Joined Up Care Derbyshire

NHS
Derby and Derbyshire
Integrated Care Board

Learning from Lives and Deaths – people with a Learning Disability and Autistic People

The LeDeR Programme

Derbyshire Quarterly Performance Report

2024/25 Quarter 2

July 2024 – September 2024

Contents

Executive Summary

This is the Derbyshire Quarterly report to summarise the recent progress made in Derbyshire. This report covers the Quarter 2 period for 2024/25 from 1st July 2024 to 30th September 2024.

LeDeR is a service improvement programme and this report aims to show the changes that have and will be made as a result of LeDeR.

Summary of notifications in Quarter 2: There was a total of 15 new notifications of learning disability deaths to the LeDeR programme for Derbyshire during Quarter 2 - 2024/25. In addition, there was also 1 notification for an individual who had a clinical diagnosis of autism (with no learning disability) in this quarter. There were no notifications received for individuals from a minority ethnic background.

Summary of completed reviews in Quarter 2: There were 15 reviews completed for people with learning disabilities in Quarter 2. 11 were completed as "Initial Reviews" and 4 completed as the more detailed "Focused" review (ie. 27% were completed as focused reviews). There were no Autism only (no Learning Disability) reviews completed in this quarter. During the quarter the top reasons for death were aspiration pneumonia (with 3 deaths) and respiratory infections (with 3 deaths) listed as the main reasons for death on the death certificate (1a on the death certificate).

It is difficult to capture any trends over such small numbers, but the report aims to show areas we have identified through actions and learning and the review of health conditions. The report also identifies priority areas for the next quarter in relation to addressing inequalities.

We have been asked to provide an overall RAG status for our Action from Learning progress as part of this report. Based on this the Derbyshire LeDeR programme is currently rag rated as *Amber – Some Concerns* due to resource issues that is resulting in us unable to continue to meet performance targets and progress action from learning.

Introduction & Background

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 quarterly report from the local ICS to identify performance against local actions that have been found through the LeDeR programme. This report is the Derbyshire quarterly report to cover Quarter 2 of 2024-25, from 1st July to 30th September 2024.

As a service improvement programme, we are working locally across the Derbyshire Integrated Care system (ICS), Joined Up Care Derbyshire (JUCD), to use the learning found through LeDeR to improve our local services for people with a learning disability and autistic people.

Our Local Population 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)

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)

Background and Findings - LeDeR in Derbyshire

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 474 in scope notifications for those age 18+, of which 401 have had a review undertaken and completed (data taken as at 30th September 2024).

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

Themes are also collated from each review and the theme form is reviewed alongside the review as part of the quality review process. The themes are broken down by 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.

Deaths in Derbyshire – Quarter 2, 2024/25

	Gender		Total new notifications
	Male	Female	
Total number of Learning Disability notifications 01/07/24 to 30/09/2024	8	7	15
	Gender		Total new notifications
	Male	Female	
Total number of Autism only (no learning disability) notifications 01/07/24 to 30/09/2024	1	0	1

There were no Learning Disability notifications received for people from minority ethnic communities.

There were no Autism only (no learning disability) notifications from minority ethnic communities.

Overall, there were **15** (8 male, 7 female) reviews completed in Quarter 2. 11 reviews were completed as "Initial Reviews" and 4 completed as the more detailed "Focused" review. There were no reviews completed for people who were autistic with no learning disability.

This equates to 27% of reviews being completed as Focused during this quarter.

Type of review	Month review completed			Total
	July 2024	August 2024	September 2024	
Initial	3	5	3	11
Focused	2	2	0	4
Focused (Autism only)	0	0	0	0

The top reasons for death were Aspiration Pneumonia and Respiratory infections.

There were no completed reviews for deaths of autistic people but no learning disability in this quarter.

All reasons for death during this period are listed below.

Reason for death	No. of occurrences
Aspiration Pneumonia	3
Respiratory infections	3
Heart Conditions	2
Cancers	2
Dementia	1
Multi Organ Failure	1
Frailty	1
Foreign Body obstruction of airway	1
Hypoxic Brain Injury	1

NB. The information in the above table all relates to reasons for death shown on section 1a of the death certificate.

Completed LeDeR Reviews in Quarter 2 2024-25 and Action Status

Appendix 1 shows a breakdown of the LeDeR reviews completed in Derbyshire in Quarter 2, the good practice and issues identified and any actions that were agreed. The table is also RAG rated to show the status of the actions.

