NHS
Derby and Derbyshire
Clinical Commissioning Group

Derbyshire Learning from Deaths of those with a Learning Disability

The LeDeR Programme

Annual Report

1st April 2020 to 31st March 2021

Derbyshire LeDeR Mortality Review
Annual Report 2020-2021

Responsible Committee	Derby and Derbyshire Clinical Commissioning Group Quality and Performance Committee
Target Audience:	Internal report for those agencies involved in the programme. LeDeR Mortality Review Steering Group LeDeR Clinical Quality Review Group Derby and Derbyshire Clinical Commissioning Group National LeDeR Programme NHS England
Date of Approval:	29th April 2021 at DDCCG Quality & Performance Committee
Review date:	
Version:	
Document Type	Annual Report (Quality)

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Version Control: Date	Version	Status
10/3/21	1.0	First draft
16/4/21	2.0	Final draft ready for comments by Phil Sugden
20/4/21	3.0	Final ready for review and discussion at DDCCG Quality & Performance Committee

Contents

List of Abbreviations

Abbreviation	Explanation
ACPPLD	Association of Chartered Physiotherapists for People with a Learning Disability
AHC	Annual Health Check
A&E	Accident and Emergency
BAME	Black Asian Minority Ethnicity
CAG	Confidential Advisory Group
CDOP	Child Death Overview Panel
CHC	Continuing Health Care
CIPOLD	Confidential Inquiry into premature deaths of people with learning disabilities
CLDT	Community Learning Disability Team
CQRG	Clinical Quality Review Group
CT scan	A computerised tomography (CT) scan uses X-rays and a computer to create detailed images of the inside of the body
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
HQIP	Healthcare Quality Improvement Partnership
LAC	Local Area Contact
LD	Learning Disability
LeDeR	Learning Disabilities Mortality Review
MCA	Mental Capacity Act
MDT	Multidisciplinary Team
NHSE/I	NHS England and NHS Improvement
OPMH	Older Peoples Mental Health
OT	Occupational Therapist
SALT	Speech and Language Therapy
SEND	Special Educational Needs and Disability
SJR	Structured Judgement Review

Executive Summary

This report is the second annual report for Derbyshire on the learning from deaths of those with learning disabilities. The report uses data collated from 1st April 2020 up until 31st March 2021 except for the table below where as a comparison for data purposes, data is also shown for the 1/4/19 to 31/3/20 year.

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, sharing the work that has been done in the previous year to address these findings to work on service improvement.

LeDeR Summary of Data for Derbyshire	
Data for year 01/04/2019 to 31/03/2020	**Data for year 01/04/2020 to 31/03/2021**
64 notifications received	**74** notifications received
35 of those received 1/4/19 to 31/3/20 were completed at 31/3/20 **55%**	55 of those received since 1/4/20 are completed at 31/3/21 **74%**
Of all reviews received since start of programme 92 completed in year 19/20 61%	**Of all reviews received since start of programme 83 completed in year 20/21** 203 reviews have been completed since the start of the programme **41% of total completed have been completed this year**
29 **were allocated at year end**	15 reviews were allocated at year end **(there are no reviews unallocated) (4 are on On Hold due to coroner or police investigations)**
44% died in their usual place of residence	**41%** died in their usual place of residence
41% died in hospital **15%** died elsewhere	**58%** died in hospital **1%** died elsewhere
58% of the deaths were males **42% were females**	**39%** of the deaths were males **61%** were females
3 of the notifications were from BAME communities	**4 of the notifications were from BAME communities**

Introduction to the LeDeR Programme

LeDeR (the Learning from Deaths Review Programme) started in April 2017 and is a national programme funded by NHSE/I and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. It grew out of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD) and was piloted in parts of the country in 2016. A commitment to continuing the LeDeR programme was made in the NHS Long Term Plan 2019. The Programme is currently being delivered by the Norah Fry Research Centre at the University of Bristol although this will end on 31st May 2021 and a new LeDeR platform and policy will then be in place.
A short summary of the development of the LeDeR programme is included in Appendix 1.

Nationally, annual reports have been produced for the past 4 years. The fourth LeDeR annual report was published on 16 July 2020. From 1st July 2016 – 31st December 2019, 7,145 deaths were notified to the LeDeR programme with 3,060 deaths notified in 2019.

All deaths of people with learning disabilities are notified to the National LeDeR programme at the University of Bristol. Notification of the death is then allocated to the Local Area Co-ordinator (the area is based on the area of the GP practice of the individual). For Derbyshire, the Local Area Contact (LAC) and Assistant LAC are employed by Derby and Derbyshire Clinical Commissioning Group (DDCCG). It is then their responsibility to allocate the review to a reviewer in order that the initial review can be undertaken for all deaths notified to the LeDeR Programme of people with learning disabilities aged 18 years and above. There is a separate process followed for children and young people from 4 to 17 years of age managed by the Child Death Overview Panel process (mentioned later in this report).

In Derbyshire, throughout the last year there has been a lot of work and effort to complete reviews in a timely manner and balance this with working on embedding the learning as well as build relationships with partner organisations and agree pathways where there is an overlap with the LeDeR programme.

We are very keen to use the learning found and improve services for individuals with learning disabilities. Through the development of end of life pathways, promoting awareness of conditions amongst people with a learning disability and working closely with providers of health and social care we are working locally in Derbyshire to improve services and make changes. It is important that we recognise the good services that are provided in many areas and which have been identified in reviews too and a large area of our work is about promoting the good work that is already done, but there is clearly more to do to improve in some areas as identified in this report.

Definition of a Learning Disability in use by the programme

The LeDeR Programme uses the definition included in the 'Valuing People', the 2001 White Paper[i] on the health and social care of people with learning disabilities which states:

'Learning disability includes the presence of:

- significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development

How does the LeDeR process work?

Anyone can notify the national programme of a death including people with learning disabilities themselves, family members, friends and paid staff.

Notifications were made by telephone number or by completing an online form.[ii]

All deaths reported to the LeDeR Programme had an initial review to establish if there were any specific concerns about the death, and if any further learning could be gained from a multiagency review [iii] of the death that would contribute to improving services and practice.

It is the job of the local reviewer to conduct the initial review of each death and where indicated a full multiagency review was held. All information is accessed, edited and completed via the web based portal/ LeDeR Review System.

The LeDeR Process is described in Figure one below. However, the initial review includes:

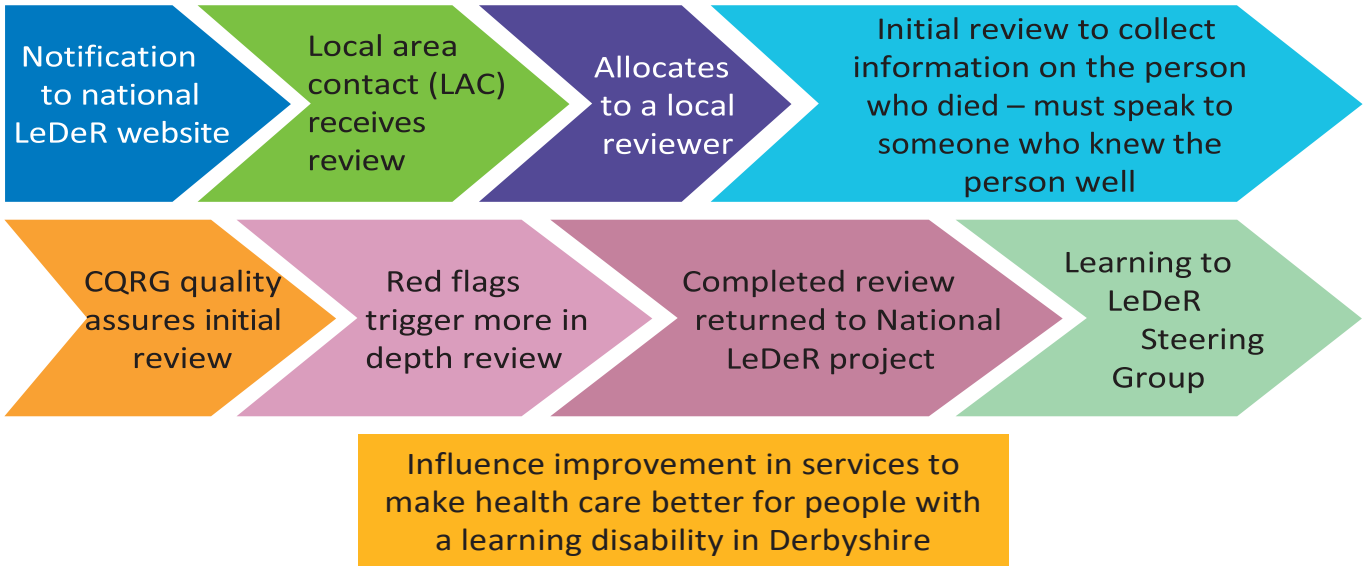
- Checking and completing the information received at the notification stage.
- Contacting a family member or another person who knew the deceased person well and discussing with them the circumstances leading up to the death.
- Scrutinising at least one set of relevant case notes and extracting core information about the circumstances leading up the persons death: for example summary records from GP, social care, Community Learning Disability Team (CLDT), or hospital records.
- Developing a pen portrait of the person who has died and a timeline of the circumstances leading to their death.
- Making a recommendation to the Local Area Contact whether a multiagency review is required.
- Completing the online documentation and an action plan which will be reviewed by the Clinical Quality Review Group and reviewed as part of the national LeDeR process.
- However, this process ceased at March 2021 and a new LeDeR process was set in place from June 2021. This is described in the LeDeR Futures section below.

i Department of Health. (2001). Valuing People: A New Strategy for Learning Disability for the 21st Century. A White Paper.

ii http://www.bristol.ac.uk/sps/leder/notify-a-death/?_ga=2.426591.1531124673-1987643447.1528363357

iii http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/multiagency-review/

Figure one – LeDeR process in Derbyshire



LeDeR Futures

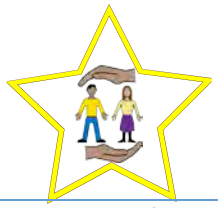
A new LeDeR web-based platform for completing LeDeR reviews will be in place by 1st June 2021. The NHSE contract with Bristol University comes to an end at 31st May 2021 and they will no longer support the platform. At the time of writing this report NHSE/I had just announced a new policy for the LeDeR programme. This policy aims to set out for the first time for the NHS the core aims and values of the LeDeR programme and the expectations placed on different parts of the health and social care system in delivering the programme from June 2021.
The detailed policy is available at https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

What are reviewers looking for?

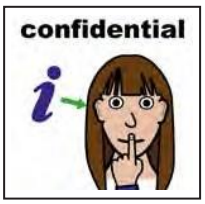
Within the LeDeR Programme reviewers are asked to consider potentially avoidable contributory factors, this refers to anything that has been identified as being a factor in a person's death, and which, could have possibly been avoidable with the provision of good quality health or social care.

