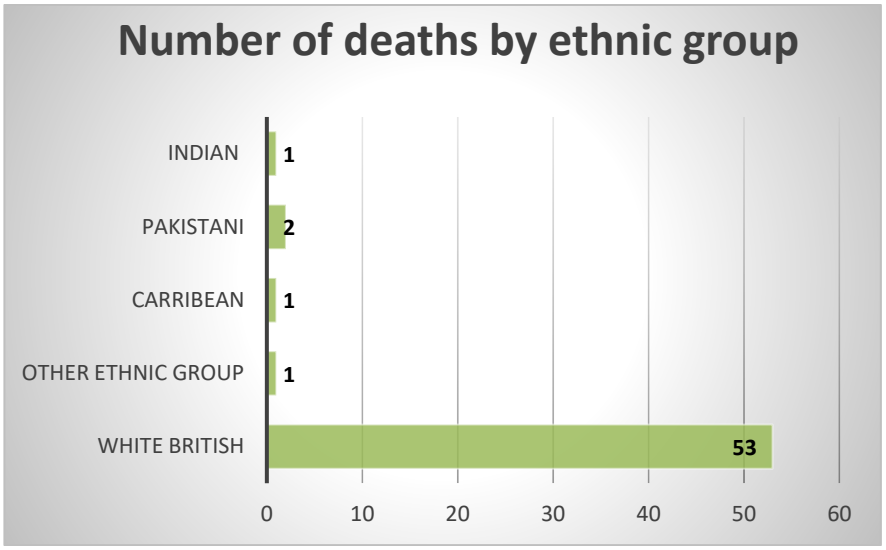
Since the programme began there have been 344 deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2023 of which 309 of these deaths have had a review undertaken and completed. [NB. As mentioned previously all notifications referred to are for 18+ only]

For the year 1st April 2022 to 31st March 2023 there were 62 notifications and 58 completed reviews in the year. From 1st April 2022 to 31st March 2023 there were 62 notifications and 58 completed reviews in that year period. Some of those 58 completed will have been notifications received in the previous year and some will be part of the 62 notifications received in 22/23. Information throughout the annual report is based on the 58 reviews that were completed during 2022/23.

The following graphs represent data taken from the 58 completed reviews for 2022/23:-

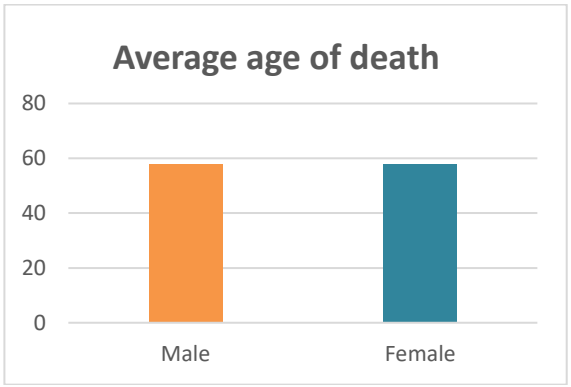


30 of the reviews were male, 28 of the reviews were female



53 of the completed reviews were for White British. Five completed reviews were from a minority ethnic community. The Other Ethnic Group was a White Italian which is classed as a minority ethnic grouping in the LeDeR programme

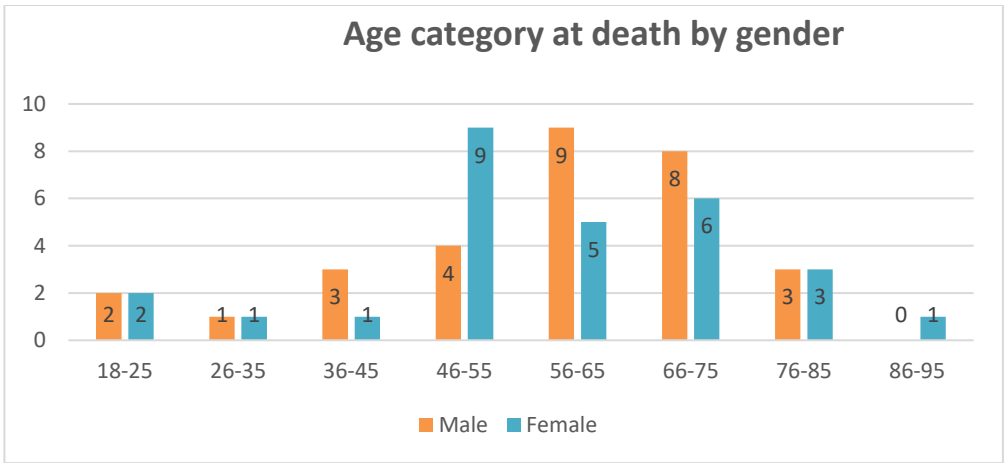
Therefore, 9% of our completed reviews were from the BAME community.



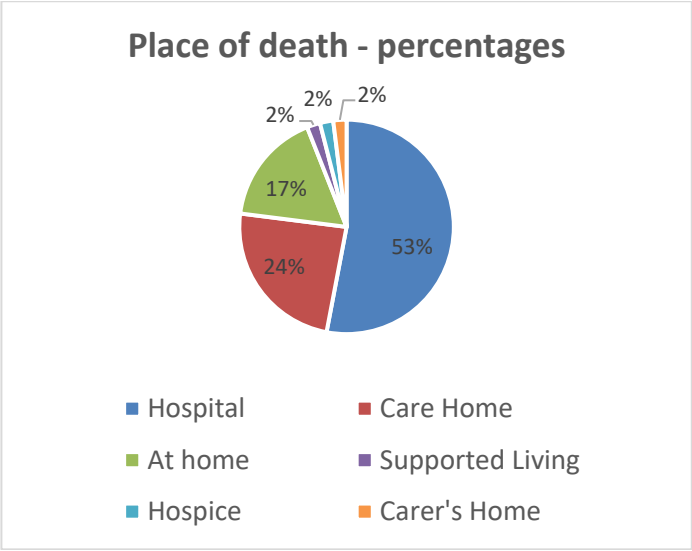
Learning from LeDeR showed that the average age of death for both males and females was the same in Derbyshire, at 58 years of age.

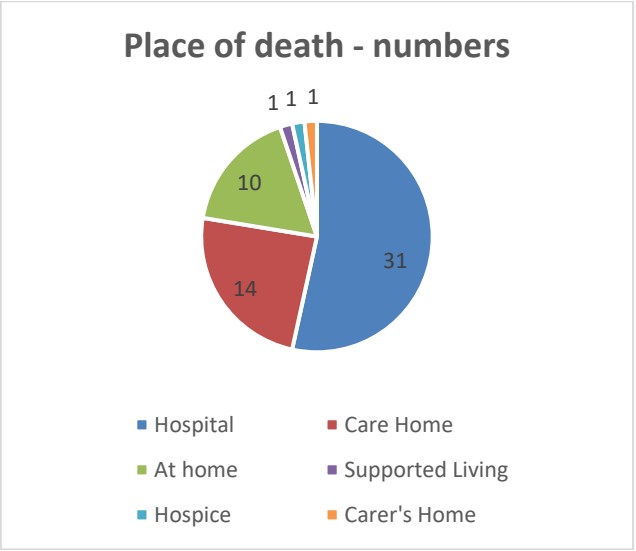
This could represent a concern as is a younger average age for both genders than the previous year. The LeDeR Annual Report in 2021/22 showed the average age at death for females was 65 and 62 years for males.

This is further broken down in the graph below to show the age at death categories of individuals.

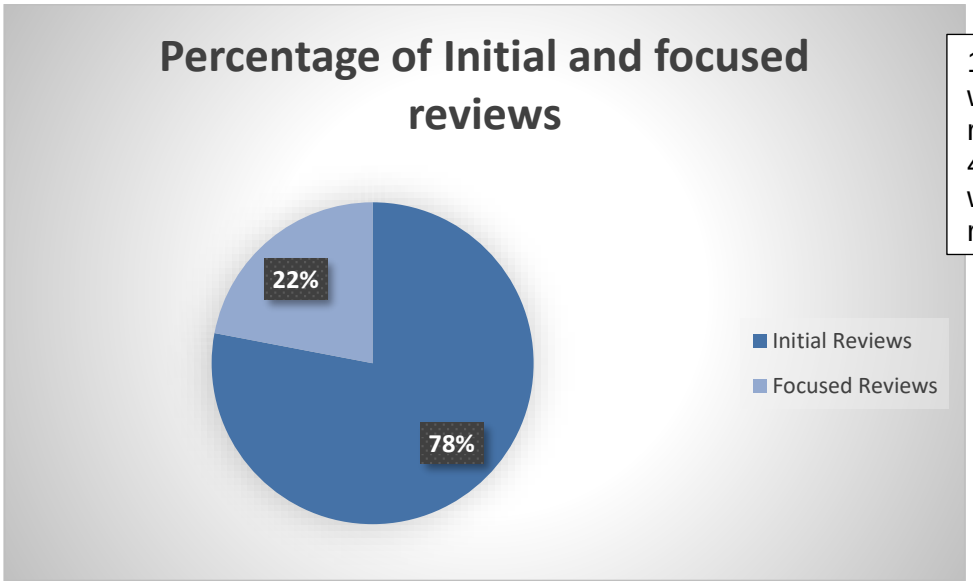


Hospital was the most common place of death, with 53% or 31 of the 58 completed reviews showing hospital as the place of death.





Focused and Initial Reviews



13 of our LeDeR reviews were completed as focused reviews.
45 of our LeDeR reviews were completed as initial reviews.

Grading of Care

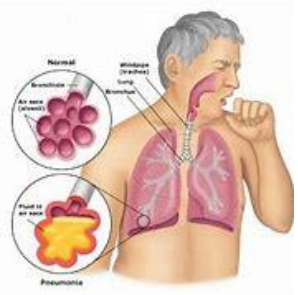
In the current version of the LeDeR platform there is only an option to grade care in reviews that are completed as Focused, and therefore the information below only relates to 13 completed Focused reviews. Also, focused reviews in the majority are completed where issues have been identified and a fair 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.

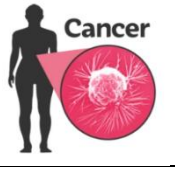
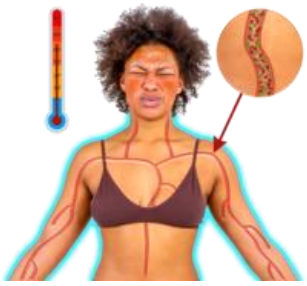
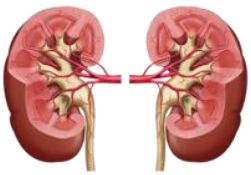
NB. If a comparison is to be looked at this can only be compared to the 2021/22 LeDeR Annual Report as in earlier years (when using the earlier LeDeR platform) grading of care was captured for all reviews.