Actions taken in Quarter 2 2024/25: Update of the Derbyshire Local Action Plan

Below is the local action plan as produced in the Derbyshire 3 Year Strategy. This has been updated with a current status column to highlight progress.

Key Deliverables	Outcomes	Key performance measures	Responsibility	Frequency of collection (if appropriate)	Date for completion	Current Status at Quarter 2 2024-25
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	Performance Report produced to monitor review status ongoing
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 until 2024 when due date amended by NHSE to September 2024	Completed - September 2024	A new report for 2023/24 for Derbyshire has been produced and now available on the JUCD website
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	Next due September 2024	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 & Minority Ethnic 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	Attendance captured in minutes of meeting	LAC	Meetings held monthly	April 2022	Completed
8) To be prepared to begin the reviews of deaths of autistic people once this	100% of reviews are completed within 6 months of notification	Monthly dataset shows ICS completion of eligible reviews within	LAC	Monthly	December 2021	Completed

goes live		six months of notification.				
9) 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 Regular meetings LAC & Senior Reviewer & reviewers	Ongoing Following each completed review	Completed – ongoing
10) 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 regularly	Ongoing	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		Monthly – as needed Quarterly		

		are meeting together to share 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.				
11) 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 monthly performance monitoring	LAC/Reviewers	Monthly monitoring	Ongoing	Ongoing

What's been done in Quarter 2 – LeDeR and wider System working

Learning from LeDeR continues to be shared across the System and is discussed at LeDeR Steering Group. In addition the LAC continues to work to improve LeDeR processes and work with other organisations across the Derbyshire System. This includes working with the Mortality Review Facilitator at DCHS to produce regular reports which includes LeDeR learning that is then fed back to the Mortality Group, working with Safeguarding Leads at Derbyshire County Council to look at specific themes that are raised as part of actions and recommendations from the LeDeR reviews and working closely with Adult Care colleagues to ensure LeDeR processes are appropriate to ensure information is gathered in a timely manner for LeDeR reviews and themes and learning are fed back to Social Care for them to use any learning.

Aspiration Pneumonia

The project to look at aspiration pneumonia deaths through LeDeR ended in August. A meeting took place towards the end of Quarter 2 to start to pull the information and learning together that has been collated as part of the project. This work has continued into Quarter 3.

DNACPR/ReSPECT

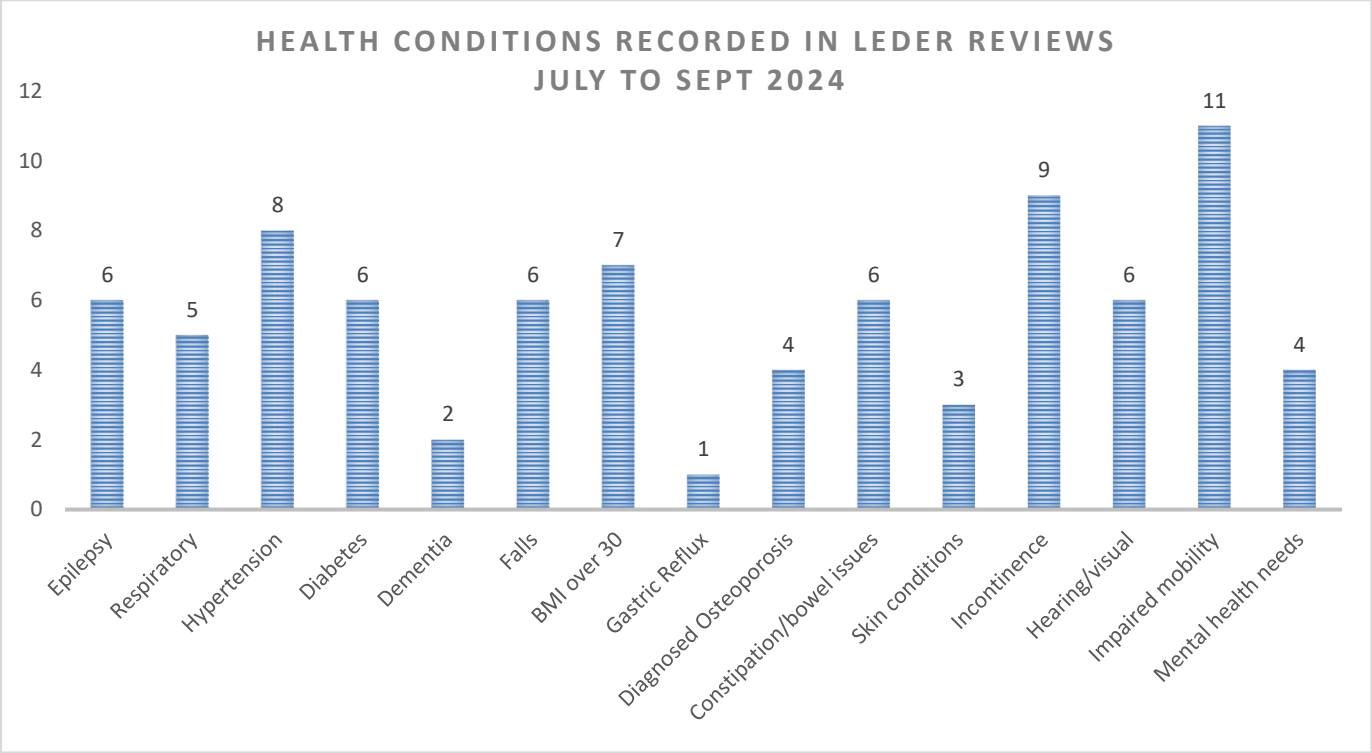
A paper has now been produced based on learning from LeDeR across 2023/24 which has been incorporated into the LeDeR Annual Report for Derbyshire 23/24. Next steps have been incorporated into this report and will be worked on in Quarter 3.

