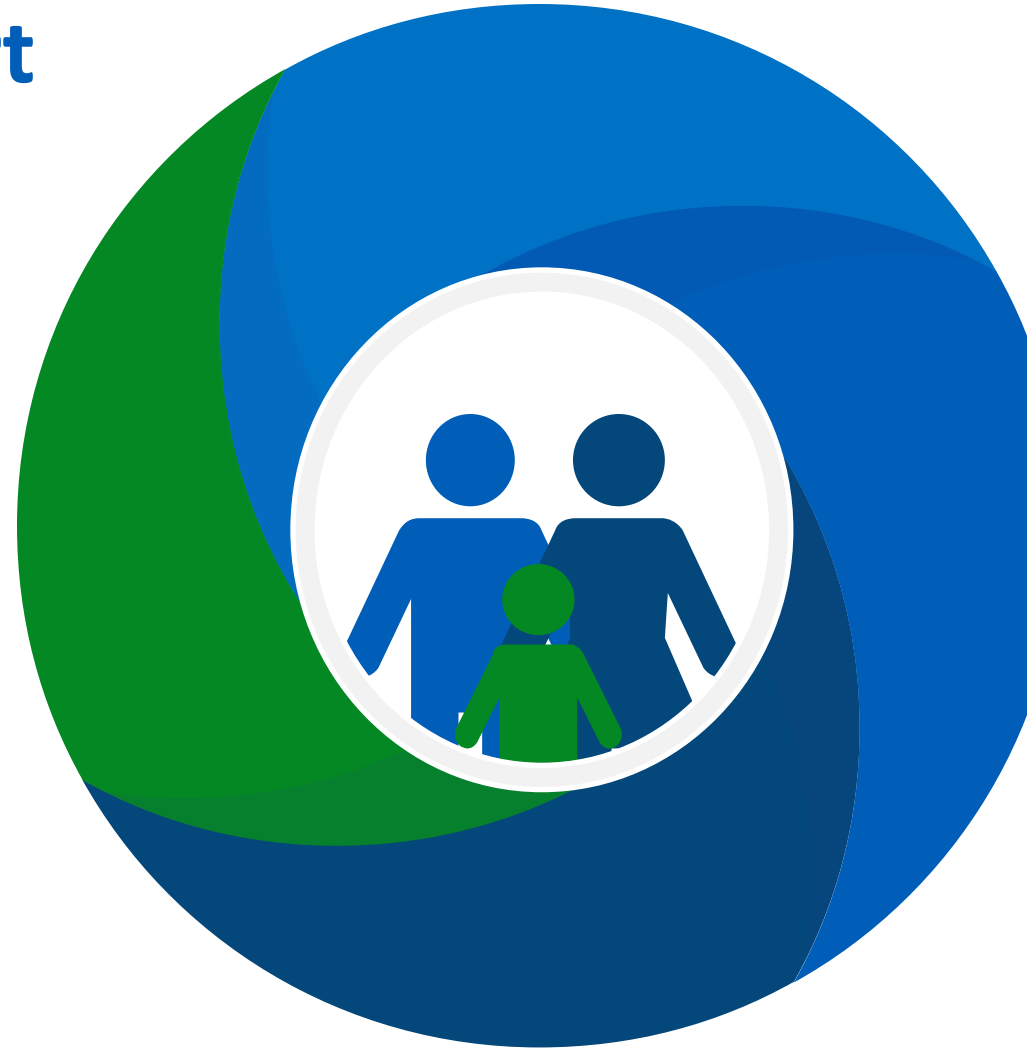
NHS
Devon
Clinical Commissioning Group

Learning from lives and deaths – people with a learning disability - "LeDeR"

Annual Report



2020-
2021

Devon LeDeR Mortality Review Annual Report 2020/21 (V1)

Report title: LeDeR ANNUAL REPORT 2020/21				
Name of committee: LeDeR Mortality Review Steering Group **Date report produced: 31/03/2021**				
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Public or Private (Governing Body only):	**Public**	✓	**Private**	

Executive Summary:

This is the second Annual Report in Devon for the Learning Disability Mortality Review (LeDeR) programme. The report focuses on 2020/2021 (up to March 15st 2021) looking at the deaths, their causes and the factors contributing to their deaths. The purpose of the report is to share the finding and the learning across Devon to enable service improvement, which aims to improve health outcomes, reduce health inequalities, and prevent premature mortality for people with learning disabilities. There is an easy read version of this report that can be found at appendix 1.

LeDeR was originally commissioned in 2015 with the aim of contributing to the improvement of quality of care and health outcomes for people with a learning disability. Devon is committed to reducing health inequalities for people with a learning disability, throughout the report there is evidence of good practice locally, demonstrating what is already working well in Devon.

The report outlines delivering service improvements based on themes emerging from learning from LeDeR reviews, good quality care, and several exciting projects this year to help to make a significant difference for the lives of people with learning disabilities, ensuring actions are implemented to improve health and social care provision.

Learning from LeDeR reviews outlines local improvement plans on emerging themes from local and national findings for constipation, respiratory conditions, soft signs of people being unwell, training opportunities for care providers and improving the uptake of Annual Health Checks for Children from 14 years onwards, young people and adults with learning disabilities.

The report will address key activity over the last year on completion of reviews and Multi Agency reviews held. The LeDeR team has had to step up its processes and systems to capture data efficiently and effectively. Datix is now used to capture key information, which means data can be provided more accurately and faster than in the past. This includes recording ethnicity, level of learning disabilities and comorbidity.

2020 bought unprecedented times and challenges with the COVID-19 outbreak. People with a learning disability are 3.6 times more likely to die of COVID than the general population. (Public Health England 2020). Devon has had 9 deaths from COVID from March 2020-March 2021.

The LeDeR team are incredibly proud of the LeDeR reviewers who have shown compassion and hard work by always putting the families and carers first in the review process, which at times has been very challenging.

Management of Conflict of interests:
Conflicts of interests are recorded on the register of interests; at each committee a list of recorded declarations is provided**,** and confirmations of declarations are requested and noted. Any new declarations must be fully recorded and included in the minutes of the meeting and notified to the Governance team via **d-ccg.governance@nhs.net** to update the central register.

Committees that have previously discussed/agreed the report and outcomes:

LeDeR Steering Group draft report scheduled 02/04/21

LeDeR Steering Group extra ordinary meeting 30th April sign off

Learning Disabilities and Autism Programme Steering Group (scheduled for 14th May)

Quality Assurance Committee (scheduled for 20th May 21)

Reviewers have also contributed to this report in Chapter 5

Quality Surveillance Group (scheduled for June 21)

Key recommendations and actions requested:

This is included in Chapter 5

Impact on Strategic Objectives

- We will improve the physical and mental health of our population of people who have learning disabilities.
- The Learning Disability Autism Partners Meeting leads the strategic direction for people with Learning Disabilities in Devon.
- Underpinned by two strategies, Living Well with a Learning Disability in Devon and Living Well with Autism in Devon.

Reference to other documents or accompanying papers:

www.DevonCCG.nhs.uk

Does this report have implications in any of the areas highlighted below?		
	If Yes, please give details	**No**
Quality of Services	The implication of quality on services can be found in chapter 5	Yes
Health Inequalities	Health inequalities are evidenced in chapter 3 and 5 this includes age and ethnicity.	Yes
Equality (staff or public)	An easy read version of the report is included in the appendixes.	No
Resource and Finance	Ongoing commitment will be required financially from the Integrated Care Systems	Yes
Legal	The LeDeR process is not currently statutory but is accountable to NHSE.	No
Engagement and Consultation	Learning Disability Partnership Board has been approached to support with aspects of consultation. Easy read questionnaires are going to be produced in 2021/22 and disseminated through the subgroups of the partnership board.	Yes
Risk	The CCG is committed to ensuring that risk management is a key part of the CCG role of improving the health of the local population and ensuring an outstanding level of patient safety through commissioning of high-quality services that meet the needs of local people.	Yes

The CCG has made every effort to ensure this report does not have the effect of discriminating, directly or indirectly, against employees, people, contractors or visitors on grounds of race, colour, age, nationality, ethnic (or national) origin, sex, sexual orientation, marital status, religious belief or disability.

What if I told you that the average age of death for a male was 54 years?
What if I told you, that for a female it was 49 years?
Do those statistics bring fear, confusion and tears?
You would want to know more, right?
You would want to know how and why?
These statistics are no lie.
These young men and women all have a level of learning disability,
And with that can come levels of health inequality.
An IQ score should never be a barrier to life.
If a label ever serves a purpose, it should be to give protected rights,
Not more uphill struggles and fights.

These individuals are far more than statistics, they are wonderful people with so much to give,
There is no question here, that they too, should live.
So, with the help and research of LeDeR, there is work to be done, and together is where it has all begun.

Joe was the blue eyed, happy, boy that everyone adored.
With him and his friends, you'd never get bored,
Frequenting the pub and roaming the moors,
Searching for his favourite wagon wheels, behind kitchen cupboard doors.
Joe was 5 when he moved to a care home, his family involved every step of the way.
He wore a waistcoat, as the proudest best man, on his brother's wedding day.
When COVID arrived, Joe became quickly unwell
And although he is gone, he has left his light and an important story to tell.

James was full of the best toilet humour and was a real good flirt.
He had a busy home life and was always happy and alert.
James would giggle at his antics or tricks and had many ways show his affection,
You could see his families love and their special connection.
James could be found be laughing and a smile on his face
Even when he was battling with complex health conditions, held in his families embrace.
James was such a fighter and passed when he was only 23,
His family are heartbroken and James's life message, is key.

From their memories there is so much learning
So let us keep their light burning.
A named GP, a specialist nurse, a hospital passport
A shared care plan with clear health and social support.
Everyone has a role to play, from the visiting nurse
To the government's purse, there is always a will and a way.
Whatever your role or title, you are vital, to an individuals life.
Start by seeing the world through their eyes,
Listen to their friends and families advice.
Spend time in their shoes,
Hear their stories and all their news.
Work together to cut through the jungle of tape,
Ramming through walls, sharing out the tools.
Changing the norms and making more time
So people with a learning disability, can live to their prime.

Having a learning disability should never be a barrier to living longer.
So it's our job to grow, make a change, and come up better and stronger.