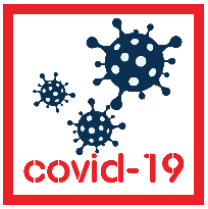
Grade		Number of occurrences	Percentage against the 13 focused reviews 2022/23 reviews	Percentages for focused reviews in 2021/22
6	This was excellent care (it exceeded expected good practice	**0**	**0%**	**0%**
5	This was good care (it met expected good practice)	**3**	**23%**	**30%**
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing)	**5**	**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	**4**	**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	**1**	**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 2022 to 31st March 2023 the reasons for death are categorised and separated out below.

	For Reviews completed 2022/23	
Death category		**Percentage with this death category at 1a of death certificate**
Pneumonia / Lower Tract Respiratory Infection / Bronchopneumonia	A Lower Tract Respiratory infection includes **pneumonia, bronchitis, and tuberculosis**. A lower 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 	**15.5%**
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.** 	**12%**
Heart Disease	When blood flow becomes limited or stopped, the body shuts down and - without intervention - can lead to death. 	**10%**
Frailty	Increased vulnerability to poor health outcomes due to underlying conditions 	**9%**

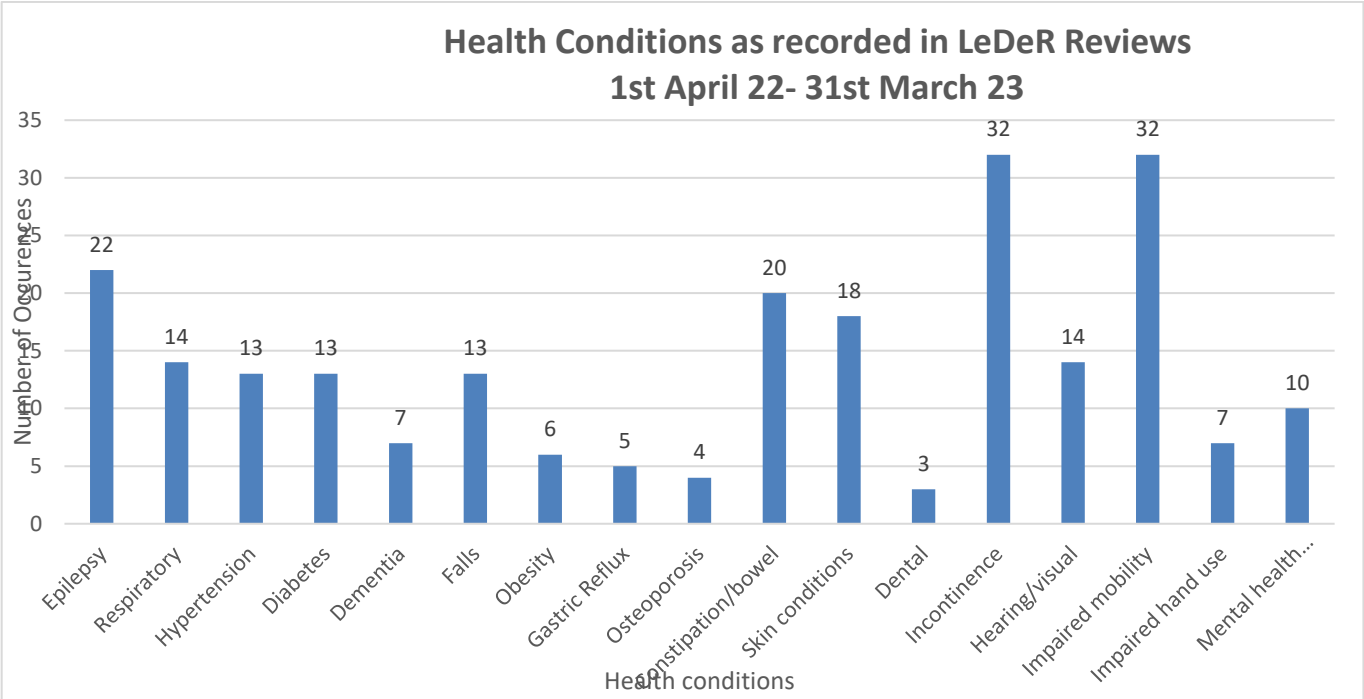
Cancers	Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body 	**7%**
Sepsis	Happens when your body overreacts to an infection you already have and starts to damage your body's own tissues and organs 	**5%**
Multi Organ Failure	When the inflammation from a severe infection or injury causes dysfunction in two or more organ systems 	**5%**
Dementia	The impaired ability to remember, think, or make decisions that interferes with doing everyday activities 	**3.5%**
Acute Kidney Injury	Where your kidneys suddenly stop working properly 	**3.5%**
Pulmonary Embolism	When a blood clot blocks a blood vessel in your lungs 	**3.5%**
Traumatic Intercranial Haemorrhage	A collection of blood within the skull 	**3.5%**

Covid-19	An infectious disease caused by a virus characterised mainly by fever and cough and can progress to more severe symptoms 	**3.5%**
Others		**19%**

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 2022/23 is shown below identifying the health conditions and the number of times each condition was identified. This information is taken from the 58 completed LeDeR reviews during that period.



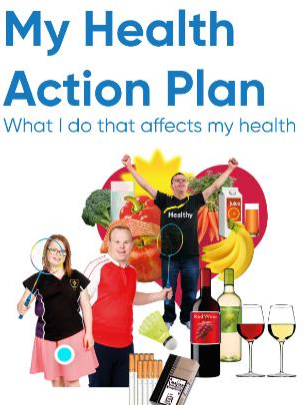
An area to highlight is the health condition for constipation/bowel. In our 2020/21 LeDeR Annual report we reported that 60% of LeDeR reviews showed that the individual had constipation/bowel issues as a health condition. Lots of work across the system followed that year to increase awareness of constipation and bowel issues. The following year (2021/22) we saw 42% of LeDeR reviews showing constipation/bowel issues as a health condition and then this year (2022/23) the LeDeR reviews have shown a further reduction to 34%. This is a great achievement and is due to the work that continues across the system in promoting the awareness of constipation and bowel conditions across such teams as the LD Health Facilitation team and the Community Learning Disability Teams.

Outcomes and achievements

As a result of learning identified through LeDeR, through themes and health conditions here's some of the work that has been done in 2022/23:-

Annual Health Checks

The LD Health Facilitation team completed a quality checking exercise with GP practices for their annual health checks and health actions plans throughout the year. A number of areas of good practice and areas for improvement were identified and the Health Facilitation Team worked with individual practices to provide recommendations of how they could improve the quality of their AHC and/or Health Action Plan. The team continue to work with GP practices to provide this service.



Bowel Screening

The lead specialist screening practitioner from the North Derbyshire bowel cancer screening programme contacted the LeDeR team to discuss the uptake of the screening programme for the LD population. They are working through their health inequalities audit and wanted to understand how many people with learning disabilities are of screening age in order to understand if there is a low uptake and reasons for this. *Note: NHS bowel cancer screening checks if you could have bowel cancer. It's available to everyone aged 60 to 74 years. The programme is expanding to make it available to everyone aged 50 to 59 years. This is happening gradually over 4 years and started in April 2021.*[6]

In Derbyshire there are screening practitioners who are learning disability champions with the aim to deliver targeted work such as education for carers and staff in registered and non-registered care and day centres as well as health promotion events for the learning disability population.

A focus group began in January 2023 and began to look at the "perfect pathway" through screening from the user perspective. This began by working with health facilitation to identify the numbers of individuals eligible.

LeDeR have supported the work initially by sharing our data on bowel cancer related deaths since the LeDeR programme started. Terminology has been checked with the pathology lead consultant to ensure we are capturing this correctly.

Separate review of Derbyshire care home

During the year it was identified through LeDeR that there had been several deaths at one of our Derbyshire care homes and it was decided by the LeDeR Governance Panel that this would be given further analysis. A report was written which identified that between August 2021

[6] Refer to References section

and May 2022 six reviews were submitted to the Panel for people who resided at the care home; five of these were focused reviews. From these reviews the following themes and trends were identified

- Lack of care coordination
- Poor communication with family / other agencies
- Poor Record keeping / loss of patient files
- Poor management
- Lack of supervision and training

As part of this report a comparison was made between other care homes in Derbyshire where more than one LeDeR review had taken place. This confirmed that the care home (Care home D in the table below) was an outlier in terms of LeDeR reviews.

Home	Number of beds	No of deaths	Average
Care Home A	15 beds	2	13.3%
Care Home B	34 beds	4	11.8%
Care Home C	12 beds	2	16.7%
Care Home D	32 beds	7*	21.9%
Care Home E	20 beds	2	10%
Care Home F	13 beds	2	15.4%

*The increase in number from 6 to 7 deaths relates to a recent death of a patient in Hospital which has not yet gone through a full LeDeR review.

A CQC inspection has been carried out separately and the purpose of our report was to assure the LeDeR Governance Panel that the LeDeR process was highlighting relevant issues in line with other processes. The report found that the LeDeR reviews highlighted issues at the care home that were also identified in the CQC inspection. This was fed back at the LeDeR Governance panel to provide assurance. Issues found were dealt with separately through the CQC inspection/process and it is emphasised that this was an exercise to provide assurance within LeDeR and is an example of the work that we continue to do to ensure that LeDeR processes are working in line with other processes and are of good quality.

Constipation and Bowel Management

We are examining the best evidence base practice to ensure DHcFT/DCHS as a service are supporting bowel management consistently and appropriately. One of the ways is by developing our physical health clinical pathway (this is not an integrated pathway yet, it is about ensuring DHcFT/DCHS clinical teams are providing care and treatment consistently, person centred and evidence based). We are also working with our partners to build better links and signposting and work on any joined-up processes.

Epilepsy

As identified through LeDeR learning it was felt that one area that needed to be followed up was in relation to training community staff in awareness of epilepsy which is something that is not currently offered by the epilepsy services. It was felt that it was worth exploring this further and an epilepsy survey was produced and shared with services to explore understanding of epilepsy, do teams know how to make referrals, and how confident are they in their understanding of the links between epilepsy and health conditions and swallowing problems.

The survey was completed by 19 staff who work within the Derbyshire Learning Disability community teams. All said that they worked with people who had learning disabilities and epilepsy. Further results of the survey are shown below. It was felt that these results do evidence some potential areas of training needs.

