Joined Up Care Derbyshire

NHS
Derby and Derbyshire
Integrated Care Board

Derbyshire Learning from Deaths of those with a Learning Disability

The LeDeR Programme

Annual Report

1st April 2021 to 31st March 2022

Derbyshire LeDeR Learning from Lives & Deaths Annual Report 2021-2022

Responsible Committee	Derby & Derbyshire LeDeR Steering Group
Target Audience:	Report for agencies involved in the programme across the Derbyshire system and for sharing across the public domain:- LeDeR Steering Group Mental Health, Learning Disabilities, Autism & Children's System Delivery Board Joined Up Care Derbyshire National LeDeR Programme NHS England/Improvement
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List of Abbreviations

Abbreviation	Explanation
AHC	Annual Health Check
BAME	Black Asian Minority Ethnicity
CDOP	Child Death Overview Panel
CLDT	Community Learning Disability Team
CQRG	Clinical Quality Review Group
CYP	Children and Young People
DDCCG	Derby & Derbyshire Clinical Commissioning Group
DCHS	Derbyshire Community Health Services
DHcFT	Derbyshire Healthcare NHS Foundation Trust
DSAB	Derbyshire Safeguarding Adults Board
DcSAB	Derby City Safeguarding Adults Board
GP	General Practitioner
HAP	Health Action Plans
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 and NHS Improvement
SALT	Speech and Language Therapy
SEND	Special Educational Needs and Disability

Executive Summary

This report is the third annual report for Derbyshire on the learning from deaths of those with learning disabilities. The report uses data collated from 1st April 2021 up until 31st March 2022.

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, to demonstrate how Joined Up Care Derbyshire (JUCD) is delivering on local actions as identified in LeDeR reviews. The annual report is published in June each year. 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 2022.

Summary of local data and findings

Since the programme began there have been 283 (adult ie. age 18+) deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2022-of which 251 of these deaths have had a review undertaken and completed.

From 1st April 2021 to 31st March 2022 there were 59 notifications and 48 completed reviews in that year period. The following information relates to the 48 completed reviews.

24 of the reviews were male, 24 of the reviews were female.

Average age at death for females was 65 years and 62 years for males.

46 of the completed reviews were for the population identifying as White British. Only 2 reviews were completed reviews for those identifying from a BAME community, both reviews had their ethnicity shown as Pakistani.

Hospital was the most common place of death, with 23 of the 48 completed reviews showing hospital as the place of death.

There were no completed reviews for individuals with autism (but no LD). There was one notification for an autism only review but this has not yet been completed.

During 2021/22 there has been four reviews completed as confirmed Covid-19 deaths. There have been two additional completed reviews where the individual had Covid-19 at death although Covid-19 was not listed as their main reason for death. There have been an additional two notifications made in the year where Covid-19 is mentioned on the notification, although these reviews are not yet completed.

The top reason for death was Dementia for 17% of our Derbyshire population. Aspiration Pneumonia was the second reason for death with 12.5%.

Local learning and making changes

Our priority is to use the learning from LeDeR to make service improvements for people with learning disability and autism in our local community and lots of work is happening in this area and detailed later in this report. One area where we can perhaps start to celebrate some success is in relation to the work that has been happening to promote awareness of constipation and bowel issues. In last year's report 60% of LeDeR reviews reported constipation/bowel issues as a health condition. This year we have seen 42% of LeDeR reviews showing constipation/bowel issues as a health condition. A reduction of 18%. We will continue to monitor this but are hopeful this is one positive move towards improving the health outcomes for people with a learning disability in Derbyshire.

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 and NHS Improvement. 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 5 years and are available to view here. The latest report (2020) concentrated on deaths over the last 3 years and showed that a total of 9,110 deaths of people with learning disabilities (622 deaths of children; 8,488 deaths of adults) occurring between 1st Jan 2018 and 31st December 2020 were notified to the LeDeR programme.

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 and NHS Improvement's (NHSE/I) 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 informed of the inclusion of LeDeR reviews for autistic people with no learning disability. This took affect from 1st January 2022.

A draft Derbyshire LeDeR 3-year strategy was produced in September 2021 using the learning that has been found and reported through the Derbyshire LeDeR Annual Report for 2020/21. This was finalised and submitted by the NHSE/I deadline of 31st March 2022.

A new LeDeR platform was introduced for 2021/22 which has altered the review process from previously. 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 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

The prevalence of learning disability in Derbyshire is approximately 0.5% of the population in Derby City and Derbyshire County who are known to have a learning disability, and this is similar to the national average. It is however estimated that the likely true prevalence is just over 2%. (taken from *East Midlands empho Public Health Observatory*)

It is estimated there may be around 8,712 people living in Derbyshire with autism. ("*Understanding Autism – Derbyshire County Council*"). We are seeing a significant growth in the number of people requesting an Autism Diagnostic Assessment. The 'prevalence' of ASD in the general population is said to be 1.1%, the 'demand' for diagnosis is much greater. There are also additional considerations around co-occurring conditions, diagnostic overshadowing and 'masking' (where people hide their autistic presentations). In Derbyshire there is work ongoing on both the 'child' and 'adults' diagnostic pathway, including pre and post diagnostic support.

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 283 notifications for those age 18+, of which 251 have had a review undertaken and completed (local collated data as of 30th March 2022). The information in this report is taken from LeDeR reviews completed between 1st April 2021 to 31st March 2022.

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 Clinical Quality Review Group (CQRG) 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.

Co-production and Engagement

In Derbyshire we are keen to work closer with our local learning disability community both as part of the LeDeR programme and delivery but also with the production of annual reports. We want to ensure the correct membership at our local Steering Group, including members from the LD community. We have found this challenging and have met recently with one of our local LD groups – Our Vision Our Future. The group are willing to work with us and share their feedback but do not feel able to attend the Steering Group. We will continue to work with Our Vision Our Future and ensure their views and feedback are fed into our learning. We are also pleased that we now have a member from a local advocacy group attending

our Steering Group.

In addition, work is in place across the Derbyshire system to develop a Joined-Up Care Derbyshire neurodevelopmental co-production and engagement framework which provides a consistent but flexible approach that can be embedded into strategic commissioning, operational commissioning, and transformation. Once this is in place LeDeR will follow this framework to further develop our aims to ensure co-production and engagement.

With regards to the co-production of this LeDeR Annual report we have worked with our local community as we are keen for them to be involved. This has involved delivering a presentation at our Good Health Group to ask for volunteers to work with us in some areas of the report. As a result of this local LD reps have met and shared their views about some of the work we have been doing in Derbyshire.

Later in the report in the *Outcomes and Achievements* section there's further evidence of co-production and engagement with regards to working together with members of our LD community, as they have been involved in the production of the constipation and LD annual health check videos. Comments and feedback received from the actors included:-

The Poobusters Video was amazing, we all did a great job, it felt great being part of it, I felt like a professional actor.

It is Important, because it is good for people to know that if they are struggling to go, it helps them understand that they need to talk to someone.

It's a good example of easy read information for people

I liked the film and enjoyed taking part. It's important to know what you should do if you can't go for a Poo

The Derbyshire Vision for LeDeR

Since the last LeDeR annual report there has been a lot of change in relation to LeDeR. In March 2021 there was a new LeDeR Policy published which introduced some key changes to the LeDeR programme. This included a new LeDeR platform, the request for a local LeDeR Strategy and the introduction of LeDeR quarterly reports. Another major change as part of the policy was the introduction of reviews for people with autism (but no learning disability) which started from January 2022. In Derbyshire the LeDeR team had all completed the autism training before January and processes were agreed and in place to start any reviews. Promotion to encourage the notification of autism only deaths has also been delivered in Derbyshire through local workshops and a presentation to the Autism Partnership Board.

As part of the LeDeR Strategy for Derbyshire that has been produced during 2021/22 we have agreed a Derbyshire vision for LeDeR.

