NHS
Shropshire, Telford and Wrekin

Integrated Care System
Shropshire, Telford and Wrekin

LeDeR: Learning from Lives and Deaths of People with a Learning Disability and Autism

Annual Report

1st April 2022 - 31st March 2023

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Credits and Acknowledgements

Shropshire Telford and Wrekin Integrated Care System LeDeR Steering Group would like to thank the following people without whom the reviews and learning would not have been possible.

- 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 and Governance Panel.
- Primary Care colleagues across Shropshire Telford and Wrekin.
- Shropshire County Council
- Telford and Wrekin Council
- Shropshire Telford & Wrekin child death overview panel (CDOP)
- The Shrewsbury and Telford Hospitals NHS Trust (SaTH)
- The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust (RJAH)
- Shropshire Community Health NHS Trust
- Midlands Partnership NHS Foundation Trust (MPFT)
- NHS South Central and West Clinical Support Unit
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- Mrs J Hampton-Pidgeon - LeDeR programme administration support
- Mr R Gough - parent/carer
- Julie Mellor and members of the group ‘Taking Part’.

Executive Summary

I am proud to present this Learning from Lives and Deaths, a service of people with a learning disability and autistic people (LeDeR) annual report for 2022-2023. It is so important that we continually drive improvement and focus on the learning from LeDeR and embed it into our everyday practices to reduce inequalities and ensure people with learning disabilities and autism have the best opportunities for healthy lives, and this report sets out our achievements, challenges and next steps in Shropshire Telford and Wrekin (STW).

The LeDeR reviews in STW have shown cancer, dementia, respiratory, and urological conditions to be the common causes of death in people with learning disabilities and autism. These are areas we will continue to be working with partners through our LeDeR governance and wider working in our system to improve the care and experience for people with learning disabilities and autism and their families.

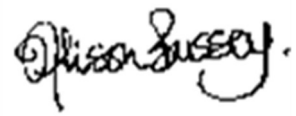
I am delighted to see the progress in the Oliver McGowan training implementation across our partners. This is a milestone in training, and I look forward to seeing the impact of this training over the coming years in improved quality and access to services as well as improved experience for people and their families.

The LeDeR reviews have shown a wide range of exemplar practices in the last year including partnership and multidisciplinary working, end of life care, use of reasonable adjustments and access to specialists when needed, to name but a few. However, we can do better.

In 2023/24 we will be working together to further improve our timeliness of LeDeR reviews working with our commissioned service, improve the uptake of annual health checks and action plans, improve the use of the Mental Capacity Act, and strengthen the use of hospital passports. We will also be working to understand and improve how we ensure our population with autism and for those people with learning disabilities from ethnic minority groups are reported into LeDeR following a death. This way we can learn and move further to reduce inequalities in our Integrated Care System.

This LeDeR Annual Report 22-23 presents many other opportunities for improvement, and we will be supporting these at every opportunity and working continuously, with the resources we have, to improve the lives and deaths of people with learning disabilities and autism.

I would like to thank all our partners for their ongoing support of the LeDeR programme, and especially those people and families that give their time voluntarily, contributing through their lived experiences, to improve the lives of others.



Alison Bussey

Chief Nursing Officer

Shropshire Telford and Wrekin Integrated Care Board

Introduction

LeDeR is a National Health Service (NHS) service improvement programme 'Learning from lives and deaths for people with a learning disability and autistic people'.

The key principles of the programme are:

- Improve care for people with a learning disability and autistic people.
- Reduce health inequalities for people with a learning disability and autistic people.
- Prevent people with a learning disability and autistic people from early deaths.

Health inequalities are unfair differences in the status of people's health that are seen when people with a learning disability or autistic people receive healthcare, and this has been proven to result in poorer outcomes. At the core of it is access to care that people receive and the opportunities that they have to lead healthy lives.

Health inequalities can therefore involve differences in:

- Health status, for example, life expectancy
- Access to care, for example, availability of commissioned services, ability of individuals from difference segments of our population such as CORE20 (the most deprived 20% of the national population as identified by the national index of multiple deprivation), (black, Asian and minority ethnic communities (BAME), and inclusion groups to access core services and this will be further impacted on by their learning disability and autism diagnosis.
- Quality and experience of care, for example, levels of patient satisfaction which we know is impacted upon by staff's awareness and knowledge of learning disability and autism and the implementation of reasonable adjustments.
- Behavioural risks to health, for example, smoking rates, food choices, not accessing screening.
- Wider determinants of health, for example, quality of housing.

Too many people with a learning disability are dying earlier than they should, many from things that could be treated or prevented. A statement from Mencap around health inequalities quotes that data reported by NHS digital 2017 that on average the life expectancy of women with a learning disability is 18 years shorter than for women in the general population. The life expectancy of men with a learning disability is 14 years shorter than for men in the general population.

Autistic people have significantly lower life expectancies than the rest of the population. A statement from the UK government in 2021 quotes the data reported by the British Journal of Psychiatry that autistic people will live 16 years fewer than their non-autistic peers.

A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. We look for areas that need improvement and areas of good practice. We use these examples of good practice to share both locally and nationally. This helps reduce inequalities in care for people with a learning disability and autistic people. It reduces the number of people dying earlier than they should.

119 reviews have been completed since 2017, 115 adult reviews and 4 CDOP reviews. We use the data and evidence to make a real difference to health and social care services across the region and share this learning nationally.

This report provides an update on the progress and impact made across Shropshire Telford and Wrekin (STW) from 1st April 2022 to 31st March 2023. The report reflects some of the extraordinary efforts of our partners working together for the second year running that has continued to challenge health and social care providers.

From April 2022/23 we commissioned an external provider South Central and West Clinical Support Unit (SCWCSU) to undertake LeDeR reviews. The Shropshire Telford and Wrekin Integrated Care Board (NHS STW) worked closely with SCWCSU to ensure that we have high quality assurance of all reviews undertaken. SCWCSU and NHS STW have worked together to monitor all reviews for STW including a small backlog reported for 2021/22.

The reviewers endeavour to maintain the high quality of reviews completed and the LeDeR Steering Group ensure the learning from these reviews are embedded into practice to improve services for people with learning disabilities and autism with the aim of reducing health inequalities.

The Shropshire Telford and Wrekin Integrated Care Board is responsible for ensuring that:

- LeDeR reviews are completed for Shropshire Telford, and Wrekin.
- There are fewer preventable deaths because people are getting the right care.
- All the organisations in the ICS learn from LeDeR to support services to prevent people dying too soon.
- There is a stronger emphasis on the delivery of the actions coming out of the reviews and holding local system partners to account for delivery, to ensure that there is evidence of service improvement locally.
- The LeDeR process involves an initial review and then a decision will be taken whether to complete a focused review.
- The LeDeR process looks at the circumstances of a death but also someone's life before death.
- For the first time deaths of adults who have a diagnosis of autism, but no learning disability have been included in the process. LeDeR reviews are done for all autistic people over the age of 18 who have been formally diagnosed by a doctor that they are autistic, and this is evidenced in their medical record. All reviews of people who are autistic without a learning disability are focused reviews in order to collect meaningful data and learning.
- All people from ethnic minority groups also get a focused review because evidence shows that the health inequalities experienced by people from these communities can be significant and there is also significant under reporting of learning disability and autism deaths to LeDeR from these communities.
- Anyone who has been detained under the Mental Health Act in the last 5 years also receives a focused review.
- Anyone who has been through the criminal justice system in the last 5 years also receives a focused reviewed.

There is a national LeDeR policy and LeDeR website where you will be able to find a lot of background information about LeDeR. Shropshire Telford and Wrekin Integrated Care System (STWICS) follows this national policy NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021

The LeDeR process (see Appendix 1)

- When a person with a learning disability or autism dies, a LeDeR death notification is completed; usually by a health or social care professional and sent to the SCWCSU to conduct a review.
- The SCWCSU and the local area contact (LAC) are then informed that a LeDeR notification has been submitted on the LeDeR platform. The LAC and the senior reviewer can then discuss the notification if needed.
- The senior reviewer in SCWCSU will assign the review to one of the reviewers. At this stage it is assigned as an initial review or a focused review according to the LeDeR policy and local themes agreed by the LAC, although some may start as initial reviews and can be escalated to a focused review, if a relative requests this or if any of the information from the review suggests that the review meets the criteria of a focused review.
- If a family member or next of kin (NOK) is listed, the reviewer will contact the LeDeR administrator for SCWCSU to request a letter is sent out to the family member or NOK explaining what LeDeR is, together with a link to access further information on the LeDeR website and a LeDeR leaflet.
- At this point a discussion with the administrator will take place to contact the GP or health or social care provider to request necessary information relating to the individuals care and treatment.
- The letter to the family member or NOK will include a date and time the reviewer will call them, and a contact number is also included should the family member or NOK wish to decline this contact from the reviewer.
- If accepted, the reviewer will set up a meeting with the family member or NOK to talk about the life and care of the relative that has died.
- The reviewer conducts the review and obtains the health and social care records from GP's, social services, and hospitals. If there are any concerns or issues, the reviewer will contact the LAC.
- Once the reviewer has collated all the information they need for the review, they submit the completed review to the senior reviewer for quality assurance. All reviews are then sent to the LAC for quality assurance. If there are any concerns the LAC will discuss this with the reviewer before it is closed on the platform or circulated to members of the Governance Panel.
- If it is an initial review, then the senior reviewer will discuss the quality of the review and the lessons learnt with the LAC and the review is completed.

- If it is a focused review, it is discussed in the Governance Panel to agree any lessons learnt and sign off before closure.
- It also feeds into the LeDeR quarterly and annual reports, which in turn, helps to improve the overall quality of care for people with learning disabilities and autism.

What does the Shropshire Telford and Wrekin Integrated Care Board LeDeR Governance panel do?

NHS STW LeDeR Governance Panel are part of the ICB quality governance structure. The LeDeR Steering Group role is to review the development plan and make sure that the lessons we are learning from the reviews improve the care and treatment of people with a learning disability and autism in Shropshire Telford and Wrekin.

SCWCSU reviewers are invited to all Governance Panel meetings to present areas of learning, good practice and areas of concern to the NHS STW Governance Panel, who sign off the quality of focused reviews and in discussion with the reviewer, agree specific, measurable, achievable, realistic and timebound (SMART) actions which feed into the strategic plan for Shropshire Telford and Wrekin. The Governance Panel meet monthly.