Health Conditions

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

A graph for Quarter 2 is shown below identifying the health conditions and the number of times each condition was identified. This information is taken from the 15 completed LeDeR reviews during that period. The top most common health condition was Impaired Mobility, which was a health condition in 73% of the 15 completed reviews, followed by Incontinence at 60% and Hypertension at 53%. We have started to monitor and collate BMI over 30 which is showing for this quarter as our fourth highest health condition at 47%.

Constipation/bowel conditions was a health condition for 40% of the 15 completed reviews and mental health needs 27%. This is a reduction from the quarter 1 report but we will continue to monitor this throughout the year. Hypertension is an increase from the quarter 1 report and this will also continue to be monitored throughout the year.



LeDeR Annual Report for Derbyshire 2023/24

The LeDeR Annual Report for Derbyshire 23/24 has been completed throughout Quarter 2 and is now published and available on the Joined Up Care Derbyshire website at Learning disabilities and autism » Joined Up Care Derbyshire.

Performance reporting

The LeDeR performance report continues to be produced on a monthly basis and will be included in these reports each quarter. These reports are shared across the System, including within the ICB Nursing and Quality Team, at LeDeR Steering Group meetings and with the System Mental Health LDA Board. The report as at 30th September 2024 is included in Appendix 2.

Next Quarter LeDeR Actions & Priorities

Particular focus is being given in the next quarter in relation to the following priority areas.

