

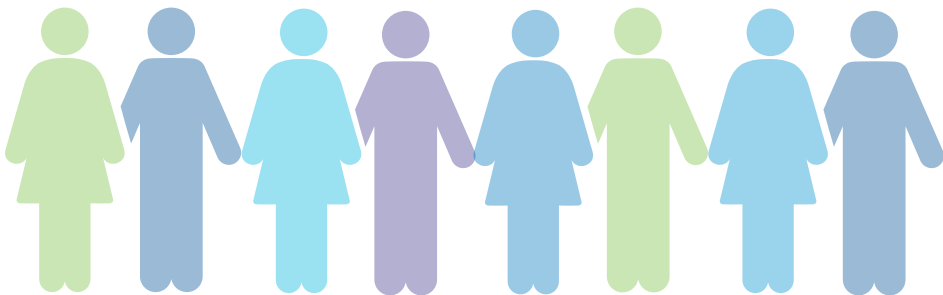
Learning Disabilities Mortality Review (**LeDeR**)



ANNUAL REPORT


Learning from deaths of people with
a learning disability in Gloucestershire

April
2019
March
2020





Gloucestershire LeDeR Mortality Review Annual Report 2019-2020

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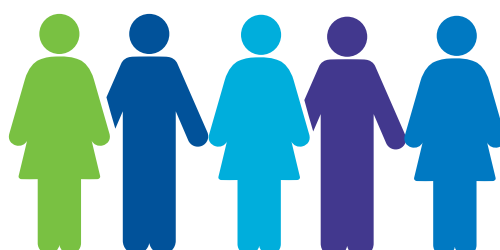
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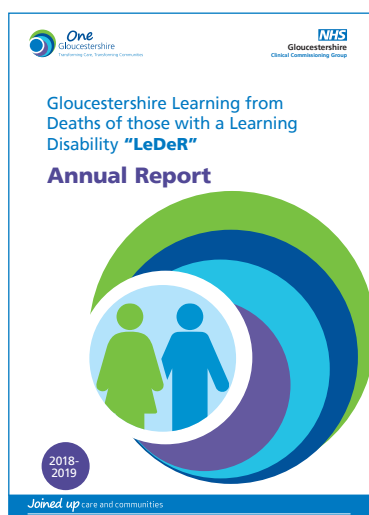




Preface: Statement from Chair of Gloucestershire LeDeR Steering group and Director of Nursing

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 May 2019 and July 2020¹) 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 2019 onwards. It is the second annual report for LeDeR Gloucestershire has published. The first report is available on the Gloucestershire Clinical Commissioning Group Publications Web pages². The purpose of the report is to share our findings from LeDeR reviews and to identify learning and changes for practice.



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.

There has been a lot of work undertaken locally to improve the LeDeR Governance including (in October 2019) setting up a Quality Assurance Panel. A positive development from this work has been the co-production partnership approach we have been supported with by [Inclusion Gloucestershire](#), who are helping us understand from people with experience of learning disability and using health services locally. 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.

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.

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

¹<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>

²http://www.gloucestershireccg.nhs.uk/wp-content/uploads/2019/12/LeDeR-annual-reportPresscopy_October19.pdf



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 anonymised³, 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.

Caroline died aged 82 from aspirate pneumonia and heart failure	Steve died aged 62 from left ventricular failure
<p>Caroline moved to Gloucestershire from Devon to live in a supported community which was to become her home for nearly 50 years. She was very much part of this community and could not remember living anywhere else. She felt safe and valued there.</p> <p>When she was younger, she used to help by looking after some of the co-workers children. She loved children, nature and animals. She enjoyed listening to music and watch TV. She loved spending time with her friends and family especially her niece and nephew who would visit her regularly and take her out for meals and day trips.</p> <p>Caroline was a regular at church joining in with the Sunday services. She made some very close friends at church although she did have a reputation of appearing quite 'brusque' with people. This was never her intention because she truly valued her friendships.</p> <p>Following a dense stroke, Caroline had to be cared for in a nursing home. Some of her carers continued to visit her in their own time to provide support and care for her. Many had known her for decades. Caroline will be sadly missed by her friends and family.</p>	<p>Steve was born with Down's syndrome. He lived with his family in the Forest of Dean. He was very much considered the 'baby of the family' with 2 older brothers and 3 older sisters. He lived with his mum and dad but started to spend more time with his older sister as his parents became frailer. His sister said 'One time he came over to stay and never went home'. He lived with his sister and brother in law for over 35 years.</p> <p>Steve took an active part in family life, playing football with his nieces and nephews. He loved going on holiday with the family. He had been to Spain, France, Italy and even a trip to Monti Carlo. He loved doing jigsaw puzzles and could complete 1000-piece puzzles before he developed dementia. He loved his food. He liked shopping for it, preparing it, and eating it. He was described as 'a very affectionate man'. He got on well with all the staff at his day care centre. At one point he had a work placement in a recycling unit. His sister joked with him, wondering how useful he actually was there, however Steve was tremendously proud of 'going to work'.</p> <p>As Steve's dementia progressed, he needed more support with his personal care and his behaviour changed. He had several hospital admissions to treat aspiration pneumonias. Eventually, and reluctantly his sister agreed that he may need to be cared for in a supported living environment. A placement was found locally to his family who remained in close contact with him until he sadly died of a recurrent chest infection. His family said they would always have such fond memories of Steve. He was very much loved by all who knew him and he will be missed by his family and friends.</p>

³ Please note that all names throughout this report have been changed to protect confidentiality



Sam died aged 46 from pneumonia and multi organ failure	Sally died aged 35 from Liver failure/ Liver Cancer
<p>Sam was described as 'a fun loving gentleman' who was hugely popular with everyone he met. His mother doted on him, visiting him every week at his supported living placement. He would look forward to her visits getting excited when she arrived.</p> <p>Sam was a keen sports man. He loved football, swimming and Zumba classes. He enjoyed listening to music, dancing and karaoke. He always had a smile on his face and could 'charm' anyone with it. He had a great sense of humour and was always playing jokes on the staff, like hiding the keys or pretending to be asleep. He got on well with staff and residents alike. He was 'happy go lucky'. He never appeared cross or unhappy. Staff have fond memories of him teasing them all saying things like 'go on hop it!!!' in jest. He made a big impression on everyone that meet him and will be fondly remembered by all who knew him.</p>	<p>Sally died aged 35 from Liver failure/ Liver Cancer.</p> <p>Sally was the youngest of 3 sisters. They were a particularly close knit family who spent a lot of time together. Although Sally could not verbally communicate she was able to make herself heard by using gestures and facial expressions. Her family described her as 'a ray of sunshine', always smiling. She made people laugh just by being with her.</p> <p>Sally loved her food and particularly liked to go out for a cup of tea and a piece of cake. She liked to go shopping with staff to choose what she would eat for supper. She was very particular about how her food was arranged on her plate. She would push her plate away if any of the food touched and wait patiently until the staff had separated it for her. Sally also enjoyed listening to music and was a big fan of Bob Marley and Abba.</p> <p>Sally was very well known in her local community. She liked to sit outside her home and wave to people as they passed by. Many would stop and chat to her. She always chose to wear bright colours. Pink was her favourite colour. She had lots of bright scarfs and hair bands which she would insist on wearing. Her room was painted pink and she had pink flowers on her curtains.</p> <p>Sally will always be remembered for her 'lovely smile' and 'cheeky chuckle'.</p>



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 Review⁴.



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 2019-2020 and is the second 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 2020. The previous year's report can be viewed on [Gloucestershire Clinical Commissioning Group's Website](#)⁵.

The Gloucestershire LeDeR Programme (as at 31st March 2020) had completed 86.1% of notified reviews (reviews received up to and including 31st March 2020), this compares to only 45% in the South West and 52% in England. Gloucestershire has continually over the last 12 months been in the top 15 LeDeR local programmes for completed reviews.

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	46	1	47	97.9%
2019-2020	26	20	46	60.8%
TOTAL	130	21	151	86.1%

⁴ Further information about the LeDeR Programme is available on the [University of Bristol Website](#). This is a national programme of service improvement

⁵ http://www.gloucestershireccg.nhs.uk/wp-content/uploads/2019/12/LeDeR-annual-reportPresscopy_October19.pdf

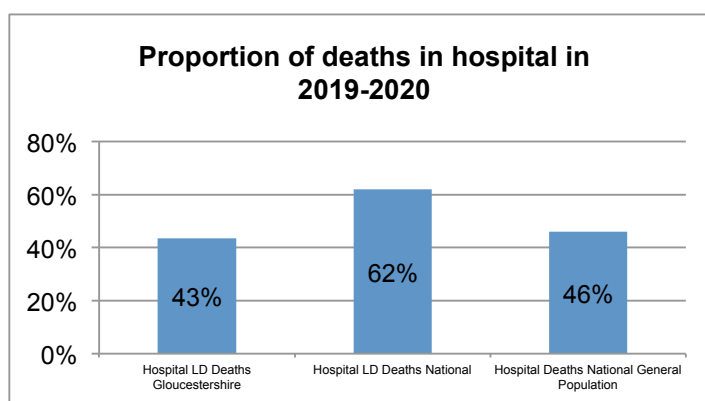


Key Findings

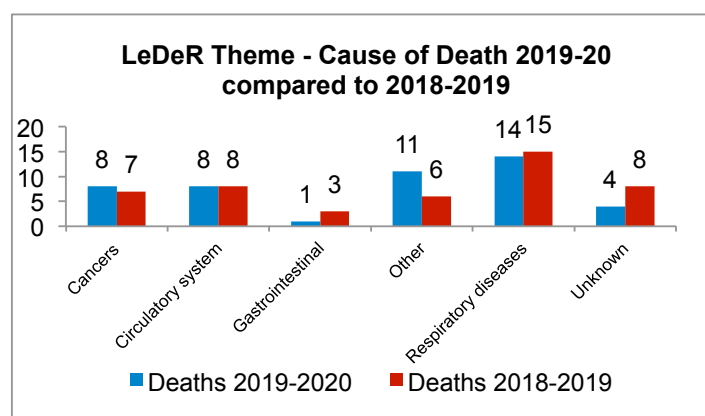
Ratio of grading of care 2019-2020 (n=46 reviews) The ratio of the grading of care has improved from 8:10 people receiving satisfactory or better care to 9:10 people in 2019-2020.



Where people died Of the 46 deaths report in Gloucestershire during 2019-2020, 43% died in hospital (with 28.3% dying in Gloucestershire Royal Hospital). The corresponding proportion for the general population is 46% (meaning that 3% fewer people with a learning disability died in hospital).



Causes of death Of the 46 deaths the top cause of death in the learning disabilities population in 2019-2020 remains respiratory causes (14 deaths) – mainly pneumonia type infections. Gloucestershire saw an increase in other causes of death⁶ during 2019-2020 compared to the previous year (n5 deaths).



Those with an end of life plan in place 56% of the 46 deaths (n=18) had an active end of life plan in place (this compares to 46% nationally). Two thirds (64%) of the 46 deaths were expected and planned for deaths, meaning that 8% of expected deaths did not have an active end of life plan in place. This is an area for improvement.

⁶ Other includes: Road traffic collisions, epilepsy, dementia and falls



Summary of Learning Outcomes

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

- 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 improving the eating and drinking pathway for those with a learning disability
- 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 are considered palliative to there is a base line in place to review frailty and advanced care planning with individuals, their family and carers
- Greater inclusion of people with lived experience in the work programme including attendance at steering groups, quality assurance panels and other training events
- Share the learning – plans to host an action from learning event in March 2020 were postponed. This is something the programme would like to pick up through a virtual conference in 2020-2021 to progress our improvement journey and key areas of focus for the wider Gloucestershire Learning Disability Clinical Programme of work

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 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.





Sammy from Inclusion Gloucestershire

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

“ It is so important that Experts by Experience are involved in quality assessing LeDeR reports as we are the experts in our own conditions. In Gloucestershire we are moving away from the stance that professionals know best and giving people with lived experience a proper voice rather than doing for and to them. We are sharing our lived experience and proving how important our voice is! ”

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



Vicci from Inclusion Gloucestershire

“ The involvement of Experts by Experience in the LeDeR panel is testament to Gloucestershire’s commitment to co-production. Our voices and experience are valued in the same way as that of medical professionals, and we bring a passion and perspective that comes from living with or alongside learning disabilities ourselves. ”

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

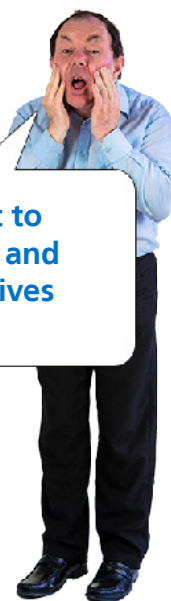
I need to be listened to as the expert in my condition



Our friends are dying too soon



We want to live long and healthy lives



My life is important!