Written by The Unheard Bird (Katy Else) in association with Livewell Southwest on behalf of the Devon LeDeR Annual Report 2021

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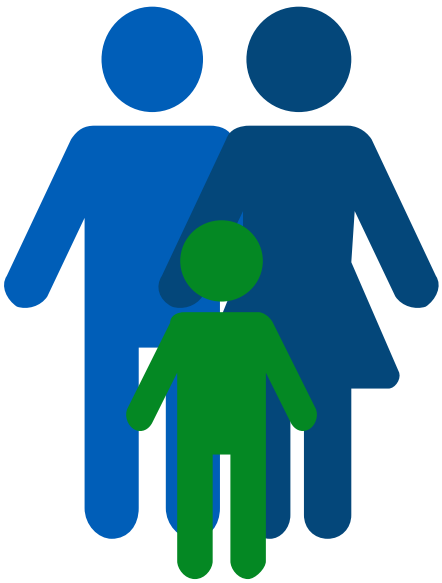


Glossary

AHCs = Annual Health Checks

ACP = Advanced Care Planning

CCG = Clinical Commissioning Group

CDOP = Child Death Overview Panel

CDR = Child Death Review

DNACPR = Do not Attempt Cardio- Pulmonary Resuscitation

DPT = Devon Partnership Trust

DOLs = Deprivation of liberty safeguards

HAP = Health Action Plan

IATT = Intensive Assessment Treatment Team

ICS = Integrated Care System

KLOE = Key Lines of Enquiry

LA = Local Authority

LAC = Local Area Contact

LDAP = Learning Disability Autism Programme

LWSW = Livewell Southwest

LeDeR = Learning Disability Mortality Review

MAR = Multi-Agency Review

MCA = Mental Capacity Act

NECS = North East Commissioning Support Group

NHSE = National Health Service England

QAM = Quality Assurance Meeting

TEP = Treatment Escalation Plan

STOMP = Stopping over medication of people with a learning disability, autism, or both

Patient Centred

This report is about people with a learning disability who have died in Devon during 2020-2021. They were loved and cherished, and their deaths have been heart breaking for their family and those who loved them.

Sometimes when we read reports such as this, we can forget that there are people at the heart of it. In the mass of data provided, there is a danger that people can become numbers, and numbers are impersonal.

We are therefore starting this report by sharing who some of the people whose deaths have been reviewed by the LeDeR programme were. All details have been anonymised, but the stories are those as told by families or paid carers to reviewers. We would like to thank the many families who have given us permission to use their stories.

"Philip was everyone's favourite. He had developmental delay and then when he was 2, we learnt he had a rare genetic disease. He was then in special school and in care from age 3 which continued until he was 18.

He moved into his care home at age 20, he was the blue-eyed boy all his life, everyone loved him at his care home. He had been there a long time and was friends with Joe. They were thick as thieves, loved going to the pub. He loved going out onto the moors, loved to see the wild horses. He loved to travel, especially on trains and getting there was as much fun as the destination. Waggon Wheels were his favourite which were no good for his diabetes, but in the early days, when he come home every other Sunday he always went straight to the cupboard. Sometimes we would hide them, and he would laugh as he looked in every place, turning the kitchen upside down. He was so proud when his brother got married. He was one of the groomsmen and wore a waistcoat.

When we heard COVID was in the care home we were very worried, and soon after Philip got it first. It was heart breaking that we couldn't see him. He went to hospital, but his health deteriorated very quickly. They asked us if we wanted to be with him, but I said no, better I remembered him laughing. I sat on my bed and knew the moment he had died; I could feel it, I could feel him. Thank you to the LeDeR reviewer for listening. I love to talk about Philip, you've made me laugh and remember the funny things. I wish LeDeR all the best for people like Philip. He had a good life in care and yet he was still part of our family"

Philip's mum – Deanna Mann

James

"This is James. He was the middle child of 5. I would describe him as a flirt and his humour was basic. Toilet humour we called it. He laughed when he saw our faces in despair at his antics. He laughed when he saw a police car, when his dog licked his feet, when he saw his favourite blonde carer. You knew what he was thinking by his face. James died in December 2020, aged 23, after a lifetime battling with complex health concerns. We had the priest to him at least 5 times but he was always a fighter, he always bounced back. Not this time. I am lost and have felt suicidal since he died. Services could have predicted I would be lost but no one was there for me"

James's mum sought support for her health and well-being.

"I found talking to my LeDeR reviewer easy. She helped me see how brave and funny he was, how brave I was, how things can be different going forward. Mostly, I would like to see this client group treated as equals, don't talk over them making decisions about their life, talk to them. Include them. Talk to the family as if they are your equals, ask us. We know our loved ones."

Name not changed as per parental request and shared with permission from the family.

1 Introduction

LeDeR Is a national programme looking at deaths of people who have a Learning Disability aged 4 and over. The programme is coordinated by the University of Bristol but commissioned by National Health Service England. In 2021 NHSE are also taking over the coordination of the LeDeR programme from 1st April 2021.

Deaths of children with a learning disability are reviewed by the statutory Child Death Review programme. The statutory process for child deaths expects that the child death review process will be the primary review process for children with learning disability and that it will not be necessary for the LeDeR programme to review each case separately.

The person notifying the death to LeDeR should provide core information about the child and the relevant Child Death Review (CDR) partners. The CDR partners should then ensure that the LeDeR programme is represented at the meeting at which the death is reviewed. In addition, the Local Area Contact for the LeDeR programme and the CDOP or its equivalent chair should discuss the potential input from a LeDeR reviewer to offer expertise about learning disabilities (if appropriate) and to ensure the collection of core data for the LeDeR programme. Any completed notes and/or Analysis Form arising from the discussion should be submitted to the Local Area Contact for the LeDeR programme by the CDR partners.

All deaths of adults with a Learning Disability receive an initial review which can go onto a Multi-Agency Review if significant learning is found. On rare occasions a LeDeR review can be passed on to the safeguarding process. Then the LeDeR review is put on hold, until the safeguarding is completed, this may affect the KLOE and our performance data. From June 1st 2021, a new platform is coming into place and processes will be changing.

Devon LeDeR team consists of members from the Nursing and Quality Directorate and support from the Commissioning Directorate, with wider representation from NHS and Local Authority partners attending LeDeR Quality Assurance Panels.

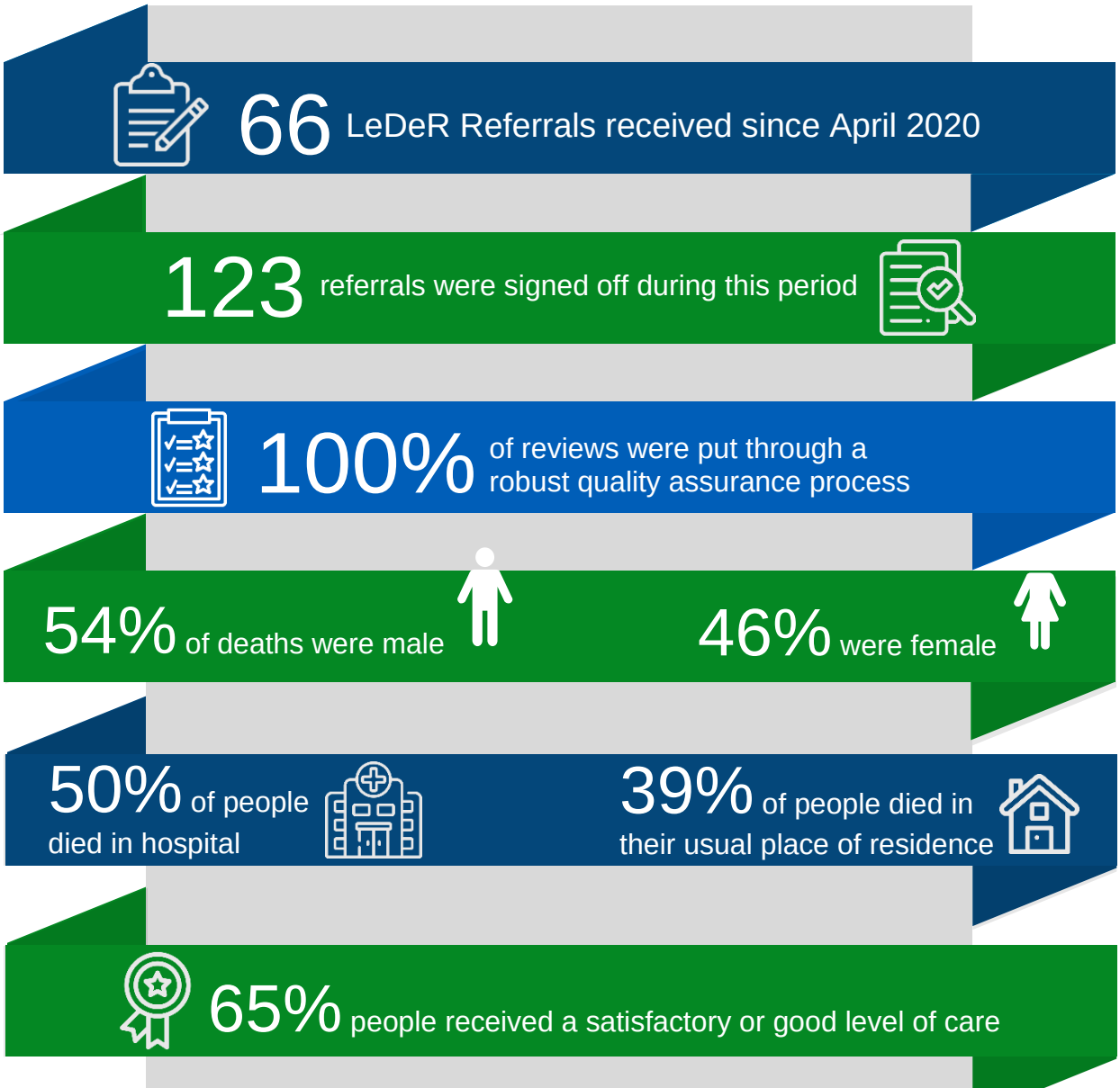
The team hold a regular LeDeR quality assurance review panel, normally weekly, to check the quality and learning within all LeDeR reviews and to gather the themes for learning. Themes are sent to Providers and Local Authorities. The CCG receives feedback on how they are addressing these areas, sharing good practice and highlighting areas requiring further support in delivering key recommendations, and service improvement to the Devon LeDeR Steering Group for sign off.

The LeDeR steering group is led by Geoff Baines, Director of Safety and Quality for Livewell Southwest. The steering group is made up of different partners across the system for both health and social care in Devon. The steering group members are responsible for ensuring service improvements action plans, taken from the learning from reviews, being implemented in their Trust or Local Authority.