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:-

1. **We will** ensure all LeDeR reviews are completed within 6 months of notification
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
3. **We will** ensure that reviews are completed and quality assured to an acceptable standard that ensures the programme can share and use learning to make meaningful changes to the lives of individuals with learning disabilities
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
5. **We will** follow the new guidance of the LeDeR policy and ensure there is clear and effective governance in place
6. **We will** use learning from the LeDeR programme and work with the BAME lead to reduce the health inequalities faced by people from Black, Asian and Minority Ethnic (BAME) communities who live locally and who have a learning disability

7. **We will** ensure we have meaningful involvement of people with learning disabilities and their families in the LeDeR programme
8. **We will** promote LeDeR and share learning from LeDeR across Derbyshire learning disability forums and with learning disability services and care providers
9. **We will** have a clear plan in place for the new quality assurance structures and processes which will be implemented for LeDeR and fully operational from 1 April 2022
10. **We will** work as an ICS to use the learning from the Derbyshire LeDeR programme to make service improvements across areas identified across 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.

Links with other local produced strategies

We also want to ensure that our Derbyshire LeDeR Vision and Derbyshire Strategy links with other Derbyshire strategies being agreed such as the Derbyshire Autism Strategy. The Autism Strategy Task & Finish group runs as an agreed offshoot of the Autism Partnership Board and has been coproducing the local response to the new Autism Strategy since January 2022. So far they have developed 5 coproduced priorities for focus over 2021-26:-

- Providing earlier diagnosis
- Increased Preventative Service
- Increasing meaningful employment opportunities
- Having a stronger professional peer support
- Deliver training that goes beyond awareness raising

In addition, there is the overarching Derbyshire Neurodevelopmental Strategy that is in its early stages of development and priorities from the LeDeR Strategy will be fed into this.

Improving the Quality of Reviews

To ensure robust quality of our reviews we have worked to produce separate pathways for the 2 types of review, Initial or Focused. See Appendix 1 and Appendix 2 for the pathways. A quality checklist has also been produced which is completed for all reviews and feedback is shared with reviewers to enable them to use any learning when completing future reviews. See Appendix 3 for the checklist.

In addition, a reviewer toolkit has recently been produced to give reviewers some guidance and expectations of conducting LeDeR Reviews and to provide some ideas of what to consider when completing a LeDeR review in Derbyshire, as well as sharing with them the quality standards expected of

the reviews.

Partnership working across the Integrated Care System

Work has continued throughout the year to ensure good partnership working across the LeDeR programme. This includes the review of membership and the terms of reference for both the LeDeR Steering Group and the LeDeR CQRG (Clinical Quality Review Group), but also additional work to promote and improve the working partnerships with Safeguarding, Child Death Overview Panel, Acute Trusts and community care providers. This has included:-

- 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.
- Working with the Child Death Overview Panel (CDOP) members to agree extra questions to be asked by CDOP reviewers in relation to deaths of children with a learning disability and working to agree themes.
- Promoting the working together between LeDeR and Safeguarding by producing a podcast which has been published on the Derbyshire Safeguarding Adults Board website.
- 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 one of our 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.
- Building relationships with United Response, who provide significant care and support in Derbyshire to local people with learning disabilities and autism, sharing learning from LeDeR and suggesting ways in which we can continue to work with them in the future to build on this work with them further.

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 6 notifications of deaths of individuals under the age of 18 which are in progress or have been completed through the CDOP process during 2021/22. Four child deaths have been completed through the CDOP process in 2021/22 and a break down of these four deaths is shown below:-

Total	Gender		Ethnicity				Diagnosis		Place of death		
	Male	Female	White (A)	Other (S)	Multiple Ethnic Group (G)	Pakistani (J)	LD	ASD only	Hospital	Family home	Hospice
4	3	1	3	1	0	0	4	0	2	1	1

Reasons for death for the 4 completed reviews:
Chronic Respiratory failure
Acute Bronchpneumonia
Volvulus
Bronchitis

Although individual actions were collated as part of the CDOP process in relation to these deaths, due to the low number of reviews that have been completed there have been no themes identified at this stage.

Staffing and Governance Arrangements

The LeDeR programme is part of the Nursing and Quality team which from 1st July 2022 is employed as part of Derby and Derbyshire Integrated Care Board (ICB). During the period of this report the team were part of Derby and Derbyshire Clinical Commissioning Group and moved to the 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 CQRG 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 (BAME) communities

Only two (4%) of our completed reviews in 2021/22 were from a BAME community, both reviews had their ethnicity shown as Pakistani.

In Derbyshire county our BAME population is estimated to be about 4.2% and in Derby City the BAME population is estimated to be about 24.7% (taken from the Derbyshire Observatory – census 2011).

We are monitoring this as part of the LeDeR Steering Group and are aware that we need to prioritise this in relation to understanding more about our BAME communities and why notifications from them are low.

During 2021/22 we had identified a BAME Lead for the LeDeR programme although he has recently stepped down from the role and we are in the process of working within the Derbyshire system to find another Lead. We have also produced a BAME report which addresses notifications as one of the issues. 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 BAME communities who have learning disabilities.

Local Action Plan

As part of the LeDeR Policy 2021 CCGs were provided with a number of delivery expectations. Please see Appendix 4 for the updated Derbyshire Local Action Plan showing delivery against these targets.

Covid-19

During 2021/22 there has been four reviews completed with confirmed Covid-19 deaths. There have been two additional completed reviews where the individual had Covid-19 at death although Covid-19 was not listed as their reason for death (one Malnutrition, one Community Acquired Pneumonia – in both cases Covid-19 was mentioned on the death certificate as a contributory condition). There have been an additional two notifications made in the year where Covid-19 is mentioned on the notification, although these reviews are not yet completed. One further Covid-19 death has been received as a child death review – an 11-year-old White Male.

Gender	Age at death	Date of death	Place of death	LeDeR status	Reason for death
Male	39	February 2021	Hospital	Completed April 2021	Covid-19
Female	59	January 2021	Hospital	Completed April 2021	Covid-19
Male	66	February 2021	Home	Completed April 2021	Covid-19
Male	75	January 2021	Hospital	Completed April 2021	Covid-19
Female	70	February 2021	Hospice	Completed Dec 2021	Malnutrition
Male	61	January 2022	Care home	Completed May 2022	Community Acquired Pneumonia
Female	58	December 2021	Hospital	Not yet completed	Not yet confirmed
Male	59	January 2022	Hospital	Not yet completed	Not yet confirmed
Male	11	Sept 2021	Hospital	CDOP – not yet gone through CDOP panel	Not yet confirmed

For the completed reviews, there have been no identified themes and trends. Two of the four are thought to have contracted Covid-19 in hospital but due to the low numbers of Covid-19 related deaths there have been no themes identified and no specific learning identified in relation to Covid-19.

Independent Reviews

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 and 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.

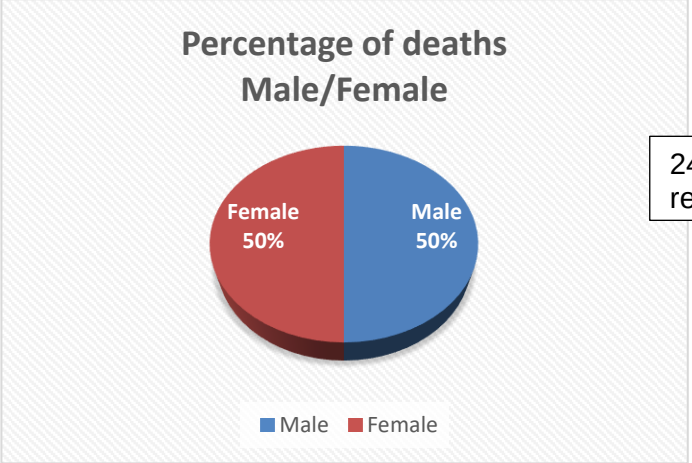
Although Clive did not receive any care and treatment in Derbyshire, the report included 10 key findings and identified a number of learnings and recommendations for consideration across health and social care providers. In Derbyshire we have produced an action plan which highlights the learning and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

Local Demographic Data & Findings

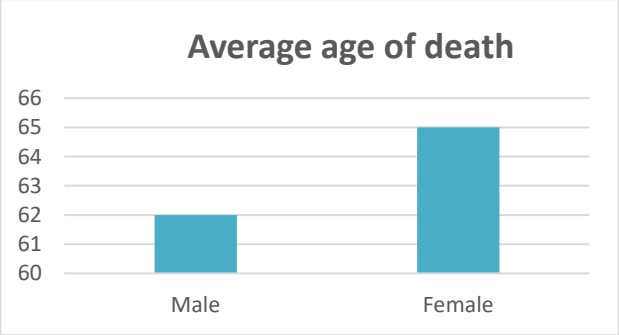
Since the programme began there have been 283 deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2022 of which 251 of these deaths have had a review undertaken and completed. [NB. As mentioned previously all notifications referred to are for 18+ only]

For the year 1st April 2021 to 31st March 2022 there were 59 notifications and 48 completed reviews in the year.

