NHS
Shropshire, Telford and Wrekin
Clinical Commissioning Group

Shropshire Telford and Wrekin Learning Disabilities Mortality Review (LeDeR)

Annual Report

This report covers the period from 1st April 2021 to 31st March 2022

Learning from lives and deaths of people with a Learning Disability and Autism

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Executive summary

The primary purpose of the Learning from Deaths of people with Learning Disability and Autism Review Programme (LeDeR) is to review the care each person has received leading up to their death and make recommendations that could help improve the care for other people and reduce premature deaths. Recommendations from each review are intended to highlight best practice and thereby support health and social care professionals and policy makers to implement positive change for people to have better experience of their care.

The purpose of this report is to share Shropshire Telford and Wrekin (STW) findings from LeDeR reviews and to report on the identified learning and the action we have taken to improve practice.

During 2021/22 progress with reviews in Shropshire Telford and Wrekin has been a challenge; reviewers were redeployed, found alternative employment, or retired and by end December 2021 none of our reviewers could continue to commit to the programme. STW Clinical Commissioning Group (CCG) received funding from NHS England for an external reviewer to undertake reviews and we would like to acknowledge the contribution that this made to the local LeDeR programme.
As part of the new LeDeR policy (2021) STWCCG awarded a contract to Southwest and Central Clinical Support Unit (SCWCSU) to undertake LeDeR reviews from 1st April 2022. The CCG will work closely with SCWCSU ensuring continued quality assurance of all reviews undertaken. The advent of a new multi-disciplinary STW LeDeR Governance Panel will enable scrutiny of the reviews and will feed into the LeDeR steering group.

Through the Shropshire Telford and Wrekin LeDeR Steering Group we have been proud to have people with lived experience and system partners who have engaged with the discussions and are passionately committed to making real changes across the health and social care system. We continue to strive to improve health outcomes for people with learning disabilities and autism with the aim to prevent people from dying prematurely, extend the average lifespan and to ensure that those with learning disability and autism are kept as healthy as they can be during their lifespan.

The core principles and values of the LeDeR programme are as follows:

- The programme overall must effect change and make an identifiable difference to the lives of people with learning disabilities and their families.
- We value the on-going contribution of people with lived experience, their families, and carers to all aspects of our work and see this as central to the development and delivery of everything we do.
- We take a comprehensive approach, looking at the circumstances leading to deaths of people with learning disabilities and autism and do not prioritise any one source of information over any other.
- The key principles of communication, cooperation and independence are upheld when working alongside other investigations or review processes.
- The programme overall strives to ensure that reviews of lives deaths lead to reflective learning which will result in improved health and social care service delivery.

This is why the LeDeR programme is so important. It represents a real opportunity to improve the lives of people with learning disabilities and autism.
There are several examples of good practice taken from discussions with family, friends, and carer discussions during reviews

- “The care home delivered end of life care, in a compassionate and professional manner”
- “Once diagnosed things were put in place very quickly regarding medication and a referral and acceptance at the hospice was quick, our son was transferred, and family and carers were allowed to support him whilst there”.
- “Our son was well known to community Learning Disability team and had good support from both the nursing team and the dietician, who were involved up until time of his death”
- “The Palliative care nurses were supporting the care home; their staff and the district nurses were visiting on a regular basis to support and manage the syringe driver”.
- “We had good support from our GP for both our daughter and the family”

Our key recommendations for 2022/23 are:

- Include an individual with lived experience on our Governance panel
- Reduce inequalities for people from minority ethnic communities
- Undertake further work to make improvements in all key areas we have identified this year, Health Action Plans, respiratory management, and cancer screening.
- Strive for better performance of Annual Health Checks
- Work with system partners to embed sustained learning and improvement of care for people with learning disabilities, ensuring learning identified from reviews informs day to day practice across our providers in health and social care.
- Undertake a system review to ensure End of Life Pathways are appropriately used and fully involve people with learning disabilities and autism and their families, including the use of accessible information and ReSPECT plans.
- Continue to promote and share action learning with the aim of ensuring all people with a learning disability and/or autism experience good and excellent care.
- Fulfil the recommendations Oliver’s McGowan’s recommednations.
- Fulfil the recommendations from Clive Treacey life and death review
- Align local recommendations with national recommendations
- Work with NHSe/I regional and national LeDeR teams to quality assure our reviews.
- Consider resource implications for the LeDeR programme across STW ICS

The STW Integrated Care System (ICS) must not rest upon the contents of this report. Instead, all partners across health and social care must embrace the findings of this report, only then will we ensure that every person with a learning disability and autism receives the high quality of care that they deserve.

On behalf of Shropshire Telford and Wrekin Clinical Commissioning Group:

Zena Young – Executive Director of Nursing and Quality and Senior Responsible Officer for LeDeR
Vanessa Whateley- Deputy Director of Nursing and Quality
Tracey Slater – Assistant Director of Quality and Local Area Contact for LeDeR

Acknowledgements

Shropshire Telford and Wrekin Clinical Commissioning Group would like to acknowledge the support provided to the LeDeR programme by the following organisations, groups, and individuals:

The families, friends, carers and health and social care professionals who have provided critical contributions to each LeDeR review. Their support has been invaluable.
Our LeDeR reviewers. Without their expertise, experience, and passion we would not be where we are.
Members of the LeDeR steering group, including a parent-carer, whose contribution has been instrumental in the LeDeR programme.
Northeast Commissioning Support (NECS)
Primary Care across Shropshire Telford and Wrekin
Shropshire County Council
Telford and Wrekin County Council
Shropshire Telford & Wrekin Child Death Overview Panel (CDOP)
Shrewsbury and Telford Hospitals
Shropshire Community Health Trust
Midland's Partnership Foundation Trust
NHS England and Improvement National Team
NHS England and Improvement Regional Team
Ms. Y. Gray – LAC- LeDeR programme
Mr R Gough - parent/carer

Introduction

The (LeDeR) programme was established to support local areas to implement a consistent format for the review of deaths of people with learning disabilities. The key principles of the programme are to identify learning from the review of deaths, for learning to inform service improvement initiatives and for those initiatives to effect meaningful change in improving outcomes for local people. A LeDeR review is not a mortality review. It does not restrict itself to the last episode of care before the person's death. Instead, it looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. LeDeR reviews take account of any mortality reviews that may have taken place following a person's death. LeDeR reviews are not investigations or part of a complaints process, and any serious concerns about the quality of care provided should be raised with the provider of that service directly or with the Care Quality Commission (CQC)

The new national LeDeR policy, published March 2021. Entitled 'Learning from lives and deaths – people with a learning disability and autistic people', set out for the NHS, 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. The programme is funded by NHS England with responsibility devolved to Clinical Commissioning Groups. The LeDeR programme is delivered through local partnerships across health and social care organisations in STW.

The policy outlines several changes to existing LeDeR processes. Some of these included changes to a web-based platform which went live on 1st June 2021. Other changes, such as staffing models and local governance arrangements were required to change in line with the development of emerging Integrated Care Systems (ICS's). The new policy, which looks at the life of a person as well as their death, now extends to include all people who are autistic – who do not have learning disability as well. During the platform transition it was acknowledged regionally and nationally by NHSE/I that there were some challenges and changes to the functionality of the LeDeR platform that led to delays in reviews. The functionality of the platform has not been fully resolved and NHSE/I is working to resolve these through a steering group.

The purpose of the LeDeR programme is:

- Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.
- Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.
- Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

The LeDeR process is summarised as follows:

- CCG/ICS are responsible for ensuring that LeDeR reviews are completed of the health and social care received by people with a learning disability (aged four years and over) and autistic people (aged 18 years and over) who have died, using the standardised review process.
- Each LeDeR referral is allocated to a LeDeR reviewer. These are trained health and social care professionals experienced in working with people with learning disabilities and autism.
- The purpose of the 'Initial Review' is to identify key learnings and recommendations to improve local health and social care services. To do this the LeDeR reviewer will consider relevant case records and speak to family, friends, and carers to form a 'pen portrait' of the individual and a coherent narrative of their care in the lead up to their death.
- Before each Initial Review is approved it undergoes a quality assurance process.
- Where there were significant concerns about the person's health and social care service delivery further information can be gathered through a Multi-Agency Review (MAR) or focused review
- On completion of the review (Initial or MAR), recommendations are made, and an action planning process identifies service improvements that may be indicated.
- The CCG/ICS needs to identify good practice and what has worked well, as well as where improvements in the provision of care could be made.
- Local actions are taken to address the issues identified in reviews. Recurrent themes and significant issues are identified and addressed at a more systematic level, regionally and nationally.
- Learning and recommendations from every completed LeDeR review is fed into national and local 'Learning into Action'.
- Deaths for children with a learning disability are reviewed as part of the Child Death Overview Panel (CDOP) process. In STW this is achieved through CDOP panels the learning and recommendations are then fed into STW LeDeR Programme and implementation of 'Learning into Action'.