Early deaths of individuals devastate the families left behind





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. 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

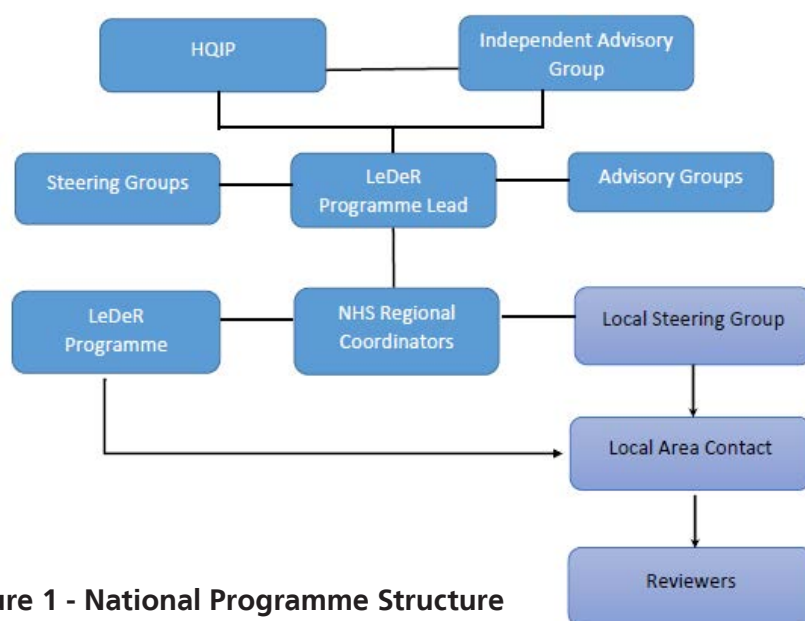


Figure 1 - National Programme Structure

Definition of a Learning Disability in use by the programme

The LeDeR Programme uses the definition included in the 'Valuing People', the 2001 White Paper⁷ 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

⁷Department 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 University 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

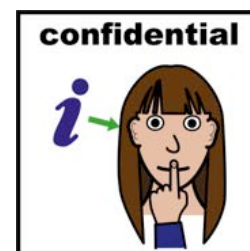
2020

- April - National LeDeR Framework approved



Data sharing and confidentiality

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



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

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

The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the legislation, and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved. The key purpose of the CAG is to protect and promote the interests of patients and the public whilst at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care. More information about Section 251 approval is available at: <http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/>

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 which started 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.



Gloucestershire LeDeR Mortality Review Steering Group - Governance

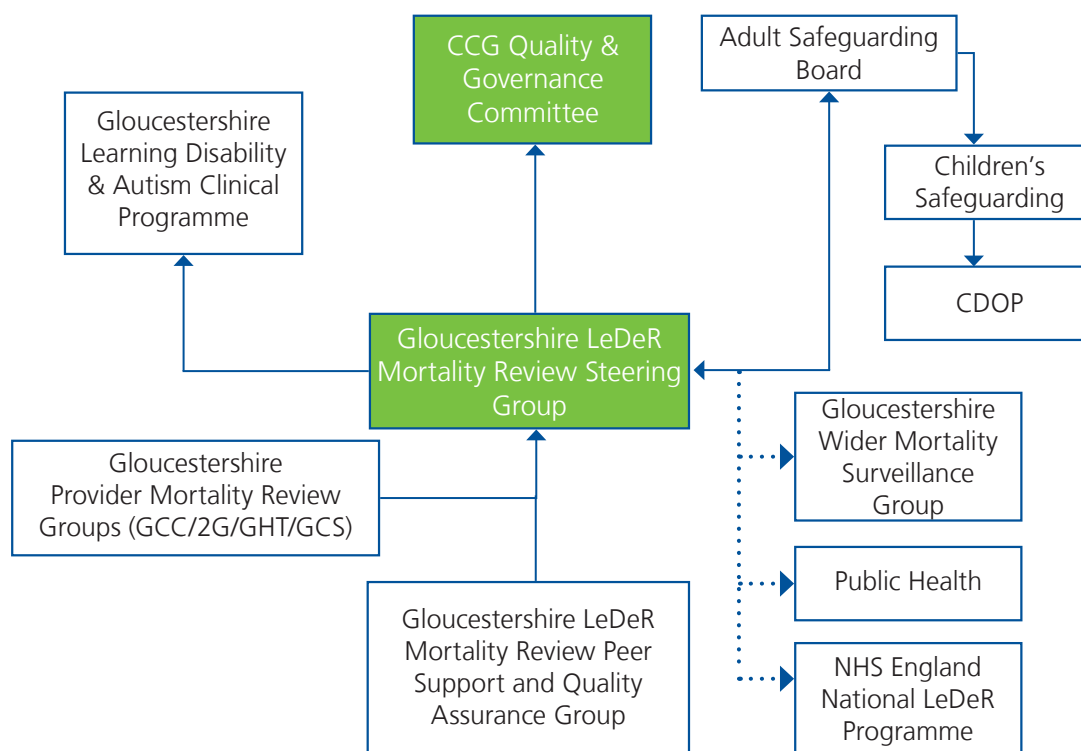


Figure 2 - Local Governance Arrangements for LeDeR

Local LeDeR Framework Policy

In order to provide assurance to the Gloucestershire LeDeR Steering group and the Quality and Governance Committee in 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](https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2020/07/100-LeDeR-Framework-June-2020.pdf)⁸.

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

⁸<https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2020/07/100-LeDeR-Framework-June-2020.pdf>



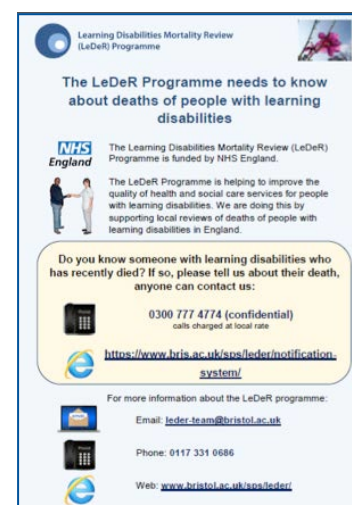
So how does the process work?

Anyone can notify the national programme of a death including people with learning disabilities themselves, family members, friends and paid staff. There is a telephone number 0300 777 4774 or an [online](#) form can be completed.

There is a 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 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](#)^{vi} will be held. All information will be accessed, edited and completed via the web-based portal/ LeDeR Review System.



The LeDeR Process is described in Figure 4 - LeDeR process. However, the initial review 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 to the person's 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](#)^{viii} and [Steering Group](#)^{ix} and reviewed as part of the national LeDeR process

LeDeR Process in Gloucestershire

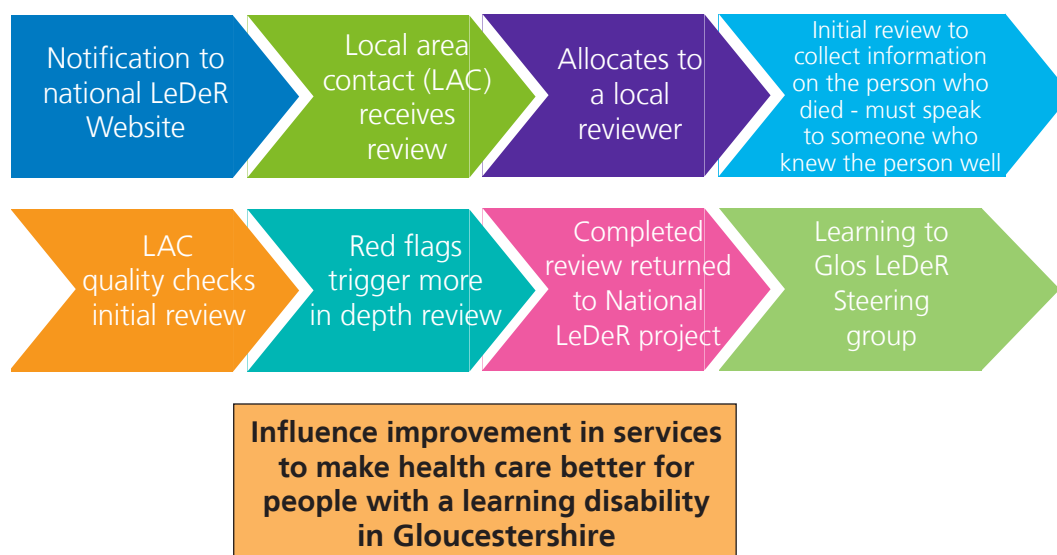


Figure 4 - LeDeR process



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.

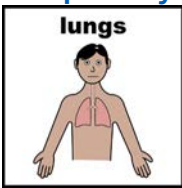
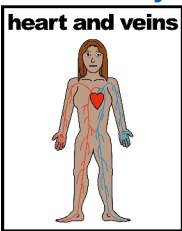
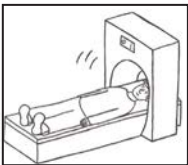

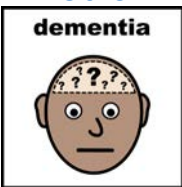
The LeDeR programme and approach offers a process of learning from a death which can enable GSAB and local structures to **focus on how to protect people** with care and support needs from the behaviours and systems that pose a risk of abuse or neglect.

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 Atherosclerosis, 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 171 Gloucestershire deaths reported to LeDeR covering the period January 2017 to end March 2020. Of which 133 of these deaths have had an initial review undertaken (Table 2 - Status of reviews by year). For the financial year 1st April 2019- 31st March 2020 there were 46 notifications (**Error! Reference source not found.**) and 26 have had an initial review completed (60.8%). This is an increase from last years' performance at year end (44%) of 16.87%.

Table 1 - Summary of deaths notified in 2019-2020

Total notifications in 2019-2020	46
Total notifications not yet assigned to a reviewer	12
Number of Open reviews from 2019-2020	20
Total number of reviews currently in progress (inc previous years)	38
Number of Multi Agency Reviews (MARs) undertaken in 2019-2020	2
Completed reviews in 2019-2020	26
Closed reviews to date (since 2017)	130

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	46	1	47	97.9%
2019-2020	26	20	46	60.8%
TOTAL	130	21	151	86.1%

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	%	Comments
Allocation of reviewers within 3 months of notification	27%⁹	This KPI was not met due to a shortage of LeDeR reviewers in previous years.
Completion of reviews within 6 months of notification	7%¹⁰	This KPI was not met due to the delay in allocating cases to reviewers in previous years.
Quality Assurance of reviews by the LAC within 2 weeks of completion	100%	This KPI was met. All cases are initially reviewed by LAC within two weeks of completion & added to the next LeDeR Quality Assurance Panel for quality review prior to closure and submission to the national programme.

⁹(n38 cases allocated within 3 months across the whole of the programme life)

¹⁰(n9 cases completed within 6 months of allocation across the whole of the programme life)



Actions taken to address KPI's 2019-2020

- Utilising funding received from NHS England we have utilised a number of paid reviewers who have a range of expertise to undertake reviews to assist us to clear the backlog
- In February 2020 there were 2 cases to allocate to reviewers which had broken the 3 month KPI, by 31st March 2020 this was down to zero
- In October 2019 we introduced monthly Quality Assurance panels which has had a real impact on improving completion rates in the fourth quarter of 2020

National and Regional comparison

Nationally the South West Region has had the least deaths notified to the programme (n786). The national reviews completed figure is 52% this is a better performance than the South West regional completed percentage of 45%. In the South West Region Gloucestershire (as at 31st March 2020) has received the most notifications (n151) compared to the regional average of 87. This equates to 19% of the regional notifications. Gloucestershire's reported % completed is the highest in the South West (86%) compared to the regional average of 45%. This information is shown in Table 4 - National and regional comparison (correct as of 31.3.2020) and Table 5 - South West Regional comparison (correct as of 31.3.2020).

Table 4 - National and regional comparison (correct as of 31.3.2020).

	Number of notifications received		All NOTIFICATIONS TO DATE						
			Total	Unallocated	In progress	Completed	Unallocated	In progress	Completed
	This month	Total	No.	No.	No.	No.	%	%	%
England total	268	3116	7979	1187	2666	4126	15%	33%	52%
NORTH WEST	39	442	1179	133	502	544	11%	43%	46%
NORTH EAST & YORKSHIRE	30	501	1420	208	408	804	15%	29%	57%
MIDLANDS	54	659	1450	133	355	962	9%	24%	66%
EAST OF ENGLAND	29	322	900	177	309	414	20%	34%	46%
SOUTH EAST	42	498	1294	265	574	455	20%	44%	35%
SOUTH WEST	18	337	786	146	287	353	19%	37%	45%
LONDON	56	357	950	125	231	594	13%	24%	63%



Table 5 - South West Regional comparison (correct as of 31.3.2020)

Steering group	Number of notifications received		All NOTIFICATIONS TO DATE						
			Total	Unallocated	In progress	Completed	Unallocated	In progress	Completed
	This month	Total	No.	No.	No.	No.	%	%	%
Gloucestershire	1	46	151	9	12	130	6%	8%	86%
Bristol, North Somerset, South Gloucestershire	3	67	124	33	25	66	27%	20%	53%
Dorset	5	44	128	10	54	64	8%	42%	50%
Somerset	3	31	82	1	41	40	1%	50%	49%
BANES, Wiltshire and Swindon	1	48	91	31	30	30	34%	33%	33%
NHS SWINDON CCG	0	9	19	9	3	7	47%	16%	37%
NHS WILTSHIRE CCG	1	28	51	14	20	17	27%	39%	43%
NHS BATH AND NORTH EAST SOMERSET CCG	0	11	21	8	7	6	38%	33%	29%
Devon	3	64	133	29	67	37	22%	50%	28%
Cornwall and Isles of Scilly	2	38	83	33	37	13	40%	45%	16%

