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Clinical Commissioning Group

# Gloucestershire Learning from Deaths of those with a Learning Disability **"LeDeR"**

# Annual Report

2018-2019

Joined up care and communities

**Gloucestershire LeDeR Mortality Review**

**Annual Report 2018-2019**

| | | |
|---|---|---|
| Responsible committee: | LeDeR Mortality Review Steering Group<br><br>Learning Disability and Autism Clinical Programme Group<br><br>Gloucestershire Clinical Commissioning Group Quality and Governance Committee |  |
| Target audience: | Internal report for those agencies involved in the programme.<br>LeDeR Mortality Review Steering Group Members<br>LeDeR Mortality Review Peer Support Group<br>Gloucestershire Clinical Commissioning Group - Quality<br>Learning Disabilities Lead Commissioner<br>National LeDeR Programme<br>NHS England | |
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| Author: | | |
|---|---|---|
| Cheryl Hampson | Outcome Manager Learning Disabilities Health<br>Gloucestershire Clinical Commissioning Group / Gloucestershire County Council<br>Joint Commissioning Learning Disabilities Services<br>Telephone Landline: 01452 425083<br>Email: cheryl.hampson@gloucestershire.gov.uk or cherylhampson@nhs.net | Report Co-Author |
| Helen Chrystal | Interim Secondary LeDeR Local Area Contact Gloucestershire<br>Email: helen.chrystal@nhs.net | Report Co-Author |
| Holly Beaman | Lead Joint Commissioner – Learning and Physical Disabilities Services<br>Gloucestershire Clinical Commissioning Group / Gloucestershire County Council<br>Joint Commissioning Learning Disabilities Services<br>Telephone Landline: 01452 328495<br>Email: holly.beaman@gloucestershire.gov.uk | Report Sponsor |
| Marion Andrews-Evans /<br>Julie Symonds | Director of Nursing / Deputy Director of Nursing<br>Gloucestershire Clinical Commissioning Group<br>Telephone Landline: 0300 421 1691<br>Email: marion.andrews-evans@nhs.net | Report Sponsor |



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| 30.04.2019 | 0.1 | First draft prepared for consideration by LeDeR Steering Group |
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| 17.05.2019 | 0.4 | Amendments following feedback from Learning Disability & Autism Clinical Programme Group |
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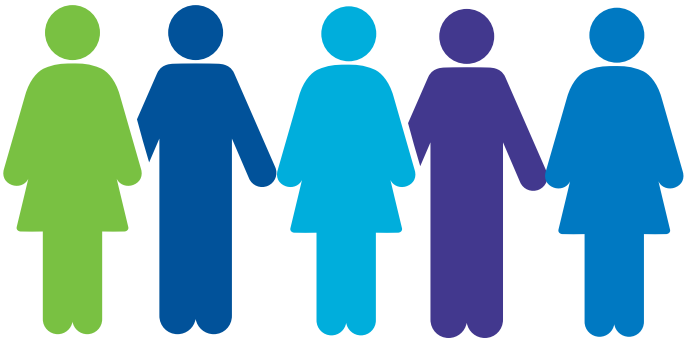
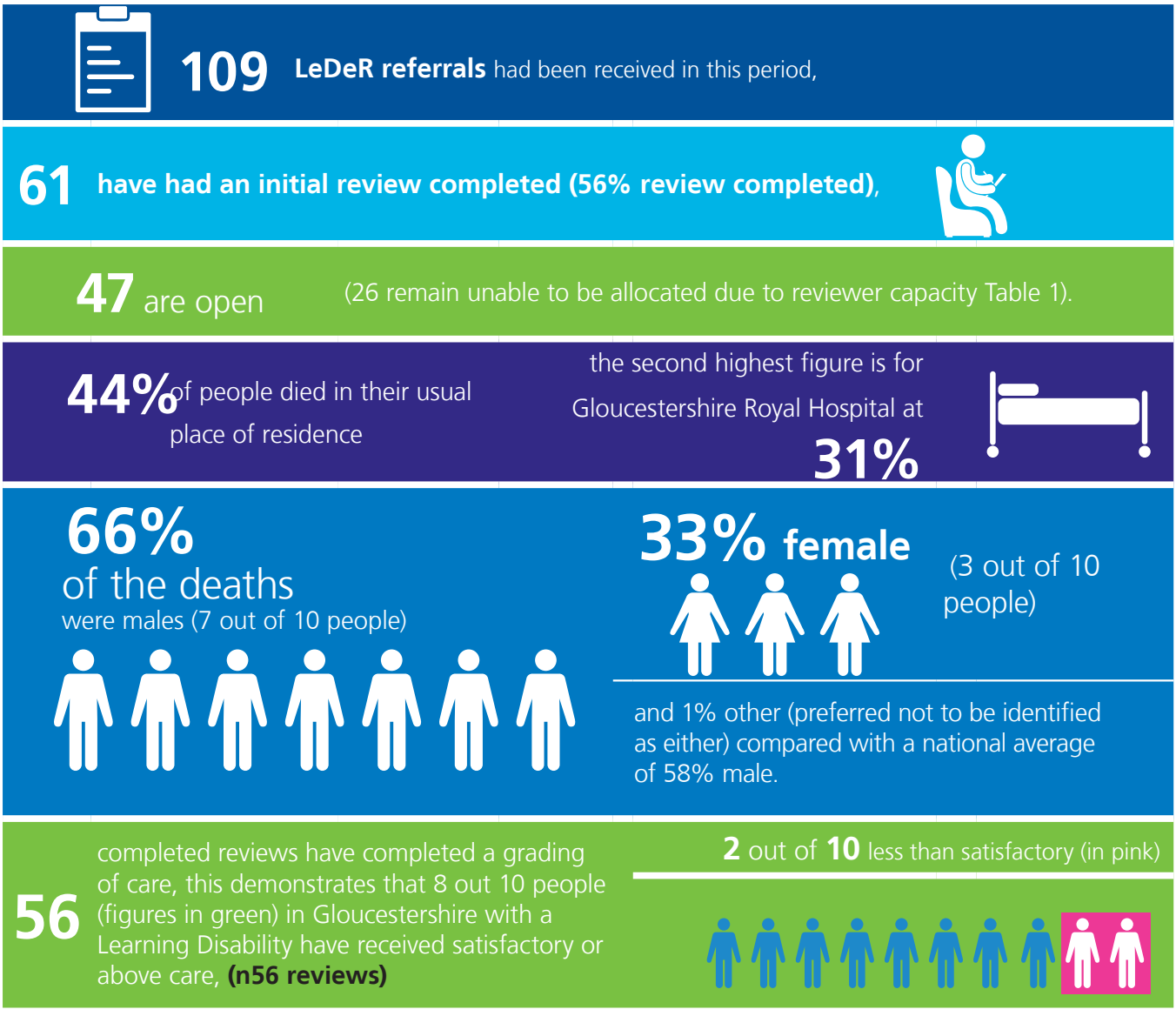


# 1. Executive Summary

The LeDeR Programme (Learning from Deaths review of people with a learning disability) is being led by the University of Bristol and follows on from the Confidential Enquiry into Premature Deaths of people with LD (CIPOLD)[i] the findings of which demonstrated that on average someone with a LD lives 20 years less than someone without. Further information about the LeDeR Programme is available on the University of Bristol Website[ii].

The issues and causes of death identified within the national LeDeR annual report (published May 2019), alongside the findings from locally completed local reviews reflect the many challenges that people with a learning disability face. There is much work already underway nationally and locally to improve access to healthcare and to address inequality for people with a learning disability. Through the development of new tools to support practitioners, and new resources to develop skills and awareness, we are creating a culture within health and social care of improved access, and vigilant and proactive support for people with a learning disability. But there is clearly more to do.

This report is the first 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 2019 Gloucestershire. The purpose of the report is to share the finding and the learning with anyone interested in care given to those with a learning disability.

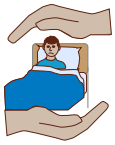



i http://www.bris.ac.uk/cipold/
ii http://www.bristol.ac.uk/sps/leder/

**Table 1 – Status of reviews by year:**

| | CLOSED | OPEN | Grand Total | % completed |
|---|---|---|---|---|
| 2017 (January to December) | 41 | 5 | 46 | 89% |
| 2018 (January to December) | 18 | 31 | 49 | 37% |
| 2019 (January to March) | 2 | 12 | 14 | 17% |
| Grand Total | 61 | 47 | 109 | 56% |

**Learning Themes:**

| | |
|---|---|
| **health checks**  | Communications and support to access primary care Learning Disability Annual Health Checks |
| **healthy and well**  | Reasonable adjustments made to access to mainstream healthy lifestyles preventative services e.g. smoking cessation, weight management and eating well |
| **staying and leaving hospital**   | Suitable reasonable adjustments being put in place in mainstream health services is inconsistent particularly around meeting communication needs. |
| **mental capacity**  | Utilisation and documentation of the Mental Capacity Act by mainstream health services is inconsistent |
| **palliative care**  | Treatment escalation practices particularly in relation to end of life protocols for those individuals who are considered to be frail. |
| **care at home**  | Spotting the signs of the deteriorating patient for those who have a learning disability can be difficult to monitor if those who are caring for them are not aware of the individuals normal baseline reading e.g. temperature, blood pressure, respiratory rates and other soft signs. |

# 2. About the LeDeR Programme

National

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

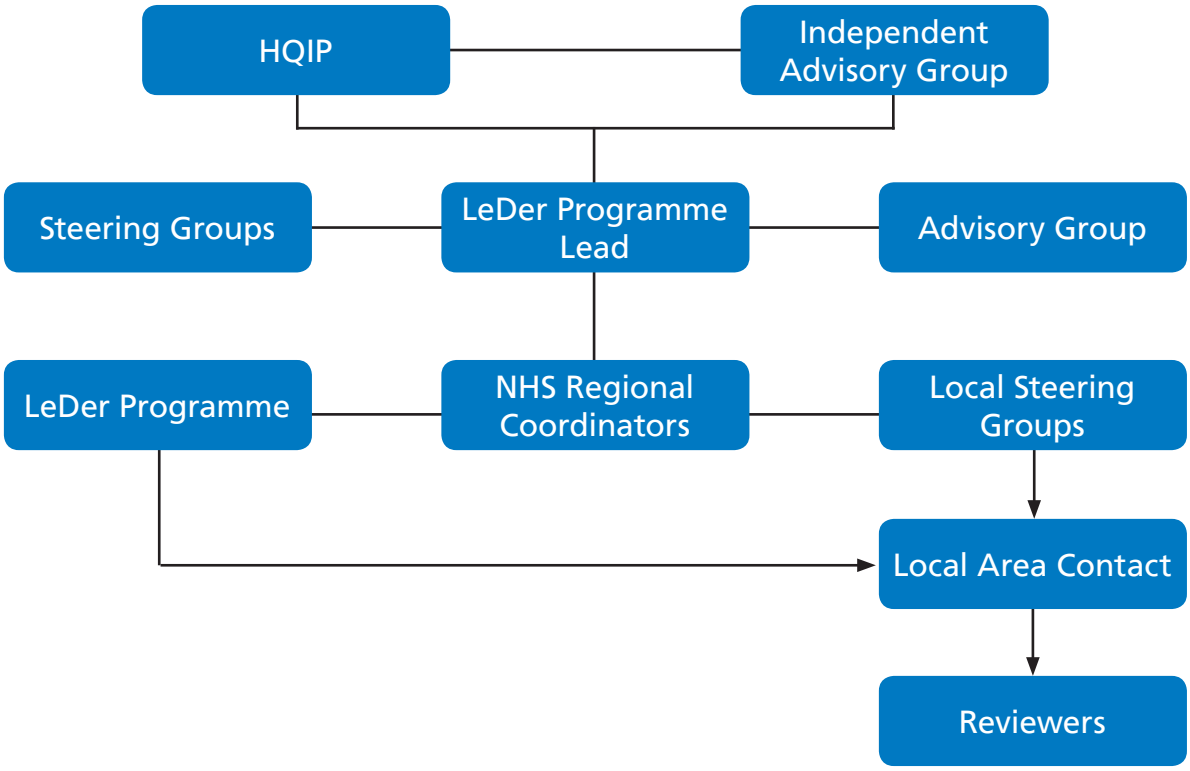
To help health and social care systems, professionals and policy makers to:

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

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

### National Programme Structure

**Figure 1 – National Programme Structure**




### Definition of a Learning Disability in use by the programme

The LeDeR Programme uses the definition included in the 'Valuing People', the 2001 White Paper[iii] on the health and social care of people with learning disabilities which states:

'Learning disability includes the presence of:

- significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development

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

## 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<br>**care at home**<br>  | 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:<br>**quality care**<br>  | 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:<br>**my care**<br>  | 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. |

## Data sharing and confidentiality


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

The national LeDeR team collect the minimal amount of personal identifying data possible, and this will be pseudo-anonymised as soon as possible. Additionally, all information will be anonymised in any presentation, publication or report, and no opportunity will be provided for readers to infer identities.

