LeDeR

Annual Report

April 2021 – March 2022

Learning from lives and deaths of people with a learning disability and Autistic adults in Gloucestershire

Gloucestershire LeDeR Mortality Review

Annual Report

Report 2021-2022

Responsible committee:	Gloucestershire LeDeR Governance and Steering Group Learning Disability and Autism Clinical Programme Group Gloucestershire Clinical Commissioning Group Quality and Governance Committee
Target audience:	Report for those agencies involved in the programme. LeDeR Governance and Steering Group Members LeDeR Quality Assurance Panel LeDeR Learning into Action Group Learning Disability Partnership Board members Autism Partnership Board Members Gloucestershire Clinical Commissioning Group - Quality and Governance Committee Learning Disabilities Lead Commissioner Autism Lead Commissioner South West Regional LeDeR Operational Group South West Regional Health Equalities Group National LeDeR Programme NHS England
Date of approval: 18 August 2022	
Review date:	
Version	1
Document type	Quality Report
Key Words	Learning Disabilities, Autism, Mortality, Health inequalities, Service Improvement

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Glossary

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

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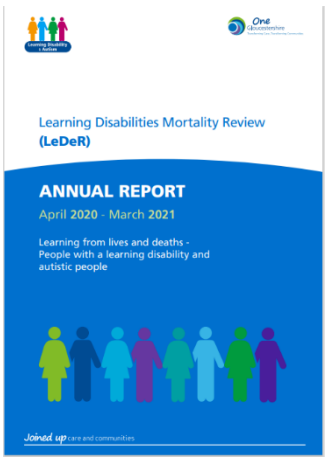
Preface:

Joint Statement from Chair of Gloucestershire LeDeR Governance and Steering group and Director of Nursing

This report includes the death of people with learning disabilities who died from 1st April 2021 to 31st March 2022. It is the fourth annual report for LeDeR that Gloucestershire has published. Previous reports are available on Inclusion Gloucestershire's LeDeR Webpage (Gloucestershire LeDeR Programme, 2022)[1]. The purpose of the report is to share our findings from LeDeR reviews and to identify learning and changes for practice.



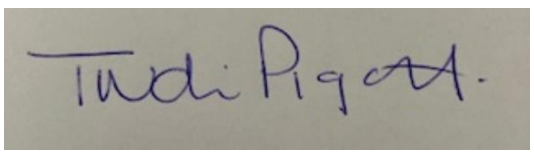
Gloucestershire stands in a strong position to address the issues and preventable causes of death identified within the national LeDeR annual report (NHS England, 2021)[2]. This reflects the many challenges that people with a learning disability face locally. The national LeDeR Policy (NHS England, 2021)[3] was updated and published in March 2021. The amendments were introduced in Gloucestershire during the Summer of 2021. Some of the changes included the introduction of a new IT system and review process which brought with it some challenges. However, Gloucestershire has continued to be a top performing area and continued to meet all its performance indicators set by NHS England for LeDeR. This annual report will provide an overview of the changes to the programme, not least the introduction of reviewing autistic adults without a learning disability from January 2022.

The local programme has an established way of working in co-production with people with lived experience and this continues to be a key contributor to the success of the programme locally. Learning from each review has been invaluable in enabling the lessons learnt and service improvements put into place in a timely way. The co-production partnership approach[4] which was implemented in 2019 continues to be invaluable in ensuring we are ahead of the curve in implementing action from learning and sharing this with a wide range of people and experts by experience have helped us get perspectives from the people who use 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.

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

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

Going forward the programme is passionately committed to listening and learning from these reviews, from people with learning disabilities and autistic adults, their families or carers and wider community and voluntary sector supports. The aim is to make positive changes across the health and social care system as we move into the new Integrated Care Board. The programme will continue to challenge health inequality, advocate and lead on service and system developments to improve health outcomes for people with learning disabilities and autistic adults.



Trudi Pigott

Chair of the Gloucestershire LeDeR Steering Group and

Deputy Director of Quality

Gloucestershire Clinical Commissioning Group

Dr Marion Andrews-Evans

Director of Quality and Nursing

Gloucestershire Clinical Commissioning Group

Gloucestershire Integrated Care Board

[1] https://www.inclusiongloucestershire.co.uk/engagement/leder/
[2] https://leder.nhs.uk/resources/annual-reports
[3] https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/
[4] We have been supported with this by Inclusion Gloucestershire

Some of the people who have died

This report is about people with a learning disability who have died in Gloucestershire during 2021-2022. They were people who were loved and cherished, and whose deaths have been heart breaking for their family and those who loved them.

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

We are therefore starting this report by sharing who some of the people whose deaths have been reviewed by the LeDeR programme were. All details have been anonymised[5], but the stories are those as told by families or paid carers to reviewers. We would like to thank the families who have given us permission to use their stories.

Pipsy

Phillipa (or Pipsy as she preferred to be known as) was 58 when she died in Gloucestershire Royal Hospital of a bowel obstruction and perforated bowel.

About Pipsy:

Pipsy was one of three siblings and grew up in the Forest of Dean. She was quite an independent lady before the covid pandemic and regularly attended her local catholic church and spent time with her sisters. Pipsy's sisters were very important to her, and she always looked forward to visiting them especially when a Sunday roast was involved. Pipsy was very happy where she lived and her days were full of activities and cups of tea, Pipsy liked the company of the people she lived with and there were no problems until Pipsy's mobility deteriorated and she required equipment to transfer which could not be accommodated in her home, so a new home was being sought when she died.

Pipsy had a mild/moderate learning disability, cerebral palsy, arthritic right hip, severe disc degeneration with mild spondylolisthesis, dysphagia and severe pain in her hips and legs. She was happy where she lived in Supported Living, but during the pandemic following a fall in June 2020 her mobility began to deteriorate, she was in a lot of pain, and she required equipment to transfer which could not be accommodated in her home environment due to the size. Pipsy had support to manage and maintain nutrition. Staff supported her with managing her personal care. She received Wiltshire Farm Foods but had lost 2.5 stone and was a frail 5.5 stone when she died. Her family were shocked at her weight lost. She was seen by her GP, however Pipsy’s sister felt that although the GP was originally responsive, they were informed that her bloods were normal and there was nothing else they could do. Family asked for a Social Care re-assessment as they felt that Pipsy needed more support with her physical and mental health. An MDT was held in June 2021, and she was allocated 14 hours of 1:1 care. Adult social care was in the process of finding a new home that could meet her needs and fit in all her equipment when Pipsy died. Before the pandemic Pipsy was quite independent and enjoyed a range of activities. However, due to the intense pain she experienced and the deterioration in her mobility in the last 16 months she was unable to participate in most of these activities and needed support with all aspects of daily living.

About her death

In October 2021, after 4 days of Pipsy feeling tired and unwell her carers contacted her GP. The GP was concerned about Pipsy’s bloated stomach and pain and agreed that the carers should contact the ambulance service due to her rapid deterioration. Pipsy was admitted to the Emergency Department for scans and tests, and it was found she had a perforated bowel and peritonitis. Pipsy was treated with IV antibiotics, IV fluids and pain relief. It was identified by the medical team that Pipsy was in her last days of life and a ReSPECT form was completed. Pipsy died three days after being admitted to hospital.

[5] Please note that all names throughout this report have been changed to protect confidentiality. Unless we have had express permission to use their names and/or pictures from their family

Learning Points & themes

- The panel noted she died from a bowel perforation but nothing in the notes suggested to the panel that she had ongoing bowel issues and the panel queried whether the pain relief prescribed for joint pain could have potentially contributed to her bowel perforation?
- The panel also discussed whether someone involved in her care could have seen and recorded changes in her bowel habits and movements.
- The panel were concerned there was potential for diagnostic overshadowing, and she potentially could have been in pain in relation to her bowels rather than musculo-skeletal (joint) pain.
- The panel felt that a medication review should have been undertaken and a best interest approach would be seen as best practice.
- The Panel also discussed whether a Pain Assessment tool should have been utilised and whether the benefit of the IHOT team being involved to support her through an appropriate BI approach to her physical health care.
- Suitable placements to house appropriate equipment (hoist) – panel did note delays due to covid outbreaks and trying to meet family's wishes.

Actions taken

- Information about diagnostic overshadowing and how people express pain to be shared in a LeDeR Newsletter
- Easy read bowel care resource to be developed
- Webinar to be delivered by a dietician on managing bowel conditions and the health implications for mainstream health and social care providers.
- Guidance developed for primary care during covid of a risk stratification tool for virtual appointments, but this guidance needs to be amended post covid. Importance of face-to-face appointments to reduce health inequalities and improve communications has been included in local LeDeR Newsletter.
- Exploring with other clinical programmes the possibility of a single pain assessment tool that has been validated for use with patients with a learning disability.
- Continue to rollout the RESTORE 2 mini documentation to all care providers in the County to support spotting the signs of deterioration, know what individual's unique wellness looks like and ultimately be able to improve communication with health care professionals.

Sarah (name anonymised*)

Sarah* was 79 when she died in Gloucestershire Royal Hospital of a spontaneous small bowel perforation

About Sarah:

Sarah* was described by her family as wonderful, creative, inventive, kind, enterprising and resourceful. She obviously brought much joy to her family. She lived to go round the charity shops and collect ornaments she also enjoyed knitting, jigsaws, cooking, drawing, and listening to music (especially songs from musicals). She also enjoyed some lovely holidays. She did not like uncertainty and the pandemic proved very difficult for her. She could not see her family and her holidays were cancelled. When things were going well Sarah had a sunny personality but was less easy when she felt threatened or was not happy, she didn't like people shouting, loud noises, doors being slammed or rude/bossy people. She lived with her family outside of Gloucestershire until her early 20's before moving to Gloucestershire and the supported living community where she remained living for 49 years.

Sarah had a mild to moderate learning disability; her last annual health check was carried out remotely in March 2021. She had a Health Check Action Plan, which appeared effective. She had her own End of Life Plan (not a RESPECT form) which was completed with her with the help of support staff where she lived. She also had a hospital passport which was given to the paramedics when she went into hospital in December 2021. Sarah felt confident to engage with health services (this being based on a history of receiving good treatment and care when admitted for cancer treatment and her hysterectomy operation), she was reported as happy and in relatively good health. However she had a diagnosis of Hypertension (diagnosed in 1991); Osteoporosis (diagnosed in December 2013) and non-diabetic hyperglycaemia (diagnosed in January 2021). She also had hearing impairment.

About her death

Sarah became unwell early in December 2021, and she was seen by her GP and admitted to hospital via ambulance (999). Observations were documented and the nurses scored her as a 6 (moderately frail) on NEWS2 (National Early Warning Score (NEWS), n.d.)[6] score. She experienced abdominal pain and vomiting and was treated with pain relief and IV antibiotics. Treatment (plus nil by mouth) continued for the next few days, but she was still vomiting and was constipated. Sarah had preparation for x- ray as doctors wanted to establish what was going on internally and this was administered via Nasogastric (NG) Tube. However, she was found unresponsive in bed when staff went to collect her for the x-ray. Adrenaline was given to Sarah alongside five lots of CPR. CPR was stopped and her family were informed that she had passed away two days after her admission.

Family was not aware that Sarah had been admitted to hospital (until they were contacted by the hospital to advise of her death) but felt assured that she would have been happy enough to be in hospital as she loved doctors and nurses and would often talk about the wonderful treatment and attention, she received in hospital previously. Family is grateful that she did not have a slow death. Family informed Sarah's care providers that she had died. The Care Provider had planned a very in-depth end of life plan with her when she had been well, which included all of Sarah's wishes. But the Family felt that the care provider had included some unrealistic expectations in the end-of-life plan which they found really distressing as they could not carry out all her end of life wishes.

Learning Points & themes

- Sarah clearly had good holistic health and social care which met her needs. She had access to all appropriate preventative support and screenings. She became ill very quickly and all appropriate healthcare to support her was accessed in a timely way.
- The panel discussed the need for expanding the triangle of communication for patients to a square of communication to include the patient, the hospital, their next of kin, and their care provider which will ensure there is better communication between provider and family members when someone is admitted to hospital.
- The panel felt that the care provider had clearly planned her end of life to include all her wishes, but her family should have also been involved in these discussions to ensure the feasibility of some of the requests were achievable.
- The panel felt it would be helpful for the end-of-life clinical programme to present to the Disabilities Care Provider Forum on end-of-life planning and documentation.

Actions taken

- Acute hospital to check on admission who to contact in the case of emergency next of kin or care provider.
- Importance of advanced decisions being documented and clearly discussed with people (with advocates if required) when they are well, and this being recorded on a RESPECT form.
- Easy read bowel care resource to be developed
- Continue to rollout the RESTORE 2 mini documentation to all care providers in the County to support spotting the signs of deterioration, know what individual's unique wellness looks like and ultimately be able to improve communication with health care professionals.

David (name anonymised*)

David* was 58 when he died in Cheltenham General Hospital of sepsis, broncho pneumonia and cellulitis

About David:

David* was described by his family as a "cheeky chappy" who loved his family, was always laughing and joking, with football being his main interest alongside watching TV programmes like Strictly Come Dancing. David would tell you if he did not like something he was doing, he "bossed" his carers around and could be exceptionally stubborn. He was very happy where he lived and had been there since 2013. He had a paid job with them delivering corporate induction training to new staff. He also used to attend horse riding and had won several medals. David liked to be in control of his daily activities and valued his independence and privacy above anything else. David

[6] Information from NHS England about the Early Warning Score https://www.england.nhs.uk/ourwork/clinical-policy/sepsis/nationalearlywarningscore/

received support from a POhWER Advocate in addition to his care staff. He had cerebral palsy and Muscular Dystrophy as well as suffering from cellulitis for many years.

Carers kept family informed and would contact them as required e.g., if David refused to take his medication. Family could sometimes persuade him to take his medication. In the end the family understood he had ulcers on his feet and wasn't taking his medication. He was so swollen that he was admitted to hospital and given antibiotics to treat the infection.

He had some understanding under the Mental Capacity Act, but he did not understand the gravity of not having his cellulitis treated effectively. He was a wheelchair user and received support with most activities of daily living. His general health was good (despite bouts of cellulitis). David's GP was treating the cellulitis in the community, David did not want to have his legs elevated and although a new chair was bought to help with this, David did not want to use it. The Intensive Health Outreach Team (IHOT) were involved to try and encourage him, but he liked his routine. Despite putting the antibiotics in the dosette box they remained unfamiliar to him, so he continued to refuse. IV antibiotics were considered at home, but this was not feasible. District nurses attended regularly to change his dressings. He received regular input from a range of healthcare professionals including physiotherapy, district nurses, speech and language therapy, occupational therapy etc.

About his death

Over a four-month period David had been prescribed four different antibiotics, which did not help his cellulitis (despite his carers trying everything to get David to raise his legs and take medication for his cellulitis), and he was then admitted to hospital with infection. The hospital had contacted the family to advise he was end of life and he died within a day. The infection (sepsis) had spread, and he died from bronchopneumonia and sepsis which was attributed to the cellulitis.

Learning Points & themes

- The panel queried whether GP fully understood antibiotic treatment failure was not due to antibiotic choice but compliance.
- Appears care staff did all they could to treat cellulitis which deteriorated into sepsis. Panel noted numerous health care services were supporting him with his healthcare needs including DNs, IHOT & Rapid response particularly around supporting him to be compliant with treating and managing his cellulitis.
- Panel noted that it is difficult to treat IV if a patient does not want it and has capacity. There was some discussion by the panel over the mixed messages on whether David had capacity and a best interest decision process may have been helpful back in December 2020 when this became a problem for him. However, as a big part of the management of the cellulitis was the raising of his legs the panel could not think of how staff would have been able to manage this short of a DoLS application, which may have impacted on his quality of life.
- The panel did note that there were a lot of people advocating for David (family, carers, formal advocate etc) and his best interests and quality of life, reasonable adjustments were put into place to support compliance, but he chose not to adhere to these.

Actions taken

- Importance of advocates and best interest process being followed to be included in local LeDeR Newsletter.
- Easy read information to be developed about cellulitis and sepsis and shared.
- Continue to rollout the RESTORE 2 mini documentation to all care providers in the County to support spotting the signs of deterioration, know what individual's unique wellness looks like and ultimately be able to improve communication with health care professionals.

Executive Summary

LeDeR is short for a programme called Learning from Lives and Deaths of people with a Learning Disability and Autistic People. Every death of someone with a learning disability (aged 4 and over) and every autistic adult (aged 18 and over with a clinical diagnosis of autism) that the LeDeR Programme is told about will be reviewed.

Through continued work to raise awareness of LeDeR we hope that the programme in Gloucestershire[7] is capturing as many deaths as possible. Although we do recognise that there may be deaths that have not been reported to the LeDeR Programme.

The aims of the LeDeR Programme are:

- To help improve health and social care services for people with learning disabilities and Autistic People.
- Reduce Health Inequalities for people with a learning disability and autistic people. Health Inequalities are unfair and preventable differences in health.
- To stop people with learning disabilities and autistic adults from dying too soon by making care better.