The following graphs represent data taken from the 48 completed reviews for 2021/22:-



24 of the reviews were male, 24 of the reviews were female

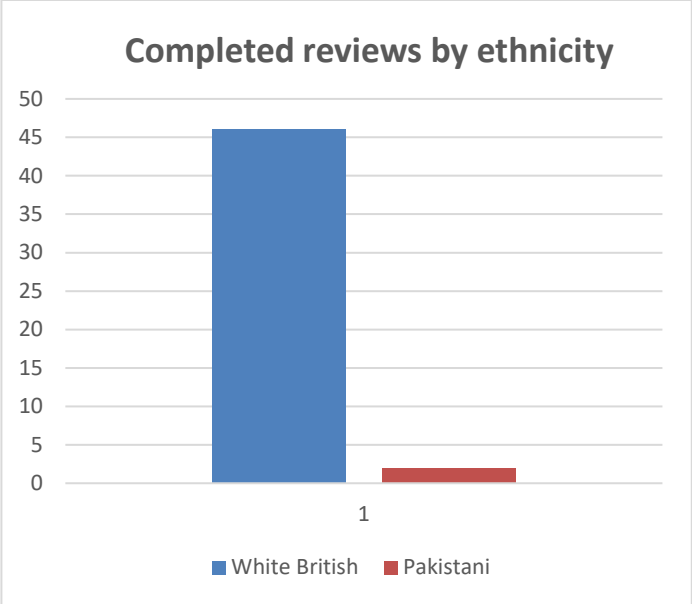


Learning from LeDeR showed there was a slightly better life expectancy for females with an average age at death of 65 as opposed to 62 for males.

The latest figures available from the Derbyshire observatory show female average age of death as 82.8 years and 79.1 years for males (NB. These figures do not include Derby City – the Derby City Census information from 2011 showed life expectancy for males to be 77.9 and for females to be 81.9.

This shows an inequality of around 18 years for females and 16 years for males.

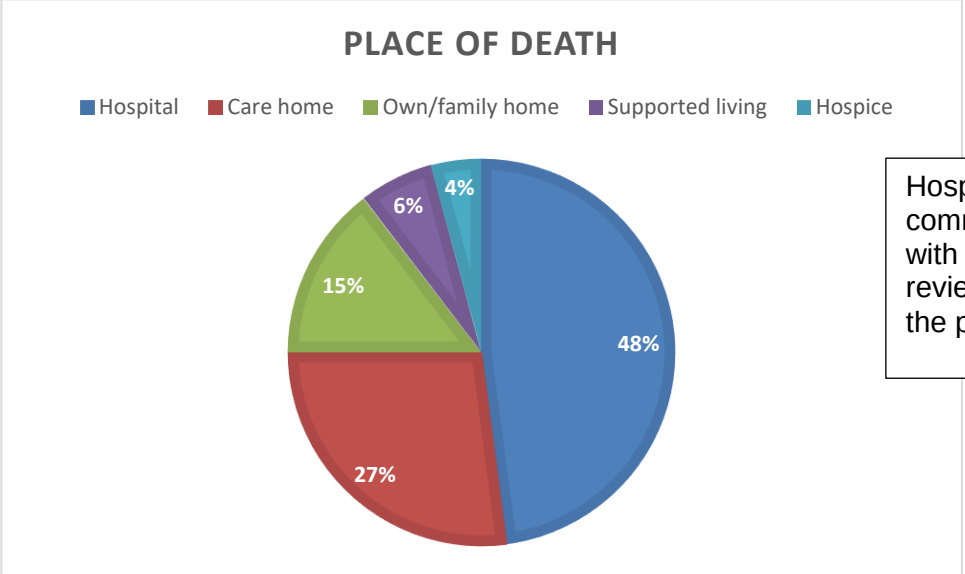
NB. Revised census information taken from 2021 is due to be published in July 2022 which will provide more up to date information to better compare in the future.



46 of the completed reviews were for White British. Only 2 completed reviews from a BAME community, both reviews had their ethnicity shown as Pakistani.

Therefore, only 4% of our completed reviews were from the BAME community.

In Derbyshire county our BAME population is estimated to be about 4.2% and in Derby City the BAME population is estimated to be about 24.7% (taken from the Derbyshire Observatory – census 2011)



Hospital was the most common place of death, with 23 of the 48 completed reviews showing hospital as the place of death.

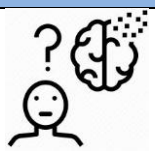
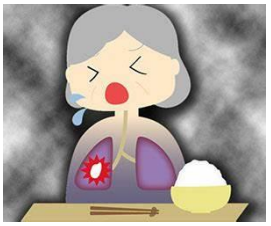
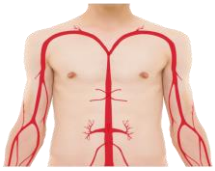
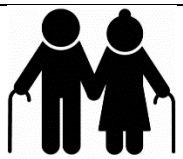
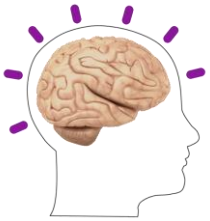
Grading of Care

It is really important to note that in the new 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 10 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. Therefore, although this is something we have been asked to collate and share, as grading of care was captured for all reviews in the previous LeDeR system (and included in previous Derbyshire Annual Reports) it must therefore be noted it is not a wise or fair comparison to make to previous years' gradings of care.

Grade		Number of occurrences
6	This was excellent care (it exceeded expected good practice	**0**
5	This was good care (it met expected good practice).	**3**
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).	**2**
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.	**2**
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.	**3**
1	Care fell far short of expected good practice and this contributed to the cause of death.	**0**
	Total	**10**

Reasons for Death in Derbyshire

Of the completed reviews that were notified during the period 1st April 2021 to 31st March 2022 the top 5 reasons for death are categorised and separated out below.

For Reviews completed 2021/22	
Death category	**Percentage across death category**
Dementia 	**17%**
Aspiration Pneumonia 	**12.5%**
Pneumonia / Lower Tract Respiratory Infection / Bronchopneumonia 	**8.5%**
Covid-19 	**8.5%**
Sepsis/Sepsis Shock 	**8.5%**
Frailty 	**6%**
Hypoxic Brain Injury 	**6%**
Heart Disease 	**4%**

Sudden cardiac death 	**4%**
Cancers 	**4%**
Others	**21%**

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. This is only for reviews that have been completed in the 2021/22 year using the new LeDeR platform, which is a total of 34 reviews (the remaining 14 reviews were completed on the previous LeDeR system and followed the old process).

24 (71%) of these reviews have been completed as Initial reviews and 10 (29%) 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 2021/22 are shared throughout this report to evidence this.

