NHS
Telford and Wrekin
Clinical Commissioning Group

NHS
Shropshire
Clinical Commissioning Group

LeDeR Annual Report
April 2019 – March 2020

Shropshire, Telford and Wrekin

LEARNING DISABILITY MORTALITY REVIEW (LEDER) PROGRAMME

1.0 Executive Summary

The Learning Disabilities Mortality Review (LeDeR) programme is a national project to review the deaths of all patients with Learning Disabilities. The programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. The programme is led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. This is a joint health and social care project, involving healthcare providers across the health economy, Local Authority and CCG's.

The NHS long-term plan, published on January 7, confirmed that the NHS will continue to fund the Learning Disability Mortality Review Programme (LeDeR). It stated: "Across the NHS, we will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives." The plan went further in saying: "Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people" and "the whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing".

Locally Quality and Outcomes Framework (QoF) data for 2015-16 states that the prevalence of learning disability on GP practice registers is 0.53% which accounts for 1,610 of the population in Shropshire. Nationally the QoF data prevalence of learning disability is lower at 0.46% of the population (263,588 people). However, QoF data only includes people registered as having learning disabilities and is most likely to include people with moderate to profound learning disabilities.

There is predicted to be a 4.9% reduction in the number of people aged 18-64 for Shropshire in the next 18 years, compared to a 5% increase in the national figure. In the over 65s Shropshire is predicted to see an increase to 37.6% during this time period, which is lower than the national predicted increase of 38.1%. The number of people in this age group is far smaller compared to the under 65 year age group, but is predicted to increase which reflects the general increase in the ageing population experienced both locally and nationally.

The LeDeR programme is led locally by the quality team, with two Local Area Contact's (LAC's) working across both CCG's. Shropshire, Telford and Wrekin have consistently been one of the best performing CCGs nationally, having in the top 5% of the lowest number of unallocated cases and the one of the highest number of completed cases.

Since the LeDeR programme started in Shropshire, Telford and Wrekin (STW) in June 2017, there have been 58 deaths notified and 39 deaths reviewed. Between April 2019 and March 2020, 20 deaths were notified locally, this is a reduction from the 29 deaths reported across Shropshire, Telford & Wrekin in 2018-2019.

17 of the deaths were Shropshire patients and 3 Telford & Wrekin. The average age of death in 2019-20 has been 49 years. This is due to four deaths under the age of 40, 3 of which were expected. There were also a higher number of deaths (7) over the age of 60 this year. The causes of death were varied during this reporting period. Pneumonia accounted for the highest cause of death with 4 people having this documented as the primary cause.

The CCG continue to support and train reviewers to ensure reviews are completed within timeframe and fully capture the learning. The quality team and reviewers from providers, aim to maintain the high quality of reviews completed and ensure the learning from these reviews are embedded into practice to transform services for people with learning disabilities with the aim of reducing health inequalities.

2.0 Review process

LeDeR reviews are not investigations of care but aim to develop learning and improve care. The focus of the reviews is to:

- Identify potentially avoidable factors that may have contributed to a person's death.
- Identify differences in health and social care delivery across England and ways of improving services to prevent early deaths of people with learning disabilities.
- Develop plans of action that will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities

For each death, there is an initial review. Someone who knew the person well, such as a family member, is invited to contribute their views. This is a fundamental part of the review. The reviewer will also look at relevant case notes relating to the person who has died, and will make contact with relevant organisations/ agencies to discuss cases and access notes if required. This involves the range of agencies that have been supporting the person who has died, (e.g. health and social care staff).

The review looks at three levels of care:

a) Initial diagnosis and management of the condition
b) Ongoing management of the condition from initial diagnosis to critical illness
c) Management and care received during final illness

There 21 reviewers trained locally. All LeDeR reviewers training is now being delivered through eLearning. Every organisation across the health and social care system has trained reviewers.