This report provides an update on the progress and impact made across Shropshire Telford, and Wrekin from 1st April 2021 to 31st March 2022, it builds on the achievements made up to March 2021, and covers local progress in our first year as an integrated CCG across both counties and within our evolving ICS. The report reflects some of the extraordinary efforts of our partners to work together through a year that has continued to challenge health and social care providers. This includes the initial and subsequent peaks in the number of cases of the COVID-19 pandemic and some of the consequential implications of restrictions placed on services. It will undoubtedly take some time to fully appreciate the impact of COVID-19, on individuals health and on the health inequalities of people with learning disability and autism.

The programme in STW is led locally by the CCG Quality Team, with a Local Area Contact (LAC) leading the work. During 2021/22 the CCG continued to support and train reviewers on the new platform to ensure reviews were completed within timeframe and fully capture the learning. The LAC and local reviewers aimed 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.

There has been Parent/Carer representation on the steering group. There has been co-production in processing the recommendations and agreeing the learning and priorities, where applicable each LeDeR reviewer has consulted with family and 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.

There has been significant learning which has resulted in changes being implemented across the systems, this has been supported and monitored by the STW LeDeR Steering Group, which continues to meet on a regular basis with engagement system wide.

LeDeR is a standing agenda item on the Learning Disability & Autism Board with active membership from several parent/carer/advocacy groups.

Our Statement of Purpose

- That LeDeR reviews are allocated and completed to a high standard within the stipulated programme timescales.
- Ensuring action is taken to address the recommendations emerging from completed reviews via action plans, dash boards and steering group meetings thereby improving the quality of health and social care services and reducing the health inequality faced by people with learning disabilities and autism.
- All our work includes the following principles: - co production, collaboration, person centred, learning and improvement, value and respect and lead through example.
- The overriding principle, clearly set out in the Terms of Reference for the steering group (appendix 1) to affect meaningful change and improve outcomes for local people.
- The outcomes that we are aspiring to achieve include supporting longer, healthier, and happier lives for people with a Learning Disability across our Integrated Care System.
- That all stakeholders, including people with learning disabilities and their family, friends, and carers, feel an equal partner in the LeDeR programme.

Local progress in 2021/22

Last year's annual report stated the intention of the STW LeDeR programme for 2021/22 was to analyse the recommendations from the completed reviews and identify the key themes to undertake change and implement improvements. However, there have been several causal factors that have largely prevented putting all learning into action and making the desired improvements.
The COVID-19 pandemic had a significant impact on the availability of reviewers, across provider organisations and local authorities across STW to undertake reviews and attend the Steering Group. In April 2021 STW had eleven trained reviewers however this reduced to 4 by June 2021. In October 21 the Local Area Contacts (LAC), left the programme and was replaced with staff new to the role and the programme. The reviewers continued to reduce in numbers and by end of December 2021 the local reviewers could no longer commit to the programme. Therefore, no reviews took place in Q3 2021/22. Between January 2021 and March 2022 following a successful bid from NHSE/I STWCCG employed an external reviewer who committed to reducing the number of outstanding reviews. The position as of 31st March 2022 was 8 outstanding reviews from 21/22 including 2 on hold due to ongoing statutory investigations.

Shropshire Telford and Wrekin progress with Oliver McGowan recommendations

Oliver McGowan was a teenager who had mild autism, epilepsy and learning difficulties, and was admitted to Southmead Hospital in November 2016 after having partial seizures. An independent LeDeR Review found that his death was 'potentially avoidable'.
In 2019, NHS England and Improvement commissioned an independent panel to review Oliver McGowan's previous LeDeR Review.

The rationale for the review related to what had been described as a number of inconsistencies in the local quality assurance processes for LeDeR, and specifically some of the reports for Oliver's LeDeR review that were sent to the family via the Freedom of Information Act in 2018.

Additionally, Oliver's family had expressed their concern about a lack of transparency within previous reports and processes. The report forms the second part of a two-stage process – the first being to review and complete Oliver's LeDeR.
An independent investigation by Fiona Ritchie OBE, Chair on behalf of Oliver's Independent Panel found fundamental flaws in the LeDeR process and subsequently NHS England and NHS Improvement made recommendations for the national, regional, and local teams, particularly the governance arrangements surrounding local LeDeR programmes. One of the recommendations was "each CCG must formally undertake, document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review"

In response to these recommendations the STW integrated workforce strategy will be updated to include a training plan to improve staff knowledge and confidence in making reasonable adjustments for people with a learning disability or autism when the final training is available. This is expected during 2022/23.

The Oliver McGowen Mandatory training will ensure staff working in health and social care receive learning disability and autism training, at the right level for their role. They will have a better understanding of people's needs, resulting in better services and improved health and wellbeing outcomes. The next stakeholder event in STW is due to take place on 25th May 2022. Once The Oliver McGowan Mandatory Training trial is complete the Department for Health and Social Care will use the evaluation to inform a wider rollout of the training.

The full report can be found at:
NHS England » Independent Review into Thomas Oliver McGowan's LeDeR Process: phase two

Shropshire Telford and Wrekin response to the Clive Treacey life and death review

A portrait of Clive

Clive Treacey was young, only 47 years old, at the time he died at Cedar Vale in Nottinghamshire, a specialist unit for men with complex needs. Clive died on 31 January 2017 following a seizure and cardiac arrest from which he did not recover. His family have fought hard for the answers to their many questions about why he died, how it was that he spent so many years detained in specialist hospitals, why he was not kept safe from harm and why he did not get to live the life he and his family hoped for. His family have raised many questions about the events that led up to his death, remaining dissatisfied with the outcome of the investigations and the inquest that followed.

In July 2020, NHSE/I Midlands commissioned an independent review in line with the principles of the Learning Disability Mortality Review (LeDeR) programme methodology, into the serious matters raised by Clive's family about his experience of care and the circumstances leading up to his death. The review found that Clive's death was 'potentially avoidable'. There were multiple, system-wide failures in delivering his care and treatment that together placed him at a higher risk of sudden death as set out in the report.

Clive should not have spent so many years of his life detained in specialist hospitals. There were extensive periods when he experienced an unacceptably poor quality of life and where he was not always kept safe from harm.
Following the Clive Treacey report and the SAR event, a national initiative was launched to ensure people with learning disabilities received a safe and well review, this included a number of elements that hadn't previously been considered or questioned as part of a

patient review. Each CCG held a number of scrutiny panels consisting of Clinicians, Medical, experts by experience, non-clinical and social care colleagues to discuss in detail the finding of the reviews, many of which prompted additional actions for the case managers to go back and further investigate, but also a number of themes were identified which will be discussed as part of the STW LD&A Board and potentially escalated to the ICS MH LD&A Programme Board. Learning events and provider collaborative planning meetings have been scheduled during May 2022 to review the learning and plan future action. There were more than 30 people invited to the events, however, at the time of writing this report they were cancelled last minute by NHSEI to be postponed until early June.

The full review can be found at: www.england.nhs.uk

Local provider progress 2021/22

Midlands Partnership Foundation Trust (MPFT)

Over the last year, MPFT have continued to work proactively alongside system partners to deliver on key health focussed targets in the local LeDeR action plan. MPFT have continued to champion the health needs of people with learning disabilities in Shropshire and Telford and Wrekin with a focus on reducing health inequalities and improving health outcomes. Key areas of focus for adult learning disability services in MPFT have included:

- Improved LD&A training within the Acute Trust (including ReSPECT documentation and MCA)
- Ensuring Acute Liaison Nurses (ALN) are based on the acute sites, with access to all relevant clinical systems and are visible on wards
- Annual Health Checks (AHC) – ongoing cleansing of GP registers; GP training, MPFT HealthCare's following up with face to face home visits when AHC appointments have been Did Not Attend (DNA); GPs are sharing lists of all patients who are overdue AHCs for face to face follow ups; supporting with pre-health check questionnaires; MPFT are flagging areas of concern back to GPs for follow up and prioritisation; developed bespoke training for Shared Lives and social care providers to outline what carers should expect from the AHC
- Covid Vaccinations – support provided regarding reasonable adjustments, clinical holds, and Mental Capacity Act (MCA) Best interest (BI) decisions.