This is a **national programme** and everyone in England with a learning disability and autistic people will have their death reviewed in the same way. It will include a 2-stage process with all people receiving an **initial review** and some people receiving a **focused** review. The format for the reviews triangulates feedback on a person's life and death from family, carers and clinicians. These sources of information are then collated by the LeDeR Reviewers and included in the national review documentation which is considered by the local Quality Assurance and Governance Panel. Additional local themes are analysed by the panel and learning into action is taken forward by the Learning into Action Group. The learning is presented to the wider Learning Disability and Autism Clinical programme, Partnership Boards and Health Action Group as well as being collated in an annual report that is signed off by the Quality and Governance Committee.

Reducing Health Inequalities (Williams, Buck, Babalola, & Maguire, 2020)[8] is a key aspect of the local LeDeR Programme and based on learning themes to date Figure 1 demonstrates the core areas of work for service improvement over the coming three years[9]. The programme uses a number of enablers to assist in its successful delivery including working with experts by experience, use of a dedicated website, regular accessible newsletters, networking and benchmarking good practice and utilisation of established links with quality, safeguarding, nursing and other system clinical leadership across the ICS. Clearly any service improvement to enable this group of vulnerable individuals to access health and social care services will ultimately reap benefits for the wider system in terms of accessibility, reasonable adjustments and consistent use of legislation such as the Mental Capacity Act.

Figure 1 - Learning into action - Key thematic areas

This report focusses on 2021-2022 and is the fourth 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 2022.

The Gloucestershire LeDeR Programme (as at 31st March 2022) had completed 92% of notified reviews (reviews received up to and including 31st March 2022).

Status of reviews by year

Year	Closed	Open	Total	% Completed
2016-2017	7	0	7	100%
2017-2018	51	0	51	100%
2018-2019	47	0	47	100%
2019-2020	46	0	46	100%
2020-2021	54	1[10]	55	98%
2021-2022	21	19[11]	40	53%
TOTAL	226	20	246	92%

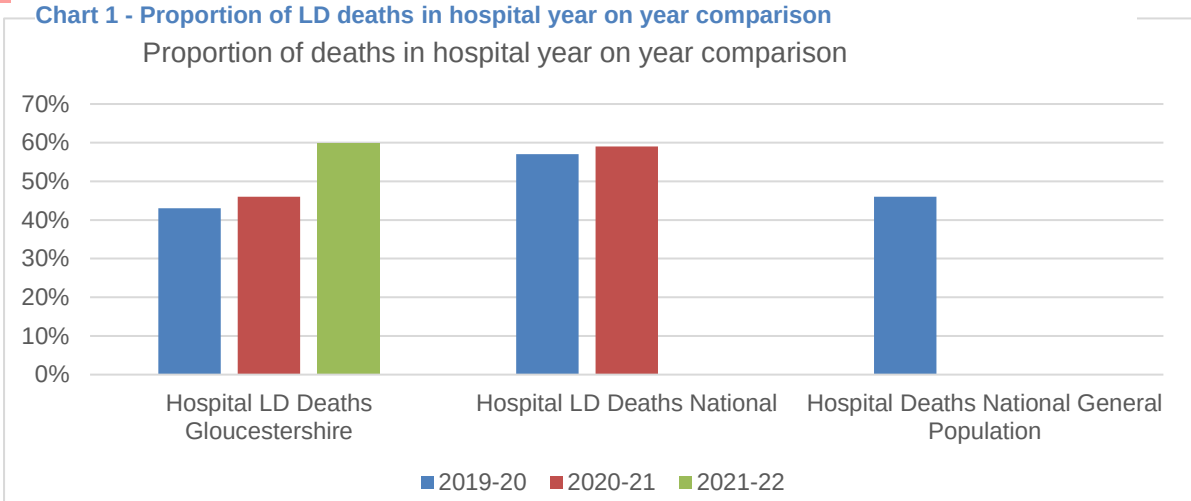
[7] In Gloucestershire reviewers will only be reviewing those who are registered with a Gloucestershire GP
[8] Definition of Health Inequalities is available on The Kings Fund Website https://www.kingsfund.org.uk/publications/what-are-health-inequalities
[9] Noting that depending on learning from new reviews additional themes may be added to this model
[10] CDOP Review that is on hold
[11] 4 cases awaiting CDOP review, 7 booked to go to Quality Assurance Panel in April and May 2022.

Key Findings

Ratio of grading of care 2021-2022 (n=21 reviews completed) The ratio of the grading of care those receiving satisfactory or better care remains at just under 9:10 (71% of people had good or excellent care and 14% had satisfactory). Care fell short of current best practice in 3 reviews (14%), of these 3 reviews all died in Gloucestershire Royal Hospital.

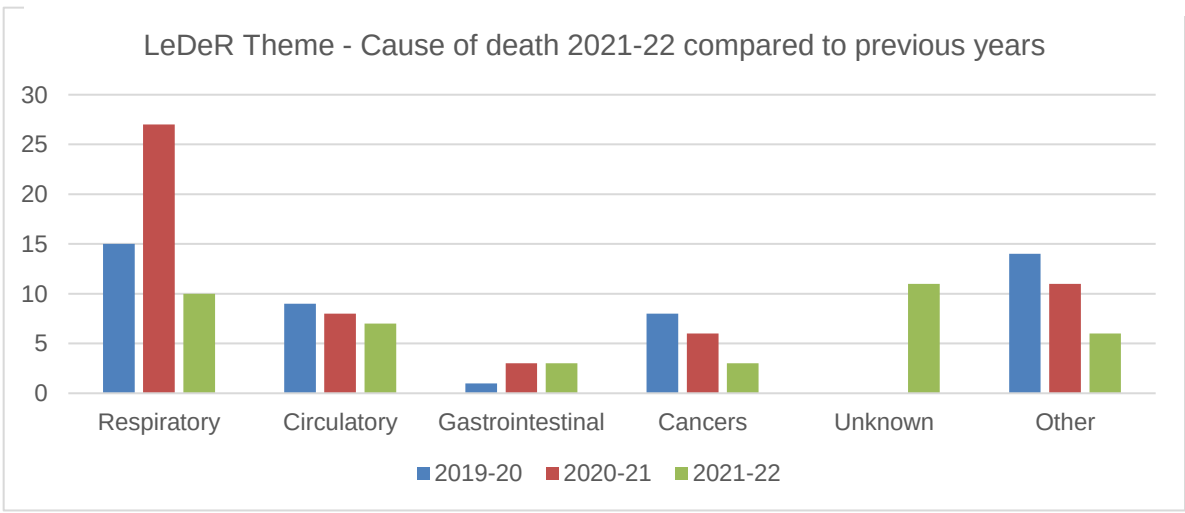
Where people died Of the deaths reported in Gloucestershire during 2021-222, 60% died in hospital. The corresponding proportion for the general population is 46%[12].

Chart 1 - Proportion of LD deaths in hospital year on year comparison



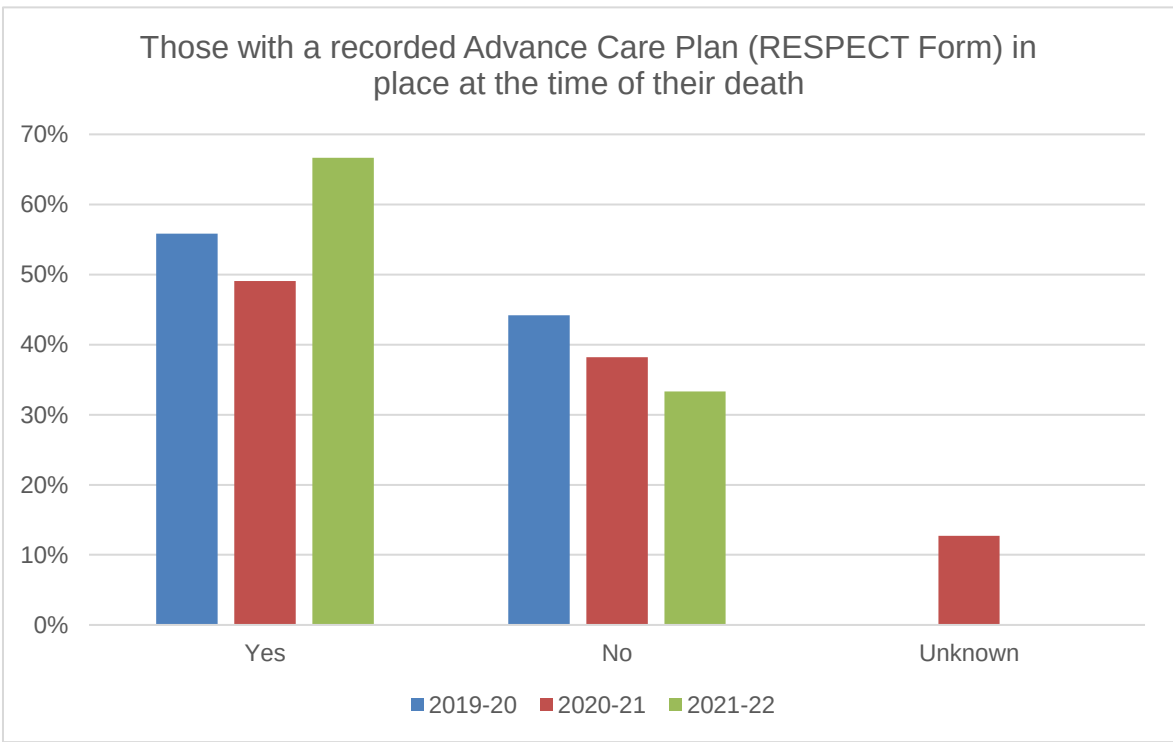
Causes of death Of the 40 deaths this year the top cause of death in the learning disabilities population in 2021-22 remains respiratory causes (n10 deaths). There have been less than 5 deaths due to covid-19 (previous year was 14).

Chart 2 - LeDeR Theme - Cause of Death



Those with an advance care plan (RESPECT form) in place 67% of the 21 deaths whose review has been completed had an active advance care plan in place (last year this was 57% (this compares to 46% nationally)). Over 50% (57%) of the deaths (44% in the previous year) of the deaths were expected and planned for deaths. Learning into action work continues around the accessibility of advance care planning and the perception on the use of the ReSPECT Form being completed and the conversations being accessible for people with a learning disability. The programme continues to work with the End-of-Life Clinical Programme and engage with the Resus Council. We are also working with Inclusion Gloucestershire to develop some co-produced material that will be available nationally to address this concern.

Chart 3 - Recorded ACP in place



[12] Noting that there is not a recent % update to the general population to take into account the impact of Covid-19, so no meaningful conclusions can be drawn from this data.

Summary of Learning Outcomes and action from learning

From the reviews completed over the course of the LeDeR programme the key recurring themes and some examples of the work undertaken are provided.

1. **Care provider market**
   - Covid prevention support
   - Provider bulletin (Integrated Disabilities Commissioning Team, n.d.)[13] continues to be published monthly
   - Workforce competencies – piloted a Learning Disabilities Fundamentals to Care (FTC) training programme (Integrated Disabilities Commissioning Team, 2021)[14] in response to identified training gaps alongside our Proud to Care team and Gloucestershire has successfully piloted the Oliver McGowan Mandatory training (Gloucestershire Health & Care NHS Foundation Trust, 2022)[15].
   - Continued accessible COVID-19 resources (Inclusion Gloucestershire, 2022)[16] - Inclusion Gloucestershire continue to review and add to their suite of accessible online resources which are aimed at those with lived experience of disabilities and people who may support them.
2. **Quality of care**
   - Telehealth project into Learning Disability Care Homes (West of England Academic Health Science Network (WEAHSN), 2021)[17] concluded and is in the process of being evaluated.
   - Monitoring and communicating signs of deterioration (West of England Academic Health Science Network, 2021)[18] (RESTORE 2 & RESTORE 2 MINI training offered by West of England Academic Health Science Network continues to be actively promoted throughout disability care provider settings in Gloucestershire. Community Learning Disability Teams (CLDT) have also been trained to deliver this training in the future and are in the process of developing a suite of locally held training resources to assist with this alongside experts by experience.
3. **Advance care planning and End of Life**
   - Easy read information for patients and carers (Gloucestershire Clinical Commissioning Group, 2021)[19] about the ReSPECT process and filling in the form has been jointly developed between experts by experience and experts by profession.
   - Accessible videos to raise awareness of the ReSPECT process and benefits of advance care planning are planned to be filmed in the Spring of 2022 and will be available on the National ReSUS Council's website. These could be utilised with professionals, people with a learning disability, family and paid carers. Gloucestershire will publicise these videos widely when they are available.
4. **Physical health**
   - Continued campaign about importance of Annual Health Checks, including the importance and benefits of being on the GP Learning Disability register.
   - Resources to support the management of complex bowel conditions (such as diverticulitis, constipation, and bowel cancer) have been actively shared. The Learning into Action Group has also identified the need to develop an easy read bowel cancer screening leaflet alongside the screening team and this will be co-produced during 2022-2023.
   - Continued campaign about the importance of reasonable adjustments in hospital settings utilising My Health Passport. Based on feedback we have developed an editable online version (Gloucestershire Health & Care NHS Foundation Trust, 2021)[20] which can be typed into and printed off.
   - Dysphagia and community speech and language guidelines following the person when they are admitted to hospital.
   - Weight and nutritional intake monitoring.
   - Audit around the Enhanced Care in Care Homes Direct Enhanced Service for learning disabilities has been highlighted by LeDeR reviews, care providers and primary care staff. Initial engagement has highlighted a need to provide a toolkit to support practices.
   - Oral Health Promotion resources.
5. **Use of legislation**

[13] https://www.gloucestershire.gov.uk/health-and-social-care/provider-information/
[14] https://www.proudtocareglos.org.uk/the-care-hub/proud-to-learn-training/learning-disability-fundamentals-of-care-programme/
[15] https://www.ghc.nhs.uk/oliver-mcgowan-mandatory-training/
[16] https://www.inclusiongloucestershire.co.uk/covid-19/
[17] https://www.weahsn.net/our-work/digital-transformation/case-study-baywater-telehealth-pilot/
[18] https://www.weahsn.net/our-work/transforming-services-and-systems/keeping-people-safe-during-and-after-covid-19/recent-coronavirus-covid-19-information-for-the-learning-disabilities-collaborative/
[19] https://g-care.glos.nhs.uk/pathway/917/resource/7#chapter_7721
[20] https://www.ghc.nhs.uk/wp-content/uploads/My-Health-Passport-EasyRead-v2-April-2021_Editable-Version.pdf

- Mental Capacity Act and the use of advocates – Click here
- Establishing a standardised agenda and information leaflet about holding best interest meetings in the hospital settings.
- The importance of advocates to support people to make decisions, especially for people who have fluctuating capacity has been a common theme.

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

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 and Governance group who monitor progress.

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

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

Picture 1 - Sammy from Inclusion Gloucestershire

'This year we have continued to hear and build on the voice of people learning disabilities and autistic adults on the QA panel and when co-producing accessible information. Experts by experience now have a role in the Steering and Learning into Action groups, making sure the valuable learning we get from LeDeR is put in to action. We have also played a key role co-producing and co presenting the learning with professionals, carers and people with a learning disability and autistic people. The increasing focus on co production puts people with learning disabilities and autistic people at the centre of the LeDeR programme in Gloucestershire going into the future'

Paul Tyrell, Content Developer at Inclusion Gloucestershire, and Expert by Experience member of the LeDeR Quality Assurance (QA) panel says:

Picture 2 - Paul from Inclusion Gloucestershire

Our voice as Experts by Experience on the LeDeR QA panel has continued to be prominent during 2021 – 2022. Our bi-monthly co-produced LeDeR newsletters are now well established, sharing the thoughts of the QA panel, examples of good practice and accessible health information resources based on the learning themes identified from the reviews. Both myself and the rest of the LeDeR team at Inclusion Gloucestershire are proud to be involved in the programme and are pleased to have been able to play our part in raising awareness of LeDeR in Gloucestershire. Recently, in partnership with our clinical colleagues, we have started to develop a suite of Easy Read resources focusing on specific health issues and things that can help make healthcare more accessible. I look forward to seeing this suite of resources grow during 2022 – 2023.

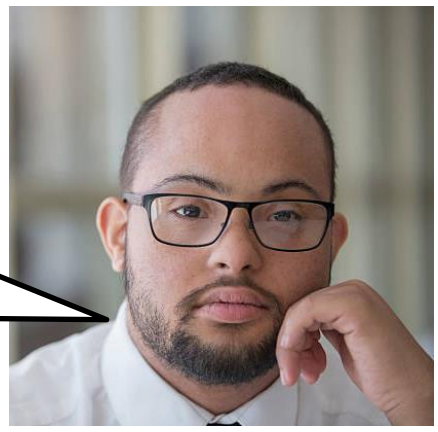
Vicci Livingstone-Thompson, CEO of Inclusion Gloucestershire says:

Picture 3 - Vicci from Inclusion Gloucestershire

'*We are pleased to provide a peer-led voice on the LeDeR Quality Assurance panel, ensuring that lived experience is at the heart of the work we are doing in Gloucestershire. It has felt really important to communicate learning from lives and deaths in an accessible and engaging way to different audiences this year, in the hope that we can all work together to address health inequalities and ensure autistic people and people with learning disabilities have the best possible lives.'*

When we asked Sammy's friends and colleagues at Inclusion Gloucestershire[21] about why LeDeR is so important and how the learning during COVID-19 has helped drive service improvements here is what they told us:

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



I'm not always aware of LeDeR.