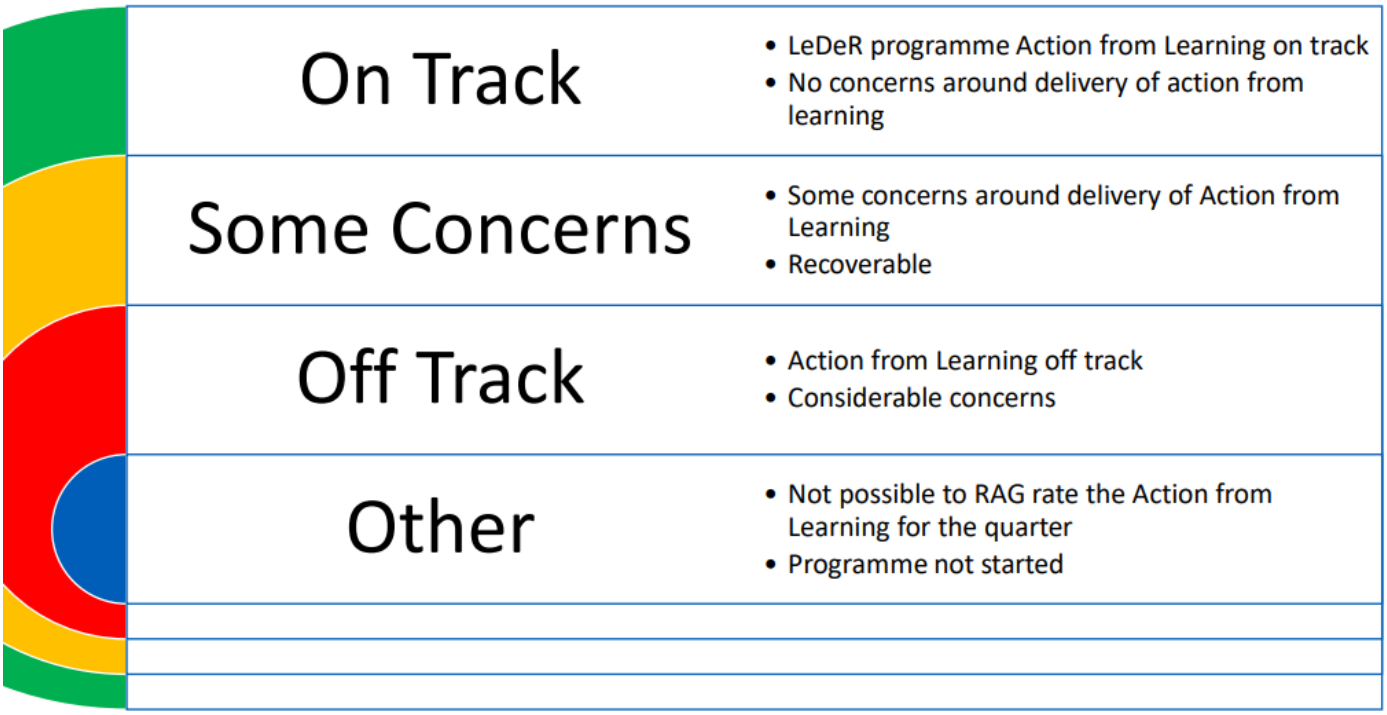
Aspiration Pneumonia –the project ended in Quarter 2 and the learning will be collated in Quarter 3 and next steps agreed.

ReSPECT/DNACPR – next steps as detailed in the LeDeR Annual Report will be worked on throughout Quarter 3.

LeDeR Annual Report – as this report has now been published focus will also be given to the priority areas included in the report.

RAG Rating for the LeDeR programme in Derbyshire

We have been asked to provide an overall RAG status for our Action from Learning progress as part of this report based on the following ratings.



For the period that this report covers there are still concerns in relation to the workforce available to continue to deliver the LeDeR programme. Based on this the Derbyshire LeDeR programme is currently still rag rated as *Amber – Some Concerns*: -

- At present we have a team of 2 reviewers (who work 0.5 wte each, ie 1.0 wte total). We have trained a member of the Nursing & Quality ICB staff as an additional reviewer and have taken this issue to the LeDeR Steering Group to see if there are any ideas as to how this issue could be resolved while working within the terms of the LeDeR Policy 2021. This has been raised as a risk through the ICB Quality & Safety Forum and at the Mental Health/Learning Disability & Autism/Children & Young People Board.

Appendix 1 – Completed LeDeR Reviews in Quarter 2 2024-25 and Action Status

Review ID	M/F	Age at Death	Ethnic Grouping as per LeDeR Programme	Main Reason for Death (1a on Death Certificate)	Additional information on Death Certificate	Current Status	Good Practice Identified	Issues/learning identified	Status of actions
25639	M	75	A	Cardiac Arrest	Aspiration of food	Completed as a focused review due to issues found	None identified	x choked on food which was not prepared according to SLT eating and guidelines. Safe-and-Well checks and SLT referrals for all residents with eating and drinking guidelines were requested .	Complete. S42 in house Dysphagia Training has taken place through CLDT SLT Team.
20715	M	54	A	Left ventricular failure	Obesity associated Cardiomyopathy	Completed as a focused review due to issues found	Person centred approach provided by SLT. Excellent support by social worker.	Better working together as an MDT from the start would have led to conversations being held where the MDT could have agreed where mental capacity assessments were needed.	Complete. Concerns shared with MDT. Good practice shared with SLT
27524	M	62	A	Multiple organ failure	Pneumonia	Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	GP offered consolidated appointments to reduce visits.Good support from CLDT nursing team with medication monitoring, easy read, arranging hospital transport and supporting hospital appointments.	None identified	Complete. Good practice shared with GP and CLDT.
24657	F	66	A	Aspiration Pneumonia	Ischaemic Stroke	Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	None identified	Day services stopped due to covid, no evidence that this was reconsidered as restrictions lifted. There was no evidence that this was explained to X or if she was involved in these conversations.	Complete. Issue shared with Adult Care .