MPFT has robust governance systems in place to ensure the learning from national and local LeDeR and internal Trust mortality reviews are used to both celebrate and promote best practice, and to take action to improve service delivery where needed. Key actions taken forward by this year have included:

- Initial assessment paperwork now includes a question on both Covid Vaccination and AHC status.
- Information regarding covid risk provided to all highest risk groups (including people with Down's Syndrome and/or from BAME communities).

- Review and development of the Physical Health Pathway for service users with learning disabilities prescribed antipsychotic medication (in line with Stopping over medication of people with a learning disability, autism, or both (STOMP) agenda
- Provision of Aspiration Pneumonia Training to the STW system via Joint Training.
- Epilepsy Care Pathway updated (includes Sudden death in Epilepsy (SUDEP) risk assessment), all staff received epilepsy awareness training and audit underway to review compliance with the epilepsy care pathway.
- Constipation – provision of staff training on the soft signs of deterioration and promotion of "Stop and Watch" resources and MPFT on-line training.

Shropshire County Council

Working collaboratively with parents, carers experts by experience, advocacy and other partners Shropshire Council's People's direct are planning the consultation for their Autism and Learning Disability strategy updates. We are also working closely with our colleagues in Public Health to address health inequalities and they link in with our partnerships board and ongoing work. In particular our Learning Disability Partnership Board members are going to be working with Health Watch and colleagues in the CCG to look at accessibility of health services along with our provider colleagues who are leading on the Treat Me Well campaign

Shropshire Council runs internal learning reviews following adverse incidents from which we are aware that there are opportunities to learn and develop our service. These are run on a case-by-case basis following a referral through to the Principal Social Worker. Action plans are developed and reviewed as a result of the learning from the learning reviews. Recently we have also been running some workshops looking into the life and death of Clive Treacey. Staff have been encouraged to reflect on the independent report and to consider the learning for Adult Social Care. Findings and reflections from this exercise will inform a report to Managers and an action plan for improvement.

Telford and Wrekin Council

Telford and Wrekin Council continue to see the benefits of a dedicated Learning Disability and Autism front line Social Work team supporting people residing and placed by Telford and Wrekin Council, supported by a Specialist Autism lead to improve practice and commissioning of services for Autistic people.

Completion of the Learning Disability strategy and pre-consultation of the Autism Strategy reinforced the importance of embedding healthy lifestyles within social care settings and care provision. Working with agencies such a Leisure Service, Public Health and specialist Learning Disability and Autism health services systems continue to push services to work together in reducing health inequalities and improving outcomes for people.

Learning from national and local LeDeR reviews also continues to drive improvements and enhance the quality of support provided. Activities to improve quality of provisions, working in partnership with experts by their experience, parent carers and specialist organisations

that champion the views of people who use services and identify improvements and drive positive change is at the heart of our co-production commitments.

Support for Care Homes across Shropshire Telford and Wrekin

The Community Learning Disability Team visited care homes to improve the understanding of the 'softer signs of illnesses. 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 those caring for people with LD and A 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. Care home provider organisations have also undertaken work to highlight softer signs of deterioration.

- The Community Learning Disability Team (CLDT) commenced a risk assessment of each person registered with the service – physical and mental health needs were assessed, and support given to the level of risk and reviewed regularly. (Green stable -monthly visits, Amber could possibly deteriorate- reviewed individually, Red - deteriorating patient weekly contact)
- The Community Learning Disability Team continue to provide face to face visits throughout the pandemic, where a person was considered vulnerable.
- Annual health checks continue with blended home visits and virtual (video link) - feedback from patient/carers/providers has been very positive
- Covid-19 passports were completed, online training i.e., awareness training for care staff
- A targeted approach with all LD providers promoting and raising awareness of annual health checks
- Easy read documents shared with the local community and partners

A video was developed by local young service users to encourage attendance at Annual health checks https://www.shropshiretelfordandwrekinccg.nhs.uk/your-health/local-services/learning-disabilities-and-special-educational-needs/annual-health-checks/

Primary Care -Learning Disability Annual Health Checks (LDAHCs) 2021-22

Although GP practices were asked to prioritise the COVID-19 vaccination programme throughout the year, practices continued to complete LDAHCs recognising the importance of this work in addressing health inequalities. The Omicron booster campaign during quarter 3 and 4 and the high local incidence of COVID-19 during March and April impacted on the local delivery of LDAHCs with the completion rate being lower than anticipated.

In 2022-22 Shropshire Telford and Wrekin completed LDAHCs for 65% of those patients on the practice Learning Disability (LD) register (1577 patients) with 18 practices achieving over the national target of 75%. This is below the national average of 71.8% and a local decrease from the 77% achieved for STW in 2020-21.

GP Practice LD register list sizes have continued to grow as lists and coding are reviewed. There has been an increase of 138 people registered with LD in the year rising to 2436 in March 22 from 2298 in April 2021.

STWCCG have worked with practices and partners to continue work to improve the offer and uptake of quality of Annual Health Checks for people with a Learning Disability throughout the year. As a system we are committed to the aspiration of offering 100% of people with a learning disability an annual health check.

Some of the key progress made during 2021/2022 is listed below.

- A local webinar was held to focus on the importance of reviewing coding at practice level and to examine processes and good practice. Stirchley Medical Practice shared their practical experience of growing their practice LD register and the learning was shared with all practices.
- A new local LDAHC quality audit tool was developed and then piloted in autumn/winter 2021. The learning has been shared with all practices. A programme of scheduled visits will start in 2022/23.
- Regular data collection and close monitoring against STW targets.
- Regular comms to practices with links to updates and resources to use.
- The MPFT Community Learning Disability Team continue to offer support to practices in terms of extra resource to complete base line observations, carrying out home visits and offering advice and support on improving quality.
- PCNs are encouraged to identify a LD lead and to share good practice across practices.
- Training is offered to practice staff.
- Engagement with advocacy groups, carers and families.
- LDAHCs included in LA training for Social Work teams.
- LDAHCs included in LA tender process on provider framework.
- Continued links with local special schools and colleges.

Plans for Learning Disability Annual Health Checks 2022/2023

- Recovery Plan: This year the initial focus for quarter 1 is to reach those who are overdue with their LDAHC and to complete these asap.
- For 2022/23 focus will pick up the work to engage the 14–18-year age group, working jointly with SEND Teams, specialist schools, The Local Authority and Parent & Carer groups to ensure LDAHC's are embedded within services i.e., EHCP's and that YP are captured on the GP LD register and offered a LDAHC.
- Work will also take place to identify and understand local variation, continue to review, and improve quality, and increase the accuracy of LD registers. A schedule of LD quality practice visits will be undertaken by the CCG and practices will be encouraged to use of the audit tool annually to support this work.
- During quarter 4, 2021/22 we also saw an increased numbers of DNAs to appointments locally from 5 in Q3 to 40 in Q4. Although this is understandable due to high local rates of COVID-19, this will be further investigated and discussed as part of the quality audit review.

LeDeR structure and Governance

The lead for the programme is STW CCG Executive Director of Nursing and Quality. The day-to-day management of the LeDeR Programme has been undertaken by the Local Area Contact (LAC) with administration support. The STW Steering Group provides bi-monthly updates to STW Learning Disability and Autism Delivery Group who provides updates to the Learning Disability and Autism Board. During Covid, representatives have attended Steering group via Microsoft teams. The Steering Group is chaired by STW LAC, and the group takes strategic level oversight of the reviews of deaths of people with learning disabilities and drives transformation to improve care.

The role of the LeDeR Steering group is to have clear Terms of Reference, agreed by membership, which reflect:

- The scope and purpose of the forum
- Representative membership
- Governance arrangements including responsibility, accountability, and reporting arrangements.