The NHS STW Governance Panel includes experts by experience, and we are in the process of recruiting from our ethnic minority group population. The Governance Panel will advise the LeDeR Steering Group of the findings from the reviews and in turn the LeDeR Steering Group will take priority actions.

The Equality Diversity and Inclusion (EDI) Lead and the LAC meet on a regular basis to discuss any issues identified around EDI.

Shropshire Telford and Wrekin LeDeR Steering Group

Our LeDeR Steering Group is chaired by the LAC, who is also a member of our Governance Panel. The NHS STW LeDeR Steering Group aims to take a strategic level oversight of the reviews of deaths of people with learning disabilities and or autism, driving transformation to improve care. STW LeDeR Steering Group meetings are held bi-monthly.

The role of the LeDeR Steering Group is to:

- Discuss the outcome of any reviews.
- Support the identification and sharing of best practice in the review process.
- Monitor actions and outcomes.
- Respond to recommendations to improve service provision and reduce likelihood of premature deaths.

- Recognise and share best practice and innovation.
- Demonstrate the impact of changes.

The STW LeDeR Steering Group is attended by representatives from all system partners. The Group consists of members, including a representative from:

- Shrewsbury and Telford Hospitals NHS Trust
- Midlands Partnership NHS Foundation Trust
- Shropshire Council
- Telford and Wrekin Council
- Shropshire Community Health NHS Trust
- Robert Jones and Agnes Hunt Orthopaedic NHS Foundation Trust
- NHS STW Integrated Care Board
- Primary Care.

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, dashboards and LeDeR 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 LeDeR Steering Group to affect meaningful change and improve outcomes for local people, with the aim to extend the average lifespan of those with a learning disability and /or autism and to ensure that those with LD&A are kept as healthy as they can be during their life.
- The outcomes that we are aspiring to achieve include supporting longer, healthier, and happier lives for people with a learning disability and autism/autistic across our Integrated Care System.
- That all stakeholders, including people with learning disabilities and autism and their family, friends, and carers, feel an equal partner in the LeDeR programme.

Learning from local reviews 2022/2023

From an overview of completed reviews for STW during 2022/2023 collective causes of deaths were identified as below:

- Cancer
- Dementia
- Respiratory
- Urology

Following all completed STW reviews in 2022/23 many areas of good practice were noted including:

- Familiar staff members were available to support the individual during hospital admission and stay.
- Good working relationships between GPs and nursing homes, where weekly team meetings were held for each resident to ensure health needs were met.
- Testing patients with learning disabilities who have epilepsy for Dravet Syndrome early.
- Good practice around personalised end-of-life care whilst remaining in the individual's own home.
- Excellent advance care planning and documentation.
- Full MDT discussions held where best interest decisions had been made for those individuals that had been deemed to lack capacity around their care and treatment.
- Good partnership working between teams, e.g., GP, social care providers, community learning disability team, community mental health team, local authorities, and acute hospitals.
- Reasonable adjustments have been implemented in a number of cases e.g., easy read information to help individuals understand, adjustments made to times of visits and home visits have been made available to support individuals.
- Access to specialist consultants and nurses where individuals have complex physical healthcare issues e.g., neurology for people with epilepsy and urology for people who have chronic kidney problems.

Following all completed STW reviews a number of areas of lessons learnt and potential for improvements were noted including:

- Annual health checks and health action plans not consistently being completed.
- Reasonable adjustments not consistently being implemented e.g., regular carers supporting individuals during hospital admissions. As a system this is being addressed to ensure individuals are fully supported by care providers during hospital admissions where applicable.
- Hospitals passports not being completed, fully utilised or taken to hospital during admission.
- Healthier lifestyles support not being considered particularly around obesity.
- Do not attempt cardiopulmonary resuscitation (DNACPR) and Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) documents being poorly completed.
- Mental Capacity/best interest decisions not always fully assessed, and documentation is not being regularly completed during hospital admissions for care and treatment.
- Deprivation of liberties (DoLS) not being applied for/fully understood during hospital admissions when restrictive interventions are required such as 1:1 supervision at all times.
- Reasonable adjustments not consistently being implemented to support individuals to access physical health screening e.g., cervical/bowel screening.

Local progress in 2022/23 against out LeDeR action plan

Oliver McGowan Training

The e-learning Oliver McGowan training has started to be rolled out amongst some of our system partners. Oliver's training is delivered in 2 tiers, the e-learning is the first part of both tier 1 and tier 2 training. Everyone across the system will need to complete the e-learning. Shropshire Telford and Wrekin ICS have recently established The Oliver McGowan Training in Learning Disability and Autism stakeholder group. The first meeting took place at the beginning of June 2023 and will continue to meet fortnightly to discuss and establish how to further roll out tier 1 and tier 2 training across the system.

Promote the need for reasonable adjustments and implementation of hospital passports.

Acute Liaison Nurses (ALN) now have office bases on each of the acute sites at Telford and Shrewsbury hospitals and have access to the clinical systems to enable regular visits to the wards to visit anyone with a learning disability. Each day (Monday to Friday) a learning disability admissions list is generated, this list is cleansed and updated by the ALN and then sent to the mental health and learning disability lead and safeguarding team within Telford and Shrewsbury hospitals. The ALNs can ensure any reasonable adjustments are implemented during their hospital admission. The ALNs have rolled out face to face training with all acute staff on the importance of reasonable adjustments and the use of hospital passports and they are available for support and work flexibly to support the needs of the individual.

Annual health checks including medication reviews.

General practice has continued to prioritise learning disability annual health checks (LDAHC) throughout 2022-23 in line with the national guidance to reduce health inequalities and proactively engage those at greatest risk of poor health. NHS STW has worked and continues to work with practices and partners to improve the offer, uptake, and quality of annual health checks delivered. The ICB is committed to offering 100% of people with a learning disability an annual health check.

General Practice have worked with Midlands Partnership Foundation Trust (MPFT) to target efforts to reach patients who were overdue their health checks as part of recovery from the pandemic and offer reasonable adjustments to encourage take up including home visits.

Despite the recent challenges on general practice due to winter pressures and the need to provide urgent Strep A capacity which resulted in a dip in activity for December 2022 and January 2023. General practice has worked hard to maintain capacity directed at LDAHCs.

As a result, for 2022-2023 STW practices have completed 76.5% (1956) LDAHCs against a target of 75%. This is a significant increase compared to 2021-2022 where we achieved 63% (1577). This is shown in diagrams 2 and 3 below.

Diagram 2

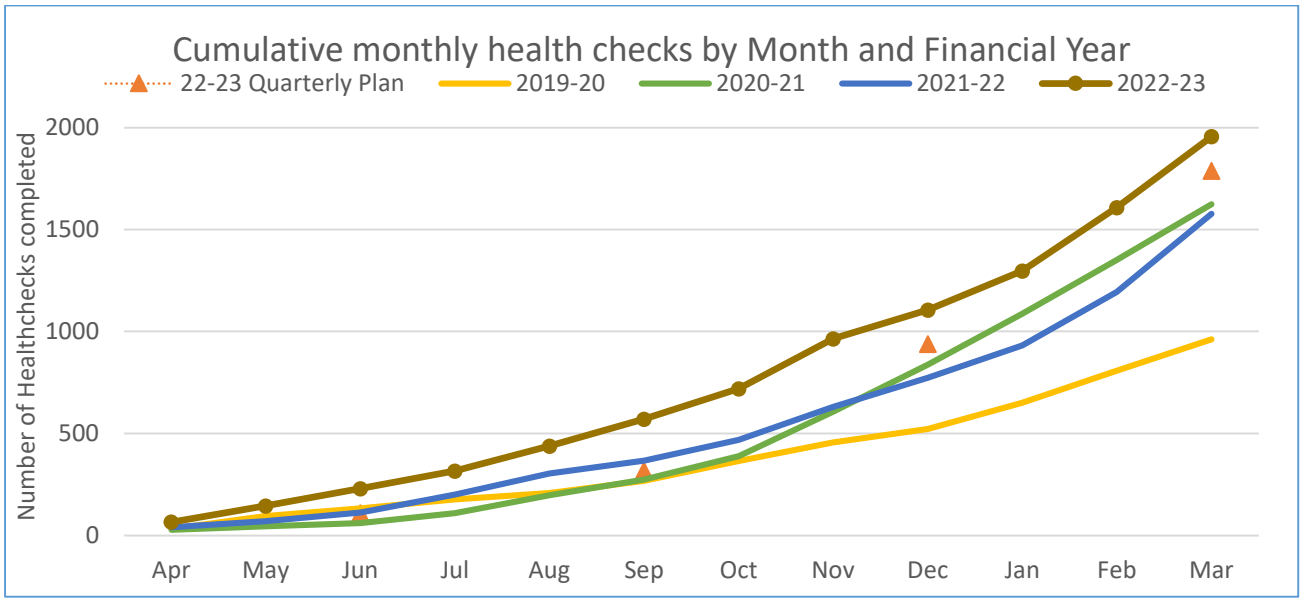
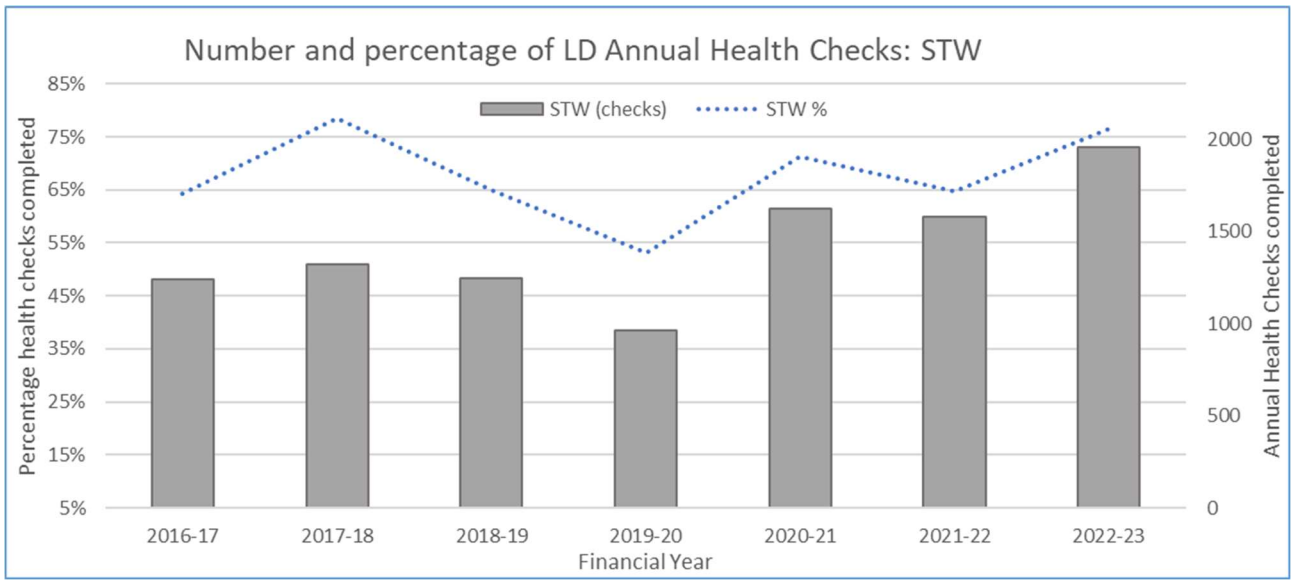


Diagram 3



Bespoke training for Shared Lives and social care providers has been developed to outline what carers should expect from the annual health checks (AHC) and is available as required.