26428	F	80	A	Dementia		Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	None identified	A safeguarding referral was made due to a choking episode where X had not been observed whilst eating.Appropriate care plans and risk assessments have been updated at the Care Home.	Complete. Issue shared with Care Home and Adult Care .
28466	M	56	A	Aspiration Pneumonia		Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	GP from Ageing Well Team offered a debrief to staff due to events surrounding death. Step mum felt that the quality of care he received from the care home was exceptional and the staff were like his extended family.	None identified	Complete. Good practice shared with Ageing Well Team and the Care Home.
28074	M	57	A	Aspiration pneumonia, Type 2 Myocardial Infarction	Acute necrotising Pancreatitis	Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	Reasonable adjustments made by hospital consultant	Support staff to x could have been made to feel more welcome by hospital staff in their role as advocates and with their knowledge of how to support X in the best way.	Complete. Good practice and hospital issues shared with Notts LAC to share with QMC, Notts.
26073	M	90	A	Frailty of old age		Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	None identified	The LD Dementia care pathway does not indicate that people with mild LD are expected to access Mainstream Services	Complete. Issue shared with Area service Manager of Neurodevelopmental Services
28879	F	79	A	Endometrial Cancer		Completed as a focused review due to issues found	Excellent observation of learning disability awareness and implementation of reasonable adjustments in hospital team	Failed hospital discharge plan: No home equipment in place when discharged .No evidence of proactive referrals to palliative care	Complete. Good practice and Issue shared with hospital
26380	F	46	A	Pneumonia		Completed as a focused review due to issues found	Adult care worker provided a comprehensive adult care review.Thera Trust provided excellent support and advocated for X in all aspects of her life.	Wheelchair services closed the referral whilst x in hospital. Hospital did not refer to the home oxygen team on discharge when NIV given.Training needs agreed for hospital staff.	Complete. Concerns raised with hospital and wheelchair services.

29871	M	52	A	Metastatic bowel cancer		Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	Good practice by surgeon in copying in Learning Disability Liaison Nurse to the GP letter where capacity and IMCA (Independent Mental Capacity Advocate) was advised.	None identified	Complete. Good practice shared with hospital
27092	M	61	A	Foreign body obstruction of airway		Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	Accessible Health Action plan and Reasonable Adjustments used by GP.	Care coordinator referred x for Shared Lives assessment but no evidence assessment took place	Complete. Issue shared with Adult Care.
27045	M	79	A	Bilateral Aspiration Pneumonia	Severe Learning Disability	Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	None identified	Inappropriate cause of death (severe learning disability) added to 1b on death certificate	In progress
27431	M	51	A	Respiratory Failure	Bronchopneumonia	Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	Good communication between SLTs in community and hospital teams to coordinate dysphagia assessment.Excellent care at hospital and care home.	Accepted for weight management Tier 3 in June 2023, not seen before time of death in January 2024.Also delay in respiratory follow up	In progress
26498	M	64	A	Hypoxic brain injury and multiple organ failure	Out of hospital cardiac arrest	Completed as an initial review. Quality Assured and actions agreed by Senior reviewer and LAC	None identified	None identified	Complete

Appendix 2 – LeDeR Performance Report as at 30th September 2024 (4 pages)