CIPOLD and numerous serious reviews of deaths nationally have highlighted many examples of potentially avoidable contributory factors, and it would not be possible to list them all here, however areas reviewers are asked to consider include:

The person and /or their environment **care at home** 	People who live in unsuitable placements for their needs including the availability of appropriate communications facilities/channels to ensure the person has access to information/support appropriate for their foreseeable needs.
	Inadequate housing that places the person at risk of falls, accidental injury or isolation in their home.
	Key information provided by family members or other carers being ignored or concerns not taken seriously or low expectations of family members.
	Families not wanting or feeling able to challenge medical professionals' authority and opinion.

The person's care and its provision: **quality care** 	The lack of provision of reasonable adjustments for a person to access services.
	Lack of routine monitoring of a person's health and individual specific risk factors.
	Lack of understanding of the health needs of people from minority ethnic groups.
	Inadequate care.
The way services are organised and accessed: **my care** 	No designated care coordinator to take responsibility for sharing information across multi-agency teams, particularly important at times of change and transition.
	Lack of understanding and/or recording of the Mental Capacity Act when making essential decisions about health care provision.
	Inadequate provision of trained workers in supported living units.
	Inadequate coverage of specialist advice and services, such as Speech and Language Therapy (SALT) or hospital learning disability liaison nurses.

Data sharing and confidentiality



The LeDeR programme aims to ensure that, as far as possible, personal information relating to individuals who have died, and their families, **remains confidential** to the services that supported them.

The national LeDeR team collect the minimal amount of personal identifying data possible, and this will be pseudo-anonymised as soon as possible. Additionally, all information will be anonymised in any presentation, publication or report, and no opportunity will be provided for readers to infer identities.

In order to learn from the deaths of people with learning disabilities so that service improvements can be made, we need to ensure that timely, necessary and proportionate mortality reviews are undertaken, involving the full range of agencies that support people with learning disabilities. Each of these organisations will hold a piece of the jigsaw that together creates a full picture of the circumstances leading to the death of the individual. Information viewed alone or in silos is unlikely to give the full picture, identify where further learning could take place, or contribute to cross-agency service improvement initiatives.

The National LeDeR Programme applied to the national Confidential Advisory Group (CAG) for Section 251 (of the NHS Act 2006) approval for the use of patient identifiable information in order that reviews can be undertaken of the deaths of people with learning disabilities. The programme has been given full approval to process patient identifiable information without consent.

Specifically, this provides assurance for health and social care staff that the work of the Learning Disabilities Mortality Review Programme has been scrutinized by the national CAG.

The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the legislation, and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved. The key purpose of the CAG is to protect and promote the interests of patients and the public whilst at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care. More information about Section 251 approval is available using the link below.

http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/

The LeDeR Programme in Derbyshire

Throughout 2020/21 in Derbyshire we have worked to balance the completion of reviews alongside embedding learning as it was felt extremely important that the learning that had been gathered was used to start to make a difference to individuals. There has also been a lot of important work done to work closely with other agencies who are involved in the LeDeR programme and agree pathways/processes where applicable. One area of work is in relation to work with the coroner, police or safeguarding where, if applicable, the LeDeR review is placed on 'Hold' while the investigation takes place.

One particular area that came out of last year's Derbyshire annual report was around promoting the awareness of learning disability annual health checks. Although this work is very much still ongoing this has been a priority area this year and we are very proud to say that at the end of March 2021 Derbyshire has achieved 78% completion of annual health checks from 1st April 2020 to 31st March 2021 of those individuals who are on the GP Learning Disability register. This figure was 58% at the end of 2019/20 and shows a great achievement by our GP practices and others involved in the promotion of and work in relation to annual health checks such as the LD Health Facilitation team, particularly at a time when they were all also dealing with the challenges of Covid-19 including redeployment and vaccinations. Due to Covid-19 it was agreed nationally that some annual health checks would have to be completed virtually where an individualised approach was made.

Below are case studies of local Derbyshire people and their experiences of their recent health checks. They have both given permission to use their real names and photos.

Denise of Ilkeston

"I had my annual health check in November 2020. I usually see the doctor at the surgery but it was done over the telephone because of the pandemic. It felt a bit strange doing this over the telephone but it was still worth doing and went well. Because it was done over the telephone, the doctor was not able to take my blood pressure or weigh me. I have now bought some scales so have been able to check my weight.

The doctor asked me lots of questions about my health, asked if there had been any changes and asked how I had been during Covid. The health check was very useful. I was able to explain to the doctor that I had been feeling tired. He said he thought that I was not getting enough iron (anaemia) and he prescribed me some iron tablets. He explained what these were for and some changes that I might notice when taking these. The tablets worked well and I did not feel so tired.

At my last health check in 2019, I was weighed and said that I would try to lose some weight. Even though we have been in lockdown, I have found out that I have lost half-a-stone in weight in the last year which I am proud about. I try to eat well and have not been drinking alcohol. I like going for a walk when I am able to go."

Asked whether she would recommend health checks to others, Denise said: "I would tell people to go and get yourselves checked out. It is not a scary thing to do. It is easy. Your doctor will listen to you and your worries and is there to help you. If you do not go, they may miss something."

James of Tibshelf

"I had my health check in September 2020. It was a video call due to being deaf and was held at home. I was asked for weight, blood pressure (which I was able to measure at home), how I was doing (particularly during lockdown), whether I have any problems and how were my worries/anxiety.

It means I can check that my body is ok, that I'm keeping myself healthy and it gives me the chance to ask what else I could do to keep myself healthy. I have a treadmill machine at home which helps me with my exercise and it keeps my anxieties lower. I also spend a lot of time with animals which calms me down. I try to eat healthily and I am learning how to cook healthy meals."

Asked whether he would recommend health checks to others, James said: "Definitely. I feel happy talking to my doctor. I talk to the same one each time so he understands me and my medical conditions and I don't have to repeat things all the time to someone new. I trust my doctor and know that he will help me to stay healthy."

Another area of importance to us in Derbyshire is to ensure we are providing families with the opportunity to be involved in the LeDeR review should they wish to be and this is something we have worked on this year to ensure contact is being made with family members and reviews shared with them.

Conversations with family can be difficult and upsetting conversations for our reviewers as well as the family member/s, and we therefore also aim to provide support for reviewers to discuss and share experiences with each other and other members of the LeDeR team. This was further evidenced through the survey we produced as a result of the national Oliver McGowan report where we asked reviewers specific questions about the support they received. Please see Appendix 2 for detail of the report produced and shared through the Derbyshire Governance process.

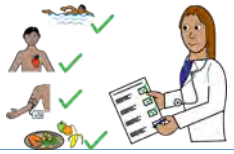
Learning from Themes:

In Derbyshire themes are collected as part of the review process:-

- On completion of each review the reviewer completes a theme form to identify any themes relevant to the review.
- The theme form is reviewed alongside the review as part of the quality review process. Our reviewers have been collecting themes in 2020/21 that also identifies the relevant type of care provider. This means when the themes are shared with organisations they can see themed areas of work that are relevant to them for potential review.
- The themes are collated and reviewed to identify areas where commissioning concerns may need to be identified. These themes are collected through the strategic action plan which is fed through the LeDeR Steering Group.

Below are some of the top themes across Derbyshire that have been identified as part of the LeDeR Programme in Derbyshire in 2020/21.

Service needs not provided 	Areas where service needs are evidenced through themes as not provided:- For Local Authority - lack of learning disability specialist residential or Nursing Homes. Commissioning or contracting issues (no LD specialist care providers for care in someone's own home), lack of LD training for staff. For GP practices - lack of; reasonable adjustments such as home visits; offering different type of health screening to achieve the same outcome; signposting referrals to other agencies. For Acute services - lack of referral to Acute liaison nurse, lack of appropriate health care assistant or 1:1 support offered to someone on the ward who needs help with anxiety, feeding etc. For CTLD - service not being offered as referrer told that person with LD can access mainstream services. Non-LD care home not monitoring baselines such as bowels/pain and not knowing about the need for Annual Health Checks or hospital passport. Care home not using monitoring tools due to person being independent with toileting so were not able to recognise when bowels became problematic.
No or poor reasonable adjustments 	A lack of or poor reasonable adjustments being made is shown in themes, particularly captured across GP and acute services. Some examples seen include:- no offer of home visits blood tests not attempted due to resistance by individuals without any evidence of attempting reasonable adjustments screening not attended, no reasonable adjustments made or documented to address this lack of accessible information on health care needs.

Poor sharing of information 	This is seen across a number of different care providers, particularly GP and acute services and care homes. Sharing of the individual's information is important to ensure care is being given based on the up to date presentation of the individual. Examples seen:- District Nurse not discussing with family what services could be accessed. Coding for conditions not being used by GP so this could be easily picked up when transferred to another practice. Condition info/advice/education could have been shared by GP with family/care home.
Lack of or poor use of best interest or consent 	Although the phrases 'mental capacity' and 'best interest decisions' are recorded in medical notes, in many cases there is no written evidence of the decision making process including weighing up of alternative options.
No GP Health Action Plan 	Although we have seen some evidence of no LD annual health check taking place, there are many cases where the individual has had the annual health check but no GP health action plan is evidenced.

The themes above are only a few of those identified. Appendix 4 contains all of the themes in Derbyshire identified between 1st April 2020 and 31st March 2021.

Identifying actions and good practice

As part of the Initial Review, the reviewer identifies issues and makes recommendations based on these. The reviewer also collates details in relation to good practice. The completed review is then quality assured and part of this process is to look at the issues and recommendations and agree actions from these. All of the actions are collated and monitored using the Derbyshire Action Tracker. Good practice is shared and celebrated.

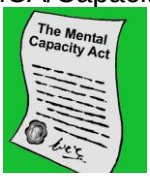
The following is a "good practice" story which has been adapted from one of our Derbyshire reviews and shows evidence of some of the good work that is being done in Derbyshire to support individuals with learning disabilities. Some of the work we have been doing in this past year is to promote areas of work such as that being done by the Dementia Palliative Care Team and this is great evidence of teams working together to make a difference to individuals and make their end of life experience as good as possible.

Derbyshire Case Study – Case Study 1

This 56yr old lady lived with her family until they died many years previously. She moved out briefly and her home was converted to supported living accommodation. She lived there with her 3 house mates until she passed away this year supported by the same staff group. She had a moderate learning disability and Down syndrome. She was an anxious lady at times so her activities, routines and familiar staff were very important to her as was her familiar home and community.

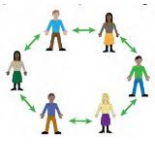
She was screened annually by the Community Learning Disability Team (CLDT) for dementia as people with Down syndrome are more likely to experience dementia. Staff from her home contacted the CLDT to report that her behaviours were changing which included her becoming fearful and hesitant with her mobility particularly using the stairs. The CLDT reassessed her and referred to Older Peoples Mental Health (OPMH) for consideration of a diagnosis.