The results were shared with community team managers and as a result of this service wide epilepsy awareness training has been rolled out across the learning disability community teams in DCHS and DHcFT. There are plans for this training to feature in their local induction training in the future where necessary. They are also following the same process as bowel management to ensure epilepsy support is central to the care and treatment that is provided.

NHSE Quality Audit

We are very keen to continually improve the quality of the LeDeR reviews where possible and have been pleased to be part of the NHSE LeDeR Review Audit 2022 where a sample of reviews completed in 2022 have been audited. Feedback provided has been reviewed and alongside the newly provided LeDeR Handbook we have used this information to improve our quality process.

Osteoporosis

There is now an Osteoporosis Screening Tool for people with Complex Physical Disabilities on SystmOne as part of the Complex Physical Disabilities Directory (DCHS Learning Disabilities).

The process involves screening individuals as part of their Complex Physical Disability review. Where results indicate moderate or high risk of osteoporosis the GP is alerted and will complete a Fracture Risk Assessment Tool (FRAX), which in most cases confirms the screened level of risk. In these cases the GP is guided to refer for a diagnostic DEXA scan.

Reasonable adjustments, enabling access to the DEXA scanner, may require a double appointment and access to two rooms (one with a hoist and hospital bed and one with the DEXA Scanner). Where people need postural support the LD physiotherapy team are able to provide guidance.

The use of screening has resulted in prescription of medication to prevent or treat osteoporosis which would not have happened without screening.

As there are no national validated osteoporosis screening tools available for people with learning

disabilities and complex physical disabilities, DCHS LD therapists modified a screening tool developed by Guys and St Thomas's Therapists.

People with complex physical disability who have a severe spinal curve or are unable to remain still due to involuntary movements may still not be able to access a DEXA scan despite reasonable adjustments. No alternative diagnostic route has been identified for this cohort of people.

Performance reporting

A LeDeR performance report (see *Appendix 1* for March 2023 report) has now been completed and has received final sign off from the ICB Quality and Safety Forum (in April 2023). This report will be used to monitor such things as how many reviews are in progress and at which stage of the review process, alongside how many reviews are completed as focused or initial. This will enable us to monitor closely where in the LeDeR process there are any "hold ups" which can then be reviewed and escalated internally where needed.

Reducing Health Inequalities Working Group

The LAC for LeDeR in Derbyshire also leads on the Reducing Health Inequalities workstream as part of the Neurodevelopmental Delivery Group which is a group that works across Joined Up Care Derbyshire (the Derbyshire system). Any areas of work that aim to reduce health inequalities for people with learning disabilities and autistic people are fed through this group including the learning from the Clive Treacey report. During the year feedback was provided to NHSE how as a system we have been affected by the Clive Treacey review and recommendations. Areas of work that come via learning from LeDeR are also fed into this group.

Reasonable Adjustments

Reasonable adjustments were our top theme in LeDeR reviews in Derbyshire for 2020/21 and work has been ongoing throughout the year to promote the use of reasonable adjustments and improve awareness.

- Ongoing training continues provided by LD Health Facilitators to GP practices and this includes the promotion of the use of reasonable adjustments.
- A Derby City GP practice is a pilot site for the NHS Digital project which aims to include a reasonable adjustment flag on the summary care record. Although this has not yet gone live across Derbyshire, the practice is continually reviewing the flag and what reasonable adjustments are included as part of individual's LD annual health checks. They are also working closely with partners across the system to promote this, such as acute trusts and have delivered updates to The Good Health Group (one of the Derbyshire learning disability forums for people with lived experience and carers).
- A post for a trainee LD Advanced Clinical Practitioner has been recruited to at DHcFT, whose focus will be on reasonable adjustments. This post will strengthen the workstream around reasonable adjustments as it is anticipated this role will act as lead in this area for the neurodevelopmental

service. DHcFT/DCHS are looking to develop a training package for reasonable adjustments for staff which the individual recruited will be developing.

- Derby Royal Hospital have recruited 2 Reasonable Adjustment Coordinators.

It is worth noting that the theme through LeDeR in relation to Reasonable Adjustments has only been identified in 15.5% of the completed LeDeR reviews for 2022/23 compared to 50% of LeDeR reviews in 2021/22 which is possibly due to the work across the system identified above in the past year. This will be monitored further over the coming year.

Working with our Acute Trusts

During the year the LeDeR reviewers have worked with one of the Consultants at UHDB (Royal Derby Hospital) to improve their Structured Judgement Reviews to incorporate specific questions relating to the care of people with a learning disability/ autism which are completed for deaths in hospitals. This has improved the information collated to support the reviews of deaths for individuals with learning disabilities and or Autism. We are currently working with Chesterfield Royal Hospital to incorporate the same additional questions in their SJRs.

Working across Systems

Throughout the year, including issues raised on the national TV programme "Panorama", our LeDeR reviews found issues around care received at Stepping Hill Hospital, which although not a Derbyshire hospital due to it being just over the border in the north of Derbyshire, is used by some Derbyshire residents. The LAC in Derbyshire has been working closely with the LAC in Greater Manchester and a process agreed to ensure that issues found locally in Derbyshire are shared with them and escalated through their correct Governance processes. This has provided assurance for the Derbyshire LeDeR Governance Panel that issues are escalated appropriately.

What's happening in our Acute Trusts

One of our Acute Trusts - University Hospitals of Derby and Burton NHS Foundation Trust – have introduced a Learning Disability and Neurodiversity Team with a Lead Nurse, Acute Liaison Nurse and two Reasonable Adjustment Facilitators. The following has been provided by the Lead Nurse to give more detail about the work they do. We're positive that this team will help improve the care delivered to patients with a learning disability and/or autistic people.

The team supports inpatients and outpatients with a Learning Disability or Neurodiversity on a day-to-day basis to ensure that they have equality of access to the same healthcare as the general population, with added support to achieve the same health outcomes as those for the general population. We engage with both adult and paediatric services.

One of our primary roles is to support acute hospital staff in the effective delivery of person-centred care to neurodiverse and learning disability patients. We act as a first point of contact to provide expert advice, professional support, guidance and education to the multi-professional teams, partner agencies, patients and carers.

The team also provides highly specialist advice to clinicians in relation to learning disability issues, including assessment of Mental capacity, best interest decisions and Deprivation of Liberty Safeguards. In addition to ensuring that appropriate tools and reasonable adjustments are used to support the patient.

We provide advice and support for families and carers.

The aim of the team is to give our patient demographic an exceptional patient experience and reduce health inequalities. If we get care right for this patient demographic, we will get it right for all.

We are currently raising awareness, developing and rolling out the service across the trust and ensuring that excellence in the provision of care and service is achieved.

We have found that we are an invaluable source of information for staff across the trust and also essential in recommending appropriate reasonable adjustment to enhance the patient experience. We are a regular point of contact for our patient and families as inpatients and outpatients; this allows us to build therapeutic relationships and trust.

The team is always supportive of one another and there is a positive management approach toward the team, alongside the significant support provided by the wider Safeguarding and Vulnerable Peoples Team.

Seeing the positive effect on patients and carers is a huge motivation, knowing that we have improved our patient's health outcomes and enhanced their experience and journey.

As a team we have a broad range of knowledge and experience that we can offer to each other, safe in the knowledge that we are making a difference on a daily basis across the trust.

Our team has many important skills, however, communication and understanding is key. Many of our patients require specific forms of communication that is not always available. Our communication techniques allow us to build a relationship with our patients and this gives them the additional security during their patient journey.

The Reasonable Adjustment Facilitators are key in the provision of care. They assess and implement reasonable adjustments and engage with patients on a daily basis. They advise on ways to reduce distress and how to engage with patients depending on their specific needs.

We are excited to continue to develop our service provision and see what the future holds.

Local Priorities and Actions from Learning

Split of focused and initial reviews

All reviews are completed either as Initial or Focused as per the national LeDeR policy.

45 (78%) of these reviews have been completed as Initial reviews and 13 (22%) as Focused reviews. 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 2022/23 are shared throughout this report to evidence this.

A national target set by NHSE is that 35% of reviews are completed as focused reviews. Increasing our current percentage of 22% is included in our priority areas for 2023/24.

Themes from reviews

Themes are collated for every completed review. This information is collated and used to highlight local priorities. Themes collated for the 2022/23 year are included in *Appendix 4* of this report.

The highest theme in 2022/23 were

1. 'No GP health action plan' – 34%
2. 'Annual Health Check not attended' – 28%
3. Poor Sharing of information – 26%
4. No care coordination – 11%

All of the above will be included in our priority areas for 2023/24.

Autism Only LeDeR Reviews

During 2022/23 we have only received notification of one autism (no LD) death (37-year-old male). This review is On Hold as the death is with the coroner for investigation. The reason for death has not yet been confirmed.

In 2021/22 we also only received one notification of one autism (no LD) death (32-year-old female). This review has still not been completed as was a death through suspected suicide and is still On Hold as with the coroner for investigation.

We have therefore not yet had any completed autism only reviews and so are not yet in a position to begin learning from our autism only reviews. We do continue to promote and raise awareness that referrals can be made to the LeDeR programme for individuals with a clinical diagnosis of autism with no learning disability. All Derbyshire reviewers have undertaken the autism training provided by the LeDeR programme.