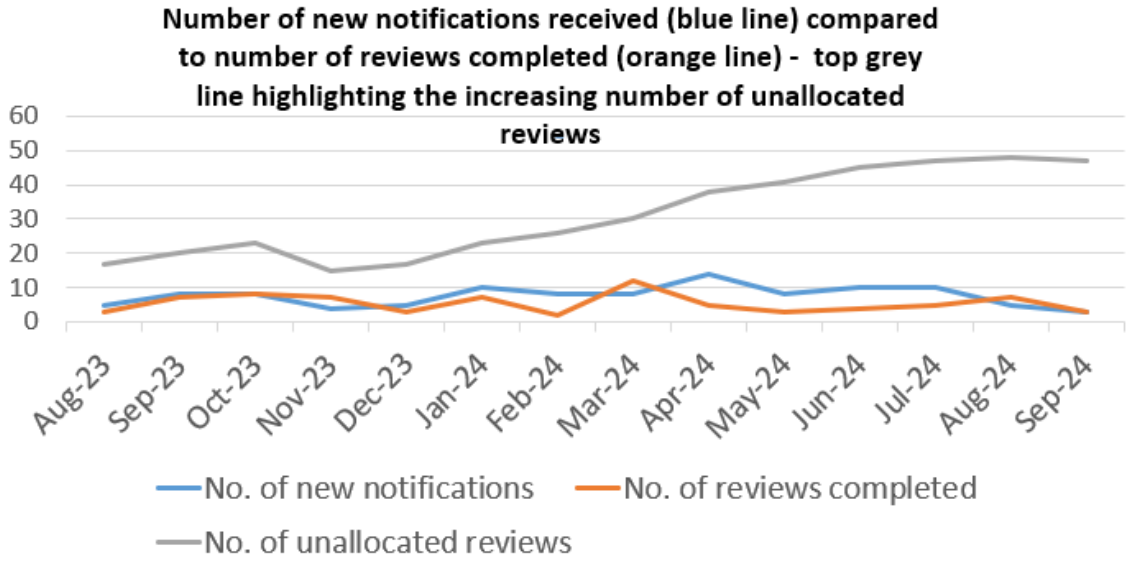
LeDeR Performance Report

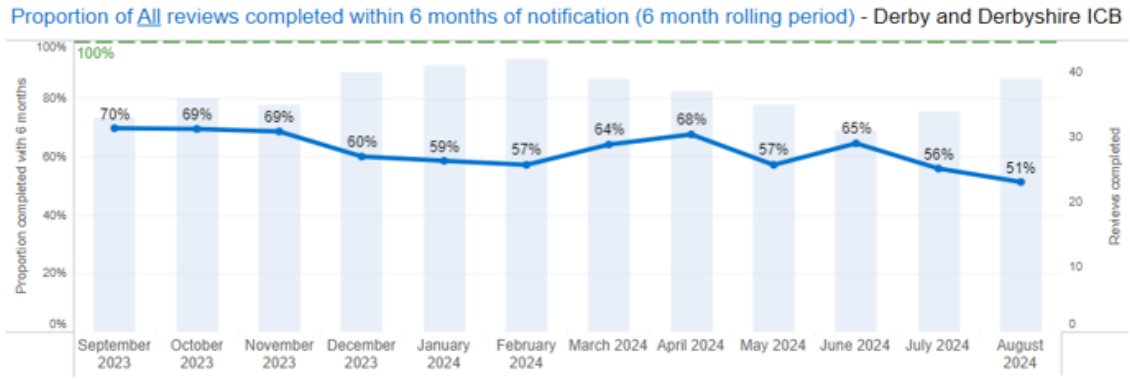
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Data to 30th September 2024

Key Highlights/Issues	Details	Mitigations
INCREASE IN UNALLOCATED REVIEWS – @ 30/9/24 there are 47 unallocated reviews	**NOT ENOUGH REVIEWER CAPACITY LEADING TO INCREASE IN NUMBER OF UNALLOCATED REVIEWS**	Global shout out to ICB staff to be LeDeR Reviewers - No volunteers Previously had some funding to use external reviewers -funding now fully spent Escalated through LeDeR Steering Group/Governance Panel - no system solutions found Escalated at MH/LDA Board in February 2024
35% of reviews to be completed as focused reviews (NHSE target)	Latest performance as per NHSE for Derbyshire is 28%. Latest info available as at 31/8/24.	
100% of reviews to be completed in 6 months (NHSE target) – unable to meet target due to limited number of reviewers and increasing numbers of unallocated reviews	Currently at 51% (this is taken from NHSE figures – latest data available at 31/8/24)	





Date of extraction

30/09/2024

Executive Summary

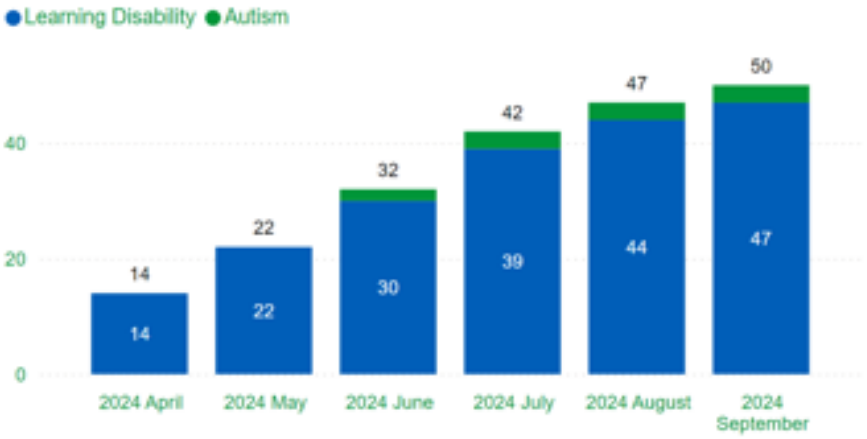
Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Current Totals for the 24/25 year – from April 2024