MCA/Capacity

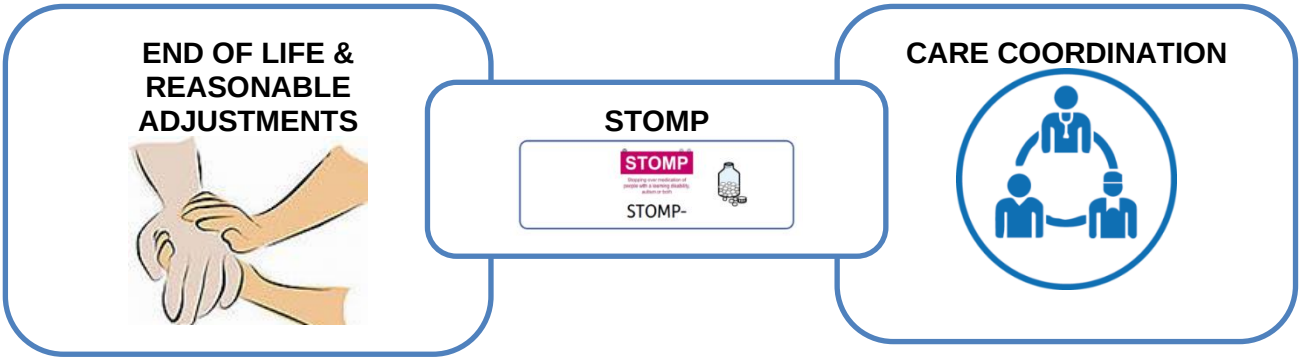


An assessment was coordinated and completed by adult care. The decision was made to swap bedrooms with her housemate and move her downstairs so her mobility needs could be supported in her environment using equipment.

PARTNERSHIP WORKING



The CLDT referred her to the Dementia Palliative Care Team prior to a diagnosis so work could start to support her ongoing needs. This was acted on quickly and benefitted her as she began to deteriorate quickly. Future planning began immediately involving all of the multi disciplinary team (MDT).



The Learning Disability End of Life Care Guidelines were followed and coordinated by the Dementia Palliative Care Team. The nurse liaised with the GP and was able to prescribe medication following the Derbyshire symptom management guidance. All MDT members remained involved and regular meetings, preferred priorities for care, RESPECT and person centred plans reviewed; care staff were supported and educated throughout.

Continuing Care fast track was completed and anticipatory medication prescribed, and non-essential medications stopped. She died at home peacefully supported by her familiar staff and her house mates. The Dementia Palliative Care Team continues to support care staff and house mates with bereavement support.

Leadership and Governance

In Derbyshire, for governance and/or assurance reports are shared across the Derbyshire system through the Derby & Derbyshire CCG Quality and Performance Committee and the Joint Mental Health, Learning Disability & Autism System Delivery Board Meeting.

Derbyshire LeDeR Steering Group

The local LeDeR Steering Group is attended by the Assistant Director of Quality for DDCCG and is currently chaired by a Senior Clinical Quality Manager. The Local Area Contact (LAC) is also in attendance and membership includes colleagues from across health and social care who represent various agencies such as Derbyshire Healthcare Foundation Trust (DHcFT), Derbyshire Community Health Services (DCHS) and Local Authority as well as carers.

The purpose of our Local Steering Group is to:

- To receive regular updates from the Local Area Contact and Clinical Quality Review Group about the progress and findings of reviews.
- To ensure that any learning, recommendations and actions arising from reviews of deaths are considered and taken forward, as appropriate, using locally agreed governance structures.
- To work in partnership with the Local Area Contact and Clinical Quality Review Group.

Derbyshire LeDeR Clinical Quality Review Group

The purpose of our local Clinical Quality Review Group is to:

- To receive regular updates from and work in partnership with the Local Area Contact and Local LeDeR Steering Group.
- To monitor progress and completion of reviews to ensure that they are of a consistent standard, to the required quality and completed in a timely way.
- To quality assure every completed review for:
    - Comprehensiveness
    - Scrutiny of sufficient and appropriate evidence
    - Focused on recommendations and actions.
    - Dissemination of lessons learnt.

Derbyshire Safeguarding Adults Board (DSAB) and Derby City Safeguarding Adults Board (DcSAB)

There are obvious and strong linkages between detecting and reducing premature mortality for individuals with a learning disability and safeguarding – particularly in relation to the preventative element of the role of DSAB and DcSAB. The Care Act clearly lays out responsibilities in relation to **safeguarding adults** as not only about abuse or neglect but also **the risk** of abuse or neglect. The emphasis is on behaviours rather than the consequence of the behaviours.

The LeDeR programme and approach offers a process of learning from a death which can enable both DSAB and DcSAB and local structures to **focus on how to protect people** with care and support needs from the behaviours and systems that pose a risk of abuse or neglect.

Such learning may usefully inform where such boundaries (or tipping points) are, and should be, **between poor quality, neglect/abuse and organisational neglect/abuse.**

Whilst the LeDeR Steering group is not a direct subgroup of either DSAB or DcSAB there is a close working relationship with key personnel involved. Members of both Derbyshire County and Derby City safeguarding boards are members of the LeDeR Steering Group in Derbyshire and trained as LeDeR reviewers. Safeguarding Boards are included on the list of members who receive 6 monthly reports in relation to LeDeR and presentations are made to DSAB and DcSAB on a regular basis to update on the LeDeR position in relation to safeguarding. Processes are in place for working alongside safeguarding teams where there are open safeguarding referrals for any LeDeR reviews.

Child Death Overview Panel (CDOP)

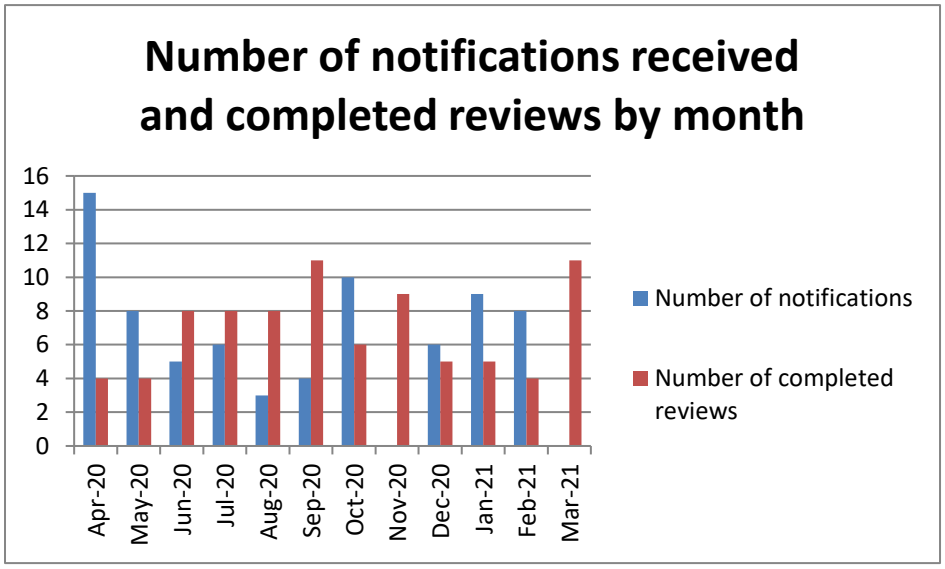
It is a statutory requirement to review all deaths of children and this process is completed by CDOP. In Derbyshire we work closely with our CCG CDOP colleagues and have developed a pathway to work together (see Appendix 3 for agreed pathway). This involves a LeDeR reviewer being part of the CDOP panel for deaths of children with learning disabilities in order to offer expertise about learning disabilities as appropriate. Any learning identified as part of the CDOP process is shared with LeDeR and uploaded onto the LeDeR system. Where any learning is identified this is included as part of the LeDeR process.

There are currently five CDOP cases that are not completed in the LeDeR system as due to Covid-19 and/or investigations these reviews have not gone through the CDOP process and therefore no learning is currently available. CDOP cases are kept separately from LeDeR reviews and are not included in any numbers shown throughout the rest of this report.

Derbyshire – what's been happening locally in the past 12 months

Deaths in Derbyshire

Since the programme began there have been 223 deaths reported to LeDeR in Derbyshire covering the period April 2017 to end March 2021 of which 203 of these deaths have had a review undertaken and completed.



For the year 1st April 2020 to 31st March 2021 there were 74 notifications and 55 of those have had a review completed.

83 reviews in total have been completed in the year.

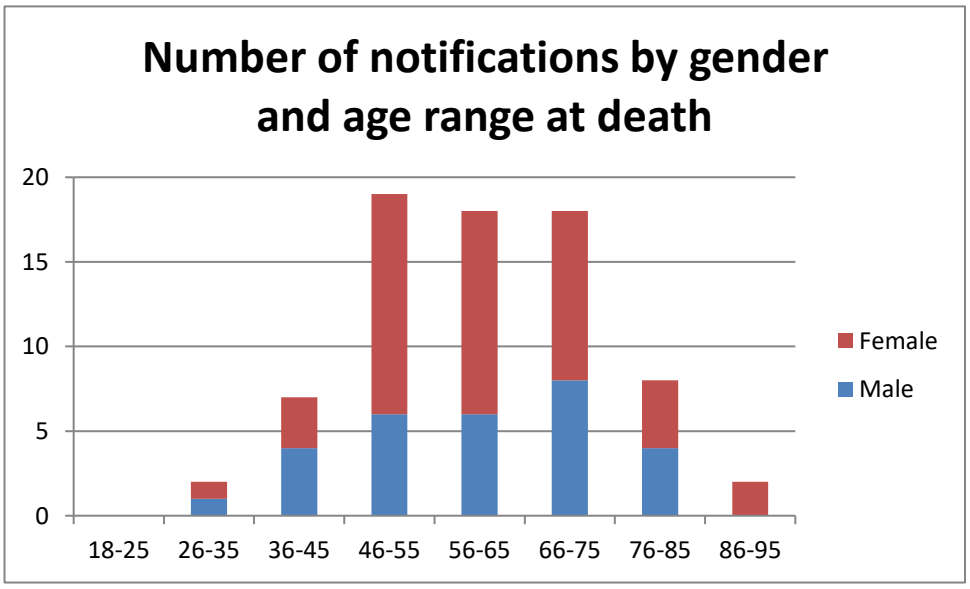
During March 2021 there have been no notifications received due to the national move to a new LeDeR platform and all notifications have therefore been put on hold and will be available for allocation when the new platform is available, expected 1st June 2021.

Deaths by gender and age range

Of the 74 notifications received there were 45 female deaths and 29 male deaths.