Reporters of deaths

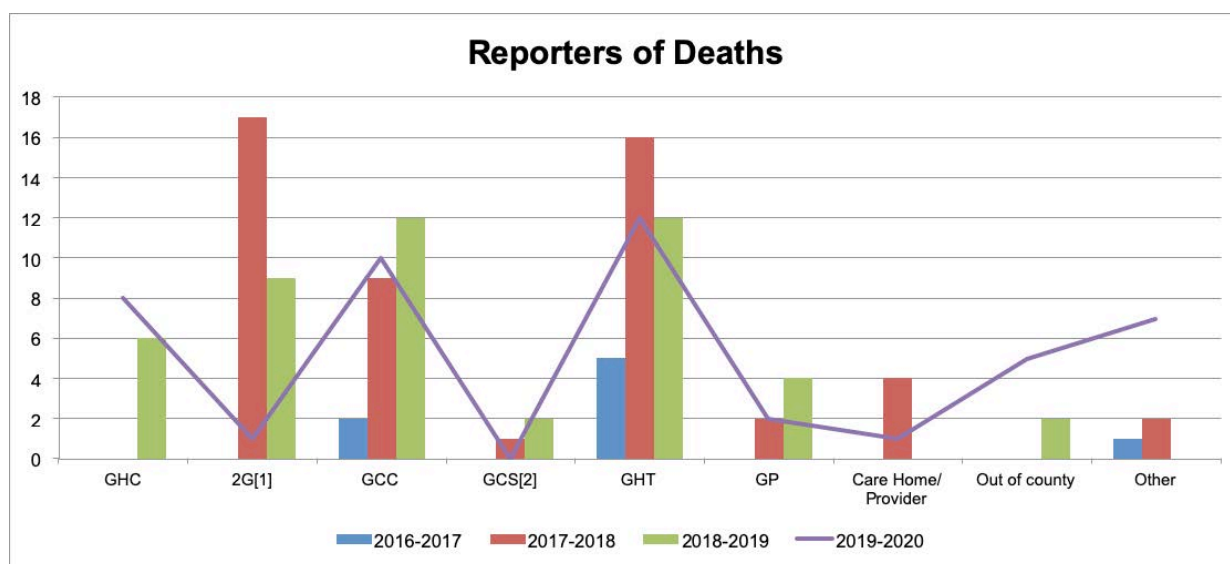
Gloucestershire Hospitals NHS Foundation Trust (which are the County's secondary physical care hospital trust) were the biggest reporters of deaths since the programme began in 2017 (n=45 deaths), with Gloucestershire County Council the second biggest reporters of deaths (n=33 deaths) [Table 6 - Reporters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

Chart 1- Reports of Deaths illustrates the breakdown of who reported the 151 deaths. For the financial year 2019-2020 (n=46) 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 ¹¹	GCC	GCS ¹²	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
2020-2021	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

¹¹ In October 2019 2G and GCS Merged to become Gloucestershire Health and Care Foundation Trust (GHC)

¹² 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 2-5 demonstrate that just over half (54%) of those who died in 2019-2020 from Gloucestershire were males. This has changed from the previous year where 59.6% of deaths were male. Broadly compared, Gloucestershire compares to the regional (58% male, 4% difference) and national (59% male deaths, 5% difference) gender notifications.

Chart 2 - Gender of those who died in 2019-2020 in Gloucestershire

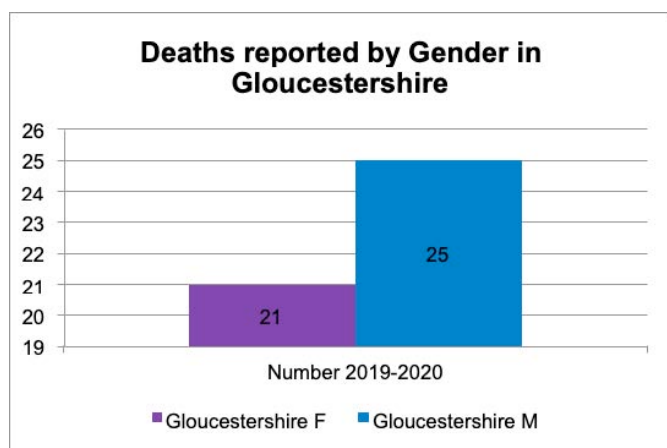


Chart 3 - % comparison M/F of those who died in Gloucestershire in 2019-2020

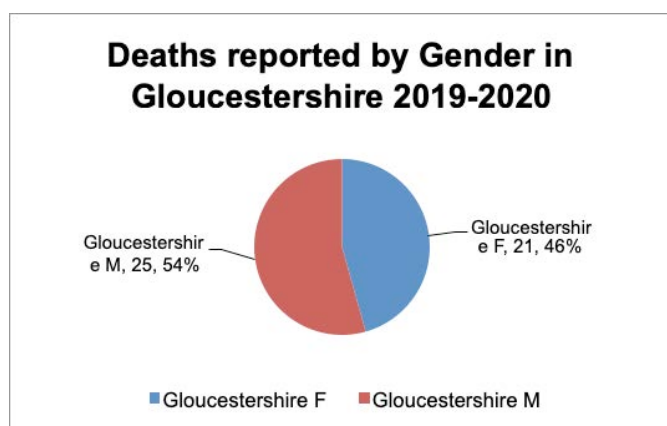




Chart 4 - Year on year comparison

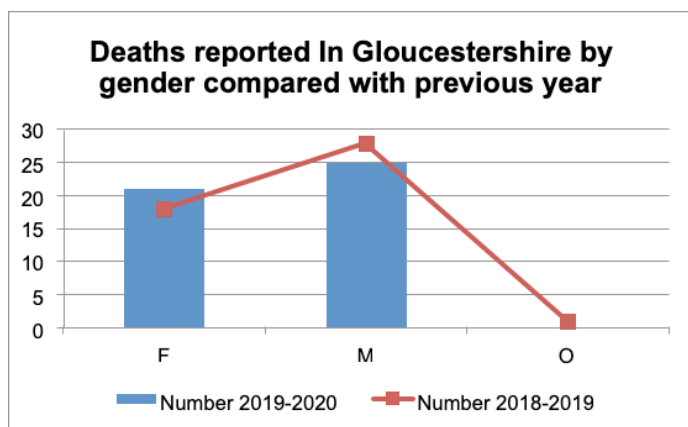
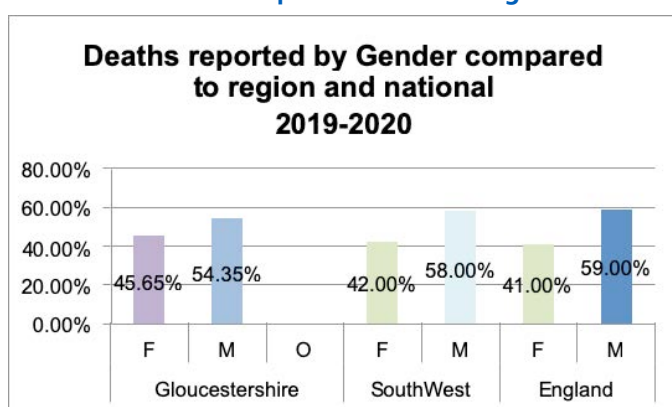


Chart 5 - Gender comparison local vs regional vs national 2019-2020

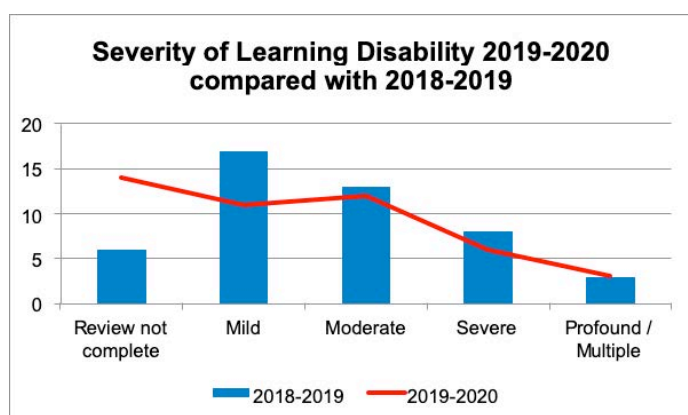


Ethnicity – is not included in this report as the deaths of fewer than five Black and Minority Ethnic (BME) people have been notified in Gloucestershire during 2019-2020. The majority were stated as “White British” on the notifications.

Severity of Learning Disability – Of the 46 deaths reported in 2019-2020 (

Chart 6 - Severity of Learning Disability in Gloucestershire), 32 have had the severity of learning disability recorded on the notification or initial review. Of the remaining 14 these are still to be reviewed and to go through a quality assurance panel. There were 6 fewer deaths (total n11) of people with mild learning disabilities in 2019-2020 when compared with the previous year (n17). However, broadly speaking the profile of severity of deaths is comparable year on year.

Chart 6 - Severity of Learning Disability in Gloucestershire





Co-morbidities –

The NICE Guideline 56¹³ 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 32 reviews where co-morbidities have been recorded in 2019-2020; 37% had 3 or more co-morbidities.¹⁴ In addition to this 50% of the reviews where co-morbidities were mentioned (n16 people) who died also had epilepsy. There was an association between the level of a person's learning disability and the number of long-term conditions they had. Those individuals with severe or profound and multiple learning disabilities (PMLD) 100% had 3 or more long term conditions recorded.

Table 7 - Co-morbidities

Condition	Number of people with the condition
Epilepsy	16
Dementia	8
Down Syndrome	7
Cerebral Palsy	7

Into County Placements

During 2019-2020 there were n5 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 n21 deaths, almost half (48%) of these were placed into the county from South West placing authorities. *indicates a number less than <5 people.

Table 8 - Into County Placement Deaths by financial year

Year	Number
2016-2017	0
2017-2018	5
2018-2019	10
2019-2020	5

Table 9 - Regions placing Gloucestershire

Condition	Number
South West	10
South East	5
Midlands	*
Wales	*
North East	*
London	*

¹³<https://www.nice.org.uk/guidance/ng56>

¹⁴Where co-morbidities were less than five these have not been included



Chapter Four – Statistics

Age –

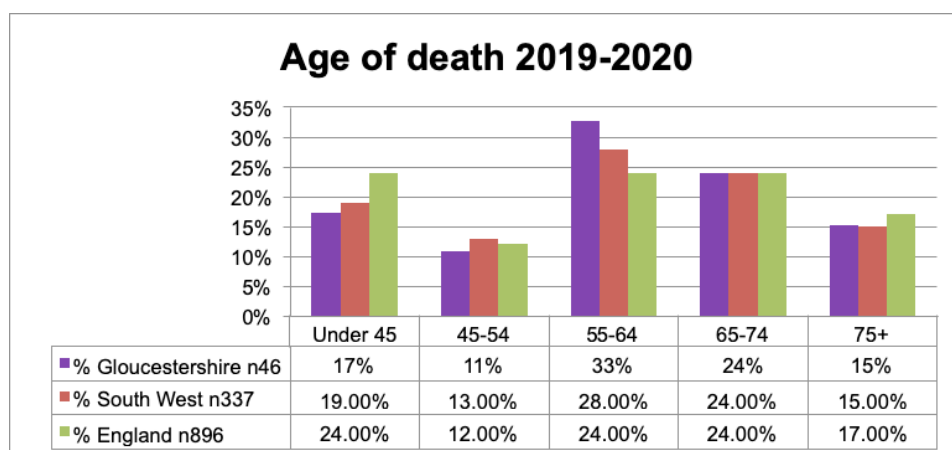
Here we report on the age at death of people with learning disabilities who died from 1st April 2019 onwards. It is important to remember that comparisons with the general population are indicative but not directly comparable. The deaths of people with learning disabilities are notified from the age of 4 years, whilst general population data also includes information about children aged 0-3 years.

In addition, as we have already mentioned, more people who died at a younger age had profound and multiple learning disabilities, and some of these would have 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, 2018¹⁵).

Chart 7 - Age of death comparison locally vs regionally vs nationally) shows the age of the individual grouped in age ranges and compared with South West and National LeDeR data. It can be seen that within Gloucestershire people with a learning disability who died in 2019-2020 are living on average to the same age – noting that there have been fewer under 45s dying when compared to the national average (7% less than the national average), and 55-64 that there have been more deaths in Gloucestershire in this age bracket compared to the national average (9% more).

Chart 7 - Age of death comparison locally vs regionally vs nationally



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 19.5 years when compared to the general population. This is an increase from the previous year of 4 years.