A targeted approach with all learning disability providers promoting and raising awareness of annual health checks. Midlands Partnership Foundation Trust (MPFT) are supporting practices in some care homes and their nurse led team are completing face to face visits for base line observations and support in completing the health check questionnaires which follow the AHC template.

Enhanced ways of communication have been developed through easy read documents which have been shared with the local community and partners; a video was developed by

local young service users to encourage attendance at annual health checks Annual Health Checks - NHS Shropshire, Telford and Wrekin (shropshiretelfordandwrekin.nhs.uk)

A pilot audit of annual health checks was carried out last year and will be completed again this year to look at the quality aspect of annual health checks completed.

Findings from the annual health check (AHC) pilot audit

All practices in the pilot demonstrated a holistic approach to AHC's and took into account the needs of the individuals, for example booking longer appointments or at quieter times of the day. Due to Covid 19 restrictions, some checks took place via video link. Practices used a template for the AHC but these varied and some captured more of the information required for the AHC. All practices discussed with the person or their carer next steps/actions but not all were given an action plan in writing. It is invaluable to spend time with the lead health professional for learning disabilities in the practice to gain that overall knowledge of how the AHC is planned and conducted.

Feedback has been received from the practices audited reporting they found it very useful, it has highlighted areas of learning that they will change in future. They would like a tool to allow them to self-audit in future.

Recommendations following the pilot audit.

- Support update training for staff
- Use of easy read format templates for letters, pre appointment questionnaires and action plans for the people to have following the annual health check which details what the GP practice is going to do and any actions for the individual/carer to complete.
- Recommendation to practices of templates which support capture of all areas of the LDAHC and how these are saved/recorded onto practice patient records.
- Modification of audit template to reflect areas identified in pilot.

Oversight of monitoring Annual Health Checks is the responsibility of the STW Annual Health Check working group.

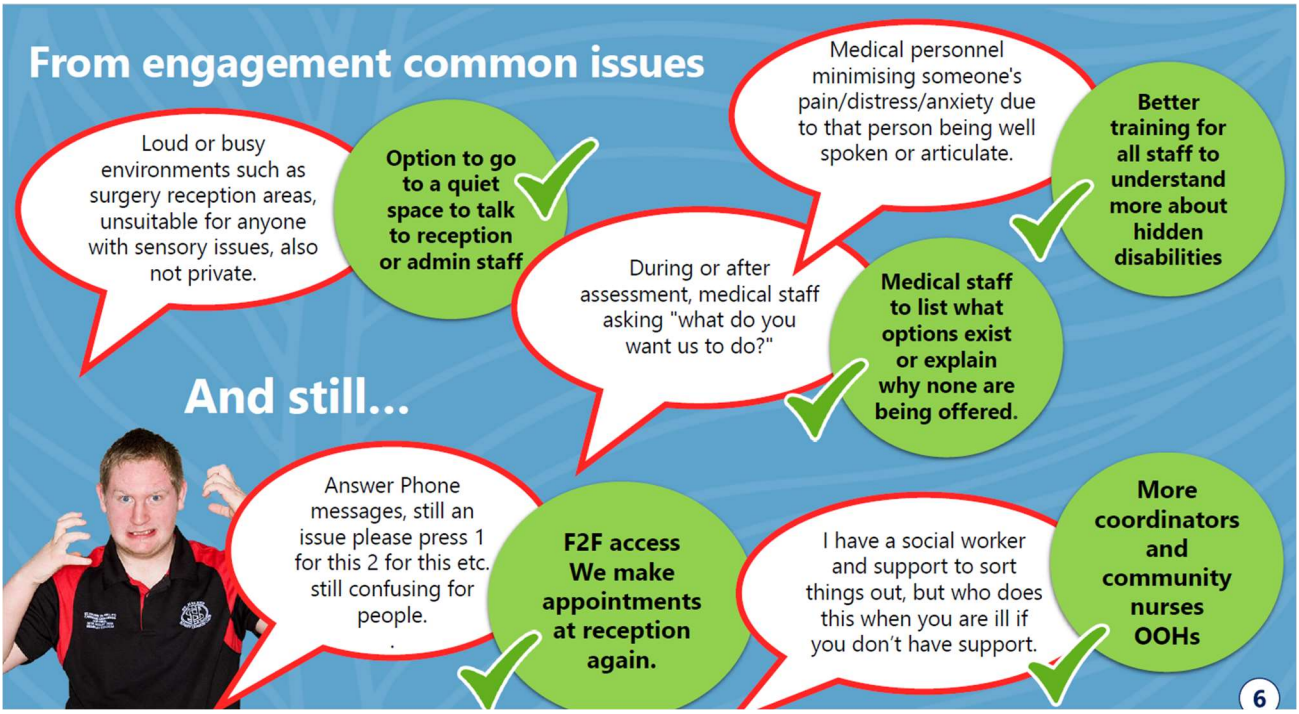
Reasonable adjustments to support better screening and access to health and social care.

System wide joint working is ongoing with our colleagues in Public Health to address health inequalities which link in with our partnership boards and ongoing work. Views are sought from our experts by experience through our partnership board for carers, mental health, learning disability and autism.

Our learning disability partnership board members are going to be working with Healthwatch and colleagues in the ICS to look at accessibility of health services along with our provider colleagues who are leading on the Treat Me Well Campaign. The Treat Me Well Campaign is a campaign to transform how the NHS treats people with a learning disability in hospital and highlights that making simple adjustments can make a big difference.

Through our partnership boards we aspire to continue to work with agencies such a leisure service, public health, the police and specialist learning disability and autism health services to continue to drive services to work together, embedding integration at place to deliver a reduction in health inequalities while improving outcomes for people.

Below is an extract from the 'Healthy Lives Project' completed by a voluntary group Taking Part, commissioned by Shropshire Council and NHS STW.



The Healthy Lives Project is a project that was developed and is run by Taking Part. This looks at what the health services experiences of people with learning disabilities and gathers what 'Health' looks like for people with learning disabilities. Taking Part looked at

what do people know about their own health, established levels of understanding of their own needs and conditions, what is missing for them and what are the barriers to fair access to health services.

They used a Checkit tool that supports talking with people to gauge their level of understanding, where they are with screenings and check-ups and what they know about their health needs. Their aim was, based on ensuring that responding to health needs often requires the knowledge of care givers and the understanding of individuals by health professionals.

Some of the examples of changes we have made are as follows:

- Easy read and visual information should be the 'norm' in most GP practices.
- Easy read leaflets that are widely distributed in all medical facilities and can be easily seen.
- Ability to talk to a person and not have to deal with a technical facility when they are likely to be anxious and stressed. The option for people to book appointments in person at the surgery.
- Don't wait to be told a person needs reasonable adjustments please ask.

Support healthy living (management of obesity, healthy eating, and exercise)

The community learning disability team (CLDT) from MPFT hold physical health clinics to support safe prescribing of medications. This includes blood testing and ECGs to monitor their physical health in relation to the medicines they take.

The physical health pathway has been developed and reviewed in line with NICE Guidance (in accordance with Stopping over medication of people with a learning disability and/or autism, (STOMP) agenda.

Support continues to be provided regarding reasonable adjustments around Covid 19 vaccinations, clinical holds, and Mental Capacity Act (MCA) and best interest (BI) decisions. During the initial Covid 19 vaccinations (first two doses) that was mandatory for everyone to receive, we have successfully supported with several clinical holds with individuals that were deemed as lacking capacity following a mental capacity assessment and received the vaccinations in their best interest.

Table 1 shows the uptake of Covid vaccinations up to the end of December 2022 for Shropshire Telford and Wrekin. The STW vaccination service visited care homes in 2022/23 to offer boosters and 1st dose COVID-19 vaccinations. The STW vaccination

service work closely with GP practices to identify eligible patients who have a learning disability (LD) and or autism (A). The STW vaccination service used social medica, local newspapers and local radio stations to promote the COVID-19 vaccination programme and encourage uptake for people with an LD &/or A. The STW vaccination service delivered a number of pop-up clinics across STW bringing care closer to home for individuals. The team offered quiet clinics to encourage individuals with an LD &/or A to come forward for their vaccination. The STW vaccination service also offered ladies only clinics to encourage individuals with an LD &/or A to come forward for their vaccination.

Table 1

	LD adults	Autism adults
Partial vaccination (one dose only)	39	121
Vaccinated (at least two doses)	2180	2194
Not vaccinated	152	543

The learning disability strategy and completed consultation of the autism strategy have reinforced the importance of embedding healthy lifestyles within social care settings and care provision. Voluntary sector workstreams are currently being funded by the ICB and local authorities to roll out awareness of reasonable adjustments and promote healthy living lifestyles to people with learning disability and autism. Below is an extract from the 'Healthy Lives Project' completed by a voluntary group Taking Part, commissioned by Shropshire Council and ICB.