In order to learn from the deaths of people with learning disabilities so that service improvements can be made, we need to ensure that timely, necessary and proportionate mortality reviews are undertaken, involving the full range of agencies that support people with learning disabilities. Each of these organisations will hold a piece of the jigsaw that together creates a full picture of the circumstances leading to the death of the individual. Information viewed alone or in silos is unlikely to give the full picture, identify where further learning could take place, or contribute to cross-agency service improvement initiatives.


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

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

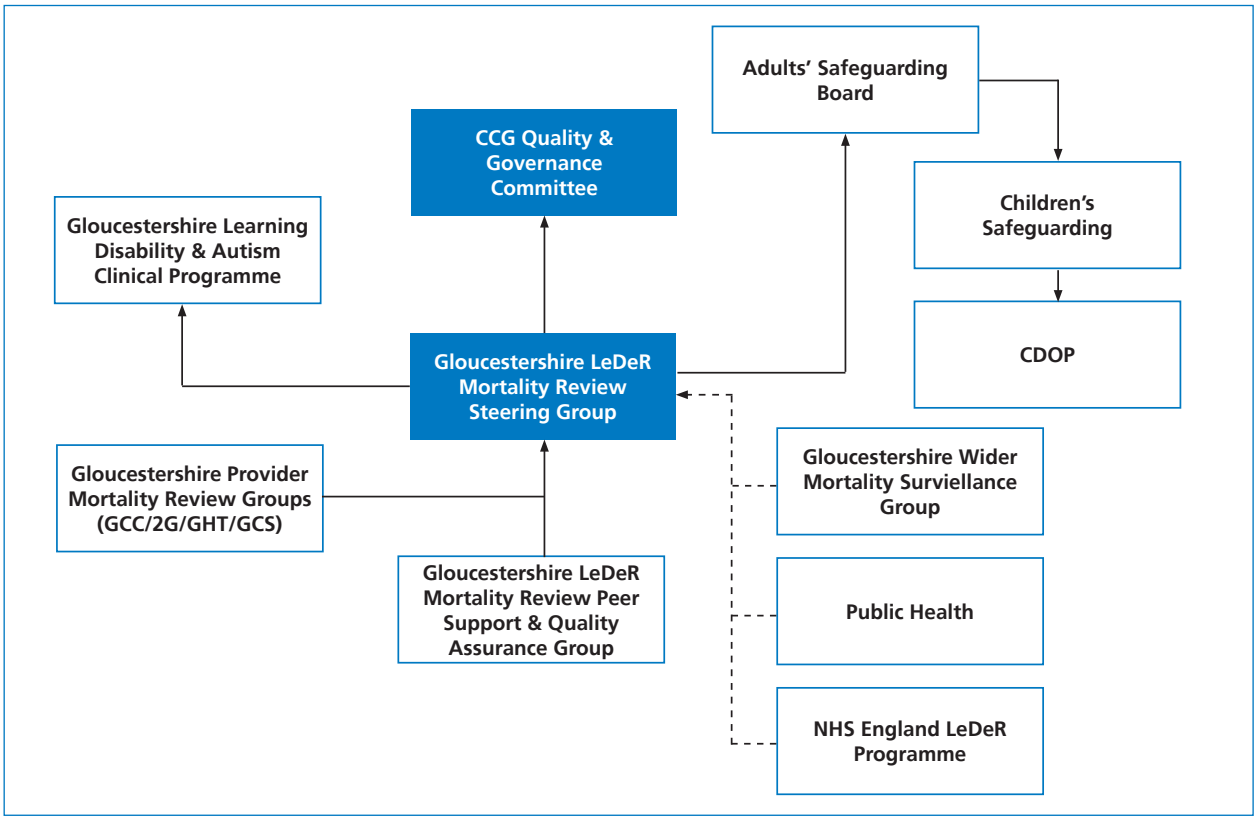
The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the legislation, and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved. The key purpose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

## Local LeDeR steering group

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

**Figure 2 – Local Governance Arrangements for LeDeR**

**Gloucestershire LeDer Mortality Review Steering Group - Governance**



## So how does the process work?

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

There is a national promotional campaign to increase notifications an example of a poster is shown in Figure 5 – National Poster >>

All deaths reported to the LeDeR Programme will have an initial review to establish if there are any specific concerns about the death, and if any further learning could be gained from a multiagency review[v] of the the death that would contribute to improving services and practice.
It is the job of the local reviewer to conduct the initial review of each death and where indicated a full multiagency review will be held. All information will be accessed, edited and completed via the web based portal/ LeDeR Review System.


The LeDeR Process is described in Figure 3 – LeDeR process. However, the initial review includes:

- Checking and completing the information received at the notification stage[vi].
- Contacting a family member or another person who knew the deceased person well and discussing with them the circumstances leading up to the death.
- Scrutinising at least one set of relevant case notes and extracting core information about the circumstances leading up the persons death: for example summary records from GP, social care, Community Learning Disability Team (CLDT), or hospital records.
- Developing a pen portrait of the person who has died and a timeline of the circumstances leading to their death.
- Making a recommendation to the Local Area Contact whether a multiagency review is required.
- Completing the online documentation and an action plan which will be reviewed by the Local Area Contact[vii] and Steering Group[viii] and reviewed as part of the national LeDeR process.

iv http://www.bristol.ac.uk/sps/leder/notify-a-death/?_ga=2.4265911.589001362.1531124673-1987643447.1528363357

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

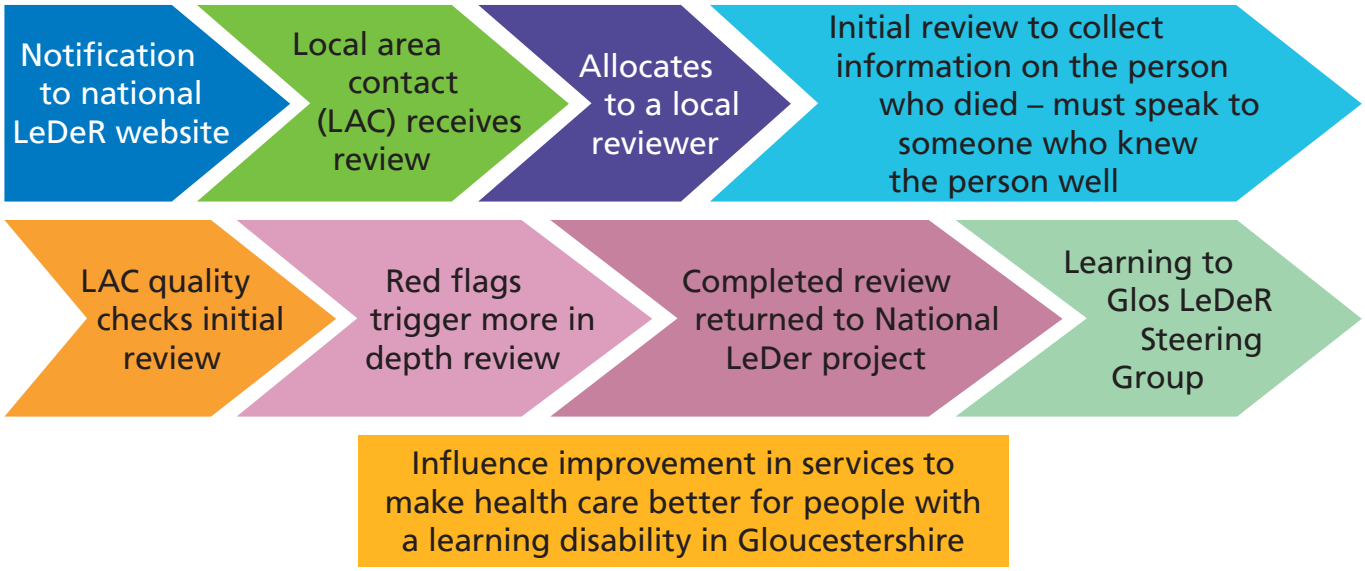
vi http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/notification-of-a-death/

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

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

# LeDer Process in Gloucestershire

**Figure 3 – LeDeR process**




### Governance connection with Gloucestershire Safeguarding Adults Boards (GSAB)

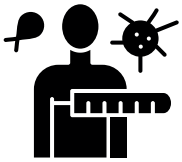

There are obvious and strong linkages between detecting and reducing premature mortality for individuals with a learning disability and safeguarding – particularly in relation to the preventative element of the role of GSAB. The Care Act clearly lays out responsibilities in relation to **safeguarding adults** as not only about abuse or neglect but also **the risk of abuse or neglect.** The emphasis is on behaviours rather than the consequence of the behaviours.

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

Such learning may usefully inform where such boundaries (or tipping points) are, and should be, **between poor quality, neglect/abuse and organisational neglect/abuse.**

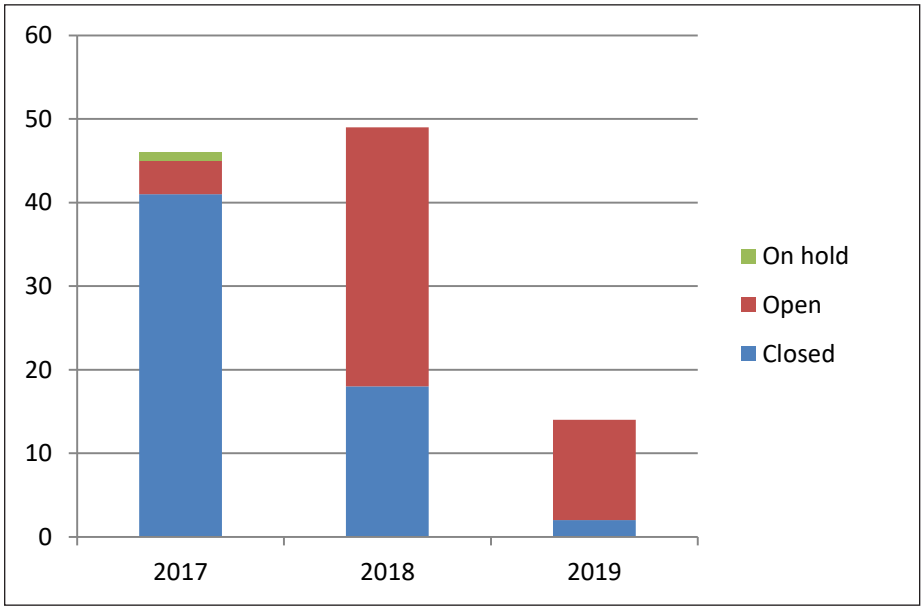
Whilst the LeDeR Steering group is not a direct subgroup of the GSAB there is a close working relationship with key personnel involved in GSAB. The independent chair of GSAB is a member of the LeDeR Steering group and is also a local LeDeR Reviewer.

**LeDeR Learning into Action Themes explained**

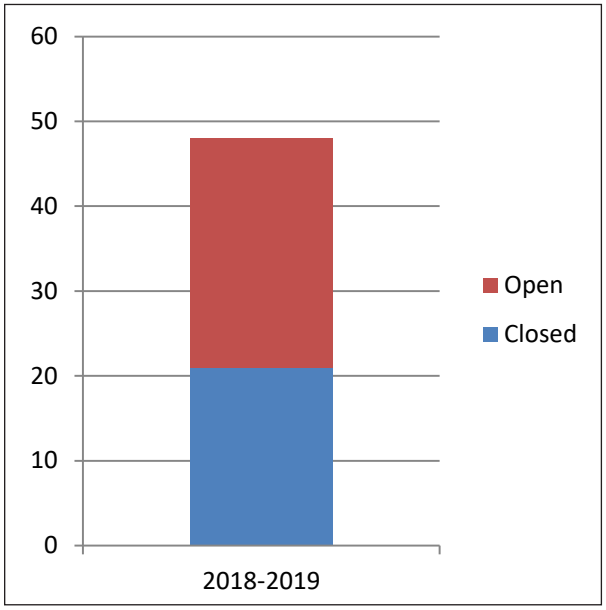
| | |
|---|---|
| **Respiratory**  | Causes of death is in relation to the breathing and lungs e.g. aspiration/ broncho pneumonia and respiratory track infections. |
| **Circulatory**  | Cause of death is in relation to the heart and blood e.g. heart failure, sepsis, Pulmonary Embolism, Coronary Artery 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, liver failure and fractured neck. |
| **Unknown**  | Reviews have not yet been completed. |

# 3. About the deaths in Gloucestershire

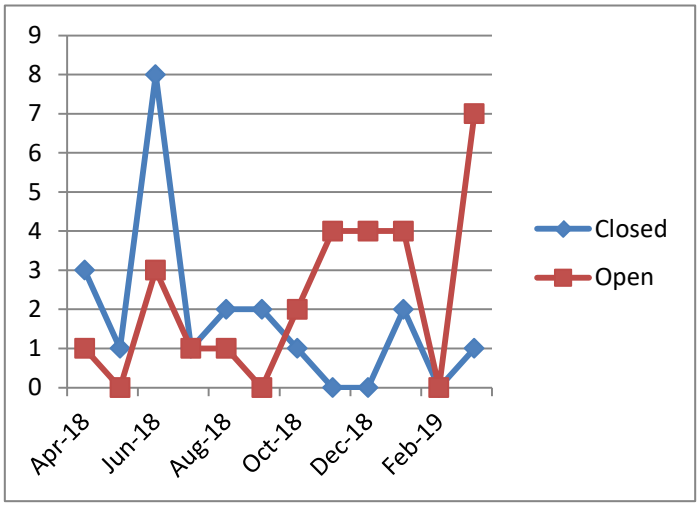
### Chart 1 – Total Deaths Notified in Gloucestershire January 2017 to 31st March 2019 (by calendar years)