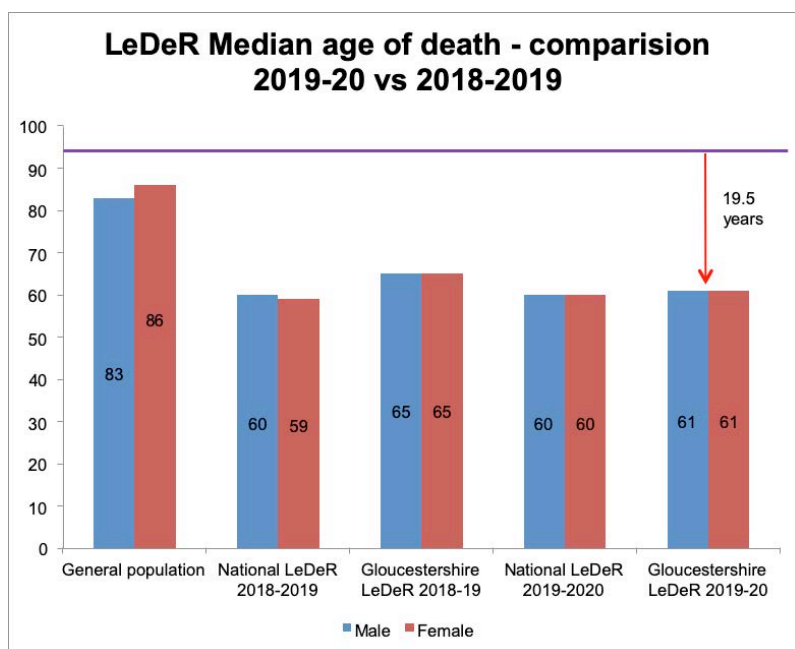
Table 10 - Average (Median) Age of death

	Gloucestershire		South West	National	General Population	
	Male	Female			Male	Female
2018-2019	65	65		59	83	86
2019-2020	61	61	62	60		

¹⁵<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk>



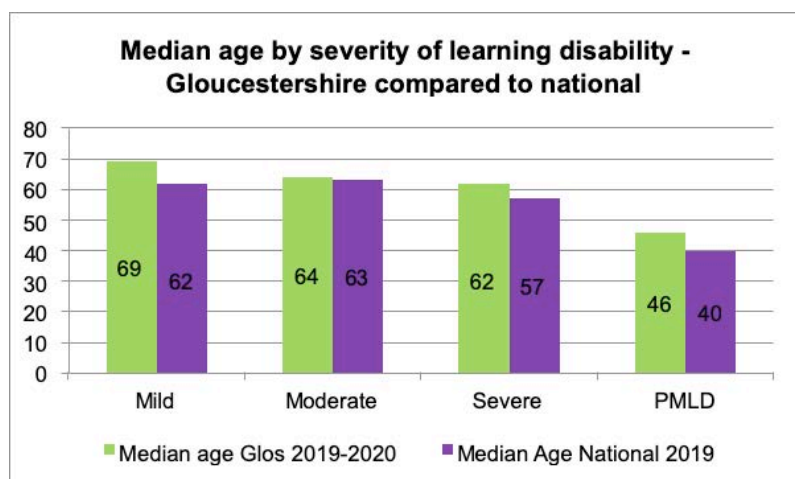
Chart 8 - Average (median) age of death



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 69 years old (compared to the national report 2019 of 62 years); for moderate learning disabilities it was 64 (compared to the national report from 2019 of 63 years); for severe learning disabilities it was 62 (national report was 57 years); for profound and multiple learning disabilities it was 46 (compared to national report of 40).

Chart 9 - Median age of death by level of learning disability



Place of death

Of the 46 deaths report in Gloucestershire during 2019-2020 43% died in hospital (with 28.3% dying in Gloucestershire Royal 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	Grand Total
Number of deaths	13	16	3	5	2	7	46
%	28.26%	34.78%	6.52%	10.87%	4.35%	15.22%	100.00%

Chart 10 - Proportion of deaths in hospital in Gloucestershire compared with national (based on 2019 National LeDeR Annual Report)

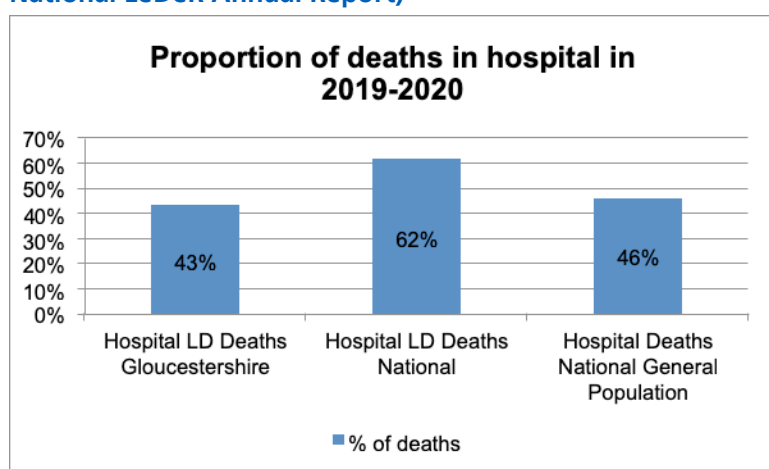
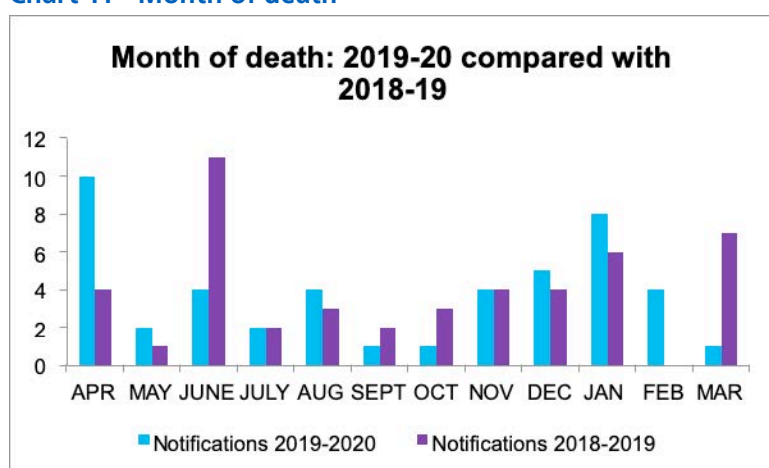


Chart 11 - Month of death



Comparing month on month between the two financial years shows a similar proportion year on year (with the exception of June 2018-2019 7 fewer deaths in 2020-2021 and April 2020-2021 6 more deaths compared to the previous year). 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.



End of life pathway/ was the death expected

Of the deaths reviewed in 2019-2020 for which coded data was available about end of life care, almost two thirds (64%) were expected and planned deaths. Of this 56% had an active end of life plan in place (this compares to 46% nationally).

Chart 12 - Expected Deaths (where recorded)

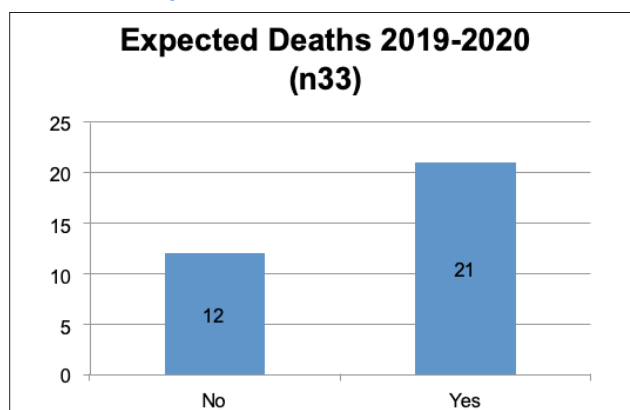


Chart 13 - % Expected deaths (where recorded on the review)

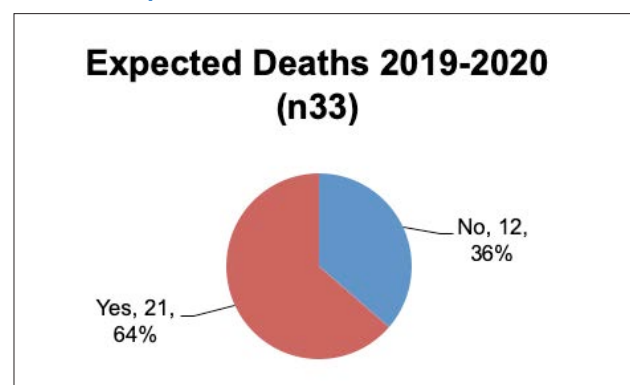


Chart 14 - Number of deaths where an end of life plan was in place

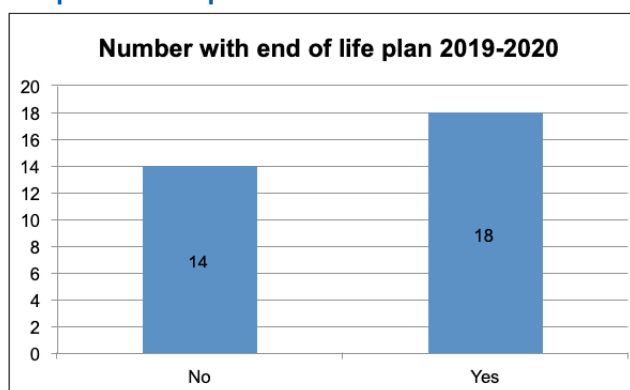
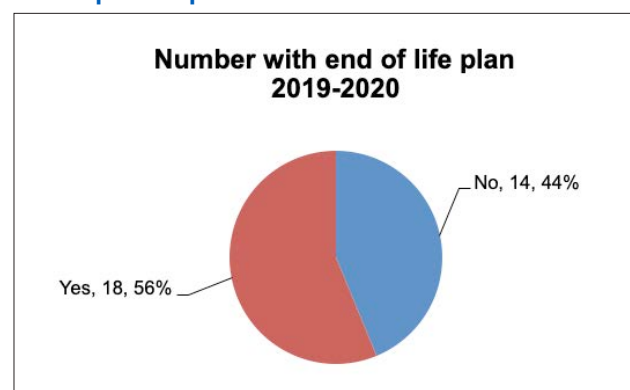


Chart 15 - % of people who died with an end of life plan in place



Deaths with a Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) order¹⁶ 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 life¹⁷.

¹⁶Cardio-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.

¹⁷<https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/>



Chart 16 - Number of people where DNACPR was noted on the completed initial review

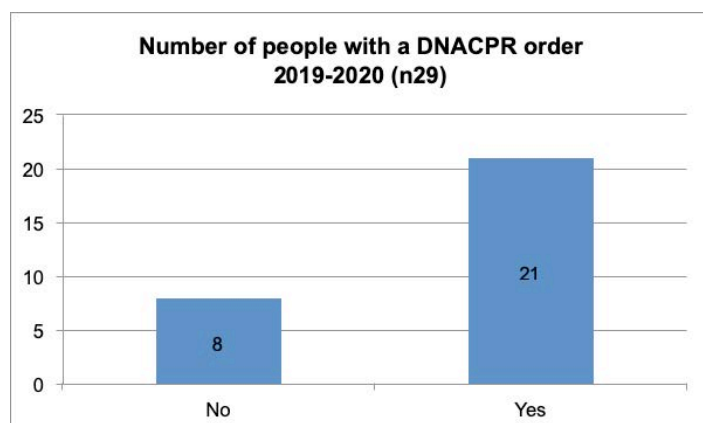
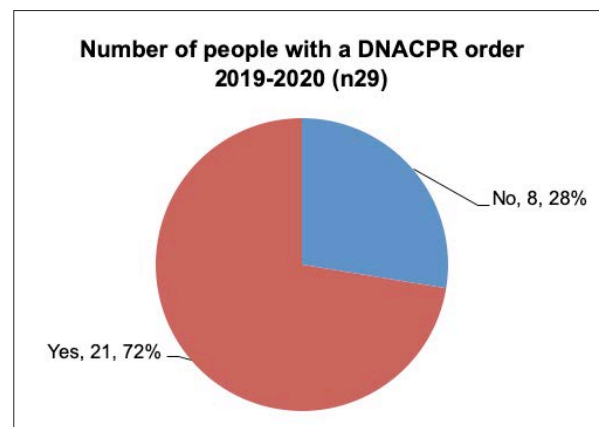


Chart 17 - % of people where DNACPR was noted on the completed initial review (n29)



Cause of deaths

The World Health Organisation defines the underlying cause of death as the disease or injury which initiated the train of event leading directly to death, or the circumstances of the accident of violence which produced a fatal injury. Table 12 - Cause of death combined 2019-2020. Pneumonia was the most frequently cited in part I of the MCCD (Death certificate) of people with learning disabilities in Gloucestershire 19.57% compared to 25% nationally. 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, there is insufficient data for any meaningful conclusions.