In conjunction with our voluntary sector, we have taken steps to address health care inequalities which make a significant contribution to the prevention agenda. We understand that poor health care can cost money – for example people with learning disabilities who are in pain associated with untreated disorders may develop challenging behaviour. People with poor mobility due to lifestyle issues such as obesity can require costly equipment,

Using the model of Understand, Prepare & Prevent (UPP), which is led by Taking Part. They provide opportunities for young people who have learning disabilities and / or autism to:

- Build their confidence to access environments outside the home reducing barriers to accessing health care.
- Benefit from peer support to build confidence and resilience.
- Increased their activity levels and establish healthy lifestyle choices early on in their lives.
- Learn about health issues and to experience health interventions in a supportive and positive way.
- Bring parent carers together to benefit from peer support and to share information that enables them to actively support young people with learning disabilities and autism to lead healthy lives.

Provision of good end of life care

Collaborative working has been established with Taking Part, Shropshire Partners in Care, Severn Hospice and MPFT to establish and roll out an end-of-life training workshop for people with learning disabilities and autism. Shrewsbury and Telford Hospital NHS Trust have their own end-of-life team and appropriate referrals, and communication is key to ensure anyone with a learning disability, autism or both receive good end-of-life care.

Good epilepsy management and care

The Epilepsy Care Pathway has been updated to include Sudden Unexpected Death in Epilepsy (SUDEP) risk assessment, the majority of appropriate staff within MPFT have received epilepsy awareness training, mandatory training is planned for the summer of 2023 for all staff and there will be a focus on those not yet trained, this training also continues to be rolled out to all providers. An audit has been undertaken to review compliance with the epilepsy care pathway. An action plan was developed in line with national recommendations. It is ensured that anyone with a diagnosis of epilepsy has access and support from an epilepsy specialist nurse or neurologist.

Appropriate consideration of mental capacity assessments (MCA) and deprivation of liberties (DoLS) and assessment recorded.

There has been improved Learning Disabilities & Autism (LD&A) training within the acute trust including ReSPECT documentation and Mental Capacity Act (MCA). Face to face workshops are ongoing with Shrewsbury and Telford Hospital (SaTH) until the end of September 2023. Positive feedback has been received on workshops to date. Our system partners assure us that all staff receive appropriate training around MCA and DoLs.

Support equity for those with a learning disability from ethnic diverse groups

As a system we are raising awareness through our parent carers and service user groups on promoting engagement to reduce health inequalities. This is an area that we are currently working to establish appropriate data so that we can target ethnic diverse groups. Some of our voluntary sectors have started to look at this.

Identify and implement mechanisms for early detection of deterioration for those with a learning disability and autism

The community learning disability team (CLDT) from MPFT have visited care homes to improve the understanding of the ‘softer signs’ of illnesses and the need to raise early concerns about subtle changes in a person’s condition. Including the sharing and promotion of “Stop and Watch” resources, increased awareness of ‘soft signs’ of deterioration can promote proactive and preventative action.

Person centred health questionnaires and health action plans are developed to support health deterioration and actions to maintain and improve health. Bespoke assessments are completed for dysphagia and appropriate training offered to identify any signs of deterioration. Pain profiles are created to look at physical cues of health deterioration and presentation of pain that may be atypical to support early detection.

Within Shrewsbury and Telford hospital NHS Trust and Robert Jones and Agnes Hunt Orthopaedic NHS Foundation Trust there is mandatory training in place for NEWS2 and sepsis screening as part of the deteriorating patient plan.

A reduction in the incidence of common causes of deaths in people with LD/A such as constipation and aspiration pneumonia. Tools to support the identification and treatment of pneumonia and constipation.

There is a pressing need for health and social care working in partnership to offer a programme of information and training around pneumonia and constipation. This includes:

- More opportunities for people with learning disabilities to understand their conditions and how to manage their own health.
- Raise awareness and offer support for prevention campaigns to include people with LD&A.
- Annual health-checks and scans for people with LD&A to understand why these are important. Understanding their conditions and the effect it can have on their health.
- Easy ways to prevent things from going wrong; - send information in a way that people understand and to know where to ask what is needed.
- Keep instructions simple, make it clear what people with LD&A need to do next.

Some good examples are that care home staff attending training to ensure they know how to care for people who have learning disabilities and autism. We now have GP surgeries who visit people in their own homes to complete assessments and share information on how to support people with certain conditions.

Communication with individual, their family/carer and MDT

We are working collaboratively with parents, carers, experts by experience, advocacy, and other partners. Shropshire and Telford and Wrekin Councils are looking to continue to strengthen their approach to ensure services are shaped and delivered in line with good practice. A4U is an organisation which aims to improve the quality of life for people with disabilities and/or long-term conditions including autism, their families and carers in Shropshire and its borders. A4U also runs the Shropshire autism hub, this is the umbrella for a range of services provided for autistic adults over 18 years old in Shropshire. The services are provided by a partnership of organisations and include, focussed small group work, peer support, user led activities, life skills and carer support.

MPFT have co-produced easy read care plans and care planning routinely involves the person and others in their family/care team (as agreed with the person). Care Programme Approach (CPA) meetings and other care review meetings are planned with the person and family/paid carers as appropriate. MPFT use Friends and Family Postcards for feedback, feedback questionnaires at the end of treatment and act on the feedback received via these routes (Ask, Listen, Do). NHS STW commission Taking Part & Shropshire Peer Counselling and Advocacy Services (PCAS) who make valuable contributions to people's care reviews and lives.

Knowing who our people are – validation of GP registers and interlinked medical information on people with LD/A across the STW systems.

GP practice learning disability register list sizes have continued to grow in 2022-23 as lists are cleansed and coding reviewed. There has been an increase of people registered with a learning disability this year with the STW list size rising to 2793 in April 2023 from 2436 at the end of March 2022.

MPFT continue to support with the ongoing cleansing of GP registers and GP training and are following up with face-to-face home visits when AHC appointments have not been attended. GPs share the lists of patients who are overdue AHCs with MPFT to enable a face-to-face follow ups and support with pre-health check questionnaires. MPFT are flagging areas of concern back to GPs for follow up appointments and prioritisation. An NHS funded nurse supports with this project.

Information is shared and priority patients flagged to GPs for them to see face to face where there are areas of concern.

Shrewsbury and Telford Hospitals NHS Trust are currently working on improving there coding on both hospital sites, they are in the process of changing their current system and their new system will be able to flag individuals with a learning disability, autism, or both to enable any reasonable adjustments required for the individual to be identified and implemented where applicable.

Table 2

PCN	Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22
CHARLTON	62	63	62	60	60	59
NEWPORT AND CENTRAL	173	174	176	178	178	181
NORTH SHROPSHIRE	476	480	482	476	465	463
SE SHROPSHIRE	227	224	224	223	222	221
SHREWSBURY	657	654	656	658	656	664
SOUTHEAST TELFORD	237	237	239	258	263	273
SW SHROPSHIRE	208	208	205	209	208	205
TELDOC	227	228	230	227	227	226
WREKIN	174	173	174	175	182	182
Total	2441	2441	2448	2464	2461	2474

PCN	Oct-22	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23
CHARLTON	61	62	62	64	66	64
NEWPORT AND CENTRAL	181	181	181	180	180	182
NORTH SHROPSHIRE	470	469	470	476	474	474
SE SHROPSHIRE	226	226	227	228	226	225
SHREWSBURY	669	670	674	678	673	677
SOUTHEAST TELFORD	287	295	295	292	297	301
SW SHROPSHIRE	207	207	207	206	207	211
TELDOC	230	235	233	235	236	238
WREKIN	183	182	184	183	186	184
Total	2514	2527	2533	2542	2545	2556

Above is table 2 which demonstrates the monthly increase of the numbers of individuals who are on the learning disability register. In the 12-month period of 2022/23 we have seen an increase of 115 people added onto the register.

Appropriate care reviews

Telford and Wrekin Council continues 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 the autism practice lead to improve practice and commissioning of services for autistic people. However, the shortage of social workers within local authorities has impacted on the timeliness of individual care reviews.

The number of individuals with a learning disability within Telford and Wrekin who require a care act review is 510. Between the period of May 2022 to May 2023 263 people received a care act review, meaning over 50% of the reviews were completed within Telford and Wrekin.

The number of individuals with a learning disability within Shropshire who require a care act review is 710. Between the period April 2022 to March 2023 409 people received a care act review, meaning over 50% of the reviews were completed within Shropshire. Shropshire Council do not currently report on individuals with autism diagnosis only, this is something they are in the process of changing.

Shropshire Council have an external review team supporting with annual care act reviews and this means they should achieve 85% of reviews this in 2023/24 with priority focus on those in supported living and learning disability residential accommodation. This is expected to improve,

Progress on Clive Treacey action plan

In 2021/22 Shropshire Council ran workshops looking into the life and death of Clive Treacey. Building on that approach, an action plan is now in place and being strengthened, in partnership with MPFT, Telford & Wrekin Council, NHS STW and other system partners to ensure consistency as far as possible to ensure actions to improve in line with the recommendations are being taken. An internal group of professionals has been established to push on with required actions and will be meeting monthly in 2023/24.

Some of the key progress made during 2022/2023 is listed below.

- Improved Learning Disabilities & Autism (LD&A) training within the acute trust and primary care. This includes online and face to face workshop training. The current percentage for this recording period for training to GP practices across STW is 24.5%, this is a low percentage, however, some of these practices have had received 2 or 3 sessions per practice. For this recording period, 40 people within SaTH attended face to face training workshops, MPFT are currently in the process of liaising with GP practices and SaTH to continue to arrange training and to encourage uptake.
- Roll out of Oliver McGowan Training across the ICS system and the establishment of the STW ICS Oliver McGowan Training in learning disability and autism stakeholder group. Robert Jones and Agnes Hunt Orthopaedic NHS Foundation Trust rolled out LD & A awareness training and now have 92.4% compliance within the trust.
- Physical Health Pathway developed and reviewed in line with NICE Guidance.
- Epilepsy Care Pathway updated (includes Sudden Unexpected Death in Epilepsy (SUDEP) and an action plan was developed in line with national recommendations.