In 2019/20 The National Health Service England (NHSE) stated improving the health of people with a learning disability/ or autism remains a key priority of the NHS. The NHS Long Term Plan commits to improving the uptake of annual health checks for people with a learning disability, so at least 75% are receiving a health check each year by 2023/24. New additional payments for GPs and Primary Care Networks to identify patients with a learning disability and to undertake annual health checks are being introduced and a national campaign to improve uptake launched. (NHS Annual Report 2019/20).

The Learning Disabilities and Autism Programme Steering Group (LDAP) ensures that there are action plans in place to reduce health inequalities and improve health outcomes for people who have a learning disability. LDAP hold to account and monitor review recommendations and lessons through LeDeR action plans. Over the last year, NHS Devon CCG LeDeR team has worked with partners such as Livewell, Devon Partnership Trust and NHS Devon CCG to put together projects to help improve health outcomes for this cohort. The longer-term aim being to increase life expectancy for people who have learning disabilities through clear action planning on how health and social care services are using the learning from LeDeR reviews to improve services.

Commencing September 2021, LeDeR will be incorporated into the routine quality reporting arrangements of the ICS and not sit separately from it, to improve learning and action locally.



About the LeDeR Programme

National

The LeDeR programme is planned and funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. It is currently being delivered by the Norah Fry Research Centre at the University of Bristol.

NHSE support the LeDeR programme by linking with local agencies and health professionals to complete LeDeR reviews and use their learning to change the way they provide services in their local area. NHSE also help local systems to learn from one another so that we can spread learning and good practice across the country.

Core principles and values of the LeDeR programme:

- LeDeR values the on-going contribution of people with learning disabilities and their families to all aspects of its work.
- LeDeR takes a holistic perspective looking at the circumstances leading to deaths of people with learning disabilities and does not prioritise any one source of information over any other.
- LeDeR aims to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.
- LeDeR's aim is to embed learning from the reviews of deaths of people with learning disabilities into local structures to ensure their continuation.

All deaths of people with learning disabilities should be notified to the National LeDeR programme at the University of Bristol. Reviews are then allocated within three months to the Local Area Co-ordinators for allocation of a review. Initial reviews will be undertaken on all deaths notified to the LeDeR Programme of people with learning disabilities aged 4 years and above.

Local

Within Devon CCG, the programme is facilitated and supported within the nursing and quality directorate. There is senior and clinical oversight alongside a dedicated LeDeR co-ordinator role and designated LeDeR reviewers.

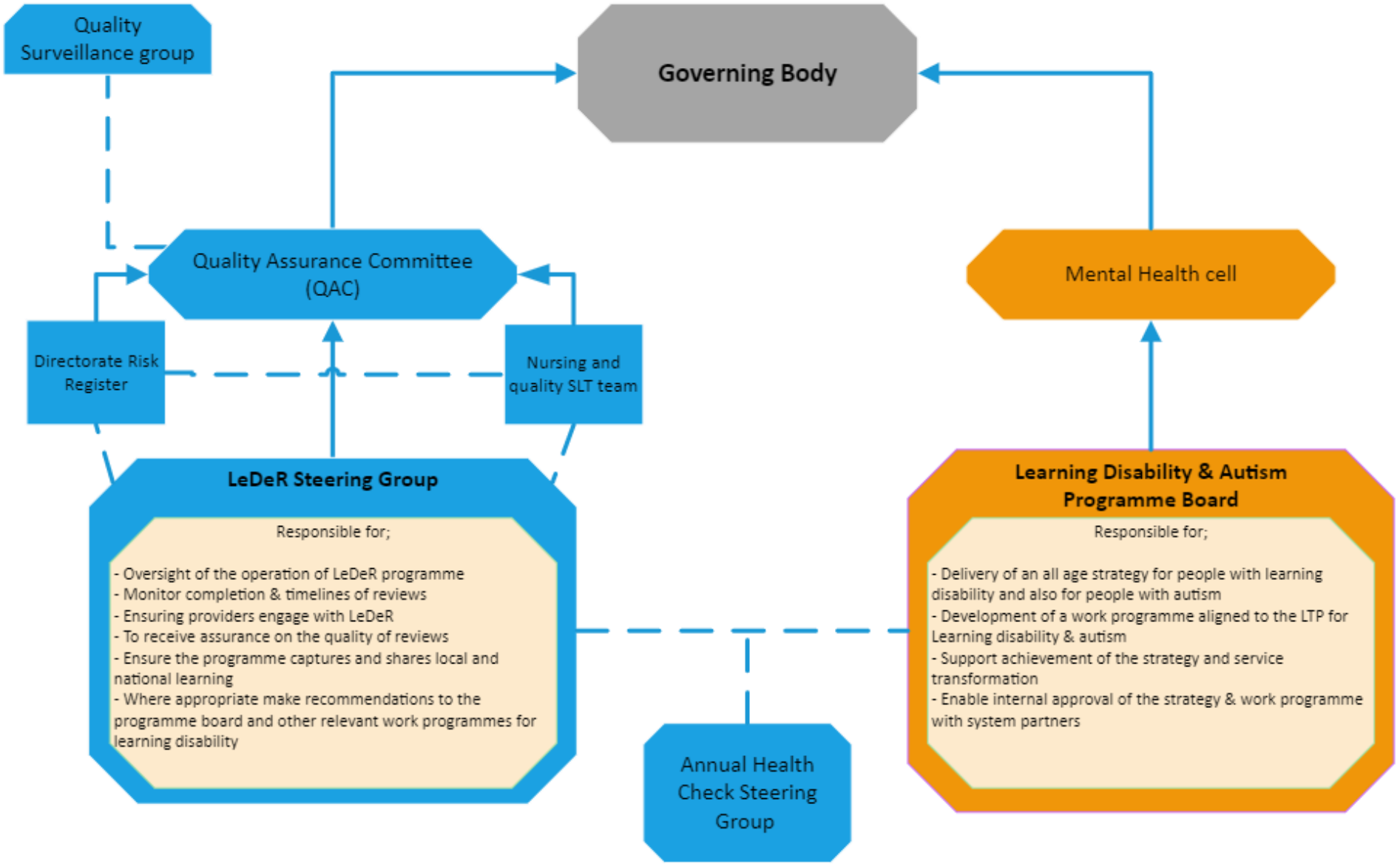
Once notification of a learning disability death is received, it is assigned to a reviewer from a pool of LeDeR trained clinicians who will examine the quality of care received by the person and family / carer. Once a review is completed and graded it is signed off by a panel consisting of the Local Area Contact, (LAC), a GP and Quality Assurance Lead before the learning being taken to the LeDeR Steering Group.

The Steering Group meet bi-monthly and include representation from stakeholders across Devon including all acute trusts, local authorities, mental health providers and has GP representation. Through this meeting learning and recommendations are shared and providers are requested to implement actions into learning at a local level.

The flow chart on page 11 shows how the steering group feeds into the Quality Assurance Committee (QAC) and how concerns can be escalated to Governing Body.

LeDeR Steering Group and Learning Disabilities/Autism Programme Board

NHS Devon Clinical Commissioning Group



Together for Devon

Devon is the fourth largest county in England and has a population of 1.2 million. NHS Devon CCG is the fifth largest CCG in England with a diverse and growing population. It includes both cities, towns and rural and urban environments. The Devon Sustainability and Transformation programme membership includes three local authorities, Devon County Council, Plymouth City Council and Torbay Council and two mental health and learning disability providers, Devon Partnership Trust and Livewell South West.

The population of Devon who are registered on a GP Learning Disability register is 6,853 (*2019/20).* There are currently no indicators that suggest that the number of people with a learning disability will increase significantly in future years, however there are more people with complex needs and multiple diagnoses. There are also increasing numbers of young people with complex needs who will require health and care support as adults.

Key system drivers are based on the expectation that people can be independent, safe and part of their community, and are able to drive the delivery of their care, health and wellbeing in communities across Devon, underpinned by two strategies, Living Well with a Learning Disability in Devon and Living Well with Autism in Devon.

The Devon LeDeR programme have started to work with the Learning Disability Partnership Board to coproduce work identified in our service improvements. The Quality Checkers, team of 14 people who have learning disabilities, visited acute settings and Learning Disabilities liaison services across Devon to provide recommendations to improve access to NHS services for people with learning disabilities.

Opening Comments

Geoff Baines
LeDeR Steering Group Chair and Director of Quality Livewell South West

"I am proud to have made a contribution to this year's annual report in my role as Chair of the LeDeR Steering Group - too many people I know personally and care about have died far too early as a result of ill health. I believe this is a serious health inequality - we all have a duty to address inequality and all have different paths and opportunities to do this. I am fortunate to have been able to work alongside a team of people as a chair of the LeDeR steering group 2020/21 and I am clear that the evidence and insight gained from the review identifies very clear changes that can be made that will have a direct impact on tackling health inequality for people with a learning disability. I urge everyone to read this report and take action that improves the quality of life for local people and families"

Susan Harvey
Nurse Consultant Learning Disabilities and Transforming Care
Interim Head of Children and Young People Continuing Care
NHS Devon CCG

"It's about valuing and sharing good practice, concentrating on identified service improvements, to help social and health care staff learn the skills needed, to break down the barriers, to accessing social and healthcare services, ensuring the holistic needs and wellbeing of people with learning disabilities needs are being met"

Lorraine Webber
Associate Director of Commissioning (Community Services)

"Fundamentally the Leder reviews are about improving the standard and quality of care for people with a Learning Disability and learning about what helps some people live longer and healthier lives than others. If we listen to families, understand the learning from Leder reviews and share this learning with all of those who design, commission and deliver health and care services, we can significantly improve the health and care services that "support people with a Learning Disability in the future"

Dr Rachel Gaywood
Strategic Clinical Adviser Learning Disability / Autism, NHS Devon CCG

"LeDeR is an opportunity to reflect and learn to improve our practice in the future. We need to keep striving to improve the quality of care for people with a learning disability and people who are autistic"

Jennie Newton
Local Area Contact and Quality Assurance Nurse Practitioner
(Learning Disability) / Local Area Contact - LeDeR, NHS Devon CCG

"As a result of the LeDeR programme we now have excellent data showing us that people with a learning disability die early and why. By having this data we are making important changes to health and social care systems across Devon to help people with a learning disability to live longer and have a better quality of life"

2 Deaths in Devon

There have been **66** deaths reported to LeDeR in Devon between 1st April 2020 to 15 March 2021. 79 reviews were carried over from the previous year. A total of **145** reviews have been completed during the year. 123 (84%) of reviews were signed off during this period with an initial review undertaken. Chart 1 breaks down all LeDeR cases processed by status during 2020/21 (Chart 1 – Total LeDeR cases by Status).