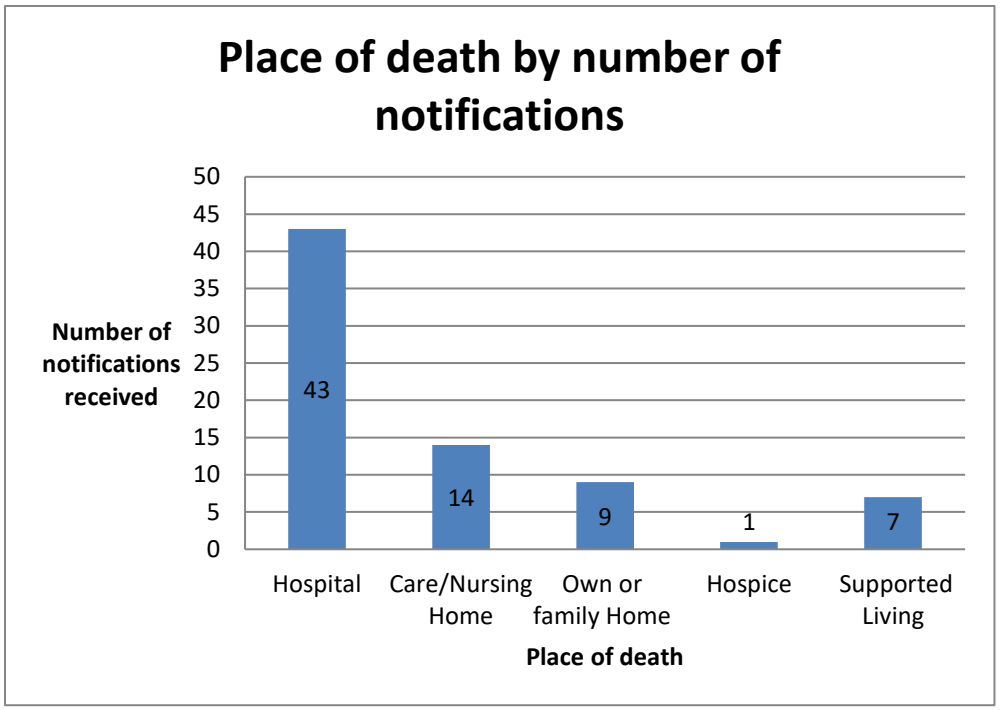
The average age at death was 62 for female and 60 for male.

If we compare this to the 2019/20 NHS England national Action from Learning Report, the average age of death was 59 for female and 61 for male.



The 2019/20 NHS England national Action from Learning Report stated that only 37% of people with a learning disability live beyond the age of 65. For the rest of the population 85% die over 65. Based on the notifications received, for 2020/21 in Derbyshire, 38% lived beyond the age of 65.

Places of death

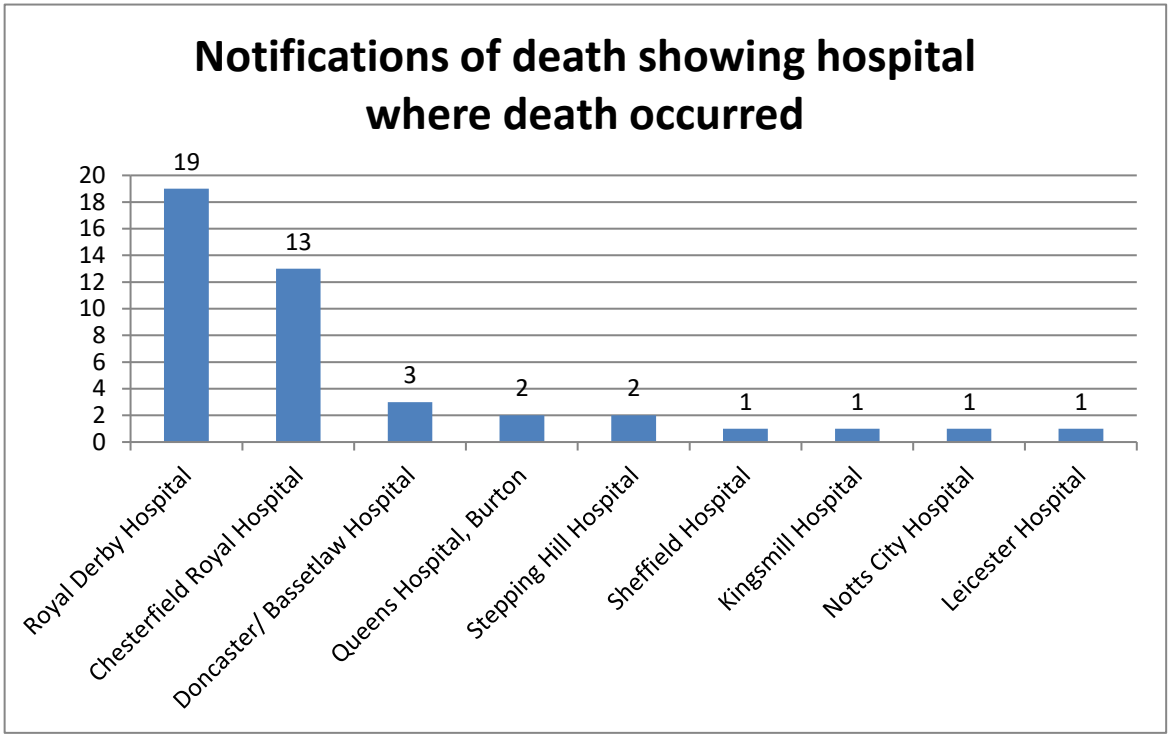


The graph shows that of the 74 notifications in the year, the majority of individuals died in hospital.

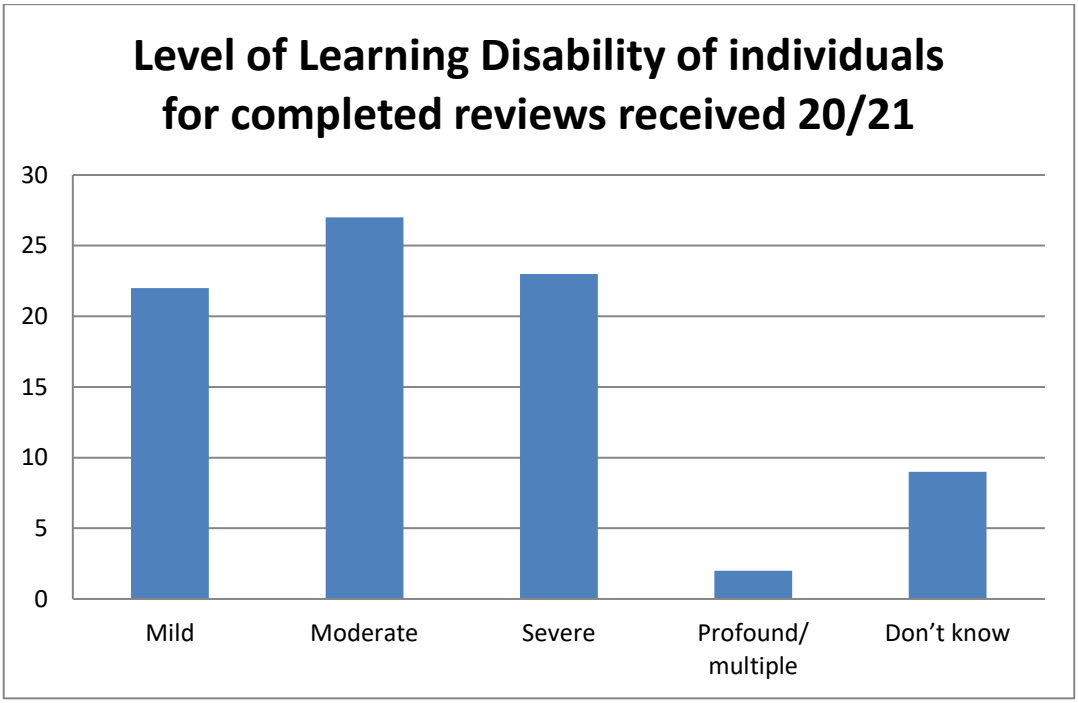
30 individuals died in their normal place of residence, split between care/residential home, supported living and their own or family home.

One individual died in a local hospice.

As expected, the two acute hospitals in Derbyshire had the majority of the hospital deaths, although due to the geography of Derbyshire there were a few deaths in out of area hospitals. We have worked to ensure we have contacts at all hospitals in order to request any information needed to complete the reviews and learning is shared where appropriate with all areas. We have particular involvement from Royal Derby and Chesterfield Royal hospitals and individuals from their organisations work as part of the LeDeR programme and are members of our LeDeR Steering Group and CQRG meetings.



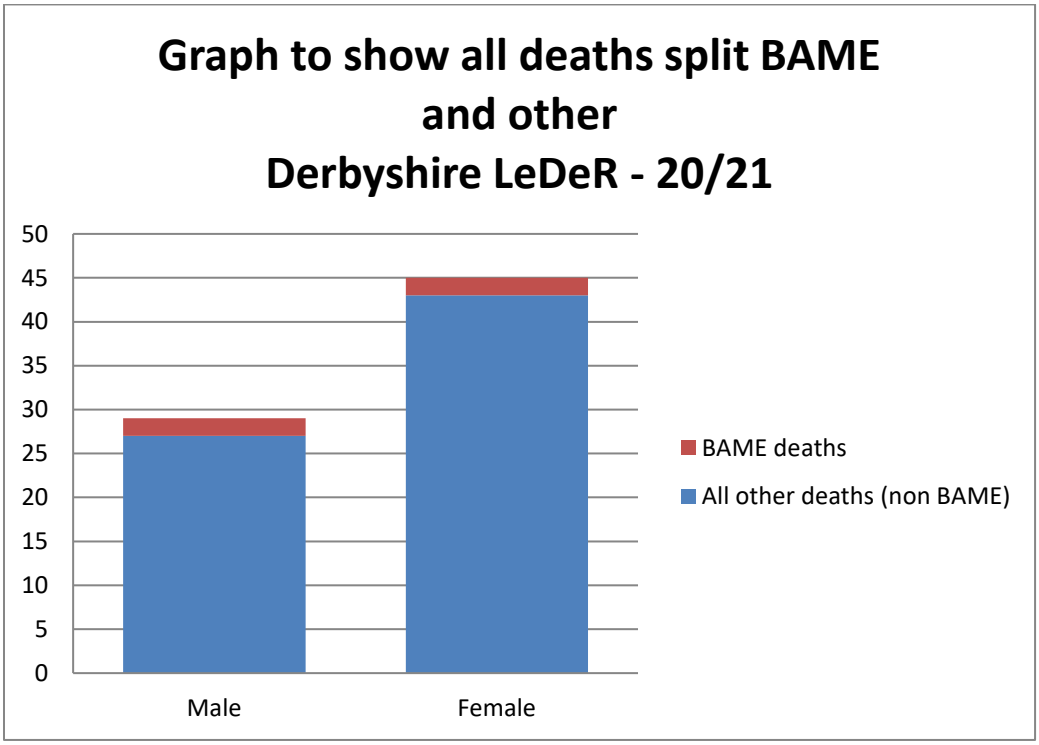
Level of Learning Disability



The majority, 33%, of the completed reviews were for individuals with a moderate learning disability.

Less than 2% were for individuals with a profound and multiple learning disabilities

Black Asian Minority (BAME) deaths



Only four of the completed reviews were for individuals of Black Asian ethnicity.

This is 5.4% of the total 74 notifications received.

Two of the individuals were male
(7% of the total male notifications)
and two were female
(4% of the total female notifications).