- Working Collaboratively with Taking Part (advocacy group), Shropshire Partners in Care, Severn Hospice and MPFT around an end-of-life training workshop for people with learning disabilities.
- Easy read documents shared with the local community and partners and a video was developed by local young service users to encourage attendance at annual health checks.
- The cleansing of hospital admissions lists by ALNs and shared with MH, LD lead and safeguarding team within SATH.
- Voluntary sector workstreams rolling out awareness of reasonable adjustments and promoting healthy living lifestyles with people with LD&A.
- Use of Understand, Prepare and Prevent (UPP) model which is led by Taking Part.
- Ongoing work to establish appropriate data to ensure ethnic diverse groups can be targeted.
- Ongoing work around the improvement of coding to flag individuals with LD&A.

Performance of Shropshire Telford and Wrekin LeDeR programme

NHSE key performance indicators for LeDeR activity require reviews to be allocated to a reviewer within 3 months of notification, for reviews to be completed within 6 months of notification and the quality assurance of initial submitted reviews by the LAC within 2 weeks of completion before taking to panel. In the year 2022/23 NHS STW received a total of 35 notifications of which 30 were adult notifications and 5 were CDOP.

Child death data

During 2022/23 there were 5 cases notified to the LeDeR platform, which related to the death of a child with learning disabilities. Child death reviews (CDR) are a mandatory process. All children's deaths must be reviewed by a local child death overview panel (CDOP)

NHSE have commissioned the national child mortality database to carry out a thematic review of all the deaths of children and young people who have a learning disability or who are autistic, and this will be produced in the next year.

From mid to late 2023/24 the process around CDOP will change. A further update will come out to all systems once more details are known.

The pattern of notifications received by STW is detailed in the table below.

Table 3 - Summary of deaths notifications in 2022/23

Total Adult notifications 1st April 2022- 31st March 2023	30
Total CDOP notifications 1st April 2022- 31st March 2023	5
Completed reviews in 2022/23 (excluding CDOP)	24
Number of initial reviews completed	20
Number of focused reviews completed	4
Number of initial reviews	19
Number of focussed reviews	11
Number of reviews on hold (as above undergoing statutory investigations)	4
Number of breaches	7

Actions taken to address our performance.

We have focused to improve on our performance with an improvement in monitoring allocating of cases and completion of cases in a timely manner. We have a fortnightly follow-up with senior reviewers to ask how the cases are progressing, checking if they need any support from us to access notes or querying if there is anything that is delaying them from completing the review. During our meeting, we highlight any cases coming up to 4 months and give them priority for completion to prevent them from breaching the time frame. SCWCSU share their key performance indicators (KPI's) to show they are on track to complete all reviews on time. We have also identified thematic areas to increase the number of focused reviews to reach the threshold of the NHS England 35% target.

Our challenges

The challenges we have faced for the period are as follows:

- Accessing information/records on time from GPs, secure services, and archived records from providers.
- Obtain the Structured Judgment Reviews (SJRs) completed and submitted on time.
- Timely access to safeguarding and police investigations outcomes and reports.
- Ensuring that all cases for people with autism are reported and for those people with learning disabilities from ethnic minority groups.

We have met and discussed the effective ways of timely sharing all necessary information regarding the requirements of LeDeR reviews. We have agreed on contacts that will notified of any information required. This is not an issue in local authorities and acute hospitals, but it will continue to be a challenge in GP practices and social care providers. We could only establish contacts with GP's and social care providers where there have been reviews related to their patients.

Lessons from our reviewers

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 may have spent time in institutional care that may have had an impact on them during their life. 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 process for the quality assurance and approval of all completed reviews has been maintained throughout this year. This process of quality assurance means that

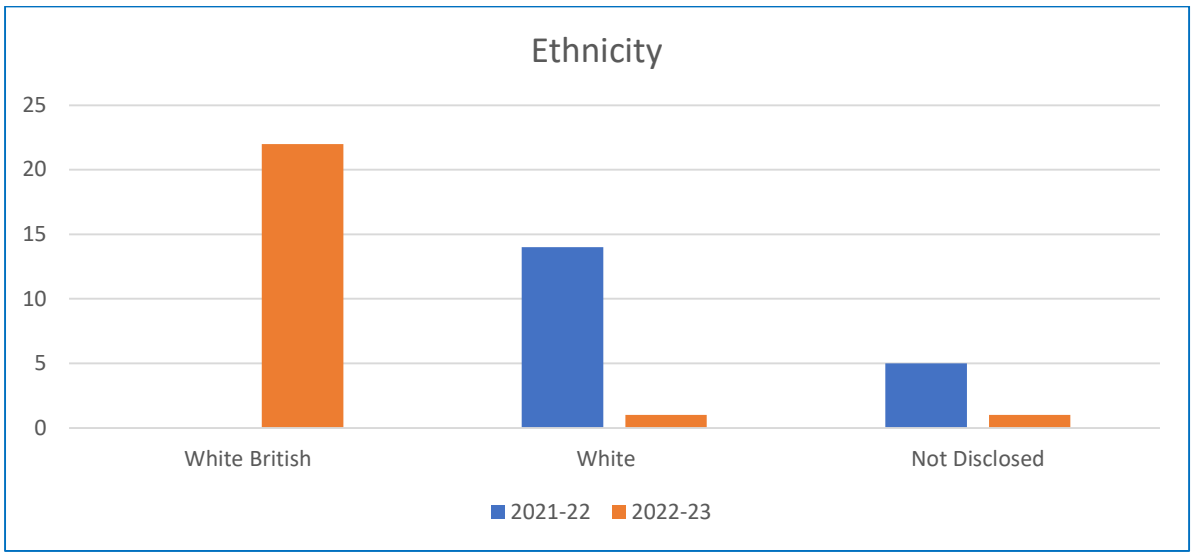
the friends and families of people with a learning disability who lose a loved one can feel confident that relevant aspects of learning are drawn from each LeDeR review with the aim of influencing improvements in the healthy future lives of others. Where the potential for care gaps or failings are apparent 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.

Demographic data and equality impact

As of 31st January 2023, the population of Shropshire Telford and Wrekin is 523,531. 422,154 are adults and 101,377 are under 18 years of age. Data from general practice at 31st March 2023 indicates there are 2556 people aged 14 and over registered with a learning disability and 2880 people across Shropshire Telford and Wrekin registered with autism.

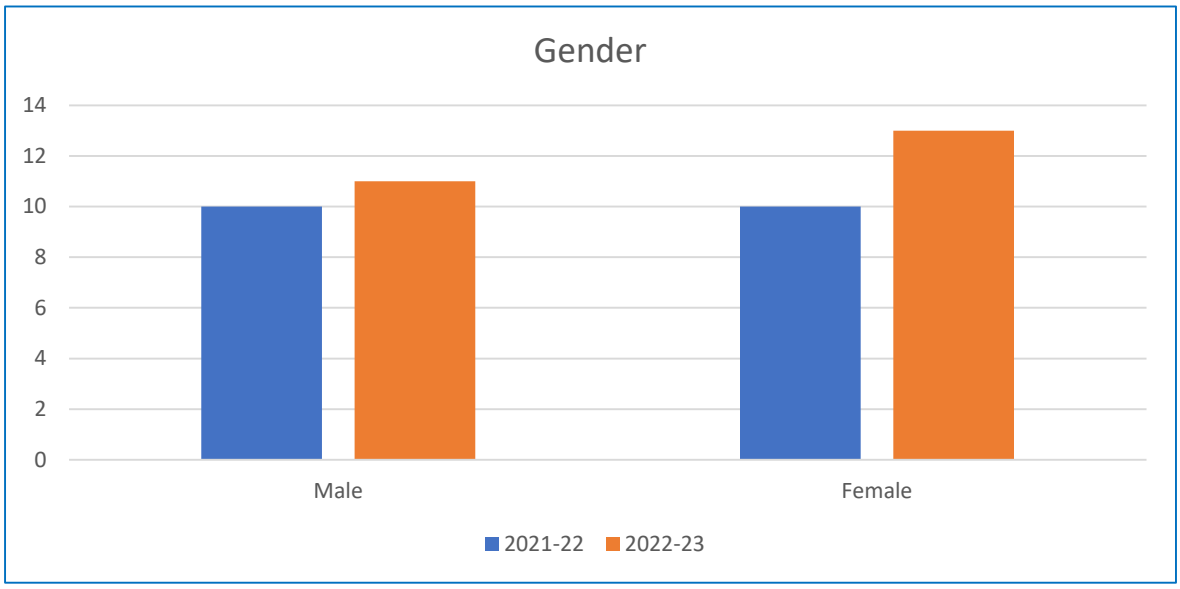
Below are tables 4 to 13 which demonstrate the analysis of the notifications that we received from the 1st of April 2022 to 31st March 2023 and comparison of data from last year.

Table 4 – Ethnicity of those reviewed.



At the point of notification one of the reviews did not state what the ethnicity of the person was and one of the reviews only stated that the person was white. However, compared to last year it shows that a person's ethnicity is more clearly documented with a person's race and nationality.

Table 5 – Gender of those reviewed.



Nationally there are more deaths of males than females. Across Shropshire Telford and Wrekin there are slightly more female deaths than male deaths, compared to last year where there was an equal divide between male and female deaths.

Table 6 – Age at death of those reviewed.