The newly formed Shropshire Telford & Wrekin LeDeR Governance Panel has been established in accordance with the NHS England directives of the Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy of March 2021. The purpose of the panel is to receive a summary of anonymised review case reports pertaining to deaths relating to people with learning disabilities or autistic people to contribute to a collective understanding of learning points and recommendations. The Governance panel will advise the LeDeR steering group of the findings from the reviews and in turn the Steering group will take this forward. The terms of reference can be found in appendix 2

Performance of Shropshire Telford and Wrekin LeDeR programme

About the people who died- Pen portrait

All the reviews include a pen portrait of the person who died.
This gives a real sense of the person; their likes and dislikes, their favourite things, what they liked to do, their friends and family, what kind of character and personality they had. The reviewers have found out some amazing things about individuals by talking to friends, family and carers however have also found out about a few people who had sad lives; some who had spent time in institutional care which may have had an impact on them for the rest of their lives. These portraits help the reviewer connect to the person and remind us to consider whether the care and treatment they received has been of a high enough standard.

Undertaking a review can often result in exposure to distressing details of the circumstances leading up to a person's death. Contact with bereaved relatives and care staff can also be emotionally demanding. It is therefore important that reviewers are supported appropriately in order that they can carry out their role effectively and with compassion. The requirement for remote working and the impact of the pandemic (both emotionally and in terms of the volume of notifications requiring timely completion) has meant that the LeDeR LAC role has been as vital as ever in supporting reviewer wellbeing and an outstanding level of timely and consistently high standard completed reviews.
The process for the quality assurance and approval of all completed reviews has been maintained throughout this year, despite periods of redeployment to alternative but vital clinical roles during the pandemic. The process of quality assurance does however mean that the friends and families of people with a learning disability who lose a loved one can feel confident that relevant aspects of learning are drawn from each LeDeR review with the aim of influencing improvements in the healthy future lives of others. Where the potential for care gaps or failings are apparent within the detail of an individual LeDeR review the LeDeR programme will work alongside colleagues and families to ensure alignment or escalation to appropriate statutory processes including NHS provider Serious Incident reporting, Safeguarding Reviews and Coroner's Office proceedings.
Notifications continue to be predominantly made by Community Learning Disability Nurses or Learning Disability Acute Liaison Nurses.
The pattern of notifications received by STW is detailed in **table below**

Table 1

Summary of deaths notifications in 2021/22

Total notifications 1st April 2021- 31st March 2022	28
Total notifications not yet assigned to a reviewer (31st March 22)	8
Number of initial reviews	20
Number of focussed reviews	0
Number of reviews on hold (as above undergoing statutory investigations)	2 (2020 & 2018)
CDOP (included in outstanding reviews)	1
Completed reviews in 2021/22	20

As discussed in the introduction, due to resource pressures there are eight reviews that will be required to be carried over into 2022/23, including two that are currently on hold) At the point of notifying a death there is an option to advise of any initial concerns with the death, this ensures priority is given to reviews where concerns with the death have been identified.

Demographic data and equality impact

As at 01.01.2022 the population of Shropshire Telford and Wrekin is 518, 272

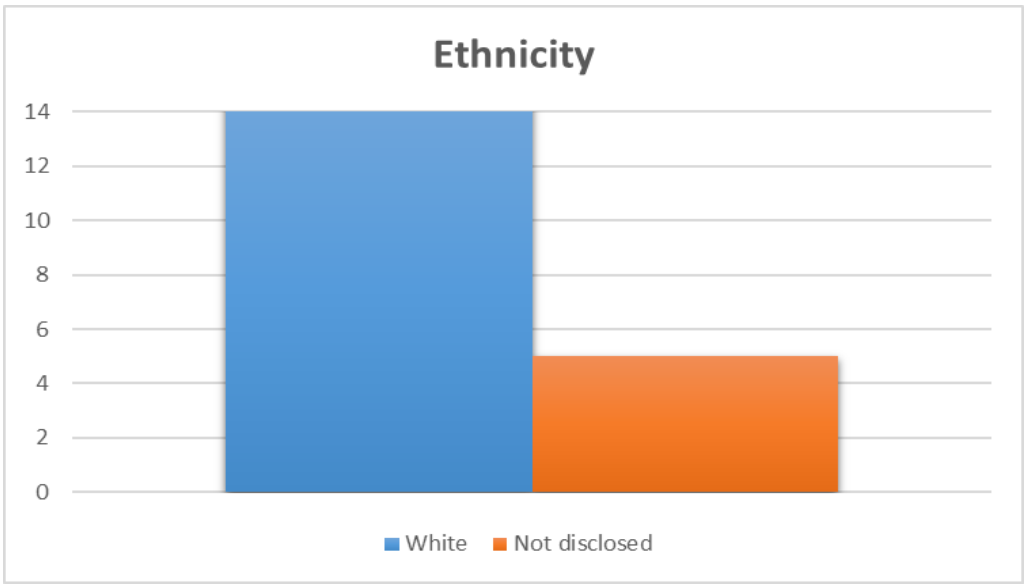
The Quality and Outcomes Framework (QoF) data indicates there are 2359 people across Shropshire Telford & Wrekin registered with a Learning Disability (0.48% of STW population). Nationally the QoF data prevalence of learning disability is 0.5% of the population. At the time of writing the report local data for Autism is being corroborated however both the Autism society and local authorities calculate the population with autism to be based on 1% of the total population. This would equate to 5183 people with autism across STW. The age and gender breakdown for LD is in the table below

Table 2

Age	Female	Male	Total
0-9	44	84	128
10-13	21	56	77
14-17	55	76	131
18-24	145	260	405
25-34	187	323	510
35-44	116	192	308
45-49	68	89	157
50-54	69	109	178
55-69	63	86	149
60-64	47	68	115
65-69	39	44	83
70-74	34	32	66
75 and over	32	20	52
Total	**920**	**1439**	**2359**