Table 12 - Cause of death combined 2019-2020

Cause of death	Number of deaths	% of cause of deaths Gloucestershire 2019-2020 n46	% England LD Population cause of death age 4+ 2018-2019 n1938	% of general population n529,605
Pneumonia	9	19.57%	25%	
Cancer	8	17.39%	14%	28%
Other ¹⁸	6	13.04%	Not able to directly compare as reported differently in the National LeDeR Report 2018-2019	
Dementia	6	13.04%		
Sepsis	5	10.87%		
Unknown ¹⁹	5	10.87%		
Respiratory ²⁰	3	6.52%	19%	14%
Heart related ²¹	2	4.35%		
Haemorrhage related ²²	2	4.35%		
TOTAL	46			

¹⁸Drug overdose, Epilepsy, Fall, Coronary artery stenosis, RTC

¹⁹Review not completed or information not on original notification

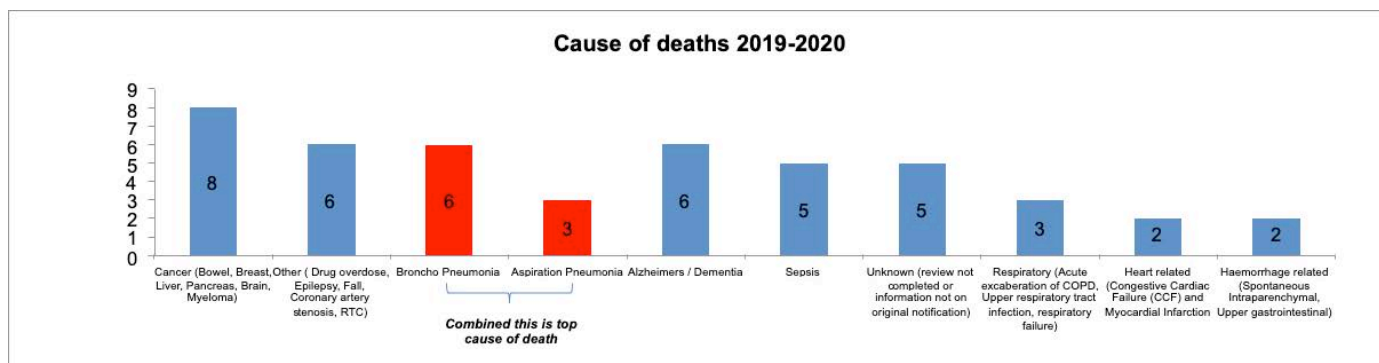
²⁰Acute exacerbation of COPD, Upper respiratory tract infection, respiratory failure

²¹Congestive Cardiac Failure (CCF) and Myocardial Infarction

²²Spontaneous Intraparenchymal, Upper gastrointestinal



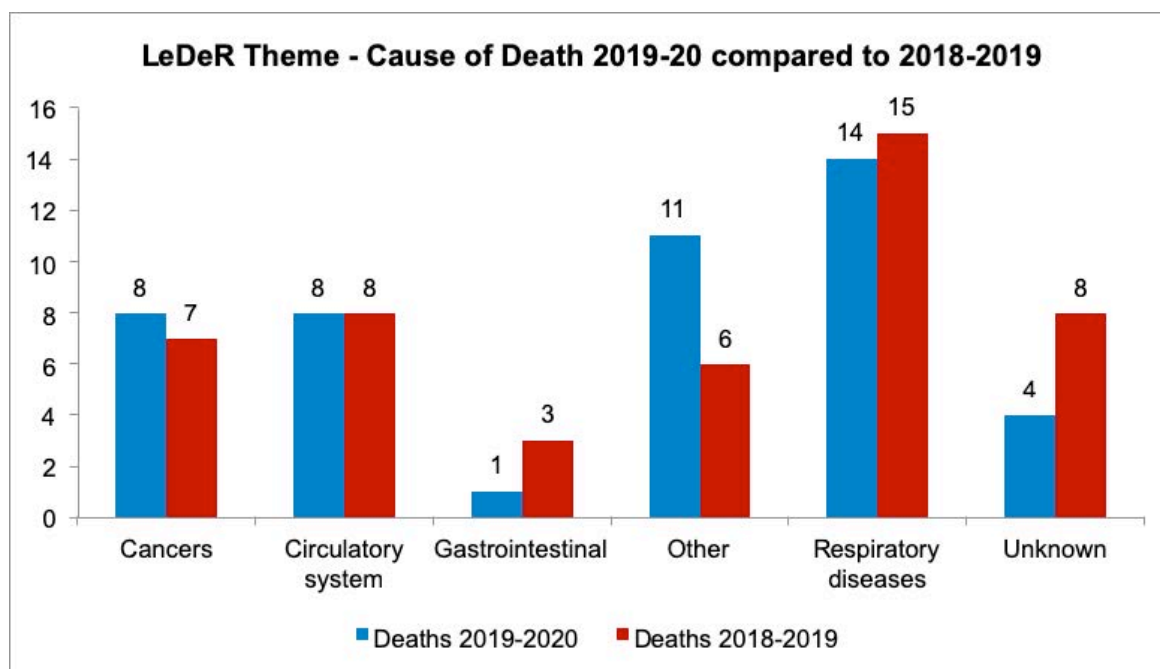
Chart 18 - Cause of Deaths reported 2019-20



Cause of death – LeDeR Themes in Gloucestershire

Chart 19 - LeDeR Theme cause of death 2019-2020 compared to previous year²³ shows that the top cause of death in the learning disabilities population remains from respiratory causes – mainly pneumonia type infections. Gloucestershire saw an increase in other causes of death²⁴ during 2019-2020 compared to the previous year (n5 deaths).

Chart 19 - LeDeR Theme cause of death 2019-2020 compared to previous year



²³Where unknown this indicates the review has not yet been completed or the notification did not have cause of death listed.

²⁴Other includes: Road traffic collisions, epilepsy, dementia and falls






Chapter Five - Quality of Care Provided

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:

<p>The person and /or their environment</p> 	<p>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.</p> <p>Inadequate housing that places the person at risk of falls, accidental injury or isolation in their home.</p> <p>Key information provided by family members or other carers being ignored or concerns not taken seriously or low expectations of family members.</p> <p>Families not wanting or feeling able to challenge medical professionals' authority and opinion.</p>
<p>The person's care and its provision:</p> 	<p>The lack of provision of reasonable adjustments for a person to access services.</p> <p>Lack of routine monitoring of a person's health and individual specific risk factors.</p> <p>Lack of understanding of the health needs of people from minority ethnic groups.</p> <p>Inadequate care.</p>
<p>The way services are organised and accessed:</p> 	<p>No designated care coordinator to take responsibility for sharing information across multi-agency teams, particularly important at times of change and transition.</p> <p>Lack of understanding and/or recording of the Mental Capacity Act when making essential decisions about health care provision.</p> <p>Inadequate provision of trained workers in supported living units.</p> <p>Inadequate coverage of specialist advice and services, such as Speech and Language Therapy (SLT) or hospital learning disability liaison nurses.</p>



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.

	<p>To be a panel of experts by experience to oversee and manage the quality assurance process for all LeDeR Reviews.</p>
	<ul style="list-style-type: none"> • To undertake a quality assurance role in respect of: <ul style="list-style-type: none"> • 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
	<p>To collate the recommendations and learning from reviews into a local action plan on behalf of the LeDeR Steering group.</p>
	<p>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.</p>
	<p>Where the group feels that it is appropriate, cases will be referred on to Safeguarding.</p>



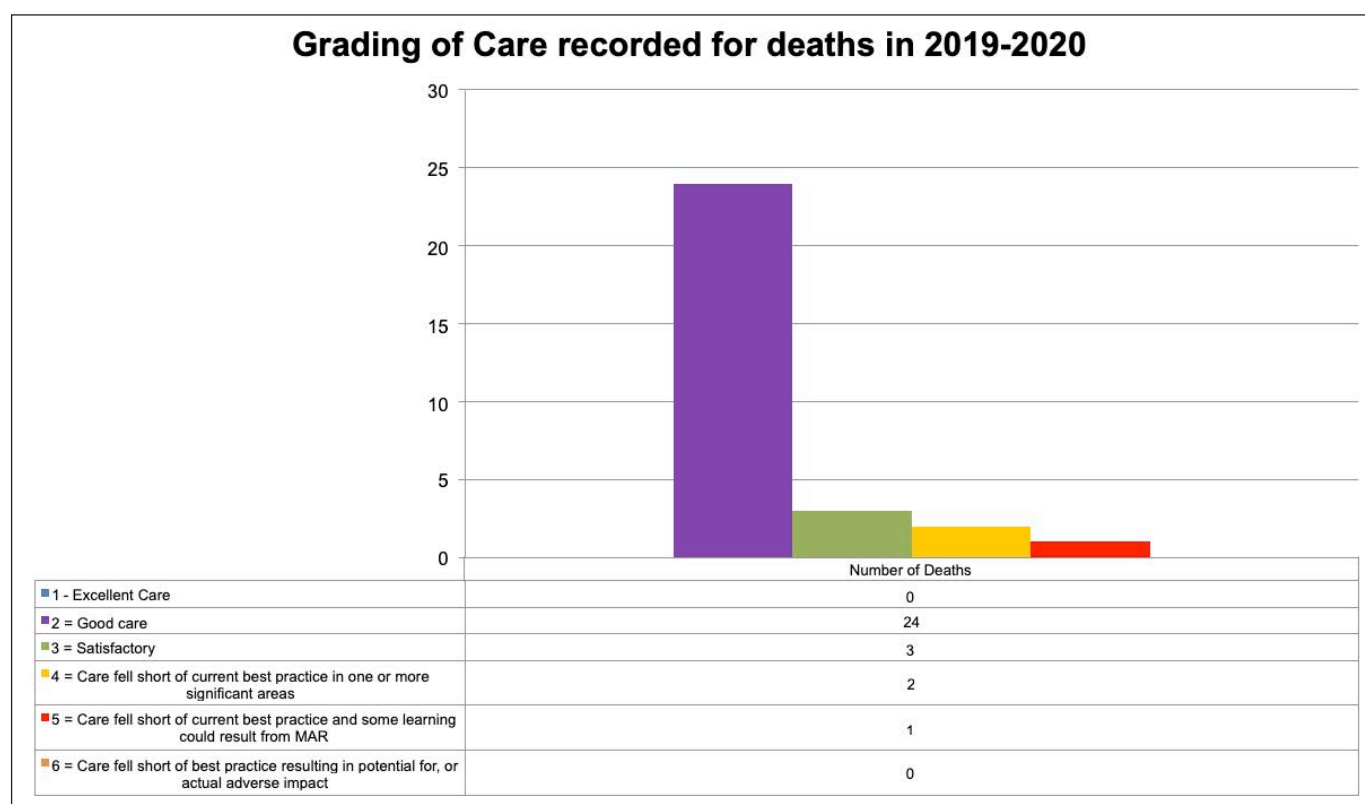
Assessment of the quality of care

On completion of a case the reviewer is required to make an assessment of the level of care provided on a range from 1 (excellent) to 6 (Care fell far short of expectations). Of the 30 cases where the quality of care has been recorded and submitted 9 out of 10 people had Satisfactory or good care.

Table 13 - Grading of care 2019-2020

	Number	%	Total & ratio
1 - Excellent Care	0	0%	27/30 9:10
2 = Good care	24	80%	
3 = Satisfactory	3	10%	
4 = Care fell short of current best practice in one or more significant areas	2	6.67%	3/30 1:10
5 = Care fell short of current best practice and some learning could result from MAR	1	3.33%	
6 = Care fell short of current best practice resulting in potential for, or actual adverse impact	0	0%	

Chart 20 - Grading of care recorded 2019-2020





Gloucestershire LeDeR Quality Assurance (QA) Panel Feedback

The QA Panel²⁵ noted the following areas of good practices for the reviews completed in 2019-2020

Local Theme	Panel feedback
Acute Hospital	Familiar carers and advocacy. Appropriate use of MCA.
Management of condition	Continuity of care was excellent with his care provider was excellent and as a result his anti psychotic drugs had been reduced.
Communications	There needs to be a way of acknowledging that during the course of a review the reviewer noted good care was identified.

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	Hospital stay at GRH – <ul style="list-style-type: none"> Community SLT Guidelines not followed in the hospital Hospital passport not utilised Paid Carers that knew him well not staying in the hospital
	Clinicians on the panel queried if he was at the end of his life why he was being fed in the last few days of his life, as this would have made him uncomfortable.
	Issues of Incontinence in the hospital - particularly the management of this by ward staff.
	Care provider management not sharing the seriousness of the choking risk and implications of feeding at risk with the care staff providing day to day care to this gentleman.
	Full blood count bottle unlabelled so significant rise in white blood count not known early enough. Delay in sending repeat Full Blood Count which delayed care. Additional distress to this gentleman.
	Altered feeding regimes and not following Community SLT guidelines in the hospital.
	The family contact details were not to hand in the hospital.
	Inadequate antibiotics – He should have had antibiotics for sepsis of unknown source. Did not receive antibiotics for 24 hours - oral route was selected but he did not take the tablets.
Death Certificate	Full completion of the death certificate by Medical examiners was not undertaken.
	Unclear why SUDEP was put down as cause of death when this condition had been well managed.
General Practice	All GPs should be following the national template for annual health checks which includes checks on mental health and wellbeing.
Management of condition	Clinicians on the panel queried if he was having TIAs why he hadn't been referred to the TIA Clinic for further investigations.
	Given that sepsis was the cause of death – it would be good to know where this originated from and whether it was preventable (e.g. was the Pressure ulcer the cause?) If so, would further clarification of Pressure Ulcer management and all grade 3 or above being reported as a serious incident and safeguarding incident be followed up by providers.
	People with Down's syndrome should be able to have definitive CT scans to diagnose dementia accurately rather than just relying on behavioural symptoms which could be associated with mental health conditions such as depression/bereavement.
	Pan Hypopituitarism wasn't being treated would explain his size/weight. What was the decision not to treat this condition? Should he have been under the care of an endocrinologist?
	The consequences of constipation can have very challenging and uncomfortable and must not be minimised by medical staff.

²⁵Noting that the panel process and formalised action tracker only began in October 2019



MCA	The individual should have been included within the BI meetings.
Medicines management	QA Panel to see if there are any national best practice guidelines for pharmacists and physicians on prescription of medications in adults who are less than 50Kgs.
Safeguarding	Discussion with Chair of GSAB and Safeguarding Lead as to the self-neglect theme coming up, and to whether a learning event and guidance could be developed to support staff in these circumstances.
Communications	Whilst we see antibiotics as the cure for infections, they also kill off a large proportion of our microbiome, which conversely leaves us more vulnerable to the next infection to come along.