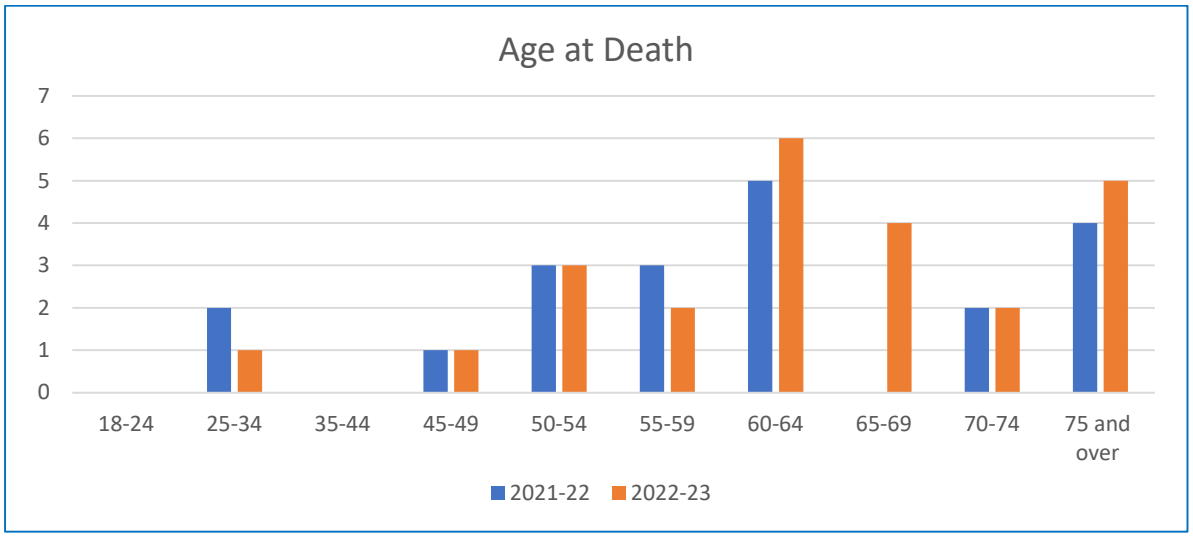
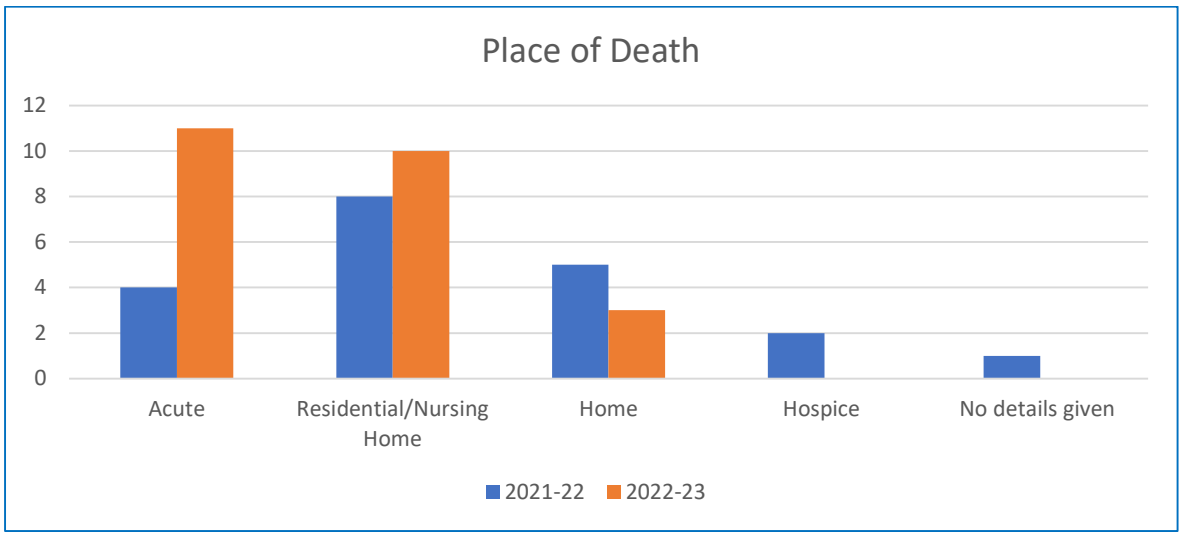


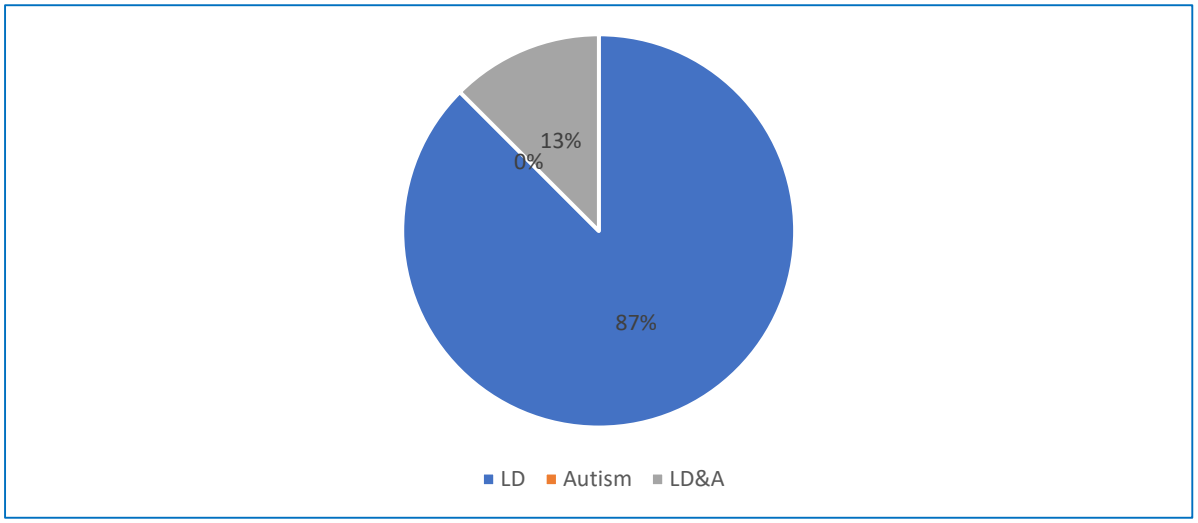
Table 6 shows the age range of all 24 reviews that were completed. Nationally the average age of death for a person with a learning disability is 62 years of age. In STW the average age of death for 2022/23 is age 62 years improvement of two years, compared to 60 years in 2021/22. However, 45% of those that died were under the age of 60 years.

Table 7 - Place of death of those reviewed.



As per table 7, thirteen people (42%) died in their usual place of residence, i.e., either their own home or a residential/nursing home, however in 2021-22 thirteen people (65%) died in their usual place of residence, i.e., either their own home or a care home. This is an area of care we are working to improve on in 2023/24.

Table 8 - Learning Disability (LD), Autism and Learning Disability & Autism (LD&A) data of those reviewed



As per table 8, 21 people (84%) had a learning disability only diagnosis, 3 people (13%) had a dual diagnosis of learning disability and autism and no reviews (0%) in this period had a diagnosis of autism only. This data was not reported for the period of 2021-22.

Table 9 – Cause of Death (2022-23) of those reviewed.

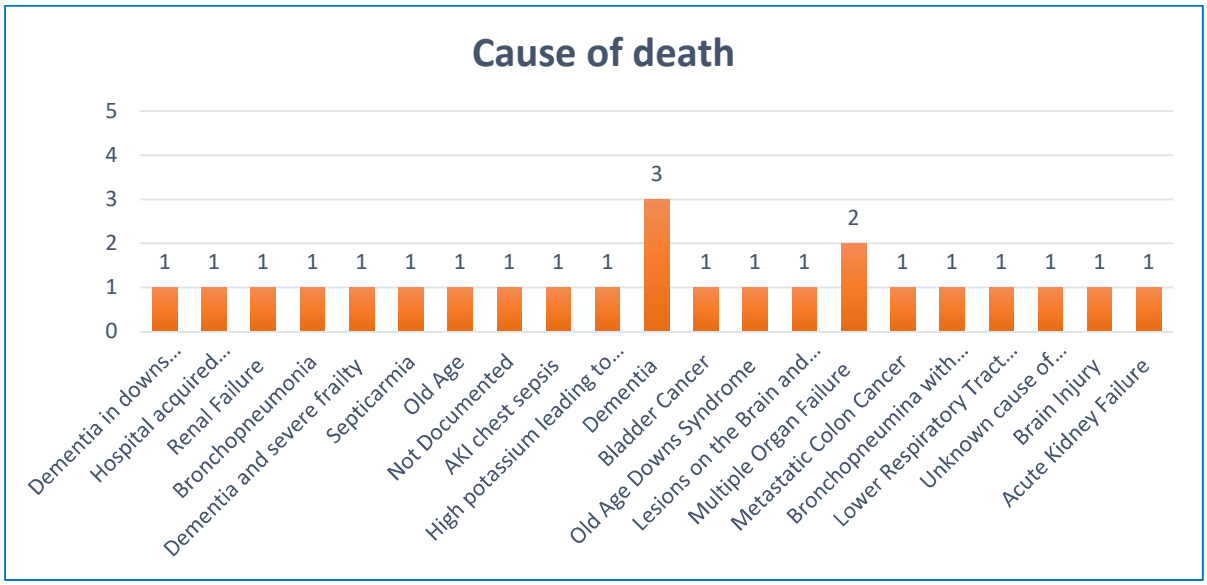
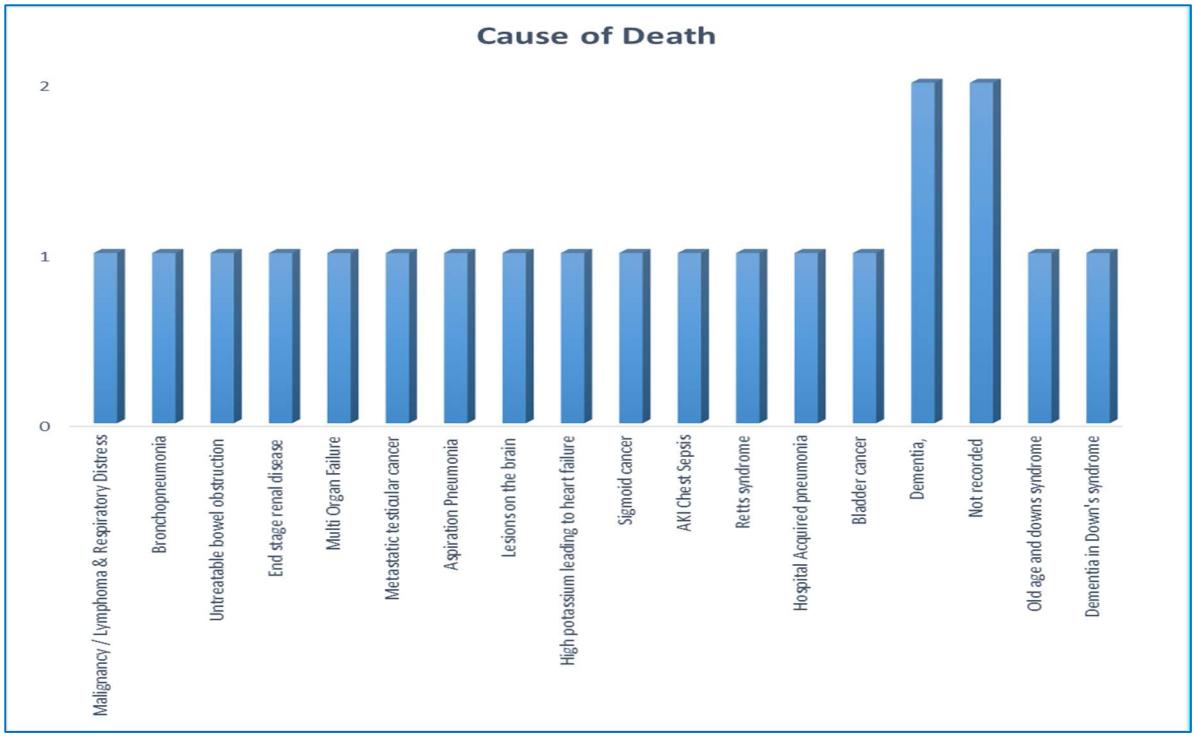
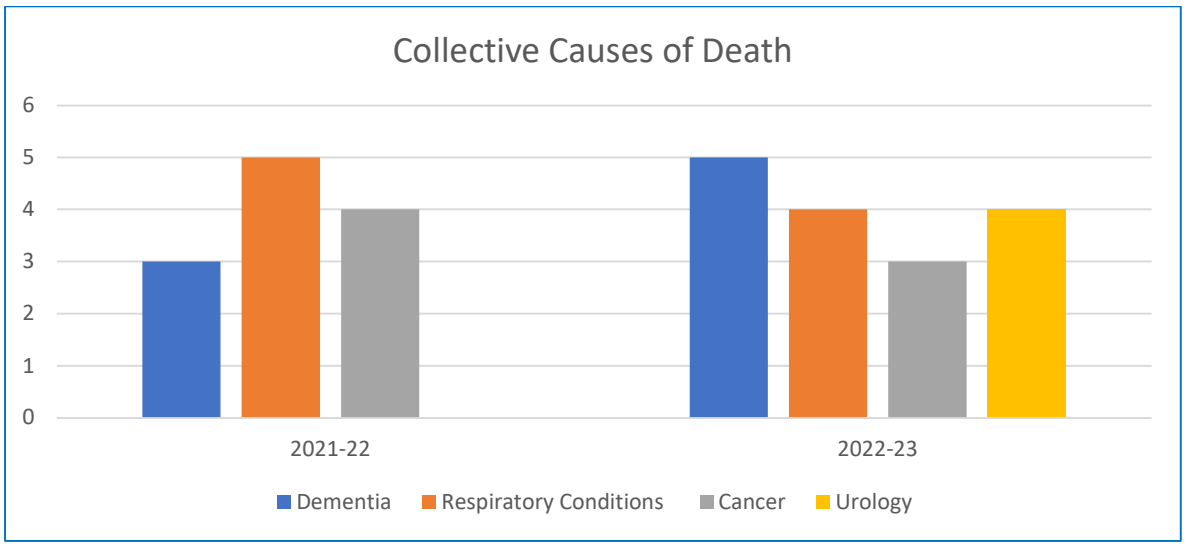