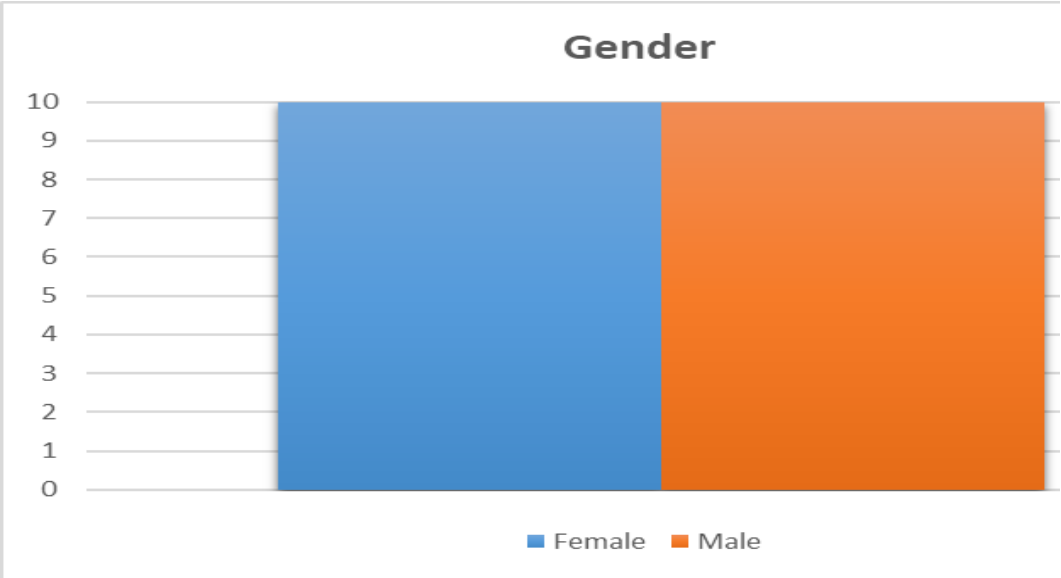
Ethnicity

Table 3



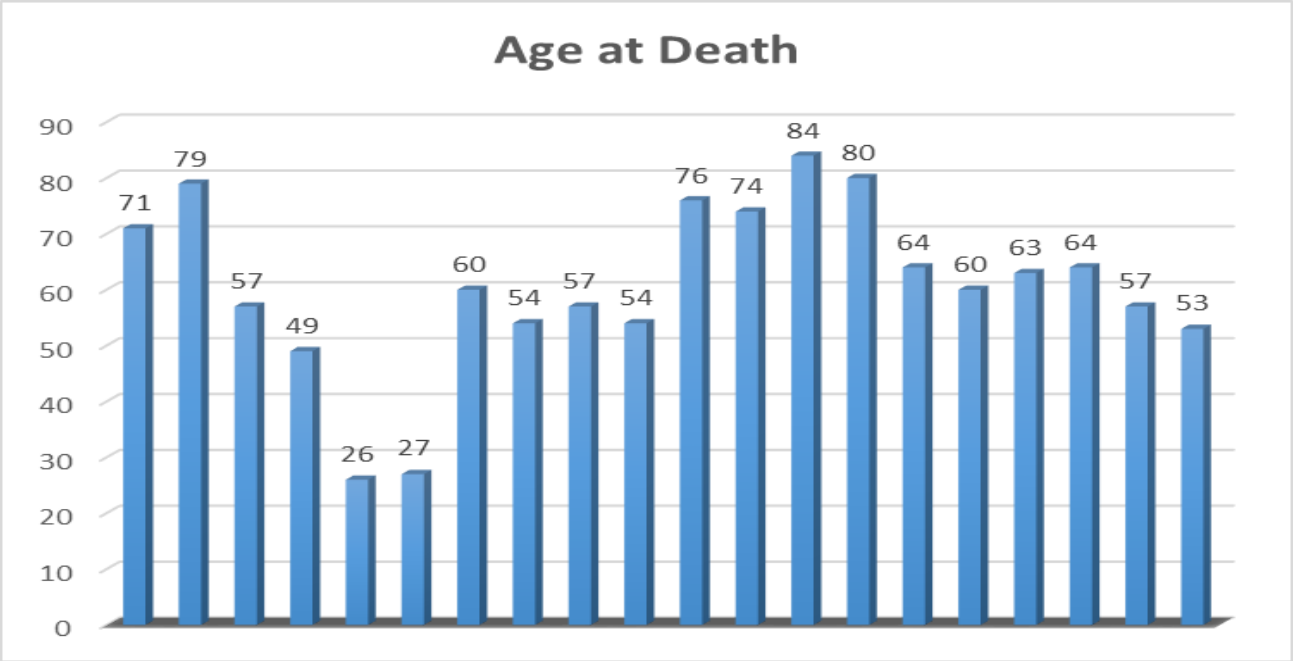
At the point of notification 5 of the reviews did not state what the ethnicity of the person was who had died. It could be that this information was not available, however a recommendation to the steering group is that there is an improvement in data capture, specifically but not exclusively for ethnicity for notifications in 2022/23.
STW have links with people from minority ethnic communities Every LeDeR steering group has been asked to identify a named lead for their area who will ensure that the challenges faced by people from minority ethnic communities are considered and addressed as part of local LeDeR work. For all minority ethnic service users on our Community Learning Disability Team caseloads, we have ensured that thought-out the pandemic all wellbeing calls (and clinical contacts) have included consideration of heightened risks and we have used these contacts to promote and proactively supported covid vaccination for this group. As a recommendation this could be strengthened during 2022/23, This will be done in conjunction with the CCG/ICS Equality and Diversity lead and system organisations.

Gender
Table 4



Nationally there are more deaths of males than females. Across STW there is an equal divide between males and female deaths

Table 5

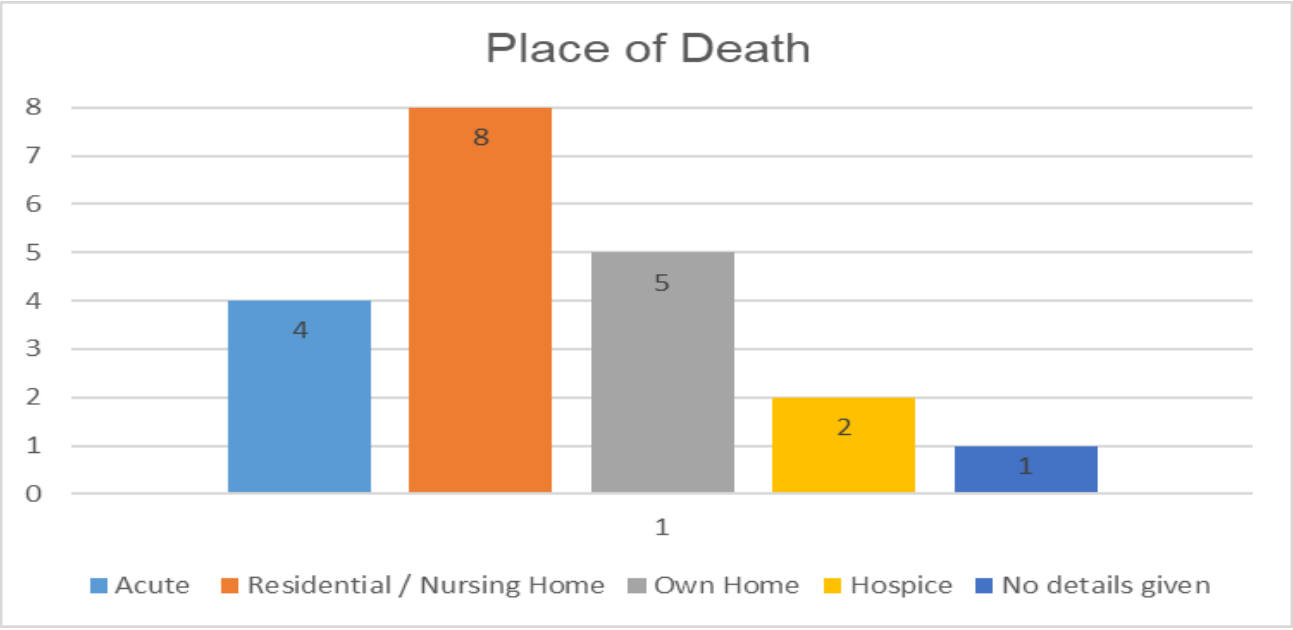


Nationally the average age of death for a person with learning disability is 61. People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability are dying earlier than they should, many from things which could have been treated or prevented.

In STW the average age of death for 2021/22 is age 60 years, compared to 55 years in 2020/21 and 50 years in 2019/20.
The learning from deaths of people with a learning disability (LeDeR) programme across Shropshire Telford and Wrekin was set up as a service improvement programme to look at why people are dying and what we can do to change services locally and nationally to improve the health of people with a learning disability and reduce health inequalities. By taking the findings of the reviews and establishing more about why people died we can understand what needs to be changed to make a difference to people's lives.

Place of death

Table 6



As per table 6, thirteen patients (65%) died in their usual place of residence, i.e., either their own home or a care home.

Cause of Death

(Taken from part 1a on the death certificate)