I think it is sad and emotional when people die too young.

Attitudes need to change. Stop seeing us all as statistics and difficult people. Help us to help ourselves!

Reasonable adjustments should always be made if we want equality!

I think doctors and nurses need to be aware of LeDeR to stop it from happening again!

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

Chapter One – Introduction to the LeDeR Programme and what it means

Meet the local LeDeR team

Senior Responsible Officer (Delegated by Director of Nursing) Chair of the LeDeR Steering and Governance Group Senior Nurse (Quality) on Quality Assurance Panel **Trudi Pigott**	
Local Area Co-ordinator (Programme Management) Chair of the LeDeR Quality Assurance Panel Member of the LeDeR Learning into Action Group **Cheryl Hampson**	
Secondary Local Area Co-ordinator (Programme Officer) Chair of the LeDeR Learning into Action Group Member of the LeDeR Quality Assurance Panel **Althia Lyn**	
Senior Independent LeDeR Reviewer (Complex, Safeguarding, Focussed Reviews, Coroner cases) Member of the LeDeR Quality Assurance Panel **Paul Yeatman**	
Senior Independent LeDeR Reviewer (Complex, CDOP reviews, Focussed reviews) Member of the LeDeR Quality Assurance Panel **Deborah Livingstone**	
Experts by experience Quality Assurance Panel and Learning into Action Group **Sammy Roberts** – Learning Disability and Autism Expert by experience **Paul Tyrell** – LeDeR Content Developer for learning into action and expert by experience on the Quality Assurance Panel	 

Clinical Experts on the Quality Assurance Panel

Consultant Psychiatrist – Dr Mark Scheepers

Consultant Psychologist – Dr Kate Allez

GP – Dr Thomas Herbert

Pharmacist – Teresa Middleton

Social Care – Anna Holder

Jeanette Welsh – Safeguarding Lead Nurse GHT

User Led Organisation (support for Experts by Experience) – Emily Luckham

Picture of Anna Holder not provided

Picture of Dr Scheepers not provided

How is the Gloucestershire programme managed?

Local LeDeR Framework Policy

To provide assurance to the Gloucestershire LeDeR Governance and Steering Group, the Clinical Commissioning Group (CCG) Quality and Governance Committee in June 2020 a local policy for how reviews are managed and learning into action is monitored was written and approved. This Policy has been reviewed and updated following the national policy publication in March 2021 and was approved by the Quality and Governance Committee in February 2022 to reflect the changes within the new National LeDeR Policy. It has been published on the Gloucestershire Clinical Commissioning Website (Gloucestershire LeDeR Programme, 2022)[22]. An overview of the reporting structure can be found in Figure 2.

Key individuals and groups involved

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

- Senior Responsible Officer – This person acts as the programme sponsor for the local programme and chairs the LeDeR Governance and Steering Group.
- Local Area Co-ordinator (LAC) – this person acts as the supervisor of the local programme and provides reports to NHS England as well as Chairs the LeDeR Quality Assurance Panel
- 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 and undertake independent LeDeR reviews.
- Gloucestershire LeDeR Quality Assurance Panel - Is a group of Experts-by-Experience[23] and Experts by profession that look at how good each review is against a quality checklist. A grading of care is given between 1 – 6 to indicate how good the health and care received was (6 being the best and 1 the worst.)
- Gloucestershire LeDeR Governance and Steering Group – guide the implementation of the programme and wherever appropriate

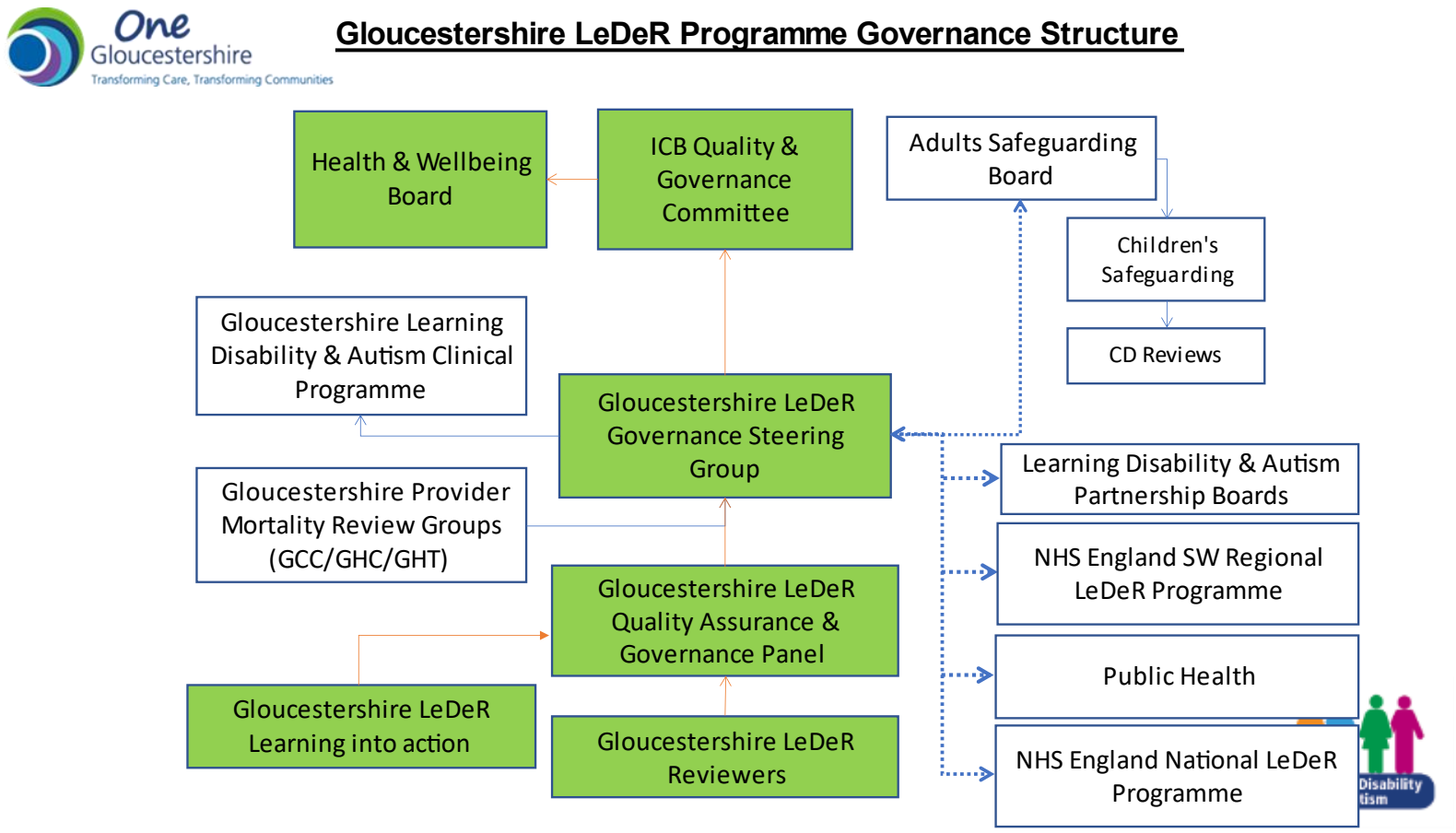
[22] https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2022/04/100.-LeDeR-3-year-Policy-Feb-2022.docx

[23] Experts-by-experience are people that are disabled, carers or people who work in health and social care.

work in partnership and collaboration with other agencies or bodies who may be involved in parallel work to take forward learning and service improvement e.g., Safeguarding, Coroners, Hospital learning from deaths etc.

- Gloucestershire LeDeR Learning into Action Group – Ensure that the learning from each review is actioned. Actions or learning identified will be used by people working in health services and social care to improve the support and care they give to people with a learning disability and autistic adults. Learning will be shared in the regular Gloucestershire LeDeR Learning into Action Newsletter which is co-produced by people with lived experience. This group will also provide regular presentations to interested people and groups on the work of the LeDeR programme locally.

Figure 2 - Local LeDeR Governance Structure



What is the purpose of LeDeR?

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a Learning Disability and autistic people by reviewing information about the health and social care support people received. It does this by:

- Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.
- Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.
- Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

What LeDeR is and isn't?

A LeDeR review is **not a mortality review**. It does not restrict itself to the last episode of care before the person's death. Instead, it looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. LeDeR reviews take account of any mortality review that may have taken place following a person's death. **LeDeR reviews are not investigations** or part of a complaints process, and any serious concerns about the quality of care provided should be raised with the provider of that service directly or with the Care Quality Commission (CQC) via their online system.

Any person with a Learning Disability, aged 4+[24] who dies and every adult (aged 18 and over) with a clinical diagnosis of Autism is eligible for a LeDeR review.

[24] The Child Death Review (CDR) process reviews the deaths of all children who are aged 4-17 years and the results are shared with the LeDeR programme.

What does the new policy mean?

Key implications and changes within the national policy: -

- The LeDeR reviews will now include people (aged 18+) with an autism diagnosis (but without a learning disability) from January 2022.
- The name will change to *Learning From Lives and Deaths – People With A Learning Disability and autistic people,* however the **Acronym will remain as LeDeR**.
- A new streamlined review process and IT system (which was implemented by local systems in line with the changes to the web-based platform went live on **1 June 2021)**.
- All reviewers must be employed on an NHS or Local Authority contract from 1st June 2021 and have access to appropriately encrypted ICT. Gloucestershire now has two band 7 senior reviewers and two band 6 reviewers employed on a bank contract who are independent. They have all been supplied with CCG IT equipment to ensure appropriate information governance standards are met. Clinical Supervision for these roles will be undertaken by the Quality Assurance Panel.

What is the review process?

Every death has a first check. We call this an **Initial Review.**

Initial reviews will contain as a minimum.

- Demographic data
- Cause of death
- Summary discussion with family/ carer or someone who knew the person well
- Summary of discussion with the GP/ and or clinician involved in the care of the person who died
- Pen portrait
- Any long-term conditions linked to the cause of death.
- Whether or not the person had DNACPR in place, with paperwork correctly completed.

Using their professional judgement and the evidence available to them, the reviewer will determine where a **focused review** is required.

The person's family has the right to request a focused review. A more focussed review is carried out if it is felt that:

1. There could be more learning from looking at more records or speaking to more people who knew the person well.
2. If anyone is worried about the care that the person received.
3. The person was an Autistic Adult who did not have a learning disability.
4. The person was from a Black Asian or Minority Ethnic Background[25].

Figure 3 provides an overview of the local process.

[25] We know that there is significant under reporting to LeDeR from Black, Asian and Minority Ethnic communities and that premature mortality in Black, Asian and Minority Ethnic communities is significantly increased from the national data gathered to date. Therefore, it is important that we review each of these deaths to understand better the health inequalities faced by each of these different groups and to help tackle inequalities identified.

Figure 3 - The LeDeR Review process - an overview

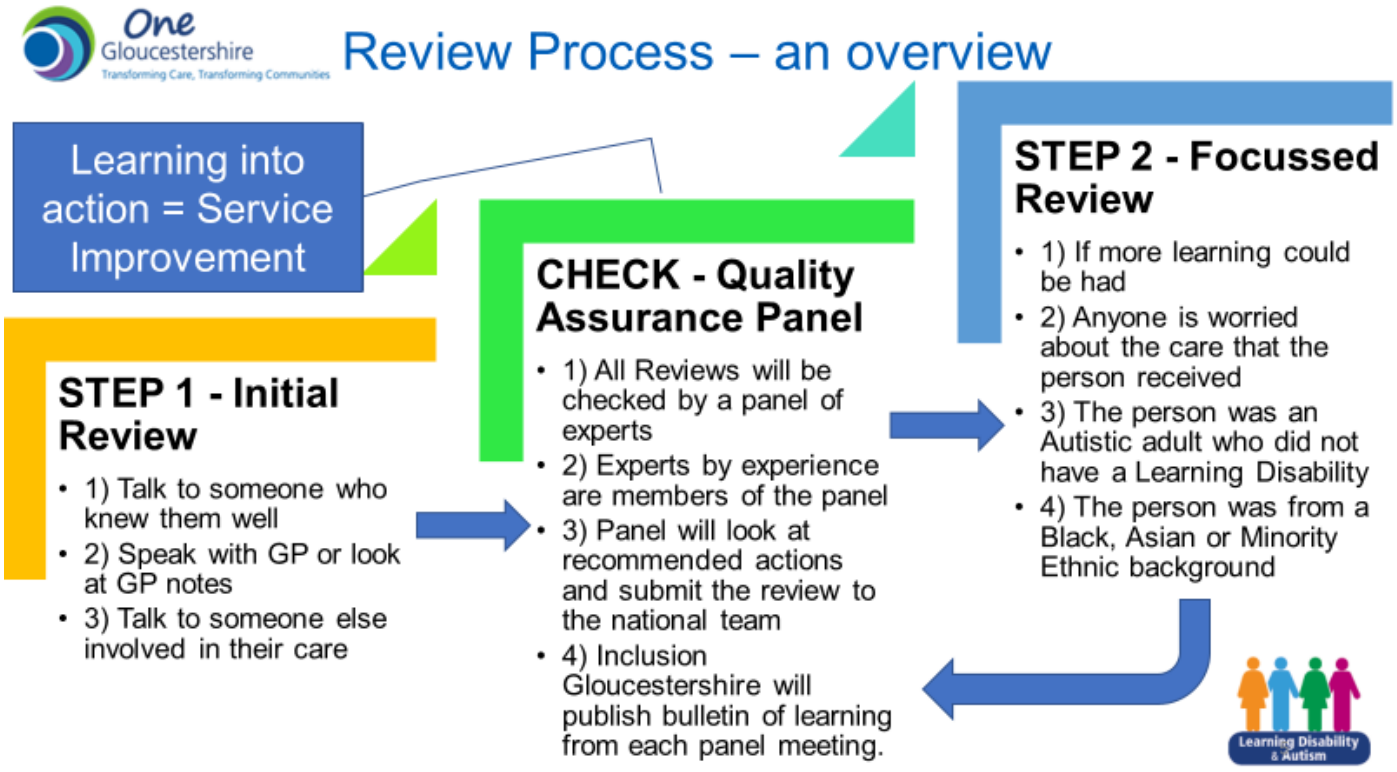


Table 1 - What are Reviewers looking for?

The person and /or their environment 	People who live in unsuitable placements for their needs including the availability of appropriate communications facilities/channels to ensure the person has access to information/support appropriate for their foreseeable needs.
	Inadequate housing that places the person at risk of falls, accidental injury or isolation in their home.
	Key information provided by family members or other carers being ignored or concerns not taken seriously or low expectations of family members.
	Families not wanting or feeling able to challenge medical professionals' authority and opinion.
	Any good practice that can be shared/disseminated wider
The person's care and its provision: 	The lack of provision of reasonable adjustments for a person to access services.
	Lack of routine monitoring of a person's health and individual specific risk factors.
	Lack of understanding of the health needs of people from minority ethnic groups.
	Inadequate care.
	Any good practice e.g., examples of reasonable adjustments that can be shared/disseminated wider
The way services are organised and accessed: 	No designated care coordinator to take responsibility for sharing information across multi-agency teams, particularly important at times of change and transition.
	Lack of understanding and/or recording of the Mental Capacity Act when making essential decisions about health care provision.
	Inadequate provision of trained workers in supported living units.
	Inadequate coverage of specialist advice and services, such as Speech and Language Therapy (SLT) or hospital Learning Disability liaison nurses.
	Any good practice that can be shared/disseminated wider

Definition of a Learning Disability in use by the programme

The LeDeR programme uses the following definition of a Learning Disability:

Individuals with a Learning Disability (*internationally referred to as individuals with an intellectual disability*) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with:
- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning) and:
- which is apparent before adulthood is reached and has a lasting effect on development.

Learning Disability is different from a specific learning difficulty (such as dyslexia), or autism or a mental health condition. Some people have all of these and also have a Learning Disability. A person does not necessarily need to have been on a locally held Learning Disability register (also sometimes called a GP quality outcomes framework [QoF] register) to be eligible for a LeDeR review.

Definition of an Autistic Adult in use by the programme

For an autistic person[26] to be eligible for a LeDeR review, they must have had a confirmed diagnosis of autism recorded in their clinical records[27] prior to their death.

- For an autistic individual to be eligible for a LeDeR review, they must have had a confirmed diagnosis of autism recorded (any of the terms as outlined in DSM or ICD) in their clinical records prior to their death.
- LeDeR does not include those who self-identify as autistic but have not sought or not received a clinical diagnosis from a qualified health professional.
- LeDeR does not include individuals who have been referred for a clinical assessment of autism, but who have died prior to the assessment having been carried out or completed. This is because the autism diagnosis will not have been confirmed. Whilst the needs and difficulties leading them to a referral are not to be dismissed, these individuals nonetheless currently do not fall within the scope of the LeDeR review inclusion criteria.