A local steering group has been in place since the onset of the programme in 2017. The aim of the LeDeR Steering Group is to monitor the actions, learning and recommendations that arose from completed reviews from providers to ensure service improvement for people with learning disabilities.

3.0 National Progress

In the 2018/19 national report, which was published in May 2019, the leading causes of death were: 19% due to respiratory related issues; 14% attributable to cancer and 7% deaths from sepsis.

A Learning into Action collaborative was set up by the NHSEI to better co-ordinate national responses to premature mortality review learning. The collaborative brings together experts by qualification, professional experience and lived experience. The Learning into Action group have provided information slide decks in relation to cancer, constipation, respiratory disease, sepsis, pharmacy, annual health checks, improvement standards and do not attempt cardiopulmonary resuscitation orders (DNACPRs). These have all been shared with the steering group for wider distribution onto partners.

An additional £5 million was invested by NHS England and NHS Improvement in 2019/2020 to address the backlog of un-reviewed cases and increase the pace with which reviews are allocated and completed. The money was invested in developing a dedicated workforce through CSU to undertake reviews and develop systems and processes to embed mortality reviews and quality improvement activity across the health and social care system. At the time of allocation STW did not have a back log of reviews to be completed and were therefore not eligible to join the scheme.

However a small amount of funding was provided directly to the CCG, some of this has been used in 2019/20 to develop a small pool of reviewers, and in order to prevent any potential back log of reviews as has happened in many areas nationally. The steering group agreed that the local process of reviewers based in provider organisations provided a greater opportunity of sharing learning into practice.

LeDeR has Section 251 approval in place to provide a legal framework for sharing of information. The Confidentiality Advisory Group has now conditionally approved moving ownership of S251 approval from the University of Bristol to NHS England this provides the statutory power to ensure that NHS patient identifiable information needed to support essential NHS activity can be used without the consent of patients.

4.0 Local Progress

Between April 2019 and March 2020, 20 deaths were notified locally, this is a reduction from the 29 deaths reported across Shropshire, Telford & Wrekin in 2018-2019. 17 of the deaths were Shropshire patients and 3 Telford & Wrekin.

16 reviews were completed and submitted to the Bristol team in the 2019-20.
One of the reviews were graded as *excellent care*; twelve reviews have been graded as *good care*; two graded as *satisfactory care* and one as 'care fell short of best practice'. The one identified as having some gaps in care, was considered that lapses did not contribute to the death.
15 reviews are still in progress of being reviewed.

The causes of death were varied during this reporting period. Pneumonia accounted for the highest cause of death with 4 people having this documented as the primary cause. Other causes of death included: cardiac related issues (MI, AF, mitral value disease); Cancer and Sepsis

Of these, 13 patients died in Hospital, 5 died in their usual place of residence i.e. either a care home or their own private home; one in the hospice and one in a new care home.

Of the 20 deaths, 11 of the deaths were males and 9 females. The mean age of death in 2019/20 was 50 years compared to 58 years in 2018/19.

Age range	Number of deaths
5 -19	0
20 - 29	2
30 - 39	3
40 - 49	6
50 - 59	2
60 - 69	6
70 - 79	0
80 +	1

In 2019/20 three key areas for development were:

- Completion of Annual Health Checks
- Improved medication reviews including STOMP/ STAMP
- Improved Advance Care planning.

Of the reviews completed in 2019/20: 75% had received an annual health check (↑ from 47% 2018/19); 75% had a medication review with the last 12 months (↑ from 68% 2018/19); and 58% had an advanced care plan (↑ - 48% 2018/19). Work continues with the community learning disability team (CLDT) who are working closely with GP's to cleanse registers and support the completion of Annual Health Checks using the Shropshire AHC tool which is combined with the HEF (Health Equalities Framework).

Shropshire/ Telford and Wrekin remain one of the best performing CCG's nationally, having a low number of unallocated cases, and a high number of completed cases. 39/58 reviews have been completed since commencement of the programme. There are currently 15 allocated cases in progress of being reviewed, 7 of these have taken over 6 months to complete. There are a number of reasons contributing to the delays in completion of reviews, including; police investigation; request of timing of family involvement; capacity of reviewers to complete; access to notes.

