Learning Disability & Autism

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Learning Disabilities Mortality Review (LeDeR)

ANNUAL REPORT

April 2020 - March 2021

Learning from lives and deaths - People with a learning disability and autistic people

Joined up care and communities

Gloucestershire LeDeR Mortality Review
Annual Report 2020-2021

Responsible committee:	LeDeR Mortality Review Steering Group Learning Disability and Autism Clinical Programme Group Gloucestershire Clinical Commissioning Group Quality and Governance Committee	
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Acknowledgements - Pictures courtesy of Easy on the i, Photosymbols and Getty Images

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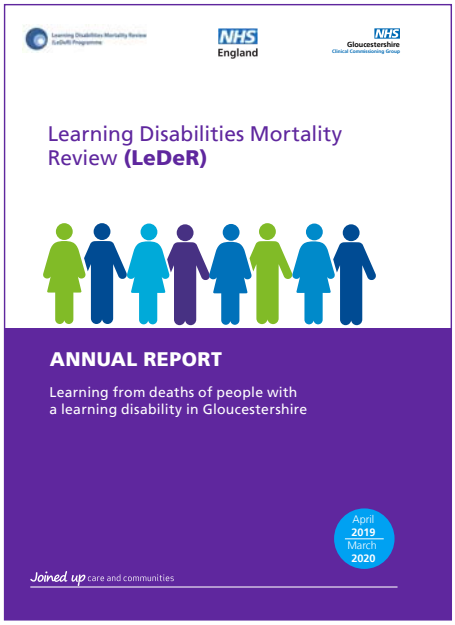
Glossary

AHC	Annual Health Check
BI	Best Interest
CCG	Clinical Commissioning Group
CIPOLD	Confidential Inquiry into the Premature deaths Of people with
CDOP	Child Death Overview Process
DNACPR	Do not attempt cardio pulmonary resuscitation
DOLS	Deprivation of Liberty Safeguards
FTC	Fundamentals of Care
GRH	Gloucestershire Royal Hospital
GCC	Gloucestershire County Council
GHC	Gloucestershire Health and Care NHS Foundation Trust
GHT	Gloucestershire Hospitals NHS Foundation Trust
GP	General Practitioner
GSAB	Gloucestershire Safeguarding Adults Board
HEE	Health Education England
IHOT	Intensive Health Outreach Team
ICS	Integrated Care System
LD	Learning Disabilities
LDA	Learning Disabilities and Autism
LeDeR	Learning from Deaths Review
MCA	Mental Capacity Act
QA	Quality Assurance
PINCHME	Pain, Infection, Nutrition, Constipation, Hydration, Medication,
PTC	Proud to Care
PMLD	Profound and Multiple Learning Disabilities
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
ReSTORE2	Recognise early Soft-signs, Take Observations, Respond and Escalate
SLT	Speech and Language Therapy or Therapist
SUDEP	Sudden Unexpected Death in Epilepsy[iv]
TIA	Trans Ischemic Attack

Table of Contents

Preface: Statement from Chair of Gloucestershire LeDeR Steering group and Director of Nursing

Gloucestershire has been actively involved in the LeDeR programme since 2017 and stand in a strong position to address the issues and preventable causes of death identified within the national LeDeR annual report (published July 2020[1]) which reflect the many challenges that people with a learning disability face locally.



This report includes the death of people with learning disabilities who died from 1st April 2020 onwards. It is the third annual report for LeDeR Gloucestershire has published. Previous reports are available on Inclusion Gloucestershire's LeDeR Webpage[2]. The purpose of the report is to share our findings from LeDeR reviews and to identify learning and changes for practice.

This year even more so than previous years has brought challenges to the Country and county of Gloucestershire that we have not faced before. During the first Covid-19 lock down there were 7 deaths due to COVID-19 over April and May 2020. All of those that died in this period had multiple co-morbidities. Local information on outbreaks in care homes mirrored national conclusions that the number of care home outbreaks in learning disabilities homes was lower than that seen in general care homes[3]. However, during the period 17th December 2020 and 8th February 2021 there were 55 disabilities care settings in Gloucestershire that had COVID-19 outbreak[4]. Gloucestershire Hospitals also saw during the last few months of the financial year an unusually large number of in-patients with a Learning Disability. This was largely due to outbreaks of COVID-19 in a very large number of learning disability community settings. Those outbreaks have now subsided and inpatient activity has returned to more normal levels. The Gloucestershire Learning Disability Clinical Programme have also actively supported the Covid-19 vaccination rollout in the County and of those aged 18 and over on the GP Learning Disabilities Register 91% have received their first vaccination[5].

It is important to remember that comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified from the age of 4 years, while general population data also includes information about children aged 0-3 years.

In addition, more people who died at a younger age had profound and multiple learning disabilities and some of these would also have had complex medical conditions or genetic conditions that may make an earlier death likely.

[1] http://www.bristol.ac.uk/sps/leder/resources/annual-reports/
[2] https://www.inclusiongloucestershire.co.uk/engagement/leder/
[3] It is difficult to arrive at conclusions with such a small amount of data, however efforts should continue to raise awareness of symptoms, ensure that cases in those with a learning disability are being identified to ensure early treatment when needed and prevent onwards transmission.
[4] An "outbreak" is considered to be 2 or more cases (in people supported or staff) includes Care Homes, Supported Living and Day Centres.
[5] Data correct April 2021.

LeDeR Governance including monthly Quality Assurance Panels continued throughout the COVID-19 lockdowns as the learning from each review has been invaluable in enabling the lessons learnt and service improvements put into place in a timely way. The co-production partnership approach[6] which was implemented in 2019 has been invaluable in ensuring we are ahead of the curve in implementing action from learning during the year; experts by experience have helped us understand from people with experience of learning disability and using health services We have a strong commitment to learn from these reviews and Chapters seven and eight set out the recommendations from reviewers and our dedication to turn this into real action, promoting learning throughout health and social care services. A Learning Event, entitled "Dying to make a difference", was scheduled to be held in March 2020, but due to risks associated with COVID-19 this was postponed until safe to hold face to face events. We are currently exploring opportunities to hold a virtual event for stakeholders during 2021.

Going forward we are passionately committed to listening and learning from these reviews, from people with learning disabilities and their families and making positive changes across the health care system. We will challenge health inequality and improve health outcomes for people with learning disabilities and aim to prevent people from dying prematurely. The new LeDeR National Policy [7] published on 23rd March 2021 will give the local LeDeR programme opportunities to further strengthen the operational, governance and service improvements and extend this to autistic people as well.

Julie Symonds

Chair of the Gloucestershire LeDeR Steering Group and Deputy Director of Nursing Gloucestershire Clinical Commissioning Group

Dr Marion Andrew-Evans

Director of Quality and Nursing Gloucestershire Clinical Commissioning Group

[6] We have been supported by Inclusion Gloucestershire

[7] https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/2

Some of the people who have died

This report is about people with a learning disability who have died in Gloucestershire during 2019-2020. They were people who were loved and cherished, and whose 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[8], 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.

Andy – 67 Years Old – Cause of death Lower Respiratory Tract (Chest) Infection with probable COVID-19

Andy died at a nursing home, where he normally lived. A COVID-19 test was not performed due to the testing regime at that time (first COVID-19 lockdown), and limited access to testing.

Andy enjoyed the company of others and had a great sense of humour. He liked other people to sing to him and loved 1950's and 1960's music.

A number of reasonable adjustments were provided, including, allowing a carer or family member to support Andy at all medical appointments or during hospital stays. The Learning Disability Liaison Nurse based at the hospital completed *a Care and Treatment of a Patient with a Learning Disability* Form and also a form for those experiencing memory loss and deterioration, where it is known they have Dementia. Andy had a Hospital Passport, and the nursing home kept a communications passport for him as well. A family member was Andy's Advocate and appointed Court Deputy for Health and Welfare. Andy's needs were addressed with input from a range of community health services, including Speech and Language Therapy (SLT), Physiotherapy and the specialist Epilepsy nurse. A ReSPECT form was completed as was an End-of-Life Shared Care Plan.

The reviewer and the Quality Assurance Panel concluded that Andy received excellent care, that was above 'good practice' in a lot of areas and this should be shared. All health and social care staff should have Learning Disability Awareness training, to include how to communicate better. Those working with people with Epilepsy should also have training on the management of the condition.

[8] Please note that all names throughout this report have been changed to protect confidentiality.

Alex – 22 Years old – Cause of death Multi Organ Failure

Alex died at a specialist residential college, where he normally lived. Alex had many medical conditions and health issues. His cause of death was multi-organ failure together with his diagnoses of Congenital Cerebral Palsy, Periventricular Leukomalacia (a type of brain injury that affects premature infants) and Epilepsy.

Alex loved music, especially the band Madness. He also enjoyed watching the gameshow Eggheads.

Alex was provided with a specialist mattress and type of bed, as a reasonable adjustment, that enabled him to take part in social activities when he wanted to. Alex had regular appointments with the Palliative Care Team and his GP. He was also looked after by a team of specialist nurses and carers at the college where he lived. Alex's needs were addressed with input from a range of community health services, including Speech and Language Therapy (SLT), Physiotherapy and the Gastrostomy and Epilepsy specialists. A ReSPECT form was not completed, although his wishes were recorded in other documents. His family described the services provided to Alex in the last 6 months of his life as truly amazing.

The reviewer and the Quality Assurance panel concluded that Alex received excellent care, which was above 'good practice' in a lot of areas. The panel also thought that the end-of-life care was 'person centred' and that the nursing care received at the college, helped Alex avoid going into hospital. The panel noted there had been excellent team working and communication in this case.

Wendy – 79 years old – Cause of death COVID-19

Wendy died in hospital, having been living in a residential care home. She had two negative COVID-19 tests, however, her symptoms suggested COVID-19 and therefore a clinical judgement was made that she probably did have COVID-19.

Wendy was diagnosed with Guillain- Barre Syndrome in 1997, after getting the flu. This affected her muscles, mobility and dexterity. She spent many months in hospital recovering. Her GP referred her to the Community Learning Disability Team (CLDT), Occupational Therapy (OT), Physiotherapy and Orthotics (to support her in getting specialist footwear). Wendy had high blood pressure, which was checked by the residential home regularly.

It was important not to rush Wendy when she was speaking. Wendy could understand simple instructions and short simple sentences. Wendy had difficulty forming sentences. She needed to be given time to process what was being said and to express herself. Wendy was accompanied to all relevant appointments and had an advanced care plan, recording her wishes.

The reviewer and the Quality Assurance Panel concluded that Wendy received good care, with the reviewer noting that the family were happy with the standard of care. Wendy's GP had made a timely referral to CLDT, a ReSPECT form had been completed, as had an Advanced Care Plan and a Shared Care Plan. These measures where identified as good practice that could benefit others.

Anne – 67 years old – Cause of death COVID-19 and Chronic Obstructive Pulmonary Disease (COPD)

Anne died in hospital, having been living in a residential home.

Anne enjoyed shopping for clothes at Asda, listening to loud music and eating traditional food such as fish and chips.

Anne was admitted to hospital before her death and put on to a COVID-19 ward for treatment of Pneumonia (chest infection). Once a negative COVID-19 test result was confirmed, she was transferred to a non-COVID-19 ward. Anne tested negative when she left, however, tested positive (for COVID-19) when she went back into hospital 4 days later.

It was reported to the reviewer that the hospital could not have done anything differently when Anne first went into hospital as they were thinking carefully about COVID-19. This case has been reviewed by the COVID-19 investigation team at the hospital.

As well as COPD, she also had Asthma and Epilepsy, She was also susceptible to falls and highly likely to develop sepsis. Her carers had been trained on how to spot the early warning signs of Sepsis from the Intensive Health Outreach Team (IHOT). Anne had accessed lots of community health services, including Physiotherapy and Psychiatry.

Anne had many reasonable adjustments provided. She moved to a different residential home when it got harder for her to move around, remaining in the care of the same provider with familiar staff. This meant that there wasn't too much change for Anne. Anne was provided with equipment and had adapted bathroom facilities so she could remain as independent as possible for as long as possible. Anne had home visits from medical professionals, and her medical history, likes, dislikes and wishes were well recorded in documents such as her ReSPECT form and Hospital Passport.

The Quality Assurance panel and the reviewer agreed that Anne's care was satisfactory, with care falling short in some areas, but this did not have a big impact on Anne's wellbeing and would not have changed the outcome for Anne. Anne's brother spoke with the reviewer at length, explaining that, in his opinion she did not have a Learning Disability before her epileptic seizures, being labelled and often experiencing care that wasn't good enough. However, he also said that the care from the last care provider was good.

There were a number of learning points and recommendations to come out of this review. The reviewer was told that Anne had Mental Capacity; however, several 'best interest' decisions were made. Mental Capacity assessments must be clearly documented and they weren't always in Anne's case. Anne's brother found it difficult to be her advocate at times, due to not knowing about hospital admissions or the seriousness of her condition. Next of kin must be fully involved in decisions about their loved one's healthcare if the person does not have capacity. Information must be communicated to them promptly. Anne was readmitted to hospital shortly after discharge. A person must always be fit to leave hospital.

[8] Data correct April 2021

Executive Summary

The Learning Disabilities Mortality Review Programme was established in 2015 nationally, and in 2017 in Gloucestershire. LeDeR is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people with learning disability over the age of 4 years are subject to a Learning Disability Mortality Review[9].

The main purpose of the LeDeR review is to:

- Identify any potentially avoidable factors that may have contributed to the person's death, and
- Develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

This report focusses on 2020-2021 and is the third local annual report on the learning from deaths of those with learning disabilities within Gloucestershire. The report covers from 1st January 2017 up until 31st March 2021. The previous year's report can be viewed on Gloucestershire Clinical Commissioning Group's Website[10].

The Gloucestershire LeDeR Programme (as at 31st March 2021) had completed 91% of notified reviews (reviews received up to and including 31st March 2021), this compares to only 78% in the South West and 83% in England.

The purpose of the report is to share the findings and the learning with anyone interested in health and social care given to those with a learning disability.

Status of reviews by year

Year	Closed	Open	Total	% Completed
2016-2017	7	0	7	100%
2017-2018	51	0	51	100%
2018-2019	47	0	47	100%
2019-2020	46	0	46	100%
2020-2021	38	19	57	67%
TOTAL	**192**	**19**	**211**	**91%**

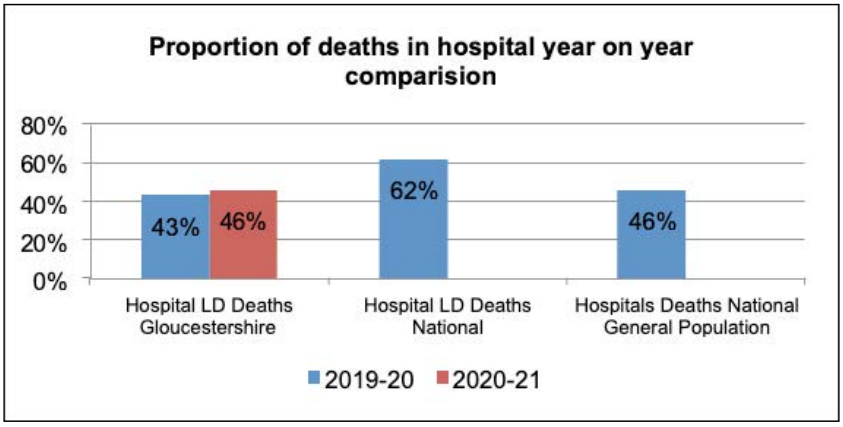
[9] Further information about the LeDeR Programme is available on the University of Bristol Website. This is a national programme of service improvement

[10] http://www.gloucestershireccg.nhs.uk/wp-content/uploads/2019/12/LeDeR-annual-reportPresscopy_October19.pdf

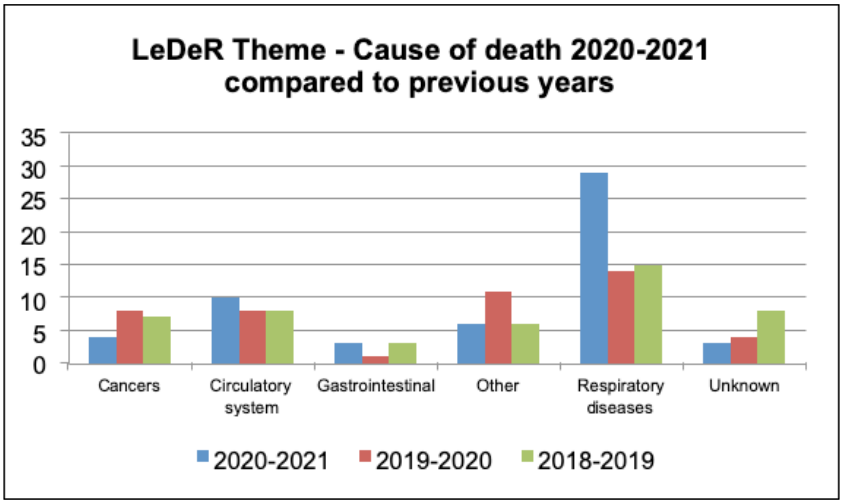
Key Findings

Ratio of grading of care 2020-2021 (n=38 reviews) The ratio of the grading of care those receiving satisfactory or better care is 9:10 people in 2020-2021.