[26] Autism is described in the diagnostic manuals used for clinical and research purposes. These manuals are the: Diagnostic and Statistical Manual of Mental Disorders (DSM) https://www.psychiatry.org/psychiatrists/practice/dsm and International Classification of Mental and Behavioural Disorders (ICD) https://www.who.int/standards/classifications/classification-of-diseases

[27] A diagnosis of Autistic Spectrum Disorder or past diagnostic term, for example, autistic disorder should be recorded in clinical notes and NHS systems, such as RIO, System One or EMIS.

History of the LeDeR Programme – locally and nationally

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

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

2021

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

2022

- January 2022 - Autistic Adults Reviews commenced nationally
- February 2022 - Amended local policy approved

Governance connection with Gloucestershire Safeguarding Adults Boards (GSAB)

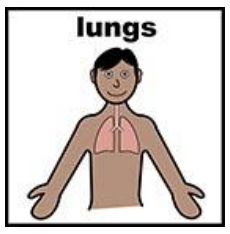
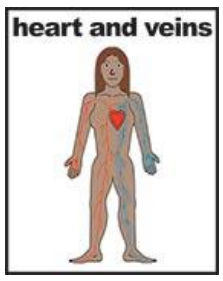
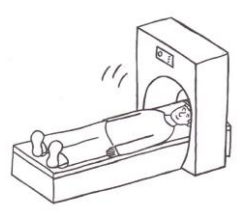
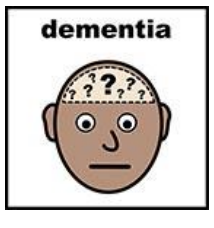
There are obvious and strong linkages between detecting and reducing premature mortality for individuals with a learning disability and autistic adults and safeguarding – particularly in relation to the preventative element of the role of GSAB. The Care Act clearly lays out responsibilities in relation 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 life and 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 Governance and 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 Governance Steering group and is also an independent local LeDeR Reviewer.

LeDeR Learning into Action Themes explained

Respiratory 	Cause 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 246 Gloucestershire deaths reported to LeDeR covering the period January 2017 to end March 2022. Of which 226 of these deaths have had an initial review undertaken (Table 2 - Status of reviews by year). For the financial year 1st April 2021 - 31st March 2022 there were 40 notifications and 21 have had an initial review completed and have been quality assured (53%).

Table 2 - Status of reviews by year as at 31st March 2022

Year	Closed	Open	Total	% Completed
2016-2017	7	0	7	100%
2017-2018	51	0	51	100%
2018-2019	47	0	47	100%
2019-2020	46	0	46	100%
2020-2021	54	1[28]	55	98%
2021-2022	21	19[29]	40	53%
TOTAL	226	20	246	92%

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.

Table 3 - Gloucestershire's LeDeR Performance

Performance indicator 2021-2022	%	Comments
Allocation of reviewers within 3 months of notification	100%	All cases notified during 2021-2022 have been allocated within 3 months
Completion of reviews within 6 months of notification	100%	This KPI was met due. At the time of writing this report 8 cases are open the oldest dating back to November 2021. Excluded from this would be the cases on hold awaiting CDOP review, case notes or outcome of other investigative processes.

Limitations with the data

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

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

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

In addition, more people who died at a younger age had profound and multiple learning disabilities and some of these would also have had complex medical conditions or genetic conditions that may make an earlier death likely.
As the numbers are less than 10 for many of the causes of death, there is insufficient data to draw any meaningful conclusions.

[28] CDOP Review that is on hold
[29] 4 cases awaiting CDOP review, 7 booked to go to Quality Assurance Panel in April and May 2022.

Reporters of deaths

Gloucestershire Hospitals NHS Foundation Trust (which are the County's secondary physical care hospital trust, sometimes called Acute Care) were the biggest reporters of deaths since the programme began in 2017 (n=78 deaths), with Gloucestershire Health and Care NHS Foundation Trust (the County's community NHS Provider) the second biggest reporters of deaths (n=47 deaths).

Table 4 - Reporters of death

Year	GHC	2G[1]	GCC	GCS[2]	GHT	GP	Care Home/ Provider	Out of county	Other	TOTAL
2016-2017	[redacted]	0	2	0	5	0	0	0	0	7
2017-2018		17	9	1	16	2	4	0	2	51
2018-2019	6	9	12	2	12	4	0	2	0	47
2019-2020	8	1	10	0	12	2	1	5	7	46
2020-2021	17	[redacted]	9	[redacted]	17	5	2		5	55
2021-2022	16				16		4		4	40
TOTAL	**47**	**27**	**42**	**3**	**78**	**13**	**11**	**7**	**18**	**246**

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

There does not seem to be any correlation in the gender and the median age of death.

Chart 4 - Gender of those who died in 2021-2022 in Gloucestershire compared to previous years

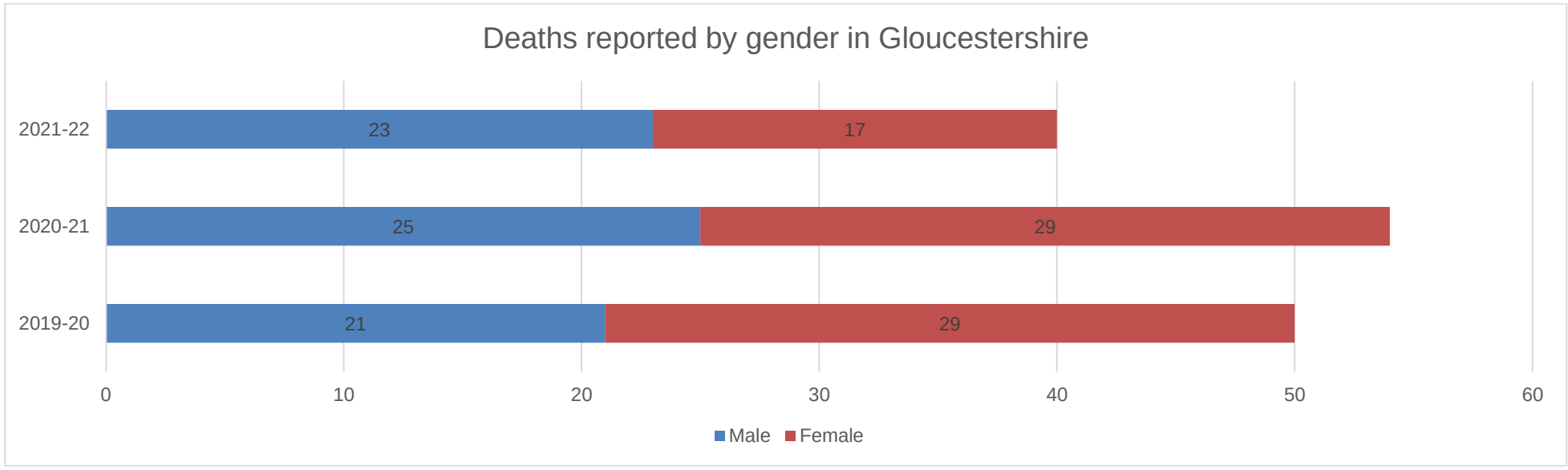
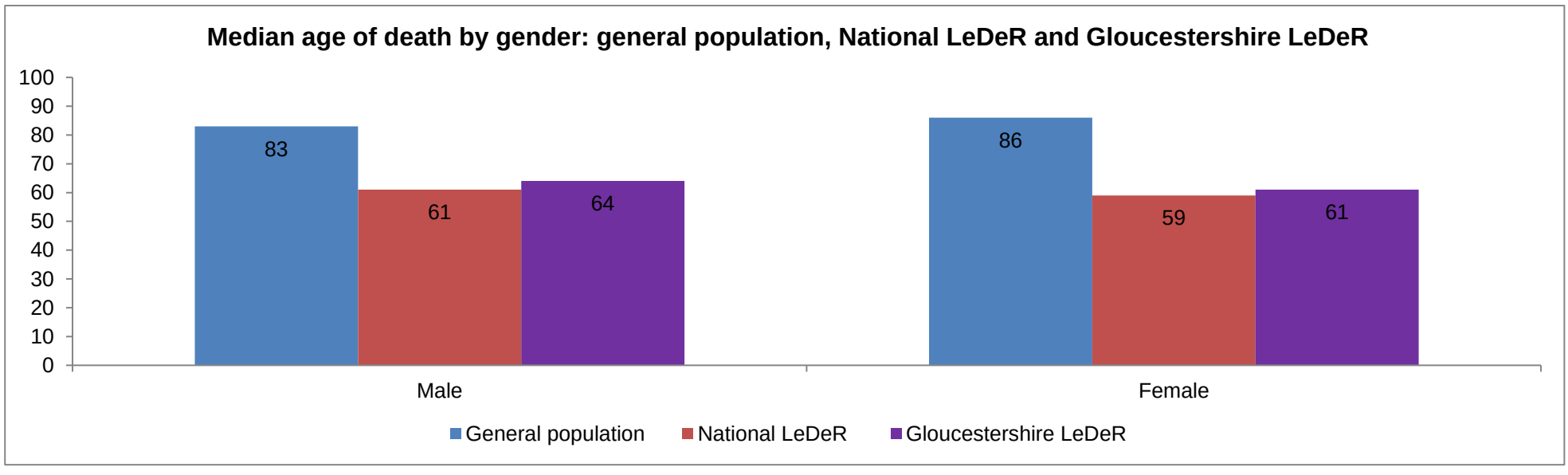


Chart 5 - Gender comparison local vs national vs general population



Ethnicity

For information governance purposes and to protect people's identity (because there were less than five deaths reported) where ethnicity was not "White British" this has not been included in this report. We recognise that further work is needed to ensure we identify, have reported deaths, and undertake reviews for people from black, Asian and minority ethnic patient groups. Scoping work with local Community Ambassadors, Community Learning Disability Teams (CLDTs) and the County Council's Community Development Team has commenced and will continue through the coming year.

Severity of Learning Disability

Of the 40 deaths reported in 2021-2022 21 have had the severity of learning disability recorded on the notification or completed initial review. Of the remaining 19 these are still to be reviewed or to go through a quality assurance panel. Broadly speaking the profile of severity of deaths in Gloucestershire is comparable year on year with about 40% of deaths for people with mild learning disabilities and 40% for people with moderate learning disabilities.

Chart 6 - Severity of Learning Disability in Gloucestershire

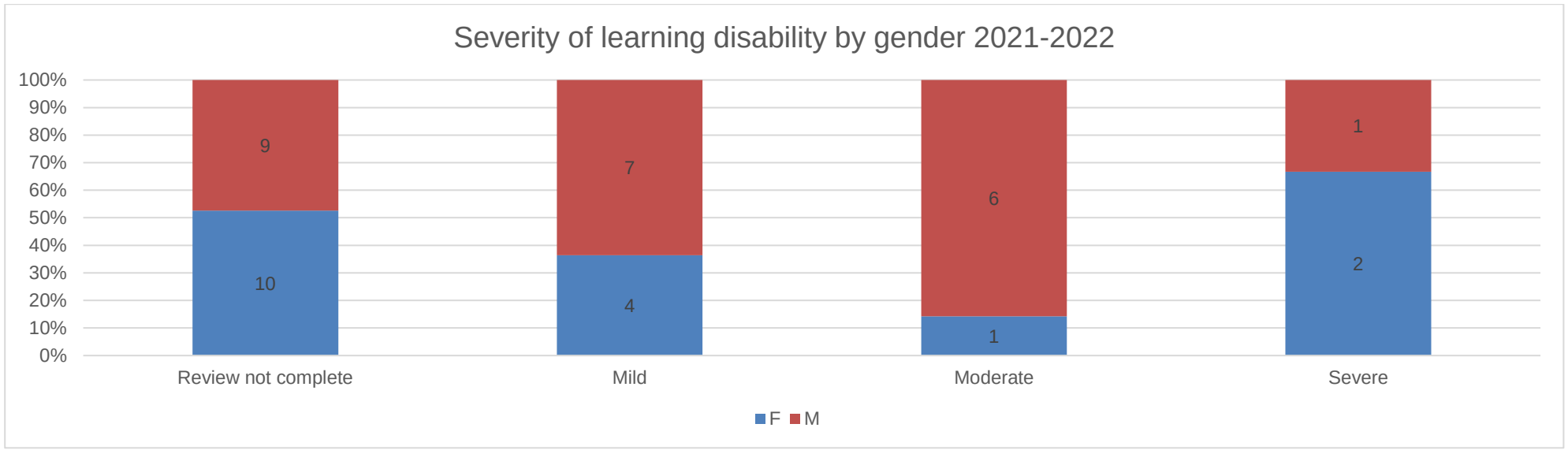
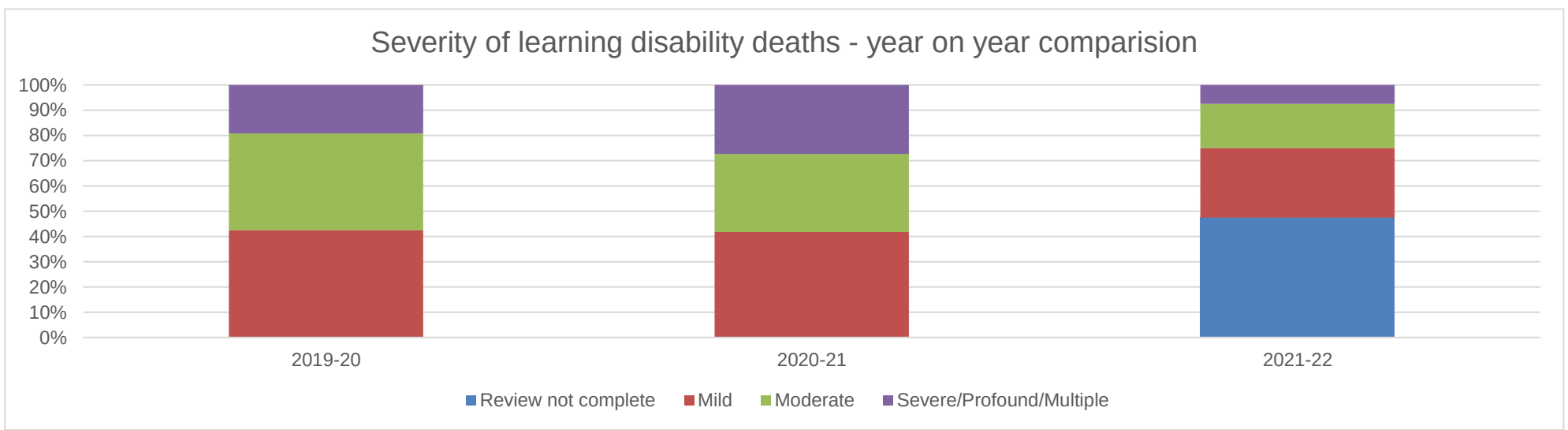


Chart 7 - Severity of Learning Disability Deaths reported to LeDeR - year on year comparison.



Co-morbidities

The NICE Guideline 56 (NICE, 2016) [30] 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 21 reviews completed, where co-morbidities have been recorded in 2021-2022; 33% had 3 or more co-morbidities recorded (this is a reduction from the previous year of 53%)[31]. In addition to this 19% (27% less than the previous year) of the reviews where co-morbidities were mentioned (n21 people) who died also had epilepsy (less than 5 people). There is little we can conclude from the remaining data sets as all long-term conditions equated to less than 5 deaths.

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

Table 5 - Co-morbidities

Condition	Number of people with the condition recorded 2021-2022	Number of people with the condition recorded 2020-2021	Number of people with the condition recorded 2019-2020
Epilepsy	*	13	16
Dementia	*	5	8
Cerebral Palsy	*	5	7
Down Syndrome	*	*	7
Hypertension	*	5	*

** Indicates less than 5 people.*

Into County Placements

During 2021-2022 there were less than 5 deaths in Gloucestershire from people who had been placed into the county from other authorities. As the numbers are less than 5 we have not included further information within this report to protect anonymity.

Since the start of the LeDeR programme in Gloucestershire there have been n28 deaths of people who had been placed into the county from other authorities, 17 of these placements have been in the last three years. 35% of into county placements were placed from Southwest authorities.