### Chart 2 - Total deaths notified for financial year 2018-2019



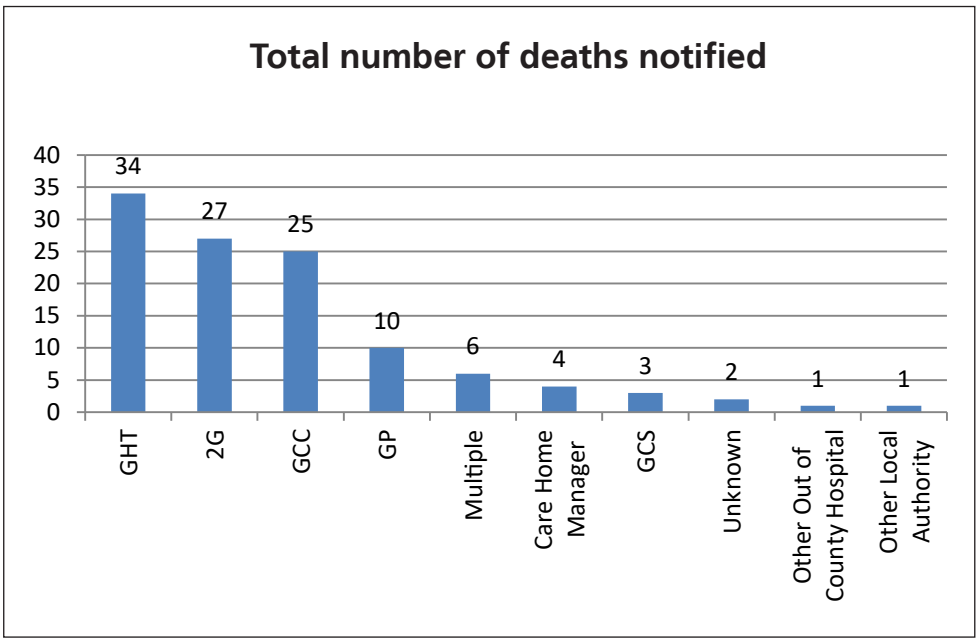

### Chart 3 - 2018-2019 status of reviews by month




Since the programme began there have been 109 deaths reported to LeDeR covering the period January 2017 to end March 2019. Of which 61 of these deaths have had an initial review undertaken (Chart 1 - Deaths Notified in Gloucestershire). For the financial year 1st April 2018- 31st March 2019 there were 49 notifications (Chart 2 - Total deaths notified for financial year 2018-2019) and 21 have had an initial review completed (44%).

Gloucestershire Hospitals NHS Foundation Trust (which are the County's secondary physical care hospital trust) were the biggest reporters of deaths in this period (34 deaths), with [2]Gether NHS Foundation Trust (the County's secondary mental health and learning disabilities trust) were the second biggest reporters of deaths (25 deaths) Chart 4 - Reports of deaths illustrates the breakdown of who reported the 109 deaths. For the financial year 2018-2019 (Chart 5 - Total number of deaths reports during financial year 2018-2019) Gloucestershire County Council were the biggest reporters of deaths (n14

### Chart 4 - Reports of deaths




| KEY: | |
|---|---|
| GHT | Gloucestershire Hospitals NHS Foundation Trust |
| 2G | 2Gether NHS Foundation Trust |
| GCC | Gloucestershire County Council |
| GCS | Gloucestershire Care Services NHS Trust |

### Chart 5 - Total number of deaths reports during financial year 2018-2019

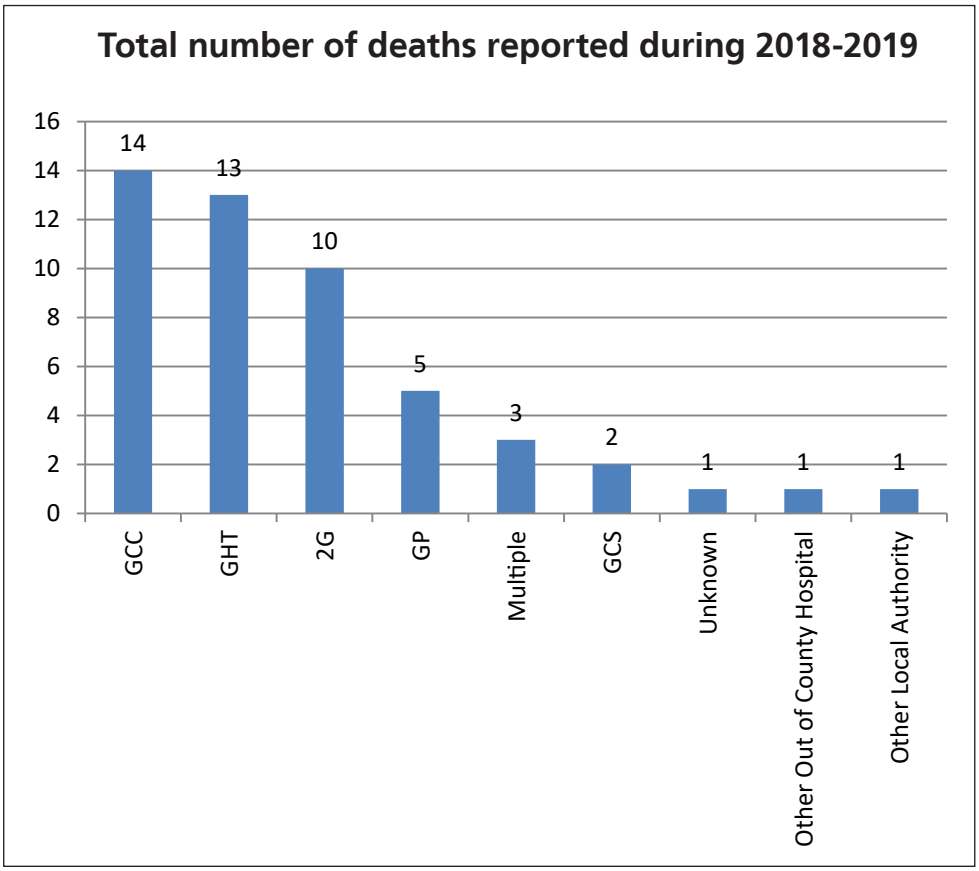
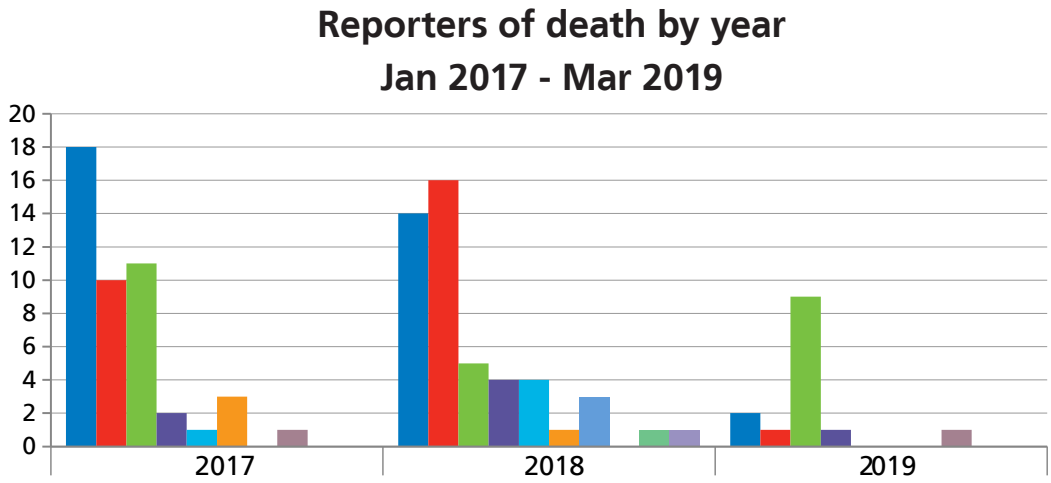


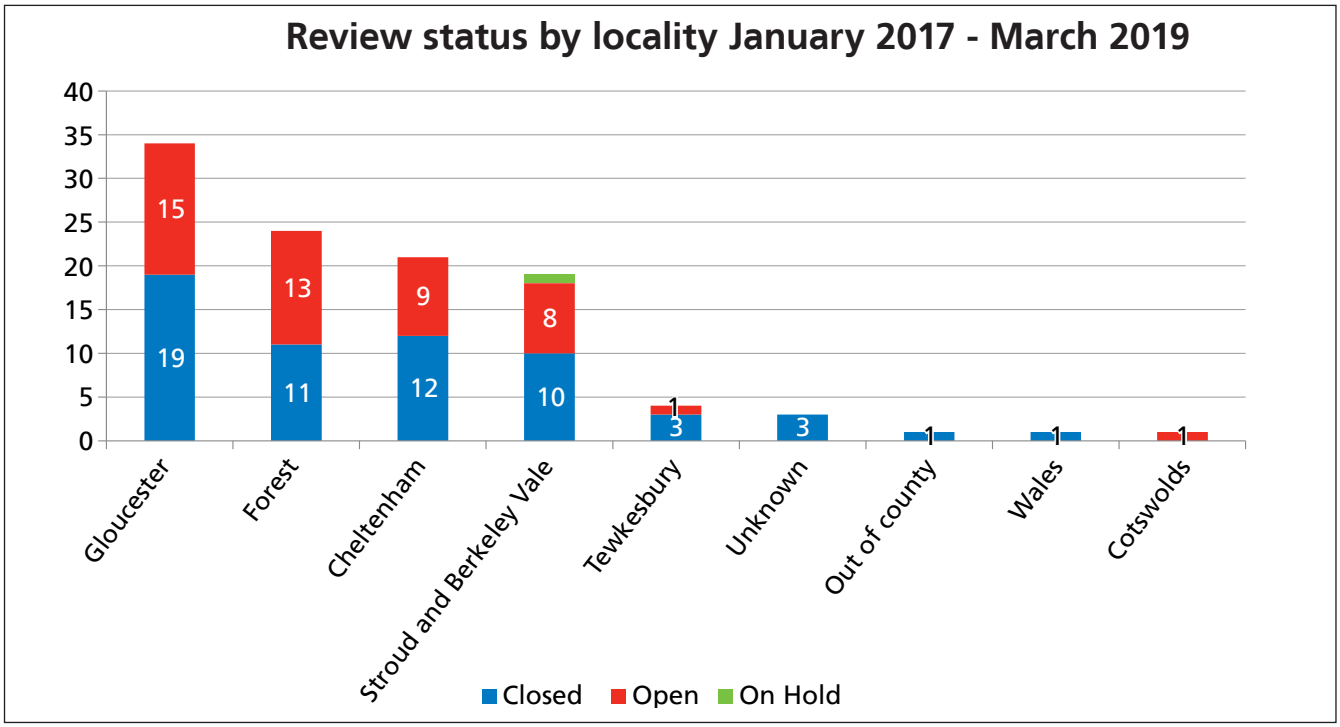
**Chart 6 - Reporters of deaths by calendar year (January to December) Note that 2019 is only January to March**