Table 7

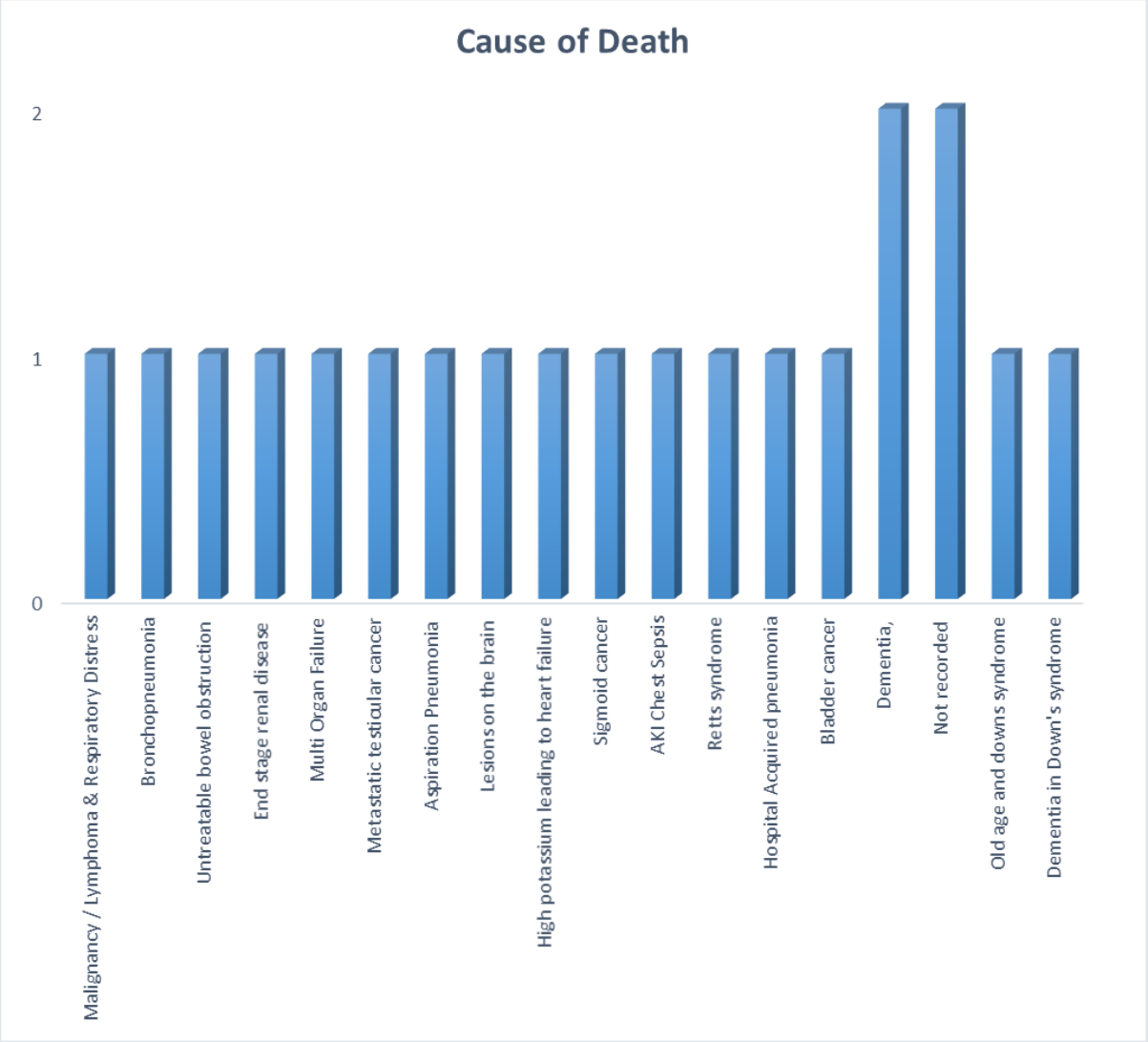
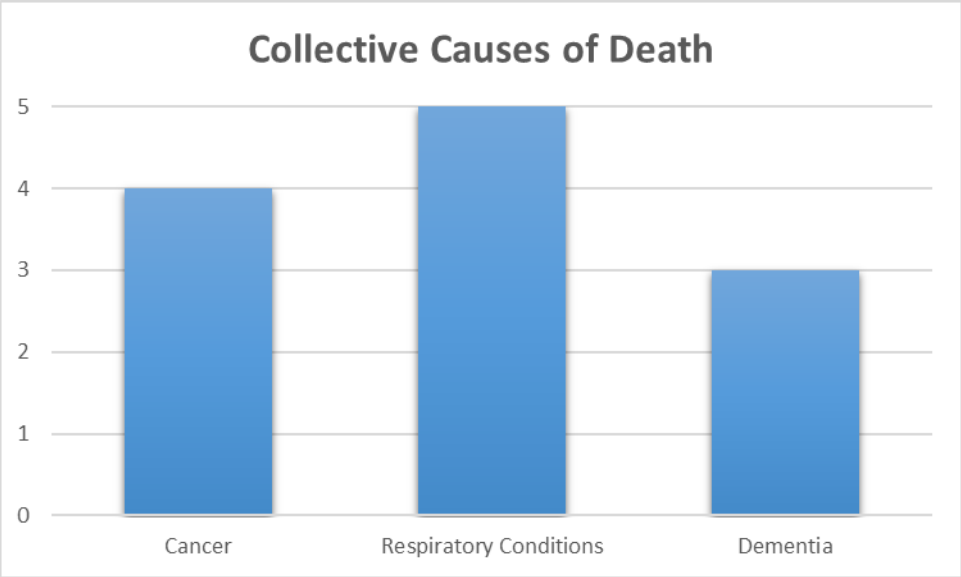


Table 8



As per table 7 the causes of death were varied during this reporting period

As per table 8 the top three themed causes of death are:

- Respiratory conditions, which counted for the highest cause of death with five (25%) people having this documented as the primary cause
- This was followed by four (20%) cancer related deaths
- Three (15%) patients had dementia as a primary cause

Nationally it has ben acknowledged that a significant number of deaths of people with Learning disabilities are as a result of respiratory conditions. Two national pieces of work commissioned last year by the LeDeR team and delayed by COVID-19 are now back on track to be delivered in 2022: NHS England and NHS Improvement commissioned guidance on pneumonia and aspiration pneumonia from the British Thoracic Society – whose members include doctors, nurses and respiratory physiotherapists and which champions 'Better lung health for all'. This guidance is being co-produced with people with lived experience. • The NHS RightCare programme, which makes recommendations to improve healthcare, is developing guides to improve the outcome for patients with respiratory conditions. As part of this it is working with the learning disability and autism programme to develop a RightCare pathway scenario for bacterial pneumonia care.

National LeDeR reviews tell us that people with a learning disability who have cancer can be diagnosed late; diagnostic overshadowing is sometimes an issue; access to investigations can be poor due to lack of reasonable adjustments and assumptions about ability or willingness to tolerate tests. Improving access to screening for people with a learning disability and autism is vital learning from national LeDeR reviews. NHSE continue to work to reduce inequalities in screening, including by informing

people of their choices, making services easier to access and supporting people who are diagnosed with cancer, and in partnership with the screening and immunisation team and Public Health England increase participation in national screening programmes.

Covid-19

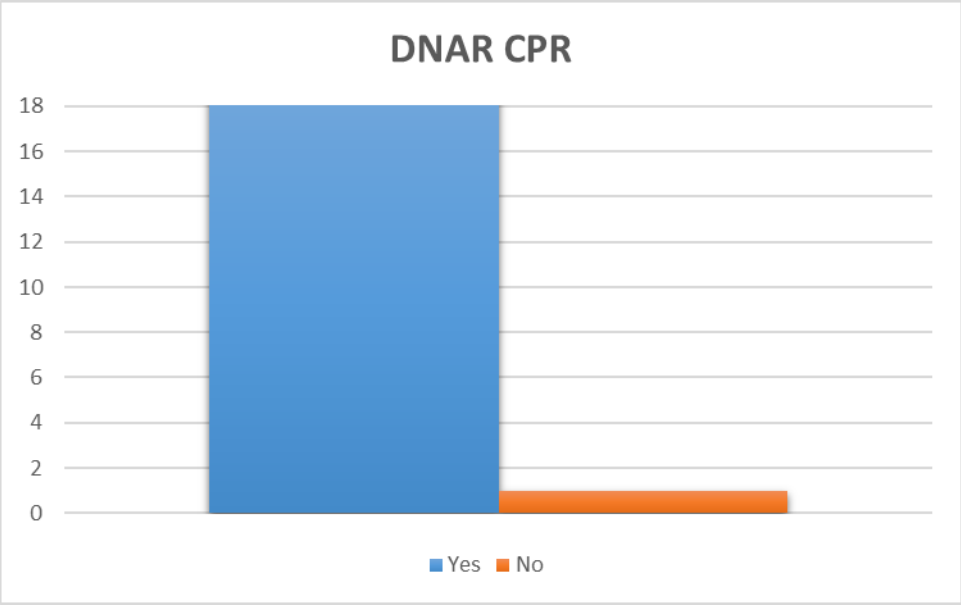
There were no covid deaths reported from 1st April 2021- 31st March 2022

Despite the challenges encountered because of the Covid-19 pandemic, the past year has seen some positive work and continued drive by local Learning Disability specialists in our hospitals and community providers. The local teams have had a focus on ensuring all those with a learning disability are offered Covid-19 vaccinations

The impact of Covid 19 may still to be evaluated fully on the LD and A population. The programme will continue to review all deaths where individuals have contracted Covid-19. Improvements in the national vaccination programme and learning from looking at the individual deaths should enable LeDeR to progress some of the key themes from these deaths throughout the coming years.

End of life

Table 9



As per table 9 the DNAR status shows improvement from 75% in 2020/21 to 95% completion in 2021/22. DNAR is captured on the LeDeR platform however the completion of ReSPECT documentation (Recommended summary plan for emergency care and treatment) is not part of the functionality of the platform to capture this data. Going forward into 2022/23 STW will ensure that this is captured

on a LeDeR dashboard and completion will be discussed at both steering group and governance panel

Learning from reviews

What we did well

- Many areas of good practice were identified in the 20 reviews completed in 2021/22. 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.
- 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 homes 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 cited in a number of reviews.
- Clear evidence of MDT working across all services
- Continued guidance and support from the LeDeR Local Area Co-ordinators i.e., sourcing hospital notes, GP notes.
- The steering group met bi-monthly in 2021/22 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.
- Increase the scope of LeDeR reviews to those who are autistic
- 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.