2020/21 Fiscal year

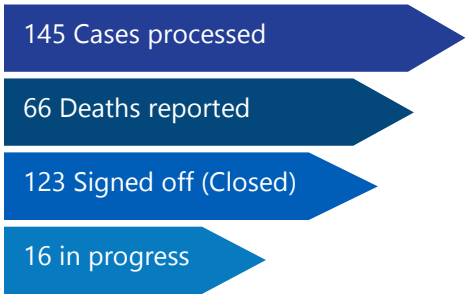
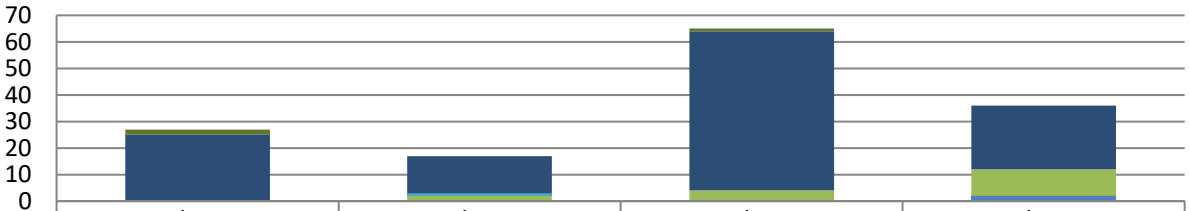


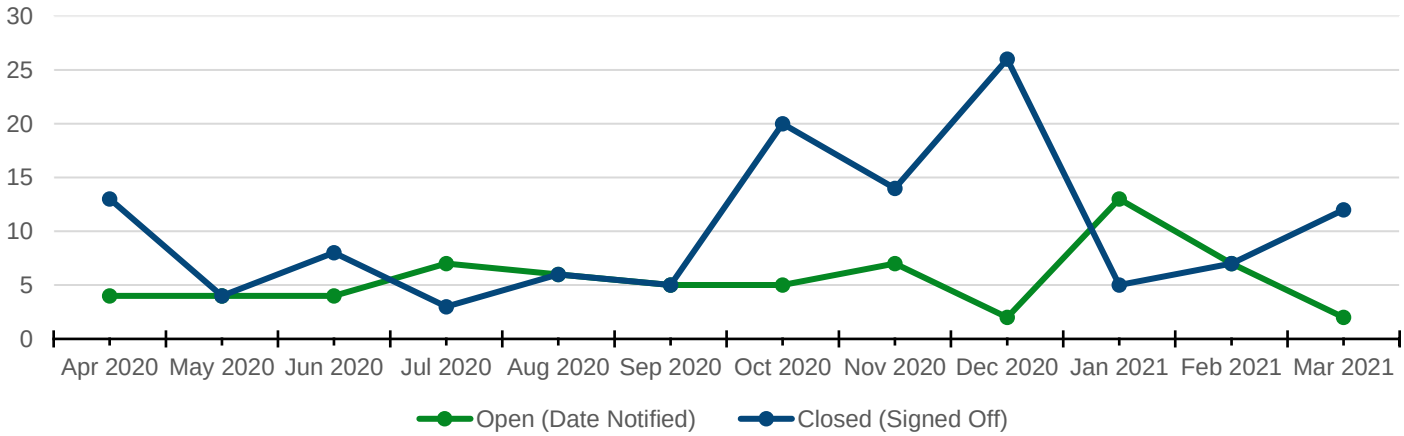
Chart 1 - Total LeDeR cases by status



	20/21 Q1	20/21 Q2	20/21 Q3	20/21 Q4
CDOP	2	0	1	0
Signed Off	25	14	60	24
Awaiting Sign Off	0	1	0	0
In Progress	0	2	4	10
Awaiting Allocation	0	0	0	2

Chart 2 below shows the rate of notified and signed off cases during 2020/21. On average the LeDeR team has received **6 cases per month**. There was a slight increase in cases received January (13) which was double the expected number, the reason for this is unclear but we can hypothesise that some of the deaths happened over the Christmas period, delaying notification. The average rate of closure per month was 12.

Chart 2 - Rate of notification and closure

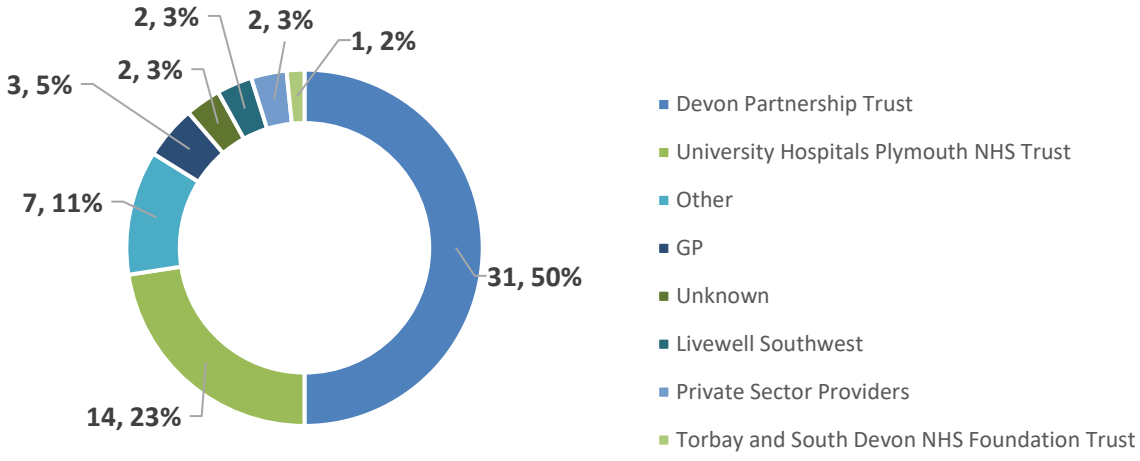


The number of cases being signed off has since increased above the average in March, this was due to a national deadline issued by NHSE. Peaks in October and December may have been due to an increase in reviewers assigned 'pay by review'. COVID caused a workload shift and freed up capacity for more reviewers, Devon employed 2 GPs under the 'pay by review' scheme during this period.

Reporters of Death

Chart 3 - Reports of Deaths illustrates the breakdown of who reported the 66 deaths. For the financial year 2020-2021. DPT reported half of the total amount of deaths with **31 (50%)**.

Chart 3 - Reporters of deaths



Devon's LeDeR Performance

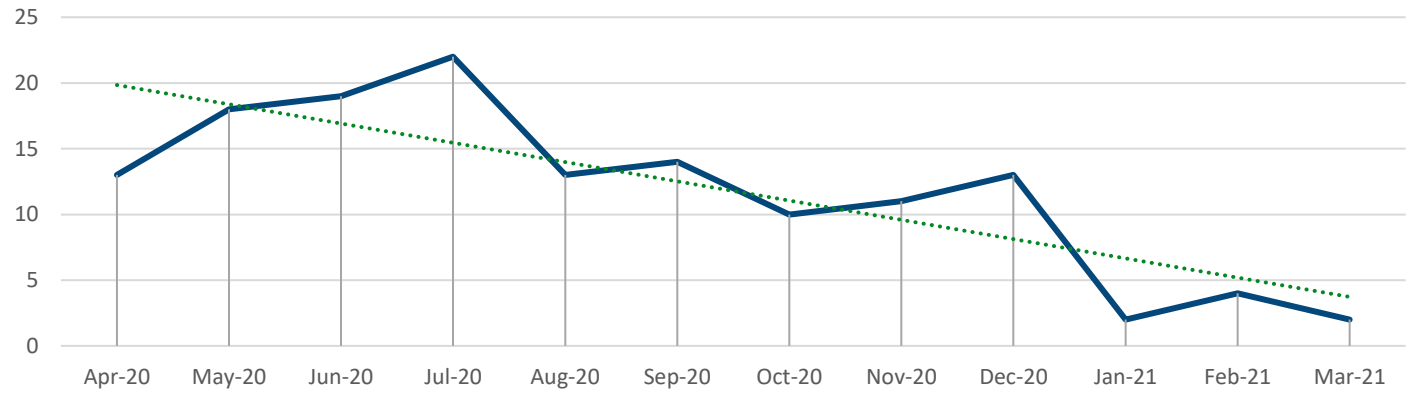
NHSE key performance indicators for LeDeR activity require all reviews to be allocated to a reviewer within 3 months of notification, for reviews to be completed within 6 months of notification and the quality assurance of reviews by the LAC within 2 weeks of completion. Our compliance against these indicators is shown below.

Performance Indicator	%	Comments
Allocation of reviewers within 3 months of notification	50%	The CCG had reduced reviewer capacity during Q1 2020/21. This meant immediate allocation wasn't possible due to reviewer workload. Reviewer numbers have since improved and allocation is now immediate.
Completion of reviews within 6 months of notification	30%	Devon originally received a large influx of notifications, with very few reviewers that were able to give time and dedication to the reviews in Q1 2020/21. This is explored further in the section below.
Quality Assurance of reviews by the CCG within 2 weeks of completion	100%	All cases are reviewed at the CCG LeDeR Quality Assurance Panel which occurs weekly prior to closure and submission to the national programme.

KPI Positive Improvement

The Devon CCG LeDeR team achieved **30%** against the 6-month notification KPI. The improvement can be seen in Chart 4. The longest time to complete a review was in July 2020, when completion took 22 months. By January 2021 the total completion time improved with the team achieving a 2-month turnaround. On average the team have managed to reduce the amount of time taken to process a review by 11 months. The team have been compliant against the KPI for all of 2021 so far.

Chart 4 - Average time taken (Months) to complete a LeDeR review



Actions taken to address KPI's

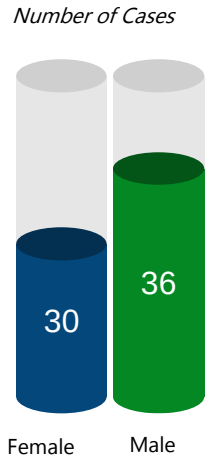
- Utilising funding received from NHS England we have recruited a number of reviewers who have a range of expertise to assist us to clear the backlog.
- Advertising to nurses, raising awareness and escalation to the LeDeR steering group enabled delivery on more reviewers.
- Targeted Presentation and marketing throughout Devon footprint raised awareness of the role and resulted in recruitment of new reviewers. For example: Presenting at the Learning Disabilities Devon Nursing Forum.

