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Transforming Care, Transforming Communities

NHS

Gloucestershire's Learning Disability & Autism LeDeR Programme

Annual Report 2022 - 2023

Learning from lives and deaths of people with a learning disability and Autistic adults in Gloucestershire. A service improvement programme

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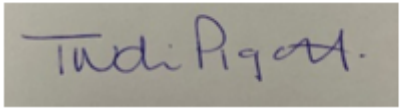
Joint Statement from Senior Responsible Officers



Trudi Pigott
Chair of the Gloucestershire LeDeR Steering Group and
Deputy Director of Quality
Gloucestershire Integrated Care Board

Dr Marion Andrews-Evans
Director of Quality and Nursing
Gloucestershire Integrated Care Board

The LeDeR Programme (Learning from Deaths Review of people with a learning disability) is led by NHS England and follows on from the work undertaken by the University of Bristol Confidential Enquiry into the premature deaths of people with Learning Disability (CIPOLD) 2013. The findings of that report demonstrated that on average someone with a learning disability lives 20 years less than the general population. On average people with learning disabilities in the Gloucestershire population live 6.5 years longer than the learning disability national average. There is still more we must do to improve quality of life and reduce health inequalities in order to narrow that gap.

This is the fourth annual report on the deaths of people with learning disabilities who lived in the Gloucestershire area. The report aims to share our findings from LeDeR reviews, to report on the learning identified and the action we have taken as a system to improve practice and service delivery, and address health inequalities for people with learning disabilities and autistic people.

Joint Statement from Senior Responsible Officers

The LeDer Quality Assurance Panel, the Learning into Action Group and the LeDeR Steering and Governance group has proved to be an effective mechanism for people with lived experience and system partners to come together to co-produce solutions to the themes and issues identified in our LeDeR reviews.

Building on feedback we wanted to ensure that the annual report is used as a live document for continued learning and service improvement and so have opted this year to produce it in a format that is more accessible to the range of system partners and allows them to use it as a toolkit for influencing change.

Gloucestershire stands in a strong position to address the issues and preventable causes of death identified within the national LeDeR annual report (NHS England, 2022). NHS England LeDeR Annual Reports This reflects the many challenges that people with a learning disability and autistic people face locally. We amended local processes and practice to meet the requirements of the updated national LeDeR Policy (NHS England, 2021) published in March 2021 and introduced in Gloucestershire during the Summer of 2021.

We have adapted to the new LeDeR IT platform and following training have embedded the new review process locally. Gloucestershire continues to be a top performing area and meets all its performance indicators set by NHS England for LeDeR. This annual report will provide an overview of the programme and includes learning and actions arising from reviews undertaken between April 2022 and March 2023. Reviews for autistic adults commenced January 2022 and data from these reviews will be included in this annual report for the first time.

Joint Statement from Senior Responsible Officers

The local programme has an established way of working in co-production with people with lived experience and this coupled with support from our dedicated group of Experts by Profession, continues to be a key contributor to the success of the programme locally. This co-production partnership approach ensures that we have the valuable knowledge, insights and co designed solutions in implementing and sharing action from learning across the health and social care system. Our Experts by experience have helped us get perspectives from the people who use health and care services locally.

We have a strong commitment to learn from these reviews and a renewed dedication to turn this into real action, promoting learning throughout health and social care services and the wider system.

The success of the LeDer programme would not be possible without the support and commitment of the many people and organisations across Gloucestershire's health and care system who have worked to notify deaths, undertake and quality assure reviews, and implemented service improvement arising from the learning from reviews.

We also wish to acknowledge the valuable input of our experts by experience who act as both critical friend and supporter of this important area of work. We have been supported with this by Inclusion Gloucestershire

The programme will continue to review, evaluate and adapt its approach in line with emerging good practice and policy in order to effectively challenge health inequality and advocate and lead on service and system developments to improve health outcomes for people with learning disabilities and autistic adults.

What is LeDeR?

LeDeR is learning about people's lives and deaths so that we can make healthcare better for people with learning disabilities and autistic adults.

- Learning Disability Profiles PHE
- LeDeR Annual Reports

https://fingertips.phe.org.uk/profile/learning-disabilities

https://leder.nhs.uk/resources/annual-reports

What is LeDeR

- 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 is reviewed by an independent reviewer.

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:

a) Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.

b) Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.

c) Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

Background to LeDeR

- Learning from lives and deaths – People with a learning disability and autistic people, or LeDeR (formerly known as the Learning from Deaths Review Programme) started in April 2017.

- It grew out of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD) 2013 and was piloted in parts of the country in 2016. A commitment to continuing the LeDeR programme was made in the NHS Long Term Plan 2019

- The LeDeR programme is funded by NHS England and NHS Improvement to improve healthcare for people with a learning disability and autistic people.

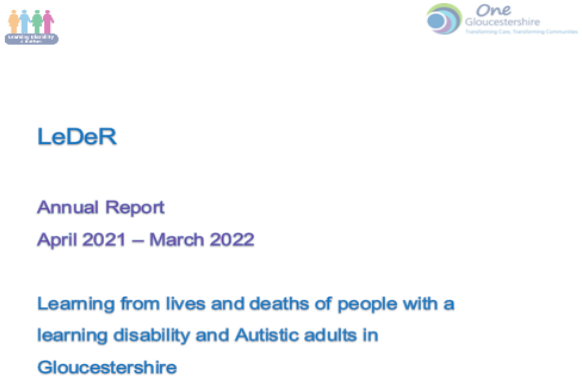
- The Gloucestershire Integrated Care Board holds responsibility for delivering the local LeDeR programme.

- This report is about reviewing deaths of people with a learning disability and Autistic adults and the health inequalities faced by them. 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.

- Notifying a death to LeDeR is not mandatory and , therefore we would not expect LeDeR to have data on all people with a learning disability who have died, but the local programme has made some important links to try and improve reporting. Furthermore, some people will have opted out of sharing their information prior to their death and in these instances these deaths will also not be referred to the LeDeR programme.

Some of the data contains a relatively small number of cases, particularly the data regarding children and ethnic minority and in some subcategories, so some findings must be interpreted with a degree of caution. 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.

Preface



- This report includes the death of people with learning disabilities and autistic adults who died from 1st April 2022 to 31st March 2023.
- It is the fourth annual report for LeDeR that Gloucestershire has published.
- Previous reports are available on Inclusion Gloucestershire's LedeR webpage. Inclusion Gloucestershire LeDeR
- The purpose of the report is to share our findings from LeDeR reviews and to share learning and changes for practice.

Some of the people who have died

This report is about people with a learning disability and autistic adults who have died in Gloucestershire during 2022-2023. 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, 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.

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

Case study 1

About the person who died
Padova

Learning Points and themes

Actions taken

Case study 2

Dysphagia training

Learning Points and themes

Actions taken

Case study 3

About the person who died

Involvement of IHOT

Learning Points and themes

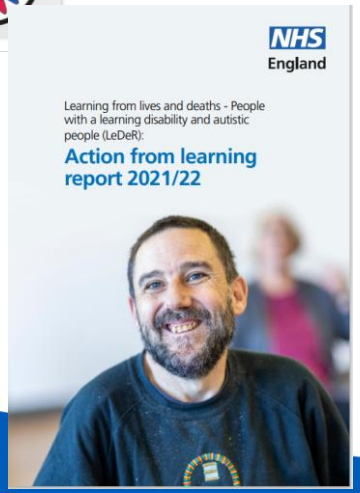
Actions taken

National LeDeR Policy Drivers

- The LeDeR programme has been set up by NHS England as **a service improvement programme** with ambitious 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 during their life. It is supposed to do this this by:
- Delivering local **service improvement**, learning from LeDeR reviews about good quality care to share best practice and identifying areas requiring improvement.
- Driving local **service improvements and action from the learning** 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.