Examples of good practice taken from discussions with family, friend and carers during reviews

- "The care home delivered end of life care, in a compassionate and professional manner"
- "Once diagnosed things were put in place very quickly regarding medication and a referral and acceptance at the hospice was quick, our son was transferred, and family and carers were allowed to support him whilst there".
- "Our son was well known to community Learning Disability team and had good support from both the nursing team and the dietician, who were involved up until time of his death"
- "The Palliative care nurses were supporting the care home; their staff and the district nurses were visiting on a regular basis to support and manage the syringe driver".
- "We had good support from our GP for both our daughter and the family"

Conclusion

The report provides detail of how the LeDeR process has been implemented, demonstrating how our governance arrangements support a robust approach to learning from deaths of people with learning disabilities and autism
National changes are being implemented as we also develop into an ICS. We are passionately committed to keep learning from reviews to continue to drive an innovative work programme that will make changes to improve services and address health inequalities experienced by people with learning disabilities and autism

Recommendations and next steps

- Continue to deliver as per national LeDeR policy and our 3-year LeDeR strategy will build on our successes, will further strengthen partnership working and actively improve the lives and death for those with Learning Disability and for autistic people.
- We will further develop our local dashboard to include elements that are identified in reviews but not captured on the LeDeR dashboard
- Improve recording of demographic data from notifications
- Review and audit the use of the health passport to ensure consistency of use across STW
- Increase demographic reporting, in particular ethnicity
- Work with SCW CSU on outcomes and findings from LeDeR reviews, ensuring all reviews are quality assured and sharing findings from the reviews from the newly formed Governance panel.
- Include person with lived experience on governance panel
- Strengthen links to ethnic minority communities raising awareness of how to report a death to LeDeR. This will be done in conjunction with the CCG/ICS Equality and Diversity lead and system organisations
- Reduce inequalities for people from minority ethnic communities Every LeDeR steering group has been asked to identify a named lead for their area who will ensure that the challenges faced by people from minority ethnic communities are considered and addressed as part of local LeDeR work. Their role includes ensuring that reviewers understand the challenges faced by people in accessing services, establishing links with organisations that represent minority ethnic groups, raising the profile of LeDeR and increasing the notification of deaths from minority ethnic communities proportionate to the local communities. The new LeDeR policy outlines the requirement to carry out a focused review for every person from a minority ethnic community to learn how to address any additional inequalities relating to race and ethnicity.
- Undertake further work to make improvements in all key areas we have identified this year, Health Action Plans, respiratory management, cancer screening.
- Strive for better performance of Annual Health Checks. The learning disability and autism programme is committed to ensuring that 75% of people with a learning disability on GP learning disability registers receive an AHC to

identify health issues before they become a problem. STW should strive to achieve higher than national requirements on this.

- Work with system partners to embed sustained learning and improvement of care for people with learning disabilities. Ensuring learning identified from reviews informs day to day practice across our providers in health and social care.
- Undertake a system review to ensure End of Life Pathways are appropriately used and fully involve people with learning disabilities and autism and their families, including the use of accessible information and ReSOECT plans.
- Greater emphasis on thematic review of LeDeR review findings, in particular but not exclusively cause of death aligning with national work
- Continue to promote and share action learning with the aim of ensuring all people with a learning disability and/or autism experience good and excellent care.
- Further work to fulfil the recommendations Oliver's McGowan's LeDeR process
- Further work to fulfil the recommendations from Clive Treacey life and death review
- Align local recommendations to national recommendations in accordance with the LeDeR policy.
- We have a detailed local/system wide LeDeR action plan to take forward priority actions within set timeframes and named individuals responsible.
- We will work with NHSe/I regional and national LeDeR teams to quality assure our reviews.
- Consider resource implications for the LeDeR programme across STW ICS
- This report once signed off by the Governing Body will be published on CCG websites as per NHSEI request.
- It will also be shared with the CCGs Quality and Performance Committees in Common, System Quality Group and LD & A Board

Measuring success

STW ICS are committed to extracting learning from LeDeR, implementing actions, and demonstrating change with ongoing commitment to sustainability of change,

Achievements will be evidenced, monitored by LeDeR Steering group, and measured by:

- A reduction in the early deaths of people with a learning disability
- Positive feedback from reviews of the quality and standards of care
- Achievements and progress of identified actions from our local LeDeR action plan
- Local dashboard data from completed LeDeR reviews evidencing increase in annual health checks, use of MCA framework, ReSPECT documentation, demographic data capture.
- Audit of action plan to ensure we are capturing all the learning and recommendations from the completed LeDeR reviews
- Benchmark local performance against national standards

More information on the LeDeR policy can be found at:
B0428-LeDeR-policy-2021.pdf (england.nhs.uk)

Any person can make a notification by accessing (leder.nhs.uk)

The national LeDeR report for 2020/21 can be found at: LeDeR-Action-from-learning-report-202021.pdf (england.nhs.uk)

Appendix 1

Shropshire Telford & Wrekin ICS
LeDeR Steering Group
Terms of Reference

Background

The Learning from Lives and deaths- people with a learning disability and autistic people (LeDeR) Programme was established as one of the key recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPoLD) (2013). During 2021 the programme will expand to include the lives and deaths of autistic people.

The aim of the Programme is to drive sustainable improvement in the quality of health and social care service delivery for people with learning disabilities or autistic people, to help reduce premature mortality and health inequalities in this population, Reviews will be undertaken to help clarify contributory factors for the cause of death that contribute to the overall burden of excess premature and avoidable mortality for people with learning disabilities or autistic people; identify variation and best practice; and identify key recommendations where there is opportunity to influence improved outcomes.

Progress made through the STW LeDeR Programme will be overseen by the Learning Disabilities and Autism (LD&A) Programme Board. The Steering Group will ensure that learning extracted from each completed review results in agreed system action to affect meaningful improvements in health equality outcomes.

Aim

- To extend the average lifespan of those with a LD/Autism in Shropshire and T&W
- To ensure that those with LD&A are kept as healthy as they can be during their lifespan.

Core shared values

As members of the LeDeR Steering Group we commit to ensuring that local LeDeR Programme delivery:

- Keeps the experience of people with a learning disability or autistic people, whose life and death we will become aware of through the course of the Group, firmly at the center of the review and learning process and the

forefront of our mind.

- Work within our respective organisations to stopping early deaths of people with a learning disability and autistic people due to health inequalities.
- Remain focused on celebrating where end of life experience is managed well, capturing examples of 'reasonable adjustments' and considering how lessons can be learnt following deaths considered to be premature or amenable to improvements in health and social care.
- Support an evolving process that will become sustainable and embedded in local culture.
- Uphold the key principles of cooperation and partnership to ensure that the programme of work affects meaningful change on reducing health inequality and increasing the opportunities for the experience of a 'good' death for people with a learning disability.

Purpose / role of the Steering Group and its members:

- Receive regular updates from the Governance Group about the progress and findings of reviews.
- Analyse the data & smart actions presented by the Governance Group
- Monitor SMART actions resulting from the outcome of reviews
- To agree priority actions based on the recommendations and themes of reviews and contributory factors that have the potential to make the greatest impact
- Support system partners to ensure all providers are working to prioritise learning from local and national LeDeR reviews
- To track the progress of agreed measurable outcomes
- To work in partnership with the regional leads for NHS Midlands LeDeR / Learning Disability and Autism Programme to incorporate learning from other areas
- To consider areas of additional learning or good practice identified by the LD & A Programme Board
- Influence partners to improve the local offers that support healthy living for people with a learning disability and autistic people.
- To agree the key benchmarks or indicators from which progress and impact of the local LeDeR programme will be evaluated.
- To review and re-prioritise or modify a Priority Action Plan in response to emerging local themes

- To ensure each identified partner agency is accountable for the delivery of action required from the organisation that they represent.
- To gain assurance from system partners that quality monitoring and improvements with providers around health inequalities are a part of their organisations 'business as usual' duties.

Membership - Membership for the LeDeR Steering Group will include broad representation including health and social care; provider and commissioning organisations; people with a learning disability and those who support them, including family carers and advocacy organisations. Where a key representative is unable to attend and where a suitable deputy should attend.