Table 9a – Cause of Death (2021-22) of those reviewed.



As per table 9 the causes of death for the 24 reviewed were varied during this reporting period, similarly to the data for 2021-22 as per table 9a. For the two years running the highest cause of death recorded was dementia.

Table 10 - Collective Causes of Death



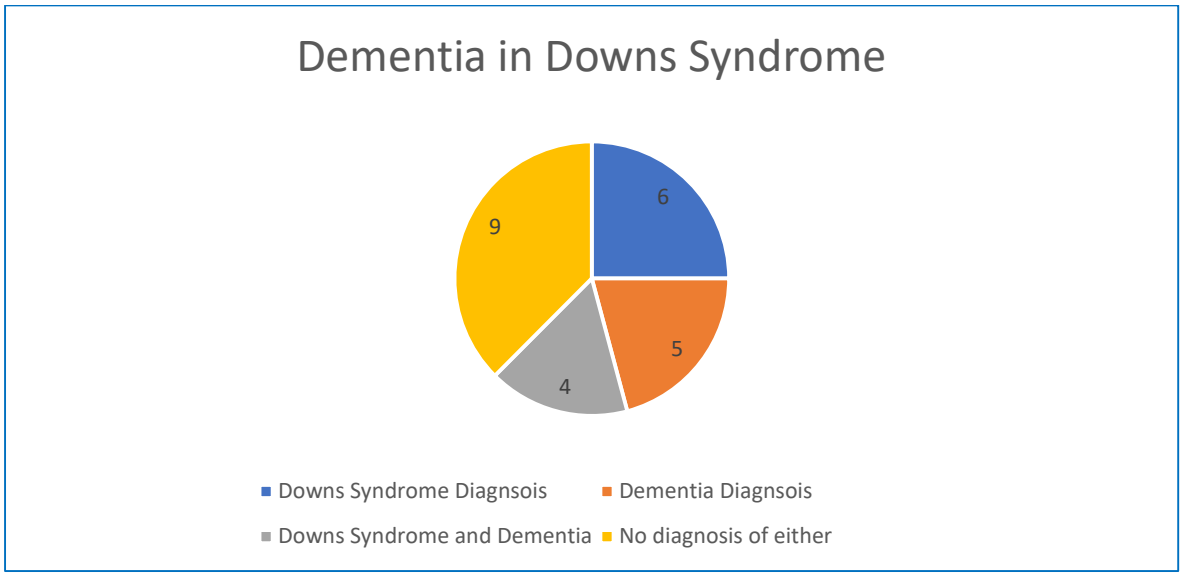
As per table 10 the top four themed causes of death are as detailed below, please note this is collective for groups with 3 or more.

- Dementia related deaths, which counted for the highest cause of death with five people (31%) having this documented as the primary cause of death.
- This was followed by four people (25%) having respiratory related deaths and four people (25%) having urology related deaths. (Urology includes diagnoses and treatments of disorders of the kidneys, ureters, bladder, urethra and can include the penis, testes, scrotum and prostate in males)
- Three people (19%) had cancer related deaths as a primary cause.

Compared to 2021-22 the causes of death were varied and had three top themed causes of death are:

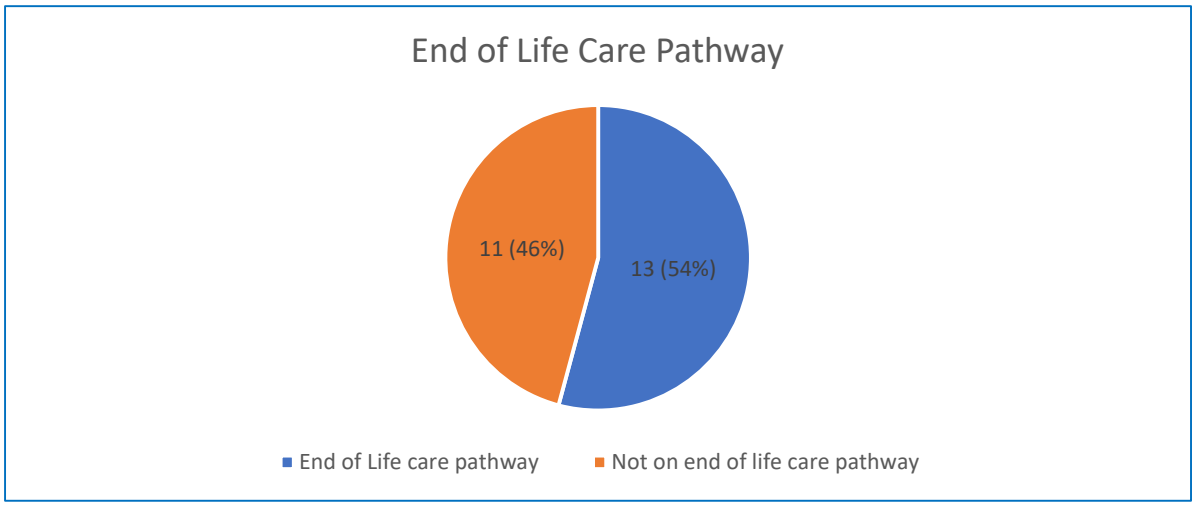
- Respiratory conditions, which counted for the highest cause of death with five (25%) people having this documented as the primary cause.
- This was followed by four (20%) cancer related deaths.
- Three (15%) patients had dementia as a primary cause.

Table 11 - Dementia and Down Syndrome



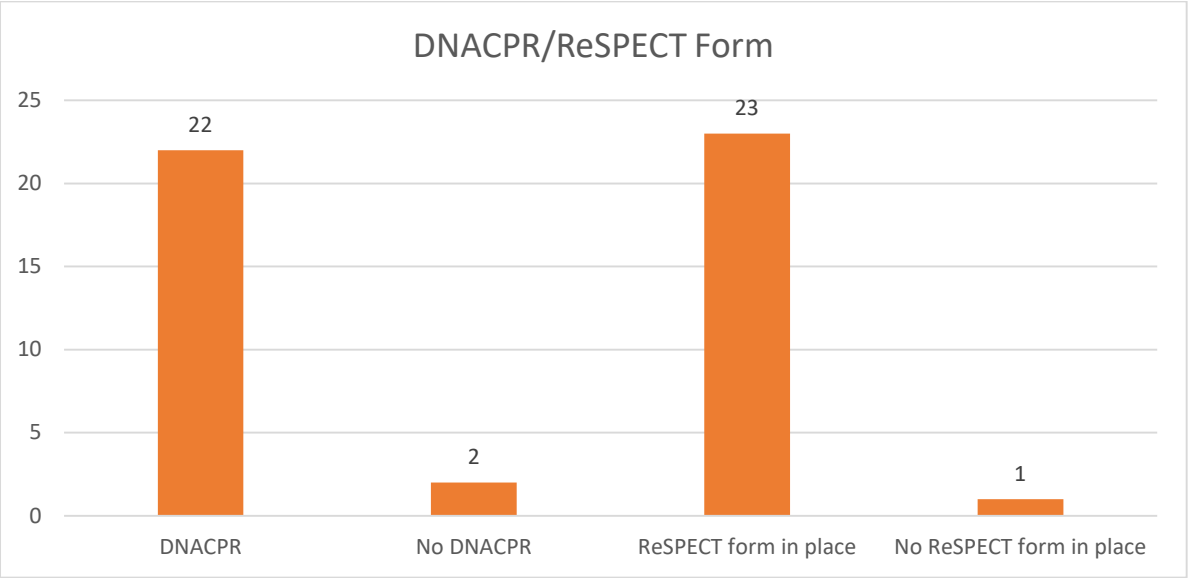
As per table 10 dementia was the leading cause of death during this reporting period. As per table 11, out of the 24 reviews 6 people (25%) had a diagnosis of Downs Syndrome and 5 people (21%) had a Dementia diagnosis and 4 out of 24 (17%) had a dual diagnosis of both Downs Syndrome and Dementia, compared with 9 people out of 24 (37%) without a diagnosis of either.