Digital Monitoring Project

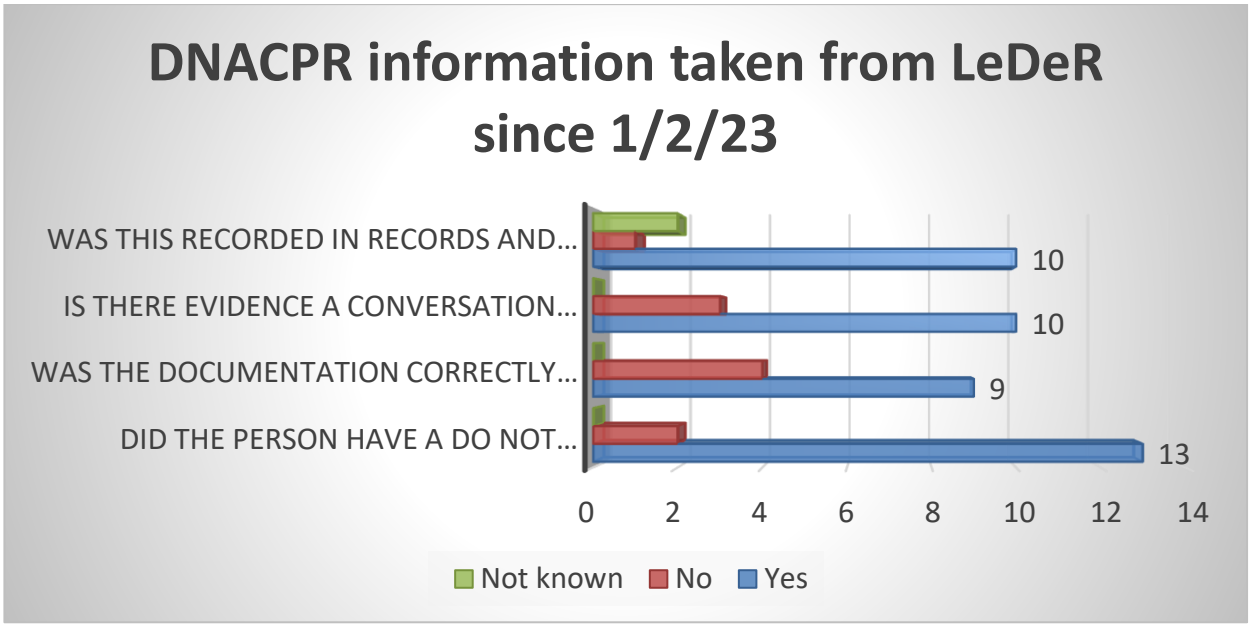
In Derbyshire we hope to be involved in a national pilot to provide individuals with learning disability and their carers with an App which aims to empower individuals to understand their physical health and encourage healthier living. We have been working locally to understand the pilot and to find local GP practices who would be interested in being involved in this pilot.

DNACPR

Data captured with regards to the completion and following of DNACPR and ReSPECT forms in Derbyshire showed us that there was a need to investigate this further. Data earlier in the year showed us that of the reviews monitored 67% of the individuals had a DNACPR in place but only 42% of those were followed correctly. 42% also gave the response as "Don't know" whether they were followed correctly (25% were recorded as a "No"). This resulted in us asking reviewers to ensure they provide more detailed information and that "Don't know" isn't necessarily an acceptable response.

In February 2023 the new LeDeR23 form was introduced to the LeDeR platform which enabled us to gather more information about DNACPR on the initial review and has allowed us to capture additional information. The graph below is new information on reviews we have completed since 1st February 2023 and shows us that 13 of 15 had a DNACPR in place (87%) and of those with a DNACPR in place 69% were correctly completed and followed. Although this is an improvement on the previous percentage this is still not good enough.

It has been agreed through our End of Life Operational Group that a DNACPR and ReSPECT Working Group will be set up to share learning and identify any gaps across the system. This group is in the process of being set up.



Easy Read Materials

As part of work to improve Reasonable Adjustments LeDeR Steering Group members were asked to share details of easy read information that is available in their organisations. The Health Literacy team (Public Health, Derbyshire County Council) attended the LeDeR Steering Group and discussed the work they have started to collate a contacts list of who works on easy read materials across the system. The aim is to understand who coordinates easy read materials across the different organisations. This has now been directed to the Neurodevelopmental Health Inequalities working group where it is being discussed further with regards to the requirement for system working to coordinate easy read materials that are available.

Epilepsy

Based on learning seen through local LeDeR reviews alongside learning seen from the Clive Treacey review we see epilepsy as one of our priority areas in Derbyshire. Although some work has been undertaken to address issues raised, such as the epilepsy awareness training being delivered for DCHS/DHcFT staff who work in the learning disability teams (as detailed in the *Outcomes and Achievements* section of this report) there are still other areas of work to be done. The Midlands Epilepsy Benchmarking exercise suggested a number of options for development for systems:

A named lead from both learning disability and epilepsy services could be identified to ensure regular multi-disciplinary care for patients
A cross-agency workforce strategy and action plan could be created
Care plans could be reviewed with the aim of ensuring all the relevant information is included (e.g., SUDEP risk, what to do in an emergency, which services to engage with) and that the care plans can be shared across services
The directory or local services working with people who have epilepsy and a learning disability could be made publicly available
Information could be shared more often between primary, secondary, specialist acute and learning disability services, either through the use of electronic health records, or through other means such as letters
A named commissioner with responsibility for learning disability and epilepsy could be identified
The number of people with epilepsy and a learning disability should be identified

In Derbyshire, there is no Epilepsy Lead across the system and/or no commissioner with responsibility for epilepsy which is possibly the starting point needed in order that some of these development options can be coordinated and taken forward across the system. This issue is being escalated within the system.

Derbyshire Case Studies

The following case studies are all reviews that have been completed during 2022/23 as part of the LeDeR Programme. They have been chosen to evidence some good practice as well as some areas of concern that we will be including as our priority areas for 2023/24.

LeDeR Review Case Study 1 - evidencing good practice Reasonable Adjustments

Background

Going into hospital can be a scary prospect for anyone, but for someone with a learning disability it can be particularly challenging.

By law public sector organisations must make Reasonable Adjustments to their approach or provision to ensure that services are accessible to disabled people as well as everybody else.

National guidance[1] outlines the importance of Hospital Learning Disability Liaison Nurses, Hospital Passports and Reasonable Adjustments.

This case study demonstrates Good Practice with some additional learning around person-centred approaches and communication with family members. Feedback was shared with all providers to build on Good Practice.

Summary of Care

Michael was a 74-year-old man with moderate to severe learning disabilities & multiple health problems including epilepsy, high blood pressure, dysphagia, and osteoporosis.

Michael's "forever home" was in supported-living accommodation with a 24-hour package of care shared between Michael and his two housemates who were all mobile to some degree.

Michael's mobility had declined over recent years and he used a walking frame to support his indoor mobility and a transit wheelchair for outdoor mobility.

Michael was very sociable man and was relaxed in familiar surroundings and in the company of family and friends, but he struggled to understand anything outside of his own experience. A lack of understanding could then trigger anxiety and escalate into verbally aggressive outbursts.

Michael loved to go on holiday to Blackpool and the year of his death was no exception, although he found it increasingly difficult to walk.

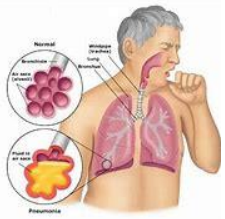
Soon after returning home, he complained of pain in his back, struggled to stand up from his chair and was incontinent of urine.

Supported by one of his care workers Michael was admitted to hospital for investigation and was diagnosed with spinal abscess, discitis (inflammation of the vertebral discs) and a vertebral fragility fracture secondary to osteoporosis.

Michael had a hospital passport updated by his care providers. This gave essential information about Michael's health, his likes and dislikes, communication needs and reasonable adjustments he would need.

Michael's care was supported by the hospital Learning Disability Liaison Nurse who made sure he received good care.

Reason for Death



Sadly, following 6 weeks bed rest and a short period of rehabilitation Michael was re-admitted to an acute hospital ward following a stroke and later transferred to a nursing home for palliative care where he died of aspiration pneumonia.

Good Practice identified through Implementation of Reasonable Adjustments during Initial Hospital Admission

Michael's prescribed treatment was a course of antibiotics and 6 weeks bedrest which, if possible, would have been managed at home to prevent any anxiety resulting from unfamiliar surroundings and people.

Every effort was made to adapt the home environment to enable safe discharge (including access to moving and handling training and equipment) but the bedroom was too small to accommodate the equipment safely.

For this reason, Michael remained on the hospital ward, where Reasonable Adjustments were agreed and implemented to overcome communication, mental health and learning disability barriers, and enable Michael to successfully engage with hospital care and treatment. Michael had an up-to-date Hospital Passport.

The hospital Learning Disability Liaison Nurse was instrumental in this process through her collaboration with care providers, adult care, and ward staff & in the implementation of Reasonable Adjustments to support Michaels needs. It was agreed that Michael's home-care staff team would be available to support Michael several hours a week during acute and community rehabilitation admissions.

The care providers spoke very highly of the care and support provided by the Learning Disability Liaison Nurse who worked collaboratively across the system to address and implement reasonable adjustments enabling optimum access to care.

Good practice was fed back to the Learning Disability Liaison nurse, ward staff, care provider and adult care.

What could have been done better?

Michael's cousin and next of kin knew Michael's wish was to die at home surrounded by his family, friends, and care support staff. Despite the good communication outlined above, there was little communication between the LD Liaison Nurse and Michael's next of kin. Although the cousin had no complaints about the care Michael received in hospital, she felt he was lonely on a side ward, and a television would have helped the time to pass. Under normal circumstances Michael would never miss an episode of his favourite soap operas and a TV would have would have enhanced Michael's patient experience. The cousin approached a member of the ward staff who said televisions were not available due to the risk of Covid-19 but Michael's cousin remained concerned about his mental health and well-being throughout his stay.

The LD Liaison Nurse said she hadn't had much contact at all with Michael's cousin, possibly due to visit times, but assured me that Michael had home care and ward staff popping in to see him all the time.

Learning

1. To apply a person-centred approach during hospital admission.

Michael was unable to mobilise, had limited communication and a history of anxiety and verbal aggression. Michael would have enjoyed watching his favourite Soaps and films in his bedroom which could have addressed feelings of loneliness, levels of anxiety and his sisters concerns for his well-being.

2. Provide family reassurance by proactively sharing updates, feedback, and the opportunity to share concerns

1.guidance on supporting people with a learning disability who are being admitted to hospital

Note: This is a real case study from a review which took place as part of the LeDeR programme in Derbyshire. Michael is not the subject's real name, and has been given this name to protect his identity

LeDeR Review Case Study 2 - evidencing good practice in the provision of care at home with support from community professionals

Background

Naomi was a 28 year old Asian female who lived at home with her parents and siblings. She had a profound learning disability with complex physical health needs including, asthma, hydrocephalus (fluid within the brain), epilepsy and constipation. She had a PEG feed (a tube into the stomach to give food, fluids and medicine) because she had problems with swallowing. She was prone to pneumonia and aspiration pneumonia.

She always had a big smile for everyone and loved to be talked and sung to. She had a mickey mouse radio that she liked to listen to.

Naomi couldn't walk and used a wheelchair, and she was hoisted for all her transfers. It was very important that she was positioned correctly to reduce the risk of aspiration (where the contents of the stomach enter the lungs). She was nonverbal but could communicate with her facial expression, eye contact and vocalising.

