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|  | **Agenda Item** |

**Quality and Governance Committee**

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| **Meeting Date** | **August 2022** |
| **Report Title** | **Approval for Gloucestershire LeDeR Annual Report 2021-2022**  **Improvements on the local Quality Assurance Process for LeDeR** |
| **Executive Summary** | Purpose:The purpose of this paper is to seek endorsement of the Gloucestershire LeDeR Annual Report 2021-2022 (Appendix 1 and the easy read version is Appendix 1a) which details the findings from the LeDeR programme in Gloucestershire over this periodThe paper will also seek approval on the improvements to the Quality Assurance process and updates to the local LeDeR Policy (Appendix 2).  1. **Background**:    1. 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.    2. Through continued work to raise awareness of LeDeR we hope that the programme in Gloucestershire[[1]](#footnote-1) is capturing as many deaths as possible. Although we do recognise that there may be deaths that have not been reported to the LeDeR Programme.    3. The aims of the LeDeR Programme are:       1. To help improve health and social care services for people with learning disabilities and Autistic People.       2. Reduce Health Inequalities for people with a learning disability and autistic people. Health Inequalities are unfair and preventable differences in health.       3. To stop people with learning disabilities and autistic adults from dying too soon by making care better.    4. Gloucestershire stands in a strong position to address the issues and preventable causes of death identified within the national LeDeR annual report (published July 2022[[2]](#footnote-2)). This reflects the many challenges that people with a learning disability face locally. The [national LeDeR Policy](https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/)[[3]](#footnote-3) was updated and published in March 2021. The amendments were introduced in Gloucestershire during the Summer of 2021. Some of the changes included the introduction of a new IT system and review process which brought with it some challenges. However, Gloucestershire has continued to be a top performing area and continued to meet all its performance indicators set by NHS England for LeDeR.    5. The local programme has an established way of working in co-production with people with lived experience and this continues to be a key contributor to the success of the programme locally. Learning from each review has been invaluable in enabling the lessons learnt and service improvements put into place in a timely way. The co-production partnership approach[[4]](#footnote-4) which was implemented in 2019 continues to be invaluable in ensuring we are ahead of the curve in implementing action from learning and sharing this with a wide range of people and experts by experience and experts by profession have helped us get perspectives from the people who use and deliver health services locally. We have a strong commitment to learn from these reviews and Chapters seven and eight set out the recommendations from reviewers and our dedication to turn this into real action, promoting learning throughout health and social care services[[5]](#footnote-5).    6. This is the fourth annual report to be written for Gloucestershire. Previous Reports are available on our LeDeR Learning into Action Webpages hosted by Inclusion Gloucestershire[[6]](#footnote-6). 2. **Key findings: 40 deaths were reported to the programme in 2021-2022**    1. The Gloucestershire LeDeR Programme (as at 31st March 2022) had completed 92% of notified reviews (reviews received up to and including 31st March 2022).    2. The ratio of the grading of care those receiving satisfactory or better care remains at just under 9:10 (71% of people had good or excellent care and 14% had satisfactory). Care fell short of current best practice in 3 reviews (14%), of these 3 reviews all died in Gloucestershire Royal Hospital.    3. Of the deaths reported in Gloucestershire during 2021-222, 60% died in hospital. The corresponding proportion for the general population is 46%[[7]](#footnote-7).    4. Of the 40 deaths this yearthe top cause of death in the learning disabilities population in 2021-22 remains respiratory causes (n10 deaths). There have been less than 5 deaths due to covid-19 (previous year was 14).    5. 67% of the 21 deaths whose review has been completed had an active advance care plan in place (last year this was 57% (this compares to 46% nationally). Over 50% (57%) of the deaths (44% in the previous year) of the deaths were expected and planned for deaths. Learning into action work continues around the accessibility of advance care planning and the perception on the use of the ReSPECT Form being completed and the conversations being accessible for people with a learning disability. The programme continues to work with the End-of-Life Clinical Programme and engage with the Resus Council. We are also working with Inclusion Gloucestershire to develop some co-produced material that will be available nationally to address this concern. 3. **Key learning outcomes:**   Figure 1is an infographic of the key themes from the last year. Interwoven within these themes are the golden threads of the LeDeR service improvement programme for the programme;   * Improving access for black and minority ethnic people to specialist learning disability services. * Ensuring that reasonable adjustments and improved communications are used by all healthcare professionals (e.g. use of Health passports, easy read resources & diagnostic overshadowing and access to advocates) * Increasing use of accessible technology and digitalisation e.g. apps and digitalised documents * Reduce waiting times for healthcare appointments * Preventing hospital admission, and where they have been admitted supporting earlier discharge. * Workforce knowledge and skills (e.g. dysphagia, spotting signs of deterioration, positioning and wheelchair management) * Personalised Healthy Lifestyles E.g. Eating well, bowel care, diabetes management, oral healthcare, access to exercise * People have the right equipment to meet their needs   Figure 1 Key themes emerging from LeDeR in Gloucestershire over the last year   1. **LeDeR Programme 2022-2023**    1. The programme’s ambition for the coming year is to;  * Focus on improved communications between professionals and with family/carers. * Focus on early detection of deteriorating physical health including sepsis. In particular, supporting the uptake and use of the ReSTORE2 mini documentation. * Focus on eating and drinking pathway including raising the awareness of oral health through Mouth care Matters, and of the importance of checking for speech and language therapy guidelines on admission to hospital. * Continue the focus on improving uptake of the Annual Health Checks and Flu/Covid Vaccinations. * Focus on encouraging the ReSPECT form to be completed earlier on for people who have complex healthcare needs, alongside ensuring that there is a base line observation (Unique Wellness) in place to review frailty and advanced care planning with individuals, their family, and carers, so this helps identify when people are deteriorating. * Continue to share the learning – plans to work with Inclusion Gloucestershire in 2022-2023 to develop accessible easy read infographics of the learning that comes out of the reviews. * All the recommendations from reviews will continue to be scrutinised by the Quality Assurance panel (Appendix 2) and put into a local action plan tracker which is shared with the Gloucestershire LeDeR Governance and Steering group who will monitor progress with the aim of improving outcomes for people who are at risk of facing health inequalities. Learning on a page (Appendix 2) from each review will be shared for every review undertaken. * The LDA Clinical Programme is passionate about keeping this work programme moving forward and the local LeDeR programme wants to continue to strengthen the partnership with family carers during 2022-2023. Whilst extending the scope to carers who support people from black and minority ethnic communities and engagement with community organisations and individuals will be crucial for the programme to be able to do this effectively. People’s lived experience will help to guide and drive the service improvement programme that will be as a result of the completed reviews. |
| **Key Issues** | This report is about reviewing deaths of people with a learning disability 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. |
| **Risk Issues:**  **Original Risk (CxL)**  **Residual Risk (CxL)** | Failure to support and deliver LeDeR locally will limit compliance with national guidance. NHS England have requested all LeDeR Steering Groups publish an annual report by July of each year. This years LeDeR Annual Report provides assurance on how the CCG/ICB has ensured robust governance and service improvement is in place to deliver the LeDeR programme in Gloucestershire effectively. |
| **Management of Conflicts of Interest** | There are no recorded conflicts of interest recorded as part of this programme of work. |
| **Financial Impact** | The programme is not currently funded recurrently by NHS England and is reliant on one off funding allocations to support delivery. Without this one-off funding the programme would not be able to fund reviewers to conduct the reviews or fund experts by experiences to support the quality assurance panel process. |
| **Legal Issues (including NHS Constitution)** | Provides the ICB with assurance on compliance with the following legal frameworks for learning disabilities patients:   * Equalities Act, 2010 * Mental Capacity Act * NHS Constitution – including Learning from Deaths Policy, 2019. |
| **Impact on Health Inequalities** | Reducing Health Inequalities[[8]](#footnote-8) is a key aspect of the local LeDeR Programme and based on learning themes to date Figure 1 demonstrates the core areas of work for service improvement over the coming three years[[9]](#footnote-9). The programme uses a number of enablers to assist in its successful delivery including working with experts by experience, use of a dedicated website, regular accessible newsletters, networking and benchmarking good practice and utilisation of established links with quality, safeguarding, nursing and other system clinical leadership across the ICS. Clearly any service improvement to enable this group of vulnerable individuals to access health and social care services will ultimately reap benefits for the wider system in terms of accessibility, reasonable adjustments and consistent use of legislation such as the Mental Capacity Act. |
| **Impact on Equality and Diversity** | **Yes**  If yes describe  Positive impact (EIA available within the Gloucestershire LeDeR Policy) |
| **Impact on Sustainable Development** | No |
| **Patient and Public Involvement** | **Yes**  This annual report has been co-produced with people with lived experience - via partnership working with Inclusion Gloucestershire, input from the LeDeR QA Panel, LeDeR Steering group and other stakeholders (via the Learning disability and Autism Clinical Programme Group) |
| **Recommendation** | Annual Report for approval to publish  Approve the changes to the local LeDeR Policy |
| **Author** | Cheryl Hampson |
| **Designation** | Senior Commissioning Manager - Integrated Disabilities Commissioning and LeDeR Local Area Co-ordinator |
| **Sponsoring Director**  **(if not author)** | Kim Forey  Dr Marion Andrews-Evans |