Reducing Health Inequalities is a key aspect of the local LeDeR Programme and based on learning themes to date demonstrates the core areas of work for service improvement over the coming three years. The programme uses a number of enablers to assist in its successful delivery including working with Definition of Health Inequalities is available on the NHS England website https://www.england.nhs.uk/ltphimenu/definitions-for-health-inequalities/

National Reports – Published July 2022



- Annual Report 2021 (Kings College) - https://www.kcl.ac.uk/research/leder

- Action from learning report 2021 - https://leder.nhs.uk/resources/action-from-learning-reports

Gloucestershire LeDeR Framework

- A local LeDeR policy which outlines how reviews are managed, learning into action is monitored provides assurance to the Gloucestershire LeDeR Governance and Steering Group and the Integrated Care Board (ICB) Quality.
- This Policy has been reviewed and updated in line with the publication of the national policy publication in March 2021 and approved by the Quality Committee in February 2022.
- The local LeDeR Policy is a 3-year strategy for delivering on the national and local priorities.

Learning from Deaths Review Gloucestershire (LeDeR) : NHS Gloucestershire ICB (nhsglos.nhs.uk)

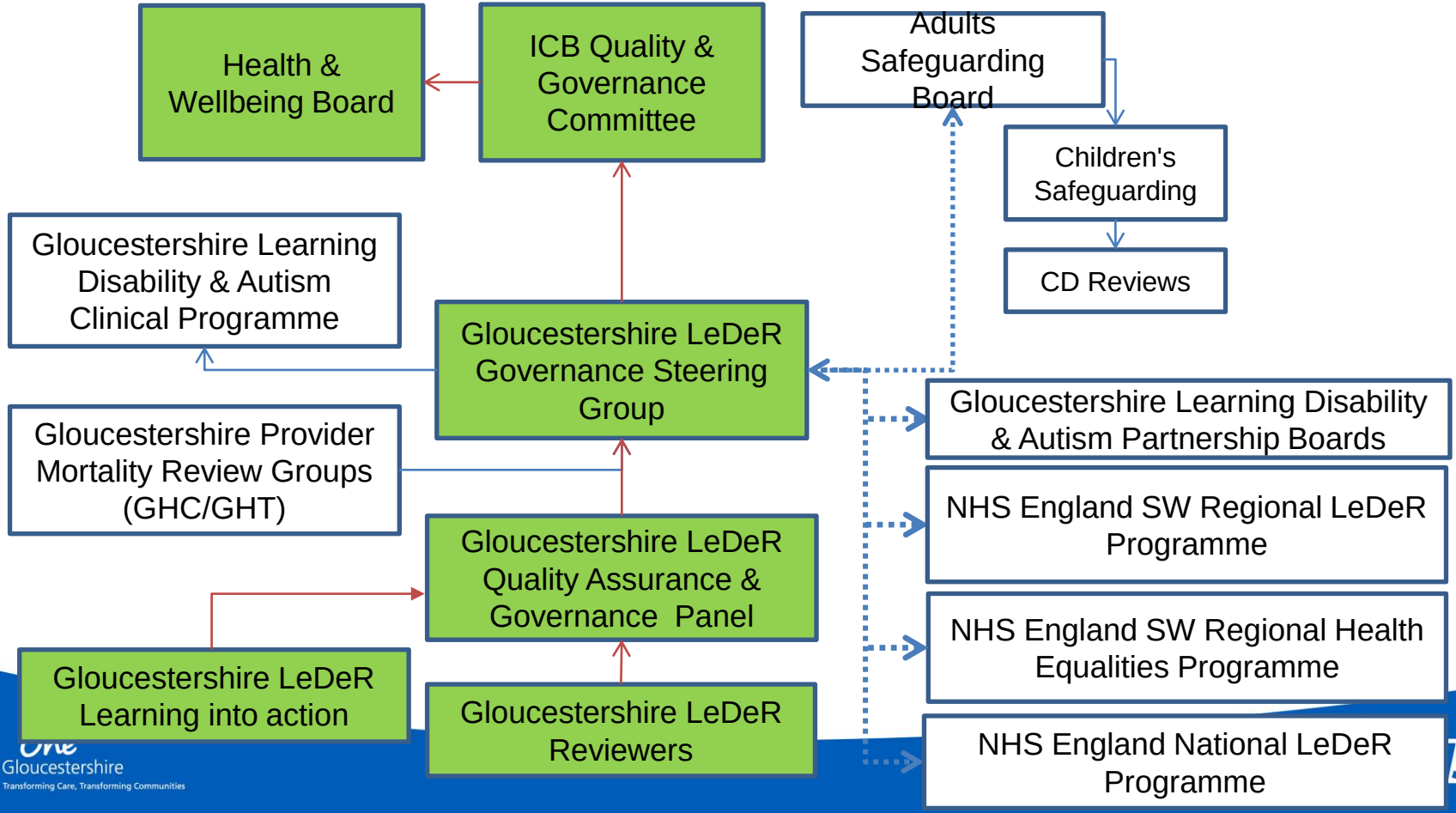
Key individuals and groups involved

- **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
- **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 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 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 is 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.

LeDeR Programme – Who's who (current)

Who	Role	Who	Role
Trudi Pigott Senior Responsible Officer Deputy Director of Quality ICB		**Althia Lyn** LeDeR Local Area Co-ordinator Chair of the LeDeR Quality Assurance Panel	
Paul Yeatman Senior Independent LeDeR Reviewer (Complex, Safeguarding, Focussed Reviews, Coroner cases)		**Deborah Livingstone** Senior Independent LeDeR Reviewer (Complex, CDOP reviews, Focussed reviews)	
Sammy Roberts – Learning Disability and Autism Expert by experience		**Paul Tyrell** – LeDeR Content Developer for learning into action and expert by experience of disability	
Dr Mark Scheepers Consultant Psychiatrist **Dr Kate Allez** Consultant Psychologist **Katherine Legget**	**Dr Thomas Herbert** GP 	**Anna Holder** – Social Care + Member of Disabilities Quality Assurance Team	**Jeanette Welsh** Safeguarding Lead Nurse GHT 

Gloucestershire LeDeR Programme Governance Structure



Overview of the LeDeR Model - Gloucestershire

Gloucestershire Local Area Contact (LAC)
Cheryl Hampson

Gloucestershire Secondary LAC
Althia Lyn

Roles & Responsibilities
- Allocate cases on system
- Manage QA Panel process (chair)
- Write Annual Report
- Manage Learning into Action Tracker
- Reporting to NHS England and attendance at regional meetings
- Lead on Learning into Action (chair)

Gloucestershire QA & Governance Panel

- Consultant Psychiatrist (LD & Autism)
- Consultant Psychologist (LD & Autism)
- GP
- Pharmacist
- Safeguarding Nurse (GHT)
- Quality Review Officer (GCC)
- Social Care Lead LD
- Mental Health and Autism Commissioning Lead
- LAC & Reviewers
- Experts by experience
- **Medical Examiner & Coroner (TBC need to invite)**
- Consultant Palliative Medicine

Roles & Responsibilities
- Read initial and focussed reviews
- Attend monthly QA panels
- Provide feedback on learning points from each review providing the panel with their professional knowledge and skills or experience
- Share learning within their own networks
- May be asked to be a part of the Learning into Action Group

Gloucestershire LeDeR Learning into Action Group

- LAC/Secondary LAC
- CLDT Representative
- Senior LeDeR Reviewer
- Safeguarding Nurse (GHT) or GHT LD Liaison Nurse
- Experts by experience
- Consultant Psychiatrist,
- Quality Review Officer