*

Table 6- Into County Placement Deaths by financial year

Year	Number
2016-2017	*
2017-2018	5
2018-2019	10
2019-2020	7
2020-2021	7
2021-2022	*

Table 7 – Deaths over the last 3 years by regions placing into Gloucestershire

Region	Number
South West	6
South East	*
Midlands	*
Wales	*
North East	*
London	*
TOTAL	17

Chapter Four – Statistics

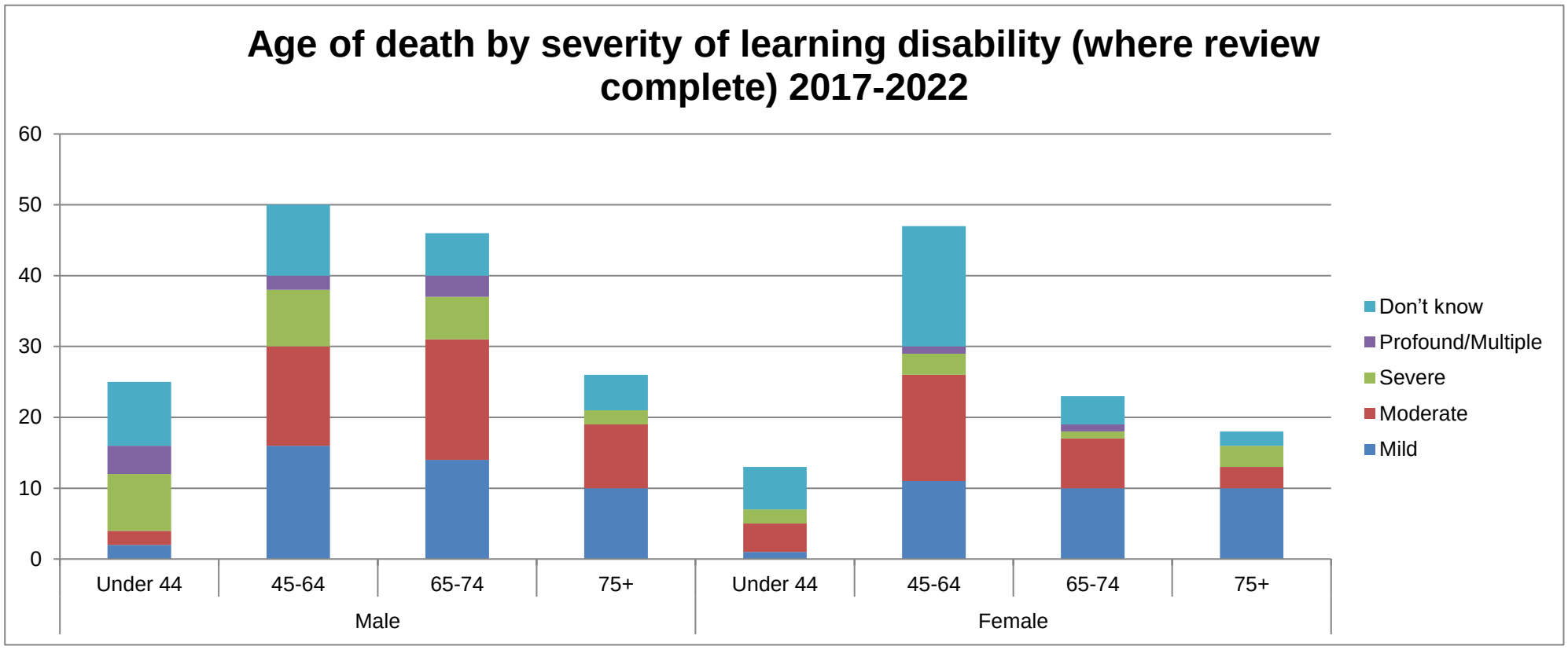
Age

Here we report on the age at death of people with learning disabilities who died from 1st April 2021 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 mentioned in previous annual reports, the people who die at a younger age had profound and multiple learning disabilities and the majority of these had complex medical conditions or genetic conditions that may make an earlier death likely.

In the general population of England from 2015- 2017, the median age at death (for people of all ages, including 0-4 years) was 83 years for males and 86 years for females (Office for National Statistics, 2019)[32]. In Gloucestershire, the median age at death for males with a learning disability was 67 (min 18 years; max 85 years) and for females was 58 (min 11 years; max 87 years).

From the data reviewed for the whole programme no one with profound and multiple learning disabilities reached over 76 years old (min 19 years old; Max 76 years old). The median age of death for those with PMLD was 62 years old across the whole of the programme (an increase from the previous year of 19 years, noting that there have been less than 5 deaths of people with PMLD this financial year so we are unable to draw significant conclusions on the data for this financial year.

Chart 8 - Age of death by severity of learning disability whole of the programme[33]



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 years when compared to the general population.

Table 8 - Average (Median) Age of death

	Gloucestershire			South West	National	General Population	
	Male	Female	Median average all			Male	Female
2018-2019	65	65			59	83	86
2019-2020	61	61		62	60		
2020-2021	61	60		No recent data available			
2021-2022	67	58	64				

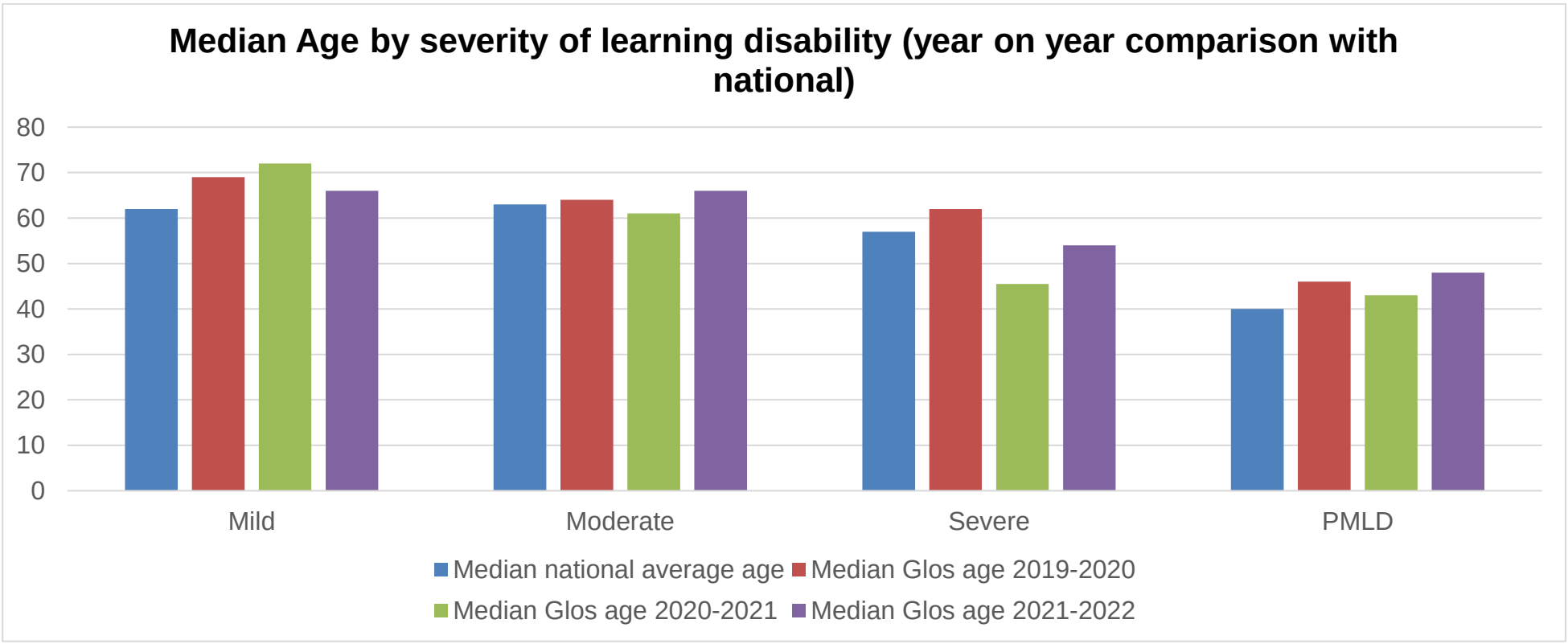
[32] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk

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

Who is most at risk of dying young?

The median age at death for people with mild learning disabilities in Gloucestershire was 66 years old (an decrease from last year of 6 years, previous year was 72 years old, compared to the national report 2019 of 62 years); for moderate learning disabilities it was 66 years old (increase from last year of 5 years, previous year was 61, and better than to the national report from 2019 of 63 years); for severe learning disabilities it was 54 years old (last report was 46 years old national report was 57 years); for profound and multiple learning disabilities it was 48 (last year was 43, compared to national report of 40).

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



Place of death

Of the 40 deaths reported in Gloucestershire during 2021-2022 53% (an increase of 7% from the previous year) died in hospital. There is currently no recent benchmarking information to be able to say whether this benchmark is higher or lower than other areas, and the impact of covid-19 on hospital admissions may also have caused this increase.

Table 9 - Place of death

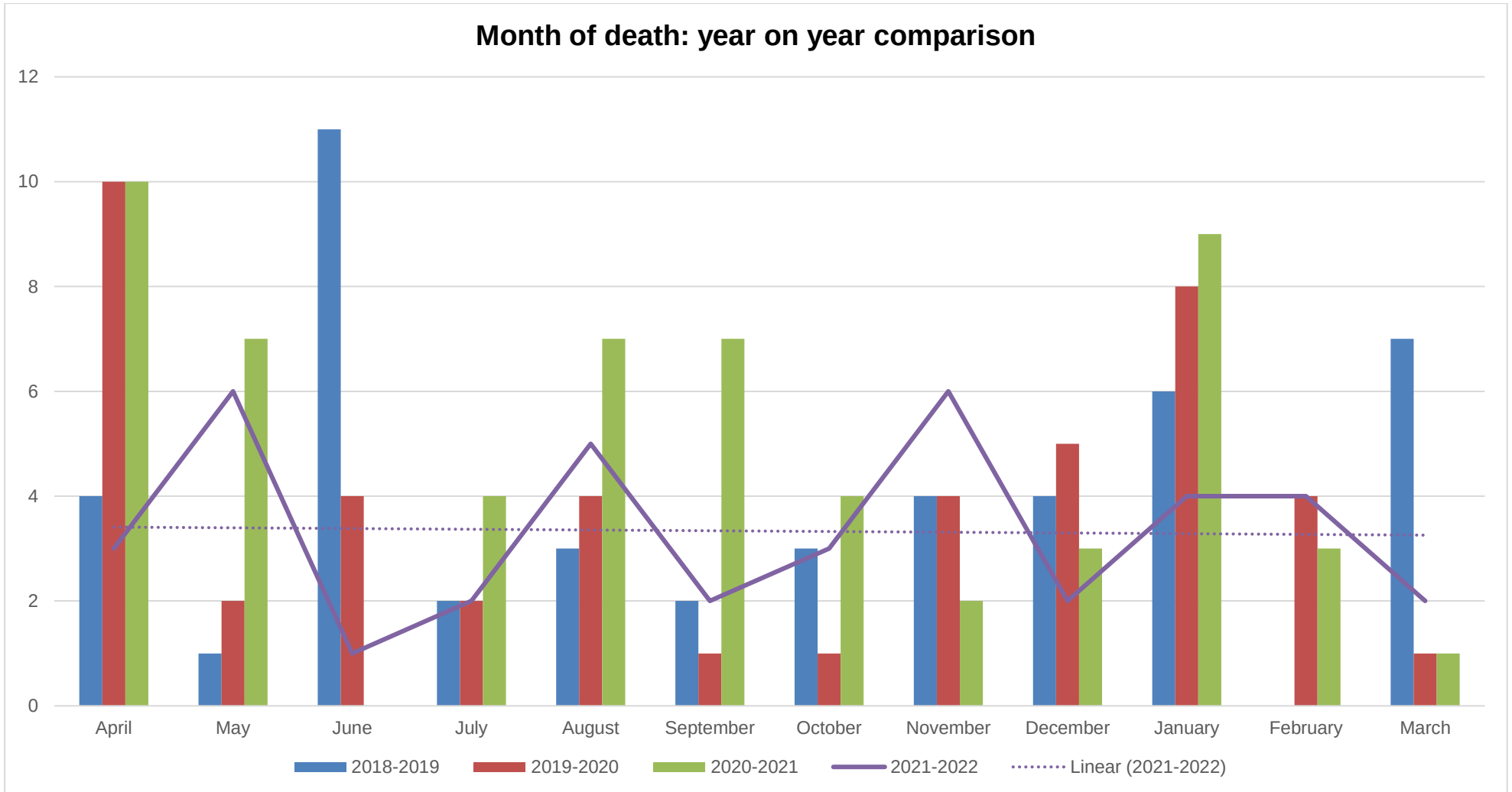
Place of death	Glos Royal Hospital	Usual Place of residence	Other community setting (e.g. hospice, with family etc)	Other Hospital	Hospital (OOC)	Residential/ Nursing Home or Residential school	Grand Total
Number of deaths 2021-2022	21	8	0	*	0	7	40
% 2021-22	53%	20%	0	10%	0	17%	100%
Number of deaths 2020-2021	26	15	*	0	0	13	57
% 2020-21	46%	26%	5%	0%	0%	23%	100%

Month of death

Comparing month on month between the four financial years shows a similar proportion year on year. On average over the previous two years per month there was 4 notifications per month, during 2020-2021 this increased to an average of 5 notifications per month (min: 0, Max 10), during the last year this reduced to an average of 3 notifications per month (min:1, max: 6).

There is a steady trendline in deaths over the year. 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. There does not appear to be any seasonal fluctuations in the reporting that we see in the general population data.

Chart 10 - Month of death



End of life and was the death expected?

Of the deaths reviewed in 2021-2022 for which coded data was available about end-of-life care, over half (57%) were expected and planned deaths.

Chart 11- Expected Deaths (where recorded)

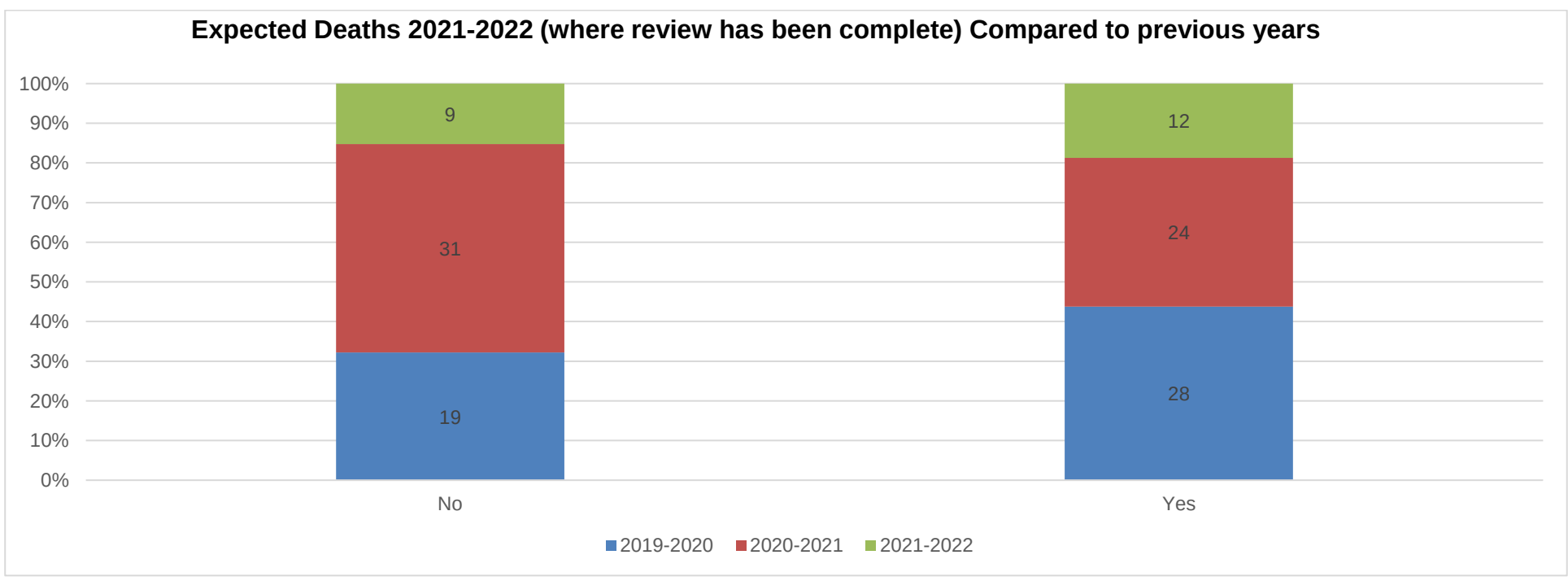


Chart 12 - % Expected deaths (where recorded on the review)