The average age at death across the four notifications was 44, significantly lower than the overall average of all deaths in Derbyshire which was 61.

One of the individuals lived in the County and 3 lived in the City.

Public Health figures from the 2011 census stated that BAME communities account for 4.2% of the population in Derbyshire County and 24.7% of the population in Derby City.

In Derbyshire:

- We have received a total of 17 death notifications in the City. BAME notifications therefore account for 18%
- We have received a total of 57 death notifications in the County. BAME notifications therefore account for 1.75%

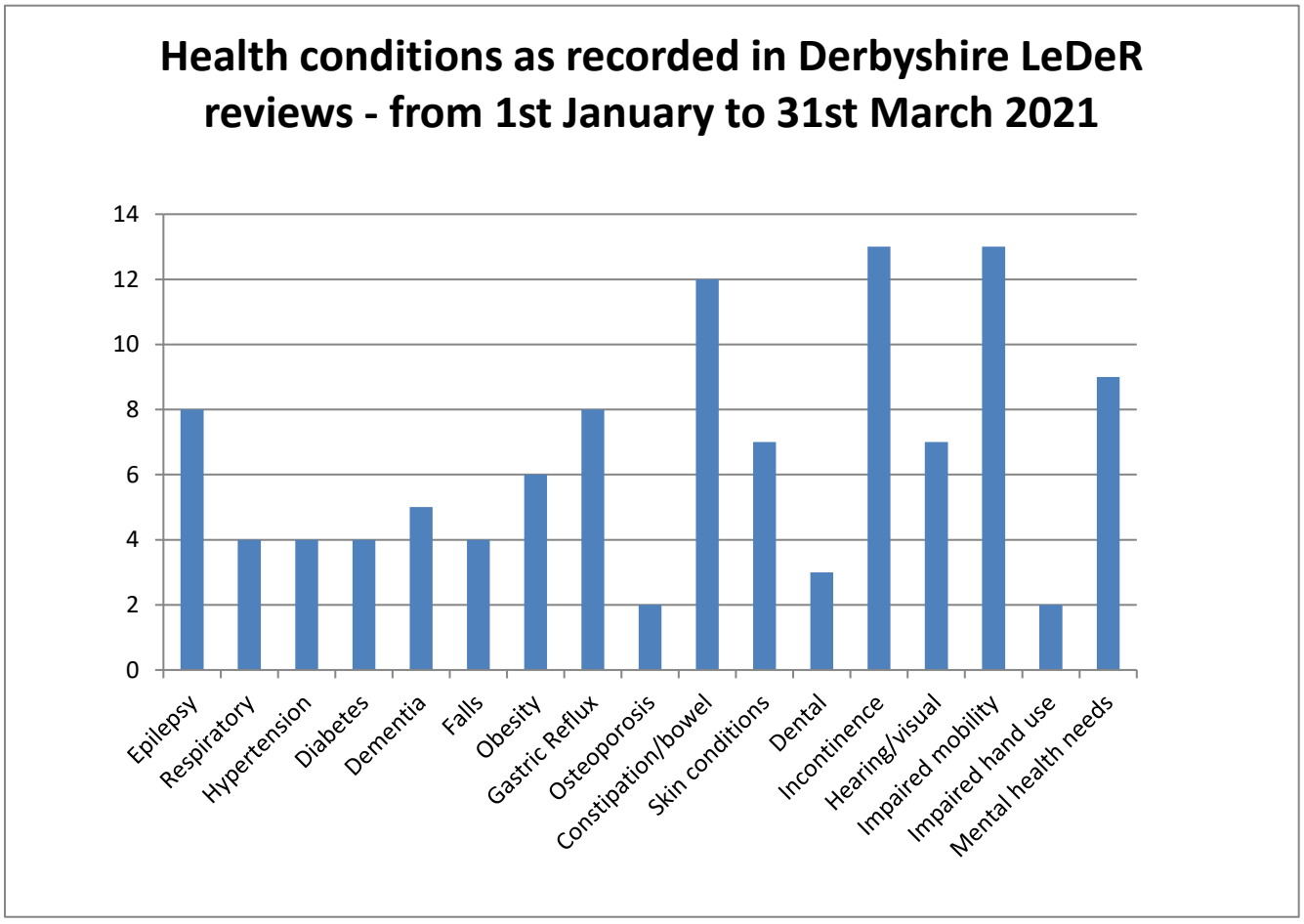
We have recently nominated a BAME lead for the Derbyshire Steering Group. We are actively looking at reasons why notifications are low and are working more closely with our BAME network to look at promotion of the LeDeR programme in BAME communities with an aim to increase the number of BAME notifications.

Multi Agency Reviews

During the year there have been four reviews that went to multiagency review. Although one only took 3 months to complete, unfortunately, due to Covid-19 the remaining 3 reviews took longer to complete than would normally be acceptable, two took 8 months and the third took 18 months.

Health Conditions

Part way through 2020/21, as part of the embedded learning work we were keen to work on, it was decided that it would be useful to start to capture the health conditions that were recorded in completed reviews. Twenty reviews were completed in the period 1st January 2021 to 31st March 2021 and the graph below shows the health conditions and the number of times each condition was identified.



This identified that in 60% of cases the individuals had some kind of bowel/constipation issue. In

addition, work that has been done in one of our local hospital showed results that presenting conditions for people with learning disabilities were often such things as increased seizures, swollen abdomen, off food & drink and vomiting. On investigation at the hospital although the reason for death was not constipation it was often seen as a common issue in the decline of the individuals' health.

As a result of this a task and finish group has been 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. Further details of the work they are doing are included in the "Learning into Action" section later in this report.

Working with partners across Derbyshire

The importance of working with our health and social care partners is crucial to the success of the LeDeR programme. Their involvement is key as reviewers, Steering Group members and CQRG members, using their wide range of knowledge and expertise to review the care and then using the learning gained to share good practice and improve care. The experience of staff who work directly in the system is so important to the programme and our reviewers are members of Community Learning Disability teams, the Learning Disability Health Facilitation team, social care staff, local hospice staff and staff members from Derby and Derbyshire CCG.

Here are some areas where our partners have worked with us and been involved in the LeDeR programme and initiatives they are working on to improve care for individuals with a learning disability :-

Training/raising awareness – the reviewer attended our team meeting to provide training and raise awareness in relation to LeDeR. Our team works with clients with complex support needs, including behaviours which challenges, many of who are in specialist residential or supported living placements. Orientation to the LeDeR programme will assist workers when undertaking their care co-ordination role.

The LeDeR programme has made a difference as it has enabled me and our organisation to share information wider and work closer with the LD teams

We have amended our reporting system to ensure we are capturing deaths of people with Learning Disabilities and set up a monthly data report of these deaths to ensure that they are reported promptly to LeDeR.
We have also strengthened our Learning from Deaths process by screening all LD deaths received and carry out case note reviews on deaths alongside the LeDeR review.
We also have a close working partnership with the CCG and LD teams to share information and improve processes. A quarterly paper is produced to the Mortality Review Group on LD deaths and updates to cascade and share actions.

We attend the LeDeR Steering Group and Quality Governance Group for DCHS. We report deaths to LeDeR and share themes/quality improvement opportunities within DCHS.

The 'easy read' information sent out by the Derbyshire LeDeR team is distributed to our team, who in turn cascade to the residential / supported living providers we work with.

The trust has completed SJRs which are fed into the CCG led LeDeR process. We have included this in the Trust review of mortality and disseminated learning from this.
Representatives from the Safeguarding team attend the LeDeR meetings and report back to the Trust. In refining the process of completing and learning from this process we have met with the Safeguarding Team to develop and agree a pathway for the SJRs and thematic feedback is being produced and reported within the Trust.

The LD liaison nurse is invaluable in supporting our patients to access services.
Patient stories are regularly reported through the Patient Experience Group and Trust Board.
In terms of developing the skills of our staff, improving understanding and raising the profile of our patients who live with neuro-diversity issues; We are embarking on developing a neuro-diversity framework / strategy; our Emergency Departments are pursuing accreditation from the National Autistic Society and we are participants in the Oliver McGowan (Health Education England/Mencap) training pilot
The Trust is undertaking a significant programme of learning from deaths to include deaths of those patients from Covid-19

Covid-19 and the LeDeR Programme

Throughout the Covid-19 pandemic the LeDeR programme in Derbyshire has continued to be a priority area. During short periods of the year, particularly when staff were redeployed to support Covid-19 clinically, LeDeR reviews were only quality assured virtually with relevant members of the group. Any actions and queries were dealt with and collated as per the normal process. LeDeR Steering Group meetings were cancelled but updates continued to be shared with the group via email. When the LeDeR Clinical Quality Review Group (CQRG) meeting and LeDeR Steering Group have taken place the meetings have been held through Microsoft Teams.

During the whole of the pandemic LeDeR reviews have continued to be completed, ensuring reviews where families are already engaged remained a priority. There were some added complications to obtaining information for reviews as many health and social care providers were redeployed as part of Covid-19 and/or are extremely busy providing care to individuals, which has led to some carers being unable to provide information to support the LeDeR review process. This meant that some reviews were taking longer than normal to complete, although the 6 month target to complete reviews as requested by NHSE/I continued to be met.

During the early stages of Covid-19, NHSE/I requested that an additional "rapid response" review was completed by the reviewer (this was in addition to the normal full review). This was in order to collate and identify any early learning (for any deaths between March and June) and this was pulled together and shared nationally. The national report is available at https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/action-from-learning/people-with-a-learning-disability-and-coronavirus/.

In Derbyshire we have had a total of 21 cases notified through the LeDeR programme where the reason for death has been recorded as Covid-19.

<table>
<tr><th colspan="3">Derbyshire LeDeR Programme</th><th colspan="3">Covid deaths - as at 31st March 2021</th></tr>
<tr><td colspan="3">Number of reported LD deaths with Covid-19 shown as cause of death</td><td colspan="3">21</td></tr>
<tr><td rowspan="2">Number died in hospital</td><td>Chesterfield Royal Hospital
= 7

4 of 7 admitted with Covid symptoms</td><td>Royal Derby Hospital
= 6

5 of 6 admitted with Covid symptoms</td><td>Doncaster & Bassetlaw Hospital
= 1

Admitted with Covid symptoms</td><td>Queens Hospital, Burton
= 1

Admitted with Covid</td><td>Stepping Hill Hospital
= 2

One of 2 admitted with Covid symptoms</td></tr>
<tr><td colspan="3">Number died in care/residential home</td><td colspan="3">4</td></tr>
<tr><td>Normal accommodation type in the community</td><td>Residential/nursing home
= 12</td><td>Family home
= 3</td><td>Supported living
= 5</td><td colspan="2">Specialised low secure unit
= 1</td></tr>
</table>

As in other LeDeR reviews, we have seen both issues and some areas of really good practice in the death from Covid-19 reviews. These are captured in the table below. We have also seen other

reviews where Covid-19 is not the reason for death but has affected the care of the individual in some way and this is therefore also captured in the information below.