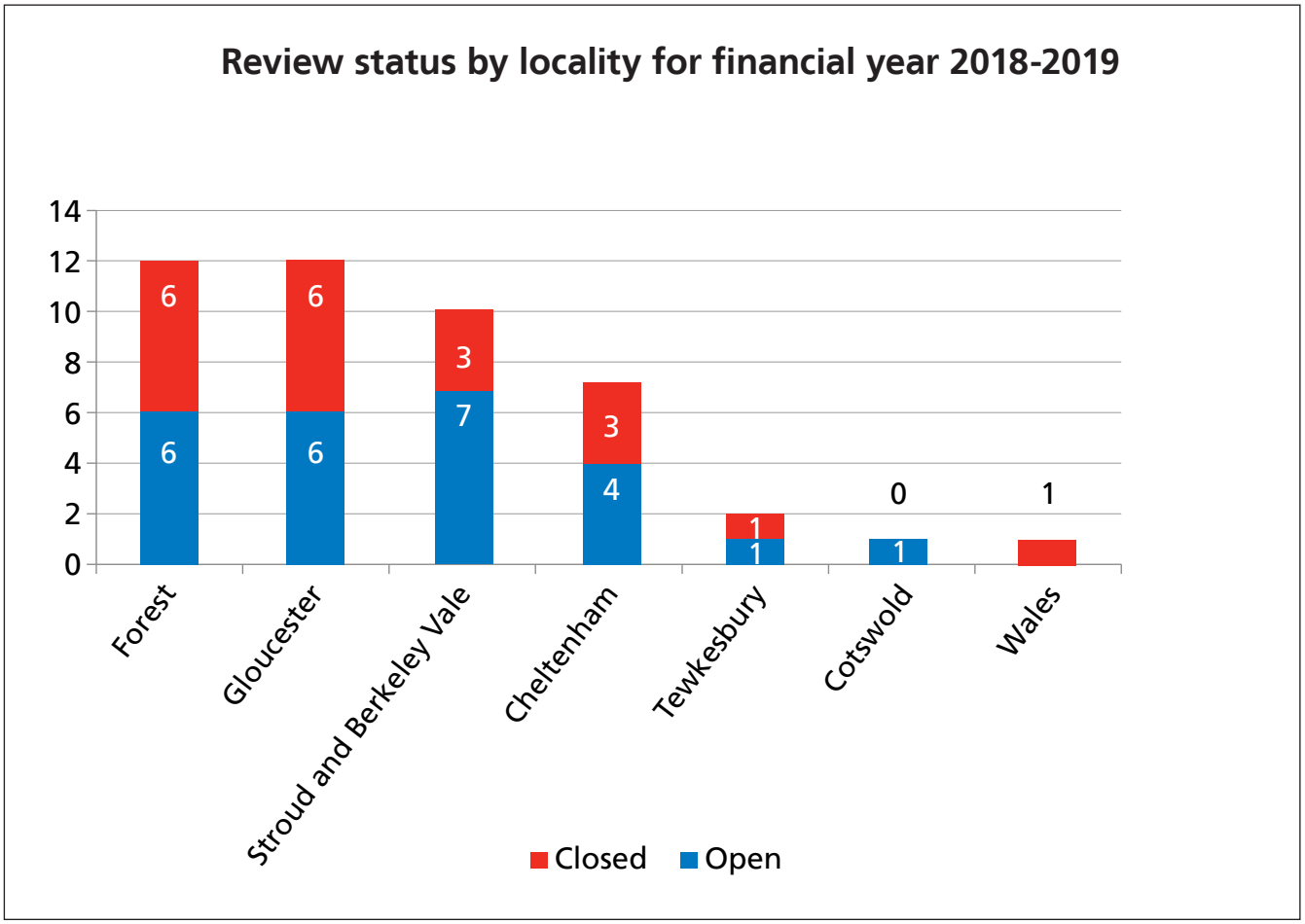

| | 2017 | 2018 | 2019 |
|---|---|---|---|
| GHT | 18 | 14 | 2 |
| 2G | 10 | 16 | 1 |
| GCC | 11 | 5 | 9 |
| GP | 2 | 4 | 1 |
| Multiple | 1 | 4 | |
| Care Home Manager | 3 | 1 | |
| GCS | | 3 | |
| Unknown | 1 | | 1 |
| Other out of county hospital | | 1 | |
| Other local authority | | 1 | |

Chart 7 **-** covers the main localities where deaths have occurred and illustrate the main LeDeR theme of the cause of death. The biggest cause of death in Gloucester is respiratory diseases compared to Cheltenham which is circulatory and unknown. It is fair to say that each locality has differing health needs for the population it serves.

**Chart 7 - Review status by locality (total for the programme)**

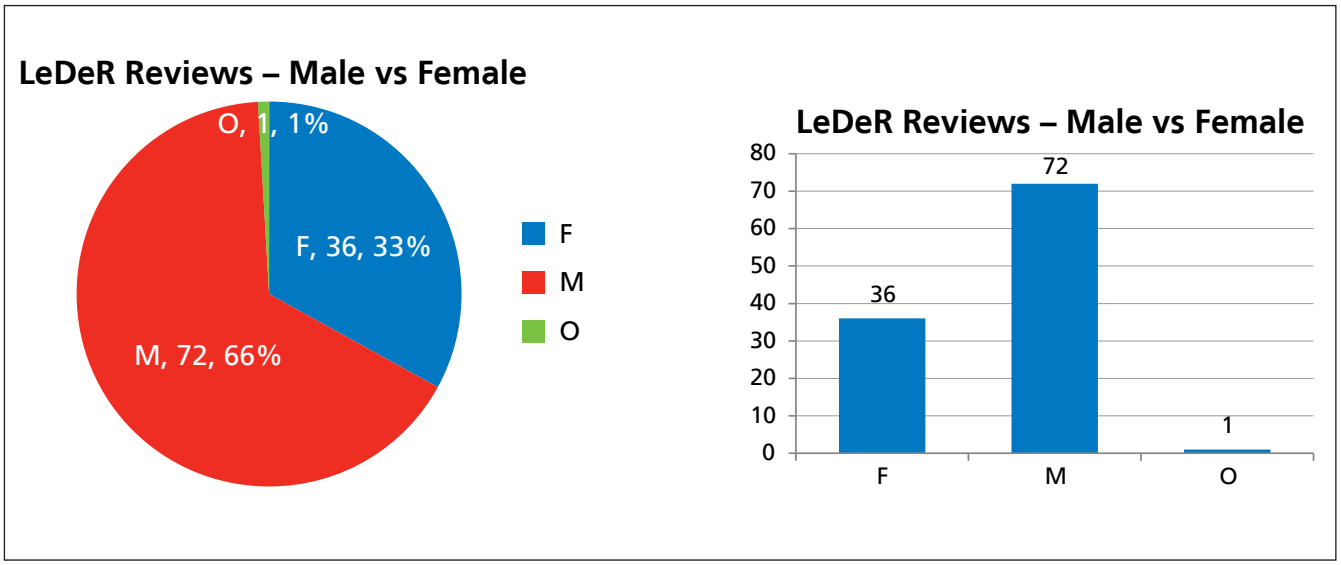


## Chart 8 - Review status by locality for financial year 2018-2019



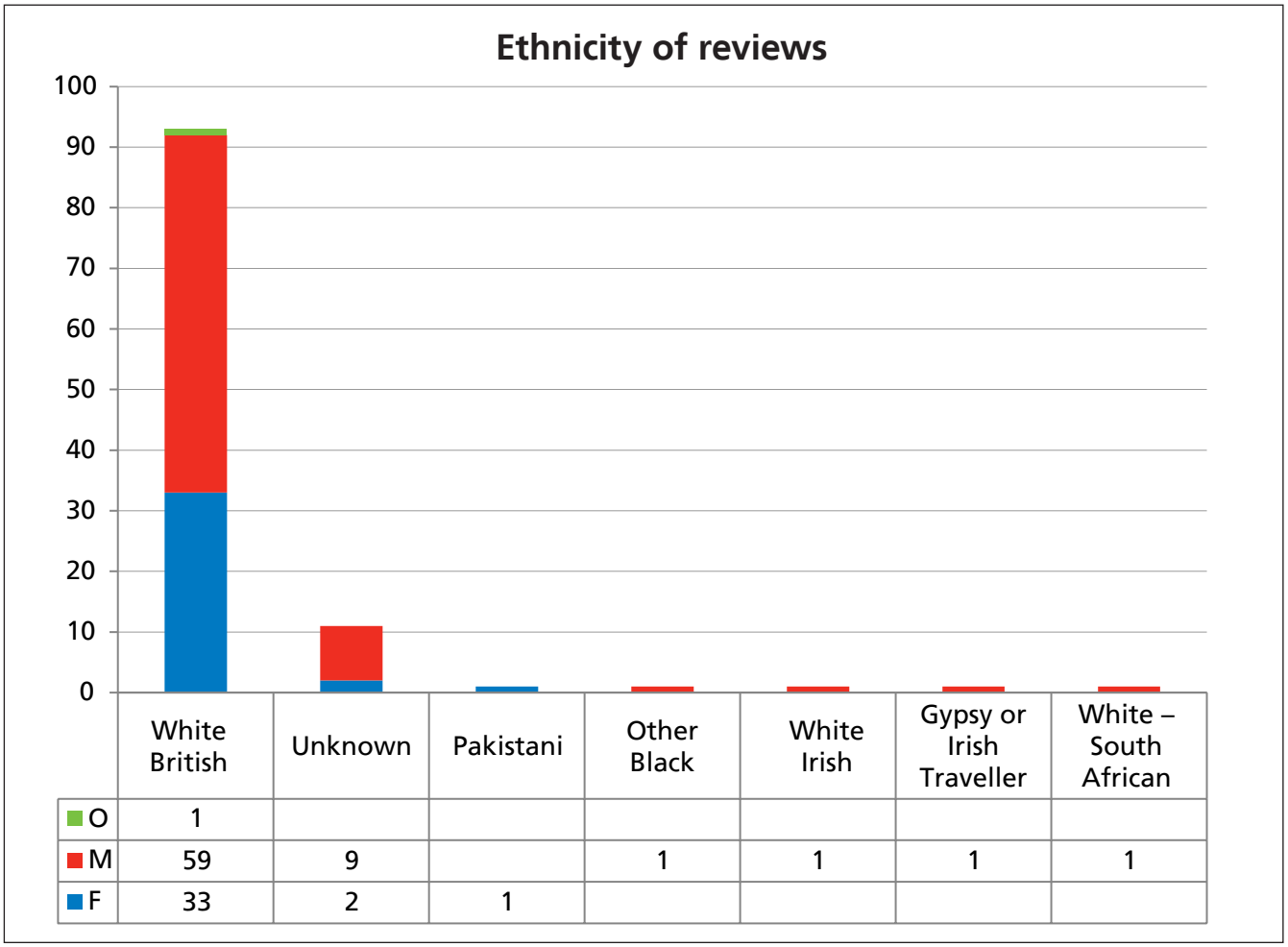

Gender - Chart 9 - Gender of those who have died demonstrates that 66% of deaths reported were males – this is compared to 57% in the South West and 55% in England.

## Chart 9 - Gender of those who have died




Ethnicity - 85% of reviews completed came from a white British background (where unknown reviews have yet to be complete), of the completed reviews less that 2% were from a BME background.