Core Membership

- Family members who are carers or a family member who are experts by experience. (No requirement for deputising in absence)
- People who have a learning disability and/or autism (appropriately supported, no requirement for deputising in absence)
- Local Area Contact (LAC)

Representatives from:

- Each of the main acute NHS providers; SATH, SCHT, RJAH
- Mental health and community learning disability team providers; MPFT
- Ambulance service; WMAS – to be agreed
- Autism service provider; MPFT currently.
- PCN representatives – to be agreed.
- Social care representative.
- Public Health
- Shropshire Local Authority
- Telford & Wrekin LA
- Nurse Specialist Child Death Reviews SCHT
- Nurse Specialist Safeguarding Adults SCHT

Governance

- Learning into Action Group meetings will be held bi- monthly
- Meetings will be quorate when at least one representative or nominated deputy of each of the following is present- expert by experience, family carer, acute hospital, specialist Community Learning Disability services, CCG, commissioning, Public Health
- Meetings will be organised by the STW ICS LeDeR Local Area Coordinator.
- The Chair will be the Integrated care System (ICS) LeDeR LAC.
- The Group will provide a monthly update to the LD & A Programme Board

- Papers will be circulated at least 5 working days before each meeting.
- High risks identified that cannot be mitigated will be escalated to the CCG System Quality Group via the STWICS Risk Register and to each relevant partner agency

Standing agenda items

1. Welcome and introductions
2. Conflicts of interest (to be managed by the Chair)
3. Review of minutes
4. Review of action log
5. LeDeR Action plan review
6. Risk log
7. Items for escalation

The Terms of Reference for the LeDeR Learning into Action Group will be reviewed annually.

Appendix 2

Shropshire Telford & Wrekin ICS
LeDeR Governance Panel
Terms of Reference

Background

Learning from lives and deaths of people with a learning disability (LD) and autistic people (LeDeR) formerly known as the Learning from Deaths Review is a programme which started in April 2017 as a result of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD).

The Shropshire Telford & Wrekin (STW) LeDeR Governance Panel is established in accordance with the NHS England directives of the Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy of March 2021.

These terms of reference set out the membership, remit, responsibilities, and reporting arrangements of the Governance Panel.

Aim

- To extend the average lifespan of those with a LD/Autism in Shropshire Telford and Wrekin
- To ensure that those with LD&A are kept as healthy as they can be during their lifespan.

Core shared values

As members of the STW LeDeR Governance Panel we commit to ensuring that local LeDeR programme delivery:

- Keeps the experience of people with a learning disability or autistic people, whose life and death we will become aware of through the course of the Group, firmly at the center of the review and learning process and the forefront of our mind.
- Work within our respective organisations to stopping early deaths of people with a learning disability and autistic people due to health inequalities.
- Remain focused on celebrating where end of life experience is managed well, capturing examples of ‘reasonable adjustments’ and considering how lessons can be learnt following deaths considered to be premature or amenable to improvements in health and social care.
- Remain open minded and agree not to pre-judge outcomes or contributory factors, giving fair consideration to all available information.
- Support an evolving process that will become sustainable and embedded in local culture.
- Uphold the key principles of cooperation and partnership to ensure that the programme of work affects meaningful change on reducing health inequality and increasing the opportunities for the experience of a ‘good’ death for people with a learning disability.

Purpose and Expected Outcomes.

It is expected that LeDeR reviews will deliver the following outcomes for the local population:

- Positive experience of the LeDeR process for bereaved families.
- Decreasing numbers of preventable deaths. Greater use of reasonable adjustments in health and care services for people with a learning disability and autistic people.
- Better outcomes for people as a result of local service improvement projects.
- Increased awareness of the main causes of death for people with a learning disability and autistic people among health and social care professionals, both locally and nationally.
- Improved data about the lives and deaths for people with a learning disability and autistic people.

Purpose / role of the STW LeDeR Governance Panel

- Receive a summary of anonymised 'Focused Review' case reports pertaining to deaths relating to people with learning disabilities or autistic people in order to contribute to a collective understanding of learning points and recommendations.
- To help interpret and analyse information submitted from local reviews, including areas of good practice in preventing premature mortality, and areas where improvements in practice could be made.
- To consider the recommendations made within completed Focused reviews, to agree the report quality and completeness and agree system or partner agency actions to be taken to ensure improvements in health outcomes and experience
- To agree priority actions based on the recommendations and themes of reviews and contributory factors that have the potential to make the greatest impact
- To require STW LeDeR Steering Group to focus on finding solutions and reporting progress with specific emerging priorities and issues.
- To gain assurance that action plans are being implemented and progressing

The responsibilities of the Panel include, but are not limited, to:

- Ensuring LeDeR governance is an integral part of ICS governance and quality reporting arrangements and is not stand-alone.
- The Panel will have final sign-off on reviews completed for the ICS and determine the actions to be taken as a result of reviews
- Helping interpret and analyse the data obtained from local reviews, including areas of good practice in preventing premature mortality, and areas where improvements in practice could be made.
- Identifying good practice locally and share this nationally via NHS England and NHS Improvement regional teams.
- Ensuring that LeDeR actions are reported on as part of routine quality assurance of the ICS and to the NHS England and NHS Improvement regional team.
- Identifying matters for escalation to STW System Quality Group (SQG)
- Ensuring agreed protocols are in place for information sharing, accessing case records and keeping content confidential and secure.

Panel members will review programme direction and make decisions to ensure that:

- They champion LeDeR's cause within and outside of their respective work areas.
- They work in partnership to support the success of the project and make sure that no single interest undermines the programme.
- Recording of programme information is accurate and coherent and shared with Panel members.
- The progress of the overall programme is monitored, and any necessary remedial action is timely undertaken so as to not hold up the project.
- All risks are assessed and managed well, putting in place actions and contingency plans for all high impact risks.
- Sufficient resources are available to complete LeDeR reviews for the ICS in line with the LeDeR policy.
- Members of the group are notified, as soon as practical, if any matter arises which may be deemed to affect development and delivery.
- They report to STW ICB LeDeR Steering Group

Term

This Terms of Reference is effective from 01 April 2022 and will be reviewed annually.

Membership

The LeDeR Governance Panel consists of a core membership which is representative of our LDA community as well as all health and social care partners in the Shropshire Telford & Wrekin system. Nominated delegates will be expected to attend all meetings, or, where not possible, send an appropriate deputy, and have decision making powers for the organisation they are representing.

Core Membership

- Family members who are carers or a family member who are experts by experience.
- People who have a learning disability and/or autism (appropriately supported).
- Local Area Contact (LAC) – who will have a key role in administering the panel.
- Senior Reviewers and respective reviewers as per the listed reviews on the agenda – service currently provided by NHS South, Central and West Commissioning Support Unit.

Representatives from:

- Each of the main acute NHS providers; SATH, SCHT, RJAH
- Mental health and community learning disability team providers; MPFT
- Ambulance service; WMAS – as required
- PCN representatives – as required
- Social care representative.
- Screening services – as required

Quorum

A minimum of the following representatives must be in attendance for a meeting of the Governance Panel to be considered quorate:

- Local Area Contact (LAC) or designated Deputy - Chair
- Expert by experience; patient, family, or carers
- Senior Reviewer and/or a relevant case reviewer
- Representatives from acute providers
- Representative from social care commissioning
- Representative from a community healthcare provider
- Representative from Telford & Wrekin Council
- Representative from Shropshire Council

If a meeting is not quorate, decisions may be taken however these will not be considered final until the absent core members have been made aware of these decisions and have approved them, in person or by email.

Panel Meetings

All meetings will be chaired by LeDeR LAC

Decisions will be made by consensus, i.e., members are satisfied with the decision even though it may not be their first choice.

Panel agenda minutes will be provided through administrative support within the ICS. This will include:

- Preparing agendas and supporting papers.
- Preparing meeting notes and information.

Frequency of Panel Meetings

Panel meetings shall be quarterly in the first instance with frequency reviewed at regular intervals to ensure meeting intervals is aligned with the number of reviews that require sign off.

Where possible, meetings will be arranged at a time convenient to the majority of members and continue to maximise the benefits of agile working.

Amendment, Modification or Variation

This Terms of Reference document may be amended, varied, or modified in writing after consultation and agreement by the LeDeR Governance Panel members and reviewed at least annually.