Themes from reviews

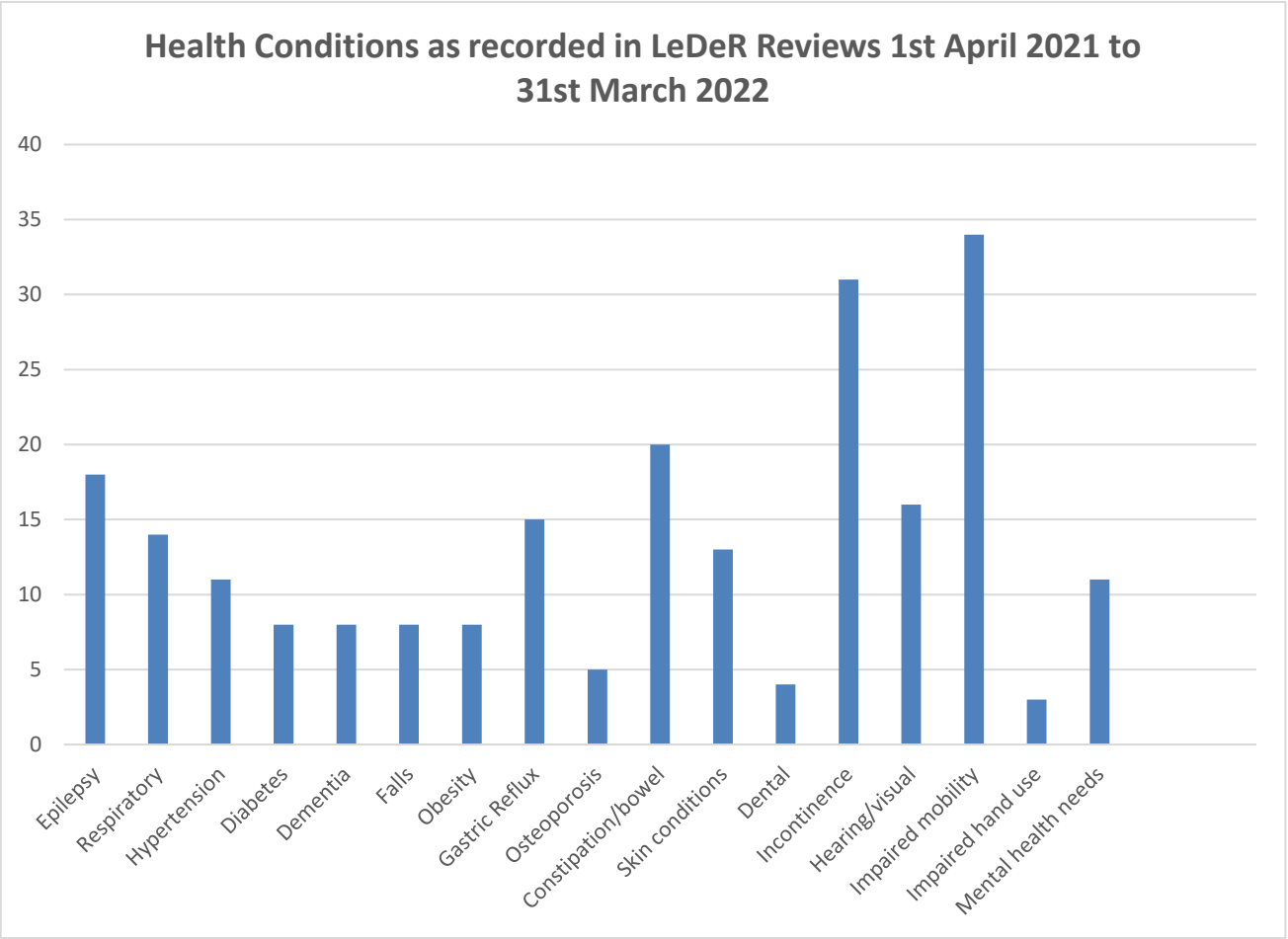
Themes are collated for every completed review. This information is collated and used to highlight local priorities. Themes collated for the 2021/22 year are included in Appendix 5 of this report.

The highest theme in 2021/22 was 'No/poor reasonable adjustments' followed by 'No GP health action plan'. This learning has provided evidence to support the work detailed later in this report in relation to LD annual health checks, health action plans and the work around supporting individuals by providing reasonable adjustments.

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 2021/22 is shown below identifying the health conditions and the number of times each condition was identified. This information is taken from the 48 completed LeDeR reviews during that period.



What is worth noting is the fact that in last year's report 60% of LeDeR reviews reported constipation/bowel issues as a health condition. As a result of that there has been work in Derbyshire to promote awareness of constipation – the "Poobusters" video, as well as a task and finish group that was set up to include Community Learning Disability Teams (CLDT) Managers, Nurses, Physiotherapists, Occupational Therapists, members of Continence services and the LD Health Facilitation Team to discuss and share best practice.

The graph above shows 42% of LeDeR reviews reporting constipation/bowel issues as a health condition a reduction of 18%. We will continue to monitor this but are hopeful this is one positive move towards improving the health outcomes for people with a learning disability.

Autism Only LeDeR Reviews

During 2021/22 we have only received notification of one autism (no LD) death. The individual was a 32-year-old white female and was a death through suicide. This has been allocated to a reviewer although it is expected that it will be placed on Hold as under police investigation. We are therefore not yet in a position to begin learning from our autism only reviews but do continue to promote LeDeR to raise awareness.

Presentations to raise awareness that LeDeR now includes individuals who had a clinical diagnosis of autism (with no LD) have taken place at various meetings, including the Derbyshire Autism Partnership Board, LD Partnership Board and the Good Health Group to promote the inclusion of autism only reviews. All Derbyshire reviewers have undertaken the autism training provided by the LeDeR programme.

Outcomes and achievements

As a result of learning identified through LeDeR, through themes and health conditions here's our main achievements for 2021/22:-

Poo Busters

One of our proudest achievements in 2021/22 is the completed constipation awareness video. This gave us the opportunity to work together with our Assistants who work as part of our local LD Health Facilitation team alongside media students from Derby University Media Department to produce "Poobusters". The video stars our three local people with learning disabilities as the "Poo Busters". It's giving a serious message – constipation can kill - but delivered in a fun way. The video is available on the LD page of JUCD website here under the 'General health' tab.

Our LD reps said about the video "*It helped you know what you needed to do if you couldn't poo"*

Annual Health Checks

LD AHCs have continued to be a major area of focus. In Derbyshire, our aim is to not just reach the national target of 75% of LD Annual Health Checks completed but that each person with a Learning Disability across Derbyshire is informed and aware of AHCs, Health Action Plans (HAPs) and reasonable adjustments and has the opportunity to attend their regular Annual Health Checks. To achieve this, we continue to work across the Derbyshire system, with the Derbyshire LD Strategic Health Facilitation team, parent carer forums, and SEND members to raise awareness on the importance of AHCs.

Work has also been taking place during the year to start to pull together a plan to review the quality of annual health checks and health action plans. This will be carried out by our LD Health Facilitation team, currently aiming for this to be in the summer.

Working with our Project Coordinator, who was employed for one year as part of the AHC Exemplar bid in Derbyshire, a "non-attenders" checklist has been produced which is currently being piloted. The aim is this will be shared across all our GP practices to provide help and advice of how reasonable adjustments can be used to work with individuals who have previously not attended their AHC.

All of the LD reps who were talked to about annual health checks said they'd had one. One of the reps

said she had always gone to the doctor's surgery for her health check and talked to 2 nurses. They gave her some easy read information and a health action plan which "helped her know about walking" and helped her to understand why walking was good for her.

Annual Health Checks awareness video

Another great example of working together with our local community was in producing the LD AHC awareness video which was completed in the year and has been shared across the system. The video is available on YouTube: https://www.youtube.com/watch?v=5FWFfh_2wVo and on the website of Joined Up Care Derbyshire: https://joinedupcarederbyshire.co.uk/about/our-governance-1/ld/annual-healthchecks.

The video was produced locally in Derbyshire sharing some local landmarks and our "actors" are all local people with learning disabilities who did a great job of being filmed and sharing information about annual health checks and their importance. The original idea for the video was agreed through in discussions with our parent carer forums who knew there are lots of awareness videos available for LD AHCs but wanted to see something that was local to Derbyshire.

Sometimes we find that individuals with a Learning Disability and their carers know about Annual Health Check(AHCs) but not about reasonable adjustments or the Health Action plan (HAP). The video emphasises that good quality Annual Health Checks and Health Action Plans can help people with a Learning Disability overcome physical and mental limitations to lead meaningful and active lives.