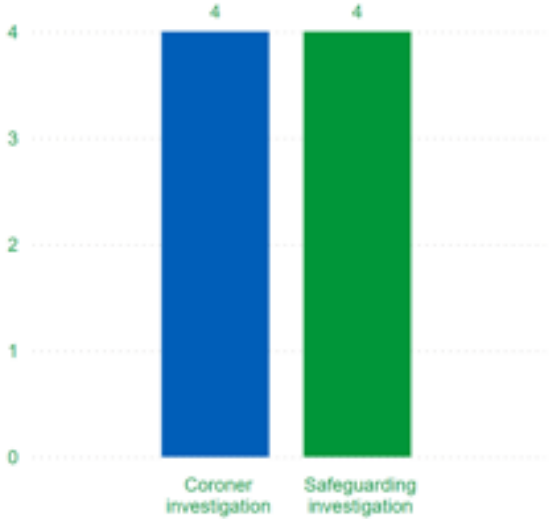
50	27	12	44%
Total Notifications 24/25	Total Completed 24/25	Total Completed in 6 months 24/25	% Completed in 6 months

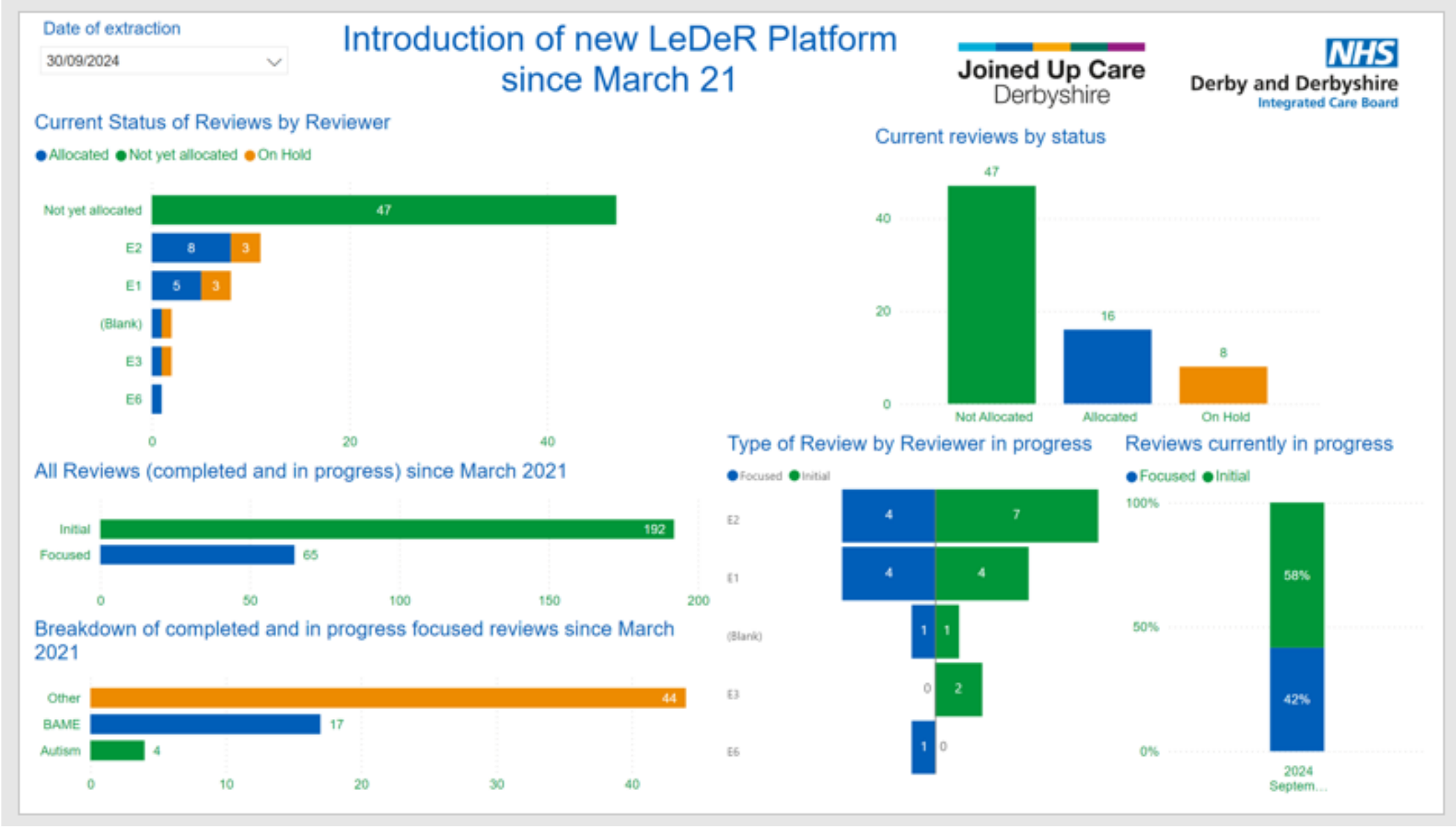
Cumulative Total of Notifications received from April 2024 split by Autism only and LD