Where people died Of the deaths reported in Gloucestershire during 2020-21, 46% died in hospital (all in Gloucestershire Royal Hospital). The corresponding proportion for the general population is 46% (meaning that does not appear to be a health inequality).



Causes of death Of the 57 deaths the top cause of death in the learning disabilities population in 2020-21 remains respiratory causes (n29 deaths). This is a 100% increase on the previous year and can be attributed to the COVID-19 pandemic (n14 people died of COVID-19 with a learning disability)



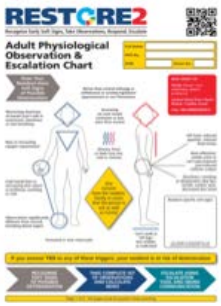
Those with an end of life plan in place 57% of the 30 deaths (where this information has been recorded) had an active end of life plan in place (this compares to 46% nationally). Over 50% (58%) of the deaths (64% in the previous year) of the deaths were expected and planned for deaths, meaning that all of the expected deaths had an active end of life plan in place (92% in the previous year). From the feedback on learning into action further work around advance care planning and the perception on the use of the ReSPECT Form being completed only once someone is identified as end of life is required.

Summary of Learning Outcomes

From the reviews these were the key areas identified for improvement of care of people with a learning disability;

1. Care provider market

- Infection control – PPE training being relaunched in community
- Provider bulletin continues to be published monthly Click here
- Workforce competencies – engaged with Fundamentals to Care (FTC) and HEE to ensure OM Mandatory training and other training offers are meeting the needs of the workforce in Gloucestershire. FTC Focus for the next 6-12 months will be on learning disabilities
- Accessible COVID-19 resources - Inclusion Gloucestershire have developed an online resource hub of material aimed at those with lived experience of disabilities and people who may support them. The regularly updated resource hub can be accessed here and includes accessible material on many aspects of COVID-19.



2. Use of technology

- Telehealth project in LD Care Homes extended to further five care provider companies expressed interest (11 care homes).
- Monitoring and communicating signs of deterioration (RESTORE 2 & RESTORE 2 MINI training offered by West of England Academic Health Science Network has been actively promoted throughout disability care provider settings. Community Learning Disability Teams (CLDT) have also been trained to deliver this training in the future) Click here

3. End of Life

- People dying without Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) Forms or advance care planning in place. The ReSPECT process (when implemented correctly in discussion with individuals/their family/carers) can be an important facilitator in effectively communicating people's wishes about their emergency care. We have commenced a ReSPECT Reasonable Adjustments Task and Finish Group which aims to bring together organisations and individuals from across the Integrated Care System (ICS) in Gloucestershire to work collaboratively to address the need to improve ReSPECT conversations for individuals with diverse needs. This will support stakeholders to adopt a person-centred, holistic approach to Advance Care Planning (ACP) for everyone in Gloucestershire.

4. Use of legislation

- Mental Capacity Act and the use of advocates – Click here
- Capacity and consent for covid-19 vaccine information guidance – Click here & guidance for families/carers – click here. A Vaccine Equity Group has been meeting regularly to ensure the needs of people who require reasonable adjustments are being met[11].

5. Hospital/Acute Care

- Engagement in covid-19 virtual ward programme. Disabilities commissioning now able to make referrals for people to be put onto virtual ward following outbreak notification in care provider settings, therefore increasing the number of people with a learning disability who had covid-19 being able to be monitored in their usual residence.
- Use of editable Health passport continumoted widely
- Reasonable adjustments Flag on SCR continues to be reviewed and discussed by the project group.
- Covid-19 Guide for staff supporting people with LD was developed during the first lockdown to support health care professionals as a quick reference guide – click here

[11] In Gloucestershire those over 18 as of 6th April 2021 was 91% of the people on GP Learning Disability Register.

Statements from our Experts by Experience

All of the recommendations from reviews are scrutinised by the Quality Assurance panel and put into a local action plan which is shared with the Gloucestershire LeDeR Steering group who will monitor progress.

Gloucestershire is passionate about keeping this work programme moving forward and embedding the action from learning to drive service improvements. Peoples lived experience will help to guide and drive the service improvement programme that will be as a result of the completed reviews.

Sammy from Inclusion Gloucestershire

Sammy Roberts, Project Worker at Inclusion Gloucestershire and Expert by Experience member of the LeDeR Quality Assurance Panel says:

> *This year our voice as Experts by Experience has played an increasingly valued part of the QA panel. We have been able to represent the voice and stories of people with learning disabilities from around Gloucestershire and make sure their voices are heard. Now we are starting to produce accessible information, which means we are accountable to the people our work affects, people with learning disabilities. Once again our role as Experts by Experience has been important to share because we are the experts in what our lives are like and how this can affect our health.*

Vicci Livingstone-Thompson, CEO of Inclusion Gloucestershire and Expert by Experience member of the LeDeR Quality Assurance Panel says:

Vicci from Inclusion Gloucestershire

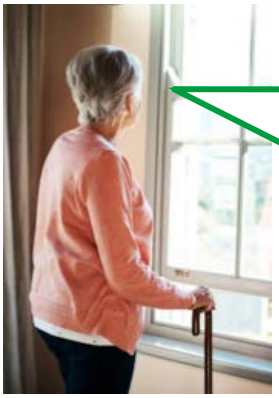
> *This challenging year has really highlighted the importance of LeDeR, coproduction and hearing the voices of people with a learning disability and autism. Not only has work on LeDeR continued at pace in Gloucestershire, but we have seen greater levels of co-production, with work starting to disseminate key themes to professionals and the community in an accessible way, and involvement of user-led organisations at a strategic level to inform important discussions and decisions around COVID-19.*

When we asked Sammy's friends and colleagues at Inclusion Gloucestershire[12] about why LeDeR is so important here is what they told us:

I need to be listened to as the expert in my condition!

My life is important!

I was relieved to hear that blanket DNACPR's are not being used in Gloucestershire.



COVID-19 has made health inequalities worse

There may be a global pandemic but we must not stop making reasonable adjustments.

In the last year, isolation has made some people's health much worse.

[12] Some of the images are from Stock photos available from www.gettyimages.co.uk

Chapter One – Structure for LeDeR

National

The LeDeR programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Until 1st May 2021 it is being delivered by the Norah Fry Research Centre at the University of Bristol. The purpose of this work can be broadly described as:

To help health and social care systems, professionals and policy makers to:

- Identify the potentially avoidable contributory factors related to deaths of people with learning disabilities
- Identify variation and best practice in preventing premature mortality of people with learning disabilities
- Develop action plans to make any necessary changes to health and social care service delivery for people with learning disabilities

All deaths of people with learning disabilities are notified to the National LeDeR programme at the University of Bristol. Reviews are then allocated to 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.**

National Programme Structure 2020-2021

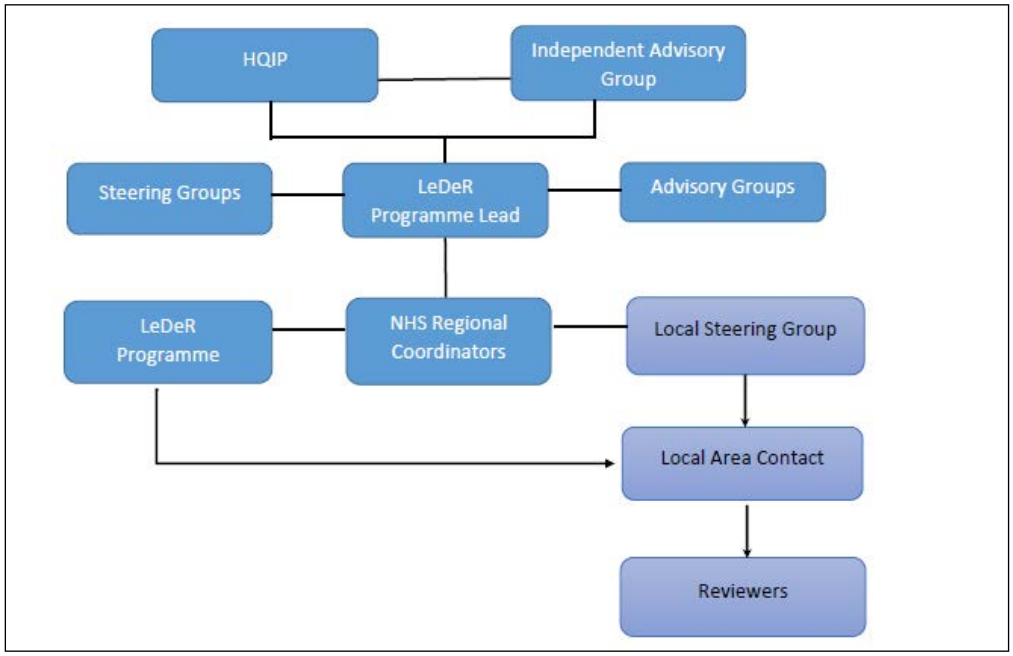


Figure 1 - National Programme Structure

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[13] 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

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

History of the LeDeR Programme

2015

- 1st June - LeDeR Established in response to CIPOLD outcomes
- University of Bristol team established

2016

- Pilot Sites established
- Oct 2016 - 1st National Annual Report published

2017

- April - National LeDeR Framework approved

2018

- May - 2nd National Annual Report published.
- Quality assurance oversight handed from Uniiversity of Bristol to NHS England

2019

- January - NHS Long term plan supports the continuation of LeDeR
- May - 3rd National Annual Report Published
- October - 1st Gloucestershire Annual Report Published for 2018-2019. Local Quality Assurance panels established

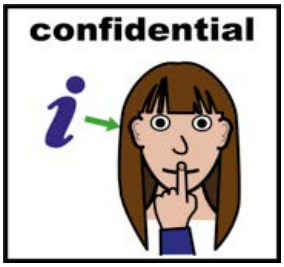
2020

- June - Gloucestershire LeDeR Framework Policy Approved
- October - 2nd Gloucestershire Annual Report published for 2019-2020.

2021

- 1st March - 31st May - No reviews commenced on any notifications during this transition period
- 23rd March 2021 - New National Policy Published
- May 2021 - Training on new LeDeR IT Platform
- 1st June 2021 - New LeDeR IT platform will be launched
- Summer 2021 - Local Annual report published
- Autumn - Reviews of Autistic People to commence

The use of data in LeDeR



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 who 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.

Legal basis for processing personal information (NHS England, 2021)[14].

The LeDeR programme submitted a request under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process confidential patient information without consent. This received approval from the Secretary of State for Health and Social Care. Section 251 of the NHS Act 2006 (ref: 20/CAG/0067 (previously 16/CAG/0056)) is the legal basis that allows identifiable information about deceased people with a learning disability and autistic people to be shared with the LeDeR programme.

The current status of the Confidentiality Advisory Group (CAG) Section 251 approval can be located at: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/ (April 2013 onward approved non-research applications).

Confidential patient information is information about either a living or deceased person that meets the following three requirements:

1. Identifiable or likely identifiable e.g. from other data likely to be in the possession of the data recipient
   and
2. Given in circumstances where the individual is owed an obligation of confidence
   and
3. Conveys some information about physical or mental health or condition of an individual, a diagnosis of their condition; and/or their care or treatment.

[14] Extract from NHS England National LeDeR Policy published 23rd March 2021

Local LeDeR steering group

As directed by the National LeDeR programme all areas should have a local steering group established. Gloucestershire's steering group is well established and has been in existence since the pilot project began in January 2017. The steering group provides oversight, support and governance to the local delivery of the programme. This group provides updates and assurance to the governance and operational groups as listed in Figure 2 - Local Governance Arrangements for LeDeR .These updates are supplied via the group's minutes of meetings, and regular governance reports provided for the purpose of assurance updates to stakeholders and the Integrated Governance Committee. Governance Arrangements for LeDeR. These updates are supplied via the group's minutes of meetings, and regular governance reports provided for the purpose of assurance updates to stakeholders and the Integrated Governance CommitteeFigure 2 - Local Governance Arrangements for LeDeR. These updates are supplied via the group's minutes of meetings, and regular governance reports provided for the purpose of assurance updates to stakeholders and the Integrated Governance Committee.

Gloucestershire LeDeR Mortality Review Steering Group - Governance Structure

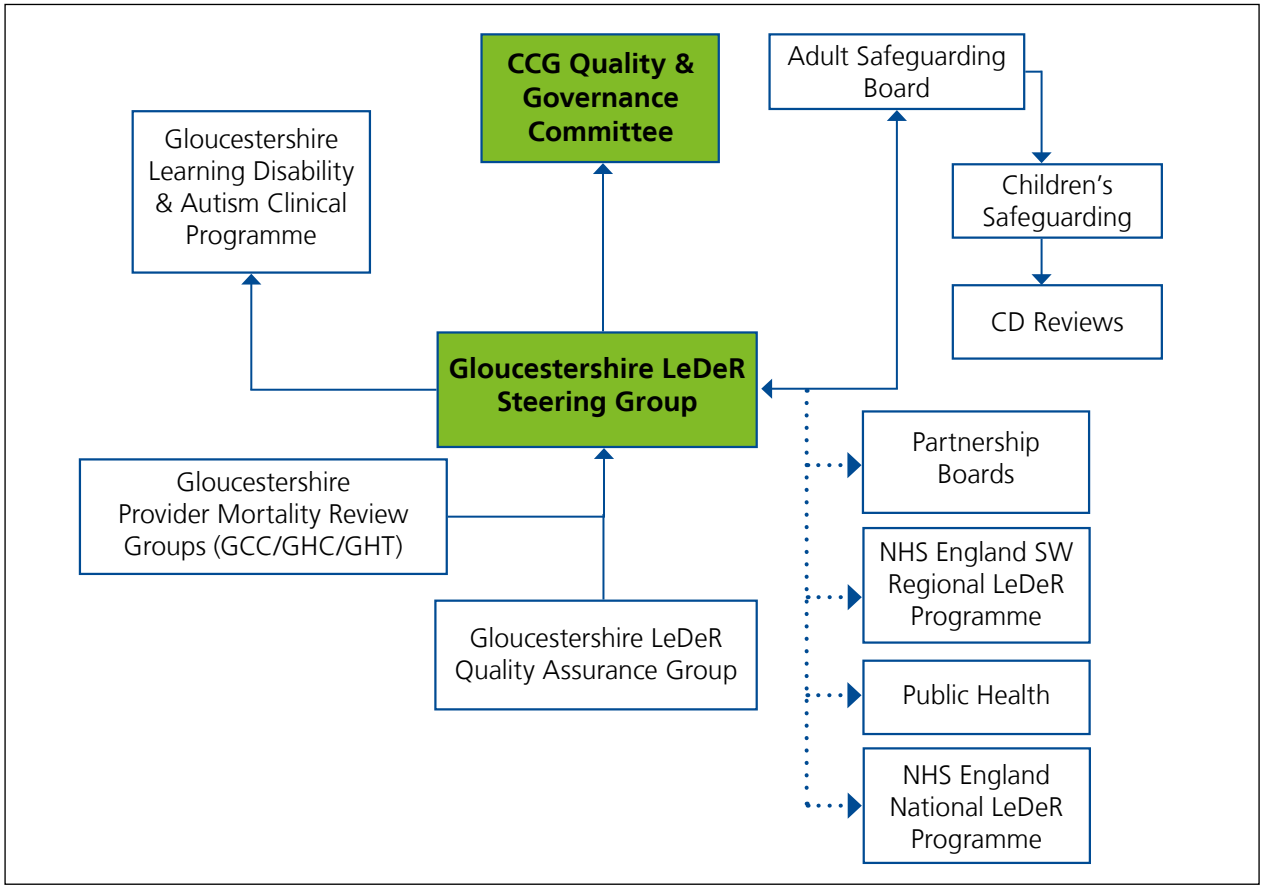


Figure 2 - Local Governance Arrangements for LeDeR 2020-2021

Local LeDeR Framework Policy

In In order to provide assurance to the Gloucestershire LeDeR steering group and the Quality and Governance Committee in June 2020 a local policy for how reviews are managed and learning into action is monitored was written and approved. This Policy has been published on the CCG website and can be found on the Gloucestershire Clinical Commissioning Website [15]. This framework will need to be reviewed and amended before April 2021 to reflect the changes within the new National LeDeR Policy.

Key individuals

To lead and manage the LeDeR Process within Gloucestershire there are a number of key individuals who ensure the local and national processes and policy are followed

- Local Area Co-ordinator (LAC) – this person acts as the supervisor of the local programme
- Secondary LAC – this person deputises for the LAC and ensures the actions from learning are followed up
- Independent Reviewers – these individuals have a range of backgrounds and skills

So how does the process work?

Anyone can notify the national programme of a death including people with learning disabilities themselves, family members, friends and paid staff. This notification until 31st May 2021 will be via the University of Bristol Website.