Roles & Responsibilities
- Attend monthly LIA Group meetings
- Identify appropriate channels for service improvement
- Maintenance of the Learning into action tracker
- Production of the LeDeR Newsletters and website
- Production of themed webinars for stakeholders
- Lead on targeted specific work areas e.g. carers, BAME etc

Roles & Responsibilities
- Complete cases on system – link in with family, and other mortality processes e.g. SAR/ CDOP etc
- Attend QA Panel (senior reviewers)
- Attend Learning into Action Group (senior reviewers)
- Share learning

Gloucestershire LeDeR Reviewers (Employed on ICB Bank Contract)

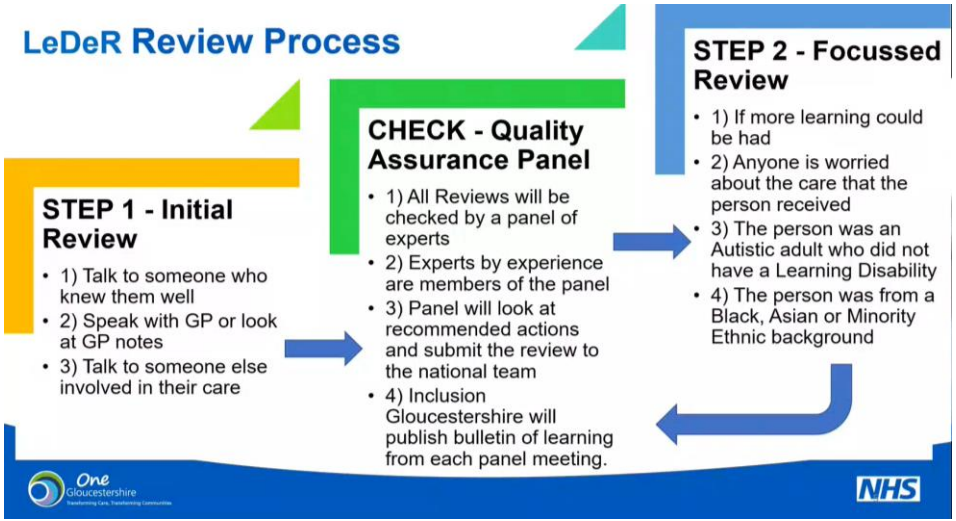
Paul Yeatman
Senior Reviewer
(Complex/ Safeguarding / Full Review cases/ attend QA panel)

Deborah Livingstone
Senior Reviewer
(Complex/ CDOP/ Full Review cases/ attend QA panel)

Carol Forbes
LeDeR Reviewer
(Initial Reviews)

Laurie-Ann Cook
LeDeR Reviewer
(Initial Reviews)

LeDeR 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.

LeDeR Review Process

- The reviewer looks to identify best practice by reviewing the person's health and social care
- records and where identified, areas where improvements could be made. There is either an
- initial review or a new focussed review - introduced into the process with the new policy.
- All reviews concerning someone from a black or minority ethnic background automatically becomes a focussed review.
- In January 2022 NHSE introduced LeDeR reviews for people with autism.

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

What reviewers are 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.
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

What reviewers are looking for?

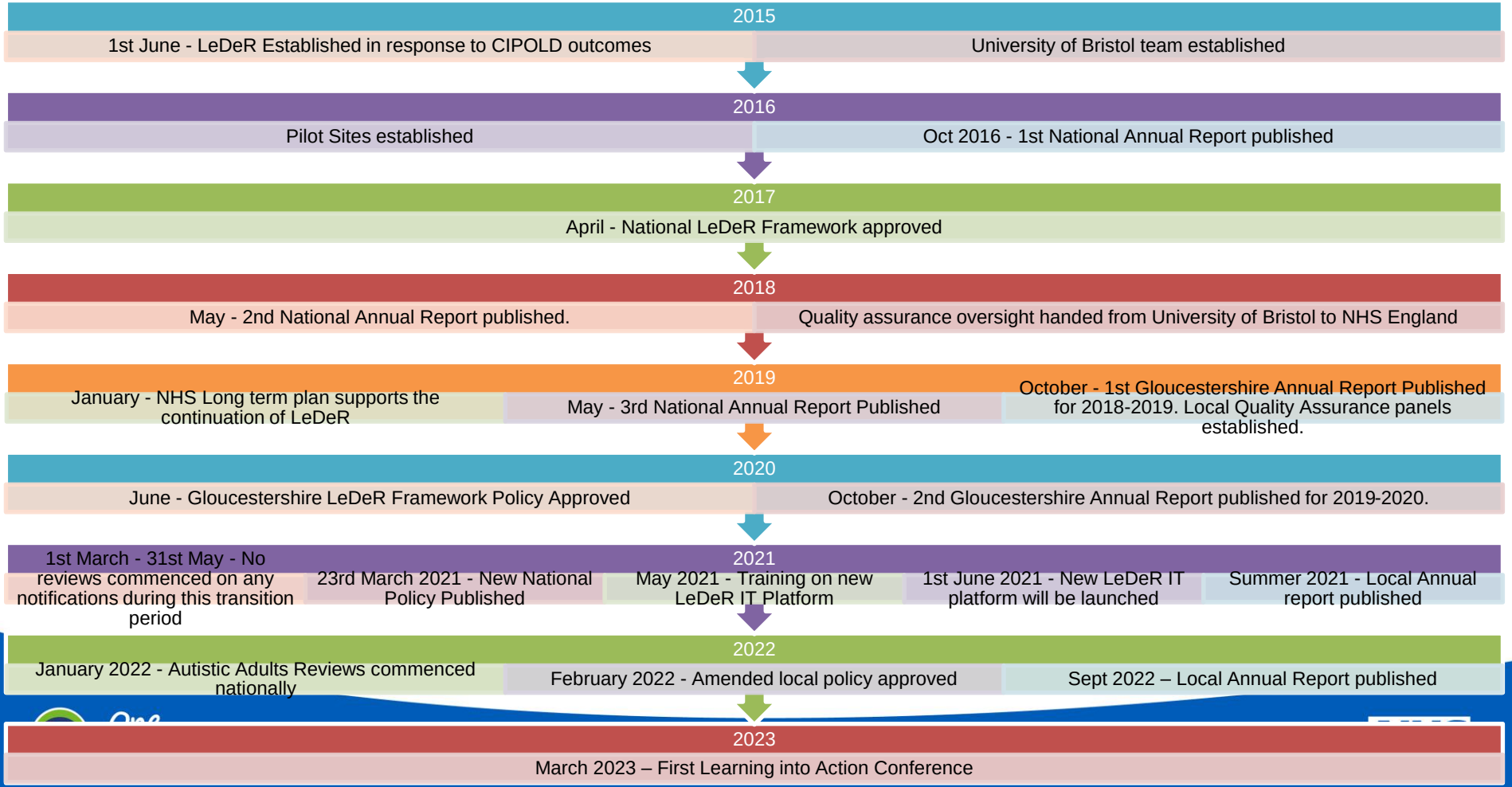
The way services are organised and accessed:  	No designated care coordinator to take responsibility for sharing information across multi-agency teams, particularly important at times of change and transition.
	Lack of understanding and/or recording of the Mental Capacity Act when making essential decisions 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

The LeDeR Review Process

The QA Panel
The LeDeR Steering Group
Learning into Action Group
Learning shared with

Care providers
NHS Trusts
Clinical Programme Groups
Commissioners
Voluntary Sector Providers

History of the LeDeR Programme



Connections with Gloucestershire Safeguarding Adults Board (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.

