Integrated Care System
Shropshire, Telford and Wrekin

NHS
Shropshire, Telford and Wrekin

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

Shropshire, Telford & Wrekin

Annual Report

1st April 2023 – 31st March 2024

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Executive Summary

Learning from lives and deaths - People with a learning disability and autistic people (LeDeR) is a service improvement programme for people with a learning disability and autistic people established in 2017.

The programme seeks to:

- **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**

Throughout 2023-24, Shropshire Telford & Wrekin Integrated Care Board (NHSSTW) has worked with a range of stakeholders to continue delivery of the LeDeR programme across our county. This has been done by carrying out a review after the notification of the death of any individual with a learning disability and/or autistic person then using the learning from each review to drive improvements in care for our people.

Each LeDeR review we have completed during 2023-24 has looked at key episodes of the individual's life and death to identify any challenges in access, provision, and delivery of care. Understanding the lived experience of people with learning disabilities and/or autistic people is central to the LeDeR programme, and our reviewers have actively sought to engage with family members and carers in each of the reviews they have carried out.

During 2023-24 NHSSTW was notified of 21 adult deaths of people with a learning disability and or/autistic people who lived in Shropshire Telford & Wrekin. A total of 21 LeDeR reviews were progressed during the year. The median adult age of death was 50 years a reduction from 2022/23. The report also shows a reduction in LeDeR notifications received compared to 2022-23. It should be kept in mind that a referral to the LeDeR programme, although strongly recommended, is not mandatory so does not have complete coverage of all deaths of people with a learning disability and autistic people and the numbers are small so must be interpreted with caution; findings and comparisons must be considered indicative rather than conclusive. A priority for the LeDeR programme for 2024-25 is to work with system partners, parents and carers groups and the voluntary sector to increase to number of notifications.

Findings from 2023/24 shows the lead cause of death as aspiration pneumonia, this accounts for 19% of all deaths reviewed. 14% of deaths were linked to bronchopneumonia and 9% of deaths were linked to epilepsy and 9% were linked to cancer. Level of disability linked to reviews showed 16% of individuals had a mild learning disability, 37% a moderate learning disability, 32% a severe learning disability, 10% profound learning disability and 5% the level was not documented. Ethnicity linked to reviews shows 90% of individuals were white British, 5% Bangladeshi and 5% Chinese.

During 2023/24 we have continued to work with a range of partners to co-produce activities that respond to the learning from reviews, and this is set out in the sections below. During 2023-24 we have worked with system partners to collate a systemwide action plan for the Clive Treacey recommendations, further detail is in the slides below and Clive Treacey recommendations are aligned to our local priorities and will continue to be a focus for 2024-25.

We can demonstrate our ongoing commitment to learn from LeDeR reviews and implement meaningful change and improvement initiatives to meet the aim of the LeDeR programme. The aim remains for people with a learning disability and autistic people across STW to enjoy good health and good care, and to no longer experience health inequalities or die from preventable causes.

Credits and Acknowledgements

We would like to thank the families, friends, carers and health and social care professionals who have provided critical contributions to each LeDeR review. Their support has been invaluable and without their input, the reviews and learning would not have been possible.

Special thanks to:

- Members of the LeDeR Steering Group and Governance Panel
- Primary Care colleagues across Shropshire Telford and Wrekin
- Our provider trusts: The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust (RJAH); The Shrewsbury and Telford Hospital NHS Trust (SaTH); Shropshire Community Health NHS Trust (SCHT); and Midlands Partnership University NHS Foundation Trust (MPUFT)
- Shropshire Telford & Wrekin Child Death Overview Panel (CDOP)
- Shropshire Council and Telford & Wrekin Council
- NHS South Central and West Clinical Support Unit
- NHS England national & regional teams
- Marilyn Jones, parent care and member with lived experience
- Rob Gough as parent care and member with lived experience
- Mrs J Hampton-Pidgeon as LeDeR programme administration support.