For 2020-2021 Gloucestershire have utilised the national promotional campaign to increase notifications, an example of a poster is shown in Figure 3 - National Poster

All deaths reported to the LeDeR Programme will have an initial review to establish if there are any specific concerns about the death, and if any further learning could be gained from a multiagency review[v] 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 will be held. All information will be accessed, edited and completed via the web-based portal/ LeDeR Review System.

[15] https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2020/07/100-LeDeR-Framework-June-2020.pdf

The current LeDeR process is described in Figure 4 - LeDeR process However, the initial review[16] includes:

- Checking and completing the information received at the notification stage[vii]
- 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 Local Area Contact[vii] and Steering Group[viii] and reviewed as part of the national LeDeR process

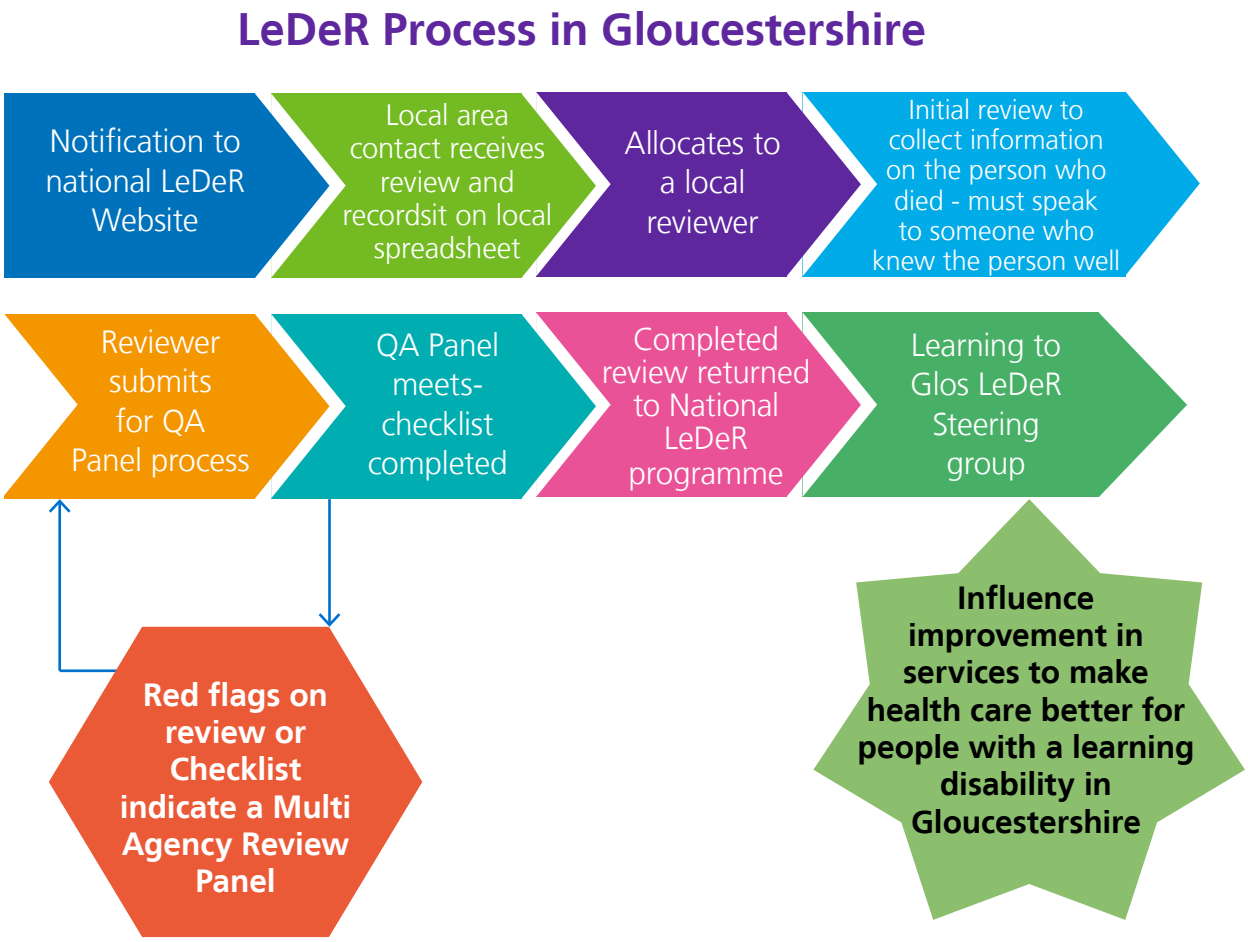


Figure 4 - LeDeR process this year

[16] Noting the initial review in the new National LeDeR Policy will change from 1st June 2021.

Governance connection with Gloucestershire Safeguarding Adults Boards (GSAB)

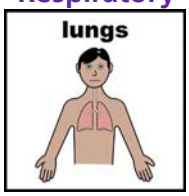
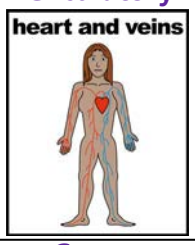
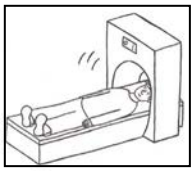
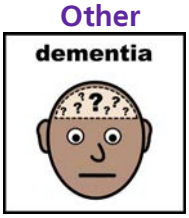
There are obvious and strong linkages between detecting and reducing premature mortality for individuals with a learning disability and safeguarding – particularly in relation to the preventative element of the role of GSAB. The Care Act clearly lays out responsibilities in relation to **safeguarding 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 GSAB 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 the GSAB there is a close working relationship with key personnel involved in GSAB. The independent chair of GSAB is a member of the LeDeR Steering group and is also a local LeDeR Reviewer.

LeDeR Learning into Action Themes explained

Respiratory 	Causes of death is in relation to the breathing and lungs e.g. aspiration/broncho pneumonia and respiratory tract infections.
Circulatory 	Cause of death is in relation to the heart and blood e.g. heart failure, sepsis, pulmonary embolism, coronary artery aaherosclerosis, pulmonary hypertension.
Cancer 	Cause of death is in relation to cancer e.g. Lung cancer, ovarian cancer, pancreatic cancer.
Gastrointestinal 	Cause of death is in relation to digestive areas e.g. gastroenteritis, abdominal infection, constipation, visceral perforation and faecal peritonitis.
Other 	A range of causes of death from road traffic accidents, dementia, epilepsy and liver failure.

Chapter Two - Deaths notified to the LeDeR programme

Notifications

Since the programme began there have been 211 Gloucestershire deaths reported to LeDeR covering the period January 2017 to end March 2021. Of which 192 of these deaths have had an initial review undertaken (Table 2 - Status of reviews by year). For the financial year 1st April 2020- 31st March 2021 there were 57 notifications (Table 1.) and 38 have had an initial review completed (67%). This is an increase from last years' performance at year end (60%).

Table 1 - Summary of deaths notified in 2020-2021

Total notifications in 2020-2021	**57**
Total notifications not yet assigned to a reviewer	**1**
Number of Open reviews (Including those on hold)	**19**
Total number of reviews awaiting Quality Assurance	**12**
Number of Multi Agency Reviews (MARs) undertaken in 2020-2021	**1**
Completed reviews in 2019-2020	**38**
Closed reviews to date (since 2017)	**192**

Table 2 - Status of reviews by year as at 31st March 2020

Year	Closed	Open	Total	% Completed
2016-2017	7	0	7	100%
2017-2018	51	0	51	100%
2018-2019	47	0	47	100%
2019-2020	46	0	46	100%
2020-2021	38	19	57	67%
TOTAL	**192**	**19**	**211**	**91%**

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.

Table 3 - Gloucestershire's LeDeR Performance

Performance Indicator 2020-2021	%	Comments
Allocation of reviewers within 3 months of notification	**100%**	TAll cases notified during 2020-2021 have been allocated within 3 months.
Completion of reviews within 6 months of notification	**95%**	This KPI was not met due to the cases on hold awaiting CDOP review, case notes or outcome of other investigative processes.

The majority of our LeDeR reviewers in the early part of the programme were volunteers who undertook reviews in addition to their day job, many of them are clinical professionals working in hospitals or in the community so they often had limited time to dedicate to complete reviews. We are grateful for their time and commitment to contribute to improving health care for people with learning disabilities. During 2020-2021 reviews have been undertaken by paid independent reviewers.

Actions taken to address KPI's 2020-2021

- Utilising funding received from NHS England we have utilised experienced paid reviewers who have a range of expertise to undertake reviews to assist us to meet the KPI
- In March 2021 there were 10 cases on hold.
- In March 2021 there were 12 cases awaiting Quality Assurance. As a result of this an additional panel has been introduced in April to clear these before the transition to the new system.

Limitations with the data

Unlike reviews of child deaths, which are required by law, reviews of the deaths of people with learning disabilities are not mandatory so professionals attending deaths are not required to report them to LeDeR. There is no automatic communication to LeDeR of the deaths of people on GP Learning Disabilities Registers. This makes it likely that notifications of deaths to LeDeR will be incomplete.

Delays in reporting deaths to LeDeR may affect monthly notification figures as deaths can be reported to the LeDeR Programme at any time.

It is important to remember that comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified to LeDeR from the age of 4 years, while general population data also includes information about children aged 0-3 years.

In addition, more people who died at a younger age had profound and multiple learning disabilities and some of these would also have had complex medical conditions or genetic conditions that may make an earlier death likely.

As the numbers are less than 10 for many of the causes of death, there is insufficient data to draw any meaningful conclusions.

National and regional comparison (correct as of 31.03.2021)

Nationally the South West Region has had the least deaths notified to the programme (n1156). The national reviews completed figure is 83% (better than the 52% in 2019-20) this is a marginally better performance than the South West regional completed percentage of 71% (higher than last year's performance of 45%).

In the South West Region, Gloucestershire has received the most notifications (n200) compared to the regional average of 169. This equates to 18% of the regional notifications (1% less than the previous year). Gloucestershire's reported % completed is the highest in the South West (89%) compared to the regional average of 81% and national average of 83%. This information is shown in Table 4 and Table 5.

Table 4 - National and regional comparison (correct as of 31.03.2021)

	All notifications to date	All notifications: complete	% Completed
Midlands	2307	1941	84%
North East and Yorkshire	2111	1796	85%
South East	1930	1624	84%
North West	1744	1429	82%
London	1434	1238	86%
East of England	1388	1022	74%
South West	1156	936	81%
Unknown	8	0	
Grand Total	**12078**	**9986**	**83%**

Table 5 - South West Regional comparison (correct as of 31.3.2021)[17]

	All notifications to date	All notifications: complete	% Completed
Gloucestershire	**200**	**117**	**89%**
Devon	206	177	86%
Dorset	179	158	88%
Bristol and NSSG	187	143	76%
BANES, Wiltshire and Swindon	144	115	80%
Somerset	131	99	76%
Cornwall & Isles of Scilly	109	67	61%
Grand Total	**1156**	**936**	**81%**

[17] the data in Table 4 & 5 is taken from the National LeDeR programme reports supplied by the University of Bristol. There is a slight delay in National LeDeR reporting, meaning the total number of deaths shown in Table 5 (for Gloucestershire) is less than the number given in the rest of the report.

Reporters of deaths

Gloucestershire Hospitals NHS Foundation Trust (which are the County's secondary physical care hospital trust) were the biggest reporters of deaths since the programme began in 2017 (n=45 deaths), with Gloucestershire County Council the second biggest reporters of deaths (n=33 deaths) **Table 6 - Reporters of death** and

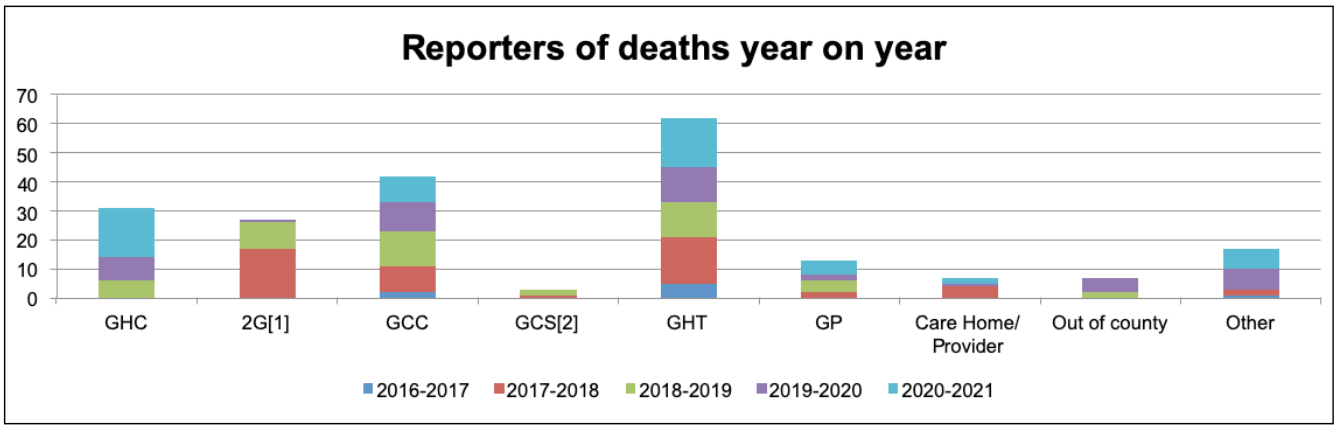
Chart 1- Reports of Deaths illustrates the breakdown of who reported the 151 deaths. For the financial year 2019-2020 (n46) GHT was the biggest reporters of deaths (n=12).

In 2019, Gloucestershire Care Services (GCS) and 2gether NHS Foundation Trust (2G) merged to form Gloucestershire Health and Care NHS FT (GHC), the data for GHC for 2016-2018 are therefore blanked.

Table 6 - Reporters of death

Year	GHC	2G[18]	GCC	GCS[19]	GHT	GP	Care Home/ Provider	Out of county	Other	Total
2016-2017		0	2	0	5	0	0	0	1	7
2017-2018		17	9	1	16	2	4	0	2	51
2018-2019	6	9	12	2	12	4	0	2	0	47
2019-2020	8	1	10	0	12	2	1	5	7	46
TOTAL	**14**	**27**	**33**	**3**	**45**	**8**	**5**	**7**	**10**	**151**

Chart 1 - Reports of Deaths - Reporters of Death



[18] In October 2019 2G and GCS Merged to become Gloucestershire Health and Care Foundation Trust (GHC)
[19] In October 2019 2G and GCS Merged to become Gloucestershire Health and Care Foundation Trust (GHC)

Chapter Three – About the people who died

Demographic data

The following charts and tables provide information about the demographic of the people who died.

Gender of people who have died

Charts 2 and 3 shows that in 2020-2021 there was an equal split of male to females' deaths this year (n 29). There does not seem to be any correlation in the gender and the median age of death.

Chart 2 - Gender of those who died in 2020-2021 in Gloucestershire compared to previous year

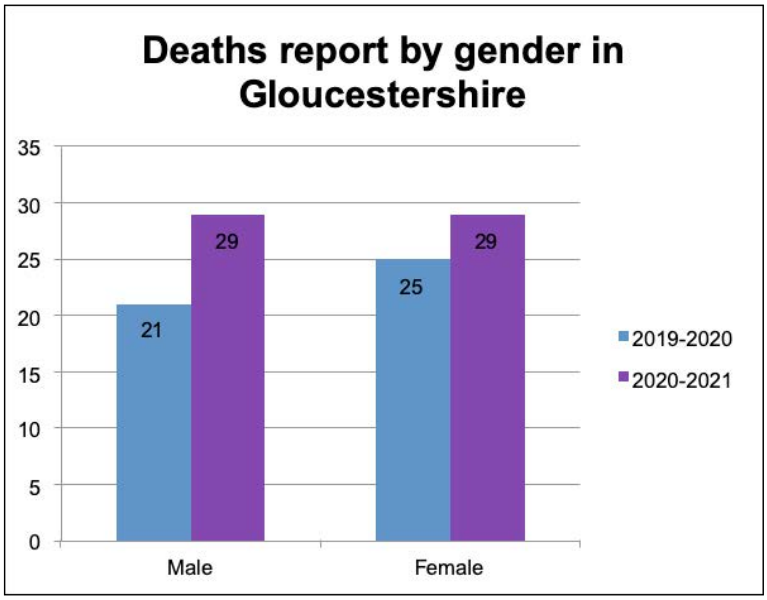
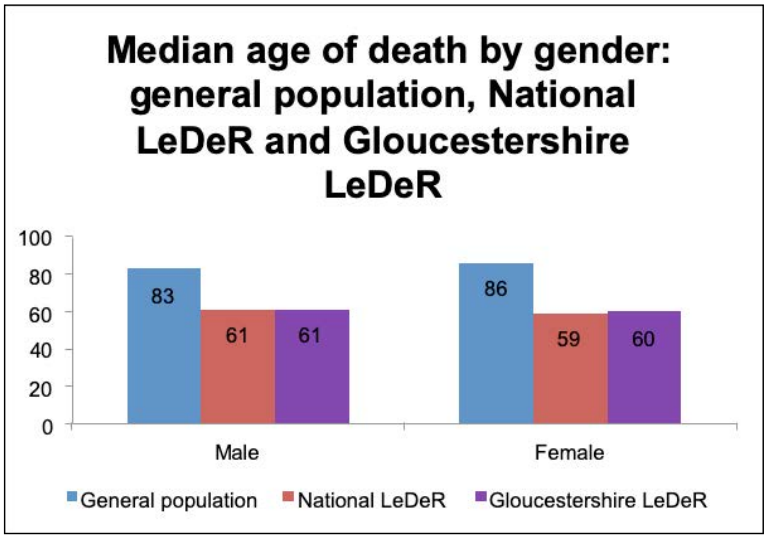


Chart 3 - Gender comparison local vs national vs general population



Ethnicity – For information governance purposes and to protect people's identity (because there was less than five deaths reported) where ethnicity was not "White British" this has not been included in this report. We recognise that further work to ensure we identify and have reported deaths from black, Asian and minority ethnic patient groups are reviewed.