Identified Issues and Learning from Covid-19 cases

Identified Issue	Detail	Learning
Alone in hospital with no one who knows them 	Earlier cases found that due to hospital Covid rules individuals with LD were alone in hospital without people who understood them or who they knew	Use of hospital passport. Link with Acute LD Liaison Nurse Correct PPE provided to support visiting to allow people who know the individual to be with them
Use of Covid-19 testing 	Earlier cases showed a delay in Covid testing in hospital due to the ward staff not identifying that this was a different health problem and assumptions made this was their normal presentation	Earlier Covid-19 testing needed
Do not attend A&E 	Earlier case where admission to hospital delayed as individual told not to go to A&E due to Covid - individual then later died of community acquired pneumonia (not Covid)	Earlier issues over understanding of when important to still use hospitals
Lack of tests for care homes 	If testing had been available in care homes the cases would have been identified sooner and measures taken to contain the cases	More Covid-19 tests to be available for care homes
Cancelled planned care due to Covid-19 	No CT scan as planned by neurology due to Covid - reduction in planned care due to Covid	This has obviously been identified as a problem for all individuals Introduction of routine planned care needed as soon as possible

The issues found were in the majority in the early days of Covid-19 and were common issues found nationally. However, later cases in particular identified some areas of good practice.

Areas of good practice identified through Covid cases

Hospital Passport 	Good use of hospital passport ensuring that staff understood the individual's needs
Hospital allowed care staff to be with individual 	Members of care staff allowed to stay with individual to offer reassurance and help doctors to diagnose and treat as they knew the individual's normal presentation
Use of technology 	Video calls made between the care home and individual's family when visiting not allowed due to Covid-19 In one case family paid for video to be available so that care staff from home could watch the funeral that they were unable to attend due to Covid-19 rules

Grading of care

83 reviews were completed in total between 1/4/2020 and 31/3/2021. Grading of care shows the LeDeR Reviewers' overall assessment of the care received (where this has been recorded on completed reviews).

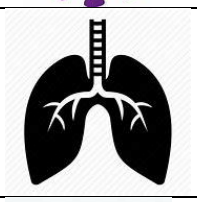
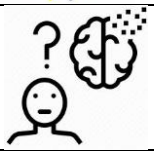
75 of the reviews completed received satisfactory or above levels of care, this equates to 90% or a ratio of 9 people out of 10 in Derbyshire receiving satisfactory care or above.

The Derbyshire report for 2019/20 showed 85% (or 8.5 out of 10 people) receiving satisfactory care or above.

Grading of care	Count of Grading of care	Percentage of overall
1 = Excellent Care	8	10%
2 = Good care	41	49%
3 = Satisfactory care	26	31%
4 = Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death	4	5%
5 = 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	4%
6 = Care fell far short of expected good practice and this contributed to the cause of death	1	1%
Grand Total	**83 reviews**	**100%**

Reasons for Death in Derbyshire

Of the completed reviews that were notified during the period 1st April 2020 to 31st March 2021 the top 5 reasons for death are categorised and separated out below.

Death category	Percentage across deaths where reviews completed 1st April 2020 to 31st March 2021
Covid-19 	**25%**
Respiratory 	**22%**
Heart failure/cardiac arrest 	**13%**
Cancers 	**11%**
Dementia/Alzheimer 	**9%**
Others (including Sepsis, hypoxia, Bowel obstruction, Epilepsy)	**20%**

In the 2019/20 NHS England national Action from Learning Report pneumonia was shown as the highest cause of death for people with a learning disability at 41%. However, there was obviously no awareness of Covid-19 at this time which has been identified as the main reason for death in 2020/21.

Areas of Improvement and Best Practice

Derbyshire Case Studies

Case Study 2 – 75 year old White man with a moderate learning disability living in Supported Living

Conditions: Anxiety; claustrophobia; Apert Syndrome (a congenital disorder characterized by malformations of the skull, face, hands and feet); gastric reflux; constipation; consideration of dementia at time of cancer diagnosis.

He had previously lived with his parents and had no contact with Social Services at all until his 93 year old mother died when he was 63. He moved into a supported living bungalow with 2 other men and continued to live there until he died 11 years later.
He was a private, quietly spoken man. He was considered able to make choices about everyday decisions such as where he chose to spend his time when in the bungalow; whether he wanted pain medication and what he wanted to eat. The GP was not sure why he was prescribed Lorazepam, Mirtazapine, Risperidone and Prochlorperazine but wrote they were for "anxiety generally but may have been for early symptoms of dementia".
By the time he was diagnosed with cancer it was stage 4 in his bladder with metastases in his spine, lungs, kidneys and urethra. He was immediately put on end of life care and lived for another 9 months (longer than expected). He had involvement from District Nurses and specialist Palliative care nurses. An Occupational Therapist was involved 4 months after diagnosis regarding equipment as he found it hard to sleep and by that time spent a lot of time in bed. He was so weak that he needed the support of 2 staff and a hoist to get out of bed. His cousin who was his only family said that the care he received at the end of his life was excellent.

Cause of death – Bladder cancer

Identified Issues and Learning from this case

Identified Issue	Detail	Learning
Lack of referral to Community Learning Disability Team 	He was diagnosed with cancer and exhibited anxiety about the changes that were happening with his physical health. Due to a childhood experience he was frightened of doctors and white coats. There was no referral to a Speech and Language Therapist (SALT) and/ or Clinical Psychologist at any point before or after the cancer diagnosis. Support staff and health professionals were not sure about his level	A referral to the CLDT would have enabled him to receive information in an accessible format to help him understand his diagnosis to some extent. Communication guidelines for health professionals could have helped people communicate with him in a consistent way thus reducing the possibility of mixed messages and increased anxiety levels.

	of learning disability. He did not have an assessment of his receptive and expressive communication. There was no guidance for staff on how to best communicate with him about his diagnosis or advice on how staff could try to mitigate his significant anxiety. He was on antipsychotic and anti-depressant medication because of his anxiety levels. He also refused all vaccinations. Again he could have had support regarding this (desensitization or appropriate augmented communication). This may have led to a reduction in his psychotropic and anti-depressant medication as well as significant reductions in his anxiety about his failing health.	
Lack of understanding of or poor evidence of consent or best interest 	There was a lack of evidence of records of mental capacity assessments and subsequent MDT best interest meeting/ decisions about the pros and cons of possible treatment or what to tell him about his cancer diagnosis and symptoms.	A discussion considering all options should have looked at how to support him to understand his diagnosis. If an MDT discussion had occurred it should have been discussed what could help him understand (referral to SALT for communication guidelines). He had significant anxiety. Not knowing what was happening to him could have increased that anxiety (as he knew he was not well) rather than the assumption that being told very little would keep his anxiety levels low.
Lack of routine health screening 	Bowel screening was offered over a number of years - GP notes recorded “No response to bowel screening programme invitation”. GP records stated that he also “refused” all vaccinations. This links to the issue of lack of a SALT communication and comprehension assessment with lack of mental capacity assessments and best interest records. Again assumptions might have been made about his	The Supported Living manager was not aware that this person had missed out on routine health screening appointments. Staff were not aware what health checks he was entitled to and why they were important. The Manager was not aware that the GP or other health professionals had a legal duty to consider what reasonable adjustments they should make to enable the man to access their services (including accessible information, home

	fear of doctors and hospitals. Again there was no mental capacity assessment and best interest decision around these significant health decisions. There was no record of any other health screening.	visits etc.)

Area of good practice identified

Reasonable adjustments made 	This man's carers were employed by a supported living provider so did not have training in monitoring health stats or end of life care. However they and their manager did not want him to have to move care providers either after the initial diagnosis or at end of life (he was offered a hospice bed at the end) as the bungalow was his 'home'. He also regularly said "stay home". In the last 6 months CHC provided funding for additional carers when he needed 2 staff to support him. Health provided the appropriate equipment for him to remain in his home (eg profile bed and rails, hoist, sleep system). The District nurses were aware that staff took him to A & E at times due to their reasonable concerns about their own lack of experience and knowledge so the DN's supported the staff as well as directly supporting him. The carers stayed in hospital with him so that they could communicate with doctors on his behalf. Family member said that carers were "brilliant. I couldn't praise them highly enough".

Case Study 3 – 75yr old gentleman with a mild LD who had lived with his brother and sister in law before moving into an older persons' residential home in Aug 2020

This gentleman had lived with his brother and sister-in-law before moving into an older persons' residential home in August 2020. As a result of the move he had a change of GP.

He experienced high blood pressure, borderline diabetes and constipation and received medication for these conditions. He was not invited for an Annual Health check within the last year. He had not received any age or gender related health screening.

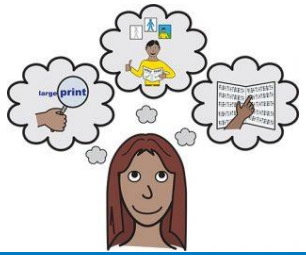
He had experienced several episodes of constipation in the last year of his life with several GP consultations and an admission to hospital with impacted bowels and secondary urine retention resulting in the need for a urinary catheter.

There was a further problem 5 months later with faecal vomiting and abdominal pain which resulted in an out of hours call. Extra bowel medication was prescribed on this occasion.
Five weeks later he was admitted to hospital with coffee ground vomiting and upper GI bleed and tested positive for Covid-19 5 days later.

Cause of Death –
Died in hospital 1 week later from Covid-19 pneumonia

Identified Issues and Learning from this case

Identified Issue	Detail	Learning
No recent Annual Health Check 	No invite to a Learning Disability annual health check in last year of life	All individuals on the GP LD register over the age of 14 should be invited to an annual health check
Poor sharing of information 	Poor sharing of information between GP practice and Residential Home	Training and awareness needed to understand the importance of sharing information
Constipation 	Constipation not managed effectively, baseline bowel habits not known, holistic approach not considered (including diet, fluids, and exercise), lack of examination and lack of	Better awareness needed of constipation and bowel management

	discussion with individual, not signposted to continence service.	
No signposting 	Lack of signposting and support offered to family	Importance of involving and supporting family
Lack of reasonable adjustments 	Lack of reasonable adjustments, monitoring charts, discussions and accessible information shared with individual	Awareness of need to use reasonable adjustments and what reasonable adjustments are available to ensure the individual understands what is happening
Workforce training issues 	Nursing home not aware of needs for LD clients or constipation management	Training needed to ensure residential homes understand the individual needs of people living in their homes

Case Study 4 – 53 year old female with moderate learning disability living in a Nursing Home

Conditions: Down syndrome; moderately obese; Alzheimer's; 'reactive depression'; severe osteoporosis (hips and knees); glaucoma and further eye infections

This lady had lived at her previous Care Home for 20 years. Her MDT (including GP) wanted to support her to remain there for as long as possible after her diagnosis of Alzheimer's three years previously.

Her Community Care Worker secured some health funding for 21 hours a week of 1:1 support around her symptoms of anxiety and to encourage her to leave her bedroom and mix with other residents.