3 About the people who died

The following section provides information about the 66 people who died during the fiscal year of 2020/21.

Gender

Over half (54%) of those who died in 2020/21 were males. This follows the national trend of 59%.

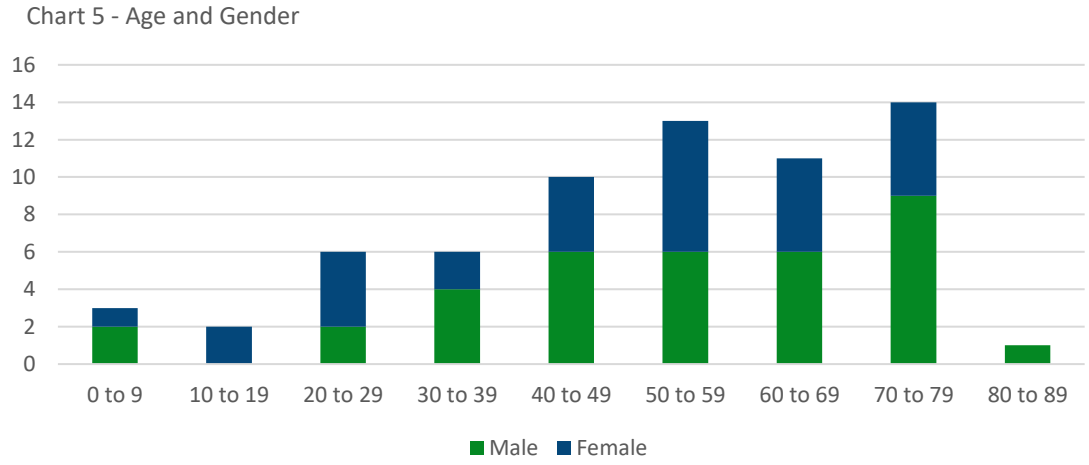


Ethnicity

All the people who had died were described as white British. The 2011 Census recorded Devon's populations as 94.9% white. These demographics might have changed since the last census which was 10 years ago. Devon has a small ethnic minority and work has been done by our colleagues in primary care to improve GPs noting ethnicity of their patients. The figures quoted may be an artefact of equality monitoring i.e. that if this is not included in the reported deaths, we wouldn't see the numbers. There is still work to do in relation to the underreporting of deaths from the ethnic community.

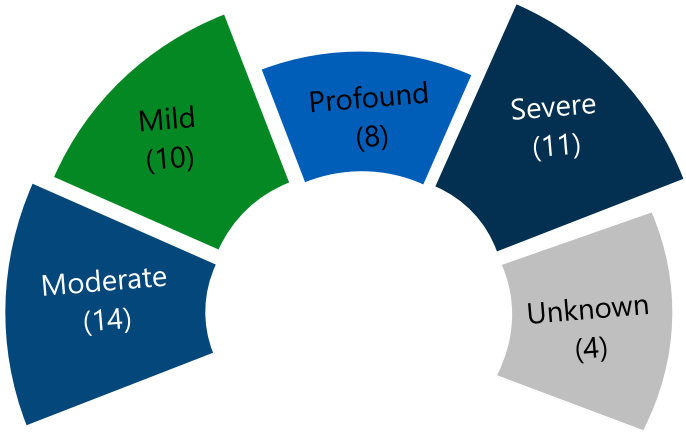
Age

Chart 5 shows the total number of reported cases split by age and gender. The average age of male deaths was 54, the average age of female deaths was 49.



Level of learning disability

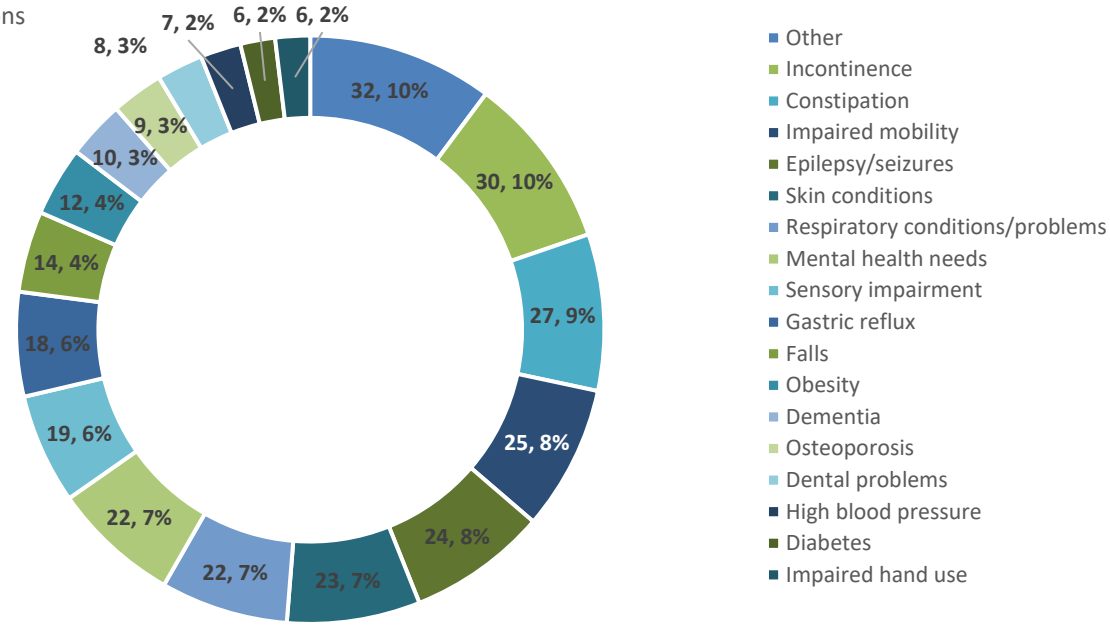
Of the 66 notifications, 43 had a known level of learning disability recorded.



Conditions

Of the 66 reviews this year, 42 (63%) recorded co-morbidities. There was a corellation between the level of a persons learning disability and the number of long-term conditions they had. The 11 individuals with severe or profound learning disabilities had 3 or more long term conditions recorded. Chart 6 shows the prevalence to those conditions. **Incontinence**, **Constipation**, and **Impaired mobility** were the most prevalent.

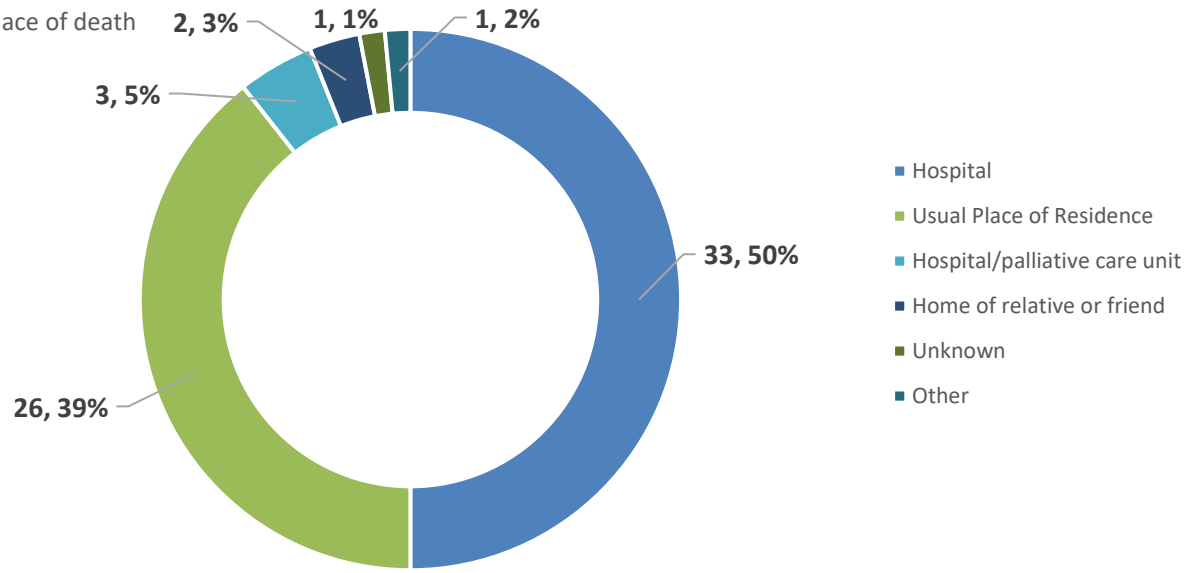
Chart 6 - Conditions



Place of Death

50% of deaths occurred in hospital. This is similar nationally; **46%** of those with a learning disability die in hospital.

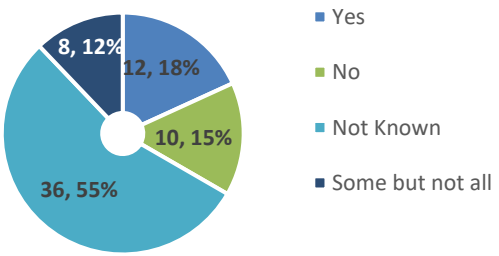
Chart 7 - Place of death



Screening

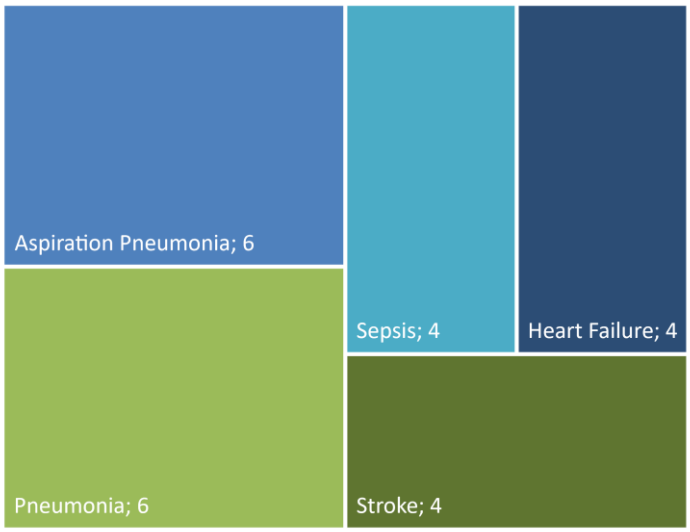
Of the 66 individuals reviewed 20 (**30%**) had undertaken some form of screening e.g a mammogram.

Chart 8 - Was screening undertaken?



Causes of death

Chart 9 - Causes of death



The underlying cause of death is defined as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident of violence which produced a fatal injury.