Severity of Learning Disability – Of the 57 deaths reported in 2020-2021 (Chart 4), 28 have had the severity of learning disability recorded on the notification or completed initial review. Of the remaining 29 these are still to be reviewed and to go through a quality assurance panel. Broadly speaking the profile of severity of deaths in Gloucestershire is comparable year on year, but noting that on average there have been 5 deaths reported per month during the year 2020-2021, in previous years this average was 4 per month. There may be a number of factors influencing this increase, not least that more people are aware of the LeDeR programme and are therefore notifying the programme of a death. We are unable to draw any meaningful conclusions from this increase as the numbers are too low to hypothesise that the increase was due to covid-19 lockdown.

Chart 4 - Severity of Learning Disability in Gloucestershire

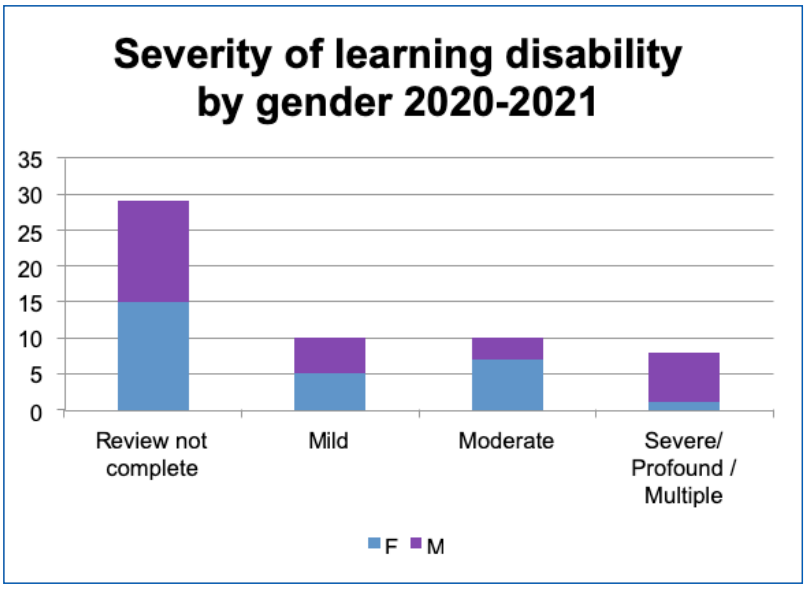


Chart 5 - % breakdown by severity of learning disability deaths in 2020-2021

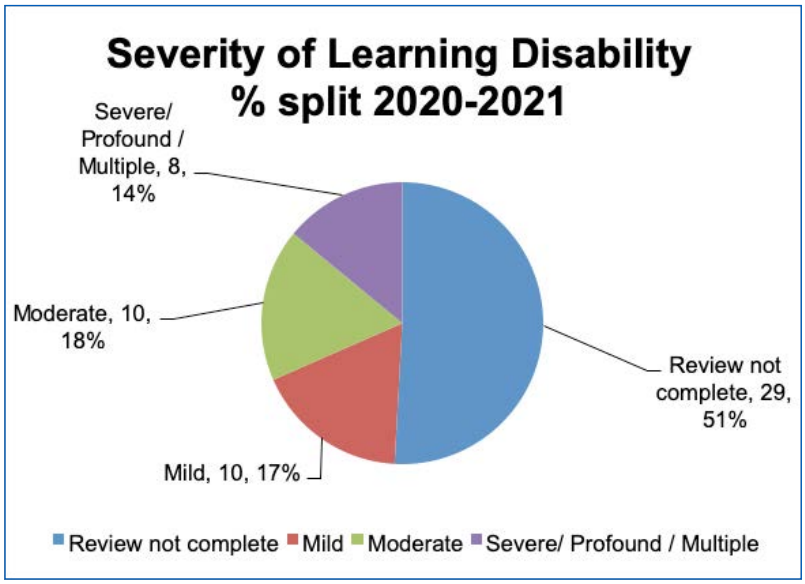
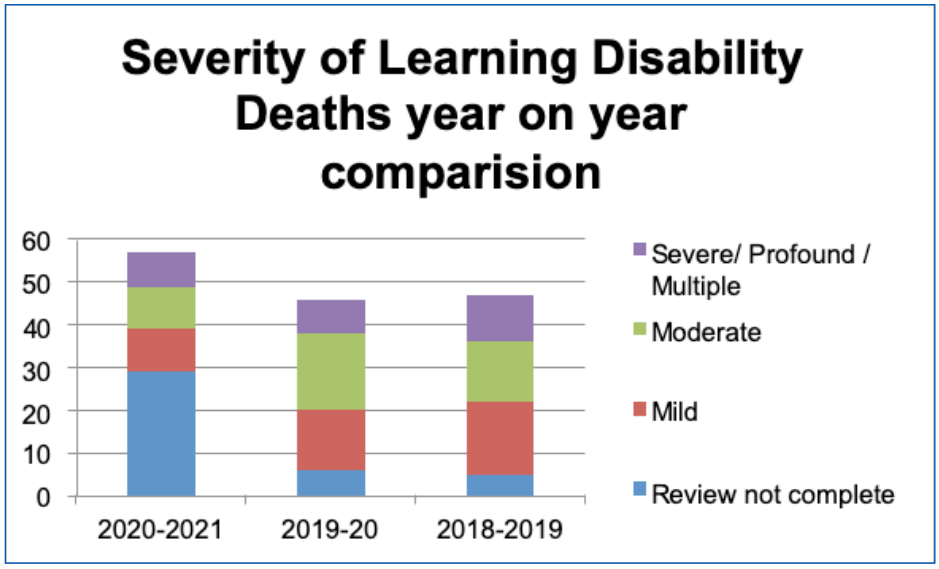


Chart 6 - Severity of Learning Disability Deaths reported to LeDeR - year on year comparison.



Co-morbidities –

The NICE Guideline 56[20] about clinical assessment and management of multimorbidity; defines multimorbidity as the presence of two or more long-term health conditions, which can include:

- Defined physical and mental health conditions such as diabetes or schizophrenia
- Ongoing conditions such as learning disability
- Symptom complexes such as frailty or chronic pain
- Sensory impairment such as sight or hearing loss
- Alcohol and substance misuse

Of the 28 reviews, where co-morbidities have been recorded in 2020-21; 53% had 3 or more co-morbidities.[21] In addition to this 46% (4% less than the previous year) of the reviews where co-morbidities were mentioned (n28 people) who died also had epilepsy (n13 people).

Table 7 - Co-morbidities

Condition	Number of people with the condition recorded 2020-2021	Number of people with the condition recorded 2019-2020
Epilepsy	13	16
Dementia	5	8
Cerebral Palsy	5	7
Downs Syndrome	*	7
Hypertension	5	*

** indicates less than 5 people*

[20] https://www.nice.org.uk/guidance/ng56
[21] Where co-morbidities were less than five these have not been included

Into County Placements

During 2020-2021 there were less than 5 deaths in Gloucestershire from people who had been placed into the county from other authorities. As the numbers are less than 5 we have not included further information within this report to protect anonymity.

Since the start of the LeDeR programme in Gloucestershire there have been n25 deaths of people who had been placed into the county from other authorities, almost half (48%) of these were placed into the county from South West authorities. *indicates a number less than <5 people

Table 8 - Into County Placement Deaths by financial year

Year	Number
2016-2017	*
2017-2018	5
2018-2019	10
2019-2020	5
2020-2021	*

Table 9 - Regions placing Gloucestershire

Region	Number
South West	11
South East	5
Midlands	*
Wales	*
North East	*
London	*

Chapter Four – Statistics

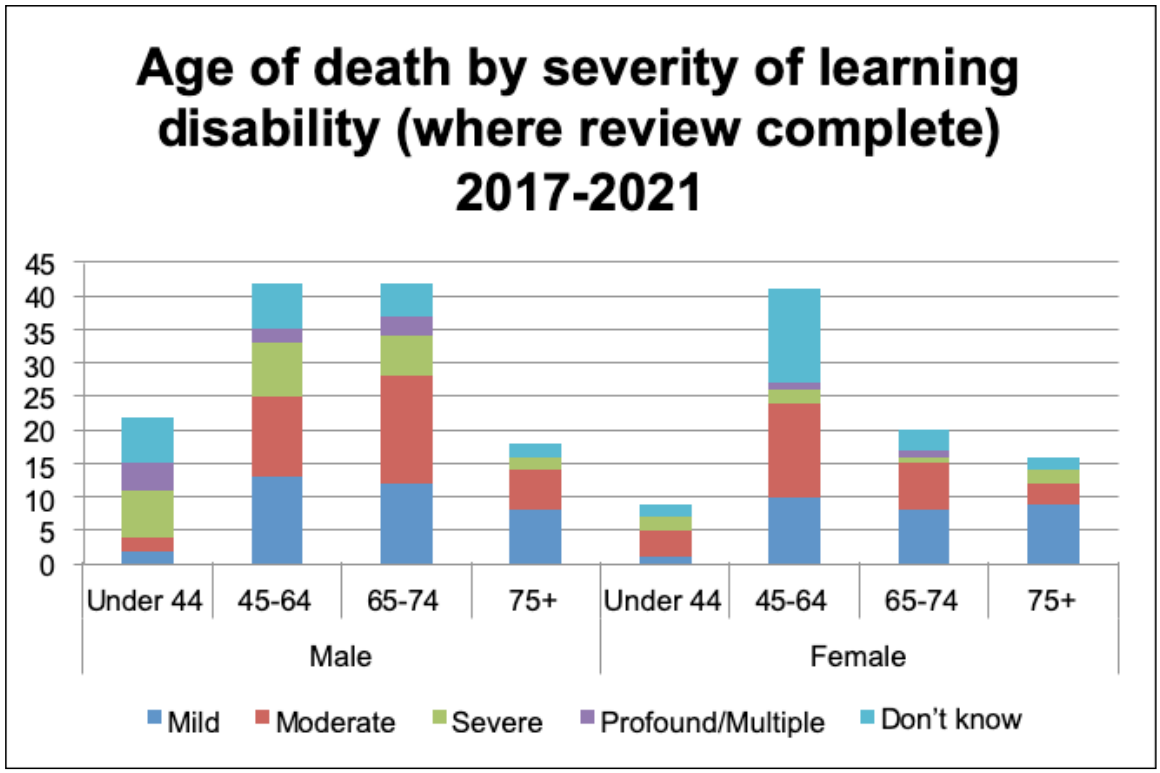
Age –

Here we report on the age at death of people with learning disabilities who died from 1st April 2020 onwards. It is important to remember that comparisons with the general population are indicative but not directly comparable. The deaths of people with learning disabilities are notified from the age of 4 years, whist general population data also includes information about children aged 0-3 years.

In addition, as we have mentioned in previous annual reports, the people who die at a younger age had profound and multiple learning disabilities and the majority of these had complex medical conditions or genetic conditions that may make an earlier death likely.

In the general population of England from 2015- 2017, the median age at death (for people of all ages, including 0-4 years) was 83 years for males and 86 years for females (Office for National Statistics, 2018[22]). In Gloucestershire the median age at death for Males with a learning disability was 61 (min 5 years; max 85 years) and for females was 60 (min 4 years; max 87 years). From the data reviewed for the whole programme no one with profound and multiple learning disabilities reached over 75 years old (min 19 years old; Max 68 years old). The median age of death for those with PMLD was 43 years old across the whole of the programme, noting that there have been less than 5 deaths of people with PMLD this financial year so we are unable to draw significant conclusions on the data for this financial year.

Chart 7 - Age of death by severity of learning disability whole of the programme[23]



[22] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk

[23] We are not able to report for each financial year as the numbers for some age brackets are less than 5 people and are potentially identifiable

Median age of death

Our data suggests a disparity (health inequality gap) in the age at death for people with a learning disability in Gloucestershire of 24 years when compared to the general population.

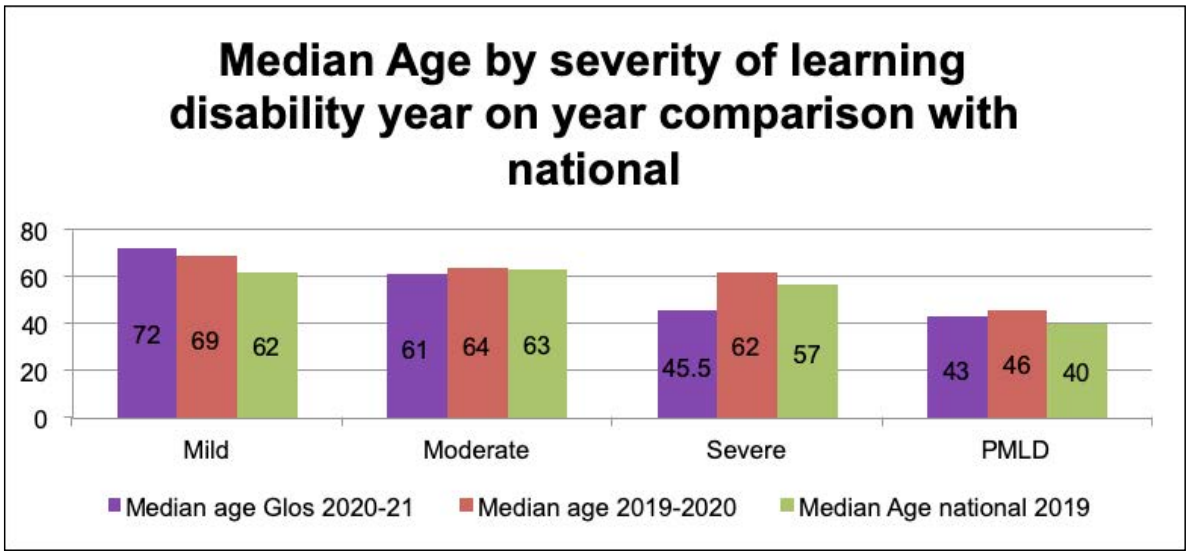
Table 10 - Average (Median) Age of death

	Gloucestershire		South West	National	General Population	
	Male	Female			Male	Female
2018-2019	65	65		59	83	86
2019-2020	61	61	62	60		
2020-2021	61	60	No recent data available			

Who is most at risk of dying young? *People with profound and multiple learning disabilities*

The median age at death for people with mild learning disabilities in Gloucestershire was 72 years old (an increase from last year of 69 years old, compared to the national report 2019 of 62 years); for moderate learning disabilities it was 61 years old (reduction from last year of 64, but comparable to the national report from 2019 of 63 years); for severe learning disabilities it was 46 (national report was 57 years); for profound and multiple learning disabilities it was 43 (last year was 46, compared to national report of 40) [24]

Chart 8 - Age of death by severity of learning disability whole of the programme[25]



[24] We are not able to draw conclusions on this data as there was less than 5 people with PMLD who died in the financial year

[25] Severe median min age of 5 and max age of 71, PMLD had less than 5 people whose review has been completed so not really enough data to draw meaningful conclusion on for this severity of learning disability.