Epilepsy

Using evidence from LeDeR reviews a presentation was given at the LeDeR Steering Group in relation to epilepsy. Local case studies were presented from LeDeR reviews identifying key areas of concern.

Case Study 1

56yr old male with Severe Learning Disability, lennox gastaut syndrome (epilepsy syndrome), history of twisted bowel (sigmoid volvulus), dysphagia (SLT guidelines in place).

The gentleman lived in a nursing home. There was difficulty in management of epilepsy although there was a management plan in place and the home were clear on procedure.

There were 19 GP visits in last 12 months which were mainly due to seizures and epilepsy protocol, including falls relating to seizures
Stoma to treat twisted bowel which gave him pain free and good quality of life

Epilepsy was the main cause for hospital admissions, latterly dysphagia became an issue.
Last admission was for seizure but also thought to be a result of aspiration. He aspirated again in hospital, this led to aspiration pneumonia.
Hospital records stated that the impression was that the increased seizure activity was secondary to LRTI (LOWER RESIRATORY TRACT INFECTION)
2 days later a discussion was held with pharmacy regarding change of medications to liquid form as he was found with a half dissolved tablet in his mouth.
3 days after this medications were changed to intravenous (IV)
Antibiotics were given for sepsis due to aspiration pneumonia

Cause of death:

I.Lennox Gastaut Syndrome
II. Dysphagia, recurrent aspiration pneumonia

Issues Raised/Learning Identified:

Number of falls and visits to GP – escalation needed
Medication review could have been carried out sooner due to known dysphagia

Case Study 2

43 yr. old male with Severe Learning Disability, cerebral palsy, epilepsy, constipation, sleep apnoea, dysphagia

The gentleman lived at home with his stepfather after recent death of his mum.

There were speech and language therapy (SLT) guidelines in place for his dysphagia.
He was a wheelchair user (moulded seating) and was seen yearly by the physiotherapists from the Community Learning Disability Team (CLDT) for posture review. He had Hypotonia (poor muscle control).

Last recorded review with GP stated that he was unsuitable long term for any annual reviews as he was not tolerating interventions

He had regular health led respite.

He had missed five epilepsy appointments over 2 years. Stepdad was not responding to letters and neurology discharged him.
There were concerns by respite nurse that dad not recognising myoclonic jerks as full seizure activity. The GP also had failed attempts to contact dad.

Social worker became concerned that seizure protocol outdated. Seizures mainly occurred at night so day centre (which the gentleman attended five times a week) had not been required to administer rescue meds. Everyone knew that epilepsy was problematic if he was struggling with constipation. Bowel habits were therefore recorded in a communication book between day service and home.

He was admitted to hospital from respite care with aspiration pneumonia
Respite service contacted GP for medication review as struggling to take tablets and medications was converted to Oro dispersible. Contact again a few months later to request a proactive approach to constipation as it can cause epileptic activity.
4 months later epilepsy protocol was escalated to EMAS by father, remained at home with advice of rescue meds. GP written epilepsy plan update with information given by dad.
There were no regular reviews by adult care, no one addressing missed appointments.

The following month whilst in respite epilepsy protocol escalated - also sounded chesty. EMAS attended and queried aspiration. Admitted to hospital with aspiration pneumonia. Critical care was provided and he was intubated.
This led to respiratory failure and his seizures worsened despite medical management.

Cause of death
1A. Aspiration pneumonia
1B. Epilepsy
II. Obstructive sleep apnoea

Learning Identified
No consideration of reasonable adjustments by GP practice to understand why he was not tolerating annual health checks and therefore no heath action plan in place.
GP not raising concerns that neurology appointments missed
No adult care review for 3 years
GP produced epilepsy plan despite seizure the day before being atypical for him
No request for SLT dysphagia review
Epilepsy services discharged

As a result of this it was agreed further work was needed to share the case studies wider, discuss pathways, share good practice and look at any gaps in the services. A meeting was held in February 2022 with the epilepsy services – in Derbyshire there are separate epilepsy services in the north and south. The meeting confirmed and identified some differences in the north and south services and some common challenges.

One area that was discussed 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 has been 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 results of the survey are being used to identify any potential training needs and this is being taken forward into 2022/23.

One of our LD reps said they'd had a good experience when they went to Chesterfield Royal Hospital about their epilepsy and that things were "*explained well*" and that their "*doctor now looked after them and their medication* [for epilepsy]".

Osteoporosis

A project has been worked on in Derbyshire to identify patients with a learning disability who are at risk of Osteoporosis. Although this did not start with evidence from the LeDeR programme, a case study from LeDeR was produced to support this alongside information found through LeDeR with regards to the number of cases we were seeing where individuals had osteoporosis as a health condition. A separate paper which includes case studies is included at Appendix 6 in relation to this work. The work that has taken place involves:-

- DCHS and DHcFT have looked at current research and interventions/guidance being undertaken regarding Osteoporosis risk in the LD population and identified there are significant gaps in current awareness, assessment and provision.
- DCHS have been tasking GPs in Derbyshire to highlight patients on the DCHS complex physical disability caseload who have been identified as moderate & high risk of osteoporosis using a screening tool adapted from work undertaken in Guys St Thomas Hospital.
- GP responses were inconsistent; some referred for further assessment & some prescribed medication based on screening, whilst others requested further guidance, or did not take any action. It became evident that there is a lack of national & local guidance for people with LD & who are under 40 years of age, & unclear guidance for people between 40 & 50 years of age.
- The plan to pilot an Osteoporosis / Falls Risk Screening Tool for people with LD has been delayed due to the lack of clear guidance (as above).
- DCHS LD physiotherapy team have been working on improved access to DEXA through reasonable adjustments where scans are indicated
- Acute LD Liaison Nurse at Chesterfield Royal Hospital (CRH) is involved in the development of:

a) DEXA Easy Read leaflets &
b) DEXA referral forms to include a section for guidance on Reasonable Adjustment

- Bone Health specialists at CRH have been approached for their guidance.
- The LD Health Facilitation team has added information on the project to their training for GP and primary care staff to highlight awareness.

Learning found on the project:

- National osteoporosis screening isn't sensitive enough to identify people with LD who are at risk of osteoporosis.
- Despite people with LD having a higher prevalence at a younger age than the general population, there is no clear assessment route for people who identify at high risk who are under 40 years of age. Although guidance is available for those between 40 & 50 years of age the NICE recommend against routine screening for anyone under the age of 50
- Inconsistent responses for GPs due to a lack of guidance.

The project was triggered by an acute fragility fracture when X Ray revealed an older/ healing fracture and osteoporosis, in addition to the acute fracture. It is hoped that further work can continue to agree, develop and promote a LD Osteoporosis Pathway (from referral to screening & assessment to treatment or referral to Specialist Bone Health) & aim to reduce pain and suffering associated with *avoidable* fragility fractures & to improve the lives of people with LD+/- complex physical disabilities.

Using learning from LeDeR to work with care teams to improve services

The following is used to evidence how we are using learning from LeDeR reviews to improve services.

One of our more complex LeDeR reviews identified a number of areas of learning and after discussion at the LeDeR CQRG it was agreed that it would be beneficial to produce as a case study and meet with the care team to understand how they could use the learning to make improvements in future care. The case study is shared below:-

Case Study 3

70 year old white British lady who had lived in a flat independently for many years with her budgie.

She had a moderated learning disability her GP records also indicated she had undiagnosed autism. She had been considered frail for many years and had osteoporosis, she had experienced several fractures over the years and her weight had also been low for many years. She had a long history of abdominal pain and constipation as well as poor skin integrity and cellulitis. She also had poor compliance with medication which care staff had to prompt her to take and it was noted by her social worker that she would only take medication she recognised.