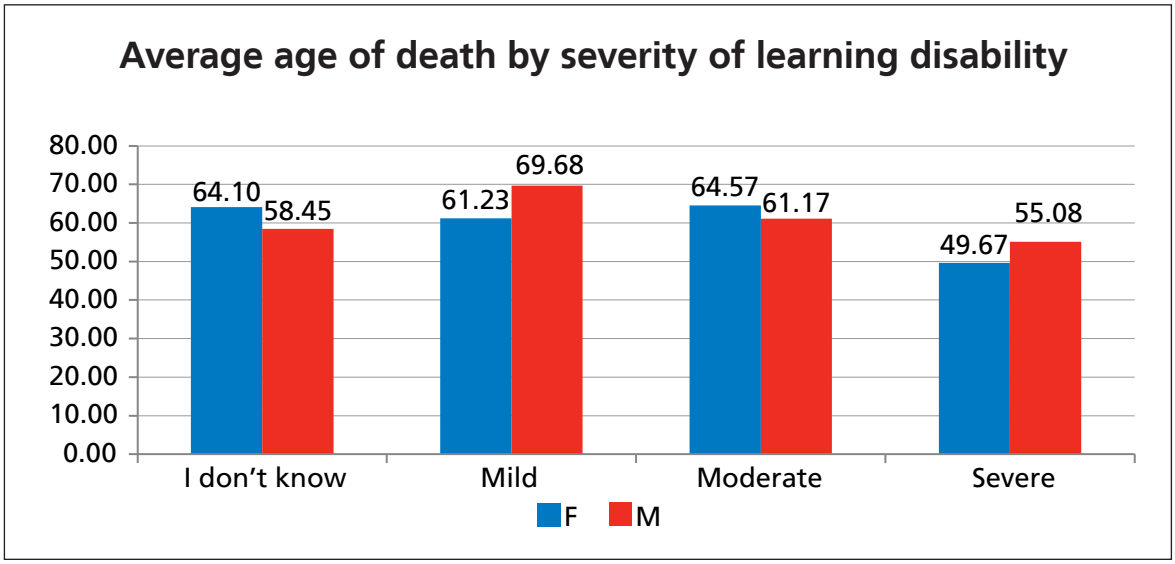
## Chart 10 - Ethnicity of reviews



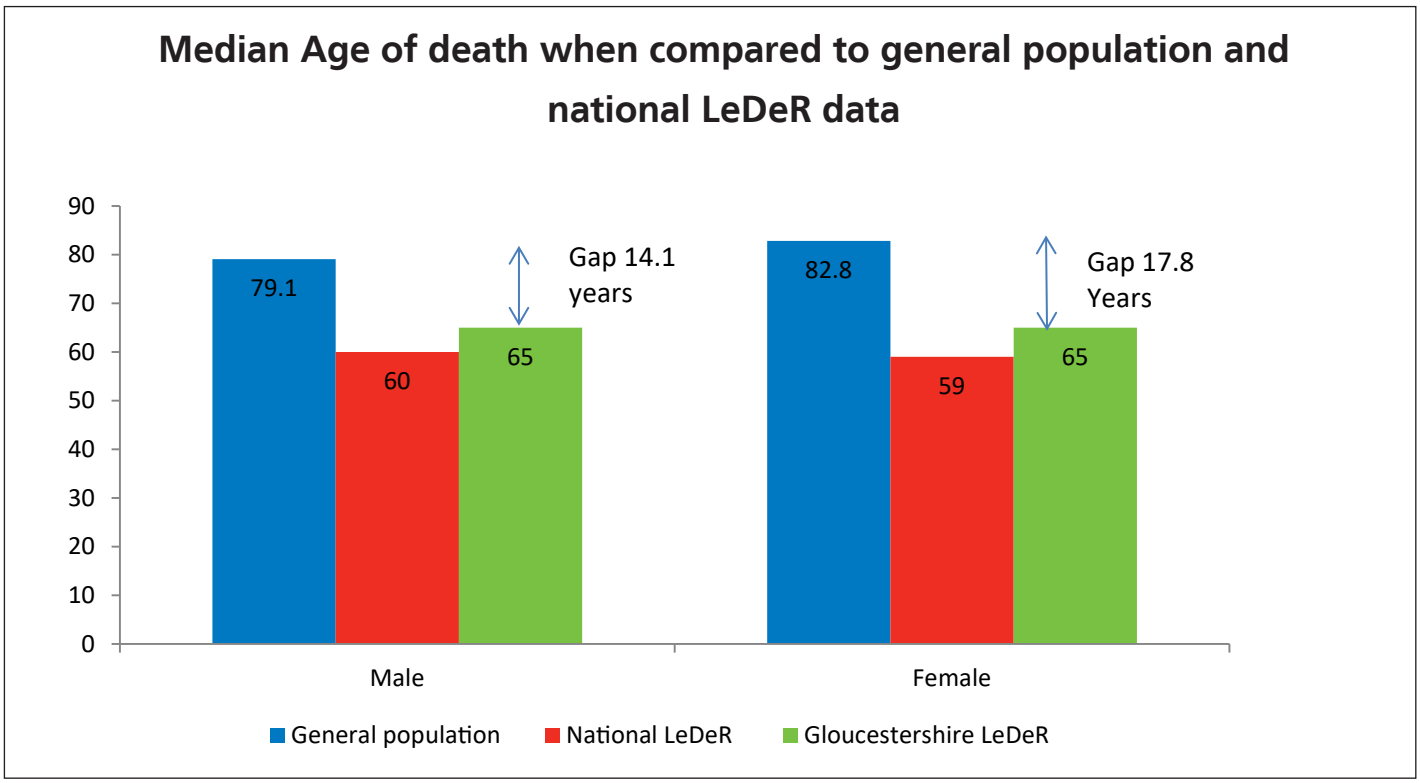

| | White British | Unknown | Pakistani | Other Black | White Irish | Gypsy or Irish Traveller | White – South African |
|---|---|---|---|---|---|---|---|
| O | 1 | | | | | | |
| M | 59 | 9 | | 1 | 1 | 1 | 1 |
| F | 33 | 2 | 1 | | | | |

Severity of learning disabilities – the median age of death across all severities is 65 years of age in Gloucestershire. However, as the severity of the learning disability rises and the possibility of other co-morbidities increase the average age of death reduces. The median average age of death in Gloucestershire for someone with a learning disability is 65 (for both male and females), this is a health inequalities gap when compared to the general population of 14.1 years for men and 17.8 years for women. However, the gap in Gloucestershire is smaller than the national reported LeDeR age of death which was 60 for males and 59 for females (see Chart 12 - Median age of death)

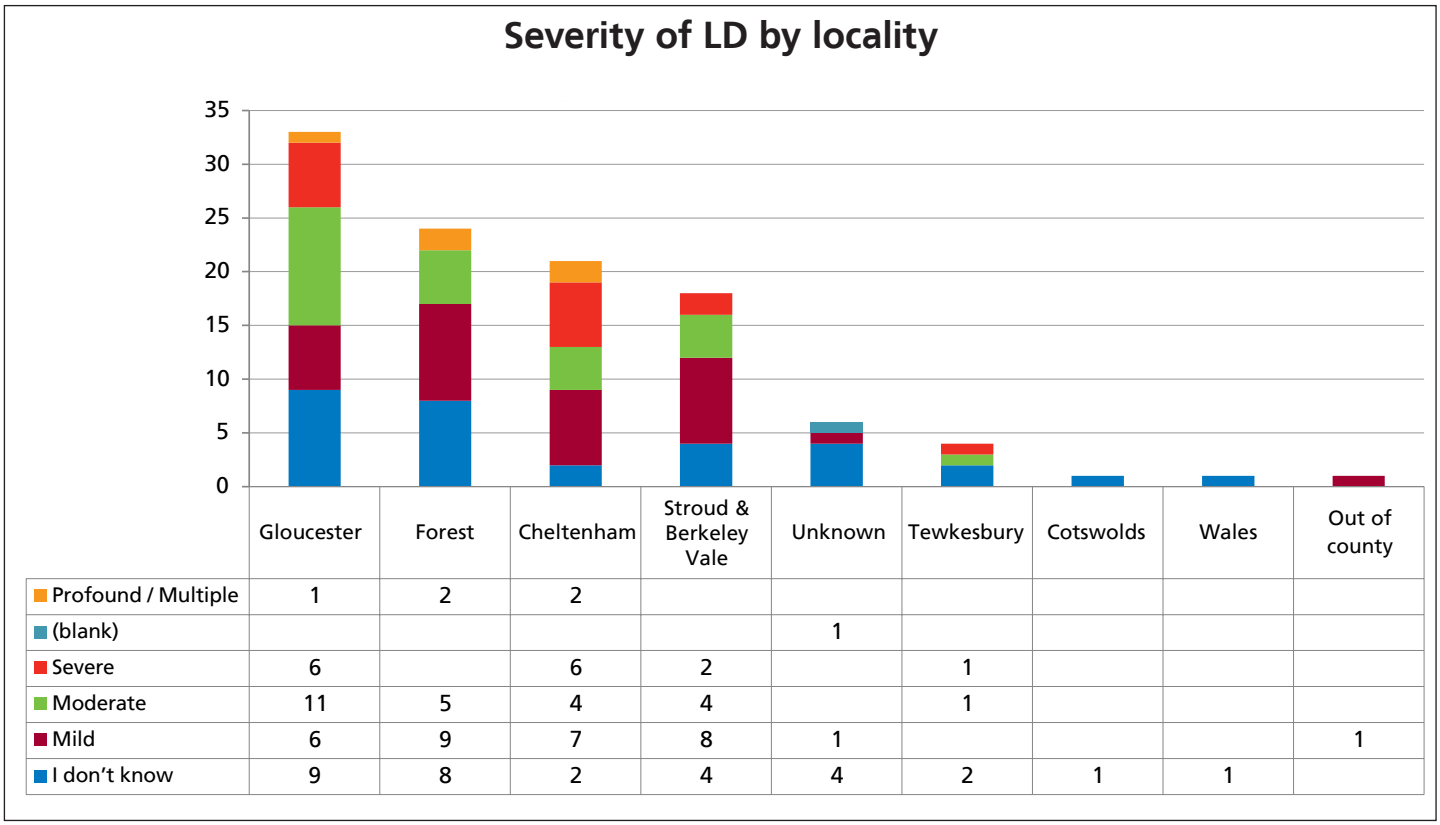
## Chart 11 - Average age of death by severity of learning disability



## Chart 12 - Median age of death




## Chart 13 - Severity of Learning Disability by Locality

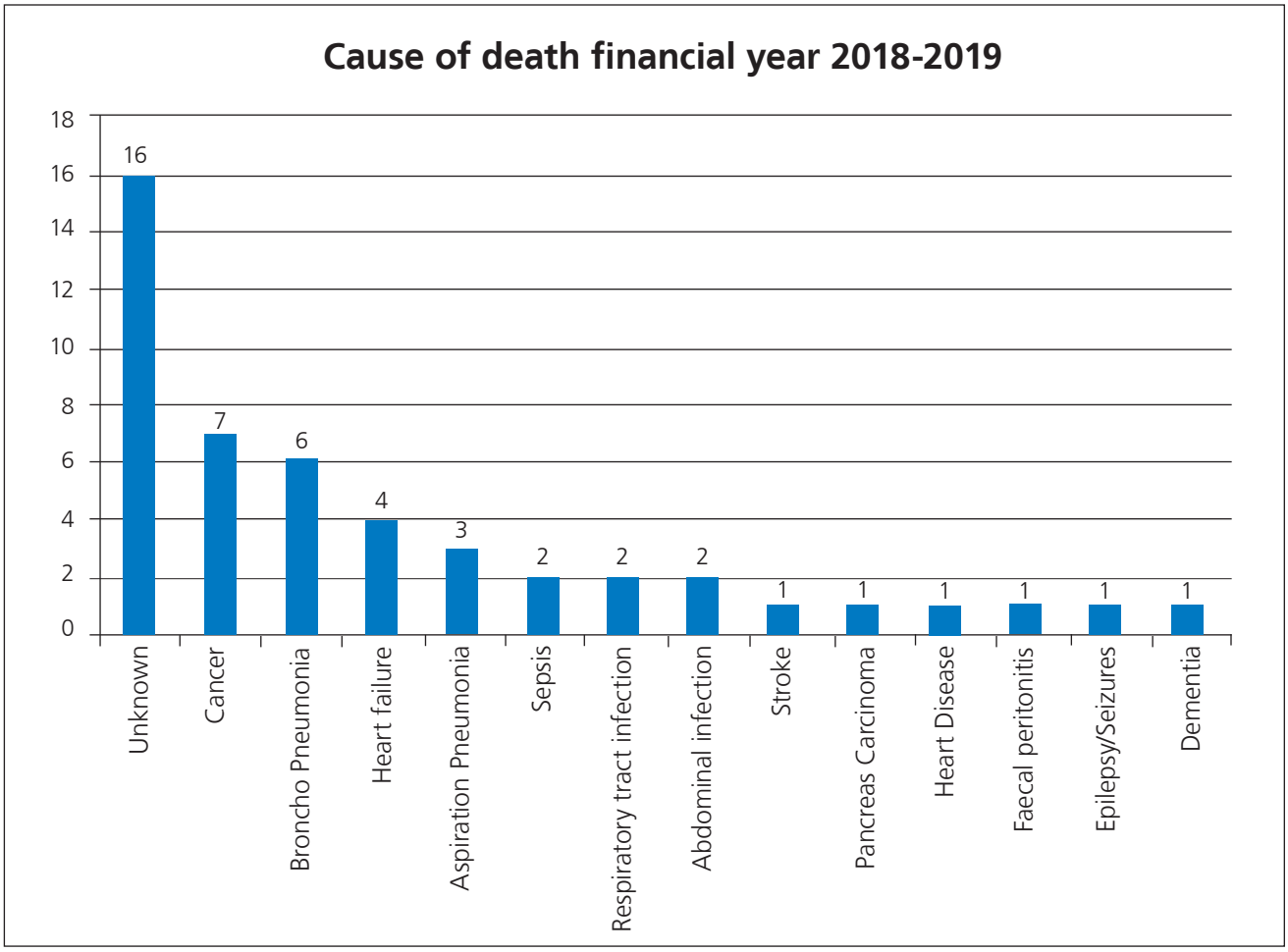



| | Gloucester | Forest | Cheltenham | Stroud & Berkeley Vale | Unknown | Tewkesbury | Cotswolds | Wales | Out of county |
|---|---|---|---|---|---|---|---|---|---|
| Profound / Multiple | 1 | 2 | 2 | | | | | | |
| (blank) | | | | | 1 | | | | |
| Severe | 6 | | 6 | 2 | | 1 | | | |
| Moderate | 11 | 5 | 4 | 4 | | 1 | | | |
| Mild | 6 | 9 | 7 | 8 | 1 | | | | 1 |
| I don't know | 9 | 8 | 2 | 4 | 4 | 2 | 1 | 1 | |