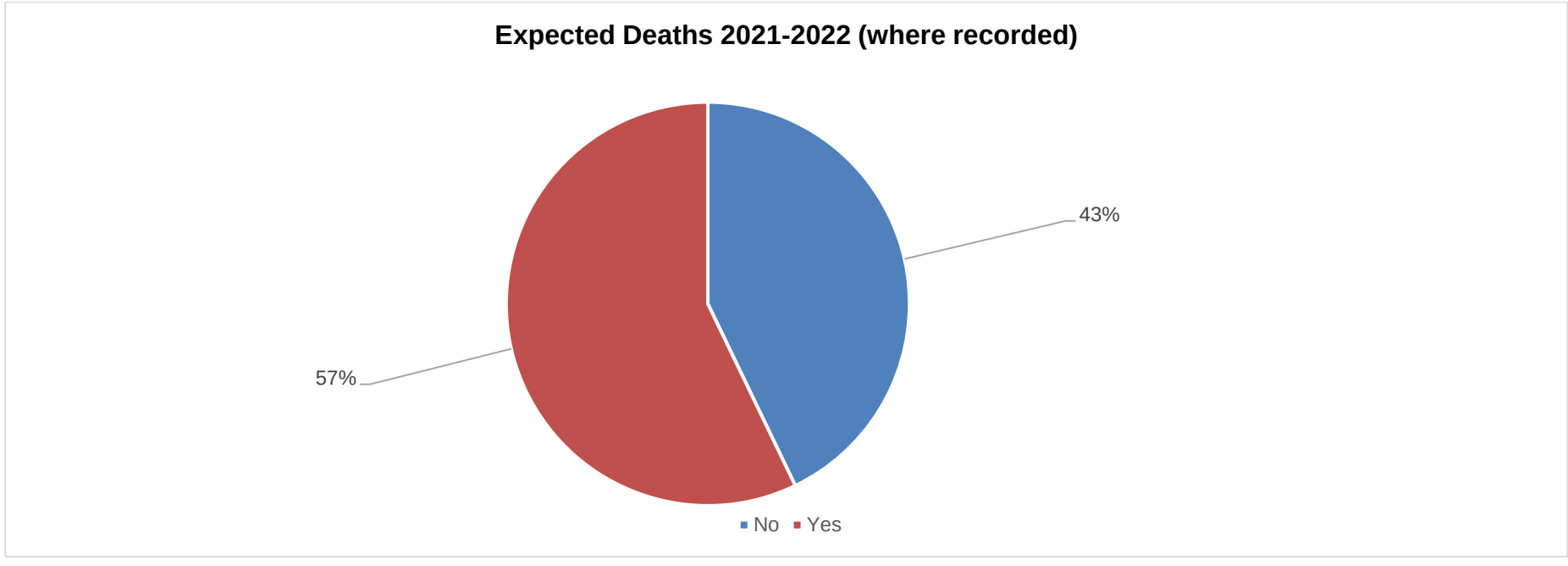


Chart 13 - Number of deaths where a ReSPECT form was in place

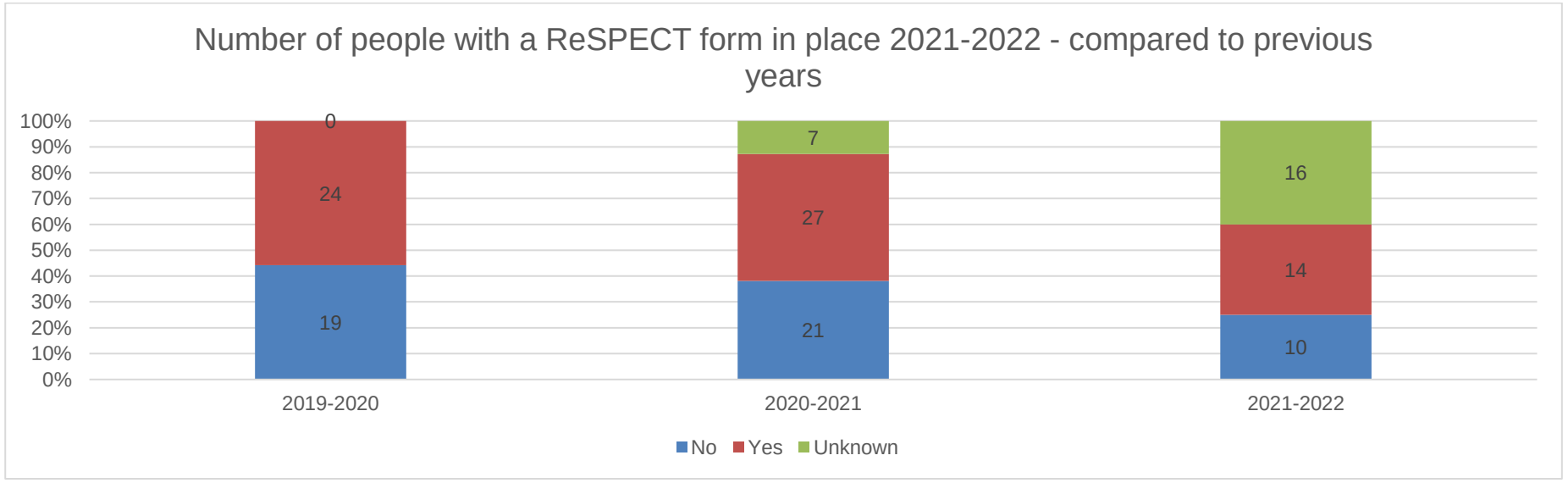
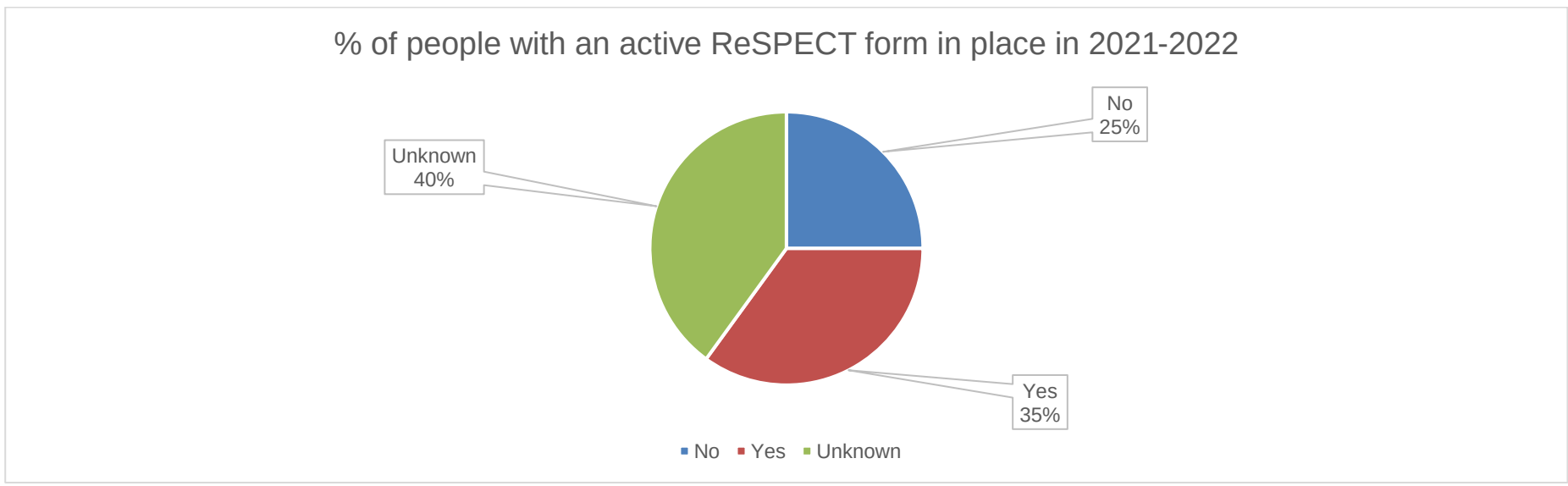


Chart 14 - % of people who died with an active ReSPECT form in place



Deaths with a Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) order[34] in place

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing explicitly states that decisions about DNACPR must not be based on assumptions related to the person's age, disability, or the professional's subjective view of a person's quality of life (Resuscitation Council UK)[35].

When used appropriately, a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order should help to ensure that a patient's death is as peaceful and dignified as possible, without traumatic and painful physical intervention at the end of their life. Sometimes referred to as DNAR or DNR, a DNACPR order applies only to

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

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

cardio-pulmonary resuscitation, where it is assessed to be clinically appropriate, and where a decision has been made with the appropriate involvement of the patient, their relatives, or carers.

For people with a learning disability, sadly, it is evident from national reports (Public Health England, 2020)[36] written during the pandemic and the issuing of a letter to all regions and clinical leads (NHS England, 2021)[37] in March 2021 that sometimes the complex combination of clinical circumstances and a lack of patient or family/carer involvement leads to the inappropriate issue of a DNACPR order. Raising questions or concerns with a doctor about a clinical decision and the decision making process is both complex and daunting, so Turning Point have worked with Learning Disability England to produce an information pack and DNACPR checklist (Learning Disability England & Turning Point, 2020)[38], that will help families and carers understand the issues and jargon involved in DNACPR orders, and enable them to raise questions and concerns appropriately. The pack includes a checklist that people can review a DNACPR order against, plus explanatory notes on people's rights and the legislation involved.

Of the people notified to the programme in 2020-2021, and of those that the review has been completed, 19 people (84% shown on Chart 15 and Chart 16) had a DNACPR order in place. This is a slight improvement from the previous year (77%).

Chart 15 - Number of people where DNACPR was noted on the completed initial review (n19)

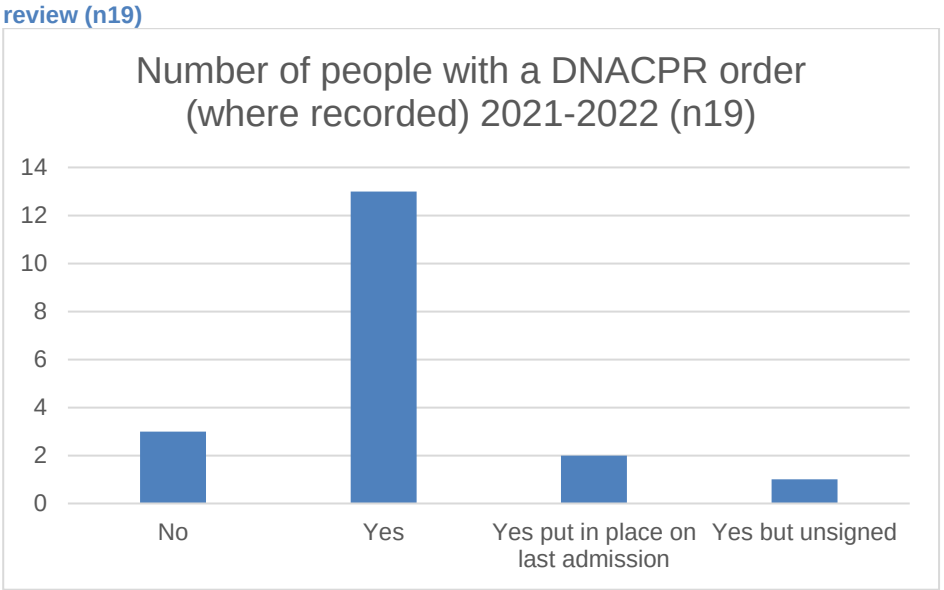
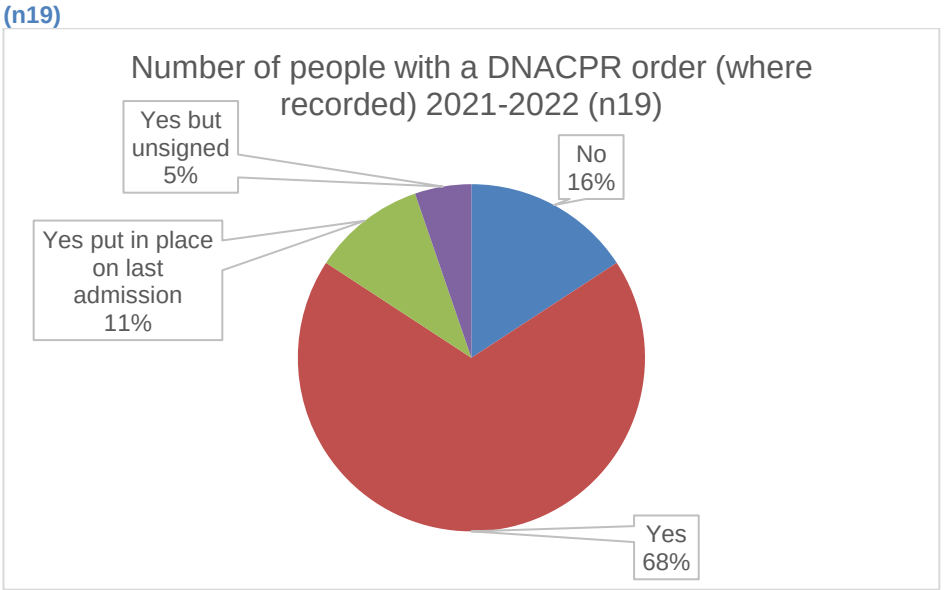


Chart 16 - % of people where DNACPR was noted on the completed initial review (n19)



Cause of deaths

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

Table 10 - Cause of death combined . Pneumonia was the most frequently cited in part I of the MCCD (Death certificate) of people with learning disabilities in Gloucestershire 15%, however, this is a reduction of 5% from the previous year. However as the numbers are less than 10 for many of these causes of death, there is insufficient data for any meaningful conclusions.

Table 10 - Cause of death combined 2021-2022

Cause of death	Number of deaths 2021-2022	Number of deaths 2020-2021	% of cause of deaths Gloucestershire 2021-2022 n40	Movement from previous year	% of cause of deaths Gloucestershire 2019-2020 n55	% England Learning Disability Population cause of death age 4+ 2018-2019 n1938	% of general population n529,605
Covid-19	*	14	8%		25%		
Pneumonia	6	11	15%		20%	25%	
Cancer	*	5	5%		9%	14%	28%
Other	6	6	15%		11%		

[36] https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities
[37] https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C1146-dnacpr-and-people-with-a-learning-disability-and-or-autism.pdf
[38] https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/DNACPR-Support-Pack.pdf#:~:text=For%20people%20with%20a%20learning%20disability%2C%20sadly%2C%20it,to%20the%20inappropriate%20issue%20of%20a%20DNACPR%20order.

Dementia	*	*	5%		7%	Not able to directly compare as reported differently in the National LeDeR Report 2018-2019	
Sepsis	*	*	5%	-	5%		
Unknown[39]	11	*	28%		2%		
Respiratory	*	*	5%		4%	19%	14%
Heart related	*	*	8%		7%		
Haemorrhage related	*	*	15%		4%		
Gastric system	*	*	8%		5%		
TOTAL	40	55					

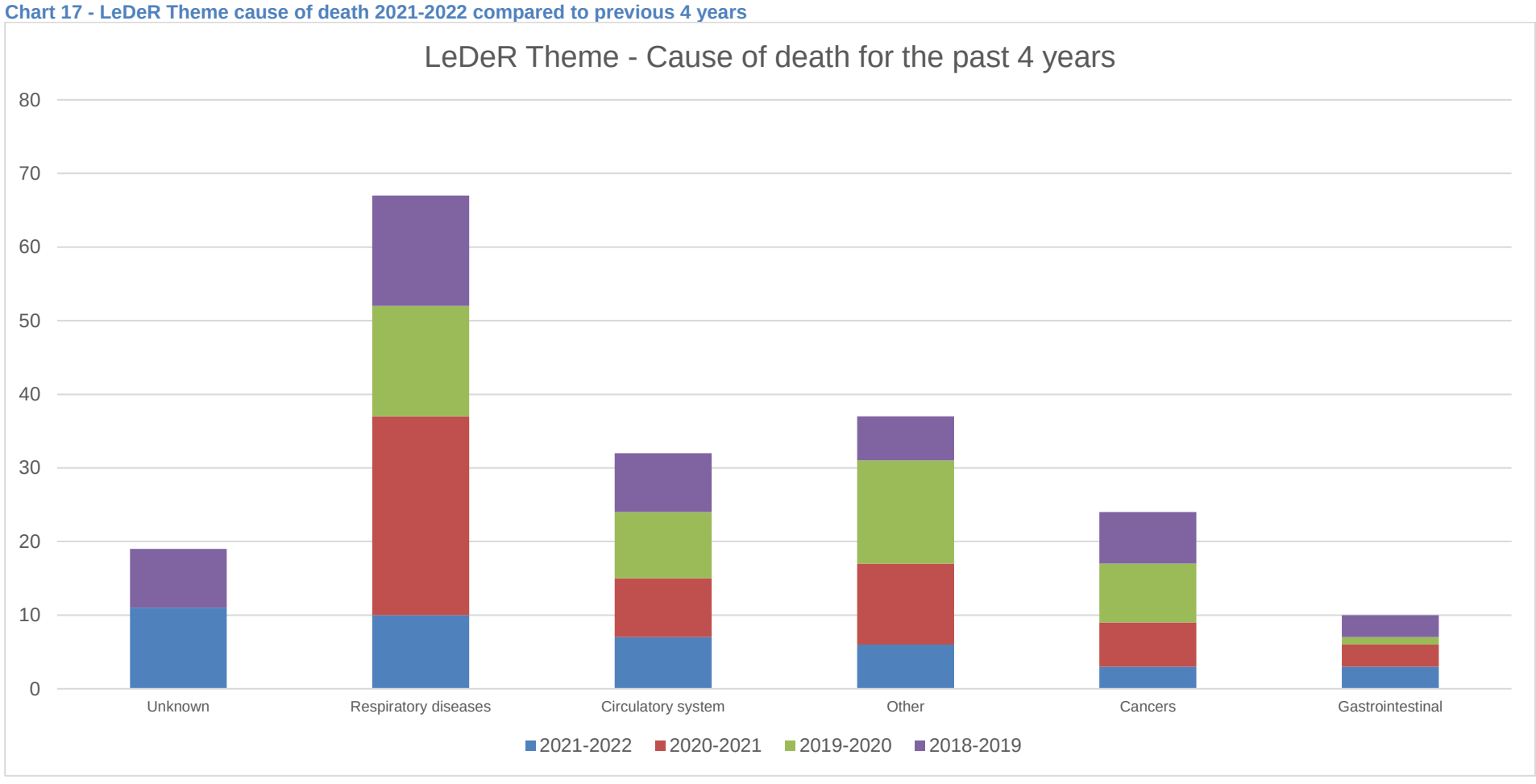
* *Indicates less than 5 people*

[39] Review not completed or information not on original notification

Cause of death – LeDeR Themes in Gloucestershire

Chart 17 - LeDeR Theme cause of death 2021-2022 compared to previous 4 years[40] shows that the top cause of death in the learning disabilities population averaged out over the last 4 years (n67 in total, median average of 15 deaths per year[41]).