She had a care agency supporting her 3 times a day through a private arrangement. This was in place for a long time until a safeguarding referral was made regarding the agency. An application was made to the court of protection by the social worker and a mental capacity assessment concluded that she did not have capacity to understand her financial affairs or for purchasing her own care arrangements; a best interest decision was made to change the care agency and the local authority became her appointee. She did not have a next of kin.
This upset her and she refused to engage with the new staff, she also started to reduce her food and drink intake. This coincided with her partner dying who also had a learning disability and lived in the same complex. She had an advocate throughout the process, but the worker also changed during this challenging time and Covid-19 compounded the situation. She was refusing new care staff entry into her flat and her health started to deteriorate.

She had been known to the CLDT for years and was known by services to be difficult to engage with attending of health appointments and screening, but it was clear she was more likely to engage with staff she had met several times. She had been re-referred to CLDT but was not engaging and was discharged from Occupational Therapy.

She was known to hate hospitals and on her last admission was clear she wanted to go home. A capacity assessment indicated that she did not have capacity to weigh up the safety risks. She had good support from the acute liaison nurse who encouraged her to eat and drink when in hospital.
When her health began to improve the MDT met to discuss discharge home, however the ward discharged her to a community hospital over the weekend which was not part of the plan. This caused a lot of distress for her which she communicated in her behaviours; the community hospital transferred her back to the acute hospital but to a different ward with no familiar staff. She disengaged and deteriorated further; she was then transferred to the hospice where she died.

Cause of death
1a malnutrition
1b anorexia
1c severe learning difficulties
11 covid 19 infection

Follow up with Community Learning Disability Team (CLDT) Case study 3 discussion

The review was sent to the clinical and deputy lead of the Learning Disability Team. This was shared as an open discussion with members of the team.

1. CLDT- Occupational Therapist (OT) engagement - it was discussed that the OT had known the individual for over 20 years and therefore knew the individual well. It was reflected that the clinical notes may not have captured all elements of the clinical decision making (ie facts that are more subjective as opposed to objective) but it was based on the OT's prior knowledge of the individual. The team are now considering how they can ensure this reasoning/decision making is recorded on the system.

2. CLDT - the initial physical health assessment documentation was not completed for the individual. It has highlighted to the team that they should ensure this is completed shortly after the acceptance of a referral. There are minimum standards that need to be completed for all services users these would then be reviewed as a new referral is received.

3. CLDT are now on the same clinical system as general practice. It was clear that Annual Health Check and DNA was a problem with this practice (despite this practice having a lot of people on LD register) Discussed that Covid-19 could be a reason but that the Health Facilitation Team are working on Annual health checks and easy read sheets as well as non attendance process for LD registered clients. Also discussed that now CLDT are on the same clinical system there is an option to task the GP practices if an annual health check is out of date/reasonable adjustments/easy read not being facilitated.

4. The team found the reflective practice useful. Initially some thought the LeDeR process to be an investigation of their practice but the process of reflection facilitated supportive conversations that considered wider system processes.

Future plans

In Derbyshire we are committed to deliver on the statements and vision as detailed in the LeDeR Strategy and on page 12 of this report.

Particular focus will also be given in relation to the following priority areas:-

Addressing inequalities across BAME communities

- Identification of a new BAME lead
- Follow up from report/actions
- Promotion of BAME inequalities
- Increase notifications through LeDeR programme from BAME communities

Epilepsy

- Share learning from the epilepsy survey
- Identify next steps, including training needs and linking in with the new Epilepsy Lead for Derbyshire

Constipation and bowel management

- How is this being led across the north and south teams

Osteoporosis

- To establish a clear osteoporosis pathway for people in this vulnerable population where clear guidance is unavailable. This is particularly important for people under 40 years of age or for those who are unable to access DEXA (e.g. with Dyskinesia)
- Update the osteoporosis screening tool to include *additional guidance* & present outcomes to Clinical Governance
- Present findings to GPs through LeDeR platform
- Escalate findings to promote research & national guidance

Continue to deliver workshops across health and social care which spread learning in relation to LD AHCs and general LeDeR learning and themes.

Continue to encourage work with United Support and other care providers offering support and advice and learning from LeDeR.

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

Our LD Reps – Andrew, Kerry, Nick and Sam – for providing their feedback about some of the work we've been doing in Derbyshire

LeDeR Steering Group members across the Derbyshire system

References

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

East Midlands empho Public Health Observatory – NB. The last census data included in this report is from the 2011 census. This document is included for reference only to show the percentage of adults in Derbyshire with LD. There is not yet an updated version of this document available based on the 2021 census results which will be available in early summer 2022.

Derby City Council 2011 Census report

"Understanding Autism" – Derbyshire County Council

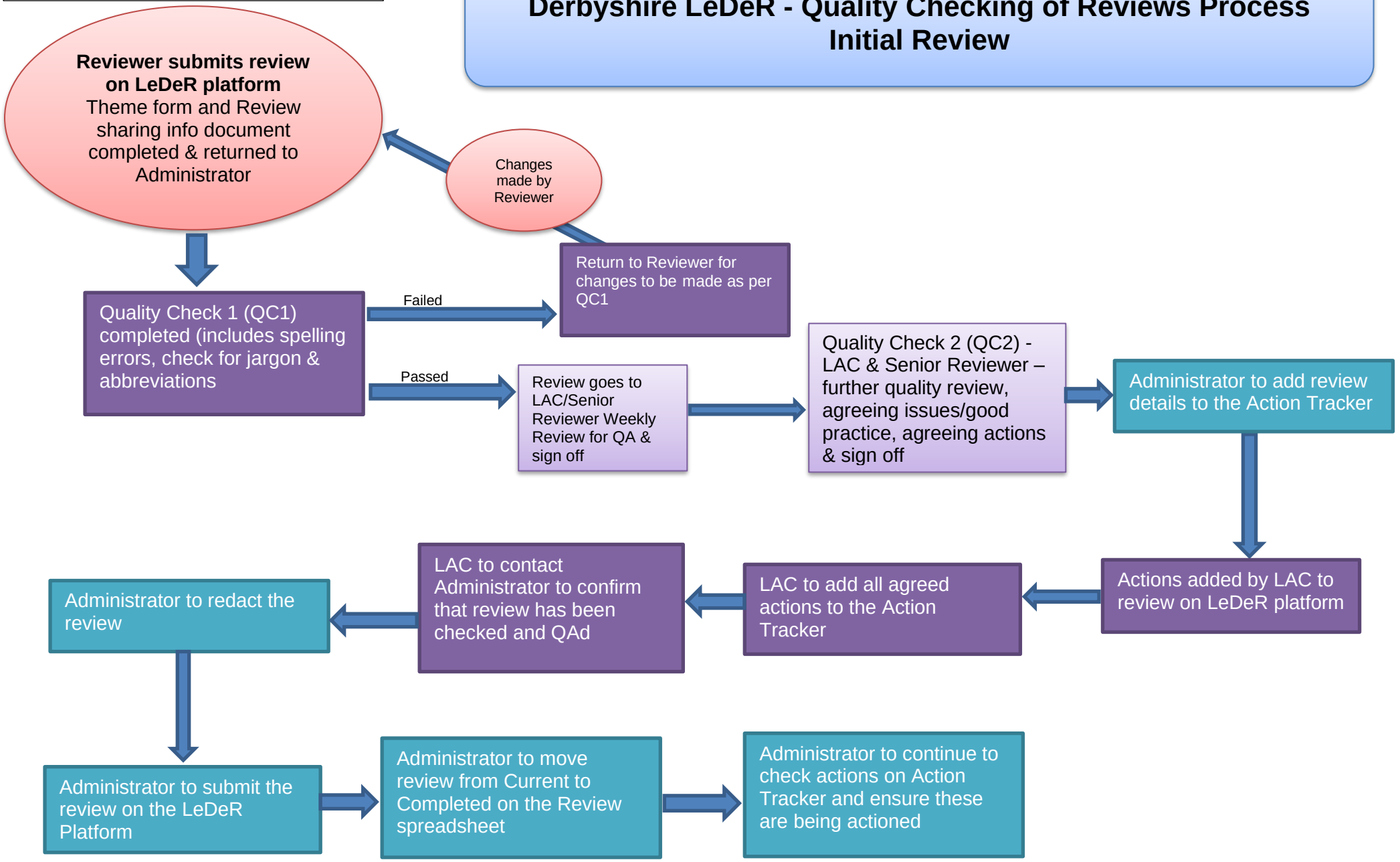
Podcasts - Derbyshire Safeguarding Adults Board (derbyshiresab.org.uk)