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 family felt that some of the Nursing staff did not know how to communicate with someone who is non-verbal. Maybe more training should be available to help professionals support the non-verbal patient. Some nurses did not explain what they were going to do before they undertook action.
	High risk of aspiration with instructions to feed upright - unclear whether this happened.
Case Management	Documentation of Unique Wellness <ul style="list-style-type: none"> Physical Observations taken when he was well so clinicians understood better when he deviated from this Utilisation of soft signs monitoring e.g. RESTORE2 or PINCHME
Documentation not completed correctly	Appropriate completion of the DNACPR documentation was not undertaken.
Healthy Lifestyles	Cancer Screenings were not undertaken due to her anxiety, perhaps additional support and reasonable adjustments could have been provided by her GP and the screening programme to enable her to undertake these screenings given that she died from breast cancer.
Management of condition	There was a query about the poly pharmacy (more than one medication) he was on and whether this would increase his risk for stroke. It was noted that the GP had conducted regular medication reviews and this risk was well managed.
MCA	Clinicians do not routinely appear to evidence appropriate use of MCA/BI prior to significant interventions/ treatment being administered.
	Her ability to care for herself reduced in the last year of her life. Her care needs were not met by the 3 hours a week allocated funded support. She required more intensive support but this was not identified in a timely way. The support workers had flagged up her deterioration from 2017 and asked for psychiatric assessment which never happened. They also asked for her care needs to be re assessed which did happen once a crisis situation was reached.
	All staff properly completing the MCA2 documentation and where appropriate involve an IMCA.
	Briefing sheet to be produced by MCA Assurance Manager on the role of Officer of Public Guardian Deputies and what this means for Health and Social care.
Family/Carer support	Family carers should be offered and encouraged to take up training in choking management so they have the skills and capabilities to provide appropriate care should their loved one choke whilst eating and drinking.



Findings from Multi Agency Review Panels (MARs)

During 2019-2020 two MAR Panels were held.

Cause of death: one person died from heart failure (age 52) and the other person died from bronchopneumonia (age 72).

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

Case	MAR Panel Feedback
1 – Heart failure	<p>The environment that X lived in in Bristol (prior to moving to Gloucestershire) was concerning for the panel and queried whether this was a safeguarding and CQC concern. It was also noted that the move to Gloucestershire was a big upheaval which could have negatively impacted upon the individual's health and wellbeing. The whole process increased anxiety levels for the individual which may have impacted upon her heart rate and potentially adding additional strain.</p> <p>Statement from family noted that they had raised concerns about the supported living provider in Bristol.</p> <p>Also noted by the panel that the individual had fluctuating capacity to be able to make decisions which were dependent upon anxiety levels. This would have impacted upon the health care staff in Gloucestershire Royal Hospital NHS Foundation Trust being able to undertake medical interventions. Family were available to assist to alleviate anxiety levels to enable interventions to be undertaken successfully, but at that time there was restricted visiting hours in the hospital.</p>
2 – Bronco pneumonia	<p>Ability to care for themselves: The individual's ability to care for themselves reduced in the last year of life. The panel noted that the person was a hoarder who self-neglected – not willing to undertake personal care or eat and perishable food throughout the flat where she lived independently.</p> <p>The panel noted that the individual's care needs were not met by the 3 hours a week allocated support. The panel felt that the person required more intensive support but this was not identified in a timely way. The support workers started to flag up deterioration from 2017 and asked for psychiatric assessment which never happened. They also asked social care for a re-assessment of needs. Which did happen, but only once a crisis situation had been reached.</p>

Potentially avoidable contributory factors in relation to care

Case	MAR Panel Feedback
1 – Heart failure	<p>Medication: Noted by the panel (GP) that the individual was a high dosage of risperidone, but it was unclear from the notes reviewed what psychotic disorder this was prescribed for. The GP on the panel noted that this medication can cause sedation. The panel queried whether this would have impacted on the individual's capacity to understand questions and medication interventions being proposed.</p> <p>Move to Gloucestershire: Very limited documentation about the individual's medical history was passed to Gloucestershire. The person had been living in Gloucestershire less than a week before a very lengthy admission to hospital.</p> <p>Heart Problem: The panel noted that the individual had a history of a hole in the heart, but that cardiology investigations had not been followed up whilst she was an inpatient in the hospital. The panel noted that the discharge summary was not available to them to view at the time of the MAR so they could not confirm whether the medical intention was to follow this up as an outpatient.</p> <p>Loss of weight: Loss of weight (over 5 dress sizes) occurred in Bristol over a fairly short time period. It was the view of the GP on the MAR panel that hyperthyroidism would have somewhat contributed to this, but that further tests should have been undertaken.</p> <p>Mental Capacity: Fluctuating capacity depending upon anxiety levels and appropriate use of the best interests' process was not followed.</p>
2 – Bronco pneumonia	<p>Mental Capacity Assessment: The panel noted that the person was assessed as having capacity by the GP and refused medical intervention. However, the panel noted that No formal MCA assessment appeared to have taken place/no documented evidence of MCA decision making. It was acknowledged that MCA is more challenging when a person has fluctuating capacity.</p> <p>Timely reassessment of needs: The panel noted that there was a potential learning point for the GP around understanding the significance of behaviour changes being caused by an underlying physical cause. The panel also noted that had the individual been regularly supported to attend annual health checks some of the monitoring of physical health needs may have been undertaken in a timelier manner.</p>



Potentially avoidable contributory factors in relation to services

Case	MAR Panel Feedback
1– Heart failure	<p>Move from Bristol: The MAR panel felt that this was poorly planned for and not discussed with the individual with the family present to enable a move to a new environment in a calm manner.</p> <p>Lack of medical history: The lack of medical history to support a safe move into Gloucestershire was a concern for the panel.</p> <p>Timely access to Discharge Summary: It was unclear who had received the summary upon the discharge from Gloucestershire Royal Hospital, the individual has only been given 2 weeks supply of medication (when 4 weeks supply was required). No-one in the community (GP, care provider or family) was aware that the person required another 2 weeks supply.</p> <p>Communication between ward and community: It was noted that ward staff due to confidentiality reasons were reluctant to talk to care provider staff over the phone to provide updates. The panel felt that with an agreed protocol in place e.g. use of a password, this issue could have been overcome. The panel also noted that the passing of information received from the hospital to all appropriate care staff could have been improved by the care provider.</p>
2 – Bronco pneumonia	The panel noted that there was good multidisciplinary working lead by the GP with involvement from Intensive Health Outreach Team, Care Provider, social care and remote input from secondary care specialists.

Lessons Learnt

Case	MAR Panel Feedback
1– Heart failure	<p>Into County Placement Guidance: Further work with placing authorities into Gloucestershire to ensure they follow the ADASS guidelines and care programme approach (CPA) when planning someone's move. All appropriate medical and care history and other appropriate information is shared.</p> <p>Mental Capacity Act: Appropriate use of the mental capacity act and best interest process for people with fluctuating capacity needs to be considered within the training for Hospital staff.</p> <p>Communication and information sharing:</p> <ul style="list-style-type: none"> • Security Protocol to be developed by hospital in the sharing of information over the phone • Consideration of who the discharge summary is shared with
2 – Bronco pneumonia	<p>Monitoring of Physical Health deterioration:</p> <ul style="list-style-type: none"> • Use of PINCH ME tool may have helped spot physical deterioration in a timelier way • Support for those who are independent to understand the importance of attending the annual health checks to assist them to remain healthy and well • Timely intervention from the Intensive Health Outreach Team is important. This team should ensure they look holistically at the person rather than just the task the referral was for • It was noted that the GP surgery has already used this case as a learning opportunity for their staff as it highlighted some of the challenges that arise when caring for someone with fluctuating capacity that does not want to engage with services and appears to be self-neglecting. This was seen by the panel as good practice to increase the knowledge and skills of staff <p>Communications with social care:</p> <ul style="list-style-type: none"> • Social care was slow to react when asked to re-assess a change in needs. Care providers should be clear on who to communicate should an individual's needs change e.g. use of Duty desk or Social Care Helpdesk to be able to triage appropriately <p>Mental Capacity Act:</p> <ul style="list-style-type: none"> • The panel noted that the MCA allows for people to make unwise decisions. However, staff may need some additional training and support about how to approach MCA for individual's who may appear to have fluctuating capacity



Case Studies Please note that these case studies are from aggregated learning from the completed reviews to date and do not relate to one specific person. Names have been changed to protect anonymity.

Richard

Richard was born with congenital cerebral palsy, developmental delay and microcephaly. He had a congenital heart defect that required major cardiac surgery during his childhood. He had epilepsy which could progress to status epilepticus despite medication and careful monitoring by the specialist epileptic team. He had moderate oropharyngeal dysphagia which meant that he was a high risk of choking and aspiration. Towards the end of his life he had a PEG feeding tube inserted to mitigate the risk of choking and maintain nutrition. Richard needed support to attend to all his personal care. He was non mobile and required hoisting for all transfers. He was non-verbal although his mother was able to understand his facial expressions and gestures and he had the most engaging smile. Richard lived at home with his family and had close contact with extended family. His mother was his primary carer, coordinating all of his care. She was supported by paid carers who would help her get Richard up and dressed in the morning and back to bed at night. Richard suffered from recurrent chest infections requiring frequent hospital admissions for IV anti biotic therapy and oxygen. Richard's mother reported that when he first started to go into hospital, she felt hospital staff 'did not listen to her'. She believed she was an 'expert' when it came to providing care for him so should have been consulted more. As time went on the ward staff got to know her and were more receptive taking her views into account. Richard died in hospital following an exacerbation of aspiration pneumonia. Richard had a comprehensive end of life plan in place and the GP had completed the ReSPECT form following a best interest decision meeting in consultation with the family.

Richard had regular Learning Disabilities Annual Health Checks with his GP. He was given an annual influenza vaccination every year except in the last 12 months of his life when he was 'too poorly' at the time the vaccination was planned. Maybe opportunist vaccinations would have ensured he had his annual influenza vaccination despite his poor health. It was recorded in his GP records that he was due to have his annual influenza vaccination and one to prevent pneumonia. His mother questioned why he was not offered this vaccine before in view of the fact that he suffered from recurrent bouts of pneumonia.

Richard's mother carefully co-ordinated all of his care. She firmly believed that there would have been gaps in his care had she not acted as his advocate and 'fought hard' to get the package of care he needed. She felt this was particularly true for people who were non-verbal like her son.

Richard's mother did have a Carers Assessment which was updated regularly to reflect the changes in his needs as his condition deteriorated. Richard's mother also stressed how important it was for a non-verbal person with learning disabilities to have a detailed up to date hospital/health passport to ensure hospital staff understood how best to care for their patient if a family member was not there to act as their advocate.

Lessons learnt

1. **Early involvement and communication with Family and carers** who are often 'the experts' when it comes to knowing what their loved one needs so it is important for hospital staff to recognise this and be respectful, taking into account their wishes and feeling when planning patient care.
2. Non-verbal people with a learning disability are particularly vulnerable when they go in to hospital. **Advocacy** is vital to ensure they receive the care they need in a respectful, timely and dignified manner.
3. An up to date **Hospital/health passports** is a valuable tool for hospital staff so they can understand how best to care for a vulnerable person with Learning Disabilities while they are in hospital.



Sandra

Sandra was the youngest of 4 siblings. She was born with Down's syndrome and autistic features. She lived with her parents until she was 30 when it was decided that it would be better for her to be living more independently in a supported living arrangement. Sandra found this sudden transition very difficult and it had a detrimental effect on her behaviour. She became very sad and withdrawn. Eventually she did settle and stayed in the same placement for 25 years. Unfortunately, she needed to be moved again because her supported living placement was to be closed down. This time the transition to a new home was carefully planned over a 3 year period. Sandra was included in some of the decisions about the new accommodation. She was able to choose her own room and some of the decorations. Her transition into her new placement was managed well and she settled quickly. Sandra was non-verbal but she was able to communicate using facial expressions and gestures. Her carers and family were able to understand what she wanted and felt Sandra had a better understanding of what was going on than she was often given credit for.

Sandra was quite obese (Last recorded BMI was 40.46kg/m²) and she suffered from osteogenesis imperfecta which did affect her mobility. Carer staff worked hard to keep her as mobile as possible but sometimes Sandra would just sit down and refuse to move until one of her favourite carers could coax her to get up. Sandra also had poor muscle tone which made her more susceptible to constipation.

In 2012, Sandra developed epilepsy which required medication and frequent reviews. Sandra was on the Adults with Down's syndrome Memory pathway; so, her cognitive ability was reviewed on an annual basis. In 2014, Sandra was diagnosed with dementia. Gradually her mobility decreased, although the carers worked hard to maintain her mobility for as long as possible. She eventually used a specialised wheelchair and required hoisting for all transfers. Sandra also developed a problem with her swallowing reflex and was frequently reviewed by the Speech and Language Therapy team who drew up guidelines to mitigate against the risk of aspiration and choking. Sandra was fed a pureed diet with thickened fluids. The physiotherapist recommended upright positioning when feeding to reduce the risk of aspiration.