Health Action Group – Findings from reviews are reported at the quarterly health action group. Case study

Partnership Boards -

What we know – setting the scene

National 2022-2023

No. of deaths 3,304

56% male / 44% female

Females median age at death: 60

Males median age at death: 61

Overall median age of death: 61

Regional 2022-2023

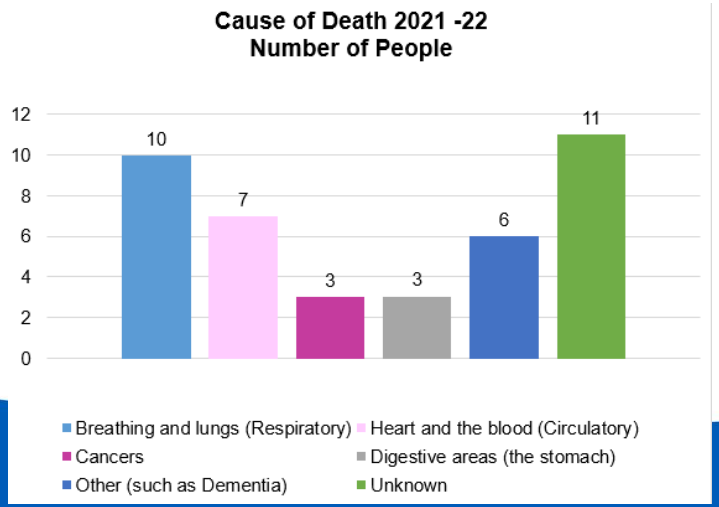
No. of deaths 336

59% male / 41% female

Females median age at death: 58.5

Males median age at death: 61

Overall median age of death: 60



Local 2022-2023

No. of deaths 40

57% male / 43% female

Females median age at death: 61

Males median age at death: 64

Overall median age of death: 62.5

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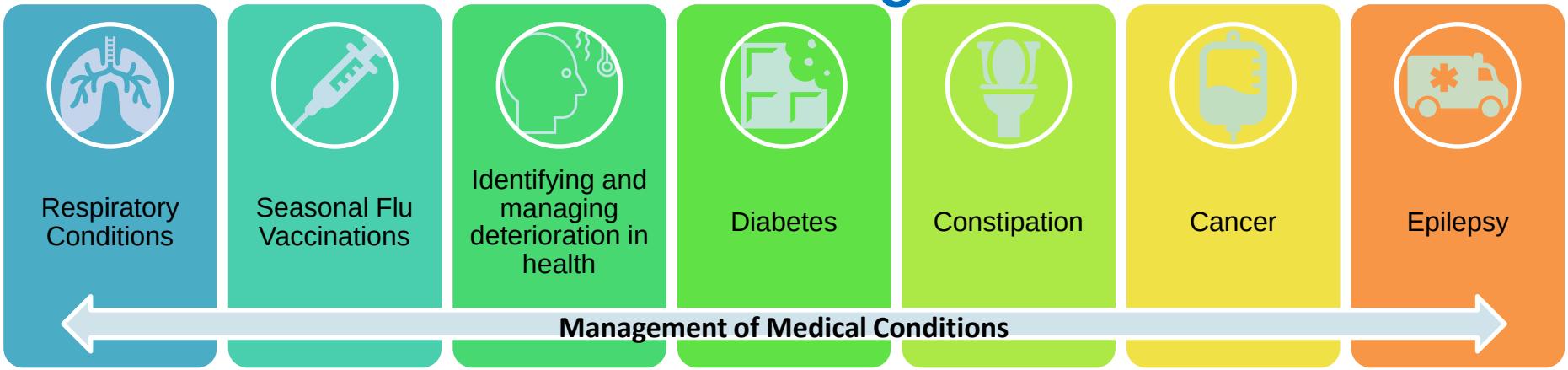
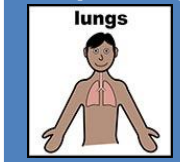
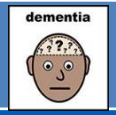
Tewkesbury
Gloucester
Cheltenham
Stroud
Cirencester
Berkeley

National Action from Learning



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.

The LeDeR Journey in Gloucestershire

Improved Quality of care

Improved use of legislation (MCA etc)

Hospital care

Advance care planning and use of RESPECT Form

Improved Physical Healthcare

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Local Performance

This report focusses on 2022-2023 and is the fourth local annual report on the learning from deaths of those with learning disabilities and autistic people within Gloucestershire. The report covers from 1st January 2017 up until 31st March 2023. The Gloucestershire LeDeR Programme (as at 31st March 2023) had completed ~~92%~~ of notified reviews (reviews received up to and including 31st March 2023).

Notifications & limitations with the data

Unlike reviews of child deaths, which are required by law, reviews of the deaths of people with learning disabilities and autistic people 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.

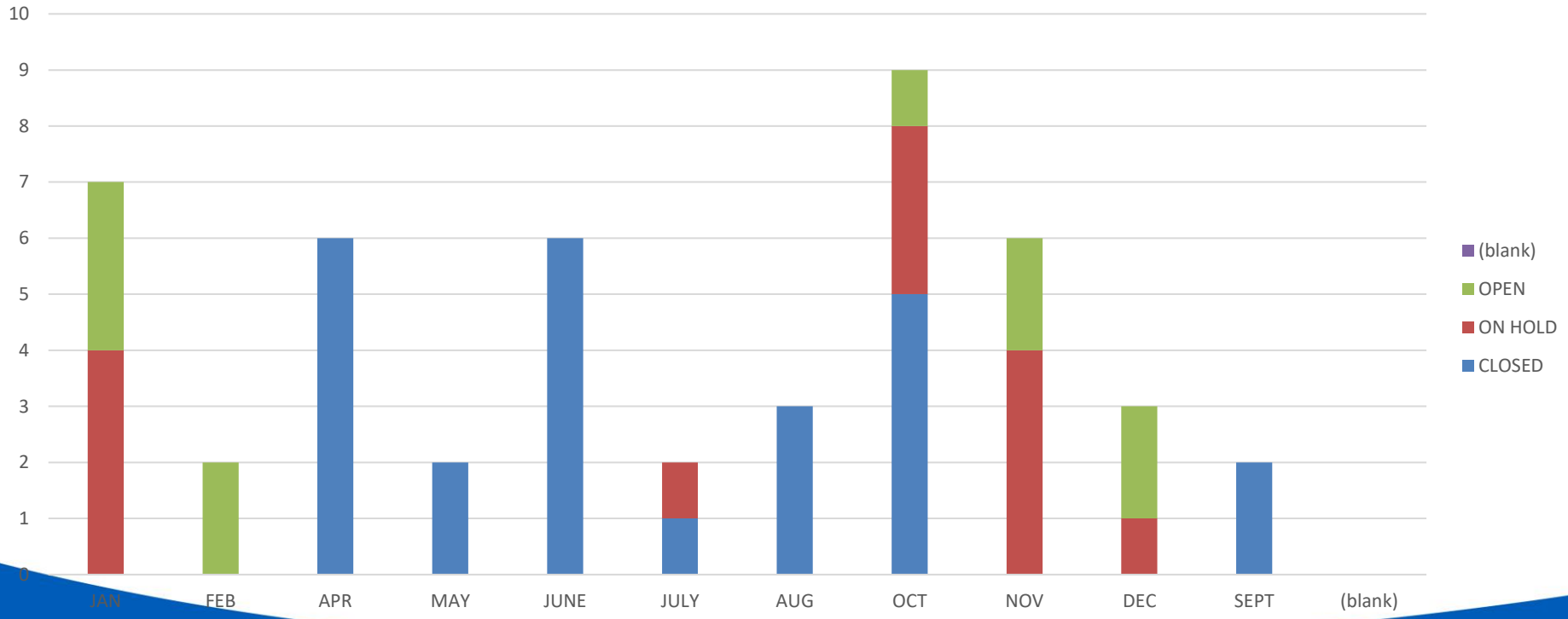
Review Status

Since the programme began there have been 294 Gloucestershire deaths reported to LeDeR covering the period January 2017 to end March 2023 of which 288 have had an initial review undertaken.