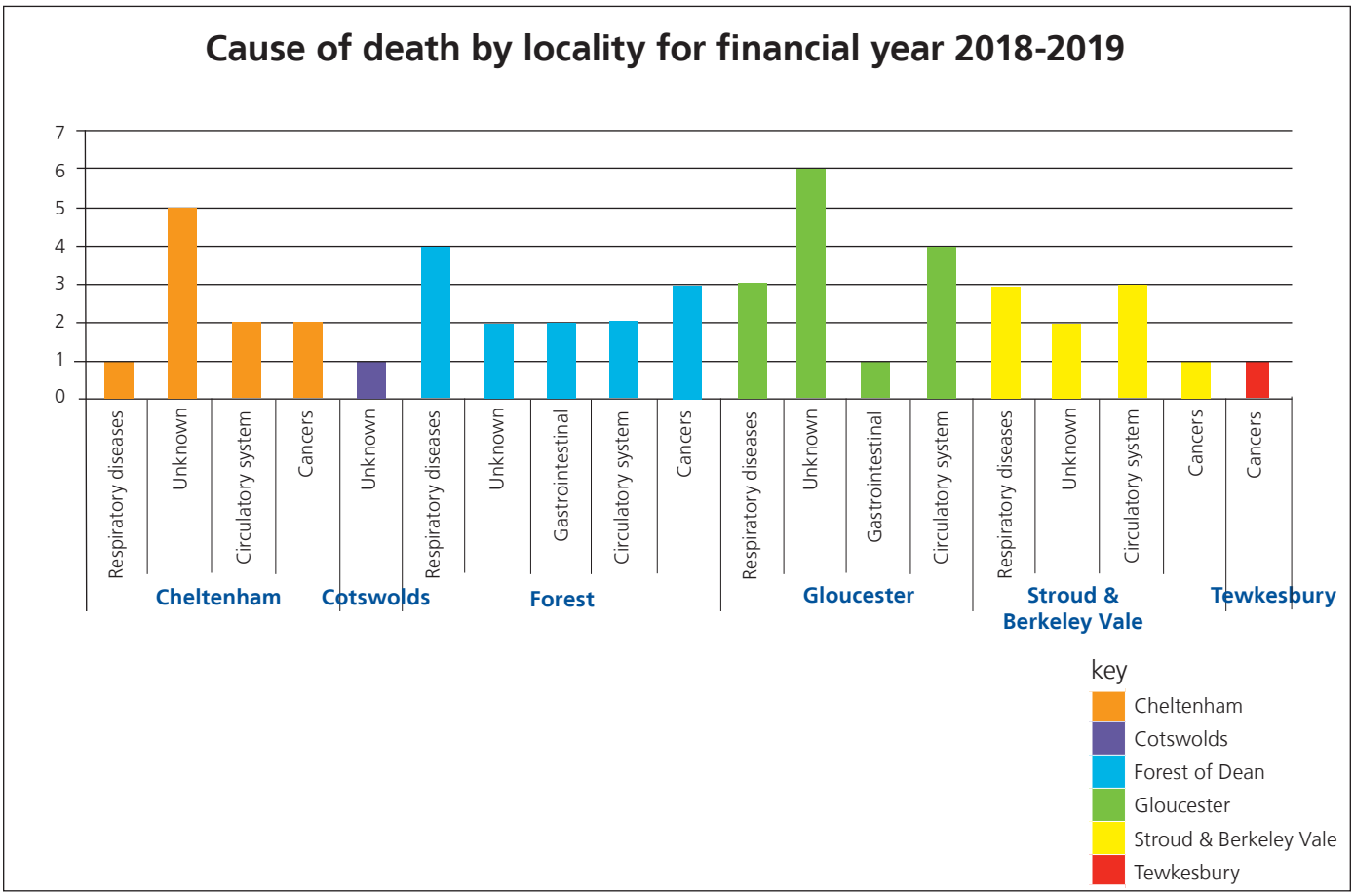
As you can see the majority of deaths have occurred in Gloucester (33 deaths), with Forest second (24 deaths). The severity of learning disability is concentrated around Gloucester, Forest and Cheltenham.

The main cause of death identified in financial year 2018-2019 was due to Pneumonia type n9 people (brocho pneumonia n6 and aspiration pneumonia n3), the second highest cause of death was due to cancer n7. Note where identified as unknown reviews have not yet been completed.

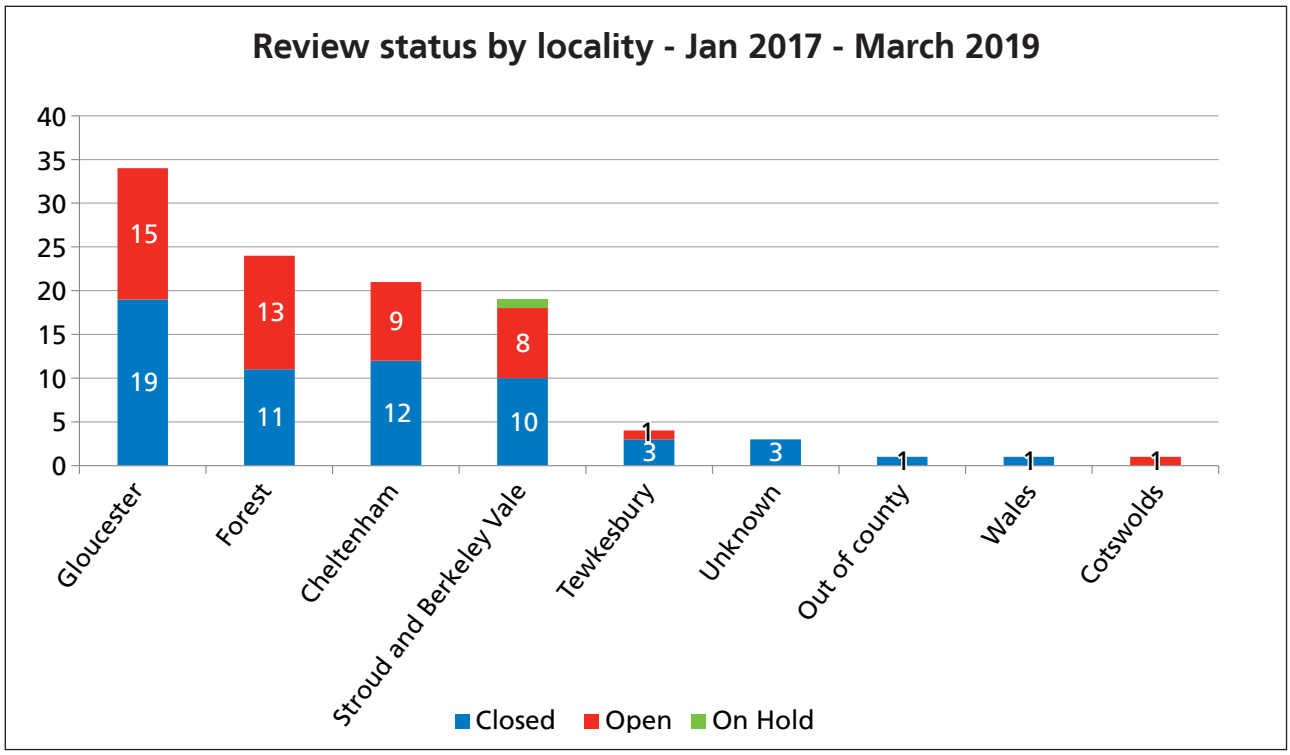
## Chart 14 - Cause of death financial year 2018-2019