Chart 9 breaks down the top 5 causes of death. Devon is similar to national data which shows, these being pneumonia (9%), aspiration pneumonia (9%), sepsis (6%) and heart failure (6%).

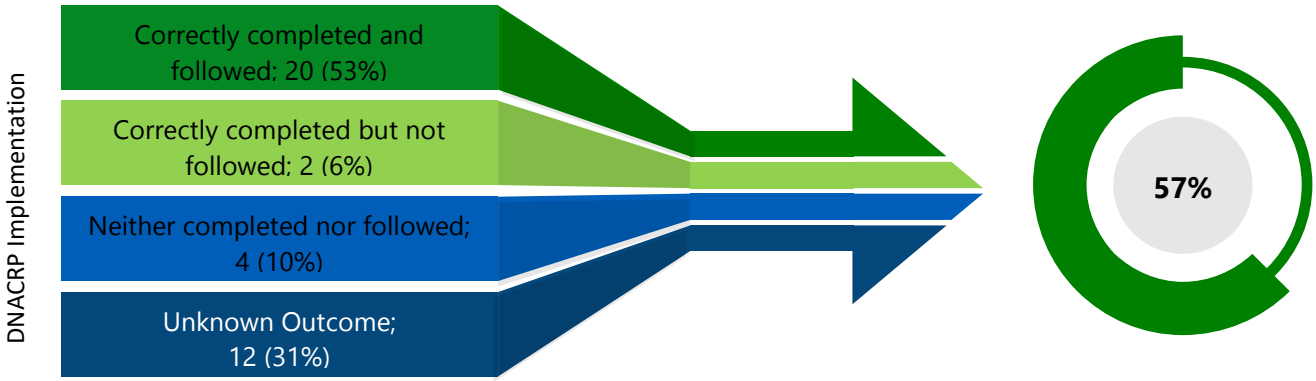
we were unable to determine the cause of death in 32 (48%) reviews.

Of the 66 reviews, **aspiration pneumonia** and **pneumonia** were the most frequent cause of death. This amounts to 18% of people with learning disabilities in Devon compared to 25% nationally. A greater proportion of people with severe learning disabilities (3) died from **aspiration pneumonia**.

Deaths with a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) in place

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing explicitly states that decisions about DNACPR must not be based on assumptions related to the person's age, disability or the professional's subjective view of a person's quality of life.

Of the 66 reviews In Devon a total of 38 (**57%**) reviews undertaken had a DNACPR order in place. 28 reviews (43%) didn't have one in place or no documentation was submitted. The graphic below shows this broken down by how well DNACPR was implemented in Devon.



Annual Health Checks

Annual health checks can enable early identification of conditions such as diabetes and heart disease and give an opportunity for health staff to promote healthy lifestyles preventing conditions and diseases from developing. A national target has been set for 75% of people with a learning disability to receive an annual health check by 2024. In Devon, 28 (42%) of 66 reviews recorded annual health check as being undertaken.

Annual Health Checks Completed in Devon

4 Quality of Care

Quality Assurance Panel

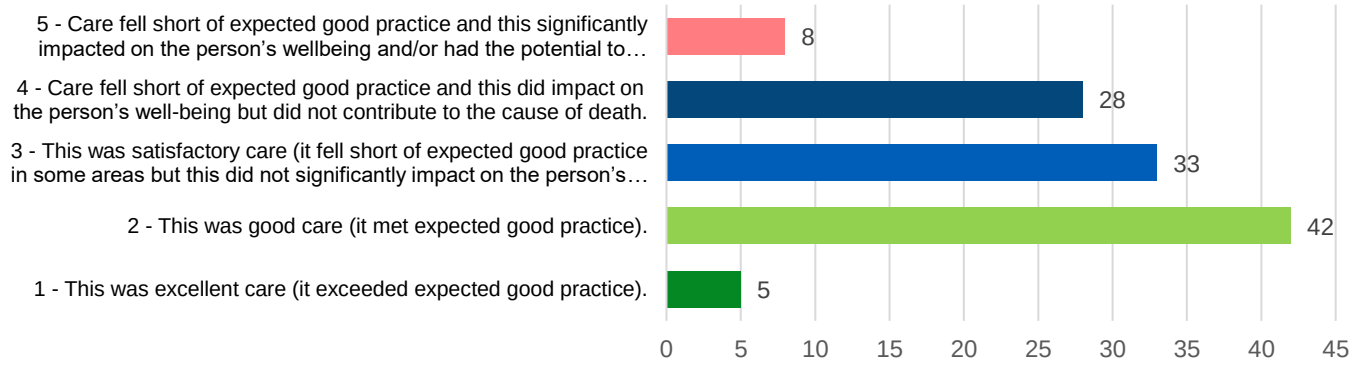
The Devon LeDeR Quality Assurance (QA) Panel provides a consistent approach to signing off completed reviews. Completed reviews are brought to the panel for review against a set of quality indicators. The panel uses the national checklist to ensure consistency of approach and a record of the discussions of each panel is kept.

Grading of Care

Each review undertaken is assessed against the quality of care provided by the case reviewer, on a range from 1 (excellent) to 6 (Care fell far short of expectations). Of the 123 cases signed off during the past fiscal year, a total of recorded and submitted 80 (65%) had Satisfactory or good care.

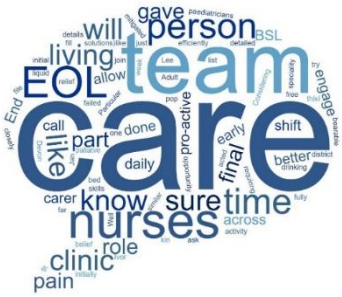
If the quality review meets an acceptable standard this is agreed, however on occasions this will change the grade according to the evidence presented through the review. All individual improvements are picked up and themed, so that the provider responsible can include their themes into their own action plans.

Chart 10 - Grading of Care



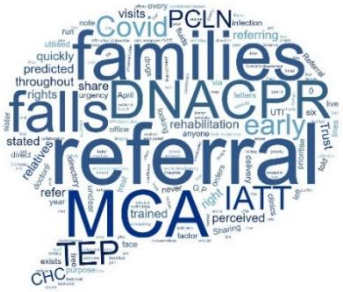
Reviewer feedback

As part of the review process, reviewers are asked to comment if identify any good practice that has taken place. Of the 123 reviews completed, 75 (61%) reviews included the identification of positive practice by the reviewer.



The following good practice themes were identified across the region; the quality of **care** received, positive **communication**, **engagement** with the **next of kin** and **end of life** plans being put into place.

The reviewers are also asked to comment if any learning or recommendations were identified. Of the 123 reviews, 104 (85%) identified learning or recommendation.



The following themes for improvement were identified from the reviewer's comments across the region; Delayed/Incorrect **referral**, implementation of the **mental capacity act**, implementation of the **DNACRP**, review of the **TEP** form and communication with **families**.

Reviewer Comments

Reflective accounts from reviews

"While speaking with a GP regarding a LeDeR review, it became clear to the GP, that there had been missed opportunities to make a safeguarding referral regarding Miss A. This prompted the GP to take advice through their supervision process and subsequent annual appraisal and add these learning elements into their personal professional development plan in line with GMC regulations. In addition, the GP shared their insight with the other GPs and practitioners in the practice, immediately implementing the learning outcomes to improve practice and make systemic changes. Part of the changes made including introducing a named GP just for leading routine learning disability and other vulnerable adult client discussions and processes"

"The ability to approach practitioners with real stories, real people and real families is so important. It allows the person to shine through and make each an ever statistic mean something.

Without the guidance of learning from LeDeR we would not be able to highlight and tackle those areas that really need to be addressed. It gives the clout required to break down the doors of bureaucracy and get some movement and drive for improvement from all stakeholders in our services.
So valuable and it's a real honour to get to know the lives of individuals and how we can do them justice beyond their passing"

"Having completed numerous reviews of LeDeR I really feel the process of reviewing deaths has made me a much more holistic practitioner. I would say I am proud to be a reviewer and the skills that it has given me are invaluable. The process of collecting information for a timeline allows you to draw together pieces of information and understand what happened and why. It has made me really think about the importance of care coordination and how this needs to be the right person at the right time and how care coordination is a skill and often clinical knowledge is there but the skill in coordinating is what is missing - not just the understanding of learning disability or reasonable adjustments.

The chance to speak with families is often difficult however brings such clarity of why we do what we do and gives such an important chance for them to be heard.
The learning from LeDeR is such a great platform to be able to affect change and this is really evident in the work we are currently doing in Plymouth. My hope is that LeDeR will underpin all the work we do for people with learning disabilities and I hope that we are able to continue the reviews to keep building a picture of what it is like in society for people with a learning disability"

"I have not done a LeDeR report yet, but I can't tell you how valuable the statistics and personal stories which arise are in my work. They are shocking and human and make it much easier to explain issues and inequalities to people. I use the stats and stories in my training, and they have been big drivers for work emanating from NHSE and the CCG this year.
I can't remember a time that local GPs were so up for thinking about the needs of people who have learning disabilities they are working so hard at getting annual health checks done. We have the biggest number of Learning Disability Champions in surgeries we have ever had. We have had good conversations with a couple of surgeries which otherwise would not have engaged with us. Long may it continue!"

"After doing a LeDeR review where an IMCA was crucial to the improved outcome I have then been suggesting in several other cases that IMCA is so useful. One care home manager, when we talking about person A where an IMCA would have been useful in hindsight, they went ahead and got an IMCA for another 3 (living) people as a direct result and I have received notification that this had had a massive impact for those 3 persons"

"I'm new to the LeDeR team and I'm so pleased I put myself forward to be a part of such a great network advocating for the human rights of people who have a learning disability. Personally, it has given me a wealth of knowledge and a new interest in palliative care.
Having completed my first review, I felt privileged to be given such detailed personal information about someone and I quickly became engaged taking a deep dive, it was important to me to capture and give justice to the person's life. Something that really struck me was the change in social care from 50 years ago to now, thank goodness!! We still have much to work on in health and social care but with programmes such as LeDeR and the passion of people to continually review and advocate for those changes it will continue to evolve for the better"

Quality assurance panel feedback

The LeDeR team are initiating a shared feedback process to implement and support learning for those teams involved in the care of people with Learning Disabilities. This will be a regular process throughout the year, with comments from the reviews fed back to providers and to share good practice, and for the LeDeR team to seek assurance that recommendations have been implemented and care improved. These improvements will then be presented to the Steering Group.

The LeDeR team have identified the following areas for improvement themes as part of its quality assurance panel. There is strong evidence of how the learning disability liaison nurses working in the hospitals are making a real difference to people's lives and providing excellent support for the families.