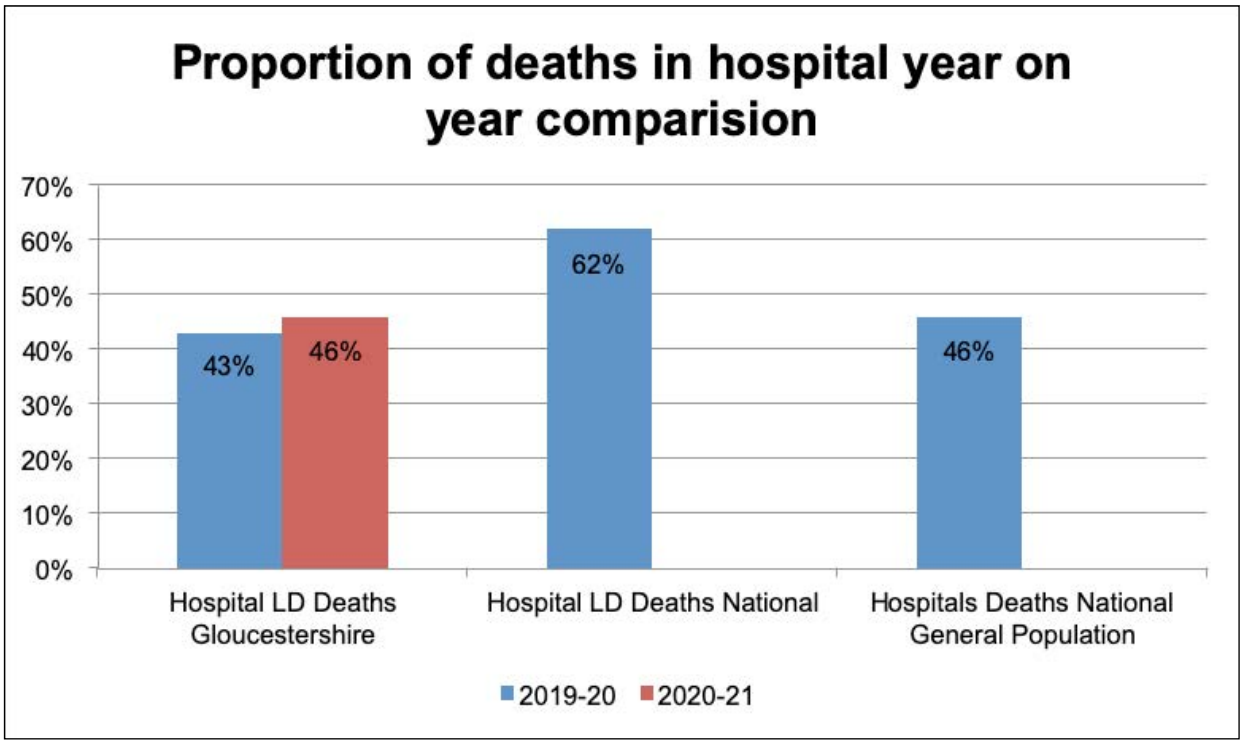
Place of death

Of the 57 deaths reported in Gloucestershire during 2020-21 46% (an increase of 3% from the previous year) died in hospital. The corresponding proportion for the general population is 46% (Chart 10 - Proportion of deaths in hospital in Gloucestershire compared with national (based on 2019 National LeDeR Annual Report).

Table 11 - Place of death

Place of death	Glos Royal Hospital	Usual Place of residence	Other community setting (e.g. hospice, with family etc)	Other Hospital	Hospital (OOC)	Residential/ Nursing Home or Residential school	Grand Total
Number of deaths 2020-2021	26	15	3	0	0	13	57
Number of deaths 2019-2020	13	16	3	5	2	7	46
% 2020-21	46%	26%	5%	0%	0%	23%	100.00%

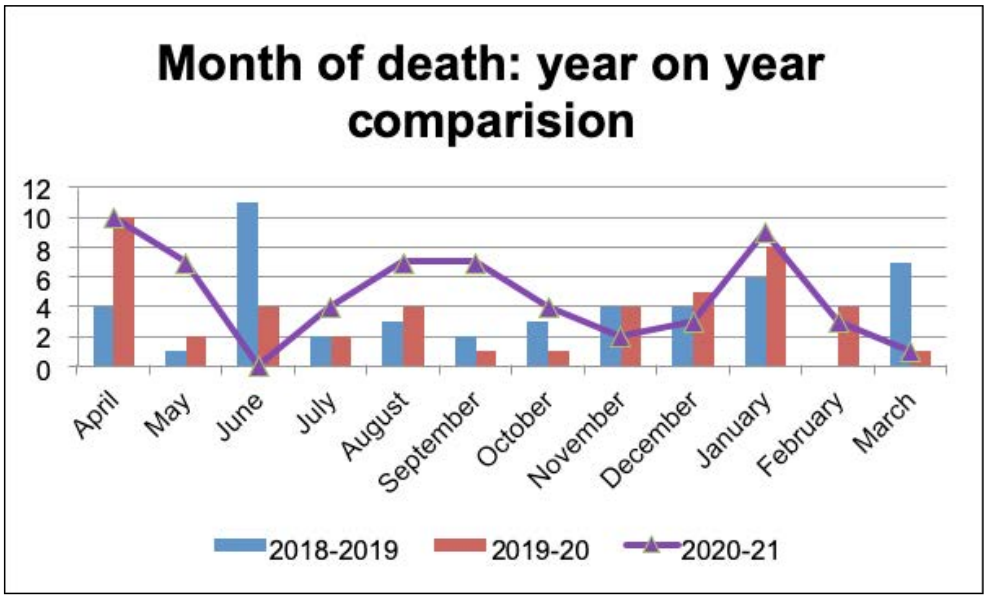
Chart 9 - Proportion of deaths in hospital in Gloucestershire compared with national (based on 2019 National LeDeR Annual Report)



Month of death

Of the deaths reviewed in 2019-2020 for which coded data was available about end of life care, over half (58%) were expected and planned deaths. Of this 57% (an increase of 1% on the previous year) had an active end of life plan in place (this compares to 46% nationally).

Chart 10 - Month of death



Comparing month on month between the three financial years shows a similar proportion year on year. On average over the previous two years per month there was 4 notifications per month, during 2020-2021 this has increased to an average of 5 notifications per month (min: 0, Max 10). There is a steady rise in deaths over the autumn and winter months. Some caution is required in interpreting this data; as without mandatory reporting of all deaths to LeDeR it may in part, reflect trends in reporting deaths to the LeDeR Programme.eDeR it may in part, reflect trends in reporting deaths to the LeDeR Programme.

End of life and was the death expected?

Of the deaths reviewed in 2019-2020 for which coded data was available about end of life care, over half (58%) were expected and planned deaths. Of this 57% (an increase of 1% on the previous year) had an active end of life plan in place (this compares to 46% nationally).

Chart 11- Expected Deaths (where recorded)

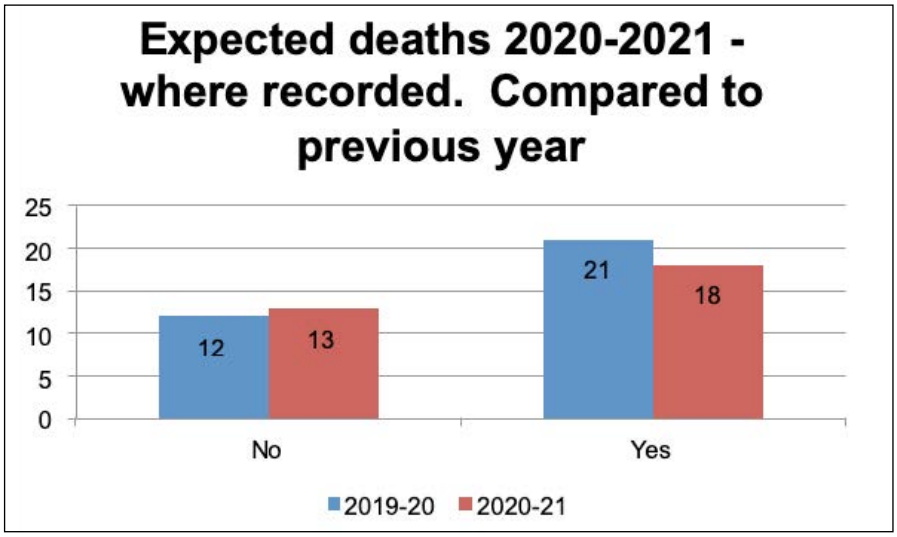


Chart 12 - % Expected deaths (where recorded on the review)

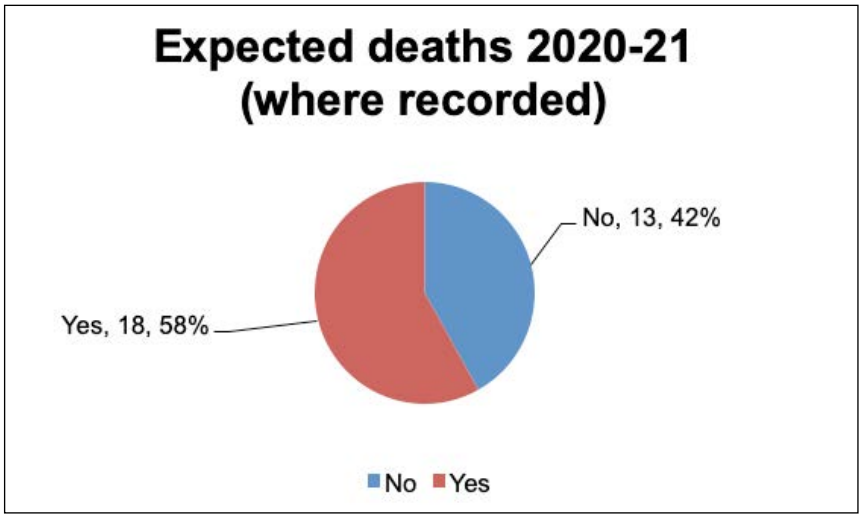


Chart 13 - Number of deaths where an end of life plan was in place

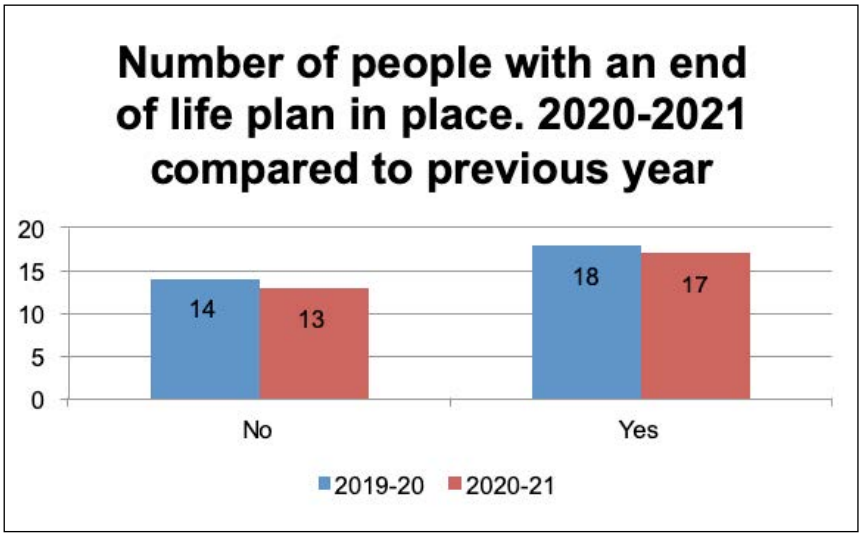
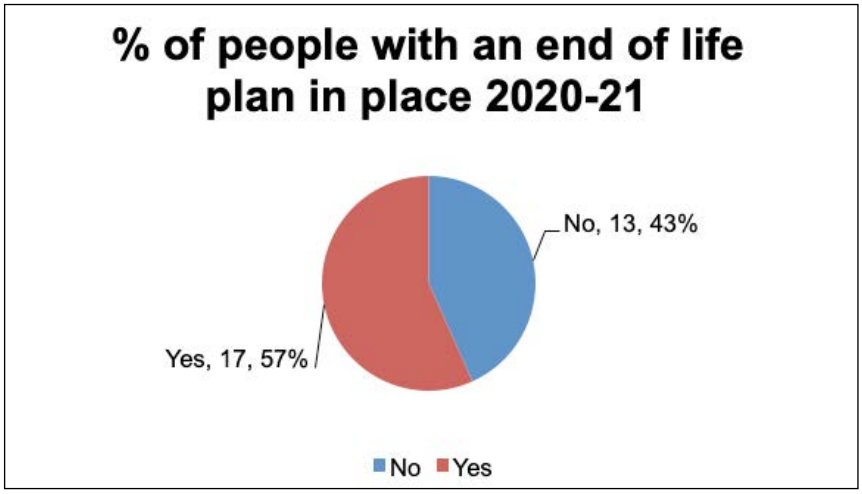


Chart 14 - % of people who died with an end of life plan in place



Deaths with a Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) order[26] in place

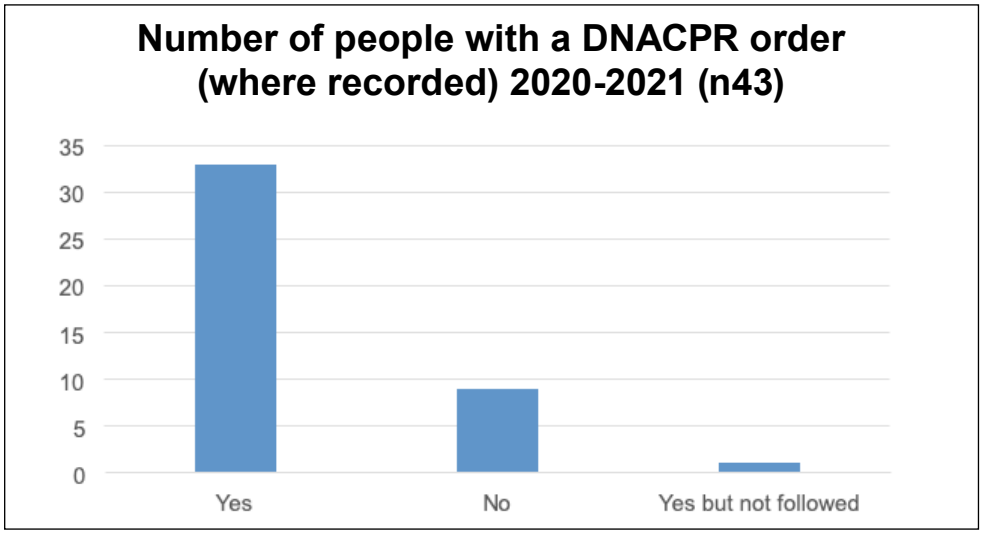
Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing explicitly states that decisions about DNACPR must not be based on assumptions related to the person's age, disability or the professional's subjective view of a person's quality of life [27].

When used appropriately, a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) order should help to ensure that a patient's death is as peaceful and dignified as possible, without traumatic and painful physical intervention at the end of their life. Sometimes referred to as DNAR or DNR, a DNACPR order applies only to cardio-pulmonary resuscitation, where it is assessed to be clinically appropriate, and where a decision has been made with the appropriate involvement of the patient, their relatives or carers.

For people with a learning disability, sadly, it is evident from national reports [28] written over the last year during the pandemic that sometimes the complex combination of clinical circumstances and a lack of patient or family/carer involvement leads to the inappropriate issue of a DNACPR order. Raising questions or concerns with a doctor about a clinical decision and the decision making process is both complex and daunting, so Turning Point have worked with Learning Disability England to produce an information pack and DNACPR checklist[29] , that will help families and carers understand the issues and jargon involved in DNACPR orders, and enable them to raise questions and concerns appropriately. The pack includes a checklist that people can review a DNACPR order against, plus explanatory notes on people's rights and the legislation involved.

Of the 57 people notified to the programme in 2020-2021, and of those that the review has been completed 33 people (77% shown on Chart 15 and Chart 16) had a DNACPR order in place and it was completed correctly. This is a slight improvement from the previous year (72%).

Chart 15 - Number of people where DNACPR was noted on the completed initial review (n43)



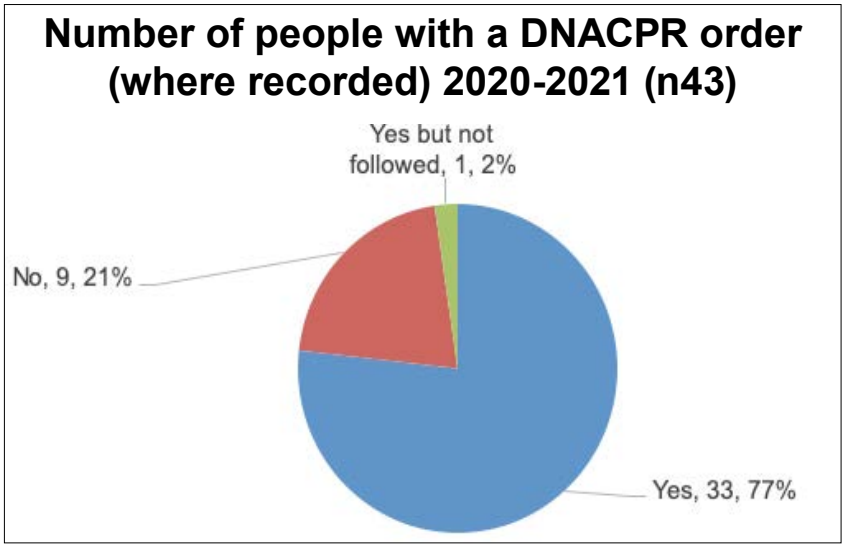
[26] Cardio-pulmonary resuscitation is when a person receives chest compressions and artificial breaths to help pump blood around their body when their heart has stopped. A decision not to attempt cardio-pulmonary resuscitation is made and recorded in advance when it would not be in the best interests of the person because they are near the end of their life or the procedure would be unlikely to be successful.