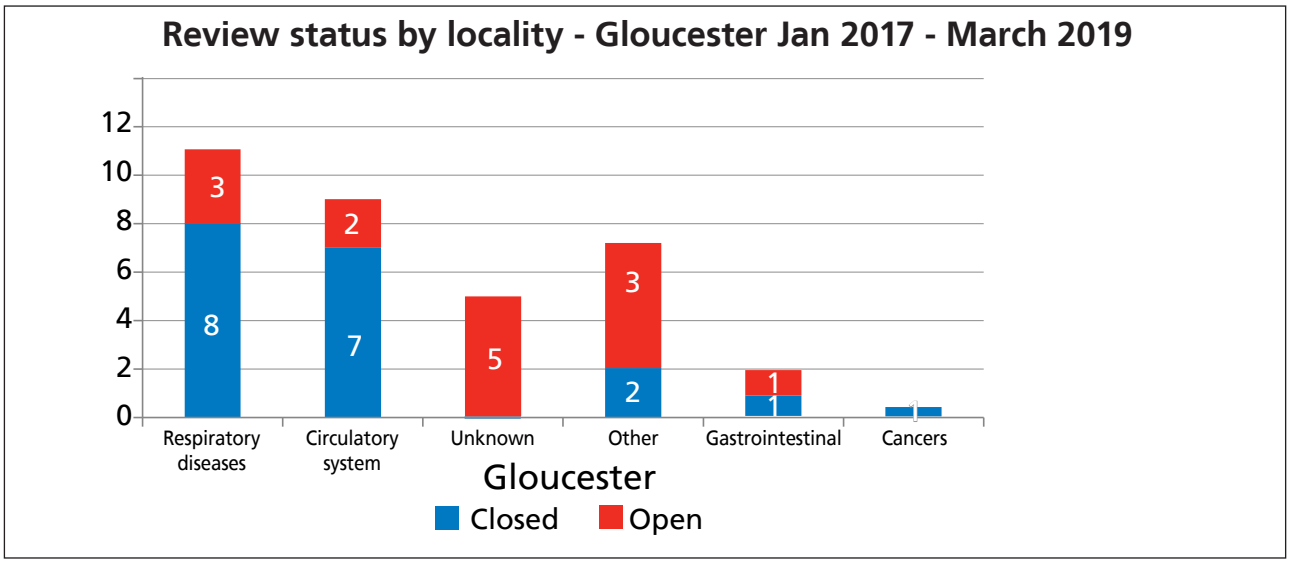

## Chart 15 - Cause of death by locality for financial year 2018-2019



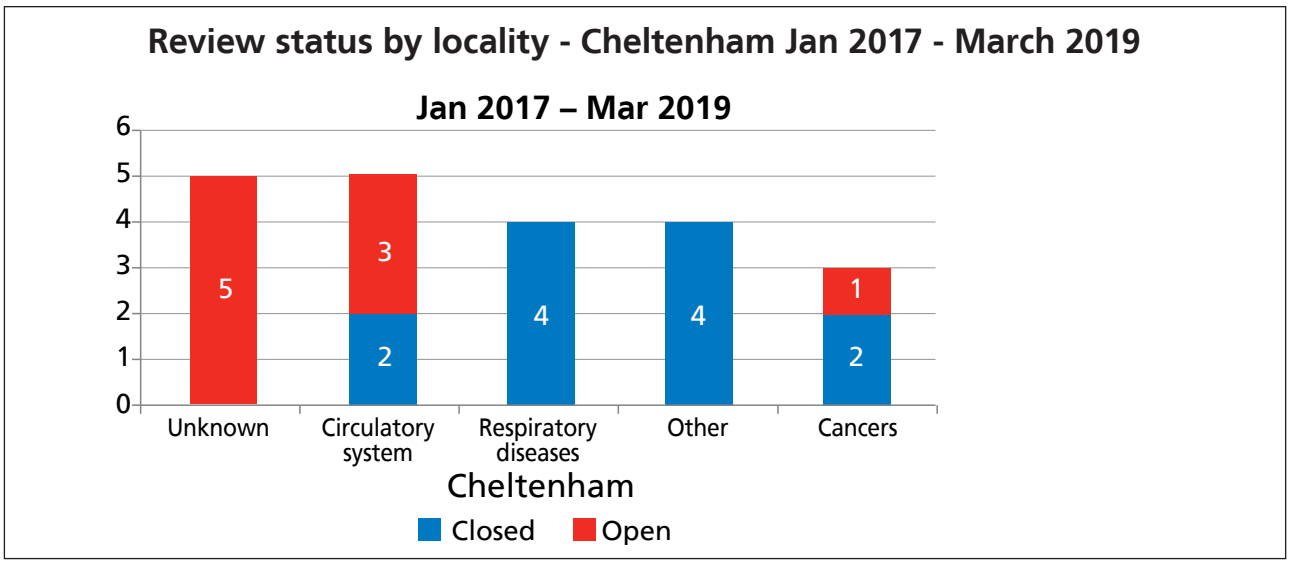
## Chart 16 - Review status by locality



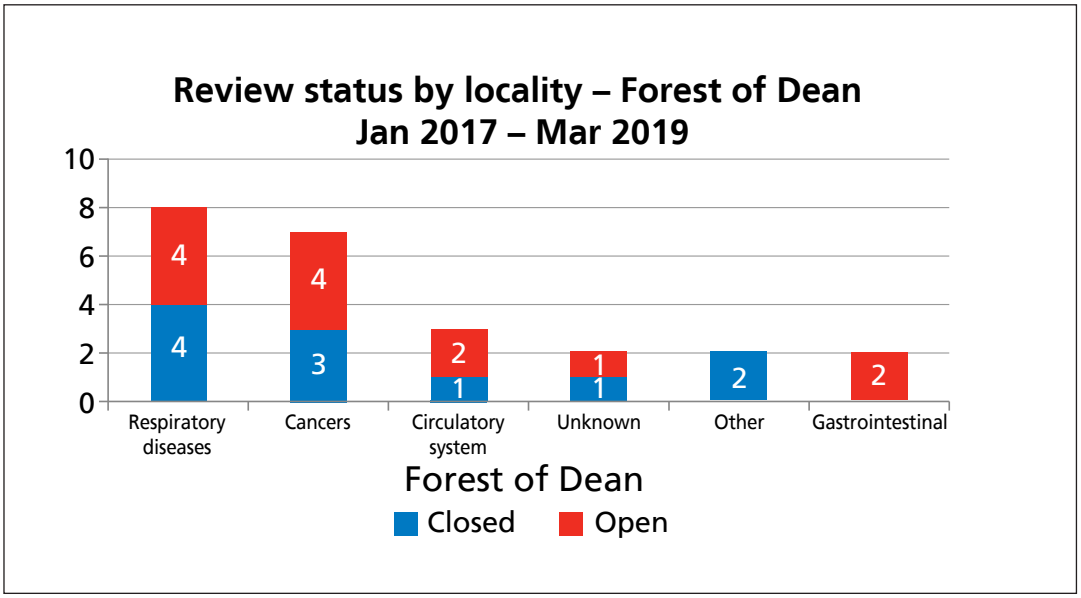

## Chart 17 - Gloucester Locality - LeDeR Causes of death




## Chart 18 - Cheltenham Locality - LeDeR Causes of death



## Chart 19 - Forest of Dean Locality - LeDeR Causes of death




## Chart 20 - Stroud & Berkeley Vale Locality - LeDeR Causes of death

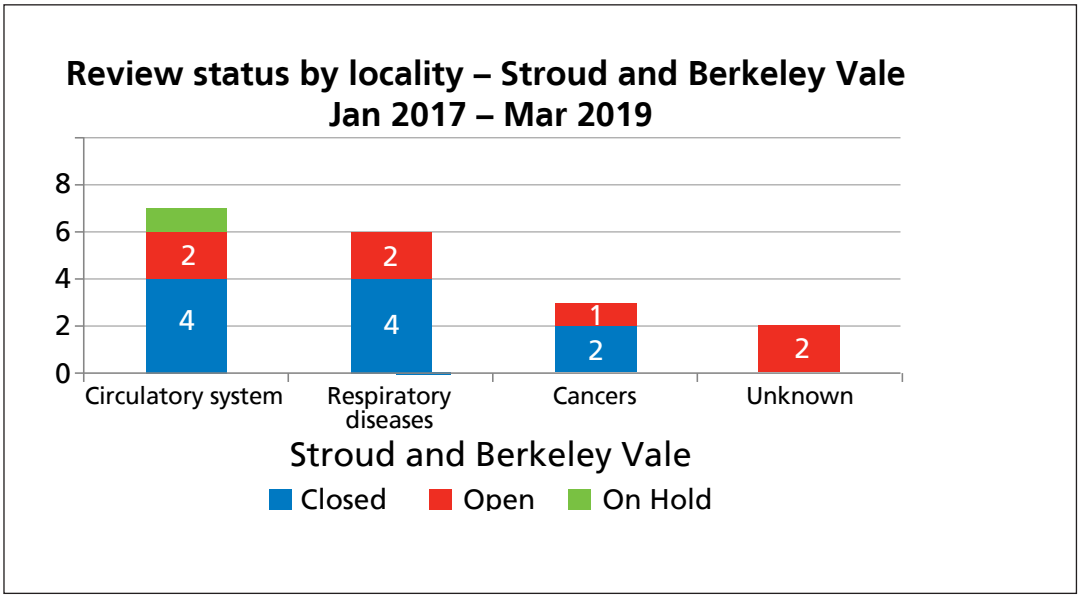
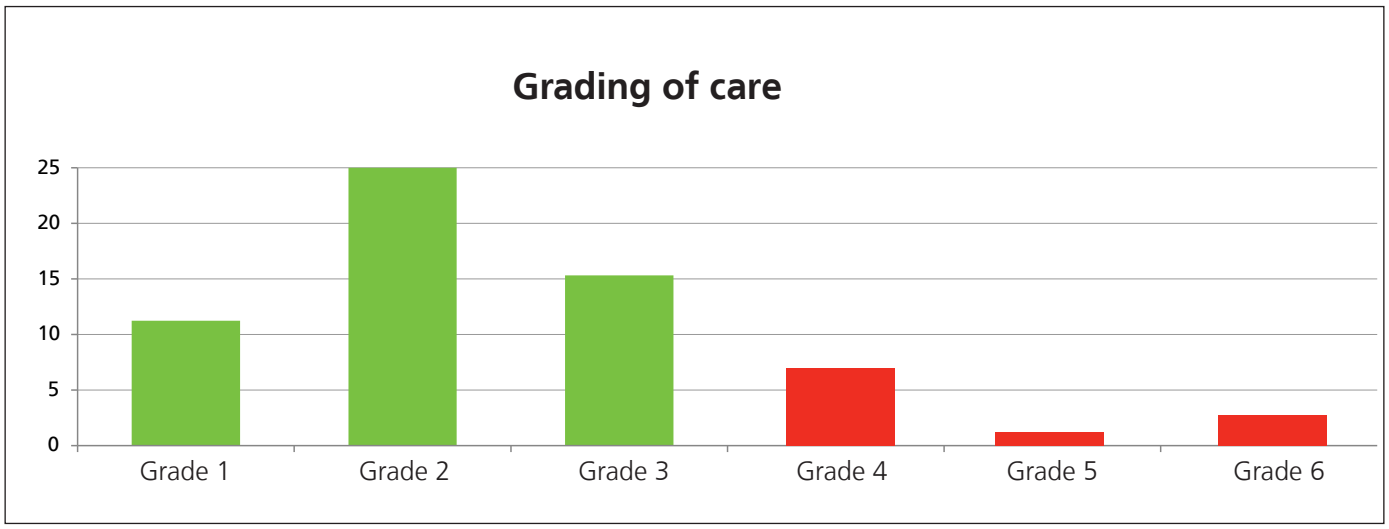


Table 1 – Grading of care shows the LeDeR Reviewers' overall assessment of the care received (where this has been recorded on completed reviews n56). 82% of the reviews completed received satisfactory or above levels of care, this equates to a ratio of 8 people out of 10 in Gloucestershire receiving satisfactory care.

**Table 2 – Grading of care**

| **Grading of care** | Count of Grading of care | Total % and Ratio |
|---|---|---|
| 1 = Excellent Care | 11 | 8:10 |
| 2 = Good care | 25 | |
| 3 = Satisfactory | 15 | |
| 4 = Care fell short of current best practice in one or more significant areas | 7 | 2:10 |
| 5 = Care fell short of current best practice and some learning could result from MAR | 1 | |
| 6 = Care fell short of best practice resulting in potential for, or actual adverse impact | 3 | |
| Grand Total | **62** | |

**Chart 21 - Grading of care**



Four cases have been identified to progress to multi-agency review, two have been completed with 1 due to meet in June 2019. One is on hold due to other statutory reviews taking place.

**Analysis of those who received less than satisfactory care:**

| Less than satisfactory care | |
|---|---|
| **Locality they lived in** | **Count of Locality** |
| Cheltenham | 2 |
| Forest | 2 |
| Gloucester | 4 |
| Stroud & Berkeley Vale | 3 |
| Grand Total | 11 |

**Less than satisfactory care cause of death**

| Grading of care | (Multiple Items) |
|---|---|

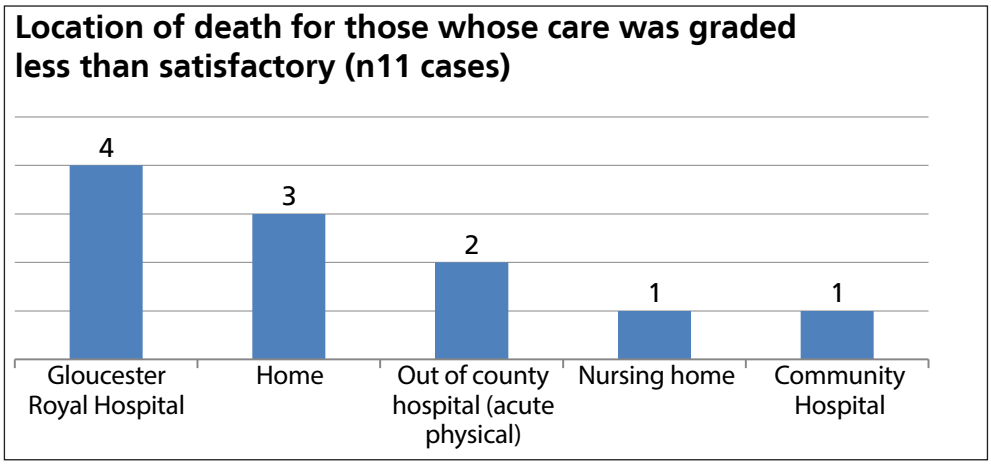
| LeDeR Themes | Count of Cause of death 1 |
|---|---|
| **Circulatory system** | 6 |
| Heart failure | 4 |
| Sepsis | 1 |
| Pulmonary Hypertension | 1 |
| Other | 4 |
| Unknown | 1 |
| Fall - # neck | 1 |
| Choking | 1 |
| Dementia | 1 |
| Respiratory diseases | 1 |
| Aspiration Pneumonia | 1 |
| Grand Total | 11 |

**Table 3 = Less than satisfactory care – location of death**

| **Less than satisfactory care – location of death** | |
|---|---|
| Grading of care | (Multiple Items) |

| Row Labels | Count of Location of death |
|---|---|
| Glos Royal Hospital | 4 |
| Home | 3 |
| Out of county hospital (Acute physical) | 2 |
| Nursing Home | 1 |
| Community Hospital | 1 |
| Grand Total | 11 |

**Chart 22: Location of death for those whose care was graded 4-6[2]**




[2]Please note that this data may not indicate inadequate care at the reported location of death. The grading refers to the whole care provided to an individual.

## Lessons learnt from those who received less than satisfactory care

| | Areas of improvement | Areas of best practice |
|---|---|---|
| **do not share information**<br>  | • Handover/transition from Oxfordshire to Gloucestershire could have been improved | |
| **community learning disability teams**<br>     | • Delay in referral to CLDT following move from 1 home to another.<br>• No suitable seating could be found and neither could a suitable sling due to contractures in both legs.<br>• Difficulty obtaining accurate weight measurements. Hearing aids lost in move.<br>• As Family were not in regular contact an advocate should have been appointed. | • CHC Funding awarded |
| **community speech & language therapy**<br>  | • Risk of choking not managed<br>• No Speech and Language Therapy involvement<br>• Unclear of the frequency with which risk assessments and care plans were updated | |
| **better care**<br>  | • The relationship between GP and Care Provider would benefit from further scrutiny as it is clear that a lack of connectivity (together potentially with a lack of staff continuity) resulted in failure to act on the diagnosis of heart problems and also a failure to administer a vital flu vaccination. | • The circle of support that he received from advocates and is particularly worthy of highlighting as best practice.<br>• Social worker worked hard to get to know him and maintained regular contact.<br>• Received excellent support from a speech and language therapist concerning his swallow, diet, fluid consumption, etc. She quickly got clear plans in place for staff to follow and delivered a staff training session specific to him.<br>• Had good NHS support about preparing for his second hospital appointment about his heart, including practising lying in the correct position for the appointment. |

## Lessons learnt from those who received less than satisfactory care

| | Areas of improvement | Areas of best practice |
|---|---|---|
| **annual health check**<br>  | • Did not have an Annual Health Check.<br>• Various appointments for mainstream services not attended or followed up by the services as to why. Mainstream services processes in relation to following up DNA's for people with LD<br>• Carers assessment would have been beneficial. | • Commenced the MAP (Memory Assessment Pathway) care pathway (Downs and Dementia monitoring). |
| **palliative care**<br>  | • Issues with earlier part of life (in another County) - concerns were raised at the time and papers have been published nationally to share the learning. | • Rapid response in place to care for at home as part of treatment escalation plan for end of life care.<br>• Best Interest decisions well documented and DOLS approved |
| **palliative care**<br>  <br>  | • Did not have a hospital passport,<br>• Poor communication between hospital, family and care staff.<br>• Poor pain management as couldn't communicate was in pain.<br>• Delay in support from palliative care | |

# 4. Case Studies – Please note that these case studies are from aggregated learning from the completed reviews to date and do not relate to one specific person.

## Case Study 1 - Young Person with Downs Syndrome and Autism

Limited verbal communication, moderate learning disability regularly seen by GP at family home

Sensory processing difficulties leading to behaviours that challenge

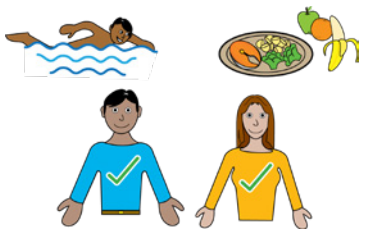
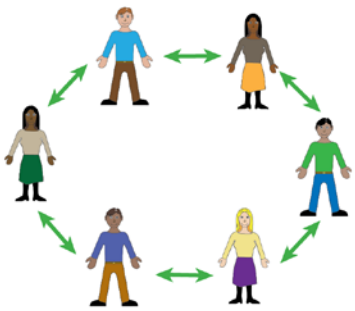
BMI 40

Heart defect problems since an early age.

Admitted to acute hospital – patient found Hospital a frightening and stressful place and like other people with autism, when stressed; could present with challenging behaviour.

**Cause of death – pneumonia.**

### Learning from this case

| | |
|---|---|
| **best interest**<br>  | 1 Consideration of best interest for each decision in relation to healthcare choices and where patients present with some challenging behaviours which may require restraining so they do not harm themselves and others. In this case study the hospital porters were introduced to the patient so that they would be less frightened if they were called upon to support with restraint. |
|  | 2 Screenings and health checks are vitally important to prevent health conditions deteriorating. |
|  | 3 Support to access healthy lifestyles support e.g. weight management via reasonable adjustments. |
| **partnership working**<br>  | 4 Partnership and dialogue between the hospital and the community teams is crucial in ensuring continuity of care both in and out of hospital – specifically when IT systems do not speak to each other. Opportunity in the future with Joining Up your Care system. |

| | |
|---|---|
| **better care**<br>  | 5 The medical consultants within the acute hospital didn't feel confident providing support to someone with autism and exhibiting behaviours that challenge – so they sought advice from a specialist that had particular expertise in managing challenging behaviour and acted on the advice given. |
|  | 6 The family were encouraged to be part of care planning and were supported by staff – particularly the Hospital Liaison nurses within the hospital with any queries they had. |
|  | 7 Reasonable adjustments should be put into place to support care. In this case the patient was supplied with pictorial information to aid their understanding. |

## Case Study 2 – Older person with Downs Syndrome & Dysphagia

Lived in the same care home for almost 50 years, was moved to a supported living setting (care continuity from the same provider, however there was a high number of agency staff in the new setting) as care home was closing.

This individual died 6 weeks following the move

No surviving family, but had a close friend/advocate.