For the financial year 1st April 2022-31st March 2023 there were 48 notifications and 25 have had an initial review completed and have been quality assured (52% completed).

Row Labels	CLOSED	ON HOLD	OPEN	Grand Total
JAN		4	3	7
FEB			2	2
APR	6			6
MAY	2			2
JUNE	6			6
JULY	1	1		2
AUG	3			3
OCT	5	3	1	9
NOV		4	2	6
DEC		1	2	3
SEPT	2			2
Grand Total	25	13	10	48

Review Status



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	55	98%
2021-2022	21	19	40	53%
2022-2023	25	10	35	
TOTAL	251	30	281	

Assessment of the Quality of care

Reviewers are asked to grade the care the person received at the end of a focussed review (cases which only receive an initial review will not be graded formally however the local QA panel will capture indicative grading as part of local processes).

Care is graded on 2 elements of the health and social care the person received:

1. Quality of care the person received
2. Availability and effectiveness of the services.

Care is graded on a scale of 1-6. 1 represents poor care , 6 excellent care.

% of the reviews completed had received excellent or good care during 2022-2023 another % had satisfactory care

What good looks like – Key ingredients for a good quality of life for people with LD's and Autistic people

Social Care

Person centred care and support plans,

Accessible information

Reasonable adjustments in provision of care

Good coordination of care

Appropriate use of MCA and advocacy to manage risk.

Soft Signs

RESPECT – Planning for emergencies and end of life.

LD and autism trained care staff providers

Access to specialist care services, CLDT IHOT to promote engagement in care.

Support for family carers

Promote healthy lifestyles

Hospital Passport

GP Care

Person centred health care

Accessible Information

Timely and reasonably adjusted appointments

Coordinated care

Appropriate use of the MCA and advocacy to manage risk

RESPECT – Planning for Emergencies and End of life.

Soft signs

LD and Autism trained staff.

Access to specialist health services CLDT,IHOT etc. to promote engagement in treatment

Support for family carers

Referral to healthy lifestyle services

Access to Annual Health checks

- Access to age and gender appropriate screening and vaccinations
- Hospital Passport

Acute Care

Person centred care

Reasonable adjustments

Coordinated Care

Use of the MCA and Advocacy

SOFT Signs

RESPECT – supporting end of life wishes where possible.

LD and Autism trained staff.

Use of specialist health services CLDT, IHOT

LD Liaison Nurses to promote engagement in treatment.

Keeping family carer informed and involved in decision making.

Referring to the individual's Hospital Passport

What good looks like – Key ingredients for a good quality of life for people with LD's and Autistic people

Community Support
suitable housing,
Equipment

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= 97 deaths), with Gloucestershire Health and Care NHS Foundation Trust (the County's community NHS Provider) the second biggest reporters of deaths (n= 66 deaths).

Year	GHC	2G[1]	GCC	GCS[2]	GHT	GP	Care Home/ Provider	Out of county	Other	TOTAL
2016-2017		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		9		17	5	2		5	55
2021-2022	16				16		4		4	40
2022-2023										
TOTAL	47	27	42	3	78	13	11	7	18	246

Annual Health Checks

Demographic data

Summary of the findings

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

Gender of those who died in 2022-2023 in Gloucestershire

Gender comparison local vs national vs general population

Gender

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

Gender of those who died in 2022-2023 in Gloucestershire compared to previous years

Demographic data - Age

Demographic data - Ethnicity

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.

Place of Death

Calculate and add % of deaths in hospital. Calculate and add % increase on 2021-2022 21 deaths

Of the 48 deaths reported in Gloucestershire during 2022-2023 25 % (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.

Deaths of Children

Involving next of Kin

National and regional top 4 causes of death from 2021 LeDeR data

National

- COVID-19
- Circulatory Diseases
- Respiratory Disease
- Cancer

Regional

- COVID-19
- Cancer
- Malformations; deformation and chromosomal abnormalities
- Influenza and pneumonia

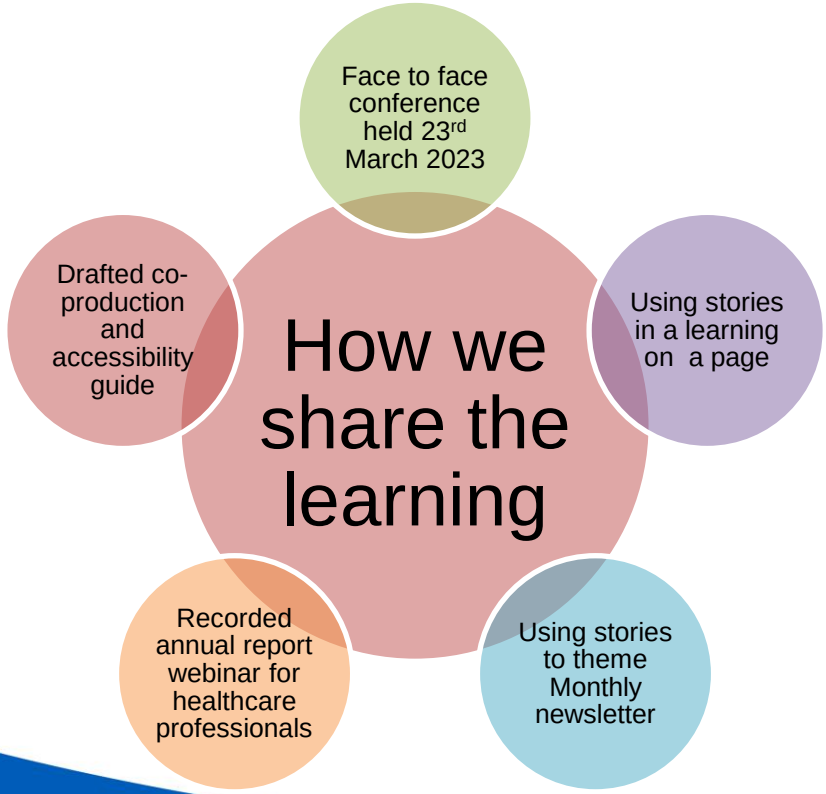
Place and Cause of Death

% Notifications received and from where. Highest/ lowest. Comparison with 2021-2022. Areas identified for improvement. Limitations: data identifies where deaths occur Home hospital, community. Prescribed protocols for notifying deaths. e.g. Hospital Trusts these account for % of notifications overall. What do we know about community deaths of people with LD? (Cheryl) where can I get this data? ACTION update data for 2022-2023 Add to table on AR worksheet

Cancer/Diabetes Screening

What have we learnt?