Sandra required support for all personal care. By 2018 she was experiencing frequent chest infections that required antibiotic treatment and on occasions a hospital admission. Carers felt it was important, at this stage, to make sure her hospital/health passport was up to date so her needs and wishes could be accommodated while she was in hospital. Due to her lack of mobility and size, Sandra developed a Deep Vein Thrombosis which required another hospital admission and daily subcutaneous Fragmin injections. Sandra's frailty was recorded to have increased from moderate to severe at this point. Following Best Interest Processes, Sandra was assessed as not having capacity to make decisions about her care and decide future management. Her family and medical team took part in this meeting. A very detailed Advanced Care Plan was drawn up. An appropriate DNACPR order was put in place. Her family wanted Sandra to receive end of life care in hospital. Continuing health care funding was applied for and approved to pay for her carers to go into hospital to provide consistent additional care (on top of the offer from the hospital) for Sandra during her end of life treatment.

In April 2019, Sandra developed another chest infection which required IV antibiotics and hospital care. She received active care but unfortunately, she did not respond to treatment and her condition deteriorated. She was extremely chesty and required frequent suctioning to maintain a clear airway. A Best Interest meeting was held with input from her family and the palliative care team. The decision was reached that end of life care should be commenced. A syringe driver was set up to administer end of life medication. Her family and carers were with Sandra when she died peacefully in hospital. RIP



Lessons learnt

1. Sandra needed time to plan and adjust to changes. She had a better understanding of a situation if people **communicated** with her in a simple clear way. This was taken into account when she had to be moved to a new placement. The staff planned the move carefully over time and involved Sandra in some of the decision making. Sandra coped well with the move. The transition went smoothly and Sandra settled quickly in her new home with familiar care staff around her.
2. The family and medical team contributed to Sandra's **end of life plan**. The plan was comprehensive and took into account both Sandra and the families wishes. The plan was followed and Sandra received the appropriate end of life care in a timely and well thought out way.
3. The carers and family made sure that Sandra's **Hospital/Health passport** was kept up to date reflecting her changing needs as her dementia progressed. An up to date hospital/health passports is a valuable tool for hospital staff so they can understand how best to care for a vulnerable person with Learning Disabilities while they are in hospital
4. There was evidence of the effective use of the **Mental Capacity Act** to ensure Sandra's wishes and feelings were taking into account when planning her future management.

Dave

Dave was born with a mild learning disability. He was also visually impaired and deaf. He had 3 older sisters who he remained close with throughout his life. As a child he was sent to a boarding school for children with special needs. He came home for Christmas and school holidays. He left school at 18 to return to live with his parents. He managed to get a job working for the Council as a refuse collector until he retired at 65. He was very proud of his job and made some good friends over the years. Dave was about 30 years old when his parents died. He then moved in with his long-term partner.

Dave lived with his partner for 35 years. They had a son who also had a learning disability. His son lived with his parents until he was 18 when he went to live in a residential care unit. The family remained in contact with this child. When Dave's relationship broke down, he was forced to move out of the privately owned house into a Local Authority warden controlled flat. He was allocated a social worker and his sisters supported him in his flat. He was able to care for himself but maybe at a 'sub optimal' level. He had poor literacy skills so he needed support to manage his paperwork and finances. He had a support worker who visited for 1 hour per week to help him with this. At this time, he was assessed as having capacity to make decisions about his health and finances provided people took the time to explain in a clear and simple way. Dave could grasp quite complex situations and make his own judgement.

Dave was in fairly good health for most of his life. He accepted the offers for most of the health screening but he did not attend for his annual Learning Disability Health Check with his GP because he did not perceive himself as a person with a learning disability. Dave was a lifelong heavy smoker and had no intention of stopping despite advice and support from health professionals and family. In 2016, Dave developed COPD (Chronic Obstructive Airways Disease) and peripheral vascular disease which limit his mobility. In 2017 he developed pain in his legs attributed to intermittent claudication, affecting his mobility further. He was assessed by a community Physiotherapist and Occupational Therapist and advised on exercises and specialist equipment was provided to help with his mobility. His ability to manage his personal care was also affected so his Social Worker undertook a needs assessment after which he was eligible for more support at home.



Dave had always maintained his body weight but in 2018 it was noted that he had lost weight. The GP sent him for some test and scans. Dave was diagnosed with terminal Carcinoma of the Pancreas plus lung metastases. It became clear that he did not really understand his diagnosis. His sister acted as his advocate during a best interest meeting to discuss a treatment plan. Using pictures and simple language Dave understood that he was 'very poorly' he deferred to his sister to make decisions regarding his future care. Dave was now assessed as not having capacity to make decisions regarding his health. He appointed his sister as his Power of Attorney. His GP acted as the single point of contact to co-ordinate his care. A decision was made to manage Dave's condition conservatively. Dave's prognosis was poor so extensive surgery was not considered to be in Dave's best interest. The risks to Dave's physical and emotional well-being outweighed the benefits of any surgery because of his poor outcomes. After considerable discussion with the palliative care team an advance care plan was drawn up in consultation with Dave and his sisters. A DNACPR order was put in place and a RESPECT form (Recommended Summary Plan for Emergency Care and Treatment) was completed, setting out Dave's wishes and feelings regarding future emergency care. All this was recorded in his hospital passport.

Dave developed faecal incontinence as a result of the pancreatic tumour. This caused him considerable distress. He was referred to the continence service who worked with Dave and his sister to manage this problem as best they could. In 2019, Dave's family noted that he was becoming more confused and his mobility was decreasing. He had a CT scan to rule out brain metastases.

His social worker carried out a FACE re- assessment (Functional Analysis of Care Environments) because Dave now needed help with shopping, cooking, cleaning, washing and all personal care. His sisters did support him but Dave lived alone and required help on a daily basis. Dave's sister accompanied him to the memory clinic for an assessment of his cognitive functioning. He was diagnosed with mild mixed Dementia and Alzheimer's disease. He was referred to the dementia team for advice and support.

Dave's condition deteriorated and he was admitted to hospital on a number of occasions with confusion, UTI's and general deterioration. The Palliative care team and District Nurse Service managed his care at home until he developed urinary retention and a lower respiratory tract infection. He was admitted to hospital for IV antibiotics and catheterisation. On admission he was assessed as entering the 'dying phase'. His family were informed but he 'rallied'. The family wanted Dave to be transferred to a community hospital for end of life care, as set out in his end of life care plan. A Mental Capacity assessment was carried out to determine if Dave had capacity to contribute to the decision. It was considered that Dave did not have capacity. Following a best interest meeting Dave was successfully transferred to a community hospital. Fast track CHC (Continuing Health Care) funding was applied for and approved to support palliative care in the community hospital. Dave died peacefully in the community hospital with his sister at his bed side. RIP

Lessons Learnt

1. Dave was able to understand relatively complex situations so long as people took time to **explain using simple language** and pictures. If this was done, Dave was able to understand and make a judgement for himself with support.
2. There was good use of the **Mental Capacity Act**. Dave had capacity but as his illness progressed, he needed to be frequently reassessed. Mental Capacity can fluctuate so it is important to keep re- evaluating the situation to ensure the best outcome for the person.
3. Any changes in Dave's situation were documented in his **hospital passport** ensuring his wishes and feelings were recorded so he received personalised care when he was in hospital
4. Dave had a mild learning disability. He lived an independent life until his health failed. He could have 'slipped through the gaps' in services but because his GP acted as his 'single point of contact' and co-ordinated his care and he had **good advocacy** in the form of his Social Worker and family, Dave received the care he required in a timely way.
5. There was effective **advanced care planning** so Dave was able to receive the end of life care that was considered to be in his best interests.



Chapter Six – Deaths of children

During 2019-2020, 3 deaths were notified to the LeDeR platform, which related to the death of a child with learning disabilities. 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 LeDeR Reviewer who worked closely with the [Child death review process](#)^{*} (CDOP). During the year; 1 case was concluded.

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. Further it is understood that when a child dies those left grieving; parents, siblings, other family members, friends and acquaintances, will need extra support and a good understanding as to what caused the loss of their loved one. 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 2018-2019](#) is available to view on the Gloucestershire Children's Safeguarding Board (GCSB) website.

Figure 8 in the CDOP Annual Report 2018-2019 shows that the co-morbidities found to have a significant impact on vulnerability are learning disability, motor impairment, sensory impairment, emotional, behavioural and mental health conditions and other disability. An example of "other disability" would be a child with an underlying chromosomal disorder or a genetic syndrome. Children with a learning disability represent the most common co-morbidity. 38 children had a diagnosed learning disability over the period 2014-2019, and this was considered to be a significant factor in all but 2 cases. Motor impairment is the second most common with 32 children in that cohort. Learning disability and motor impairment are also identified as the most common comorbidities in children reviewed by CDOP panels across the South West.



Chapter Seven – Recommendations from reviewers

Recommendations made by reviewers for local action

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.

Learning Theme
Physical Health Care ²⁶
Annual Health Checks and Health Check Action Plan
Legal frameworks including: Best Interest, MCA and DoLS
End of Life care: Including advance planning and having difficult conversations
Communications
Hospital Care

Concerns raised

It was noted of the 46 deaths in 2019-2020 n=7 (15%) had concerns raised as either part of the LeDeR Process or prior to the individuals' death e.g. through safeguarding enquiries.

Actions taken during 2019-2020

Learning Theme	Area of improvement	Area of best practice
Physical Health Care²⁷	<p>Bowel cancer screening</p> <ul style="list-style-type: none"> Did not take up the offer of bowel screening. The individual did not respond to the invitation so was discharged from the programme. May be the person would have responded more positively if someone had taken the time to explain the procedure to her Education and advice for care providers and supported living providers on how they can support people to undertake samples – education advice and advertising in easy read formats would be beneficial Staff in care homes should be made aware of national health screening programmes Consideration of alternative bowel screening options or some wider thinking from his carers in how to obtain a stool sample <p>Breast cancer screening</p> <ul style="list-style-type: none"> Screening was not undertaken due to the persons anxiety, perhaps if additional support and reasonable adjustments could have been provided to undertake these screenings given that she died from breast cancer 	<p>Weight Management</p> <ul style="list-style-type: none"> Fed through a PEG tube because he was a high risk of choking. The dietician reviewed him every 8 weeks. His weight was carefully monitored weight, bowel movements. The team would visit more frequently in response to his condition <p>Equipment</p> <ul style="list-style-type: none"> Following a best interest meeting towards the end of his life, the home used special monitoring equipment at night so they could monitor him remotely, safeguarding him from harm from choking <p>Pressure care</p> <ul style="list-style-type: none"> She was visited regularly at home during her last 6 months of life by a District Nurse in order to dress her legs (Cellulitis/Ulcers). She also received visits as required from her GP The district nurses visited him at the care home every day to clean and dress his pressure wounds, the GP visited at least weekly and more often when needed

²⁶The physical health care theme includes improvements in screening, immunisation, detection of sepsis and deterioration, constipation, dysphagia and aspiration pneumonia.

²⁷The physical health care theme includes improvements in screening, immunisation, detection of sepsis and deterioration, constipation, dysphagia and aspiration pneumonia.



Learning Theme	Area of improvement	Area of best practice
	<p>Dysphagia</p> <ul style="list-style-type: none"> Care provider management did not share the seriousness of the choking risk with all care staff <p>Equipment</p> <ul style="list-style-type: none"> His nursing home did not have a long enough bed so his heels were resting over the bottom bed post. He had pressure ulcers and there was not a suitable chair he could transfer to <p>Constipation</p> <ul style="list-style-type: none"> How did she get so constipated? What was done at home to prevent constipation? Bowel movements were recorded in hospital, but would there have been justification in more regular radiation-based imaging to see how well that was resolving (or not)? I am not surprised that with that amount of faecal loading and inflammation of her bowel mucosa that she did not want to eat – I don't think I would have done. I do think, with hindsight, that more attention should have been paid to ensuring all constipation had cleared before everyone got so focused on feeding 	<p>Reasonable adjustments</p> <ul style="list-style-type: none"> IHOT's involvement to enable blood samples to be taken <p>Deteriorating physical health needs</p> <ul style="list-style-type: none"> There was a risk that he would 'fall through the gaps' in services because he had a mild learning disability and had been independent of services for most of his life but because he had good advocacy in the form of his family, when his cognitive function and physical health deteriorated they brought it to the attention of services so the level of support could be stepped up in response to his increased need
Annual Health Checks and Health Check Action Plan		<p>Reasonable adjustments</p> <ul style="list-style-type: none"> AHC completed at home by GP who knew her well Regular annual health checks
Legal frameworks including: Best Interest, MCA and DoLS	<p>Process</p> <ul style="list-style-type: none"> Concerns about the use of the MCA by the LA. She has written to the LA with her concerns and is awaiting a response When assessing a person's capacity and their understanding of a situation it is important to give the person time to reflect and be sure they truly understand <p>Advocacy</p> <ul style="list-style-type: none"> Crucial for a person who is vulnerable in hospital to have an advocate in order to keep them safe Refer to the IMCA service as early as possible in order that Mental Capacity Assessments and Best Interest Decisions are properly executed and documented <p>Best Interest process</p> <ul style="list-style-type: none"> Felt that professionals did not always listen to relatives when considering their relatives best interest in hospital. Family and friends know the person best and should be listened to when care is planned 	<p>Advocacy</p> <ul style="list-style-type: none"> IMCA involved for BI meetings IMCA also offered good support to the family IMCA was fully utilised for BI decisions <p>DNACPR</p> <ul style="list-style-type: none"> There was a DNACPR in place and correctly documented <p>Family Involvement</p> <ul style="list-style-type: none"> Very good use of the Mental Capacity Act and well recorded. Best interest decisions always included family and they told the reviewer they felt very well informed and even when decisions were very difficult to make they believe they were always in her best interest