Chart 17 - LeDeR Theme cause of death 2021-2022 compared to previous 4 years



[40] Where unknown this indicates the review has not yet been completed or the notification did not have cause of death listed.
[41] Noting that for 2020-2021 the number of deaths increased due to covid-19

Chapter Five – Action from Learning

Indicators of the quality of care provided

What are reviewers looking for?

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

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

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

What the Quality Assurance Panel role is?

The Gloucestershire LeDeR Quality Assurance (QA) Panel was set up in October 2019. It provides a consistent approach to signing off completed reviews. Reviewers are invited to bring cases to the panel for advice and guidance. The panel uses a checklist (this can be found in the Gloucestershire LeDeR Policy (Gloucestershire LeDeR Programme, 2022)[42] to ensure consistency of approach and a record of the discussions of each panel is kept.

	Is a group of Experts-by-Experience that look at how good each review is. They give ideas of what can be done better. Experts-by-experience are people that are disabled, carers or people who work in health and social care.

[42] https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2022/04/100.-LeDeR-3-year-Policy-Feb-2022.docx

	To look at: ○ What the reviewer does. ○ How good the review is and making sure something is done to make things better. ○ How we help reviewers do their job well. ○ Think about what changes need to happen. We call this learning from action.
	To work out what the information from the reviews mean. This could be something good, helping to stop someone dying too early. It could be something that could be made better.
	Cases will be given to Safeguarding if the group feels it is needed.
	A mark between 1 – 6 is given to how good the care is. 6 being the best and 1 the worst.
	When a review has been looked at, the person who leads on LeDeR in Gloucestershire (this person is called the Local Area Contact or LAC), does the following: □ Fills in the Gloucestershire LeDeR checklist □ Tells the reviewer that… 1. the review has been closed. **Or…** 2. Asks the reviewer to make changes or get more information. □ Asks the reviewer to tell everyone who they spoke with about the review. □ Share learning with the LeDeR Learning into Action Group.

Assessment of the quality of care

Reviewers are asked to grade the care the person received at the end of a focused review (cases which only receive an initial review will not be graded formally, but the local Quality Assurance Panel will capture indicative grading as part of local processes). Care is graded on two elements of the health and social care the person received: 1. Quality of care the person received 2. Availability and effectiveness of services the person Care is graded on a scale of 1-6 where 1 represents poor care and 6 represents excellent care (see Figure 4). 72% of the reviews completed (n21) had received excellent or good care during 2021-2022, another 14% had received satisfactory care (Chart 18 and Chart 19)

Figure 4 LeDeR Grading of care table

Grade	Quality of care	Availability and effectiveness of services
6	This was excellent care (it exceeded expected good practice). Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.	Availability and effectiveness of services was excellent and exceeded the expected standard
5	This was good care (it met expected good practice). Please identify in the review learning and recommendations any features of care that current practice could learn from.	Availability and effectiveness of services was good and met the expected standard
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing). Please address these issues in your recommendations for service improvement, and identify in learning and recommendations any features of care that current practice could learn from	Availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement, and identify any features of care that current practice could learn from.	Availability and effectiveness of services fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death.
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	Availability and effectiveness of services fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
1	Care fell far short of expected good practice and this contributed to the cause of death.	Availability and effectiveness of services fell far short of the expected standard and this contributed to the cause of death.

Chart 18 - Grading of care recorded

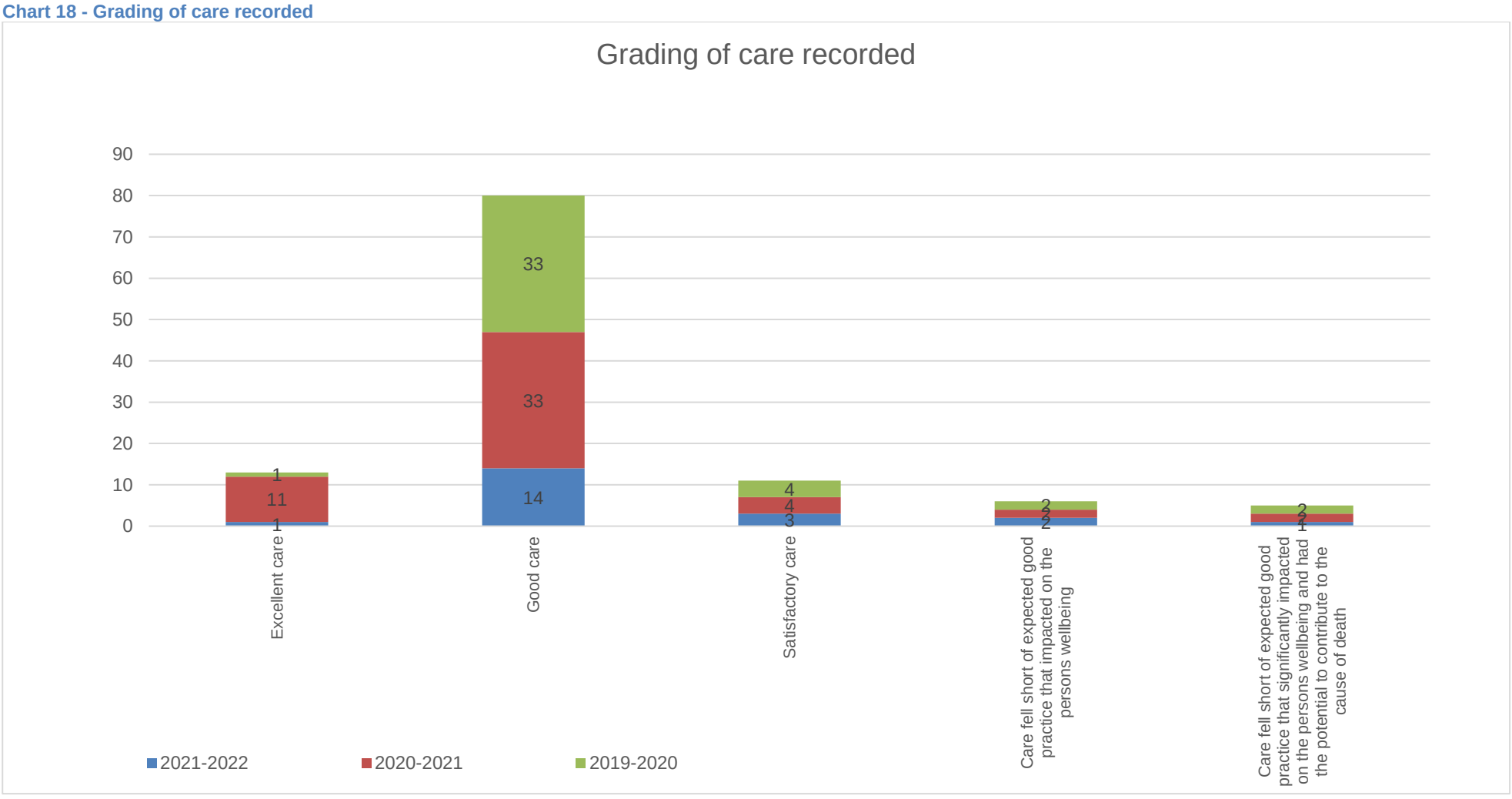
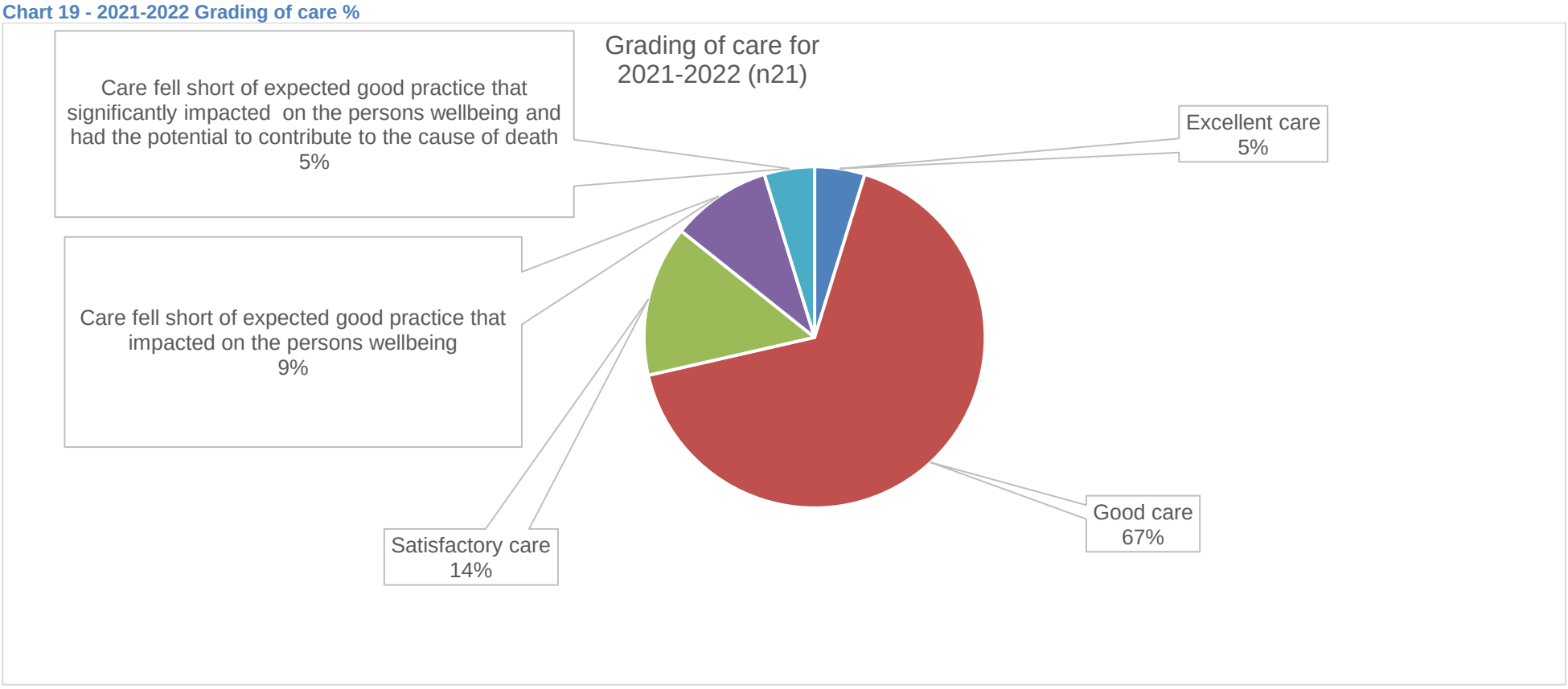


Chart 19 - 2021-2022 Grading of care %



Gloucestershire LeDeR Quality Assurance (QA) Panel Feedback

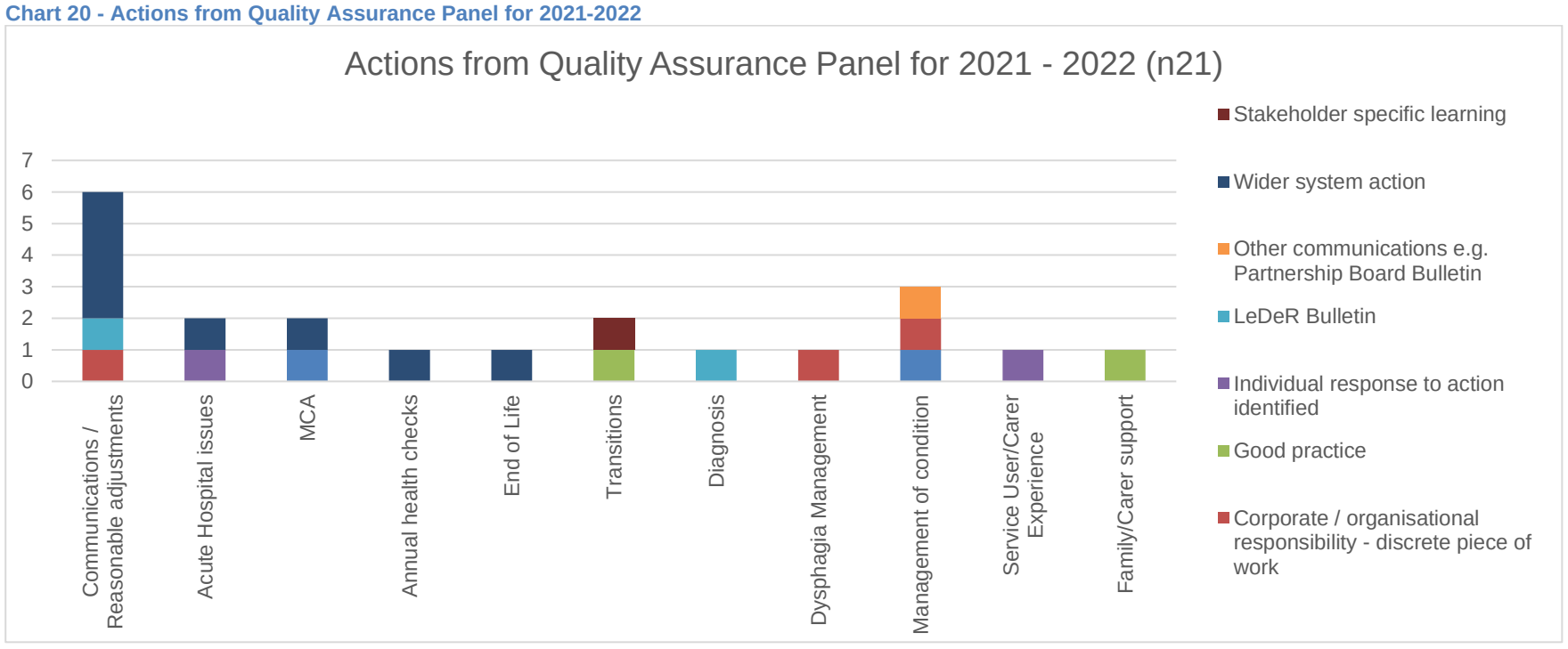
Chart 20 shows that communications and reasonable adjustments to support care (29%) was the biggest reason for action coming from the quality assurance panel, management of specific conditions (14%) was the second. These numbers are relatively small and therefore not big enough for us to draw conclusions up for wider system action. However, the LeDeR Programme continues to have common themes emerging which inform the action from the learning. These themes are listed in Table 11.

Table 11 Glossary of themes for learning into action

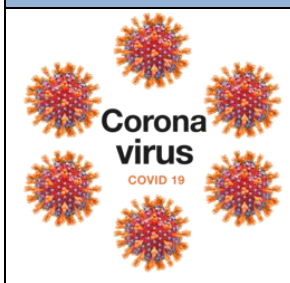
Acute Hospital issues	Issues with the care and treatment received at Gloucestershire Royal or Cheltenham General Hospitals.
Annual health checks	Issues with the annual health check that the person did/ or did not get.
Case Management	Issues with how health and social care worked together to jointly support someone.
Communications and reasonable adjustments	Issues with how health and social care communicated with the person, their carers or their family e.g. use of easy read and reasonable adjustments for example longer appointments.
Dysphagia Management	Issues with how care between the community speech and language therapy plans were communicated with hospital and utilised in hospital care.
Diagnosis	Issues with finding out why someone is poorly e.g. blood tests etc.
Family/Carer support	Issues with how the person was provided carer or family support including reasonable adjustments and documentation such as hospital passport to support an individual with learning disability to be appropriately supported.
General Practice issue	Issues highlighted with specific GP surgery or primary care guidance.
Healthy Lifestyles	Issues highlighted with support provided to the individual to remain healthy e.g. weight management, stopping smoking advice, exercise etc.
Management of condition	Issues with how specific conditions are managed by health care professionals including the resources, guidelines and training provided to health care professionals

MCA	Issues with how the Mental Capacity Act (MCA) was followed including use of advocacy, Best Interest processes and recording and having the conversations about DNACPR etc.
Self-neglect	Issues with how people choose to make unwise decisions in relation to their health and care, and then how professionals act upon concerns.
Documentation not completed correctly	Issues with how professionals completed documentation.
End of Life and advance care planning	Issues with those who were at the end of their life and planning for their care including advance plans e.g. ReSPECT, funeral planning, bereavement support for carers etc.
Pressure Ulcer Management	Issues identified with how pressure ulcers were managed and treated including use of equipment and dressings.
Transitions	Issues with the how care was co-ordinated between childhood and adulthood including ensuring the person was on the GP Learning Disabilities register. OR Issues with how the care was co-ordinated between out of area placing authorities and Gloucestershire.