Programme Achievements so far…



Action into Learning

Summary of best practice examples

• Well co-ordinated End of Life Care and consistency of support for a dignified death
• Very good MDT meeting to discuss DNA CPR with family as patient had advanced Alzheimer's
• Excellent co-ordination of care and carers tailoring opportunities such as playing piano and taking him to recitals of classical music
• Advocating on the person's behalf with ambulance staff, insisting person was taken to hospital.
• Many examples of the Learning Disability and Autism Liaison Team making timely assessments and supporting people in hospital which significantly improved their care
• A sensitive and compassionate approach in hospital – withdrawal of treatment was delayed until all family members could be present at the bedside
• MDT meeting held prior to discharge to consider Mum's ability to care for son as she had just recovered Covid and son was immuno-compromised
• Several examples of well timed advanced care planning involving the person, their family or an IMCA
• Effective follow up from GP and primary care team when discharged from hospital
• Lots of examples of collaborative working and involvement of family members
• Excellent co-ordination of care between primary and secondary care with innovative reasons adjustments
• Taking person's wishes into account in End of Life care allowing the person to die in their own home with friends and family, supported by palliative care
• Reasonable adjustments were made so mum could stay in hospital with her son as he died.
• Use of supported living environments being a positive alternative to care homes for people who prefer a family environment

Summary of improvement recommendations – individual reviews

• Breaking bad news about a terminal cancer diagnosis needs to be done after a careful assessment of the persons understanding with appropriate supports and resources in place
• Checking learning disabled patients for pressure area injuries during prolonged hospital stays
• Ensure sepsis guidelines are followed in hospital to identify sepsis in the learning disability population which may be overlooked due to diagnostic overshadowing
• With staff turnover, new carers need training and support to understand someone's personal history and get to know them so they can provide the best possible support
• Regular monitoring of weight gain or sudden weight loss and taking action when the person has a low or high BMI with dietary protocols to support staff
• Training for surgeons on mental capacity and the patient's right to choose NOT to have life saving surgery and make 'unwise decisions'
• Lack of placement review by local authority when person(s) was placed in unsuitable accommodation
• Ensure ambulance staff are aware of the different presentation of Covid in people with learning disabilities
• Training/awareness raising for community staff on when to refer to End of Life and Palliative care services for guidance and advice
• Delays to putting DOLs in place whilst people were in hospital
• Develop an eating and drinking pathway for dysphagia that includes adaptations to textured diets, tools and resources and keeping food tasty/edible
• Carers assessments to be completed for those living with a family member
• Hospitals to ensure death notifications are sent to GP's
• Patients with Williams Syndrome to be considered for abdominal CT scans to assess for bowel obstruction when they present with diarrhoea and 'coffee ground' vomit
• Video calls to be routinely arranged with family members who cannot visit hospital.
• Professionals must explain clearly the pros and cons why something is needed to parents/family members in a person's best interests – for example a change of PEG

Feedback about LeDeR and what is found out…

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

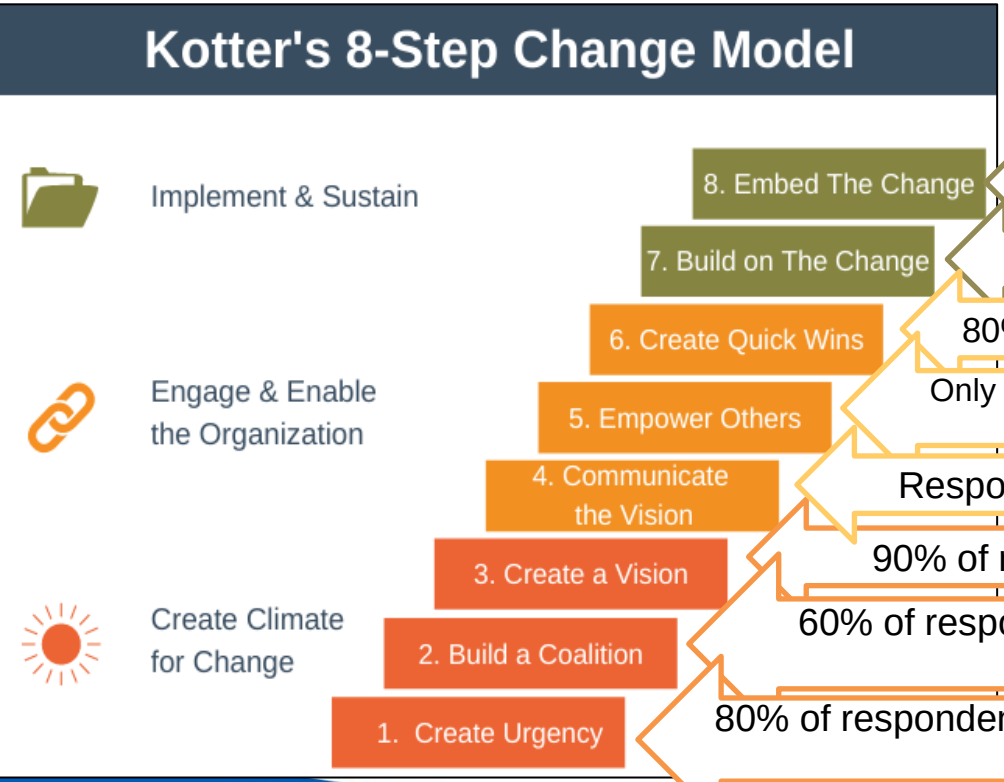
I think doctors and nurses need to be aware of LeDeR to stop it from happening again!

We have the right people involved who are just so motivated to make change happen

"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"

The QA Panel is a strong example of co-production in action. We work together as a multi-disciplinary team to discover the learning opportunities we can share

Research project – Summer 2022



50% felt the workforce had the right skills to deliver change

100% felt the programme had managed to sustain momentum

80% felt the programme had achieved some short term wins

Only 40% felt the programme had engaged and enabled the whole system in taking learning forward

Respondents felt learning should have SMART objectives

90% of respondents felt the programme had a clear vision

60% of respondents felt the programme had support from senior leaders

80% of respondents felt the programme had been effective in engaging stakeholders

What works well and not so well?

What does the programme do well

1. Strong collaborative approach and Quality assurance processes and governance
2. Co-production
3. How we communicate with those who are interested – respondents liked the communication that comes from the programme and found it useful.

What does the programme need to change

1. Sharing the learning more widely with care providers, other clinical programmes, frontline workers etc Maybe a face-to-face conference, podcasts and videos
2. Getting communications expertise to help sharing the learning e.g. development of podcasts and a suite of learning resources in various mediums
3. Support frontline workers with a more practical focus/application of what reasonable adjustments are.
4. How we prioritise the actions for the programme – cannot do it all! Capacity of the current programme team was cited on more than one occasion as an area for improvement.
5. Membership of the QA panel to be extended – triangulation of evidence between LeDeR, Safeguarding, Health teams, Social care teams and Quality Assurance reviews to support discussion and agreement of learning into action SMART objectives.
6. Need to get better at informing business cases for investment into developing system capacity to take on the improvements recommended.
7. Respondents felt further knowledge sharing around the MDT approach was require, as was advanced and challenging conversations.
8. People felt that the annual report was too data driven and a greater focus on sharing of stories to bring the learning to life would be helpful.

Demographic data – Severity of Learning Disability

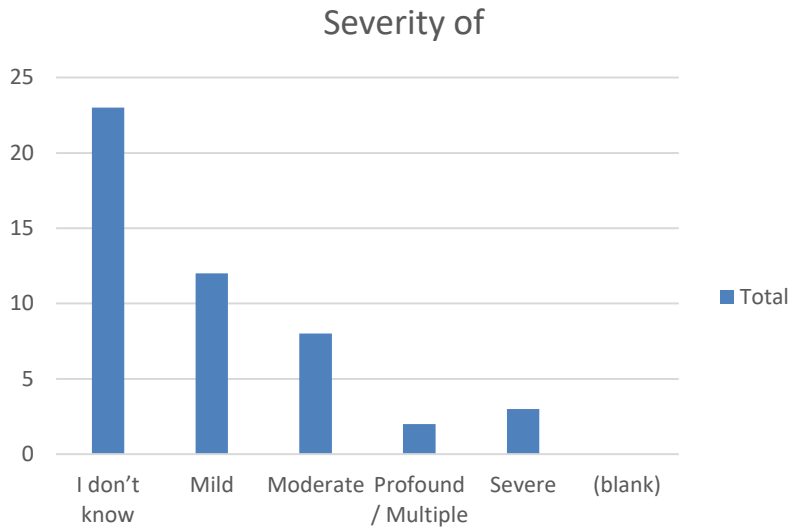
Of the 48 deaths reported in 2022-2023 24 have had the severity of learning disability recorded on the notification or completed initial review. Of the remaining 24 these are still to be reviewed or to go through a quality assurance panel. Broadly speaking the profile of severity of deaths in Gloucestershire is comparable year on year with about 12 ~~**40%**~~ of deaths for people with mild learning disabilities and 8 ~~**40%**~~ for people with moderate learning disabilities.