Care received

She had many health professionals involved in her care, including her GP, Consultants (rehabilitation and palliative care), Dietician, Nutritionist, Respiratory Team, District Nurse, Community Learning Disability Physiotherapist/Occupational Therapist and Palliative Care (Macmillan and Tree Tops).

Reason for Death

It was recognised that Naomi was deteriorating in the months before her death, she had lost weight and was experiencing more infections. She was placed on end of life care and died peacefully at home of Aspiration Pneumonia.

What worked well

- Communication between all professionals involved
- Coordination of care
- Optimising processes for hospital admissions (LD physio support into hospital with sleep system)
- Hospital passport

- Home visits
- Long term planning
- Timely discussions with family and health team on ReSPECT/End of life wishes with regular reviews
- Home care support agency with Asian carers (LD physio trained in positioning)

- Symptom management/anticipatory medication
- Reasonable adjustments
- Palliative care night sitting service
- Family support

Note: This is a real case study from a review which took place as part of the LeDeR programme in Derbyshire. Naomi is not the subject's real name, and has been given this name to protect her identity.

LeDeR Review Case Study 3 - evidencing the need for better care coordination for people with a mild learning disability to improve access to health care

Background

Bella was a 53 year old who grew up in South Africa, she moved to the UK as a child with her parents and sibling and latterly lived in her own tenancy in a ground floor flat. Her parents predeceased her, and her sibling lived away.

Bella had a mild learning disability, type 2 diabetes, obesity, cellulitis of the legs and lymphoedema, poor hygiene and skin integrity.

Bella loved animals and had a chihuahua named Tia. She liked to watch Strictly Come Dancing and Disney films. She also loved children and collected life like dolls.

Bella struggled with many aspects of her life and gave the impression that she understood when she didn't. This was clear to her sibling when after her death she found many unopened letters and unused blister pack medication. She was also in a lot of debt. It became apparent that she had missed a lot of health appointments.

Bella used a mobility scooter to get out and about but struggled within her flat. She had carers for 1.5 hrs every day.

She was described as being kind but vulnerable.

Summary of health and care

Decline in health towards the end of her life

Bella had carers every day directly commissioned by adult care. Care plans were in place outlining what support Bella needed, including help with medication and hospital appointments. Despite this these were missed and therefore risks not communicated between health and social care. There was no named person responsible for the health coordinator role or a process for escalation of concerns.

Bella had been unwell for 4 days feeling sleepy and with stomach pains and on a Sunday she called 111, a service that gives a person emergency health advice. She was offered an appointment but declined and waited to see her own doctor on the Monday. On the Monday she was offered an appointment at the Red

Hub (a place where people are sent with certain symptoms, possibly covid related), she did not answer the phone when the clinician called her. The hub uses a different computer system and did not share this information with her GP straight away. This is because she did not answer the phone and give consent for them to share the information.

Bella was admitted to hospital the following day when her social worker had visited her at home and rang the GP explaining that she was short of breath and in and out of consciousness and was advised to call an ambulance. Bella had investigations and was transferred to Intensive Care Unit (ICU). She died in hospital the following day.

Cause of death

1a multiple organ failure

1b acute renal failure, acute pulmonary embolus

2 morbid obesity, diabetes mellitus

What didn't work

Sharing information in her best interest

There was no flag that indicated that her learning disability made her vulnerable

No one coordinating her care

No escalation plan/safety netting between services

Communication – she was sent text messages from her GP surgery and the Hospital that she did not respond to

The hospital discharged her when she did not respond to a request to make an appointment and did not inform her GP they had done this

Telephone reviews

What could have worked better

A nominated health coordinator

Annual health check and health action plan, not completed fully or accurately

Health screening

Mental capacity assessments-understanding health needs and appointments/finances/medication/hygiene/weight

Face to face medication reviews

Reasonable adjustments

Accessible information

Communication between health and social care and safety netting

Information sharing between hospital departments on reasonable adjustments

Information sharing between SystmOne (clinical system) units in best interests

Referral for advocacy support

Note: This is a real case study from a review which took place as part of the LeDeR programme in Derbyshire. Bella is not the subject's real name, and has been given this name to protect her identity

LeDeR Review Case Study 4 - evidencing the need for better care coordination for people with a mild learning disability with complex conditions

Background

Ben was a 68-year-old gentleman who lived in his own tenancy in a ground floor flat. He had a diagnosis of Laurence-Moon-Biedl syndrome, reflux, hypertensive disease, Barrett's oesophagus, type 2 diabetes, peripheral neuropathy (lack of sensation in his extremities), and severe frailty. He had 4 care calls per day supporting with medication, personal care, shopping, and meals.

Summary of Care

He was having daily checks on his blood glucose by the district nurses and his skin was also checked on his feet at each visit due to him walking around without footwear. Insulin was administered if necessary as he didn't understand how to do this. Nor did he understand how to look after his diet.

Ben had no friends or family. On several occasions he refused to let health and care staff into the flat, he said he didn't want this anymore but had also been aware of burglaries in the area. He was also missing a long-term carer who had left her job who he had a good relationship with and who he trusted. Ben had also had learning disability nurse involvement for many years and they supported him to his hospital appointments but the referral was closed in 2021 with advice to carers on how best to support.

Ben liked to talk about local news and music, he liked to feel safe and secure and needed a lot of reassurance. If he was taken out he loved to buy CDs.

A mental capacity assessment was completed and found that he did not have capacity to understand his health needs. It was considered by staff who knew him well that he took information literally when he was told to lock his door and not let anyone in. It was also noted by the care coordinator following a multi-agency review that he did not have a good rapport with his support workers.

Decline in health

Ben had a hospital admission due to peripheral oedema and iron deficiency; his insulin was stopped whilst in hospital and nurse visits reduced to once weekly once back home.

A few weeks later he fell but refused to go to hospital, EMAS stated he had capacity, but his GP said he didn't.

Ben was losing weight and refusing food and drink and stating he wanted to die. A further admission to hospital and a referral to mental health liaison who asked the ward to complete a mental capacity assessment. This was not actioned as the staff felt he was being selective with them. Fractured ribs and a small haemothorax were diagnosed and he was discharged home where he continued to refuse food and medications.

Ben was admitted to hospital again 5 weeks later and died the same day.

Ben died of 1a ischaemic heart disease, 2 Type 2 diabetes, hypertension, Laurence-moon-Biedl syndrome.

What didn't work

No one coordinating his care, the expectation that a care agency can provide this is not realistic.

No escalation plan/safety netting between services

Lack of communication between agencies

Lack of agreement on capacity between GP and EMAS

Lack of signposting back to learning disability service

Reasonable adjustments from all services involved in his care

What could have worked better

One agency agreeing to support ongoing health in the absence of a family or long-term carer. This had worked well when the specialist learning disability team remained involved who understood the complexities of his learning disability and complex health needs. A trusting relationship was in place.

EMAS made a decision on capacity regardless of what his GP and other professional had reported.

A clear person-centred plan on how best to provide health support to Ben with regular reviews and safety netting/escalation plans.

Referral for advocacy support

Note: This is a real case study from a review which took place as part of the LeDeR programme in Derbyshire. Ben is not the subject's real name, and has been given this name to protect his identity.

LeDeR Review Case Study 5 – evidencing the need to improve uptake of cancer screening for people with learning disabilities

Background
The NHS runs three cancer screening programmes:

- Breast Screening
- Cervical Screening
- Bowel Screening

Part of the learning from the Case Study reflects evidence that eligible people with a learning disability are less likely to take part in cancer screening compared to those without a learning disability which leaves them at risk of undetected cancer. The attitudes and knowledge of both professionals and carers supporting people with learning disabilities play a part in the poor uptake of screening.

A lot of accessible information and resources are available to help people with learning disabilities understand the need for screening, what it involves and how to be prepared for it. However, many staff are unaware of these resources and do not make use of them. Feedback from the Case Study reinforces the need to raise this awareness and promote the use of the available information

Summary
Joan was a fun-loving 62-year-old lady with severe learning disabilities, stable epilepsy, hypothyroidism, and gall stones. Joan wore hearing aids and glasses and was independently mobile until the last 10-months of her life when she needed more support following a terminal diagnosis of colorectal bowel cancer.

Joan lived in a Derbyshire residential care home for over 20 years of her life, and it was clear she was happy there. Her friends and family were very important to her and played a big part in her life. Joan loved to sing and dance, she loved Minnie Mouse Disney character, and enjoyed looking through leaflets over a cup of tea.

Joan communicated in short sentences using familiar language and could make simple choices given the opportunity. Staff made reasonable adjustments within the home environment (photographs and picture timetables) to support Joan's understanding

In 2019 at the age of fifty-eight Joan developed abdominal pain for which the GP requested blood tests. Concerned by the results the GP referred Joan for further investigation but there were delays in appointing Joan for a CT scan; it is not possible to determine whether these delays contributed to Joan's death.

Most learning from this review relates to the delays in bowel investigations, but gaps were also identified in cancer screening.

The Care manager described Joan as "generally compliable with" health appointments except for those where Pam had to be alone in a room and/or remain still (as is the case with cervical and breast screening).

Despite recommendations encouraging Joan to familiarise herself with screening (staff and equipment) before appointments, and the willingness of care staff and family to support Joan, Pam did not attend cervical or breast screening.

Reason for Death

In September 2021 at the age of sixty-one Joan (supported by family) received the devastating diagnosis of inoperable colorectal (bowel) cancer.

Good Practice identified with Bowel Screening

1. Joan was eligible for bowel screening in 2020 when she was 60 years old. Poo samples were taken and sent for testing and the results were reported as normal.

Good Practice identified with End-of Life Care

1. Joan was on the End-of-Life Care Register and referred by the GP to the Community Palliative Care Team immediately following terminal diagnosis. Joan died at home (in-keeping with family wishes, and Best Interest Decision) in October 2022 at the age of sixty-two

2. Good integrated care where community teams (district nursing, learning disability, palliative care), worked with private care providers, Joan, and her family to ensure she received the best end of life care at home (in Residential Care)

Positive Feedback was shared with all care and service providers.

What could be better?

Cancer screening must be everyone's business, to make improvements across the System, raise awareness, increase screening uptake, and reduce risk of death due to cancer.[5]

Feedback was shared with:

1.Primary Care, Strategic Health Facilitation Team, and the Ageing Well Team

- To complete accessible Health Action Plans (HAP)[7] with the individual and their support at their Annual Health Check and include any anticipated Cancer Screening
- To include links to Easy Read cancer screening leaflets, guidance[,2,3,] and accessible on-line videos in the HAP

2.Care Providers

- To consider training care staff to champion cancer screening[1,4,5,7] and deliver accessible information to individuals using easy-read information and video links
- To use person-centred approaches in preparation for cancer screening appointments. Joan, for example loved looking through "leaflets over a cup of tea" which could have been a perfect way to engage with a care support worker in preparation for screening

Learning

Although not directly linked to the cause of death in this case, this review has raised some important learning in relation to raising awareness of cancer screening across the system. Each cancer screening programme is as important as the next and there needs to be access to up-to-date training and resources with collaborative and streamlined processes in place to improve the uptake of cancer screening and reduce the risk of premature cancer death in the LDA population.