[27] https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/

[28] https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities

[29] https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/DNACPR-Support-Pack.pdf#:~:text=For%20people%20with%20a%20learning%20disability%2C%20sadly%2C%20it,to%20the%20inappropriate%20issue%20of%20a%20DNACPR%20order

Chart 16 - % of people where DNACPR was noted on the completed initial review (n43)



Cause of deaths

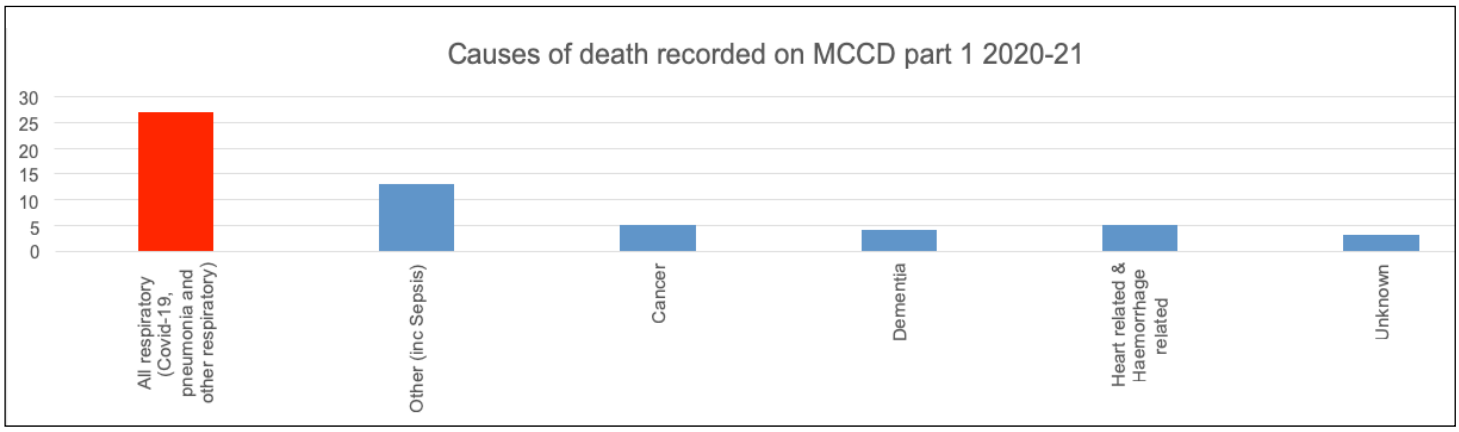
The World Health Organisation defines the underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury. Table 12 - Cause of death combined. Covid-19 was the most frequently cited in part I of the MCCD (Death certificate) of people with learning disabilities in Gloucestershire 25%. Pneumonia was more frequently the cause of death in people with severe or profound and multiple learning disabilities (55.5%) compared to people with mild/moderate learning disabilities (44.5%), However as the numbers are less than 10 for many of these causes of death, there is insufficient data for any meaningful conclusions.

Table 12 - Cause of death combined 2020-2021

Cause of death	Number of deaths 2020-2021	% of cause of deaths Gloucestershire 2020-2021 n57	Movement from previous year	Number of deaths 2019-2020	% of cause of deaths Gloucestershire 2019-2020 n46	% England LD Population cause of death age 4+ 2018-2019 n1938	% of general population n529,605
Covid-19	14	25%	-				
Pneumonia	6	19%	↓	9	19.57%	25%	
Cancer	4	9%	↑	8	17.39%	14%	28%
Other[30]	9	21%	↓	6	13.04%	Not able to directly compare as reported differently in the National LeDeR Report 2018-2019	
Dementia	4	7%	↓	6	13.04%		
Sepsis	1	2%	↓	5	10.87%		
Unknown[31]	8	5%	↓	5	10.87%		
Respiratory[32]	3	4%	↑	3	6.52%	19%	14%
Heart related[33]	2	5%	↓	2	4.35%		
Haemorrhage related[34]	2	4%	↓	2	4.35%		
TOTAL	57			46			

[30] Drug overdose, Epilepsy, Fall, Frail, Multiple organ failure, Large bowel obstruction, natural causes, multiple injuries, Urinary tract infection,
[31] Review not completed or information not on original notification
[32] Respiratory tract infection, respiratory failure,
[33] Congestive Cardiac Failure (CCF), coronary artery occlusion, Sudden cardiac death in the setting of complex congenital heart disease
[34] Upper gastrointestinal haemorrhage, Stroke, Spontaneous Intraparenchymal haemorrhage

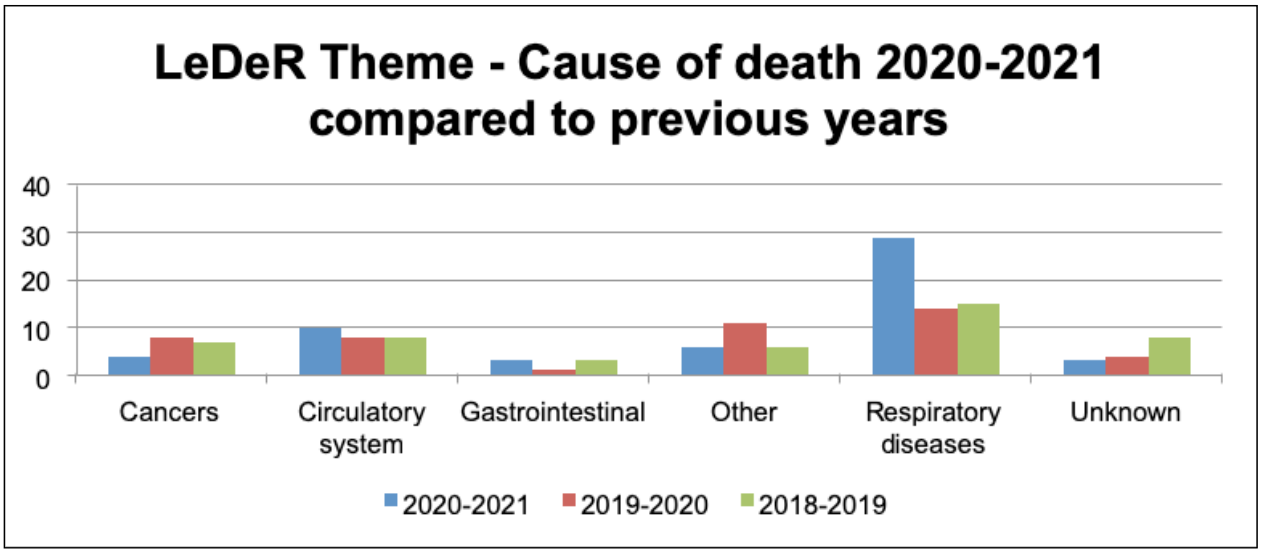
Chart 17 - Cause of Deaths reported 2020-21



Cause of death – LeDeR Themes in Gloucestershire

Chart 18 - LeDeR Theme cause of death 2020-21 compared to previous years[35] shows that the top cause of death in the learning disabilities population remains from respiratory causes (n29). This is a 100% increase on the previous year and can be attributed to the covid-19 pandemic (n14 people died of covid-19 with a learning disability)

Chart 18 - LeDeR Theme cause of death 2020-21 compared to previous years



[35] Where unknown this indicates the review has not yet been completed or the notification did not have cause of death listed.

Chapter Five - Action from Learning

Indicators of the quality of care provided

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 area reviewers are asked to consider include:

The person and /or their environment 	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: 	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: 	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 (SLT) or hospital learning disability liaison nurses.

What the Quality Assurance Panel role is?

The Gloucestershire LeDeR Quality Assurance (QA) Panel was set up in October 2019. It provides a consistent approach to signing off completed reviews. Reviewers are invited to bring cases to the panel for advice and guidance. The panel uses a checklist (this can be found in the Gloucestershire LeDeR Policy) to ensure consistency of approach and a record of the discussions of each panel is kept.

	To be a panel of experts by experience to oversee and manage the quality assurance process for all LeDeR Reviews.
	To undertake a quality assurance role in respect of: • the role of the reviewer (training/train the trainer, buddy system, etc) • the quality of reviews (sharing learning of reviews and best practice) • Provide support for reviewers' professional development e.g. bereavement, report writing etc
	To collate the recommendations and learning from reviews into a local action plan on behalf of the LeDeR Steering group.
	To help interpret and analyse the data submitted from local reviews, including areas of good practice in preventing premature mortality, and areas where learning and improvements in practice could be made and provide update reports to the LeDeR Steering group as required.
	Where the group feels that it is appropriate, cases will be referred on to Safeguarding.

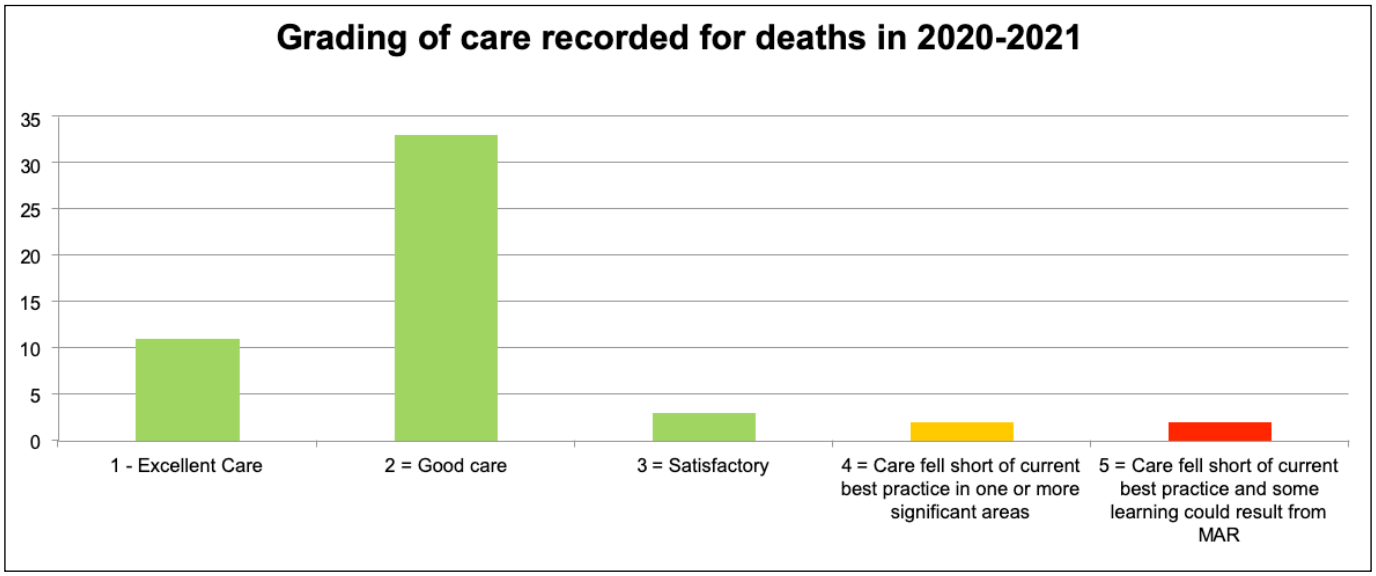
Assessment of the quality of care

On completion of a case the reviewer is required to assess the level of care provided on a range from 1 (excellent) to 6 (care fell far short of expectations). Of the 51 cases where the quality of care has been recorded and submitted 9 out of 10 people had Satisfactory or better care. Compared to the previous year 22% of people had excellent care which is an improvement on the previous year.

Table 13 - Grading of care 2020-21 compared to previous year

	Number 2020-2019	%	Total & ratio	Number 2019-2020	%	Total & ratio
1 - Excellent Care	11	22%	47/51 9:10	0	0%	27/30 9:10
2 = Good care	33	65%		24	80%	
3 = Satisfactory	3	6%		3	10%	
4 = Care fell short of current best practice in one or more significant areas	2	4%	4/51 1:10	2	6.67%	3/30 1:10
5 = Care fell short of current best practice and some learning could result from MAR	2	4%		1	3.33%	
6 = Care fell short of current best practice resulting in potential for, or actual adverse impact	0	0%		0	0%	
Cases where grading of care has not recorded (CDOP or not complete	6					

Chart 19 - Grading of care recorded 2020-2021

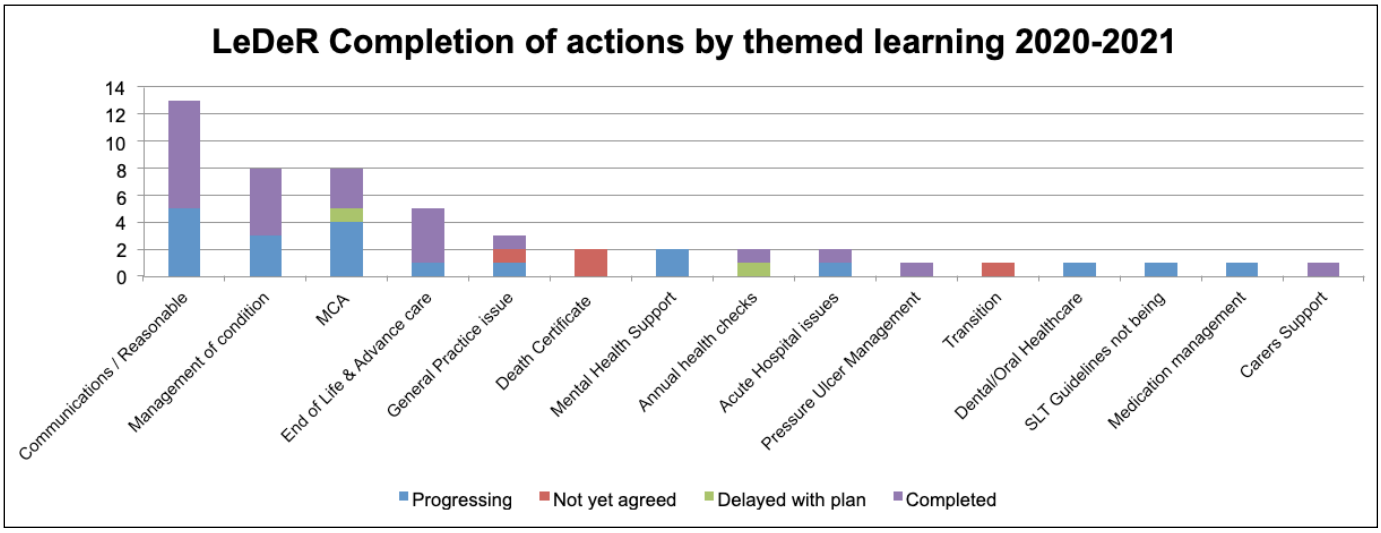


Gloucestershire LeDeR Quality Assurance (QA) Panel Feedback

Glossary of themes for learning into action

Acute Hospital issues	Issues with the care and treatment received at Gloucestershire Royal or Cheltenham General Hospitals.
Annual health checks	Issues with the annual health check that the person did/ or did not get.
Case Management	Issues with how health and social care worked together to jointly support someone.
Communications and reasonable adjustments	Issues with how health and social care communicated with the person, their carers or their family e.g. use of easy read and reasonable adjustments for example longer appointments.
Diagnosis	Issues with finding out why someone is poorly e.g. blood tests etc.
Family/Carer support	Issues with how the person was provided carer or family support inc reasonable adjustments and documentation such as hospital passport to support an individual with learning disability to be appropriately supported.
General Practice issue	Issues highlighted with specific GP surgery or primary care guidance.
Healthy Lifestyles	Issues highlighted with support provided to the individual to remain healthy e.g. weight management, stopping smoking advice, exercise etc.
Management of condition	Issues with how specific conditions are managed by health care professionals including the resources, guidelines and training provided to health care professionals.
MCA	Issues with how the mental capacity act was followed inc use of advocacy, DNACPR etc
Safeguarding	Issues with how safeguarding concerns were acted upon.
Death Certificate	Issues with the cause of death that was recorded.
Documentation not completed correctly	Documentation not completed correctly.
Documentation not completed correctly	Issues with those who were at the end of their life and planning for their care including advance plans e.g. ReSPECT, funeral planning, bereavement support for carers etc.
Pressure Ulcer Management	Issues identified with how pressure ulcers were managed and treated including use of equipment and dressings.
Transitions	Issues with the how care was co-ordinated between childhood and adulthood including ensuring the person was on the GP Learning Disabilities register.

Chart 20 - Actions from Quality Assurance Panel for 2020-2021



The QA Panel noted the following areas of good practice for the reviews completed in 2020-2021.