Learning Theme	Area of improvement	Area of best practice
End of Life care: Including advance planning and having difficult conversations	Bereavement support for care staff <ul style="list-style-type: none"> Care staff did not receive any emotional support or bereavement counselling following this death End of life planning (ReSPECT Form) <ul style="list-style-type: none"> Given the individuals age (84) no consideration of end of life care appears to have taken place On reflection the Care home manager felt that RESPECT forms should be completed sooner for all residence so everyone is clear what emergency care options are and a baseline for a person's frailty is recorded It would be good practice if the RESPECT form was completed as part of the annual LD health assessment so there is a base line in place to review frailty and advanced care planning 	End of life care <ul style="list-style-type: none"> Well co-ordinated end of life care Carers found the Palliative input 'hospice at home' providing someone to sit with her overnight during her last days very reassuring There was good communication between professionals so he received good care at the end of life. The palliative care team were excellent Gold Standard of Palliative Care seems to have been excellent practice Daily involvement of District nurse to support end of life care End of life planning <ul style="list-style-type: none"> Advance funeral plan put into place so the individuals' wishes could be met
Communications	How to effectively communicate <ul style="list-style-type: none"> Needed training when caring for a non-verbal patient Difficult conversations <ul style="list-style-type: none"> No discussion of deterioration with the family Timely re-assessment of needs <ul style="list-style-type: none"> Support workers were not listened to when deteriorating needs were raised. Communication between social care and health care was limited Care Package needed fundamentally reviewing as soon as his terminal diagnosis was made. His supported living environment and one hour a day one to one care was never going to be sufficient to meet his needs. The coordination necessary between health and care providers to make necessary changes with speed was inefficient. Inter -dependencies between care plan and treatment plan led to one negatively impacting on the other Into County Placements: <ul style="list-style-type: none"> In the last six months of his life he had 3 moves (where was the continuity of care) by care provider in Bristol, Bristol Royal Infirmary and Gloucestershire care provider (name removed) He arrived at the care home from Bristol Royal Infirmary very ill. He was non-weight bearing and had to be nursed in bed 	Reasonable Adjustments <ul style="list-style-type: none"> Most medical appointments were done at home because he became agitated and distressed when he had to go to an unfamiliar place Positive Behavioural Support <ul style="list-style-type: none"> Staff put a 'Positive behaviour support plan' in place to try to manage his agitation and reduce the amount of self harm GP Enhanced service <ul style="list-style-type: none"> Care home had an enhanced service with the GP who visited the home every 2 weeks Into County Placements <ul style="list-style-type: none"> First class transition arrangements between Bristol and North East Somerset and Gloucestershire. Lengthy hand over of services and extended period of shared responsibility between professionals from both areas resulted in cohesive and coordinated transition Documentation and care plans <ul style="list-style-type: none"> Good documentation held within the Home. Carers responded appropriately to changing health needs - evidenced by regular GP appointments Carers had identified he was blue and followed guidance and used defibrillator Multi-disciplinary working <ul style="list-style-type: none"> There was good collaborative team work. The Rapid response team were 'excellent' according to the care home manager





Learning Theme	Area of improvement	Area of best practice
Hospital Care	<p>Speech & Language Therapy Guidelines</p> <ul style="list-style-type: none"> • Ward staff not following Community SLT Guidelines • Family felt hospital staff needed better training about SLT guide lines and feeding • High risk of aspiration with instructions to feed upright – unclear whether this happened in hospital <p>Funding</p> <ul style="list-style-type: none"> • Frustration about the funding issues that existed between Health and Social Care and funding should be something that follows the patient rather than from different budgets <p>Weekend cover</p> <ul style="list-style-type: none"> • No senior clinical review over the weekend <p>Hospital Discharges</p> <ul style="list-style-type: none"> • Whilst in hospital he had a LD Liaison nurse, however there was very little information exchange on discharge and included in his medical history with the GP in Gloucestershire before his death <p>Family/Carer Involvement</p> <ul style="list-style-type: none"> • Whenever possible it is preferable to have familiar carers who know the routines so that people are cared for appropriately and staff don't constantly have to be trained and constantly supervised • Family carers should be respected and fully involved in the care and treatment of their loved ones 	<p>Health (Hospital) Passport</p> <ul style="list-style-type: none"> • Passport was kept up to date • Hospital passport was up to date and utilised by hospital on admissions • Up to date passport • Hospital passport in use • Had a comprehensive Hospital Passport in place to assist with her care and treatment in hospital • Use of hospital passport <p>Intensive Health Outreach Team (IHOT)</p> <ul style="list-style-type: none"> • Some desensitisation input from IHOT to improve compliance with health appointments - progress was limited but better than it would have been without <p>Family/Carer involvement</p> <ul style="list-style-type: none"> • Carers stayed with xxx when she was in hospital and helped the ward staff with medication, personal care, eating and drinking • Carers stayed with him in hospital to reduce confusion and manage behaviour which others found difficult • The carers from * [care provider name removed] went 'the extra mile, by going into the hospital on their days off to care and support her at crucial times like meal times and drug rounds • Familiar Care Staff were funded to support her in hospital • Mum stayed with her son when he was in hospital and overnight a diary was kept to ensure that mum was informed • The more he stayed in hospital, it became evident that the nursing staff started to respect and value Mum's suggestions • Mum also mentioned that she felt the doctors kept her fully informed and they involved her appropriately in decisions regarding her son's health

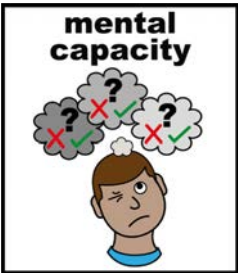





Learning Theme	Area of improvement	Area of best practice
Hospital Care		Reasonable adjustments <ul style="list-style-type: none"> • Sedation given to undertake scan, biopsy and physical examination • Availability of LD Liaison nurse when needed for procedure • Use of Makaton by LD Liaison nurses • The practices of Gloucester Royal Hospital in respect of patients with learning disabilities are commendable. Coordination of services by LD Liaison nurses result in effective reasonable adjustments being made and high quality care being delivered once he had been admitted • Actively involvement from the LD Liaison nurse regarding all hospital care and treatment • Was visited by an acute learning disability liaison nurse during relevant hospital admissions • Use of purple butterfly on notes

Action from learning



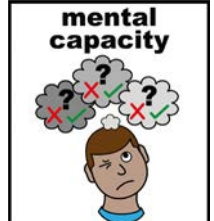



Learning Theme	Actions underway	
good health 	Physical Health Care	<ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website to reduce clinical variation. 2. System enablers - Telehealth pilot project and evaluation is ongoing. 3. Rollout ReSTORE2 and ReSTORE2 mini alongside West of England Academic Health Science Network. 4. Conclusion of the Community Dietetic pilot project and business case developed for further investment. 5. Dying for a poo awareness campaign. 6. Eating Well training to be continued.
health checks 	Annual Health Checks and Health Check Action Plans	<ol style="list-style-type: none"> 1. A project group was established in 2017-2018. 2. Further enhance the information on the G-Care website https://g-care.glos.nhs.uk/pathway/576 3. Attended Locum GP Conference 4. "Supercharged Me" campaign commenced in September 2019. 5. Review of the training provision from Strategic Health Facilitation Team. 6. AHC Toolkit for GP practices and communications reviewed. 7. Primary Care Learning disability champions identified in most practices. 8. Forum theatre training commissioned via Inclusion Gloucestershire – undertaken May 2019 and further plans being developed for remote Making Adjustments Training and Worksheet to be available on the Primary Care Webpage during Q3 2020-2021. 9. Developing webinar type training packages for Primary care colleagues to sign up to during Q4 2020-2021.



Learning Theme		Actions underway
	Legal frameworks	<ol style="list-style-type: none"> 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	<ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website to reduce clinical variation. 2. Establishment of a expert advisory group for disabilities, dementia and carers for the End of Life Clinical Programme to ensure consideration of this vulnerable group is considered in end of life planning. 3. Begun review of End of Life resources for those with learning disabilities e.g. leaflets and easy read guides.
	Communications	<ol style="list-style-type: none"> 1. Learning into Action Event was planned for March 2020 but due to Covid-19 this was postponed and the programme is exploring how to undertake a remote webinar during 2020-2021 in place of a face to face event. 2. Improved local LeDeR governance and quality assurance of the programme established October 2019. 3. Work with NHS England has commenced to scope out regional into county placement protocol. 4. Positive Behavioural Support review concluded in January 2020. Funding has been approved to expand offer in Gloucestershire. Implementation will begin in 2020-2021. 5. Workforce competency skills gap analysis against the Skills for Health Learning disability Competency framework has been undertaken in 2019-2020. Full report to be approved in 2020-2021 with recommendations to address gaps. Business case to be developed to address gaps.
	Hospital Care	<ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website to reduce clinical variation. 2. June 2018 - NHS Improvement LD Standards published. November – 2nd National Benchmarking completed – 3. Work with Safeguarding to develop a local promotional/ training film for clinicians about Was not brought https://youtu.be/jK7YaXoC5dc 4. Work with Inclusion Gloucestershire to develop a range of short films on “Getting Checked, Staying well” over a range of clinical areas Click here to view the range of films. 5. Constipation awareness programme to be planned for 2020. 6. Dysphagia training for ward staff to be scoped out for 2020. 7. Eating and drinking pathway review planned for 2020.



Chapter Eight – Conclusions and recommendations 2020-2021

Learning Theme	Actions underway
 <p>good health</p>	<p>Physical Health Care</p> <ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website to reduce clinical variation. 2. System enablers - Telehealth pilot project and evaluation to be completed. 3. Adapt (and then adopt) the Restore2²⁸ to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by: <ul style="list-style-type: none"> • Involving people with learning disabilities, their families and professional organisations • Disseminating for use across acute, primary and community settings 4. Conclusion of the Community Dietetic pilot project and business case developed for further investment. 5. Dying for a poo campaign continues 6. Eating Well training to be continued.
 <p>health checks</p>	<p>Annual Health Checks and Health Check Action Plans</p> <ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website. 2. Supercharged Me campaign continues. 3. AHC Deep dive to be undertaken. 4. Making Adjustments training based on the Forum theatre training delivered in 2019 to be developed as a remote training tool for primary care.
 <p>mental capacity</p>	<p>Legal frameworks</p> <ol style="list-style-type: none"> 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 – Working closely with the MCA Manager to amend training content.
 <p>palliative care</p>	<p>End of Life care</p> <ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website to reduce clinical variation. 2. Establishment of a expert advisory group for disabilities, dementia and carers for the End of Life Clinical Programme to ensure consideration of this vulnerable group is considered in end of life planning. 3. Begun review of End of Life resources for those with learning disabilities e.g. leaflets and easy read guides.
	<p>Communications</p> <ol style="list-style-type: none"> 1. Work with NHS England has commenced to scope out regional into county placement protocol. 2. Workforce competency skills gap analysis Full report to be approved in 2020-2021 with recommendations to address gaps. 3. Further links to the Learning Disabilities and Autism Clinical Programme to be established.
 <p>staying and leaving hospital</p>	<p>Hospital Care</p> <ol style="list-style-type: none"> 1. Further enhance the information on the G-Care website to reduce clinical variation. 2. Review the Learning Disability GHT Steering group and key service improvement priorities. 3. Constipation awareness programme to be planned for 2020. 4. Dysphagia training for ward staff to be scoped out for 2020. 5. Eating and drinking pathway review planned for 2020.



Conclusion

This is the second Learning Disability Mortality Review (LeDeR) annual report for Gloucestershire. The report provides the detail of how the LeDeR Process has been implemented and monitored, demonstrating the improved governance arrangements to support a robust approach to learning from the deaths of people with a learning disability.

Performance of reviews complete when compared with regional steering groups demonstrates the need to have an adequate resource of paid reviewers to be able to allocate and complete reviews within the given timeframes.

From the completed reviews that 9 out of 10 people with a learning disability received satisfactory or good care.

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

- 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
- 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 are considered palliative to there is a base line in place to review frailty and advanced care planning with individuals, their family and carers
- Greater inclusion of people with lived experience in the work programme including attendance at steering groups, quality assurance panels and other training events
- Share the learning – plans to host an action from learning event during 2020-2021

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 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.



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/notify-a-death/?_ga=2.4265911.589001362.1531124673-1987643447.1528363357
- ^{vi} <http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/multiagency-review/>
- ^{vii} <http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/notification-of-a-death/>
- ^{viii} <http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/people-involved-review/>
- ^{ix} <http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/people-involved-review/>
- ^x <https://www.gsrb.org.uk/media/2097132/child-death-review-protocol-for-gloucestershire-2020-v1.pdf>

Glossary

AHC	Annual Health Check
BI	Best Interest
CCG	Clinical Commissioning Group
CIPOLD	Confidential Inquiry into the Premature deaths Of people with Learning Disabilities
DNACPR	Do not attempt cardio pulmonary resuscitation
DOLS	Deprivation of Liberty Safeguards
FACE assessment	Functional Analysis Care Environments
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
IHOT	Intensive Health Outreach Team
LD	Learning Disabilities
LeDeR	Learning from Deaths Review
MCA	Mental Capacity Act
GSAB	Quality Assurance
PINCHME	Pain, Infection, Nutrition, Constipations, Hydration, Medication, Environment
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
TIA	Trans Ischemic Attack

