LeDeR Annual Update Report
April 2020 – March 2021

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 currently led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

During 2021/22 there will be significant changes to the LeDeR programme with a new platform, training and processes required to be in place in line with the development of the ICS (Integrated Care System), the LeDeR policy 2021 published in March 2021 outlines the changes. This policy introduces the inclusion of autism into the programme. New governance processes are required with Integrated Care Systems now becoming responsible for the delivery of the LeDeR programme including undertaking reviews and the delivery of improvements.

The NHS long-term 10 year plan (2019), 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".

The programme is led locally by the CCG Quality Team, with a Local Area Contact (LAC) leading work across both CCG's. Shropshire, Telford and Wrekin CCG have consistently been one of the best performing CCGs nationally, in the previous year being in the top 5% of the lowest number of unallocated cases and the one of the highest number of completed cases.

The CCG continues to support and train reviewers to ensure reviews are completed within timeframe and fully capture the learning. The Quality team and local reviewers 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 and autism with the aim of reducing health inequalities.

Locally, there has been significant learning which has resulted in changes being implemented across the systems, this has been supported and monitored by the local LeDeR steering group.

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.

Currently, for each death there is an initial review. As part of the 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 are 13 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. The new LeDeR platform commences on the 1st June 2021 which require the current reviewers to undergo further training to take place during May 2021.

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 arise from completed reviews to ensure service improvement for people with learning disabilities. Due to the Covid-19 pandemic there have been system pressures which has impacted on the ability for the steering group to meet in its entirety, this has now been resolved.
During 2021 the LeDeR programme has been undergoing significant changes, with the current web platform pausing on the 31st March 2021 until June 2021 (allowing for the platform changes to be implemented) and all CCG's were tasked with ensuring that outstanding reviews were completed, Shropshire and Telford and Wrekin met this target. The new LeDeR platform will commence 1st June 2021. The LeDeR team are currently managing the changes and ensuring that current reviewers will have further training to support the new platform. LeDeR reviews will recommence 1st June 2021.
As we move into ICS's (Integrated Care Systems) the new LeDeR programme is supporting a dedicated LeDeR work force which will have an impact on the current reviewer process.

3.0 National / Regional Progress

The LeDeR programme produced the Action from Learning Report 2019 – 2020, which was set up to better co-ordinate national responses to premature mortality review learning. Respiratory conditions remain the most significant cause of premature mortality for people with a learning disability. The collaborative brings together experts by qualification, professional experience and lived experience. The action from learning report details just some of the work that has taken place across the NHS over the past year in response to findings from reviews of deaths, with further examples provided via the Learning Disability Mortality Network on NHS Futures.

It contains information and examples of good practice at both a national and local level to show what has been learnt from the reviews so far of deaths of people with a learning disability and the changes that have happened and are planned as a result of that learning. The report also provides details of the actions taken to address the key clinical priorities identified from last year's LeDeR report namely: respiratory conditions, sepsis, reducing hospital admissions for people with complex care needs, constipation and cancer screening. This has all been shared with the steering group for wider distribution onto partners.

The NHS long-term 10 year plan (2019), 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”.
NHSE continue to provide a small amount of funding directly to the CCG, some of this has been used to provide administration support, care provider training, web site development, and easy read documents and to develop a small pool of reviewers 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.

There is a new LeDeR policy 2021, published March 2021 ‘Learning from lives and deaths – People with a learning disability and autistic people’. This policy sets out for the NHS, the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the programme from June 2021. It will serve as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR.
This policy outlines a number of changes to existing LeDeR processes. Some of these changes, such as the new review process, will need to be implemented by ICS’s in line with the changes to the web-based platform which will go live on 1 June 2021. Other changes, such as staffing models and local governance arrangements will need to change in line with the development of ICSs and relevant human resources processes. It will be the responsibility of ICSs to ensure that appropriate communications are in place for these in collaboration with their regional colleagues.
From 2021, adults who have a diagnosis of autism without a learning disability will also be eligible for a LeDeR review; further advice will be published in coming months.
By 1 April 2022 all changes within this policy must be implemented by ICS’s, subject to legislative changes relating to ICS’s being passed in coming months.