4.1 **What we have learnt in 2019/20**.

Much learning was gained from the 16 reviews completed in 2019/20. The recommendations made by reviewers, as identified below, will continue to be followed up in 2020/21.

Increase knowledge and awareness of caring for people with Learning Disabilities within the Acute Trust:

- Promotion of the hospital carer's policy. Review content and include detail around the importance of patient advocates. Review accessibility of services when carers stay with their relative in hospital.
- When carers are unable to continue to support an individual when they are admitted to hospital, hospital staff to recognise that the people who know the person best may not be there when the individual needs them most.
- Review the use of the health passport to ensure consistency of use; areas noted to be poorly completed include medical history and holistic assessment of patient baseline abilities.
- Consideration of how assessment tools can be modified for use in patients with learning disabilities.
- Hospital staff to increase knowledge of MCA process for people with LD.
- To utilise NHS England's Learning into Action Group resources developed to support quality improvement and enhance compliance with MCA within secondary care - It has a specific focus on the issues around assessing capacity and best-interest decisions for deteriorating patients who have learning disabilities.

Primary Care:

- Continue to promote the importance of the annual health check, with the aim to get 100% of patients offered a check and to meet the national target of 75% of people with LD receiving a health check.
- Increase the uptake of AHC's for 14-19 age group.
- GP's to support transition into Adult services, identify gaps and ensure good relationships with both patient and family
- GP's to ensure appropriate screening at all age levels.

Learning Disability Services:

- Community team to raise awareness of services provided with partner organisations.

- Newly established Intensive Health Outreach Team (IHOT) to continue to establish links with local GP Practices. Acute trust LD liaison team to make clear recommendations needed on discharge to the community team, family and carers.

Local Authority and Care Homes:

- Ensure resources are in place to support vulnerable adults across the county.
- Increase knowledge and understanding of ensuring timely communication about changes in a client's condition. Acknowledgment of 'soft signs' and the need to raise concerns about subtle changes in a person's condition early. Individuals with LD can often deteriorate slowly. But, if care staff/ carers can flag simple changes sooner, appropriate action can be taken and avoid unnecessary, and often distressing, transfers to hospital. This is particularly important for people with learning disabilities. Early changes were noted in sleeping patterns; feeding; toilet habits; an increased lack of interest, or more fatigue than usual or increase in behaviours issues. People with learning disabilities can struggle with having their blood pressure, or temperature, taken using medical equipment. Therefore increased use of a 'soft-signs' system could lead to fewer hospital stays.

Healthcare and social care appointments across the system:

- Consistent flagging systems to ensure staff are aware when appointments are being made that the person has a learning disability.
- Timing of appointments to be made at a time of day to meet the needs of the individual.
- Referral letters into specialist services to advise of the reasonable adjustments that would be helpful for the individual, not just state the patient has a learning disability. This will enable providers to make reasonable adjustments in advance of the appointment.
- Improved follow up processes, for DNA's to understand why an individual did not attend.
- RESPECT forms need to be written so they can be shared or reviewed when a person moves between hospital and community. This can avoid inconsistency and repeat conversations.

4.2 What we did well

Many areas of good practice were identified in the 16 reviews completed in 2019/20. These will be shared in order to maintain these areas of good practice and promote consistency across the system for all people with a learning disability.

- Reasonable adjustments made for family to attend appointments
- Completion of MCA and best interest decision assessments, with good documentation of conversations with parents.
- Consistent contact, ensuring the same clinician saw the individual at all their hospital appointments.
- Pro-active Intensive Health Outreach team (IHOT) - providing good support for care home's over a long period.
- A number of care homes were noted as 'exceptional' by family members for the care shown to individuals.
- Very good care from Hospice, GP and District Nurses was sited in a number of reviews.