She eventually had to move from the Home due to her reduced mobility and need for hoist, worsening short term memory and symptoms of Alzheimer's. This happened during the Covid -19 lockdown restrictions. The 1:1 hours did not transfer with her as she was partially funded by Health in her Nursing Placement. She died 3 months after moving Home.

Cause of Death
Ischemic small bowel and small bowel obstruction

Learning from this case

Identified Issue	Detail	Learning
Lack of referral to CLDT 	This lady was moved from a specialist Residential Home for people with learning disabilities to a generic Nursing Home (without a dementia specialism) at a time when her mobility was decreasing; she had a variety of health issues; was experiencing anxiety and distress as symptoms of Alzheimer's. It would have been extremely useful if the new Home had made a referral for support and advice from the CTLD team and specifically the Community Nurse around the particular health issues that people with Down Syndrome experience. This would have assisted the nursing and care staff to ensure that they were monitoring her physical health appropriately and reduced the chance of diagnostic overshadowing (where physical	The Home had a number of new managers in the 3 months after she moved in and then after she passed away. It was difficult to find out whether they were aware of the local CTLD team. The move and the death occurred during the Covid Pandemic restrictions. Had a referral been made to the CTLD, staff at the Home may have been more aware of physical health symptoms to be concerned about (such as constipation) and had a care plan for when to escalate concerns to GP or hospital for further investigation.

	health symptoms are not spotted as they are mistaken as symptoms of her Alzheimer's or her 'learning disability').	
Service needs indicated but not provided 	This lady would have benefited from a Nursing Home that had specialist knowledge of supporting people with learning disabilities with physical health needs and dementia. This was not available in the area near her family. The Senior Social Worker stated that it is hard to find Nursing Home placements for people with learning disabilities and dementia (that are aged under or over 65) close to or in Derby. Workers often have to ask mainstream Older Person's Homes (where residents are usually in their 70's, 80's and beyond) to agree to one off contracts.	It is important for Integrated Care Services to take account of the facts that people with Down Syndrome (and other diagnosis) are tending to live longer, with symptoms of dementia and other significant physical health comorbidities. This should be reflected in future service commissioning, Care Home registration and Integrated Health Budget development.
Not recognised that person was deteriorating/ no person centred support plan describing care and support needs 	This lady experienced a number of painful physical health conditions. There was no apparent detailed person centred support plan which described each condition and what 'not good' looked like. It is possible that carers who knew her better would have understood that her presentation was not 'normal' for her, that her apparent constipation was more than that (as she did not have a record of suffering from this) and needed further investigations.	Constipation was recorded in care home notes for 4 days before she was sick which led to GP being called and then hospital admission. During transition from one care setting to another it is extremely important that the details of care and support are transferred even if the care plans cannot be. Assumptions should not be made about constipation being 'normal' for anyone.
Lack of understanding of or poor evidence of consent or best interest	When this lady was diagnosed in hospital as having an ischemic bowel it was recorded that after a discussion with her brother (who did not want her to be have any further stressful interventions) that she was not for surgical intervention and was to have ward based ceiling of care. The hospital notes described that "given her comorbidities surgical intervention would not be in her best	There was no suggestion of a short term surgical action to be taken on the day of admission (a Saturday) to deal with the immediate health emergency to then enable a best interest decision meeting involving her full MDT to be convened virtually on the Monday to look at both the harm and benefit of alternative courses of action.

	interests" and that she would not tolerate a stoma as she was already pulling out her cannulas and catheter. There was no record of a discussion of the harms and benefits of 2 possible courses of action. The alternative to not operating appears to have been pain medication to support her as she died.	The Mental Capacity Act provisions question the right of clinicians to make unilateral decisions to deny lifesaving emergency treatment without full best interest decisions and records of such analysis. A best interest meeting may have resulted in the same conclusion as occurred.

Area of good practice identified

Person Centred Support 	This lady appears to have experienced very person centred support during her time at the previous Care Home. Her GP advocated for her rights to remain at the Home and to have increased support based on her developing needs. She also had thorough support from the CTLD team for a number of years around her physical health and her dementia diagnosis. They worked jointly with the Mental Health team at time of diagnosis.

Learning into Action – How learning from LeDeR Reviews is being used to drive quality improvement in Derbyshire

Training & awareness of the LeDeR programme and sharing the themes/learning 	'Sharing The Learning, Improving Health Outcomes of people with Learning Disabilities and/ or Autism' development sessions are being provided to a variety of Health and Social care teams and care providers. This has included all of Derby City Council Adult Social Services Teams, many locality and LD specialist teams in Derbyshire, student nurses and major care and support providers in Derbyshire. During Covid restrictions these sessions were initially put on hold but we then provided them as virtual sessions which have in fact enabled larger number of attendees from agencies. Sessions planned for this year include delivery to specialist and community advocates, Shared Lives carers and unpaid carers. As lockdown restrictions are reduced we hope to provide development sessions to families, people with learning disabilities and anyone else in a supporting role. Session content includes: • sharing information on the LeDeR process and why it is needed • identifying the causes of the health inequalities • information and guidance on what we can all do to improve health outcomes by, for example, advocating for reasonable adjustments • promoting annual health checks • and being clear about the legal framework for 'best interest' decision making.
Working more closely with providers of care 	As well as their involvement in the LeDeR Steering Group and LeDeR CQRG we are working closely with care providers:- • sharing learning from LeDeR through themes and reporting • regular update reports • attending GP practice sessions • attending LD care home information sharing sessions • delivering training sessions

Annual Health Checks 	Communications and support to access primary care Learning Disability Annual Health Checks (AHC) in some reviews could have been improved. Quality of the check could have been improved in some cases and the need for a good quality Health Action Plan. **Actions completed to date:** 1. Survey of Parent Carer forum members 2. Promotion of AHCs through parent carer forums 3. Promotion of AHCs using Joined Up Care website 4. Collating patient experiences 5. Recruitment of Project Coordinator in LD Health Facilitation team. Main work area to raise awareness of LD AHCs and develop processes to ensure future/ongoing attendance at AHCs, including share good practice, developing good health action plans **In progress:** 1. AHC promotional video – particular emphasis on 14+ and health action plans. The video is being produced with input from parent carer forums and their members and Healthwatch volunteers who have a learning disability, as well as the LD health facilitation team. 2. Working with CYP SEND colleagues to promote AHCs in 14-25 year old 3. Working with Project Coordinator to develop workplan of action to promote AHCs
Mental Capacity 	Utilisation and documentation of the Mental Capacity Act by mainstream health services was shown to be inconsistent in some of the reviews completed. Best interest decision making information is offered through the training and awareness sessions.
Bowel Awareness and Constipation 	We often see constipation or other bowel related issues as something a person with learning disabilities has to deal with during their lifetime – see conditions graph on page 23. **Actions in progress:** 1. Production of constipation video – to promote awareness of bowel issues and constipation 2. A regular meeting has been set up with Community Learning

	Disability Teams (CLDT) managers, nurses, physios, OT's, continence services and the LD Health Facilitation Team to discuss and share best practice 3. Continence team have been sharing their work with the group – review of training offered and who this is delivered to with the offer of additional training to teams. 4. South CLDT physios offer abdominal massage and training to carers - work now in progress on sharing best practice and skills to assist in developing this service with the North CLDT team. The Learning Disability Health Facilitation Team have delivered bowel management training to the North team - to continue to roll out across county – including LD homes & smaller supported living providers. A training flyer has been produced that will be shared with the acknowledgement letter for referrals into the CLDT for people to contact and arrange training. 5. Existing documentation and leaflets have been reviewed and bowel information leaflets are being sent out by the North CLDT when referrals are received to care teams and families to increase bowel awareness. 6. The north and south physio teams have reviewed the national training and available research into abdominal massage as part of bowel management. Training has now been identified through the ACPPLD (Association of Chartered Physiotherapists for People with a Learning Disability) 7. The North CLDT have reviewed their initial assessment and nursing assessment paperwork to ensure the right questions are asked with regard to bowel management. An additional prompt sheet that supports depth of questioning in the initial information gathering has been shared within the county for agreed consistency. Additionally existing constipation risk assessment screening tools are being reviewed and work is underway to develop a tool that will trigger where extra support or signposting is required. 8. The health facilitation team will share and update this through their work with GP's. 9. Links with medicine management have been made and plans to discuss with LD psychiatry.
End of Life Care 	We are in the process of working with care providers to promote the "Improving end of life care for people with learning disabilities" resource pack which has been developed with an aim to take steps to reduce the barriers faced by the patient group and support all involved in providing high quality and equitable care at end of an individual's life. The resource pack ensures: • Delivery of high quality care for all people in all locations

	ensuring that those with learning disabilities are not disadvantaged. • The early identification of all individuals approaching end of life. • Initiation of discussions about preferences and wishes for end of life care. • Inclusive Advance Care Planning that includes: assessing needs and preferences. • Agreement of a care plan and ensuring regular review. • Knowledge and awareness of resources and tools available to support care delivered.
Quality Care in Care and Nursing Homes 	One of our recurring themes is in relation to workforce training for care homes. **Actions completed and in progress:** 1. Offering training to care homes 2. Working with CCG care home quality members 3. Attending local LD care home meetings – sharing information
Epilepsy 	The CLDT in the North are exploring what epilepsy training is available both for nursing staff and across the wider team. Epilepsy guidance is being reviewed particularly “Step Together Integrating Care for People with Epilepsy and a Learning Disability” 2020.

Conclusion and Recommendations

1. Acknowledgement of all the work and effort that has gone into continuing to complete reviews in a timely manner as well as working on embedding learning relevant to care provided to people with learning disabilities in Derbyshire.

2. The ongoing commitment from Derbyshire to ensure all reviews are completed within 6 months of notification.

3. Continue to 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. Continue to build relationships and work with health and social care partners in relation to the LeDeR programme and acknowledging the importance of making service improvements across the whole system as we develop into an Integrated Care System (ICS).

5. To follow the new guidance of the LeDeR policy and ensure there is clear and effective governance in place.

6. 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 communities who live locally and who have a learning disability.

7. To ensure we have meaningful involvement of people with learning disabilities and their families in the LeDeR programme.

8. This report will be shared across Derbyshire learning disability forums and shared with learning disability services and care providers. It will also be produced in an easy read format and shared across Derbyshire learning disability forums and care providers. Both versions will be made available on public areas of the DDCCG and Joined Up Care Derbyshire websites.

References

Links to relevant pages on the Bristol University website are shared below:-

Department of Health. (2001). Valuing People: A New Strategy for Learning Disability for the 21st Century. A White Paper.