Table 12 - End of life



As per table 12, 13 people (54%) of the 24 reviews were on the end-of-life care pathway compared to 11 people (46%) who were not. This data was not reported for the period of 2021-22.

Table 13 - DNACPR / ReSPECT Form



As per table 13, 22 people out of 24 had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) in place compared to 2 people who did not and 23 people out of 24 had a ReSPECT form in place compared to 1 who did not. In 2021-22 completion of DNACPR was 95% the completion of ReSPECT documentation (Recommended Summary Plan for Emergency Care and Treatment) was not captured on the LeDeR platform, this is a change for 2022-23.

Measuring success

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

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

- A reduction in the early deaths of people with a learning disability and/or autism.
- 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 mental capacity assessment (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 and regional standards.

Recommendations and next steps

It is proposed that while the key recommendations for 2023/24 are supported by NHS STW we should also seek support our system partners enabling us to:

- Strengthen links with and reduce inequalities for people from minority ethnic communities.
- Widen the membership of the LeDeR Steering Group and LeDeR Governance Panel to include people with lived experience and representation from a minority ethnic community.
- Make improvements in all key areas we have identified this year through a robust strategic plan that is led by our LD&A working group.
- Continue to strive for better performance of learning disability annual health checks (LDAHC).
- Ensure learning identified from reviews informs day to day practice across our system partners through the development of strong links and platforms for sharing information and to influence national improvements.
- To ensure that we continue to focus on delivering the recommendations from the Oliver McGowan and Clive Treacey reports.
- Explore the term reasonable adjustments and its meaning and what people need compared with what they can expect and continue to explore the barriers individuals experience and support them to access what can make the difference to them.
- Increase the training around reasonable adjustments and healthy living across the STW system partners that incorporates Healthwatch/Treat me well.
- Work with GPs across Shropshire Telford and Wrekin to ensure GP records include the number of individuals with a diagnosis of autism to improve our database for people with autism.
- Looking at how services can be improved to support autistic people to fully meet their needs adequately.

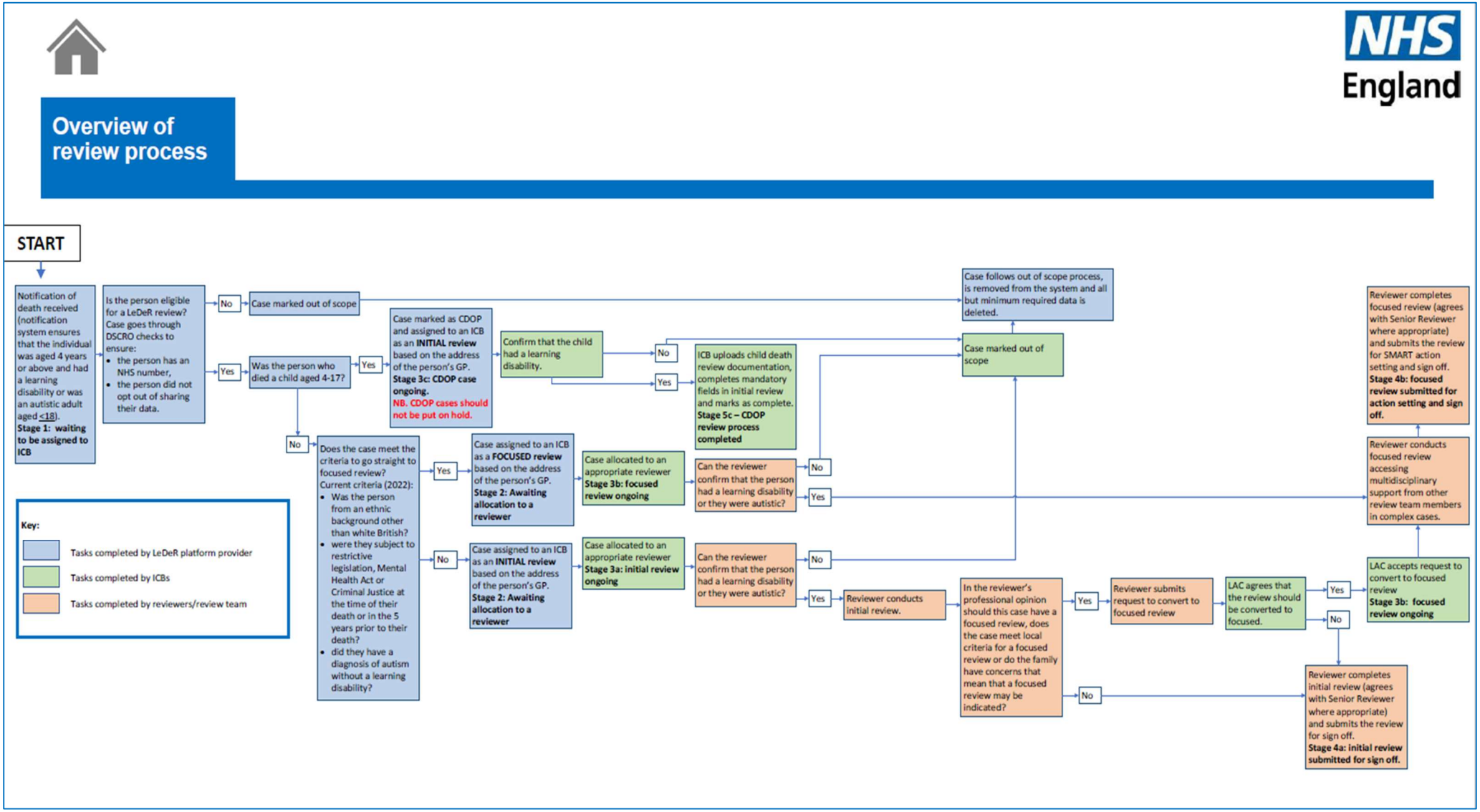
- NHS STW to carry out an audit on the adherence of mental capacity act and DoLS and the use of DNACPR and ReSPECT documents.
- To improve the collection of data for ethnic minority groups and to also promote appropriate recording of someone's ethnicity in demographic data.
- To explore and develop a regional interlinked system to identify people with a learning disability and autism when accessing health and social care services.
- To improve on the use of hospital passports across the STW system, for the work to be undertaken to use the One Health and Care Integrated Care Record to identify a person with a learning disability and/or autism and the hospital passport/reasonable adjustments so that no matter where the individual is in the system, this information can be accessed.
- Improve opportunities for personalised end of life care.

Conclusion

We value the on-going co-production of LeDeR related quality improvements across our system. This is central to the development and delivery of everything we do to improve the lives of people with LD and A and their loved ones. We would like to thank the contribution of the family members, reviewers, and STW LeDeR Steering Group members who have contributed to the reviews of deaths of people with learning disabilities and autism and worked to put service improvements in place.

The LeDeR programme in Shropshire Telford and Wrekin has seen strong engagement with stakeholders across the system who are committed to achieve the aims and objectives of the LeDeR programme. Although we have identified a number of areas that require improvement, we have also seen examples of good practice within our reviews that we will take as positive learning and thrive to improve at all times.

Appendix 1


NHS England
Overview of review process
START
Notification of death received (notification system ensures that the individual was aged 4 years or above and had a learning disability or was an autistic adult aged <18). Stage 1: waiting to be assigned to ICB
Is the person eligible for a LeDeR review? Case goes through DSCRO checks to ensure:
• the person has an NHS number,
• the person did not opt out of sharing their data.
No
Case marked out of scope
Case follows out of scope process, is removed from the system and all but minimum required data is deleted.
Yes
Was the person who died a child aged 4-17?
Yes
Case marked as CDOP and assigned to an ICB as an INITIAL review based on the address of the person's GP. Stage 3c: CDOP case ongoing. NB. CDOP cases should not be put on hold.
Confirm that the child had a learning disability.
No
Yes
ICB uploads child death review documentation, completes mandatory fields in initial review and marks as complete. Stage 5c – CDOP review process completed
Case marked out of scope
No
Does the case meet the criteria to go straight to focused review? Current criteria (2022):
• Was the person from an ethnic background other than white British?
• were they subject to restrictive legislation, Mental Health Act or Criminal Justice at the time of their death or in the 5 years prior to their death?
• did they have a diagnosis of autism without a learning disability?
Yes
Case assigned to an ICB as a FOCUSED review based on the address of the person's GP. Stage 2: Awaiting allocation to a reviewer
Case allocated to an appropriate reviewer Stage 3b: focused review ongoing
Can the reviewer confirm that the person had a learning disability or they were autistic?
No
Yes
No
Case assigned to an ICB as an INITIAL review based on the address of the person's GP. Stage 2: Awaiting allocation to a reviewer
Case allocated to an appropriate reviewer Stage 3a: initial review ongoing
Can the reviewer confirm that the person had a learning disability or they were autistic?
No
Yes
Reviewer conducts initial review.
In the reviewer's professional opinion should this case have a focused review, does the case meet local criteria for a focused review or do the family have concerns that mean that a focused review may be indicated?
Yes
Reviewer submits request to convert to focused review
LAC agrees that the review should be converted to focused.
Yes
No
LAC accepts request to convert to focused review Stage 3b: focused review ongoing
No
Reviewer completes initial review (agrees with Senior Reviewer where appropriate) and submits the review for sign off. Stage 4a: initial review submitted for sign off.
Reviewer conducts focused review accessing multidisciplinary support from other review team members in complex cases.
Reviewer completes focused review (agrees with Senior Reviewer where appropriate) and submits the review for SMART action setting and sign off. Stage 4b: focused review submitted for action setting and sign off.
Key:
Tasks completed by LeDeR platform provider
Tasks completed by ICBs
Tasks completed by reviewers/review team