Areas for Improvement

Acute/Community Providers

- Consideration and documenting of Mental Capacity Act
- Relatives are not being involved in Best Interest Assessments
- Implementation of reasonable adjustments across acute settings
- Completion of, availability of, and adherence to Hospital Passports
- Improved recording in notes and other documentation
- Processes around safe discharge for people with Learning Disabilities co ordinating with community services.
- Availability and provision of Easy Read information
- Involvement of Learning Disabilities Teams
- Provision of training on how to support people with Learning Disabilities
- Timely initiation of an End of Life pathway
- Reviewing of Treatment Escalation Plans
- Use of NEWS2 and RESTORE scoring systems

Primary Care

- Initiating Mental Capacity Assessment including Best Interest decisions
- Completion and updating of Health Action Plans
- Completion and updating of Advanced Care Plans
- Provision of Easy Read documents / leaflets / information
- Training regarding reasonable adjustments for people with Learning Disabilities
- Completion and updating of Treatment Escalation Plans
- Effective communication with people with Learning Disabilities
- Monitoring of medication and ensuring regular medication reviews
- Completion and updating of DoLs Assessments
- Encouraging and enabling access to dental care
- Enabling access to, and better understanding of, routine screening
- Completion and updating of Annual Health Checks
- Involvement with EoL processes and decisions

Care Homes

- Enabling discussions around will writing
- Monitoring of medication and ensuring regular medication reviews
- Involvement with EoL processes and decisions
- Encouraging access to, and better understanding of, routine screening
- Effective communication with people who have a learning disability.

Progress related to areas for improvement themes so far:

- Identified nominated learning disability leads sought from the acute hospital.
- Community providers have nominated leads to initiate improvements.
- Primary Care learning is now shared via bulletin, webinar, and through learning disability Champions
- Care Home feedback to be shared via PEN, regular mail outs, and Care Home training updates
- Improvements to provider training and improving knowledge in relation to the Mental Capacity Act in both Primary and Secondary Care.
- Plymouth City Council are collecting AHC data as part of contract monitoring. Report to LDAP March 21. This will identify where social care partners can support uptake through communication to support providers on importance of COVID vaccinations/Flu Vaccinations/Screening/AHC
- Devon LeDeR Steering Group agreed an action in response to the Oliver McGowan NHSE report, this resulted in the LeDeR team auditing their processes and systems to ensure these are robust, appropriate and of good quality. As a result, supervision has become more formalised, with 6 weekly peer group review meetings.
- TSDFT have worked with the Learning Disability Partnership Board Ambassadors who have agreed that there is a benefit of the Treat Me Well group reporting into this meeting. The Ambassadors are subsequently well placed to influence the activity and priorities of the Treat Me Well work plan.

5 Improvement (What has been done)

General

The Devon LeDeR programme was strengthened at the beginning of this financial year. There was a new recruitment strategy. NHSEI provided additional support through the NEC programme.

Doctor Rachel Gaywood was appointed as Strategic Clinical Adviser Learning Disability / Autism, NHS Devon Clinical Commissioning Group (CCG) and has been leading the work on improveing Annual Health Checks (AHCs).

The Devon LeDeR programme have recruited new reviewers to the team. There are also some reviewers provided by other Trusts within Devon. The reviewers are offered a drop-in peer group review meeting every six weeks which has been extremely popular. The group has the opportunity for peer group support and to have guest speakers. The feedback has been incredibly positive.

The Livewell Learning Disability team have improved their links with primary care, attending regular meetings, to introduce themselves. There also has been a Learning Disability Charter adopted.

Introduction of a weekly Quality Assurance (QA) panel, responsible to review all the LeDeR reviews before signing off and attend MAR reviews.

Children's Services

- Children's services have started to engage with parents in relation to AHCs.
- A pilot commenced in February 2021 to improve the identification of young people with a learning disability, to improve the uptake of annual health checks, and to facilitate preparing young people for transition to adult services.

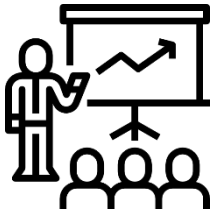
Annual Health Checks

- Communiction has been sent out to GP practices to promoting AHCs and ensuring staff know who their Learning Disability Champion is.
- GPs have been provided with training to support them in completing health checks for people with a learning disability and to ensure appropriate use of medication as part of the national STOMP programme.
- In early 2021 we recruited Learning Disability Champions for 92% of GP Practices across Devon. We are planning training regarding AHC and LeDeR and forming a support network for the Champions. This includes communication with their Primary Care Liaison Nurses, a dedicated email address for queries and a Champions webpage for resources.

Sepsis

- DPT have sent information to people with a learning disability about what sepsis is.

Training



- The LeDeR team have delivered training to a ranvgeof professionals over the year including care home staff, student nurses and doctors, and community service managers.
- The LeDeR team have improved links with the CCG safeguarding team after a recent MAR. This has led to further training for primary care networks.
- Following a successful bid to The Burdett Trust; UHP have developed a Trust wide learning disability and autism training programme.

Equality

- The CCG LeDeR team have started work to engage with representatives from ethnic minority communities. In Plymouth, the local Livewell team have supplied learning disability awareness training to local ethnic minority organisation representatives to improve awareness of additional needs and reasonable adjustments.
- In accordance with national requirements the panel has identified an ethnic minority lead in Sally Parker, NHS Devon CCG Equality, Diversity and Inclusion Lead.

Vaccinations

- LeDeR data has showed that the main cause of death for people with a Learning Disability is due to respiratory conditions, both Livewell and DPT have developed courses for flu vaccination and provided an online seminar for care providers.
- In January, a webinar was held to prepare care homes for the vaccination programm.

Primary Care

- Devon Partnership Trust (DPT) are developing folders for every GP practice in Devon, containing information for AHCs and Health Action Plans. The folder will have copies of forms that can be used quicky and as an alternative to the digital forms.

Governance

- Since the LeDeR dedicated team came into place in 2020 all the governance arrangements have been reviewed. As a result, an updated Terms of Reference was written and approved. New Standard Operating Procedures are being developed. A new data system is being used to capture the critical data to allow the LeDeR team to be immediately responsive to requests for information.
- DPT have reviewed the acute and primary care liaison service to ensure that there is seamless working across the teams.

Funding

NHSEI contribution for Devon LeDeR funding for April 2020-March 2021 was used in the following way:

- Contributed to employment of reviewers to support the backlog of reviews.
- A proportion of the funding was allocated between Livewell and DPT following action from learning on training and development.
    - We provided folders for every GP practice in Devon to support AHCs
    - We funded expansion of the Restore2 pilot which was rolled out to care and supported living homes in Plymouth
- Funding has been allocated over the financial year 2020/2021. This was to complete the training development programme for learning disability nurses, to develop the trainer's course for care providers. The nurses will ensure that the training delivered across Devon will be consistent across the area – previously, training has been provided by different people with different providers in Devon. Area identified by LeDeR such as constipation, epilepsy etc will be part of the training package.

Making a difference

John was born in Devon. As a child he lived with his parents and his sister. Both his sister and John were diagnosed with learning disabilities. John was also diagnosed with general anxiety disorder.
He was well known in the local area and both his sister and him moved into a residential care home near the family.

John did not really interact with his peer group but was deeply affected by the death of his father and his sister, which happened in quick succession. There were also significant changes within his care provision that coincided with his loss. John had poor communication skills and self-expression but talked repeatedly about his family.

John had a cousin who was very involved in his life and was a great advocate for him. His cousin visited him frequently and was active in his care and support. John was a very sociable man and loved having visitors to come to see him. He enjoyed listening to other people and people watching. He liked attention and interaction.

It was not surprising that during this period his behaviour that challenged increased significantly.
The Community Learning Disability Team were frequently involved, especially in relation to risk management and strategies to try to reduce his anxiety and behaviours which challenged. John was funded for 1:1 support. He also had regular reviews from the psychiatrist and was prescribed both an anti-psychotic medication and an anti-depressant.

John had frequent chest infections. In 2019 he was referred for a video fluoroscopy and have food and drink guidelines put into place by the speech and language therapist. He had a modified pureed diet.
In January 2020 he was seen by his GP x3 and treated for a chest infection.
John died in February. He had seemed 'off colour' the day before he died. He saw the GP and his chest was clear.

During the night of his death, he was checked once during the night. He was found dead the next day. The provider and commissioning care plan did not outline how frequently he should be checked during the night. It was thought that he had rapid deterioration. *Note – this profile has been anonymised but is based on a LeDeR review in 2020*

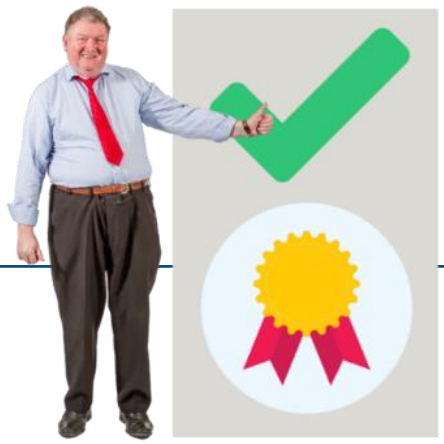
A **LeDeR Multi-Agency Review (MAR)** was held after his death. The MAR **identified the need for care plans to clearly state the recommended level of support** 24 hours per day and identified the need for good record keeping.

The MAR also identified how the use of NEWS2 and RESTORE2 could have helped identify his rapid deterioration.

As a result of the MAR **John's care home was identified as an early adopter of the oximeter roll out to care providers who support people with a learning disability**. A two-week baseline is kept and recorded for every person so that when they become unwell it becomes immediately clear if their blood oxygen levels are out of range of their normal presentation. This evidences a possible early indication that something is wrong, and that the person is likely to need urgent medical attention. The provider has also been introduced to using NEWS2 and Restore2.