Of the 48 deaths reported 12 also had a clinical diagnosis of Autism.

Chart 6 - Severity of Learning Disability in Gloucestershire

Severity of learning Disability in Gloucestershire by gender 2022-2023

Severity of learning Disability Deaths reported to LeDeR – year on year comparison



Demographic data – Co-morbidities

Co-morbidities

The NICE Guideline 56 (NICE, 2016) 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.

https://www.nice.org.uk/guidance/ng56

Of the 16 reviews completed, where co-morbidities have been recorded in 2022-2023; 8 33% had 3 or more co-morbidities recorded (this is a reduction from the previous year of 53%). 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.

Where co-morbidities were less than five these have not been included check with Cheryl

** Indicates less than 5 people.*

Condition	Number of people with the condition recorded 2022-2023	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	6	*	13	16
Dementia	*	*	5	8
Cerebral Palsy	*	*	5	7
Down Syndrome	*	*	*	7
Hypertension	*	*	5	

Demographic data - 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). 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.
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk

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

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

Median age of death

Our data suggests a disparity (health inequality gap) in the age at death for people with a learning disability in Gloucestershire of 19 years when compared to the general population.

	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				

National and regional numbers 2021

National

- No. of deaths 3,304
- 56% male / 44% female
- Females median age at death: 60
- Males median age at death: 61
- Overall median age of death: 61

Regional

- No. of deaths 336
- 59% male / 41% female
- Females median age at death: 58.5
- Males median age at death: 61
- Overall median age of death: 60

LeDeR headlines – national LeDeR annual report for 2021

- Males died 22 years younger and females died 26 years younger than the general population
- An improvement of 1 year in median age of death between 2020 and 2021 – from 60 years in 2020 to 61 years in 2021
- Significant increase in deaths occurred during COVID-19 peaks in April 2020 and January 2021

Place of death table

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 2022-2023	25	8	*	0	0	9	48
% 2022-23			0		0		100%
Number of deaths 2021-2022	21	8	0	*	0	7	40
% 2021-22	53%	20%	0	10%	0	17%	100%

Statistical data – Month of death

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 2022-2023 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.

Add bar chart

Palliative care and end of life

End of life and was the death expected?

Of the deaths reviewed in 2022-2023 for which coded data was available about end-of-life care, **over half (%)** were expected and planned deaths.

Insert chart: Expected deaths (where recorded) add 2022 - 2023 data. Insert bar chart

% Expected deaths (where recorded on the review)

Add 2022-2023 Insert Pie chart

Statistical data – DNACPR

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

Add 2022-2023 data insert bar chart

Insert chart 14 2022-2023 data No. of people with a DNACPR order (where recorded) 2022-2023

Nsert % of people where DNACPR was noted on the completed initial review 2022-2023 pie chart

Display side to side

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

2022-2023 data

Insert pie chart

Local Action from Learning 2023 Priorities

Dysphagia

Identifying and managing deterioration in health (RESTORE2)

Diabetes, Weight Management and Obesity

Constipation

Management of Medical Conditions

LeDeR Policy in action – Sharing the learning

Use of legislation

Health Inequalities & People from Minority ethnic groups

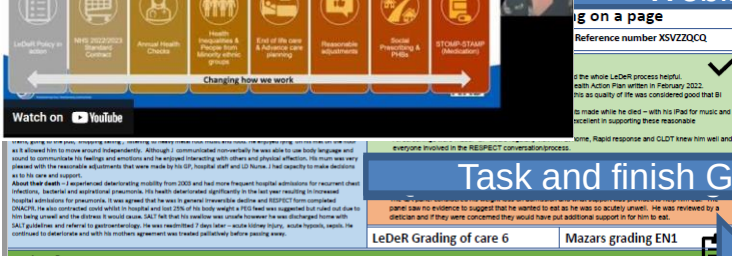
End of life care & Advance care planning (RESPECT)

Reasonable adjustments

Support for carers

Changing how we work

Supporting “learning into action” - Progress



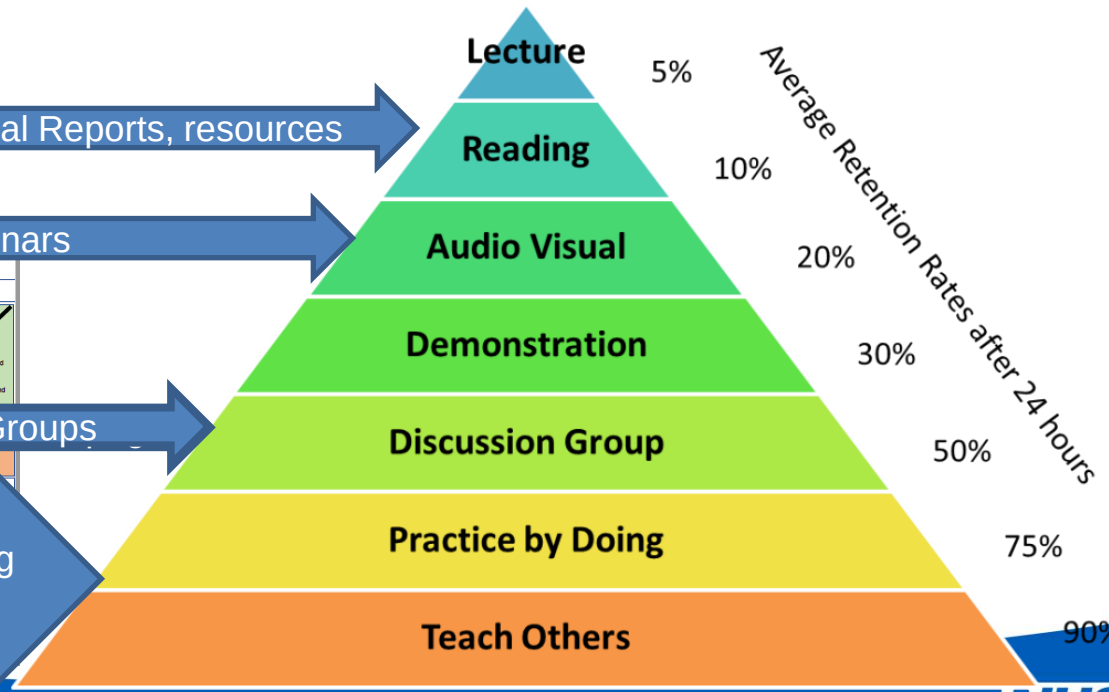
ers, Annual Reports, resources

Webinars

Task and finish Groups

Annual Conference – share learning and network

The Learning Pyramid



Source: National Training Laboratories, Bethel Maine

One Gloucestershire
Transforming Care, Transforming Communities

NHS

How we share what we are doing and learning from reviews?

LeDeR September 2022
Newsletter number: 7

Update on learning using a case study

LeDeR helps us learn about the lives and deaths of people with a Learning Disability or Autistic Adults. LeDeR wants to reduce the unfair differences in healthcare that can be prevented.

Ralf

Ralf liked steam trains and visits to the countryside. He had a great sense of humour, and his family were very important to him. Ralf had a Learning Disability, and he was autistic. Ralf used a communication book and was supported by Speech and Language Therapy. He had Cerebral Palsy and he was PEG (tube) fed, but enjoyed tasting some foods. Ralf was more likely to get chest infections because of his health conditions. He lived in a supported living setting and needed help from carers with lots of things. Ralf's family told the reviewer that he had led a long and happy life.