ICS’s should have a clear plan in place by 30th September 2021 for the new quality assurance structures and processes which will be implemented for LeDeR and fully operational from 1st April 2022. In the meantime, ICSs will need to agree with their regional teams how they will assure quality during this transition phase.
The roles expected of the LAC (Local Area Coordinator) will sit within the ICS. This is a different role to the current LAC role and there will be greater independence between the review team and the LAC in future, reviewers and senior reviewers need to be independent from providers of services, so should sit within commissioning arms of ICS’s, or be commissioned from a separate body within the NHS family or local authorities.
ICS’s should move towards teams of reviewers with senior reviewer and administration support roles as quickly as they are able. This should be a priority for LeDeR programmes within ICSs, to ensure robust quality reviews that use resources as effectively as possible.
Reviewers, senior reviewers and their administrative support will either be NHS or local authority employees (using appropriate IT equipment supplied for this purpose and encrypted to suitable standards).

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

Shropshire, Telford and Wrekin CCG remains one of the best performing CCG's nationally, continuing to meet the targets set by NHSE and ensures learning and actions are in place to reflect the learning from the completed LeDeR reviews.
In March 2020 NHSE tasked each CCG in England to complete all of their outstanding LeDeR reviews by December 2020, both locally and regionally the target was 100% achieved.
In preparation for the closure of the current LeDeR platform in March 2021 each CCG was again tasked with completing any outstanding reviews, locally we were 100% compliant, with 3 reviews outstanding due to Child Death Overview Panel (CDOP) and Police investigations (these were agreed with NHSE); these will transfer to the new LeDeR platform in June 2021.

During 2020/21 the Covid-19 pandemic had a significant impact on the LeDeR programme locally with several reviewers being redeployed to frontline duties, the completion of reviews continued but at a slower pace.
There has been Parent / Carer representation throughout the LeDeR process however this has been challenging during the Covid-19 pandemic. There has been co-production in processing the recommendations, interpreting the data and agreeing the learning and priorities, this is ongoing. Each LeDeR reviewer has consulted with family / carers; information has been shared and noted as part of the recommendations. There have been several reviews where family members have required support which has been provided. Whilst the LeDeR reviews often focuses on the final episode of ill health, locally we feel it is equally important to review earlier in the person's journey to ensure all learning is captured.
LeDeR is a permanent agenda item on the Learning Disability & Autism Board with active membership from several parent/care/advocacy groups.

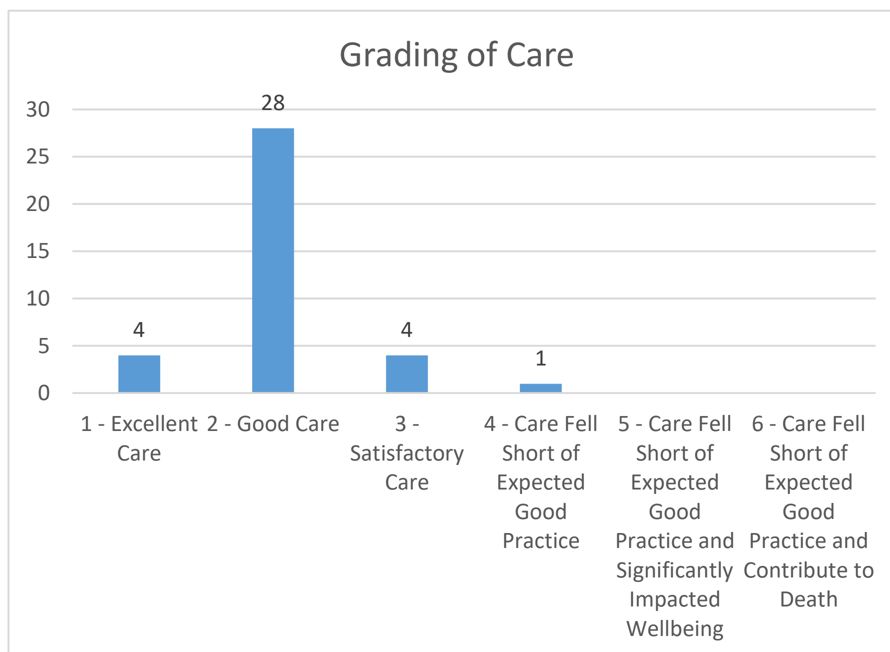
Locally, the county's population is estimated at 323,136 (2019).The Quality and Outcomes Framework (QoF) data indicates there are 1,654 in Shropshire (0.52% of the population) and 814 (0.42%) in Telford & Wrekin registered with a Learning Disability. Nationally the QoF data prevalence of learning disability is 0.5% of the population. Our commissioned Learning Disability provider MPFT is currently working across all Shropshire and Telford and Wrekin GP practices supporting with cleansing the GP learning disability registers and supporting with the uptake of annual health checks.