New guidance (March 2023) from "Learning Disability- applying All Our Health"[1] will help frontline workers use their trusted relationships with clients, families, and communities to provide the best possible support for people with a learning disability and their families, across an age continuum. Important actions are also recommended for managers and staff in strategic roles.[1,5]

1. Learning disability - applying All Our Health - GOV.UK (www.gov.uk)
2. Bowel cancer screening – An easy read guide (publishing.service.gov.uk)
3. Information_for_LD_Carers_leaflet.pdf (derbyshirehealthcareft.nhs.uk)
4. Cancer screening: making reasonable adjustments - GOV.UK (www.gov.uk)
5. LD-Fwk-Briefing-Paper-23-Oct-19-2.pdf (skillsforhealth.org.uk)
7. Health Action Plan: Derbyshire Healthcare NHS Foundation Trust (derbyshirehealthcareft.nhs.uk)

Note: This is a real case study from a review which took place as part of the LeDeR programme in Derbyshire. Joan is not the subject's real name, but has been given this name to protect her identity

Local Priorities for 2023/24

1. Increasing the number of focused reviews to reach the national target of 35%
2. Improving the number of (and quality of) GP Health Action Plans
3. Reduce the number of LD annual health checks not attended
4. Ensuring that services are made aware where the LeDeR review has evidenced poor sharing of information
5. To 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
6. To promote LeDeR and the notifying of deaths, both for autism only reviews and those with a learning disability.
7. Working 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.
8. To continue to identify issues found in relation to those individuals with epilepsy and highlight the importance of an Epilepsy Lead across the system.
9. To set up a DNACPR working group and share learning across the system, identifying any gaps or training issues.

Special thanks to the following people who have been involved in co-producing this report:-

Our experts by experience – Denise B, Dan W and members from Our Vision Our Future

LeDeR Steering Group members across the Derbyshire system

References

Links to various documents mentioned in the report are shared below:-

National LeDeR Policy 2021

Derbyshire LeDeR Strategy 2021

Joined Up Care Derbyshire (JUCD) website

Office of National Statistics, 2021 Census

NHS – Bowel cancer screening

Appendix 1 – Derbyshire LeDeR Performance Report (4 pages)

Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

LeDeR Performance Report

Data to the 31 March 2023

There have been 4 new notifications since the last report at 15th March 2023
There have been 4 reviews completed since the last report at 15th March 2023
4 have been completed as an initial review and 0 have been completed as a focused review
All 4 reviews were completed within 6 months.

Derbyshire performance compared to Midlands region and England
Information provided by NHSE

	Completed - All Notifications					Completed - Initial Reviews (Stage of Review is 5, 6 or 7) - Since June 2021					Completed - Focused Reviews (Stage of Review is 5, 6 or 7) - Since June 2021					% of Focussed Reviews - Since June 2021				
	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23
Region, & CCG	%	%		%	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
England total	87%	87%	89%	87%	88%	88%	88%	90%	89%	89%	78%	79%	83%	80%	82%	20%	21%	21%	21%	22%
MIDLANDS	94%	94%	93%	93%	94%	95%	95%	94%	94%	95%	89%	89%	90%	86%	89%	28%	29%	29%	29%	30%
Derbyshire	99%	99%	99%	99%	98%	98%	98%	98%	98%	100%	100%	100%	100%	100%	91%	26%	27%	27%	26%	25%

Date of extraction

31 March 2023

Executive Summary

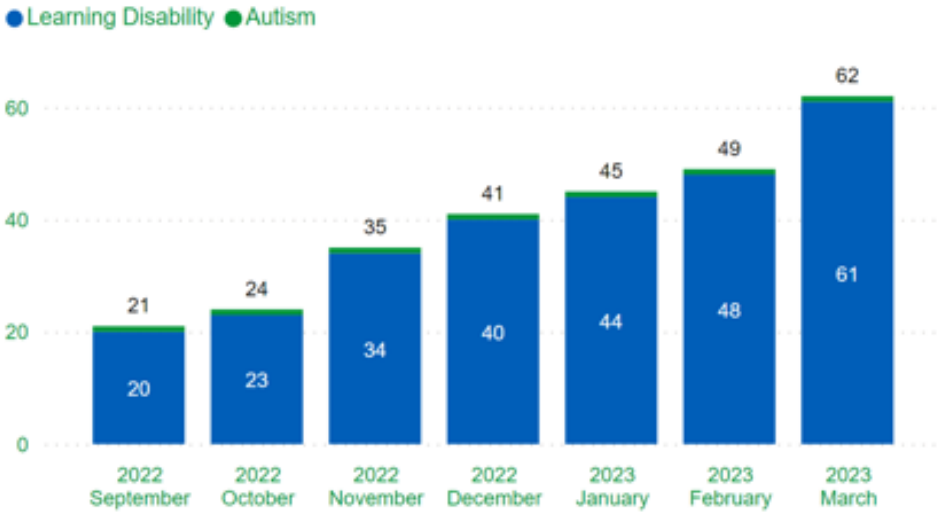
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

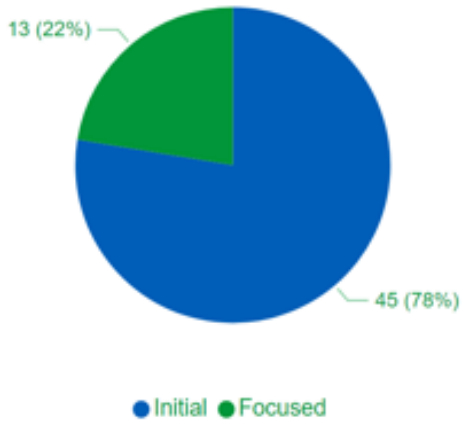
Current Totals for the 22/23 year – from April 2022

62	58	44	76%
Total Notifications 22/23	Total Completed 22/23	Total Completed in 6 months 22/23	% Completed in 6 months

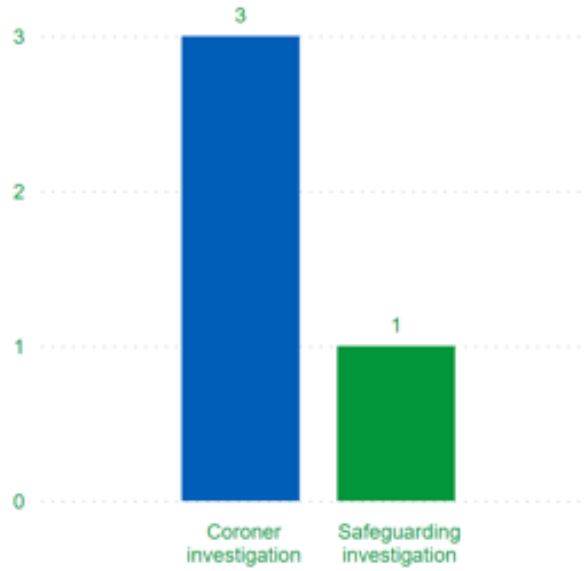
Notifications received from April 2022 split by Autism only and LD



Total number of completed reviews from April 2022



Reason for on hold



Date of extraction

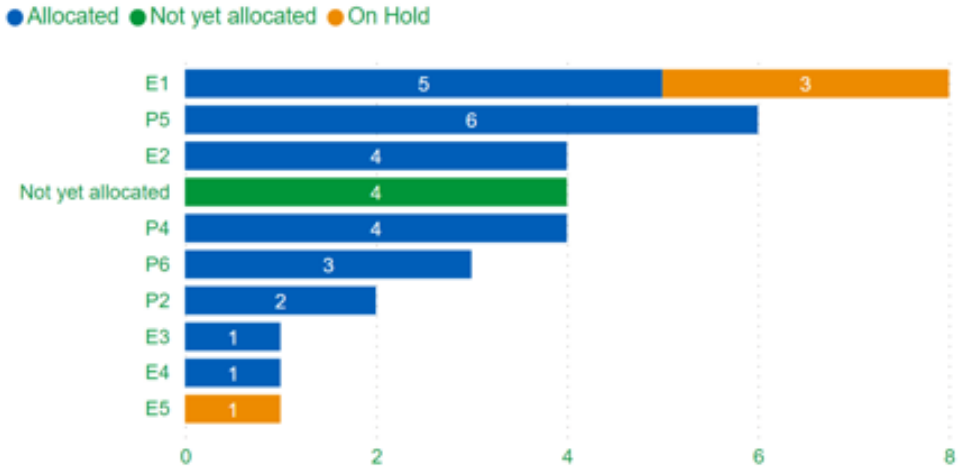
31 March 2023

Introduction of new LeDeR Platform since March 21

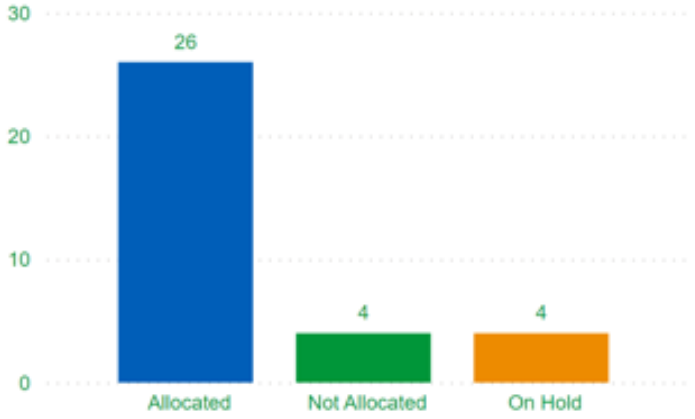
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