National LeDeR Policy 2021

Derbyshire LeDeR Strategy 2021

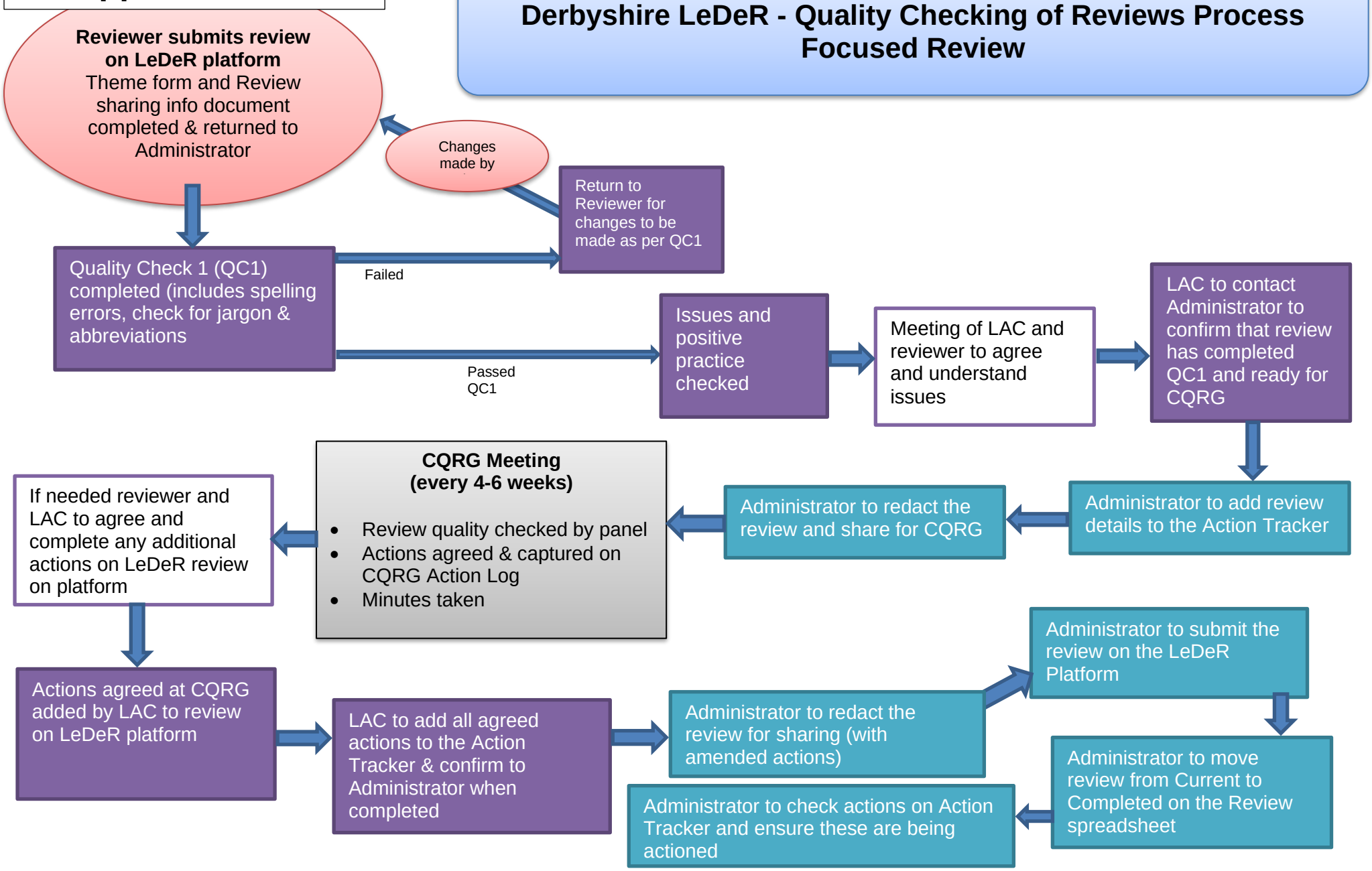
Appendix 1

Derbyshire LeDeR - Quality Checking of Reviews Process Initial Review



Appendix 2

Derbyshire LeDeR - Quality Checking of Reviews Process Focused Review



Appendix 3

Joined Up Care Derbyshire

LeDeR - Quality Check 1

LeDeR Review ID	
Date	
Quality Checked By	

	Yes	No	Additional Information
Did the reviewer speak to/obtain information from someone who knew the person well?			
Has the reviewer confirmed that family members are happy to receive a copy of the LeDeR review? If not, check with reviewer. Is email address included in review? If not, check with reviewer.			
Has the reviewer suggested how feedback can be given to the family?			
If family not involved has the reviewer given details of how they tried to make contact?			
Does the review include information from GP/GP notes, or clinician involved in care?			
Is information included from at least one other person?			
Cause of death is included?			
Pen portrait completed?			
Have all word counts been kept within?			
Has a check been done for spelling and grammatical mistakes?			
Has a check been done for abbreviations?			
Has a check been done for jargon?			
Has a check been done that patient notes have not been copied and pasted into the LeDeR review?			
All issues included in the body of the review are picked up in the Issues?			
Has the reviewer suggested how feedback can be shared with care providers?			

Appendix 4 – Derbyshire Local Action Plan – deliverables against the LeDeR Policy

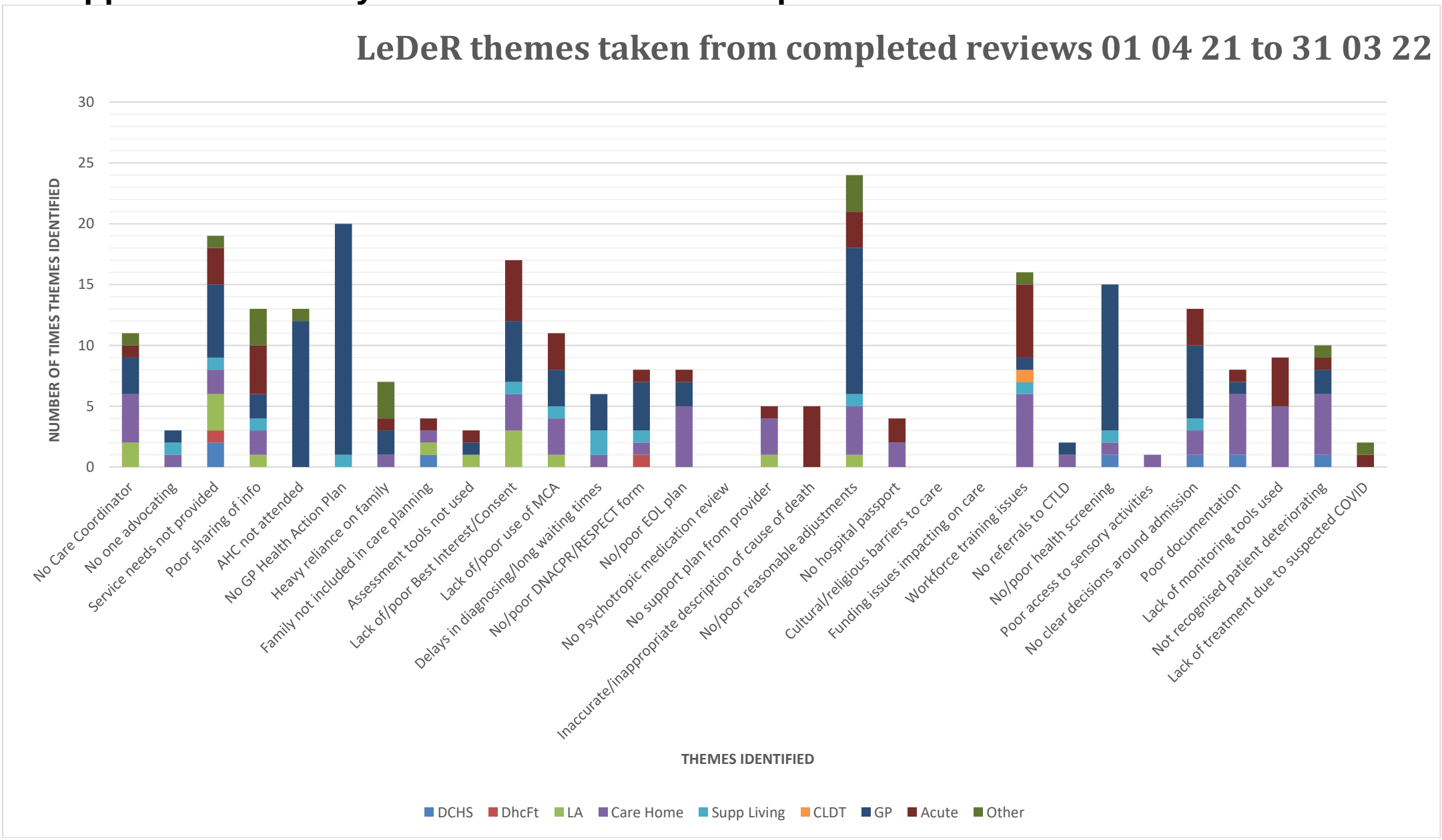
Key Deliverables	Outcomes	Key performance measures	Responsibility	Frequency of collection (if appropriate)	Date for completion	Current Status end of year 2021/22
1) A robust plan will be in place to ensure that reviews are completed within six months of the notification of death.	100% of reviews (both initial and focused) are completed within six months of notification.	Monthly dataset shows ICS completion of eligible reviews within six months of notification.	LAC	Monthly	Ongoing	On Track – for all reviews that have **not** been part of an investigation
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
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	Some local work evidenced in this report. Further work needed.
4) Clear and effective governance in place which includes LeDeR governance within mainstream ICS quality surveillance and governance			ICS	Annually	Operational from 1st July 2022	Not yet due but on track for delivery