Since the LeDeR programme started in Shropshire, Telford and Wrekin in June 2017, there have been 83 deaths notified and 80 deaths reviewed. There are 3 outstanding reviews due to 2 CDOP and 1 Police investigation. Between April 2020 and March 2021, 25 deaths were notified locally, this is an increase from the 20 deaths reported across Shropshire and Telford & Wrekin in 2019-2020, this is likely to be have been impacted by Covid-19. 15 of the deaths were Shropshire patients and 10 Telford & Wrekin.

The average age of death in 2020-21 was 55 years. The causes of death were varied during this reporting period. Pneumonia accounted for the highest cause of death with 8 people having this documented as the primary cause. This was follow by 7 Aspiration Pneumonia, followed by Covid-19 at 7, Heart failure 5 and Cancer 4.

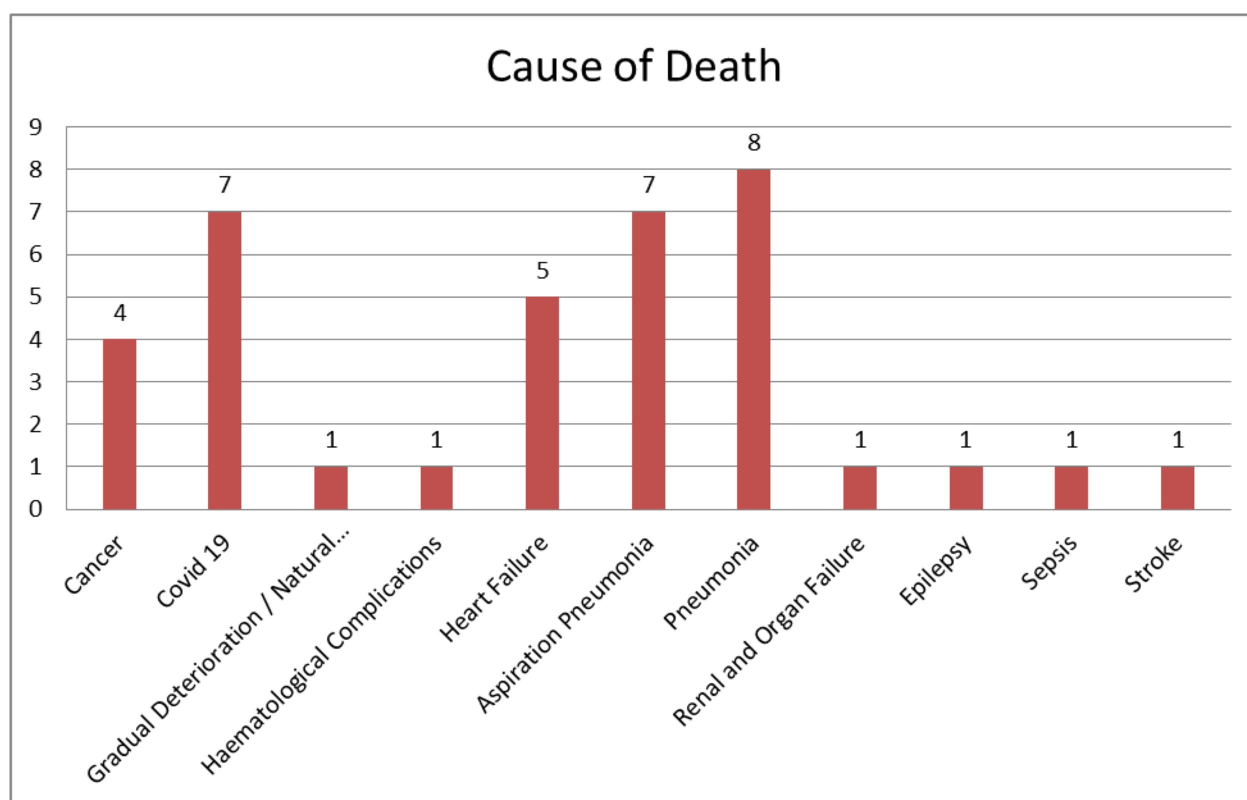
There were 37 reviews completed and submitted to the Bristol team in the 2020-21, this increase in number was due to the impact of Covid-19 on the reduced completion of reviews at the beginning of 2020, and several reviewers were redeployed.
Of the 37 completed reviews, just one person reviewed was from a BAME (Black, Asian and Minority Ethnic) background. The grading of care for this review was 2 - good care.