Could communicate with simple instructions – didn't like to be rushed with instructions.

Developed a few health problems in later life including difficulty swallowing and frequent chest infections (which may have been associated with aspiration of food). Had dry skin and developed pressure sores.

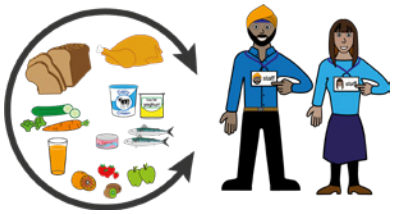
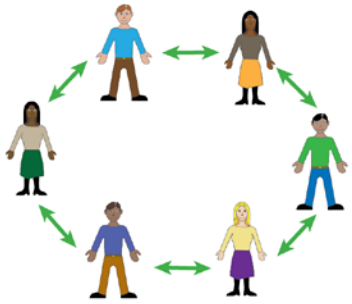
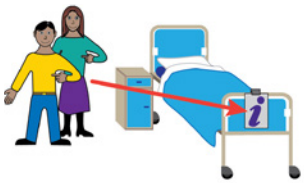
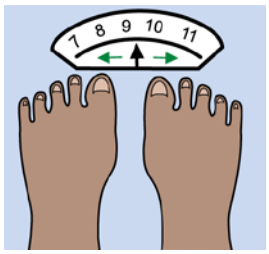
There was a delay in treatment which lasted months. The paid carers and friends felt they were not listened to by the health staff.

There were numerous GP appointments but the seriousness of the patient's dysphagia was not identified.

There were delays in identification of the dysphagia which meant that the person had significant weight loss and recurrent chest infections. GP referred to the Speech and Language Therapy Service who advised on a regime of thickened fluids and pureed food to prevent the risk of choking. This information was not always communicated to ward staff on admissions to hospital with chest infection so on occasions was fed a normal diet and un-thickened fluids putting him at risk of aspiration and choking.

**Cause of Death – Aspiration pneumonia**

## Learning from this case

| | |
|---|---|
| **better care**<br>  | 1 There was poor communication between the GP practice and the Care home. It was never acknowledged how significant the dysphagia was. |
|  | 2 There was a lack of appropriate feeding equipment on the hospital ward to prevent the risk of choking. |
|  | 3 The hospital did not always have anyone available who could communicate with nonverbal patients. |
| **partnership working**<br>  | 4 The Intensive Health Outreach team (2Gether NHS Foundation Trust) & Rapid Response team (Gloucestershire Care Services NHS Trust) visited regularly. |
| **my information**<br>  | 5 There was joint working with Hospital LD Liaison nurse and care staff when in hospital. |
|  | 6 The Care Provider was slow to react to changes in need which resulted in dramatic weight loss and deterioration in health status. |

| | |
|---|---|
|  | 7 This individual died 6 weeks after transitioning from one care home to another which raises issues around planned transition of care. |
|  | 8 There was no continuity of care staff because of the high number of agency staff |

## Case Study 3 – Person with mild learning disabilities in sheltered accommodation

Well known to the Local Authority who provided funding to live as independently as possible in a sheltered accommodation complex. Regular contacting with family. Like to smoke (heavy smoker), but did not drink.

Admitted to hospital following a fall at home had an indwelling catheter in situ and was faecally incontinent. Discharged home with plan for community services to support health care. There were delays in arranging appropriate physiotherapy to maximise his mobility and he was nursed in bed acquiring a pressure sore on buttock.

Person's weight began to drop and complained of abdominal pain and low mood. It was clear that the health care needs had increasing and there were fears that health need could not be met in the sheltered accommodation complex.

Person had capacity (a number of best interest meetings were regularly held) and expressed a wish to stay in their home.

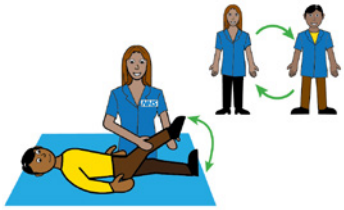
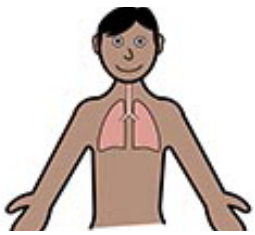
There were discussion around whether the person should have further investigative procedures to find out the cause of their pain and weight loss but it was decided that it would not be in the patient's best interests.

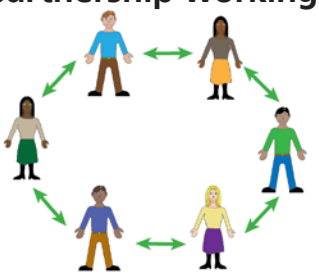
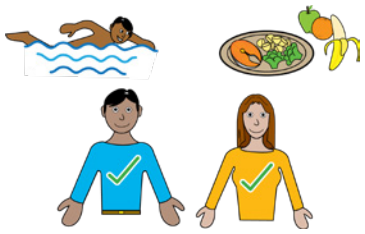
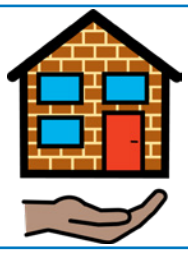
The District Nurse was visiting to attend to the pressures sores with some input from the specialist tissue viability service. However, the weight started to drop again and a request for monitoring of food and fluid intake in the sheltered accommodation was not being monitored as per the plan.

It was decided that the Intensive Health Outreach Team (IHOT Learning Disability nurse) would visit daily and record observations. Person became very unwell and was admitted to hospital with infected pressures sores, malnourished and dehydrated. Hospital treated with antibiotics and fluids.

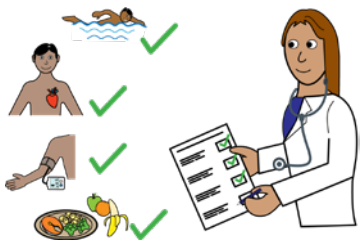
Whilst in hospital refused food and drink but, with gentle encouragement, could be persuaded to eat yogurt and ice cream and fortisips. After several days the pressure ulcers were no longer infected and the person was certified as medically fit for discharge but no nursing placement could be found. The person remained in hospital for nearly 2 months waiting for a suitable placement. Unfortunately, during this time, the person developed hospital acquired pneumonia and died in hospital.

**Cause of Death – Pneumonia**

| | |
|---|---|
| **learning from this case**<br>  | 1 There were several instances where care fell short of the expected standard, The Care Provider was slow to react to changes in need which resulted in dramatic weight loss and deterioration in health status. |
| **support received at home**<br>  | 2 The sheltered accommodation care provider could not offer the level of care required. This should have been identified earlier and an alternative placement found to meet needs before he became so unwell. |
|  | 3 There was uncertainty of how to measure and accurately record the weight of someone who was not mobile e.g. sit – on scales/ sling scales. |
| **effective**<br>  | 4 There was a change in Provider care staff which meant the senior carer left the service and there was no replacement so no one had oversight or leadership of the person's care in the community. Fluid charts and turn charts were not completed and level of care was below standard. |
| **physiotherapist**<br>  | 5 There was a delay in receiving treatment from a community physiotherapist. There is a view that had this person received physiotherapy immediately after the initial fall, then mobility may not have been impaired to the point that they required nursing in bed, and as a result may not have acquired pressure sores and health may not have deteriorated to such a degree. |
| **lungs**<br>  | 6 There was a delay in finding a suitable placement for this person once deemed medically fit for discharge from hospital. This delay exposed the individual to the risk of developing hospital acquired pneumonia. |

| | |
|---|---|
| **partnership working**<br>  | 7 There was joint working with LD Liaison nurse and ward staff when in hospital. |
|  | 8 Whilst the individual received annual health checks they were not offered any healthy lifestyles advice to support smoking cessation. |
| **better care**<br>  | 9 There were well attended multi-agency meetings in relation to best interest decisions and good communication between family, Social care and health who worked well together. |
|  | 10 The IHOT team responded in a timely manner to support at home as his health deteriorated. |

## 5. Learning into Action – How learning from LeDeR Reviewers is being used to drive quality improvement

| | |
|---|---|
| **annual health check**<br>  | Communications and support to access primary care Learning Disability Annual Health Checks (AHC) in some reviews could have been improved.<br>**Actions completed to date:**<br>1. A project group was established in 2017-2018.<br>2. Further enhance the information on the G-Care website https://g-care.glos.nhs.uk/pathway/576<br>3. Attend Locum GP Conference<br>4. Updates via What's new this week for practices<br>5. Review of the training provision from Strategic Health Facilitation Team<br>6. AHC Toolkit for GP practices and communications launched on 22nd May 2018<br>7. Primary Care Learning disability champions identified in most practices<br>8. Forum theatre training commissioned via Inclusion Gloucestershire – due May 2019.<br>9. Dashboard to be developed – Due June 2019 |

| | |
|---|---|
| **Access to healthy lifestyle services**<br>  | Reasonable adjustments made to access to mainstream healthy lifestyles preventative services e.g. smoking cessation, weight management and eating well were contributory factors in some of the reviews completed.<br>**Actions completed to date:**<br>1. Further enhance the information on the G-Care website to support clinicians around healthy lifestyles<br>2. Engaged with Public Health initiatives to further enhance reasonable adjustments within new initiatives<br>3. Updates via What's new this week<br>4. Work with ICE Creates (Gloucestershire Healthy Lifestyles Service Provider) to support reasonable adjustments and pilot a clinic in Treasure Seekers Hub in Gloucestershire<br>5. Eating well training for care providers and family commissioned and commenced April 2018P - evaluation of outcomes expected June 2019.<br>6. Community dietetics pilot commenced October 2018 – due to finish June 2019. |
| **staying and leaving hospital**<br>  | Suitable reasonable adjustments being put in place in mainstream health services was shown to be inconsistent particularly around meeting communication needs within some reviews.<br>**Actions completed to date:**<br>1. Further enhance the information on the G-Care website to reduce clinical variation<br>2. June 2018 - NHS Improvement LD Standards published. November – National Benchmarking completed – awaiting outcome.<br>3. Audit of "Did Not attend" protocols vs "Was not brought"<br>4. Work with Safeguarding to develop a local promotional/training film for clinicians about Was not brought https://youtu.be/jK7YaXoC5dc<br>5. Work with Inclusion Gloucestershire to develop a range of short films on "Getting Checked, Staying well" over a range of clinical areas Click here to view the range of films |
| **mental capacity**<br>  | Utilisation and documentation of the Mental Capacity Act by mainstream health services was shown to be inconsistent in some of the reviews completed<br>**Actions completed to date:**<br>1. Further enhance the information on the G-Care website to reduce clinical variation<br>2. System enablers - Flagging of people with a learning disability and reasonable adjustments being considered by Glos Hospitals NHS F Trust IT system<br>3. Training & Workforce competencies– Engagement with MCA Manager and training provided to LeDeR Reviewers<br>4. Local Learning into Action Event to be planned for Q2 2019-2020 |

| | |
|---|---|
| **palliative care**<br>  | Treatment escalation practices particularly in relation to end of life protocols for those individuals who are considered to be frail and are at higher risk of deterioration.<br>**Actions completed to date:**<br>1. Further enhance the information on the G-Care website to reduce clinical variation<br>2. Closer working links with the end of life clinical programme group to ensure reasonable adjustments are considered for all service improvement areas |
| **care at home**<br>  | Spotting the signs of the deteriorating patient for those who have a learning disability can be difficult to monitor if those who are caring for them (family or paid carers) are not aware of the individuals normal baseline reading e.g. temperature, blood pressure, respiratory rates and other soft signs.<br>**Actions completed to date:**<br>1. Further enhance the information on the G-Care website to reduce clinical variation<br>2. Telehealth pilot project commenced in January 2019 in Forest of Dean led by LD & Autism GP Lead working with stakeholders (including clinicians, those with a learning disability & a Learning Disability Residential care home). A presentation was given at a regional event on 24th April. Further evaluation is required.<br>3. Further development of a tool to support all carers to spot the signs of a deteriorating patient<br>4. Development of a Frailty pathway during 2019-2020. |

# 6. Recommendations

1. Note the progress made to complete reviews in Gloucestershire as outlined in this report, including the positive completion and percentage complete being above south west average of 25%
2. Note the continued backlog and difficulties in allocating reviews within 6 months of them being notified. Possible consideration of developing a business case for investment in an employed reviewer.
3. Continue to share the learning into action and consideration of a learning event during 2019-2020.
4. Continue to work with the South West Regional Learning into Action Collaborative to share learning and best practice.

# Appendix 1 – References and End-notes

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

[ii] http://www.bristol.ac.uk/sps/leder/

[iii] http://www.bristol.ac.uk/sps/leder/notify-a-death/?_ga=2.4265911.589001362.1531124673-1987643447.1528363357

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

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

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

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

# Glossary

| | |
|---|---|
| 2G | [2]gether NHS Foundation Trust |
| AHC | Annual Health Check |
| CCG | Clinical Commissioning Group |
| GRH | Gloucestershire Royal Hospital |
| GCC | Gloucestershire County Council |
| GCS | Gloucestershire Care Services NHS Trust |
| GHT | Gloucestershire Hospitals NHS Foundation Trust |
| GP | General Practitioner |
| IHOT | Intensive Health Outreach Team |
| LD | Learning Disabilities |