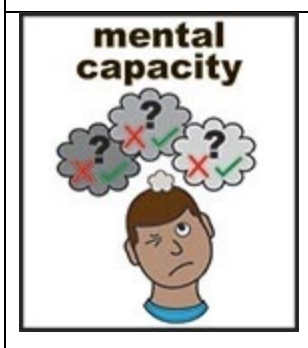
Chart 20 - Actions from Quality Assurance Panel for 2021-2022



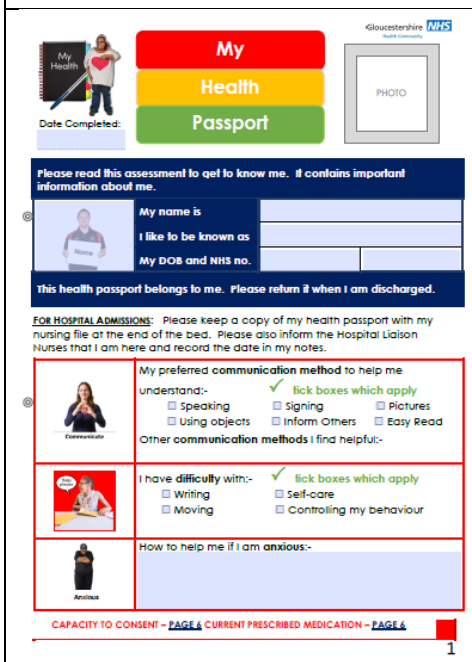
Achievements - a look back at what has been achieved in the last year

Learning Theme		Actions undertaken
	Covid-19	1. Accessible covid-19 resources continue to be reviewed and updated by Inclusion Gloucestershire. Material is aimed at those with lived experience of disabilities and people who may support them. The regularly updated resource hub can be accessed here and includes accessible material on many aspects of covid-19. 2. Achievement of highest covid-19 vaccination of people on the GP Learning Disability Register within England.
	Physical Health Care	1. Monitoring and communicating signs of deterioration (West of England Academic Health Science Network, 2021)[43] (RESTORE 2 & RESTORE 2 MINI training offered by West of England Academic Health Science Network continues to be actively promoted throughout disability care provider settings in Gloucestershire. Community Learning Disability Teams (CLDT) have also been trained to deliver this training and following a bid to NHS England the programme is in the process of developing a suite of locally held training resources alongside experts by experience. 2. Telehealth project into Learning Disability Care Homes (West of England Academic Health Science Network (WEAHSN), 2021)[44] concluded and is in the process of being evaluated. 3. Resources to support the management of complex bowel conditions (such as diverticulitis, constipation and bowel cancer) have been actively shared. The Learning into Action Group has also identified the need to develop an easy read bowel cancer screening leaflet alongside the screening team and this will be co-produced during 2022-2023. 4. Continued campaign about the importance of reasonable adjustments in hospital settings utilising My Health Passport. Based on feedback we have developed an editable online version (Gloucestershire Health & Care NHS Foundation Trust, 2021)[45] which can be typed into and printed off. 5. Dysphagia and community speech and language guidelines following the person when they are admitted to hospital quality improvement project has been scoped and testing of solutions will continue into 2022-2023 6. Weight and nutritional intake monitoring – Capital bid for hoist scales to be purchased through Community Equipment Services. 7. Audit around the Enhanced Care in Care Homes Direct Enhanced Service for learning disabilities has been highlighted by LeDeR reviews, care providers and primary care staff. Initial engagement has highlighted a need to provide a toolkit to support practices.

[43] https://www.weahsn.net/our-work/transforming-services-and-systems/keeping-people-safe-during-and-after-covid-19/recent-coronavirus-covid-19-information-for-the-learning-disabilities-collaborative/
[44] https://www.weahsn.net/our-work/digital-transformation/case-study-baywater-telehealth-pilot/
[45] https://www.ghc.nhs.uk/wp-content/uploads/My-Health-Passport-EasyRead-v2-April-2021_Editable-Version.pdf

Learning Theme		Actions undertaken
		8. Oral Health Promotion resources and training is being reviewed as an ICS and a working group has established links with Public Health leading on this work.
	Care Provider Market	1. Covid prevention support and grants continues to be provided to care providers. 2. Provider bulletin (Integrated Disabilities Commissioning Team, n.d.)[46] continues to be published monthly. 3. Workforce competencies – piloted a Learning Disabilities Fundamentals to Care (FTC) training programme (Integrated Disabilities Commissioning Team, 2021)[47] in response to identified training gaps alongside our Proud to Care team. 4. Gloucestershire has successfully piloted the Oliver McGowan Mandatory training (Gloucestershire Health & Care NHS Foundation Trust, 2022)[48] as part of the national pilot and therefore stands in good position to roll out this training during 2022-2023. 5. Continued accessible COVID-19 resources (Inclusion Gloucestershire, 2022)[49] - Inclusion Gloucestershire continues to review and add to their suite of accessible online resources which are aimed at those with lived experience of disabilities and people who may support them.
	Annual Health Checks and Health Check Action Plans	1. In Gloucestershire, much work has been done to encourage people with a Learning Disability to have an annual health check. Highlights include: - a. Uptake of annual health checks is 79% in 2021-2022 b. Gloucestershire was successful in becoming national exemplar site during 2021-2022 and this work will continue during 2022-2023. In particular, this includes increasing the number of Health Check Action Plans, increasing the number of children and young people on the registers and understanding the barriers children and parents face in getting onto the register. As well as improving the quality of Annual Health Checks. c. Further enhance the information on the G-Care website https://g-care.glos.nhs.uk/pathway/576 which provides guidance to health care professionals using a risk stratification approach during covid-19. d. Supercharged Me campaign (Integrated Disabilities Commissioning Team and Kingfisher Treasure Seekers, 2020) continues (website www.superchargedme.com).
	Legal frameworks	1. Mental Capacity Act and the use of advocates continues to be a common area for improvement – Click here Presentations to carers groups, care providers and experts by experience on the importance of capacity and support to make decisions have proven successful and will continue during 2022-2023 2. Establishing a standardised agenda for best interest meetings in the hospital settings. 3. The importance of advocates to support people to make decisions, especially for people who have fluctuating capacity has been a common theme.

[46] https://www.gloucestershire.gov.uk/health-and-social-care/provider-information/
[47] https://www.proudtocareglos.org.uk/the-care-hub/proud-to-learn-training/learning-disability-fundamentals-of-care-programme/
[48] https://www.ghc.nhs.uk/oliver-mcgowan-mandatory-training/
[49] https://www.inclusiongloucestershire.co.uk/covid-19/

Learning Theme		Actions undertaken
	End of Life care and Advance Care Planning	1. Easy read information for patients and carers (Gloucestershire Clinical Commissioning Group, 2021)[50] about the ReSPECT process and filling in the form has been jointly developed between experts by experience and experts by profession. 2. Accessible videos to raise awareness of the ReSPECT process and benefits of Advance Care Planning are planned to be filmed in the Spring of 2022 and will be available on the National ReSUS Council's website. These could be utilised with professionals, people with a learning disability, family and paid carers. Gloucestershire will publicise these videos widely when they are available.
	Hospital Care	1. Use of editable Health Passport continues to be promoted widely. 2. Reasonable Adjustments Flag continues to be reviewed and discussed. 3. Sensory equipment has been purchased to support autistic people's admission to Gloucestershire Royal Hospital and Cheltenham General Hospital.

[50] https://g-care.glos.nhs.uk/pathway/917/resource/7#chapter_7721

Chapter Six – Deaths of children

During 2021-2022, there were less than 5 children notified to the LeDeR platform from Gloucestershire. All child deaths are reviewed as part of the statutory Child Death Overview Process (CDOP) and therefore separate LeDeR Reviews were not undertaken. The deaths were allocated to a Senior LeDeR Reviewer who worked closely with the Child death review process (Safeguarding Children's Board, n.d.)[51] (CDR).

Due to the small number of cases, demographic data has been withheld to prevent inadvertent identification of the individuals.
All Local Safeguarding Children Boards have a statutory duty to hold a review whenever a child dies.

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

- 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.
- An overview of all child deaths in the Local Safeguarding Children Partners area (in this case the Gloucestershire Safeguarding Children Partnership 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 reports[52] are available to view on the Gloucestershire Children's Safeguarding Partnership (GCSP) website.

The tables on page 9 of the CDOP Annual Report 2020-2021 shows that the highest cause of death (total 35% of deaths) found to have is due to chromosomal, genetic and congenital anomalies and chronic medical conditions.

[51] https://www.gloucestershire.gov.uk/gscp/gloucestershire-statutory-reviews/child-death-process/#:~:text=All%20Local%20Safeguarding%20Children%20Boards,a%20child%20or%20young%20person.
[52] https://www.gloucestershire.gov.uk/gscp/gloucestershire-statutory-reviews/child-death-process/cdop-annual-reports/

Chapter Seven – Conclusions and 2022-2023 Action Plan

Table 12 - Gloucestershire LeDeR 3-year action plan

LeDeR Thematic Area	LDA Programme Area	Year 1 2021-2022	Year 2 2022-2023	Year 3 2023-2024
Training Gaps	Improving Quality of Services	• Complete Training gaps analysis with providers • Fundamentals of Care (FoC) Learning Disability Pilot • AHSN RESTORE2 Mini train the trainer sessions • We will develop and embed increased knowledge and understanding of best practice in primary care networks	• Evaluate FoC Learning Disability Pilot and business case for continued funding • RESTORE2 Mini local training resources developed • Implement Oliver McGowan Mandatory Training • Learning Disability AHC Training offer reviewed, and gaps identified with solutions to address • Implement LeDeR Action learning sets with specific learning for different professional groups initial stakeholders inc GPs, Hospital staff, Social Care, Care Providers • Work with Primary Care Training Hub to standardise the offer for primary care staff. • Continue to promote system learning to ensure all learning from death and examples of best practice are shared across the health, social care and third sector services, rather than sitting in silos	• Implement recommendations from FoC Evaluation • Address any training gaps identified through the LeDeR Reviews over the last 1-2 years.
Use of technology	Improving Quality of Services	• Evaluate Telehealth/Bayswater pilot with AHSN • Implement regular electronic LeDeR Newsletters	• Further development and refinement of a local Information dashboard utilising Power BI to inform local health inequalities.	• Reasonable adjustments digital flag in summary care records rolled out for people with Learning Disability and Autistic Adults. • Scope with other regions any new innovative technology.
End of life and Advance Care Planning (ReSPECT)	Reducing Health Inequalities	• Work with End-of-Life Clinical programme and RESUS Council to develop easy read resources	• A range of co-produced film RESPECT2 accessible films will be developed and shared. • Continued engagement with the ICS End of Life Clinical Programme to ensure reasonable adjustments and personalised end of life care for people with a learning disability and autistic adults.	• Continued engagement with the ICS End of Life Clinical Programme to ensure reasonable adjustments and personalised end of life care for people with a learning disability and autistic adults.
Legal Frameworks	Improving Quality of Services	• To increase knowledge, appropriate use and improved recording of Mental Capacity Act (MCA) and Best Interest (BI) decisions within primary care and acute care. • Guidance written to ensure consistent approach to BI meetings in Acute Care.	• To continue to support and promote the appropriate use and recording of MCA/BI/Use of advocates. • Consider impact of implementing LPS. • Implement Hospital Best Interest (BI) Meeting guidance and leaflets.	• To continue to support and promote the appropriate use and recording of MCA/BI/Use of advocates.

LeDeR Thematic Area	LDA Programme Area	Year 1 2021-2022	Year 2 2022-2023	Year 3 2023-2024
Hospital Care (reasonable adjustments and communications)	Reducing Health Inequalities	• Amend the Health Passport to be editable and easy read in co-production. • Focus on Oral Health care and dysphasia within hospital settings • Develop easy one page checklist for supporting people with Learning Disability and Autism during covid-19 times.	• Continue to promote the use of the passport with hospital colleagues • Focus on Oral Health care and dysphasia within hospital settings. • Continue to work with colleagues in Mental Health Inpatient settings to ensure all reasonable adjustments are put in place to ensure equitable health outcomes	• Continued engagement with the LDA Clinical Programme to ensure reasonable adjustments and personalised care for people with a learning disability and autistic adults when going into hospital are and address any gaps identified through reviews.
Physical Health Care	Improving Quality of Services & Reducing Health Inequalities	• Continue to meet Learning Disability AHC 75% target and make better use of the Health Check Action Plan • Exemplar project Learning Disability AHC commenced • Raise awareness of national campaigns such as Mouthcare Matters, dysphagia and Dying for a Poo. • Development of a CCG/ICB Clinical Champion for LDA. • Establish links with social prescribers	• We will work to continue to meet the 75% target and improve the quality and effectiveness of AHCs, and access to screening services. • Learning Disability AHC children and young people deep dive of barriers and co-produce solutions to overcome barriers. • Continue to support reasonable adjustments for people to access flu and covid-19 vaccinations. • Continue to engage and influence national campaigns around physical healthcare for people with a learning disability or Autistic adults. • We will work to improve the recognition and management of pain – by recognising soft signs of deterioration, to understand when individuals are distressed, in pain or poorly and how they communicate to take prompt clinical action. • Embed CCG/ICB Clinical Champion in learning into action work. • Partnership with social prescribers established and support provided to improve their competency to support the LDA programme and learning into action. • Improve the understanding and awareness of additional health needs in our community care providers	• Continue to promote RESTORE2 and RESTORE2 mini across Gloucestershire • Continue to embed the role of Social Prescribers to support people with a learning disability and autistic adults.

Conclusion

This is the fourth LeDeR annual report for Gloucestershire. The report provides the detail of how the LeDeR Programme has been delivered during the year 2021-2022 and demonstrates the improved governance arrangements following the publication of the NHS England and NHS Improvement 2021 Policy. This report provides assurance that Gloucestershire has a robust approach to reviewing deaths of people with a learning disability. With clear plans to undertake reviews of autistic adults from January 2022. Ultimately improving outcomes for people who are at risk of facing health inequalities.

This year, even more so than previous years, has brought challenges to the country and the county of Gloucestershire that we have not faced before as we move out of a pandemic response, health and social care services are ever more in high demand. Covid-19 outbreaks have subsided, and inpatient activity has returned to more normal levels for people with a learning disability. It is a testament to the dedication of those working and supporting people with a learning disability that of the completed reviews 9 out of 10 people with a learning disability received excellent, satisfactory, or good care. In addition to this, Annual Health Checks have continued to be delivered and Gloucestershire achieved 79% uptake (more than the national target of 75% and the highest performing area in the Southwest). Another achievement to note is that the Gloucestershire Learning Disability Clinical Programme has actively supported the Covid-19 vaccination rollout in the County and of those aged 18 and over on the GP Learning Disabilities Register 94% have received their vaccinations[53].

The co-production partnership approach[54] which was implemented in 2019 has been invaluable in ensuring we are ahead of the curve in implementing action from learning during the year. Experts by experience have helped us understand from people with experience of learning disability and using health services locally during these unprecedented times. Table 12 provides an overview of the planned work for the LeDeR programme which has been mapped against the wider Learning Disability and Autism Clinical Programme. By doing this the programme's ambition is to;

- Focus on improved communications between professionals and with family/carers.
- Focus on early detection of deteriorating physical health including sepsis. In particular, supporting the uptake and use of the ReSTORE2 mini documentation.
- Focus on eating and drinking pathway including raising the awareness of oral health through Mouthcare Matters, and of the importance of checking for speech and language therapy guidelines on admission to hospital.
- Continue the focus on improving uptake of the Annual Health Checks and Flu Vaccinations.
- Focus on encouraging the ReSPECT form to be completed earlier on for people who have complex healthcare needs, alongside ensuring that there is a base line observation (Unique Wellness) in place to review frailty and advanced care planning with individuals, their family, and carers, so this helps identify when people are deteriorating.
- Continue to share the learning – plans to work with Inclusion Gloucestershire in 2022-2023 to develop accessible easy read infographics of the learning that comes out of the reviews.

All the recommendations from reviews will continue to be scrutinised by the Quality Assurance panel and put into a local action plan tracker which is shared with the Gloucestershire LeDeR Governance and Steering group who will monitor progress with the aim of improving outcomes for people who are at risk of facing health inequalities. Learning on a page from each review will be shared for every review undertaken.

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 2022-2023. Whilst extending the scope to carers who support people from black and minority ethnic communities and engagement with community organisations and individuals will be crucial for the programme to be able to do this effectively. People's lived experience will help to guide and drive the service improvement programme that will be as a result of the completed reviews.

[53] Data correct January 2022.
[54] We have been supported by Inclusion Gloucestershire

Going forward we are passionately committed to listening and learning from reviews, from people with Learning Disabilities and Autistic people and their families and making positive changes across the health care system. The Gloucestershire Learning Disabilities and Autism Clinical Programme will continue to challenge health inequality and improve health outcomes for people with learning disabilities and aim to prevent people from dying prematurely.

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