Table 1



As per table 1 : four of the reviews were graded as excellent care; twenty-eight reviews have been graded as good care; four graded as satisfactory care and one as 'care fell short of best practice'. In the one review identified as having some gaps in care, there were lapses which did not contribute to the death. The recommendations from the review had already been addressed and coordinated by CQC which has led to changes to practice.

Table 2

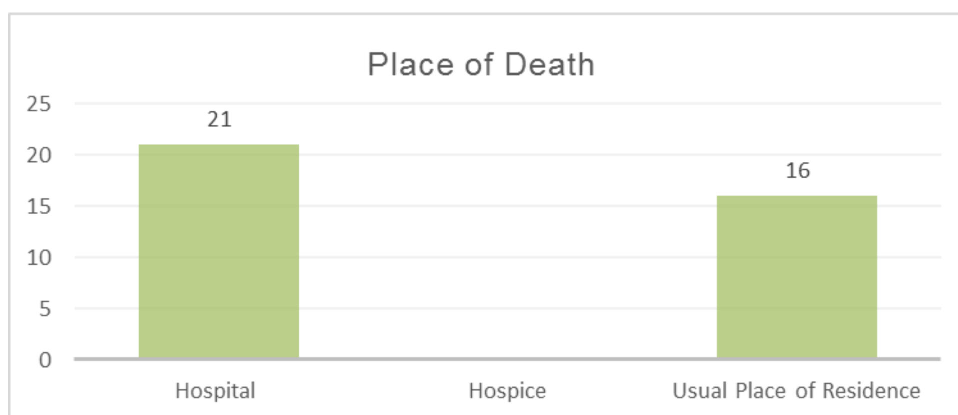


As per table 2: the causes of death were varied during this reporting period.

- Pneumonia accounted for the highest cause of death with 8 people having this documented as the primary cause.
- This was follow by 7 deaths due to Aspiration Pneumonia,
- Of the 7 Covid-19 deaths, 5 of these were confirmed hospital acquired Covid-19, of these 5 they were confirmed diagnosis of Pneumonia. 2 were confirmed acquired in the community,
- 5 deaths due to Heart failure
- 4 deaths due to Cancer.

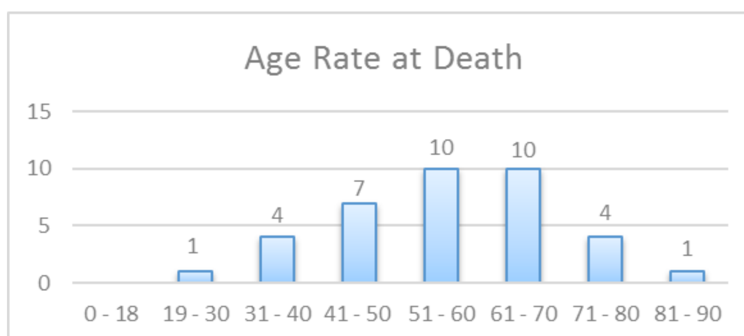
As a system, further work is being completed regarding the Covid-19 deaths; the local acute hospital is completing independent reviews into the hospital acquired Covid-19 deaths as per NHSE guidance (we have several LeDeR reviews which will be part of this), once this has been completed findings will be shared and this will be presented to the LeDeR steering group.