Total number of completed reviews from April 2024

Reason for on hold




Date of extraction
30/09/2024
Introduction of new LeDeR Platform since March 21
Joined Up Care Derbyshire
NHS
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Integrated Care Board
Current Status of Reviews by Reviewer
Allocated
Not yet allocated
On Hold
Not yet allocated
47
E2
8
3
E1
5
3
(Blank)
E3
E6
0
20
40
Current reviews by status
47
40
20
16
8
0
Not Allocated
Allocated
On Hold
All Reviews (completed and in progress) since March 2021
Initial
192
Focused
65
0
50
100
150
200
Type of Review by Reviewer in progress
Focused
Initial
E2
4
7
E1
4
4
(Blank)
1
1
E3
0
2
E6
1
0
Reviews currently in progress
Focused
Initial
100%
50%
0%
58%
42%
2024 Septem...
Breakdown of completed and in progress focused reviews since March 2021
Other
44
BAME
17
Autism
4
0
10
20
30
40

Date of extraction

30/09/2024

Overall Position

Joined Up Care Derbyshire

NHS Derby and Derbyshire Integrated Care Board

Since 2017 the start of the LeDeR program

474

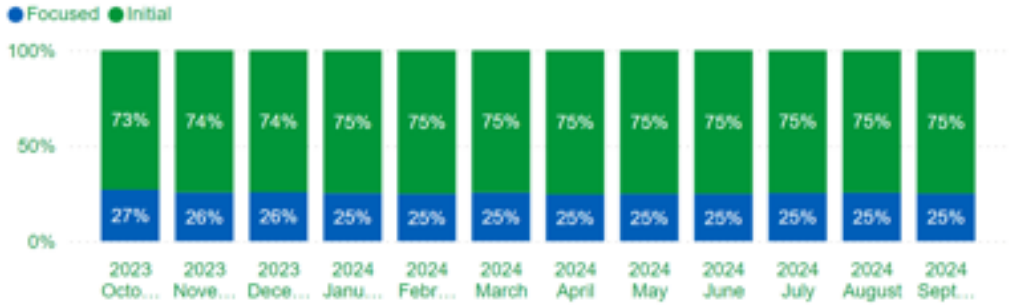
Total Number of notifications since 2017

401

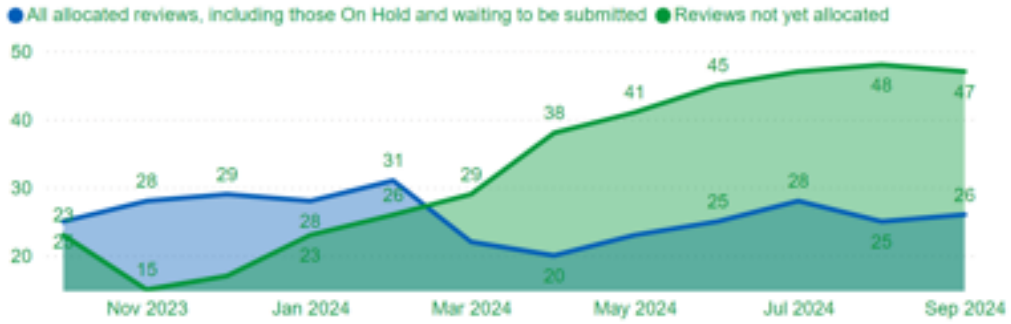
Total Completed since 2017

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

Type of Review Completed since March 2021



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



Current Reviews by Status