About his death

Ralf sadly died at Gloucester Hospital. An ambulance was called and the ambulance staff treated Ralf with oxygen for a chest infection. Ralf had a DNACPR, which means he did not want doctors to try and restart his heart if it stopped. At the hospital the hospital staff completed a ReSPECT form, and Ralf was put on end-of-life care. Ralf's family were with him when he died.

Learning

- Ralf's Speech and Language Therapist did not know about his chest infections. This meant there had been delays in looking at his eating and drinking. **People who are PEG fed, who are being given tasters and have regular chest infections, should be urgently seen by a Speech and Language Therapist.**
- When the Speech and Language Therapist visited, they could not find Ralf's communication book. **Communication books should always be with the person, so they can communicate.**

Good Practice

- Ralf's end of life wishes were written down and followed.
- The hospital staff communicated well with Ralf. They made reasonable adjustments for him.
- He had a specialist wheelchair and did not have any pressure sores.

We would like to thank the families who have kindly given us permission to share the stories of their loved ones to help improve services.

Resources and Action from Learning

From the case study of 'Ralf' above, the panel wanted to share information on training about when to refer for dysphagia assessment. Dysphagia is the medical word for when you have difficulties swallowing. The panel also wanted to tell care staff about some online Dysphagia training.

Access Dysphagia training via your LearnPro account, telephone 01452 324306 or email: Proudtolearn@gloucestershire.gov.uk

Link to a list of Dysphagia Videos on YouTube: https://bit.ly/3BzX7z4

- Annual report – Published September 2022
- Gloucestershire LeDeR Newsletters
- Easy read resources
- Presentations – GSAB, GHC, Carers PB, Health Action Group
- Conference (23rd March 2023)

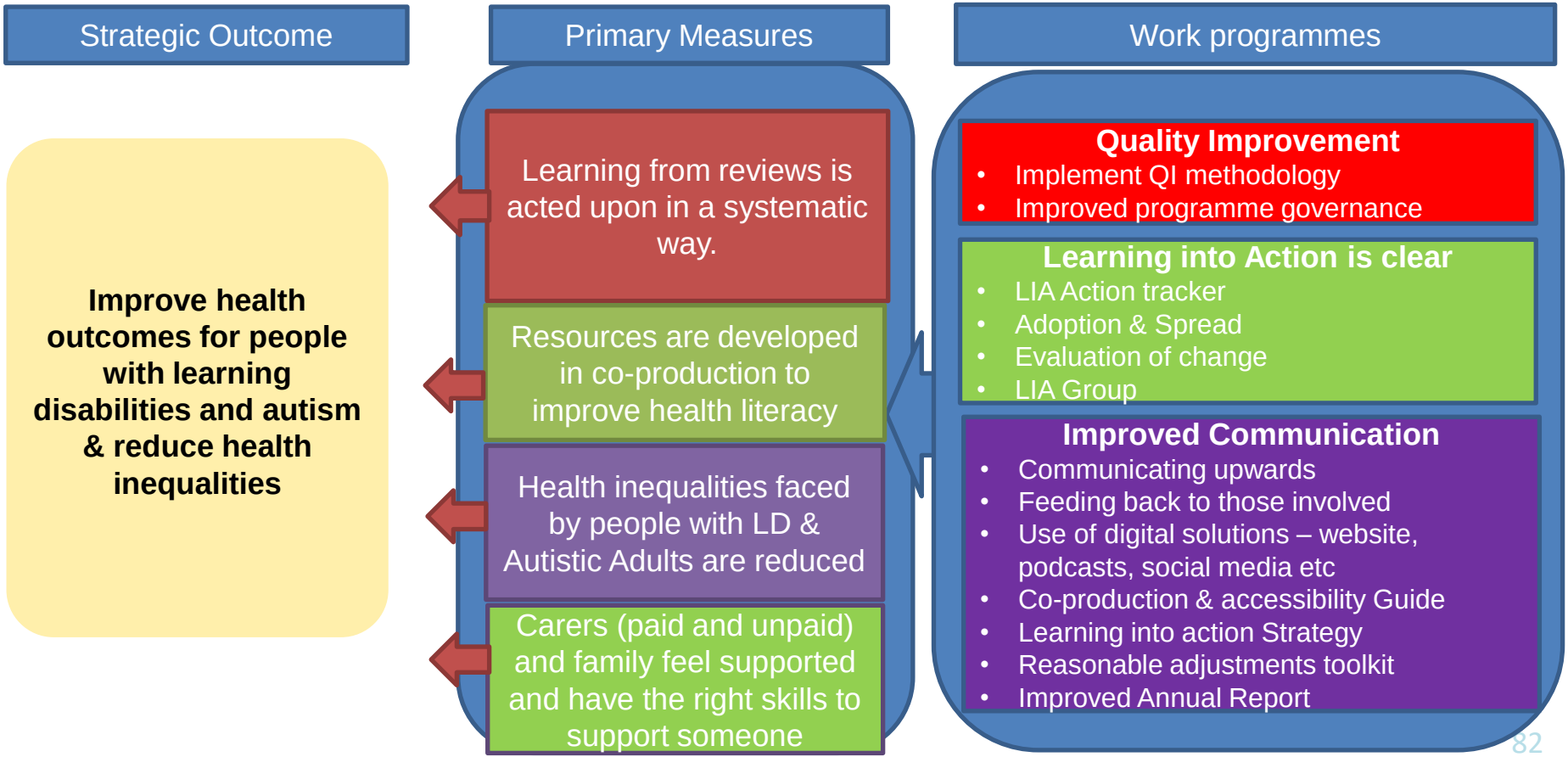
Access information on Gloucestershire LeDeR Webpage:
https://www.inclusiongloucestershire.co.uk/engagement/leder/

Conclusion

Glossary

AHC	Annual Health Check
BI	Best Interest
CCG	Clinical Commissioning Group
CIPOLD	Confidential Inquiry into the Premature deaths of people with Learning Disabilities
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
ReSTORE2	Recognise early Soft signs, Take Observations, Respond and Escalate
SLT	Speech and Language Therapy or Therapist
SUDEP	Sudden Unexpected Death in Epilepsy
TIA	Trans Ischemic Attack

LeDeR Programme Service Improvement Driver Diagram



Risks / issues and controls

Financial	Develop robust evidence base to inform business cases of benefits of undertaking the change to improved outcomes and potentially also savings opportunities.
Pace of change	Rationalise the number of LeDeR Learning into action tasks by prioritising themes at the beginning of each year in co-production with stakeholders.
Programme Capacity	Rationalise the number of LeDeR Learning into action tasks by prioritising themes at the beginning of each year in co-production with stakeholders.
Impact on the people we are supporting	Ensure all learning actions have SMART objectives so we are able to measure the impact of the change.
Spread and adoption of the change at scale	Group events, global briefs/newsletters, team meetings and individual supervisions and use of social media are all recognised methods for engaging with people when it comes to change management
Resistance to change from operational teams	Engagement of key transformational leaders across the system to help the programme embed and sustain change by embedding the learning into Transformational change programmes

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
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Author:		
	LeDeR Local Area Co-ordinator Email: althia.lyn@gloucestershire.gov.uk	Report Author
Sammy Roberts Emily Luckham Paul Tyrrell	Inclusion Gloucestershire Experts by experience and user led feedback	Report co-authors
Holly Beaman	Head of Integrated Commissioning - Learning and Physical Disabilities Services Gloucestershire Clinical Commissioning Group / Gloucestershire County Council Integrated Disabilities Commissioning Hub Email: holly.beaman@gloucestershire.gov.uk	Report Sponsor
Trudi Pigott	Deputy Director of Quality and Chair of the Gloucestershire LeDeR Governance and Steering group Gloucestershire Clinical Commissioning Group Email: Trudi.pigott@nhs.net	Report Sponsor

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