Table 3



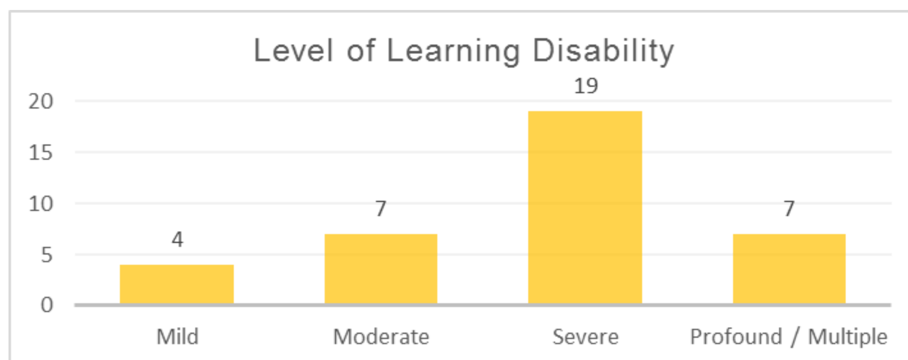
As per table 3: 21 patients died in Hospital, 16 died in their usual place of residence i.e. either a care home or their own private home.

Table 4



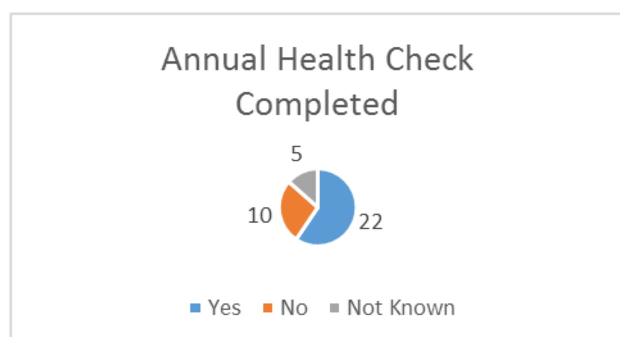
As per table 4 the mean age of death in 2020/21 was 55 years compared to 50 years in 2019/20. 19 of the deaths were males and 18 females.

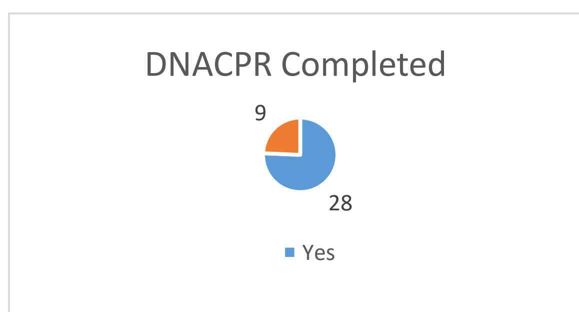
Table 5



As per table 5: this confirms that people with a severe learning disability continue to be the higher number of reported deaths.

Table 6 and 7





As per tables 6 and 7, completed Annual Health Checks and DNACPR.
The LeDeR reviews confirm that there has been has been an increase in the completion of Annual Heath Checks in 2020/21.

Locally, during 2019 / 2020 the percentage of Annual Health Checks completed was 48%, completed across Shropshire and Telford and Wrekin, during 2020/21 there has been a focus on the completion of annual health checks with the LeDeR action log focusing on increasing the uptake of the annual health checks, supported across the systems. The uptake has increased significantly during April 2020 -March 2021 there were 77.3% Annual Health Checks completed across Shropshire. Data shows the progress of completed Annual Health checks from April 2020 to August was 8.7% and at September was 12%. October was 17.4%, the numbers continued to increase month on month until March 2021 there were 77.3% completed.

In 2020/21 key areas for learning/development were:

- Annual Health Checks remain a priority
- Improve the uptake and quality of hospital passports
- Improved the hospital and carers policy and promote the use of this
- Integrating the acute liaison team within the hospital setting
- MCA and DOL's improve awareness and understanding
- Improve admission and discharge planning and communication
- Improve care of the deteriorating patient

The above key areas were the main focus of the LeDeR action log with each system providing support and regular updates of progress.

4.1 **What we have learnt in 2020/21**.

Much learning was gained from the 37 reviews completed in 2020/21. The recommendations made by reviewers, as identified below, will continue to be followed up in 2021/22.

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

- Continued promotion of the hospital carer's policy.
- 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.
- Appropriate consideration to wording of ReSPECT documentation including consultation with relevant parties
- LD liaison Nurses to be integrated within the acute hospitals

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 77.3% of people with LD receiving a health check.
- Increase the uptake of AHC's for 14-19 age groups and 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.
- 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. 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.
- Reasonable adjustments to be embedded in practice when planning the care of the person

4.1 What we did well

LeDeR:

Many areas of good practice were identified in the 37 reviews completed in 2020/21. 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.
- Increased uptake of Annual Health Checks
- Increased uptake of the completion of MCA and best interest decision assessments
- 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.
- Clear evidence of MDT working across all services
- Increase uptake of hospital passports and regular quality audits

Good quality reviews have been continuously submitted with only a very few needing returning for additional information. The findings of the reviews achieving level 2 or above have increased reflecting an improvement in the quality of care delivery. LeDeR reviewers continue to be committed to completing the reviews, and sharing the learning within their own practice areas. Regular support and Reviewer peer supervision has been in place throughout the period. Continual guidance and support from the LeDeR Local Area Co-ordinators i.e. sourcing hospital notes, GP notes.