Local Theme	Panel Feedback
Aute Hospital	• Hospital Learning Disability Liaison Nurse involvement. • Completion of Hospital Passport to aid his care, support and treatment whilst in hospital. • Completion of Patient Experiencing Memory Loss and Deterioration Known to have Dementia Form to further aid his care, support and treatment whilst in hospital. • Enhanced care when in hospital, a Health Care Assistant was provided for inpatient care. • Excellent communication between the Doctor at GRH and the home manager during his last admission. The home manager told the reviewer that doctor caring for the individual made lots of phone calls to her, giving in-depth explanations so she felt fully informed. • Someone familiar stayed with him when he was in hospital to try and ensure a positive outcome. • The individual had an up to date hospital passport which supported the nurses in the acute trust to provide appropriate care. The LD liaison nurse also supported while she was in hospital. • Mum was allowed to stay with her in hospital despite the COVID restrictions which supported effective care and treatment and reduced the individual's anxiety
Case Management	• Involvement of IHOT, Rapid Response and CLDT as required. • Intensive Health Outreach Team (IHOT) was invaluable in supporting the residential care home. IHOT were able to work with the residential care home to provide expert LD support and intervention which enabled the person to stay at home rather than further hospital admissions. • Underwent annual health checks, annual reviews for conditions and had a comprehensive health check action plan in place. • Had a Hospital Avoidance Admission Care Plan in place. • Good liaison between all people involved. Planned transition from out of county to Gloucestershire. • Had a Hospital Avoidance Admission Care Plan in place, but there was good communication between medical staff and next of kin during her final admission. • Was well supported by carer's, his GP and a District Nurse to remain at home.

Local Theme	Noted specific feedback from QA Panel
Reasonable adjustments	• Staff were willing to undergo and do intensive de-sensitisation programmes about medical procedures with this individual to try and persuade her to participate in her care. Person centred care and reasonable adjustments to allay fears should always be encouraged. • Excellent use of reasonable adjustments especially the easy read letter which the GP sent following Annual Health Checks.
Care provision	• Personalised care in regards to reasonable adjustments. Carers were creative and resourceful in order to ensure he was able to enjoy the activities he valued until the end of life. • Carers were creative and resourceful ensuring he was able to continue getting out into the community whenever possible and replicating his activities at home when he was unable to leave the house. • Familiar carers who knew him well and he trusted were central to ensuring a great quality of life (team leader had known him for more than 30 years). • Care staff and GP knew the person for 20 years and were familiar with his form of communication. Staff said they felt they were listened to and their concerns about his health were taken seriously by the GP. • Excellent advance care planning – care home went above and beyond to keep the individual at home to die and the staff all received palliative care training. The reviewer also noted that the individual's family were "supportive and amazing" working very closely with the care staff alongside Rapid Response team and the District Nursing team. • Had a Hospital Passport and Positive Behaviour Support plan in place.
Communications and use of technology	• Ingenious use of aids and technology - as the person's verbal communication was limited carers used objects of reference, picture cards, an egg timer and photographs of staff so the individual knew what/who to expect and when. Alexa gave the person prompts about medication. • Excellent communication with all concerned working together in the person's best interests whatever the time of day or night. • Good range of communication aids including use of iPad and communications software/Makaton (staff also trained)
End of life care and Advance care planning	• Completion of Advance Care Plan (ACP), ReSPECT form and Shared Care plan. • RESPECT Form in place, Completion of Gloucestershire End of Life Shared Care Plan for the expected last days of life booklet. • Early and effective advance care planning. • Palliative Care Stage identified early. • Good End of Life Care at home with support of GP/District Nurse.
Use of legislation e.g. Mental Capacity Act	• Effective use of MCA and advocacy services. IMCA was actively involved as there was no family.

The QA Panel noted the following areas which had a negative impact on the persons care and treatment that adversely affected their health.

Local Theme	Noted specific feedback from QA Panel
Acute Hospital	• Safe discharges are paramount to prevent re-admission.
Management of condition	• Despite being informed of the persons' learning disability the paramedic did not adjust his method of communication, use comforting aids or encourage family to assist to reduce anxiety

MCA	• Mental Capacity Assessments not always clearly documented. • Next of Kin must be informed in a timely manner and fully involved in decisions regarding the health and treatment of their loved ones (if the person has capacity they can request this). Health outcomes are improved if an advocate is involved. • Poor use of MCA - family not involved in RESPECT Form/DNACPR
Medicines management	• The panel were concerned that he had been on an old style anti psychotic drug for a while, the pharmacist on the panel noted that this should have been reviewed more frequently, only mentioned once in medicine table. Couldn't see evidence of a recent medication review as part of annual health check.

The QA Panel noted the following problems with organisational systems and processes that led to a poor standard of care.

Local Theme	Noted specific feedback from QA Panel
Acute Hospital	• The panel noted that the individual's family highlighted 'poor care' in the hospital. They felt the ward staff did not understand how to care for people with a learning disability. They were grateful for the LD liaison nurses who visited him on the ward and signposted the ward staff to his hospital passport which then assisted with reasonable adjustments.
Case Management	• There were a couple of failed appointments which were not fully followed up by the GP's. Was Not Brought campaign to be shared. • Frailty score for LD to be considered by the national programme.
Care Provision	• A smaller care home which had the competencies to support people with a learning disability may have been able to give him more bespoke care to meet his needs. He did have good care and was happy in his older persons placement but it was not set up to cater for people with a learning disability so his needs could not be fully addressed. He was placed in a larger care home that provided nursing care. His family and carers felt that he would have been happier if he had been placed in a specialised unit that catered for people with a learning disability, dementia and nursing care.
Management of condition	• There could be wider learning regarding ensuring people with learning disabilities who had known risk factors are on official shielding lists and have the support to understand what is required for shielding. • Weight monitoring and nutritional state – scales, eating and drinking. Are care homes clear where they can access weighing scales for people in wheelchairs? • Depression – wasn't prescribed medication or referral to CLDT by the GP to review mental health and impact of lockdown and not seeing family. • Dental – work to be done around education of dental issues and where to seek support. Action: include easy read resources and case study about why dental hygiene is so important. • There was a delay in investigating his deterioration. The panel noted that due to covid many people had routine investigations delayed. The panel could not comment on whether early identification of a condition would have altered the outcome for him. His family believe that it would not have made a difference and that he would have been reluctant to have invasive investigations or treatment.
End of life care and Advance care planning	• Late completion of the RESPECT Form and timely end of life planning. Consideration of those who are frail to have early conversations about their wishes (RESPECT).

Findings from Multi Agency Review Panels (MARs)

During 2020-2021 two MAR Panels were held virtually because of the covid-19 pandemic.

Cause of death: one person died from bowel cancer (age 61) and the other person died from natural causes (age 52).

Potentially avoidable contributory factors in relation to the person and their environment

Case	MAR Panel Feedback
1 – Bowel Cancer	**Supported living** 1. Additional support for providers to help people with a learning disability understand the importance of screening programmes. 2. Resources to help people with a learning disability communicate when they are in pain. **Hospital stay** 1. Best interest notes and MCA forms completed and available on the ward would be of help. **Social Care** 1. Timely communication with social care that XX was palliative and would require access to nursing care and ground floor bedroom as his disease progressed
2 – Natural Causes	**Reasonable adjustments:** 1. XX was extremely anxious and unsteady on their feet, a chair to move them in could have been provided by the paramedics. 2. Family members were not listened to and during the last hours of XX's life which increased the persons anxiety. **Environment:** 1. Access to the street was down a steep concrete stair that was uneven and indifferently lit. Given concerns regarding community support and XX's anxiety in accessing the community, consideration should have been given to providing the family with accommodation that allowed easier access to the community, for example a ground floor supported living home. **Hate Crime:** 1. There was evidence of hate crime by neighbours but no appropriate action taken by the police or housing.

Potentially avoidable contributory factors in relation to care

Case	MAR Panel Feedback
1 – Bowel Cancer	**Primary Care -** 1. Pain management – XX regularly complained of abdominal pain. A consistent approach to monitoring of pain in people with a learning disability would have been helpful for clinical staff. They were too reliant on what he was telling them. The panel queried if there was some diagnostic overshadowing occurring because XX did not know how to consistently tell health care professionals he was in pain – they therefore put it down to overeating. 2. Pain relief – delay in prescribing XX with any pain relief. **Glos Hospital -** 1. Delays in referring XX to the palliative care team resulted in delay in application for CHC End of life funding and therefore timely access to nursing care. **Social Care -** 1. Unclear why XX's care and support plan was reliant on results of his biopsy results, when it had already been agreed he was palliative and end of life. Overall the panel agreed that a multidisciplinary meeting would have been in XX's best interests, ideally as a minimum involving; primary care, secondary care, social care, XX and his family. The GP would have been best placed to call this meeting prior to him being admitted to hospital.

Case	MAR Panel Feedback
2 – Natural Causes	**Reasonable adjustments:** 1. Despite being informed of XX's learning disability the paramedic did not adjust their method of communication, use comforting aids or encourage XX's family to assist. **Management of condition:** 1. The paramedic did not take a second set of observations or administer oxygen. 2. XX was very unwell upon the arrival of the ambulance crew and later died from a Pulmonary Embolism, which is associated with a high mortality rate when managed in the pre-hospital setting. Therefore, whilst it is acknowledged that best care was not provided, it cannot be definitively confirmed that good care would have altered the outcome in this instance.

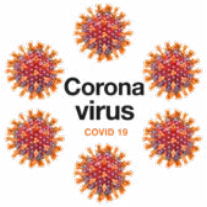
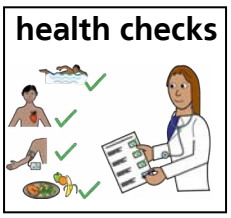
Potentially avoidable contributory factors in relation to services

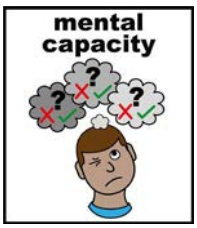
Case	MAR Panel Feedback
1 – Bowel Cancer	**Primary Care -** 1. Pain management – No clear methodology for recording pain in use for those with a learning disability. 2. Pain relief – delay in prescribing XX with any pain relief. **Glos Hospital -** 1. Delay in application for CHC End of Life funding – greater clarity over the process so all stakeholders are aware to reduce delays. Overall the panel agreed that a multidisciplinary meeting would have been in XX's best interests, ideally as a minimum involving; primary care, secondary care, social care, XX and his family. The GP would have been best placed to call this meeting prior to him being admitted to hospital. Noted by the panel that XX's cancer was rapidly progressive and his death was not avoidable. However, timely access to pain medication and palliative care support would have prevented him suffering as much in his final weeks of life.
2 – Natural Causes	**Diagnostic overshadowing:** 1. Had it been identified by the Ambulance crew that XX was acutely unwell and not suffering from an anxiety attack, the utilisation of a second crew may have been considered which would have allowed for additional hands to assist with the use of the carry chair. The additional pressure placed upon XX's heart during the walk to the ambulance is likely to have worsened the condition and could have potentially been avoided had the carry chair been used.

Lessons Learnt

Case	MAR Panel Feedback
1 – Bowel Cancer	**Primary Care -** 1. Pain management – A consistent approach to monitoring of pain in people with a learning disability would have been helpful for clinical staff e.g. DISDAT or Abbey pain scale. 2. Pain relief – Easy read resources and communication tools for people with a learning disability to be made available to support them to communicate their pain and identify what the pain relief options open to them are. **Glos Hospital -** 1. Use of the MCA forms on the wards. 2. Clear process for referral to Palliative Care team to prevent unnecessary delays. 3. Involve Social Care team not just care provider in any Best Interest Meetings. **Social Care -** 1. Care and support plan to not be reliant on results of biopsy results or health treatment plans when people have been identified as end of life. **MDT working -** 1. Early identification of people who are end of life and their treatment escalation plan / RESPECT form to be undertaken and led by the GP.
2 – Natural Causes	1. LeDeR to take forward an action for SWAST that all ambulance staff should undertake Oliver McGowan Mandatory training so the importance of involving carers in treatment and decision making, the use of reasonable adjustments and the art of effective communication is recognised. 2. Housing and police colleagues to be supported regarding the identification of hate crime and the appropriate action to be taken in such circumstances.

Achievements - a look back at what has been achieved in the last year

Learning Theme		Actions undertaken
 	**Covid-19**	1. Accessible Covid-19 resources - Inclusion Gloucestershire have developed an online resource hub of material aimed at those with lived experience of disabilities and people who may support them. The regularly updated resource hub can be accessed here and includes accessible material on many aspects of COVID 2. Covid-19 Guide for staff supporting people with LD – click here 3. Engagement in covid-19 virtual ward programme. Disabilities commissioning now able to make referrals for people to be put onto virtual ward following outbreak notification 4. Capacity and consent for covid-19 vaccine information guidance – Click here & guidance for families/carers – click here The NHS have also created a great video detailing the vaccination for people with learning disabilities and/or autistic people. Check it out here.
	**Physical Health Care**	1. Telehealth project in LD Care Homes extended to further 5 companies who expressed interest (11 care homes). 2. Monitoring and communicating signs of deterioration (RESTORE 2 & RESTORE 2 MINI) Click here 3. Rollout of Pulse Oximeters. 4. Flu Vaccination and reasonable adjustment pilot project
	**Care Provider Market**	1. Provider bulletin continues to be published monthly Click here and any learning from deaths is shared in this for care providers.
	**Annual Health Checks and Health Check Action Plans**	1. In Gloucestershire, much work has been done to encourage people with a Learning Disability to have an annual health check. Highlights include: - a. Uptake is approximately 74% in 2020-2021 b. Two listening events held in Winter 2020 and learning was utilised to inform local strategy. c. Further enhance the information on the G-Care website https://g-care.glos.nhs.uk/pathway/576 which provides guidance to health care professionals using a risk stratification approach during covid-19. d. Virtual Making reasonable adjustments training for primary care colleagues e. Working with Stakeholders across the south west region to develop standardised training programmes. f. Increasing the number of children and young people on the GP Learning Disability register by working with paediatrics and educational colleagues to identify those children at an earlier age who would benefit from being on the register. g. Supercharged Me campaign (website www.superchargedme.com).

Learning Theme		Actions undertaken
	**Legal frameworks**	1. Further enhance the information on the G-Care website to reduce clinical variation 2. System enablers - Flagging of people with a learning disability and reasonable adjustments pilot during 2019 as part of NHS England wider project 3. Training & Workforce competencies– Engagement with MCA Manager and training provided to LeDeR Reviewers
	**End of Life care and Advance Care Planning**	1. Further enhance the information on the G-Care website to reduce clinical variation 2. Establishment of a ReSPECT task and finish group consideration of this vulnerable group in advance care planning and the reasonable adjustments required. 3. Begun review of ReSPECT resources for those with learning disabilities e.g. leaflets and easy read guides working with Resus Council and Health Action Group
	**Communications**	1. Oliver McGowan Mandatory Training Pilot content development co-produced www.ghc.nhs.uk/oliver-mcgowan-mandatory-training
	**Hospital Care**	1. Use of editable Health Passport continues to be promoted. 2. Reasonable adjustments Flag on SCR

Chapter Six – Deaths of children

During 2020-2021, there were less than 5 children notified to the LeDeR platform from Gloucestershire. All child deaths are reviewed as part of the statutory child death overview process and therefore separate LeDeR Reviews were not undertaken. The deaths were allocated to a Senior LeDeR Reviewer who worked closely with the Child death review process [ix] (CDOP).

Due to the small number of cases, demographic data has been withheld to prevent inadvertent identification of the individuals.

All Local Safeguarding Children Boards have a statutory duty to hold a review whenever a child dies.

The Child Death Review (CDR) process is designed to ensure Local Safeguarding Children Partners are in a position to learn any lessons there might be from the unexpected death of a child or young person. The child death review process is designed to help with providing the appropriate support to families and schools to gain information about why children die. There are two aspects to a CDR.

1. A rapid response by a group of key professionals who come together for the purpose of enquiring into and evaluating each unexpected death of a child.
2. An overview of all child deaths in the Local Safeguarding Children Partners area (in this case the Gloucestershire Safeguarding Children Executive area), undertaken by a panel.

Over the course of the year the LeDeR Programme has taken an active participative role in any child deaths of those with a learning disability. One Gloucestershire reviewer has been allocated the lead role in this area.

The Gloucestershire CDOP programme produce yearly annual reports. The CDOP Annual report from 2019-2020 [36] is available to view on the Gloucestershire Children's Safeguarding Board (GCSB) website.

Figure 5 in the CDOP Annual Report 20219-2020 shows that the second highest modifiable factor found to have a significant impact on vulnerability is due to chromosomal, genetic and congenital anomalies.