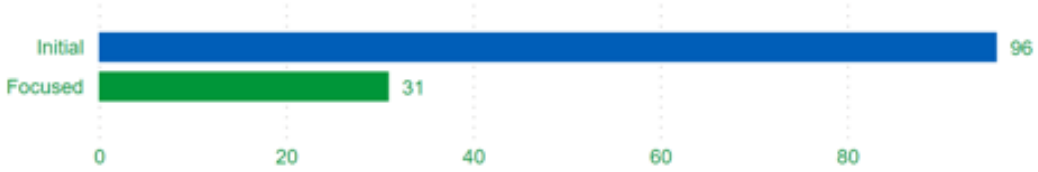
Current Status of Reviews by Reviewer



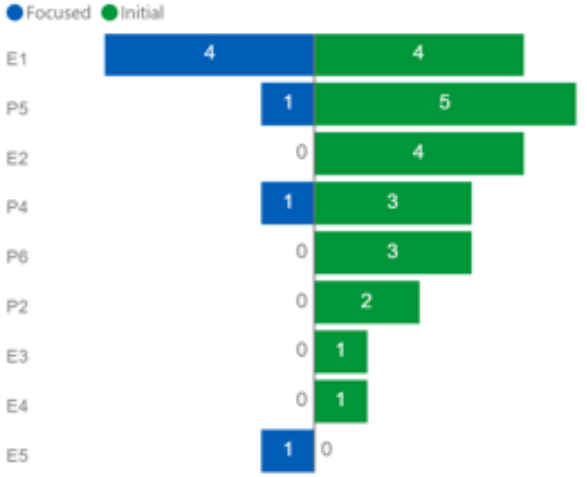
Current reviews by status



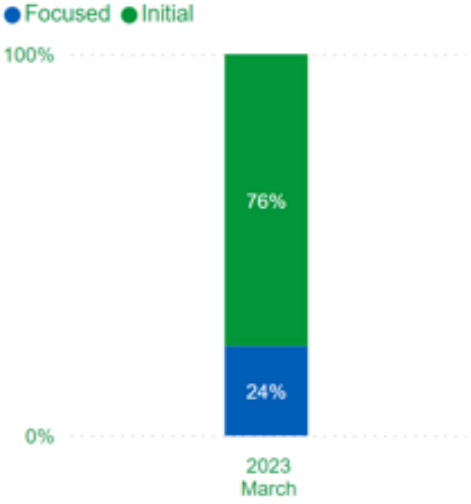
All Reviews (completed and in progress) since March 2021



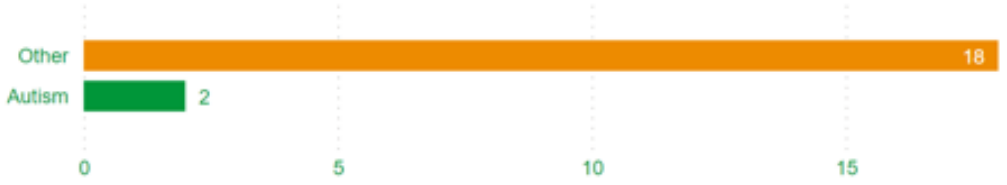
Type of Review by Reviewer in progress



Reviews currently in progress



Breakdown of completed and in progress focused reviews since March 2021



Date of extraction

31 March 2023

Overall Position

Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Since 2017 the start of the LeDeR program

344

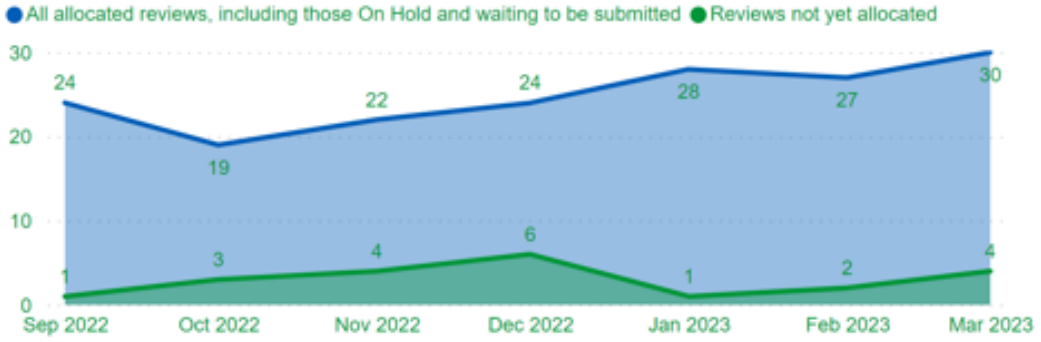
Total Number of notifications since 2017

309

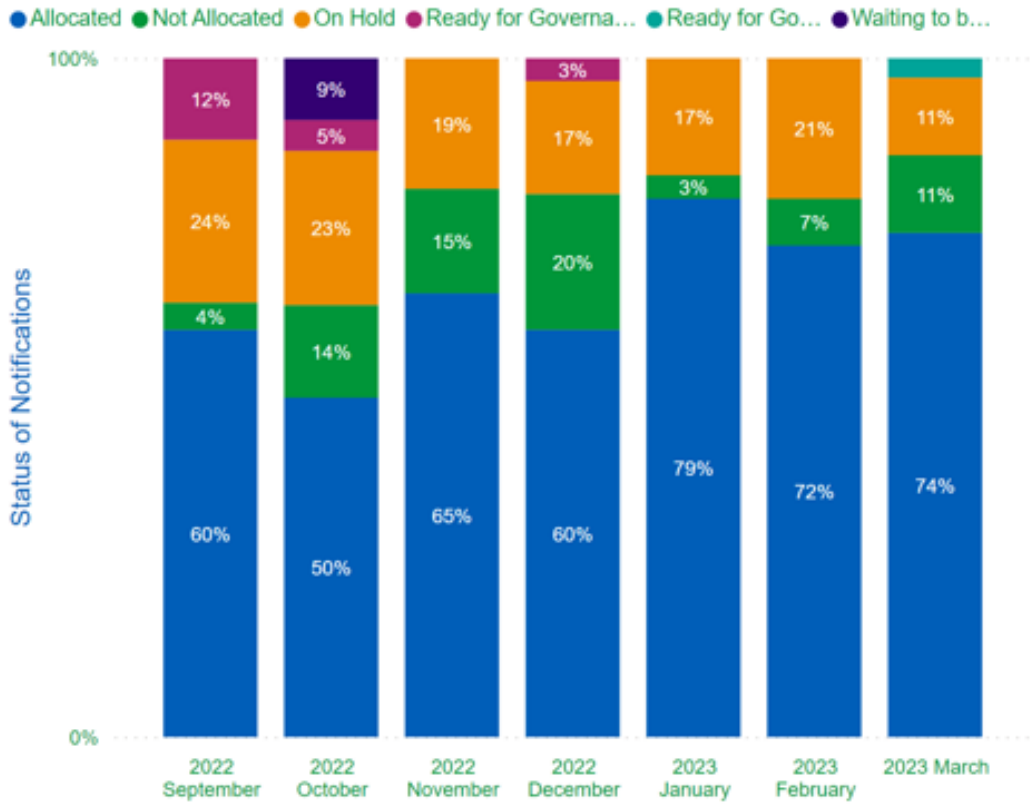
Total Completed since 2017

Type of Review Completed since March 2021

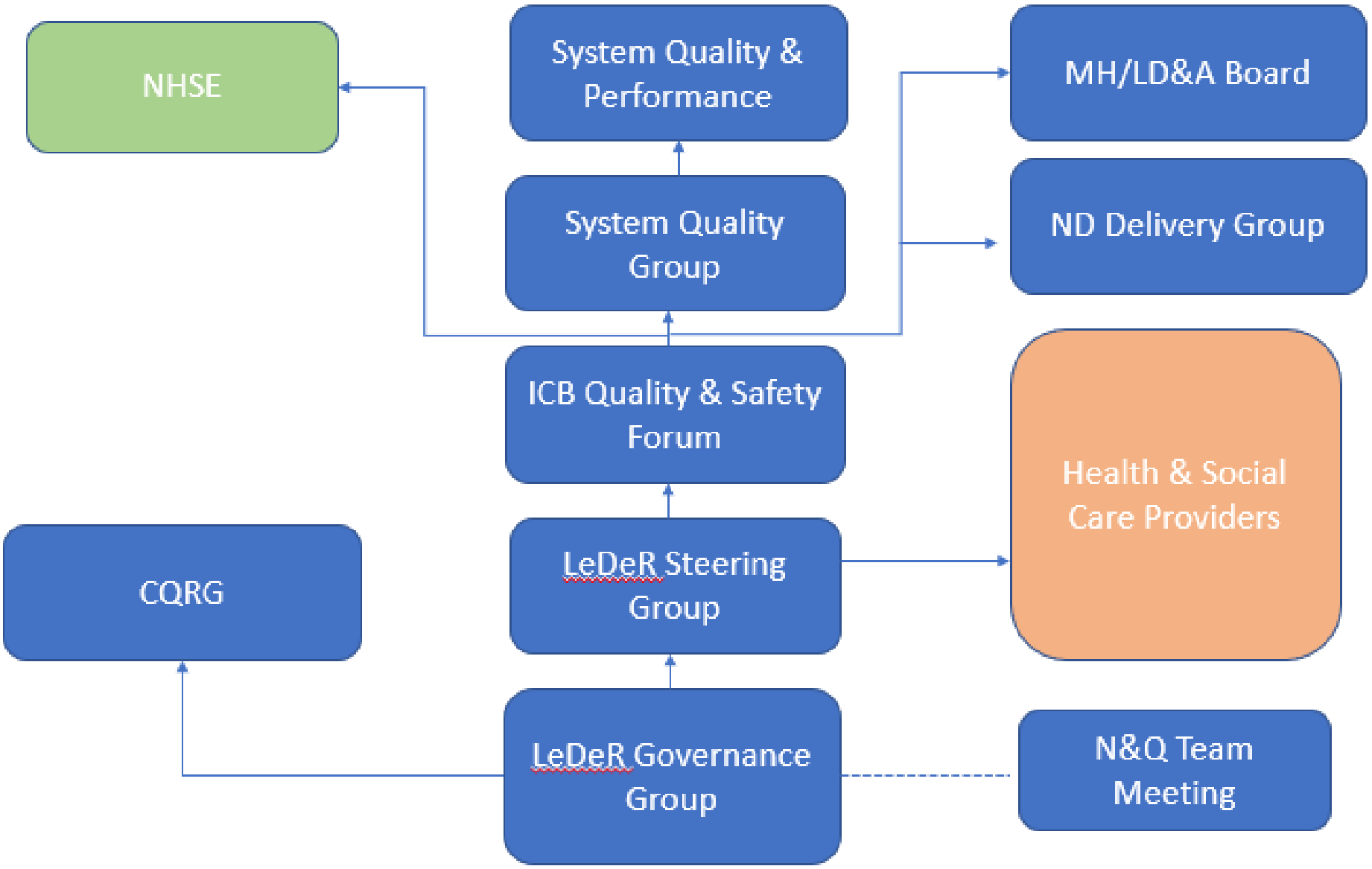
Comparison of notifications received but not yet allocated against allocated reviews (including On Hold reviews)