The steering group met quarterly in 2020/21, 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.

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.

System Wide:

Shropshire Telford and Wrekin system has worked together to co-produce a 3 year Road Map LD&A 2021-2024 plan, to support people with learning disability and or autism.
'Our principles run through all the work, we do:-co production, collaboration, person centre, Learning and improvement, Value and respect and lead through example.'

There will be a focus on the health inequalities as part of this plan:

- Build on the AHC check offer by having the right people, on registers and identifying 14-19 year olds better
- Increase accuracy of LD registers, including clear criteria
- Start the development of ASD registers
- Develop and Implement STOMP (Stopping Over Medicating People with a learning disability, Autism or both) /STAMP (Supporting Treatment and Appropriate Medicine in Paediatrics) action plan
- Increase the scope of LeDeR reviews to those who are autistic
- Work as a system to consider how the new LeDeR policy will impact delivery
- Develop communications plan for LeDeR
- Set up LeDeR panel
- Develop Health Inequalities Assessment Tool (HEAT) for LDA
- Increase staff awareness of reasonable adjustments
- Address any access issues to IAPT services
- Increase MH services awareness, skills and competencies on ASD
- Update acute LD liaison nurses function
- Increased focus on improving activity levels within LD/A community
- Develop task and finish group to review pathways from CJS

Across the system there has been excellent support resulting in an increase in the uptake of Annual Health Checks April 2020 - March 2021 data shows an increase to 77% from 48% in the previous year.
There has been training around soft signs of the deteriorating patient; a training platform is in development where training will be accessible in the future.
There has been the development of a Website for the new CCG with LD and Autism webpages including access for professionals. There has also been the development of a co-produced webpage, easy read information.
The Local LD & A Board continue to meet monthly; there is excellent attendance and commitment from across the systems in order to deliver improved outcomes for those individuals who have a diagnosis of LD/ Autism.

5.0 Next Steps in 2021-2022

There are significant changes to the LeDeR programme as outlined in the LeDeR policy 2021 the recommendations need to be in place within the timeframe recommended by NHSE, this will have resource implications in the report please, and further details are being shared by NHSEI. There will be support but no financial support to implement these changes, this will be a cost pressure to the CCG and then ICS, but mandated by NHSEI.

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

We have a detailed local/system-wide LeDeR action plan to take forward priority actions within set-timeframes and named individuals responsible. The learning from the LeDeR reviews in 2020/21 will continue to build on current progress identified in the LeDeR action log but will focus on:

- How the system supports /increases the resources around reducing the risks associated with Pneumonia / aspiration Pneumonia. Aspiration Pneumonia was the highest category the previous year and also features in the recent data, therefore an increased focus on this area is required
- The learning disability team (CLDT) Continue to work 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)

- Further MCA/DOL's awareness training
- Further training in completion of the ReSPECT form
- Audit of the quality of the Annual Health Checks
- Consideration of individual/carer/family training re: healthy lifestyles
- Further work to fulfil the recommendations Thomas Oliver's McGowan's LeDeR process
- Continue with co-production with Parent/Carer representation
- Increased focus on the BAME population to ensure inclusivity
- Improving methods to detect failing / deteriorating health at a much earlier stage

The steering group will continue to meet on a quarterly basis.
The steering group will:

- agree a set of key local priorities for 2021/22 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/learning reviewed and are implemented
- ensure the LeDeR policy 2021 recommendations are in place within the timeframe recommended by NHSE

6.0 NHSE Assurances

There are 4 key priorities for LeDeR as a programme across the Midland and East

1. Improving the rate at which reviews are assigned. NHSE have now specified that reviews should be allocated within 3 months and CCGs have to report on this monthly.
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.
4. Rolling out the NHSE changes in line with the LeDeR policy 2021.

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/