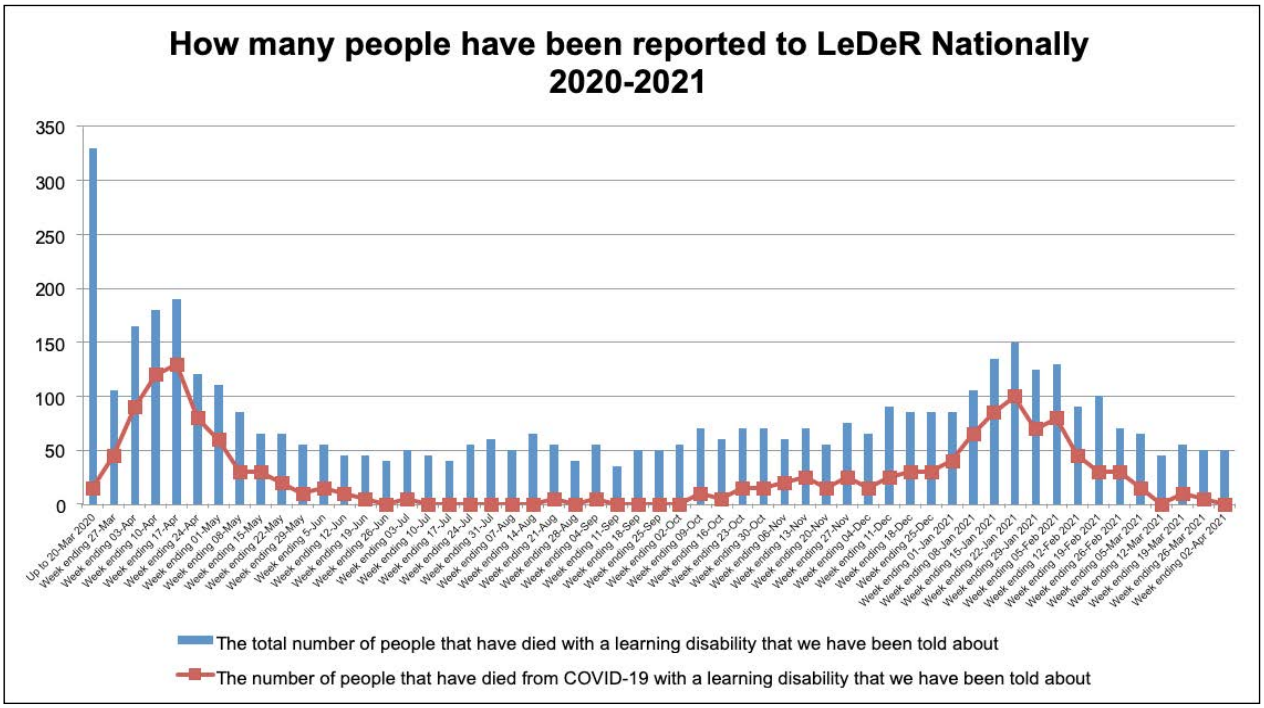
[36] Where unknown this indicates the review has not yet been completed or the notification did not have cause of death listed.

Chapter Seven – Impact of Covid-19

Nationally

The pandemic has placed unprecedented pressure on health and care services, clinicians, professionals and care workers. Together, they have worked to respond to the challenges that the pandemic has created, whilst continuing to provide people with the care, treatment and support they need. Nationally there have been 1,545 people reported to LeDeR since February 2020 who have died of covid-19. Chart 20 shows how many people with a learning disability have died whilst showing signs or testing positive for Covid-19 and have been reported to the LeDeR programme.[37]

Chart 21 - How many people have been reported to LeDeR with Covid-19 nationally (data correct to week ending 2nd April 2021)



From the beginning of the COVID-19 pandemic, there were concerns that appropriate reasonable adjustments and 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were being made without involving people, or their families and/or carers if so wished, and were being applied to groups of people, rather than considering each person's individual circumstances. At the end of April 2020 Gloucestershire responded by producing a quick reference toolkit for all clinicians and care workers to remind them of how to support someone with a learning disability with or without autism (Figure 5).

[37] https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/

The CQC report noted that some areas nationally had proposed a "blanket" DNACPR for people with learning disabilities during the report Protect, respect, connect – decisions about living and dying well during COVID-19 [38]. This report also found that there was a general lack of awareness and confidence among people, families and care workers about what a DNACPR decision meant and how to challenge this (check out the Turning Point DNACPR Toolkit mentioned in this report on page 26). Across the review process, whilst CQC inspectors did find some examples of good practice nationally, they also found that the pressure of responding to Covid-19 had an impact, including on the time that staff had to hold meaningful conversations. A lack of training and a large amount of rapidly changing guidance about all aspects of providing care during the pandemic also presented significant barriers.

[38] https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19

Local Impact

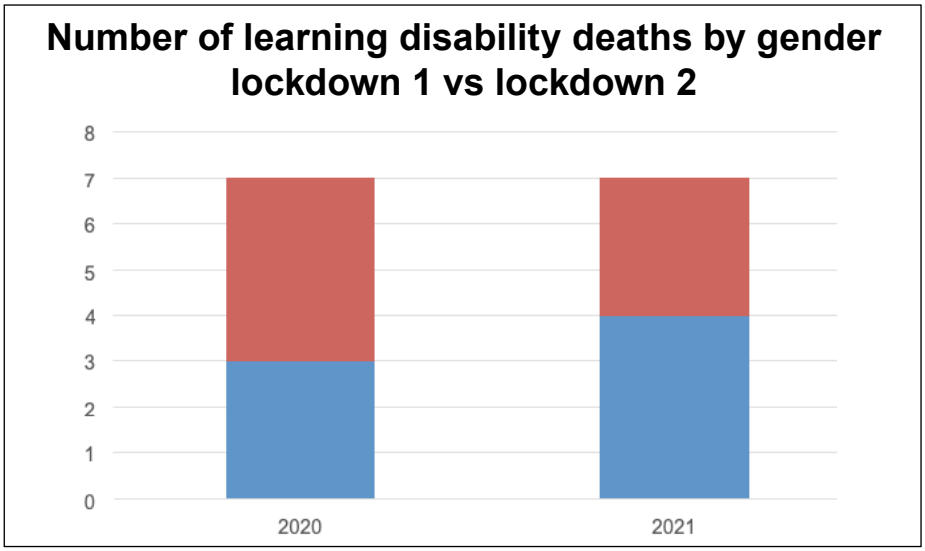
Summary

All recommendations from reviews will be developed into an action plan with our partners defining our priorities across the system. The following recommendations for action have been collated from LeDeR Reviews over the last year.

The themes have been grouped under the following broad headings and will inform the work programme for 2020-2021 for quality improvements.

- 14 people with learning disabilities have died of covid-19 in Gloucestershire and been reported to LeDeR.
- 7 people who died of covid-19 were males (50%) and 7 were female (50%).
- 9 peopled died of covid-19 and had a learning disability recorded in Gloucestershire Royal Hospital.
- 5 people died of covid-19 in their usual place of residence.
- 7 people (50%) of those who died had mild learning disabilities.
- 7 people (50%) also had epilepsy.
- 5 people also had hypertension.
- The average age was 70 years old (min age 56; Max age 79).
- All had other long-term health conditions (Alzheimer's, COPD, depression, lung disease, chronic kidney disease, serious mental illnesses).
- Gloucestershire continued to review deaths during both lockdowns which meant that as a system we could respond to learning in a timely manner.

Chart 21 - Number of learning disability deaths due to covid-19 by gender

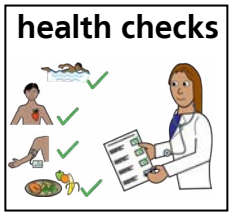


Local information on outbreaks in care homes mirrored national conclusions that the number of care home outbreaks in learning disabilities homes was lower than that seen in general care homes. However, during the period 17th December 2020 and 8th February 2021 there were 55 disabilities care settings in Gloucestershire that had covid-19 outbreak.

Gloucestershire Hospitals also saw during the last few months of the financial year an unusually large number of in-patients with a Learning Disability. This was largely due to outbreaks of COVID-19 in a very large number of learning disability community settings. Those outbreaks have now subsided and inpatient activity has returned to more normal levels.

The Gloucestershire Learning Disability Clinical Programme have also actively supported the Covid-19 vaccination rollout in the County and of those aged 18 and over on the GP Learning Disabilities Register 91% have received their first vaccination.

Chapter Eight – Conclusions and 2021-2022 Action Plan

Learning Theme		Further Actions
	**Physical Health Care (inc Covid-19 response joined up)**	1. System enablers - Telehealth pilot project and evaluation to be completed 2. Continue to rollout Restore2 [39] to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by: • Involving people with learning disabilities, their families and professional organisations. • Disseminating for use across acute, primary and community settings. 3. Dying for a Poo awareness campaign. 4. Mouthcare Matters awareness campaign. 5. Eating Well training. 6. Links established with Frailty Clinical Programme
	**Annual Health Checks and Health Check Action Plans**	**Model of improvement for 2021-2022 to be agreed and project group established;** 1. Interactive dashboard to be developed. 2. Continue to review resources including use of LD Liaison nurse within primary care to support good uptake. 3. Increase the number of children and young people on the register. 4. Agree pathway for diagnosis of a learning disability.
	**End of Life care and advance care planning**	**Small working task and finish group established;** 1. To develop ReSPECT as a process and a conversation about future care planning and not just about filling in a form. 2. Resources – Easy read, pre-health check questionnaire/ Health Passport to prompt discussion. 3. Communication - Training & raising awareness.
	**Training Gaps**	**Learning Disabilities Training Pathway Established;** 1. Workforce competencies – engaged with Fundamentals to Care (FTC) and HEE to ensure OM Mandatory training and other training offers are meeting the needs of the workforce in Gloucestershire. FTC Focus for the next 6-12 months will be on learning disabilities. Use funding to develop FTC LD Training package working with Gloucestershire Health and Care NHS Foundation Trust. 2. Infection control PPE Training to be re-launched with care providers. 3. Continue to raise awareness through CCG Medicine Matters Bulletin of any STOMP considerations

[39] https://wessexahsn.org.uk/projects/329/restore2

Learning Theme		Further Actions
staying and leaving hospital 	**Hospital Care (Reasonable adjustments and communication)**	GHT Learning Disability Steering group is well established and links with the programme to share learning. They have a Learning Disabilities Improvement plan that covers; **1. Data capture and management** – covering how to contact the LD Liaison nurses, how people with a LD are flagged within the hospital system, creation of a daily report on inpatients with a learning disability and the creation of a LD specific dashboard. **2. Patient experience** – including promoting the use of the My Health Passport, facilitating familiar carer visits, how and where reasonable adjustments are recorded and made (in particular those patients who are non-verbal). Establishment of a clear referral pathway for procedures requiring a general anaesthetic as a reasonable adjustment. Work across divisions within the hospital to improve the assessment of swallow reflex and provide the correct consistency food and fluids to prevent choking and aspiration pneumonia. There is some interesting evidence emerging that poor oral hygiene is linked to aspiration pneumonia. We will need to work collaboratively with Mouth Care Matters campaign to spread the messages that positive changes to oral hygiene can prevent a very common cause of illness for those with a learning disability. **3. Staff experience** – Encourage attendance at training, review of staff LD intranet pages, and create an autism intranet page. **4. Family/Carer experience** – Routinely capture who is the first point of contact (can only be one) between next of kin and/or care home. Routinely ask and record whether anyone holds power of attorney for health and wellbeing or whether there is a court appointed deputy. Routinely ask about ReSPECT forms and whether these have been discussed with the family or carers in the community prior to admission.

Conclusion

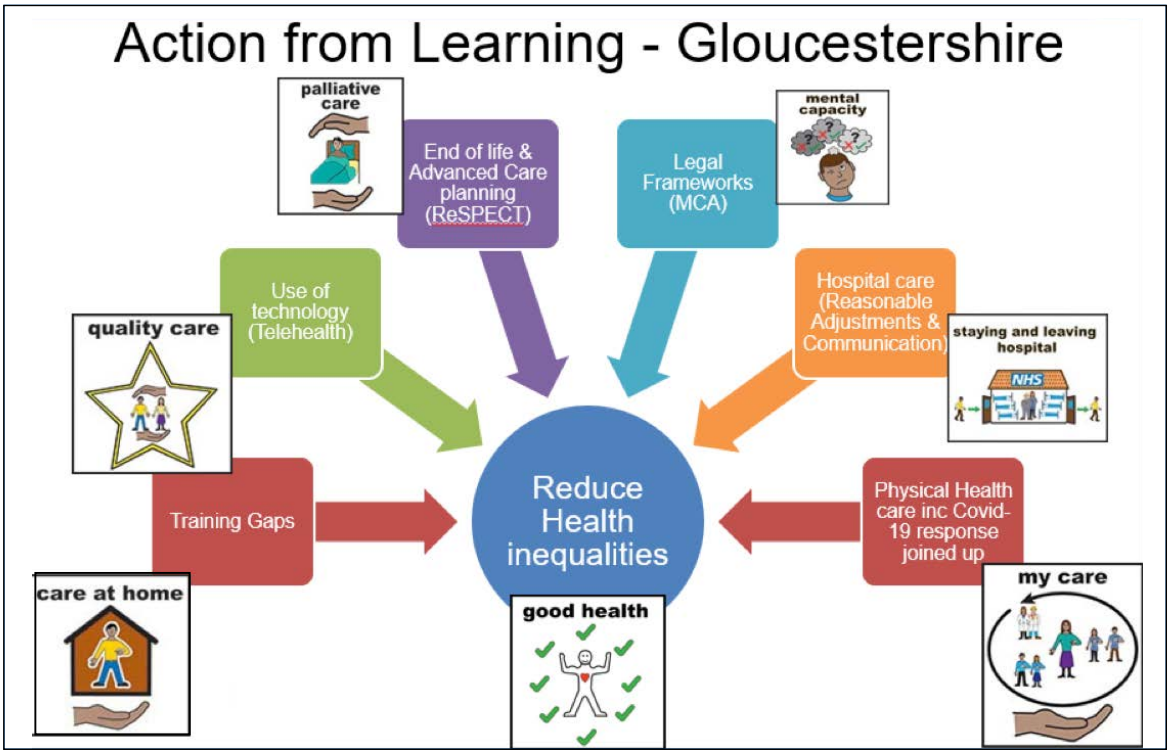
This is the third Learning Disability Mortality Review (LeDeR) annual report for Gloucestershire. The report provides the detail of how the LeDeR Process has been delivered during the covid-19 pandemic and this report demonstrates the improved governance arrangements to support a robust approach to improving services by learning from the deaths of people with a learning disability.

This year even more so than previous years has brought challenges to the Country and county of Gloucestershire that we have not faced before. Covid-19 Outbreaks have now subsided and inpatient activity has returned to more normal levels. It is a testament to the dedication of those working and supporting people with a learning disability that of the completed reviews 9 out of 10 people with a learning disability received excellent, satisfactory or good care. Which is an improvement from the previous year. In addition to this annual health checks have continued to be delivered and Gloucestershire achieved 74% (more than the national interim target of 67%). Also, to note that the Gloucestershire Learning Disability Clinical Programme have also actively supported the Covid-19 vaccination rollout in the County and of those aged 18 and over on the GP Learning Disabilities Register 91% have received their first vaccination[40].

In response to the pandemic many LeDeR Programmes nationally paused to respond to the emerging needs. In Gloucestershire the Quality Assurance Panels continued virtually throughout all of the covid-19 lockdowns as the learning from each review has been invaluable in enabling the lessons learnt and service improvements put into place in a timely way. The co-production partnership approach[41] which was implemented in 2019 has been invaluable in ensuring we are ahead of the curve in implementing action from learning during the year; experts by experience have helped us understand from people with experience of learning disability and using health services locally during these unprecedented times.

From the reviews these were the key areas identified for improvement of care of people with a learning disability

Figure 6 - Action from learning summary 2021-22



[40] Data correct April 2021.

[41] We have been supported by Inclusion Gloucestershire

- Focus on improved communications between professionals and with family/carers.
- Focus on early detection of deteriorating physical health including sepsis. This will mean continued close partnership working with West of England Academic Health Science Network.
- Focus on eating and drinking pathway including raising the awareness of oral health through Mouthcare Matters, and of the importance of checking for speech and language therapy guidelines on admission.
- Continued focus on improving uptake of the annual health checks and flu vaccinations.
- Focus on encouraging the ReSPECT form to be completed earlier on for people who have complex healthcare needs, alongside ensuring that there is a base line observation (Unique Wellness) in place to review frailty and advanced care planning with individuals, their family and carers, so this helps identify when people are deteriorating.
- Continuing to share the learning – plans to work with Inclusion Gloucestershire in 2021-2022 to develop accessible easy read infographics of the learning that comes out of the reviews.

All of the recommendations from reviews will continue to be scrutinised by the Quality Assurance panel and put into a local action plan which is shared with the Gloucestershire LeDeR Steering group who will monitor progress.

Gloucestershire is passionate about keeping this work programme moving forward and the local programme wants to continue to strengthen the partnership with family carers during 2020-2021. Peoples lived experience will help to guide and drive the service improvement programme that will be as a result of the completed reviews.

Going forward we are passionately committed to listening and learning from reviews, from people with learning disabilities and their families and making positive changes across the health care system. The Gloucestershire Learning Disabilities and Autism Clinical Programme will continue to challenge health inequality and improve health outcomes for people with learning disabilities and aim to prevent people from dying prematurely. The new LeDeR National Policy [42] published on 23rd March 2021 will give the local LeDeR programme opportunities to further strengthen the operational, governance and service improvements and extend this to autistic people as well during the course of the year.

[42] https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

Appendix 1 – References and End-notes

i http://www.bris.ac.uk/cipold/

ii https://www.resus.org.uk/respect

iii https://wessexahsn.org.uk/projects/329/restore2

iv https://sudep.org/

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

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

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

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

ix https://www.gscb.org.uk/media/2097132/child-death-review-protocol-for-gloucestershire-2020-v1.pdf

Joined up care and communities