arrangements.						
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	Further work needed
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 2 monthly	September 2021	Further work needed as evidenced in co-production and engagement section
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 CQRG	Attendance captured in minutes of meeting	LAC	Meetings held 6 weekly	April 2022	Completed (membership reviewed) – ongoing through capture of attendance in minutes
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	December 2021	In progress. On Track.
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	Reviewers/LAC/ Senior Reviewer	Training monitored 6 monthly	Ongoing	Processes in place. Ongoing

		• The LAC and Senior Reviewer will meet regularly to quality assure reviews and refer to the LeDeR Clinical Quality Review Group (CQRG) where wider quality review is required. • Quality Checklist form to be completed for each completed review		Weekly meetings of LAC & Senior Reviewer	Weekly Following each completed review	
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 • 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	LAC/ICS	Annually - ToR for Steering Group reviewed Q4 2021/22 Monthly – as needed Bi-monthly	September 2021	Ongoing

		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				
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 weekly performance monitoring	LAC/Reviewers	Weekly monitoring	Ongoing	In progress & On Track

Appendix 5 – Derbyshire LeDeR Themes Graph



Appendix 6 – Osteoporosis Case Study and details of the project

Improving Access to Bone Health Assessment & Treatment for Adults with LD & Complex Physical Disability through Osteoporosis Screening

A Case Study

Introduction

Osteoporosis & fragility fracture are a secondary complication of complex physical disability. Despite fragility fracture having a higher prevalence in young people with LD compared to the general population, there are no national guidelines or validated screening tools to identify & manage risk in this vulnerable population.
Following an incident in Spring 2021 involving an avoidable fragility fracture, an action plan was developed to modify & pilot the use of an osteoporosis risk screening tool (developed by Guys & St Thomas' Trust). The proposal was presented & approved by Clinical Governance & 23 clients were screened for risk of osteoporosis.

Health & Social Circumstances

D is a 47-year-old gentleman & the youngest of 5 siblings. He lives in a bungalow with 2 brothers who are his main carers. D attends a day-service for people with profound and multiple learning disabilities (PMLD) 3 times a week. D is diagnosed with Tuberous Sclerosis which is a rare genetic condition that causes benign tumours to develop in different parts of the body, including the brain as in D s case. D has a severe learning disability, complex physical disability, epilepsy & dysphagia. He has a history of constipation and is prescribed PRN laxatives.

Due to the severity of D's learning disability, he is unable to make decisions relating to his complex health needs, & therefore health & lifestyle decisions were agreed with D's brothers in his best interest (Mental Capacity Act 2005)

At the day centre D is hoisted for all his transfers, and similarly at home D has an overhead hoist for transfers in the bedroom and bathroom. The brothers have previously declined a portable hoist in the lounge because they are convinced the room is too small & they prefer to lift D from his wheelchair to the floor, where he likes to sit in the evenings.

A Moving & Handling Risk Enablement Plan was agreed by an OT in Adult Care (2020) to continue to manually lift D to and from the floor with an understanding that the family would request a moving & handling review if circumstances changed. The family were made aware of the risks involved in lifting D & understood that if he was injured it would become a safeguarding issue.

Screening for osteoporosis could lead to a change in the level of risk associated with moving & handling if D is diagnosed with osteoporosis.

The results of screening indicated that all the osteoporosis risk factors associated with LD & complex physical disability were present in D's case indicating a high risk of osteoporosis. The GP was alerted & a request made to complete the Fracture Risk Assessment (FRAX) & to request a referral for a DEXA scan (Derbyshire Joint Area Prescribing Committee (JAPC) Osteoporosis Guidelines 2019). Reasonable adjustments to enable successful access to DEXA were included in communication with the GP who agreed to make the referral.

Outcome

Despite an entry on System one suggesting that D would be unable to access DEXA, he was scanned successfully using reasonable adjustment, and the results indicated osteoporosis.
D was prescribed bisphosphonates and will be referred by the GP for a repeat scan in 2 years-time

Following diagnosis, one of the brothers was observed lifting D from the floor into his chair at home. Due to D s significant knee flexion contractures his left foot remained under his thigh as his brother lowered him into his seat. D s brother denied this had happened previously, but he acknowledged the "near miss". We talked about the upmost

importance of careful handling, particularly now that D is diagnosed with osteoporosis. It was important to emphasize that provided the family & all care givers are adequately trained and aware of the associated risks the presence of osteoporosis shouldn't preclude activities enjoyed by D and his family & friends.

D's brothers were very receptive to exploring alternative ways to transfer D, but were clear about what they didn't want, having already trialled & found standard portable hoists to be more of a burden. It was agreed that a joint home visit with the Lead moving and handling advisor could be arranged to discuss and agree a plan.
D s brothers have since agreed to an assessment using a small portable & folding hoist and if acceptable will reduce the potential risks of fragility fractures during transfers

Learning Outcomes

The pilot project and evidence from the case study confirm that screening for osteoporosis has demonstrated:

1) a raised awareness of the prevalence of osteoporosis in people with LD & complex physical Disabilities:
    - 74% of the sample population were screened as moderate and high risk of osteoporosis &
    - 31% are 40 years old and above
    - 43% are younger than 40 years old
2) an increase in GP referrals requesting DEXA scans (from 0% pre-screening to 22% post-screening)
3) that successful access to DEXA scans can be achieved through reasonable adjustment
4) there is no clear referral pathway for people with complex physical disability under the age of 40 or for people with a diagnosis of dyskinesia
5) that management of bone health has improved for people in this population
    - 22% are prescribed bisphosphonates
    - 35% prescribed Vitamin D
6) that osteoporosis awareness & training in careful handling are essential & should be included in moving & handling plans

Work in progress

1)To establish a clear referral pathway for people in this vulnerable population who are under 40 years of age +/- a diagnosis of dyskinesia
2)Update the osteoporosis screening tool to include additional guidance & present outcomes to Clinical Governance
3) Present findings to GP s as recommended by LeDeR team
4) Escalate findings to promote research & national guidance

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