Future Improvements (What we will do)

- To improve knowledge of constipation, 5 health promotion stool kits have been purchased to assist in the delivery of training. Training will be rolled out from Summer 2021.
- In order to reduce the number of deaths from pneumonia, Speech and Language Therapy capacity has been increased to ensure that every person with a learning disability is offered a dysphagia screening and provided with a care plan for eating and drinking safely.
- DPT and LeDeR reviewer nurses are planning to develop of health training pack to be delivered across Devon, to all care providers and partner Trusts about the health needs of people who have learning disabilities.
- UHP have piloted an adult Autism Liaison Nursing services, which if successful could be rolled out across all Acute services in Devon.
- There is a frequent theme of poor discharge from acute hospitals across Devon. Plymouth have started to review discharge from hospital and patient flow, but there is more work to be done for the acute hospitals across Devon and planned discharge.
- The LeDeR team intends to work in coproduction with people who have learning disabilities and are currently developing some easy read questionnaires for data analysis in relation to end of life care.
- When the new platform is launched it is the intention that both the Local Area Contact and the Mortality LeDeR Co-Ordinator use their smart cards to access information to make the information flow more efficient.
- Commencing September 2021, LeDeR will be incorporated into the routine quality reporting arrangements of the ICS and not sit separately from it, to improve learning and action locally.
- The 3 year Learning Disability and Autism Plan, submitted in March 21 and overseen by Head of Learning Disabilities, will incorporate service quality improvements/delivery of actions identified, reporting to Devon's Integrated Care System.



6 Acknowledgments

The LeDeR team in Devon would like to thank everyone in Devon who have been instrumental in making improvements to the LeDeR programme over the last year.

We are deeply indebted to the families who shared their experiences and often laid bare their soul and their grief regarding their terrible loss. We heard enlightening stories that made the LeDeR team cry, laugh and often be in awe of the wonderful people that had died, or the families supporting the person who had died.

We would not have been able to have cleared the backlog without the reviewers: all the reviewers from different Trusts within Devon, employed CCG reviewers, block contact reviewers, and the NEC Team have worked extremely hard and diligently to achieve reviews being completed in a timely manner. Without them we would not be able take forward the LeDeR programme into the next stages of delivering improvements throughout Devon.

Thank you to Primary and Secondary Care, we heard some astonishing stories of exemplary practice that demonstrated how wonderful the NHS staff are.

Thank you to the Steering Group whose membership includes every Trust in Devon and the Councils/ Local Authority. The membership helps to make improvements in their organisations and providing better experiences for people who have a learning disability.

Thank you to the Quality Assurance Board who weekly read every review to ensure the learning is captured and to appraise the quality of the report.

Thank you to members of the Nursing and Quality Senior Leadership Team and Learning Disabilities Commissioning Team within the CCG, who have supported the LeDeR process.

Thank you to the regional team at NHSE who have worked alongside us, being encouraging and given us resources to succeed.

Thank you to the LeDeR Team both past and present in Devon. Devon LeDeR team won ‘Best Team’ category for NHS Devon CCG, Celebrating You Awards held in November 2020.

Conclusion

2020 has been a massive learning curve for everyone involved in the LeDeR programme, with new processes and quality assurance measures going in to place since day one of the new LeDeR team.

We want change and change is not happening quickly enough. People with a learning disability deserve the same health treatments and opportunities as others, but often with reasonable adjustments to enable this to happen. It is heartening to see so many providers wanting change and willing to work in collaboration to achieve this. Through, the LeDeR reviews we also have seen compassion, friendships, and some pockets of outstanding practice, that we must build upon.

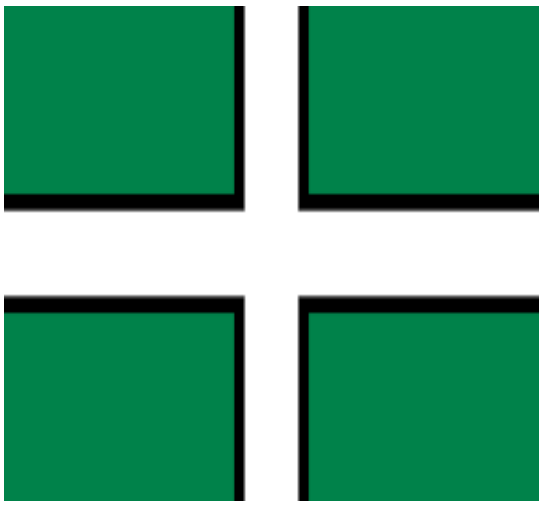
The NHS Devon CCG is completely committed to making improvements by strengthening and embedding systems and processes systematically across Devon to make improvements. We will continue to work with our partners to ensure a proactive approach to change by ensuring all the providers have an action plan to counterbalance the areas already identified for improved through the themed learning that has been collated throughout 2020.

With the new national policy published in March 21, Learning from Lives and deaths, People with a learning disability and autistic people (LeDeR) policy 2021, with a “*stronger emphasis on the delivery of the actions coming out of the reviews and holding local systems to account for the delivery, to ensure that there is evidence of service improvement locally.”* The new policy responds to the Oliver McGowan review recommendations. Devon LeDeR steering group will incorporate delivery of actions they identify reporting to Devon’s Integrated care systems.

Report published by the NHS Devon CCG LeDeR team.
Graphics and design by Chris Blevin, Learning Disabilities Mortality Review Coordinator.
Data obtained from the national LeDeR system. Data correct at time of download 15/03/2021.

Appendix 1: Easy Read

Learning from Deaths for people with a Learning Disability in Devon



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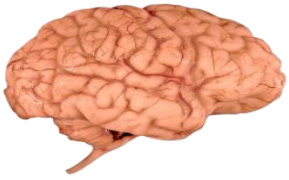
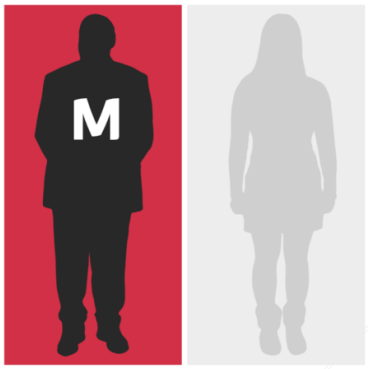
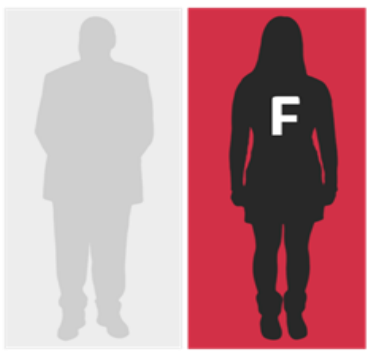
5.	What have we learnt?	

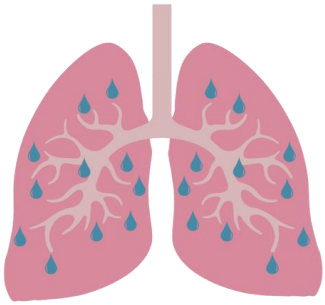
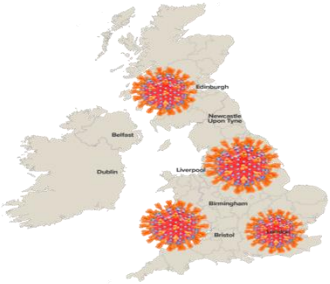
1.Introduction

	**We are looking at how many people have died who had a Learning Disability**
Learning Disabilities Mortality Review (LeDeR) Programme	**Every person who died with a Learning Disability, had a review which is called a LeDeR review**
	**We have LeDeR reviews in Devon**
	**We have made a lot of progress in the last year and improved our recordings and information**

2. How many deaths have we had?

	**Devon had 66 deaths reported from April 2020 to March 15th 2021**
	**Most people who died had not had NHS Screening such as their breasts checked, a cervical smear, or checking of their poo**
	**Most people who died were men with most men dying age 54 years old**
	**Women died younger than men with most women dying age 49 years old**

3. About people who died and what Covid has meant?

	**The highest number of deaths in Devon were caused by pneumonia**
	**In Devon 9 people who had a learning disability died because of Covid**
	**Devon has written a report about covid deaths**
	**The Learning Disability teams have been helping people with a learning disability to stay safe and support them with their care**

4. What our reports told us

	**All reviews go through a Quality Assurance check before being agreed**
	**We know we need to improve:** • **Hospital Passports** • **Hospital discharge** • **The person being involved in making choices about their care, or other people making these choices in their best interests**
	**Good practice found:** • **Positive Communication** • **Talking to the next of kin** • **End of life plans**

What have we learnt and what we are doing?

 	**We needed to improve Annual Health Checks – Rachel Gaywood is helping GP practices with this**
	**We needed to improve professional's understanding of reasonable adjustments -We are developing training packs for everyone**
	**We needed to improve the quality of LeDeR reviews – We put into place quality assurance checks**
	**We needed to improve all the different services working together – We are putting together improved ways of working**


We are improving the amount of people from age 14 onwards going for their Annual Health Check
We have introduced early warning assessments to tell us when people are unwell
We are developing tools to support people at the end of their life
We are improving training for health and social care workrs

Appendix 2: COVID Report

Learning Disabilities Mortality Review (LeDeR) Programme

NHS Devon Clinical Commissioning Group

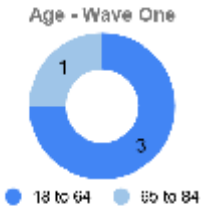
Learning Disabilities and COVID-19

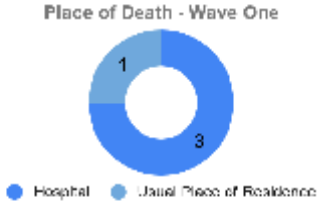
NHS Devon CCG - LDA Steering Group Briefing Report - February 2021

This briefing paper undertakes an analysis into learning disability related deaths in Devon that were attributed to COVID 19 for the period of March 2020 to February 2021. The paper aims to benchmark Devon's local data against the national findings documented in PHE and UoB 'Deaths of people with learning disabilities from COVID-19' report.

Devon COVID-19 Deaths (Wave One)

COVID 'Wave One' refers to the period of COVID infection that took place between 02/03/2020 to 09/06/2020. The national findings documented the occurrence of 9 deaths in the south west region during this period. This is attributed to 6% of the total national deaths related to COVID-19. Of the nine deaths, Devon had four deaths related to COVID during this period. The four deaths that occured in Devon are explored further below.





- **Place of residence and death** - National data suggests the majority of patients who died from COVID, were living in a residential home (35%). This is reflected in the Devon regional data whereby two cases (50%) were living in a residential home. Three patients (75%) in Devon died in Hospital, this is also in line with national findings with 77% of patient deaths occurring in hospital.

- **Age** - The large difference recognised nationally in age between COVID deaths in the general population compared to people with learning disabilities is also reflected in the Devon regional data. All four patients (100%) were under the age of 84.

- **Level of Learning Disability (LD)** - The national data suggests the majority of COVID related deaths affects patients with Mild LD with a total of 210 (65%). This is in contrast to Devon data that suggests the majority of deaths were related to patients with Severe LD.