**Appendix 1** 

**Appendix 2** ****

1. In Gloucestershire reviewers will only be reviewing those who are registered with a Gloucestershire GP [↑](#footnote-ref-1)
2. <https://leder.nhs.uk/resources/annual-reports> [↑](#footnote-ref-2)
3. <https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/> [↑](#footnote-ref-3)
4. We have been supported with this by [Inclusion Gloucestershire](https://www.inclusiongloucestershire.co.uk/) [↑](#footnote-ref-4)
5. It is important to remember that comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified to LeDeR from the age of 4 years, while general population data also includes information about children aged 0-3 years.

   In addition, more people who died at a younger age had profound and multiple learning disabilities and some of these would also have had complex medical conditions or genetic conditions that may make an earlier death likely. [↑](#footnote-ref-5)
6. <https://www.inclusiongloucestershire.co.uk/engagement/leder/> [↑](#footnote-ref-6)
7. Noting that there is not a recent % update to the general population to take into account the impact of Covid-19, so no meaningful conclusions can be drawn from this data. [↑](#footnote-ref-7)
8. Definition of Health Inequalities is available on the NHS England website <https://www.england.nhs.uk/ltphimenu/definitions-for-health-inequalities/> [↑](#footnote-ref-8)
9. Noting that depending on learning from new reviews additional themes may be added to this model [↑](#footnote-ref-9)