Bristol – CIPOLD enquiry - http://www.bris.ac.uk/cipold/

Bristol – about LeDeR - http://www.bristol.ac.uk/sps/leder/

Multiagency review details - http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/multiagency-review/

Section 251 approval - http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/

Bristol notification of a death –

http://www.bristol.ac.uk/sps/leder/notify-a-death/?_ga=2.4265911.589001362.1531124673-1987643447.1528363357

http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/notification-of-a-death/

Bristol review process - http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/people-involved-review/

NHSE Action from Learning report 2019/20 - https://www.england.nhs.uk/publication/leder-action-from-learning-report/

National LeDeR annual report 2019 - https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-programme-annual-report-2019/#.YEjalP1FDIU

LeDeR Futures Policy 2021 - https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

Covid National report - https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/action-from-learning/people-with-a-learning-disability-and-coronavirus/

Appendix 1 – Development of the LeDeR Programme

2015	1ST June **– The LeDeR Programme (Learning from Deaths review of people with a learning disability) is established by NHS England and led by the University of Bristol. This follows on from the Confidential Enquiry into Premature Deaths of people with LD (CIPOLD),the findings of which demonstrated that on average someone with a Learning Disability lives 20 years less than someone without.** **The LeDeR acronym stands for Learning Disabilities Death Review and LeDeR is pronounced as 'leader'** **The team based at the University of Bristol are responsible for developing and rolling out a review process for deaths of people with learning disabilities**
2016	**Pilot sites are established across England with a trial review process** (Derbyshire is not one of the pilot sites) **The NHSE National Operational Steering Group is established.** **Each NHS region is appointed an NHS England Regional Coordinator to guide the roll out of the LeDeR programme across their geographical region.** October 2016 **– the first LeDeR annual report is published describing the 'set up activities for the programme.**
2017	February & March 2017 **– first Derbyshire reviewers attend face to face training sessions** February 2017 **– First LeDeR Steering Group in Derbyshire** April 2017 **– Derbyshire starts to receive first notifications**
2018	May 2018 **– second annual national report published** September 2018 **– handover of quality assurance of completed reviews from University of Bristol to local areas** **Train the trainer model, and e-learning introduced for training reviewers and local area contacts.**
2019	May 2019 **– third annual national report published** May 2019 **– NHSE start "backlog project" project to ensure more timely completion of reviews. NHSE set performance targets for local areas to meet.**
2020	Publication of Action from Learning report by NHS England. NHS Long Term Plan supports the continuation of the LeDeR programme. **Department of Health and Social Care publish response to third LeDeR annual report.** March 2020 **– work starts to discuss the future of LeDeR including a new LeDeR system** **The LeDeR Programme and the work done locally continues throughout the Covid-19 pandemic and is still classed as a priority area of work within Derbyshire CCG** July 2020 **– first Derbyshire LeDeR annual report published** July 2020 **– fourth annual national report published** **NHSE commissioned IPSOS Mori to undertake independent research into views of stakeholders about how to improve the LeDeR programme**
2021	23rd March 2021 **– the new LeDeR policy is shared**

Appendix 2 - Independent Review into Thomas Oliver McGowan's LeDeR Process – Derbyshire LeDeR Process Assurance

Assurance was asked of the Derbyshire Quality and Performance Committee following the publication of the Independent Review into Thomas Oliver McGowan's LeDeR Process (https://www.england.nhs.uk/publication/independent-review-into-thomas-oliver-mcgowans-leder-process-phase-two/) with local and regional recommendations for CCGs & NHSE.

Report Summary

In October 2020 NHS England shared a recently published report by Fiona Ritchie OBE, Chair on behalf of an Independent Panel for NHS England and NHS Improvement. It was suggested that this was essential reading for all Systems to gain valuable insight into the findings of the Review and particularly the governance arrangements surrounding local LeDeR Programmes.

Summary and Action Plan

The delays and difficulties in completing the LeDeR process for Oliver was found to be characterised by poor governance contributed to by poor leadership, reorganisation, changes in personnel and lack of oversight by the CCG executive team.

Recommendations from the Independent Panel

The independent panel has made a number of recommendations to ensure that:

- the CCG takes its leadership responsibilities seriously
- the national LeDeR processes are more robust
- Learning is taken forward nationally and not continually repeated.

The Derbyshire LeDeR Local Area Co-ordinator reviewed the CCG recommendations to ensure compliance or to identify any gaps in the current processes.

RECOMMENDATIONS & ACTIONS FROM THE INDEPENDENT REVIEW AND THE DERBYSHIRE POSITION

As part of the Derbyshire LeDeR programme we have reviewed the report and recommendations found as part of this independent review against our Derbyshire processes. This has included running a Survey Monkey to see responses/opinions from our Derbyshire reviewers. The table at the end of this report includes all the recommendations from the independent review and which organisation holds responsibility for the recommendation. A rag rating is included to show the Derbyshire position for all those that are CCG or LAC responsibility.

Survey Monkey

The survey was shared with any LeDeR reviewer who had completed a review in the last year or is currently working on a review. This was a total of 12 individuals. Responses were received from 7 individuals and full details are below. The responses received were used to complete the table of recommendations at the end of this report.

Questions & responses

1) **Were you allocated a 'buddy' who was experienced in the LeDeR process when you were new to the role of lead reviewer? Yes = 2 (29%) No = 5 (71%)**

Additional Comments:

- *I wasn't allocated a 'buddy' but was supported by a colleague who is an experienced reviewer*
- *I did have the support of staff at the CCG (not Derbys) but this was not an official "buddy"*

2) **Do you feel as though dedicated time and administrative support is given to reviewers and LACs to undertake complex LeDeRs: Yes = 5 (100%) Skipped = 2** (see last 2 comments below for reason why skipped)

Additional Comments:

- *Administrative support is very good*
- *admin support yes; dedicated time - no*
- *I can't comment as I have not yet completed a complicated review*
- *I work independent of the NHS so this is not as appropriate. I have always had the support I need from the LACs though*

3) Do you feel that the LeDeR process in Derbyshire is transparent, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes: Yes = 7 (100%)

Additional Comments:

- *Robust procedures in place*

4) At the onset of a review do you feel as though you have enough support? Yes = 7 (100%)

Additional Comments:

- *Support received and any queries are promptly addressed*

5) Do you have regular, appropriately documented supervision? Yes = 4 (67%) No = 2 (33%) Skipped = 1

Additional Comments:

- *Supervision received through our organisation*
- *This is through our own organisation*
- *I can speak to my LAC any time I want and she always has time for my questions or concerns. She actively tries to help or signposts me. The admin support is brilliant.*

Compliance against the recommendations are as follows:

RECOMMENDATIONS & ACTIONS FROM THE INDEPENDENT REVIEW AND THE DERBYSHIRE CCG POSITION (RAG rated)			
	Recommendations	**Action/Responsibility of**	**RAG**
3	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.	CCGs	
	Derbyshire LeDeR response to 3 above: At the start of the LeDeR programme we did allocate a main reviewer and buddy to each review. This process was reviewed and discussed at a Derbyshire reviewer training session and a group decision was made, supported by the LeDeR Steering Group, that the buddy process would no longer be a requirement, although available as an option for anyone that wanted to still work in this way. Most reviewers found that it was difficult to complete reviews – arranging meetings with health and social care providers being a particular problem – to agree a suitable date that was acceptable to all, and having a buddy and reviewer just provided an additional person to agree dates with. It was therefore agreed that any new reviewers could have the option to have a buddy if they wanted one. As we now have CCG employed reviewers we now also ask that any new reviewer meets with our CCG reviewers before their first review for training, information sharing and to give the new reviewer an opportunity to ask any questions and/or raise any concerns. Our CCG employed reviewers are available at any time to work with the reviewer and offer any advice, second opinion etc.		

5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.	CCGs	
	Derbyshire LeDeR response to 5 above: There is a full time administrator currently in post to support the LAC and reviewers. However, this post is on a secondment basis and is currently funded through NHSE monies. Although NHSE have agreed to funding being used to secure this secondment until 31st March 2022 there is still concern about the future funding of this post.		
9	The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).	LACs and lead reviewers	
	Derbyshire LeDeR response to 9 above: Reviewers are supported with a support pack and provided with details of our CCG reviewers who will offer support. Our 2 CCG employed reviewers have regular contact and we run weekly LeDeR meetings to offer support. Once a review is completed it goes through our quality review process where the review is quality assured and actions/next steps are agreed as a team responsibility.		
12	The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.	CCGs	
	Derbyshire LeDeR response to 12 above: A process is in place to escalate any concerns from the LAC through to the CCG executive lead		
13	When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.	LeDeR reviewers and LACs	
	Derbyshire LeDeR response to 13 above: The MAR process is seen as a group responsibility and decision to take a review to MAR although originally highlighted in the review by the main reviewer is then agreed at LeDeR CQRG by the group.		

	The MAR process is agreed by the LeDeR team and the reviewer works with the LAC and LeDeR Administrator to agree the steps for the MAR along objectives and required outcomes of the MAR		
15	In regard to the MAR meeting itself, it is recommended that there is action taken to:		
	ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish	CCGs	
18	There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.	CCGs	
	Derbyshire LeDeR response to 18 above: CCG employed reviewers have supervision as part of their 1:1s at the CCG. Non CCG employed reviewers who continue have been asked previously about supervision and confirmed this is provided as part of their clinical roles. However, they stated at the time they were happy to use this clinical supervision if needed. **Action:** This will be re-visited and taken for discussion to the next LeDeR Steering Group		
20	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	CCGs	
	Derbyshire LeDeR response to 20 above: All LeDeR reviews and recommendations are taken through our quality process. Actions are agreed and monitored through our Derbyshire LeDeR Action Tracker. The Derbyshire Annual report is shared with NHSE and is available to view by all on the CCG website. Learning is taken from the Bristol LeDeR system and local annual reports and pulled into the LeDeR annual national report by Bristol University/NHSE.		
21	Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.	CCGs and ICSs	

Appendix 3 – LeDeR & CDOP Pathway

Identification of Child with a learning disability.

- Aged 4-17.
- Diagnosed with a learning disability (does not include Autistic Spectrum Disorders). LeDeR defines learning disabilities to include; a significantly reduced ability to understand new/complex information & to learn new skills, with a reduced ability to cope independently, which started in childhood with a lasting effect on development.
- Or a child with a specific syndrome that is associated with a learning disability even if formal identification is yet to take place.

LeDeR Notification

- Notification to be completed by Lead Nurse for Child Death review
- Via phone **0300 777 4774**
- Or online **https://www.bris.ac.uk/sps/leder/notification-system/**

Child Death Review

- Child death review process continues as usual.
- **This will be the primary review process for children with a learning disability, it is not necessary for LeDeR to complete an addtional review.**

Child Death Overview Panel

- Invite the LeDeR reviewer to Child Death Overview Panel, where a child with a learning disability is to be discussed, for their representation to offer expertise about learning disabilites.
- Contact: Lisa Randall - lisa.randall2@nhs.net
- Consider a learning disability themed panel; at which common contributory factors, learning points and recommendations can be reviewed together.

Child Death Review Outcome

- Share analysis form and learning from CDOP with the Local Area Contact for the LeDeR programme.
- Contact: Lisa Coppinger - lisa.coppinger@nhs.net

Regional/National themes of LeDeR Programme

- LeDeR, in liaison with the National Child Mortality Database, will collate completed mortality reports relating to children with learning disabilities and identify common themes at regional/national levels.
- These will be reported back to the CDR partners and CDOP on an annual basis.

Appendix 4 – Derbyshire LeDeR Themes Graph