Current Reviews by Status



Appendix 2 – LeDeR Governance Structure



Appendix 3 – Derbyshire Local Action Plan – deliverables against the LeDeR Policy

Key Deliverables	Outcomes	Key performance measures	Responsibility	Frequency of collection (if appropriate)	Date for completion	Current Status at end of 2022-23
1) A robust plan will be in place to ensure that reviews are completed within six months of the notification of death.	100% of reviews (both initial and focused) are completed within six months of notification except those that go to external investigation.	Monthly dataset shows ICS completion of eligible reviews within six months of notification.	LAC	Monthly	Ongoing	In Progress to improve monitoring of reviews
2) An annual LeDeR report demonstrating how the ICS is delivering on local actions addressing those areas identified in LeDeR reviews. It will demonstrate effective delivery of actions from learning from LeDeR reviews.	Published report and available to the public	The report will be approved via the JUCD MH/LDA Board	LAC	Published in June each year	June 2022 & yearly	Completed - Ongoing
3) ICS will demonstrate how they are narrowing the gap in health inequalities and premature mortality for those who have a learning disability in their local area	• A reduction in the repetition of recurrent themes found in LeDeR reviews in a local area. • Reduced levels of concern and areas for improvement • Reduced frequency of deaths that were potentially avoidable or amenable to good quality healthcare.	Through LeDeR reporting and analysis	ICS	Annually	June 2022 & yearly	Ongoing reporting & tracking

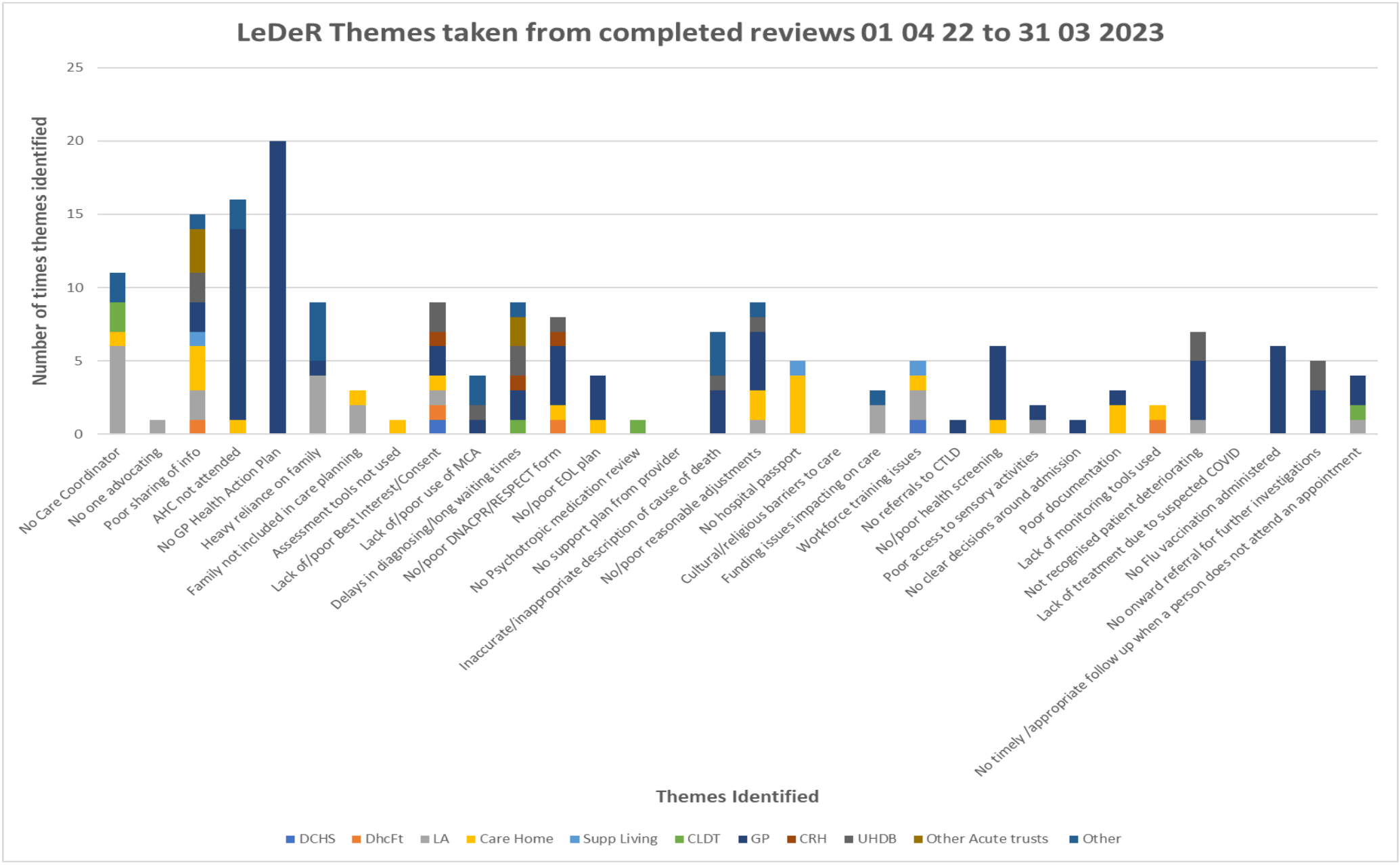
4) Clear and effective governance in place which includes LeDeR governance within mainstream ICS quality surveillance and governance arrangements.			ICS	Annually	Operational from 1st July 2022	Complete
5) Increased reporting of deaths from people from relevant Black, Asian and Minority Ethnic communities within the ICS proportionate and relative to the communities living within that geography	Increase in number of notifications received through the LeDeR platform	Captured through LeDeR reporting	LAC & BAME lead	Weekly reporting	Ongoing	In Progress
6) Clear strategy for meaningful involvement of people with lived experience in LeDeR governance	Membership at LeDeR Steering Group	Attendance captured in minutes of meeting	LAC	Meetings held quarterly	September 2021	Completed
7) Senior ICS leaders, including local authority partners are involved in governance meetings where issues found in local reviews are discussed and actions agreed collaboratively, to support joined-up actions to improve services, reduce health inequalities and reduce premature mortality.	Membership at LeDeR Governance Panel (previously called CQRG)	Attendance captured in minutes of meeting	LAC	Meetings held 6 weekly	April 2022	Completed
8) To be prepared to begin the reviews of deaths of autistic people once this goes live	100% of reviews are completed within 6 months of notification	Monthly dataset shows ICS completion of eligible reviews within six months of notification.	LAC	Monthly – following go live (currently expected end of 2021)	December 2021	Completed

9) To be prepared to begin the reviews of deaths of autistic people once this goes live	100% of reviews are completed within 6 months of notification	Monthly dataset shows ICS completion of eligible reviews within six months of notification.	LAC	Monthly – following go live (currently expected end of 2021)	December 2021	Completed
10) To ensure that reviews are completed and quality assured to an acceptable standard	The programme can share and use learning to make meaningful changes to the lives of individuals with learning disabilities.	• Training of reviewers will be monitored to ensure training provided by the programme is attended • The LAC and Senior Reviewer will meet regularly to quality assure reviews and refer to the LeDeR Governance Panel where wider quality review is required. • Quality Checklist form to be completed for each completed review	Reviewers/LAC/ Senior Reviewer	Training monitored 6 monthly Weekly meetings of LAC & Senior Reviewer	Ongoing Weekly Following each completed review	Completed – ongoing
11) To continue to work with partners as part of Joined Up Care Derbyshire ICS in relation to the LeDeR programme	To enable service improvements to be agreed, developed and made together across the whole system	• To review the terms of reference and attendees for the LeDeR Steering Group to ensure correct membership in order that system change can be discussed and agreed based on learning from LeDeR	LAC/ICS	Annually - ToR for Steering Group reviewed Q4 2021/22 Monthly – as needed	September 2021	Ongoing

		• To escalate risks and issues through Joined Up Care Derbyshire Mental Health/Learning Disability/Autism Board to ensure LeDeR is an ICS responsibility • To continue to work closely with health and social care partners through the LeDeR Steering Group, sharing learning and discussing and implementing change through the sharing of themes and reviewing of good practice • LeDeR LAC is also workstream lead for Health Inequalities at a Neurodevelopment Delivery Group held monthly across the Derbyshire system. A Health Inequalities Working Group has been set up as part of this workstream to ensure partners are meeting together to share		Bi-monthly		

		learning, identify gaps and share work that is in progress across the system. Such things as learning from LeDeR, work on LD annual health checks, STOMP STAMP and recommendations from the Clive Treacey report are part of the areas of work shared and discussed. This work continues and is fed back in a monthly highlight report to the Neurodevelopment Delivery Group.				
12) To promote LeDeR and share learning from LeDeR across Derbyshire learning disability forums and with learning disability services and care providers.	Increase in notifications made to the LeDeR programme Increased awareness of the LeDeR programme and its aims	Increase in notifications through weekly performance monitoring	LAC/Reviewers	Weekly monitoring	Ongoing	Ongoing

Appendix 4 – Derbyshire LeDeR Themes Graph


LeDeR Themes taken from completed reviews 01 04 22 to 31 03 2023
Number of times themes identified
25
20
15
10
5
0
No Care Coordinator
No one advocating
Poor sharing of info
AHC not attended
No GP Health Action Plan
Heavy reliance on family
Family not included in care planning
Assessment tools not used
Lack of/poor Best Interest/Consent
Lack of/poor use of MCA
Delays in diagnosing/long waiting times
No/poor DNACPR/RESPECT form
No/poor EOL plan
No Psychotropic medication review
No support plan from provider
Inaccurate/inappropriate description of cause of death
No/poor reasonable adjustments
No hospital passport
Cultural/religious barriers to care
Funding issues impacting on care
Workforce training issues
No referrals to CTLD
No/poor health screening
Poor access to sensory activities
No clear decisions around admission
Poor documentation
Lack of monitoring tools used
Not recognised patient deteriorating
Lack of treatment due to suspected COVID
No Flu vaccination administered
No onward referral for further investigations
No timely /appropriate follow up when a person does not attend an appointment
Themes Identified
DCHS
DhcFt
LA
Care Home
Supp Living
CLDT
GP
CRH
UHDB
Other Acute trusts
Other