Good quality reviews have been continuously submitted with only a very few needing returning for additional information.

LeDeR reviewers continue to be committed to completing the reviews, and sharing the learning within their own practice areas

STW have managed to avoid a backlog of reviews with timely allocation, in the main within a week of notification (the national target is allocation within 3 months)

The steering group met quarterly in 2019/20, and continues to include members from across the health and social care system. The group review completed cases to gain a wider discussion on learning into action.

Regular newsletters on LeDeR learnings from reviews are sent to the CCG which are forwarded to all steering group members for wider distribution. Leaflets from the National Team in Bristol for e.g. the management of constipation, dysphasia and aspiration pneumonia are shared with our main providers, General Practices and care homes.

Between March – May 2019, the local Healthwatch carried out an engagement plan based on the NHS Long Term Plan. A series of focus groups took place from across the county with people with dementia and their carers, and adults with learning disability (& autism) and their carers. The focus groups were delivered in partnership with Taking Part, an Independent Service for people with learning disabilities with Health and Social Care needs. The findings showed that what matters most to people in Shropshire, Telford & Wrekin who have learning disabilities and autism. The report was shared with the steering group and will also continue to be used to inform the action plan and learning from LeDeR reviews during 2020/21.

healthwatch
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NHS England has produced a guidance document explaining how best to make information accessible for people with a learning disability. It sets out guidance on what needs to be considered so that information is easy to understand. This guidance has been shared with all providers to include as part of the organisations Accessible Information Standard.

5.0 Next Steps in 2020-2021

This report once signed off by the LD & A Board will be presented at both CCG Boards and will be published on the CCG websites. It will also be shared with the CCGs Quality Committee; PPQ and the four main providers at CQRM.

The steering group has not yet met in 2020/21 due to changes as a result of the Covid pandemic, but it is due to meet in July.
The steering group will:

- agree a set of key local priorities for 2020/21 based on the findings above;
- continue to compare the local findings to national findings and share learning from other areas;
- use the information collected and talk to key partners;
- will include people with learning disabilities and their carers to inform decision making and co-produce any new developments;
- review the deaths of those during the Covid period to capture any learning related to service changes.
- ensure the actions required are implemented;
- closely monitor the impact of reviewers being redeployed to frontline services, to prevent a back log of reviews.

6.0 NHSEI Assurances

There are 3 key priorities for LeDeR as a programme across the Midland and East

1. Improving the rate at which reviews are assigned. NHSEI have now specified that reviews should be allocated within 3 months and CCGs have to report on this monthly. 90% of local reviews have been allocated within 3 months.
2. Improving the length of time which it takes for the reviews to be completed. NHSE have now specified that reviews should be completed within 6 months and CCGs have to report on this monthly.
3. Ensuring action is taken to address the recommendations emerging from completed reviews.

There are also four key statements NHSE requires each CCG to report against when assessing how well we are doing with local delivery of the LeDeR programme.
These statements are:

- CCG's are a member of Learning from Deaths Report (LeDeR) Steering Group and have a named person with lead responsibility.
  - ✓ STW Rating is Green
- There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.
  - ✓ STW Rating is Green
- Each CCG has systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.
  - ✓ STW Rating is Green
- An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.
  - ✓ STW Rating is Green

Anyone can notify LeDeR of a death, including people with learning disabilities themselves, family members, friends and paid staff. Notifications can be made online via this link https://www.bris.ac.uk/sps/leder/notification-system/ or by calling 0300 777 4774.

7.0 Recommendations to committees

CCG Boards/ LD & A Board/ Safeguarding Board/ QC and PPQ are asked to:

1. Receive and acknowledge the key points identified in this report.

2. To note that the capacity of reviewers may become a concern in 202/21 due to redeployment of reviewers to frontline services.

3. To note that further assurances are requested from providers regarding the implementation of learning and improvement to ensure robust processes are in place to address the gaps identified and improve care for people with learning difficulties.