Glossary of abbreviations

A	Autism
AHC	Annual Health Check
CDOP	Child Death Overview Panel
CIPOLD	Confidential inquiry into premature deaths of people with learning disabilities
CLDT	Community Learning Disability Team
CYP	Children & Young people
DNACPR	Do not attempt cardiopulmonary resuscitation
GP	General Practitioner
HAP	Health Action Plan
ICB	Integrated Care Board
ICS	Integrated Care System
LAC	Local area contact
LD	Learning Disability
LeDeR	Learning from Lives and Deaths of People with a Learning Disability and/ or Autism
NHSE	National Health Service England
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SaLT	Speech and Language therapist
SCW CSU	South Central & West commissioning support unit
SMART	Specific, measurable achievable, realistic and timebound actions
STW	Shropshire Telford and Wrekin
QA	Quality Assurance

Introduction to LeDeR

LeDeR was established in 2017 and was one of the key recommendations of the confidential inquiry into premature deaths of people with learning disabilities (CIPOLD). CIPOLD reported that some people with learning disabilities were dying sooner than they should. Some of the reasons for this were related to the standard of health & social care that individuals received. The learning from deaths – people with a learning disability and autistic people (LeDeR) programme 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 autistic people and reduce health inequalities. By finding out more about why people died we can understand what needs to be changed to make a difference to people's lives. The scope of LeDeR is that every adult aged 18 and over with a learning disability or with a clinical diagnosis of autism is eligible for a LeDeR review when they die.

The key principles of the programme are to:

Life expectancy & Health inequalities

Life expectancy

On average women with a learning disability **die 23 years younger** than women in the general population and men with a learning disability **die 19 years younger** than men in the general population (LeDeR, 2023; ONS, 2022). Nationally there is not accurate data for the life expectancy for autistic people.

LeDeR is part of the system and national wide context linked to the NHS Long Term Plan, which aims to improve people's health. A number of barriers are preventing people with a learning disability and or autism from getting good quality healthcare.

Health inequalities

Are the unfair differences in the status of people's health and wellbeing that frequently arise from the disparities and difficulties for people with a learning disability and/ or autistic people when they attempt to access health and/ or social care. These are known to result in poorer outcomes. These inequalities are what damage the level and effectiveness of care that people receive and reduce the opportunities for them to lead not only healthy but also their best lives.

LeDeR Process (see appendix 1)

1) Notifying a death: When a person with a learning disability or an autistic person dies a LeDeR death notification should be completed.
2) Allocation to reviewer for completion: At this stage it is assigned as an initial or a focused review (see next slide for further information)
3) The reviewer will then prepare for the review and access information relating to individuals care and treatment.
4) The reviewer will then contact family members & professionals
5) The reviewer will conduct the review
6) The review to be quality assured (QA) by a senior reviewer
7) The completed review is then sent to the LAC/deputy LAC for QA
8) If it is an initial review, following the QA by the LAC/deputy LAC, the review can be signed off on the LeDeR platform
9) If a focused review, following the QA by the LAC/deputy LAC the review is presented at ICS Governance Panel.

Where to notify a death

Report the death of someone with a learning disability or an autistic person (leder.nhs.uk)

LeDeR Policy

NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021

LeDeR reviews

Types of reviews

- **Initial Review:** The initial review is intended to be a short assessment to see if there is a need to progress to a focused review.
- **Focused review:** The focused review builds on the initial review. It asks for more information about known medical conditions and the social care the person received. There is also an opportunity to describe challenges or good practice around the care the person received.

Categories for a Focused review

- All autistic people who do not have a learning disability aged 18 and above
- People from ethnic groups other than white British (including travellers, Jewish people and other white backgrounds)
- People who have been in a detained setting in the criminal justice system /or who have been under a Mental Health Act restriction within five years of death
- Following an initial review where there is likely to be significant learning from the life of the person to inform service improvements
- Local priorities for focused reviews
- Where the family have requested a focused review
- Where there are any concerns about the care the person received.

LeDeR Governance Panel & Steering Group

Table 1

Core Membership
Family members who are carers or a family member who are members with lived experience.
Local Area Contact (LAC) and deputy LAC – who will have a key role in chairing the panel.
The Shrewsbury and Telford Hospital NHS Trust (SaTH),
Shropshire Community Health Team (SCHT)
The Robert Jones and Agnes Hunt Orthopaedic Hospital (RJAH).
Midlands Partnership University NHS Foundation Trust (MPUFT).
ICB including Individual Commissioning Team
Primary Care
Shropshire Council and Telford & Wrekin Council

The LeDeR Governance Panel meets monthly and is chaired by the deputy LAC. The LeDeR Steering Group originally met bi-monthly, but it was felt that priorities needed to be discussed more frequently, therefore from January 2024 they are held monthly and chaired by the LAC.

Table 1 lists the core representatives that attend the LeDeR Governance Panel and the LeDeR Steering Group

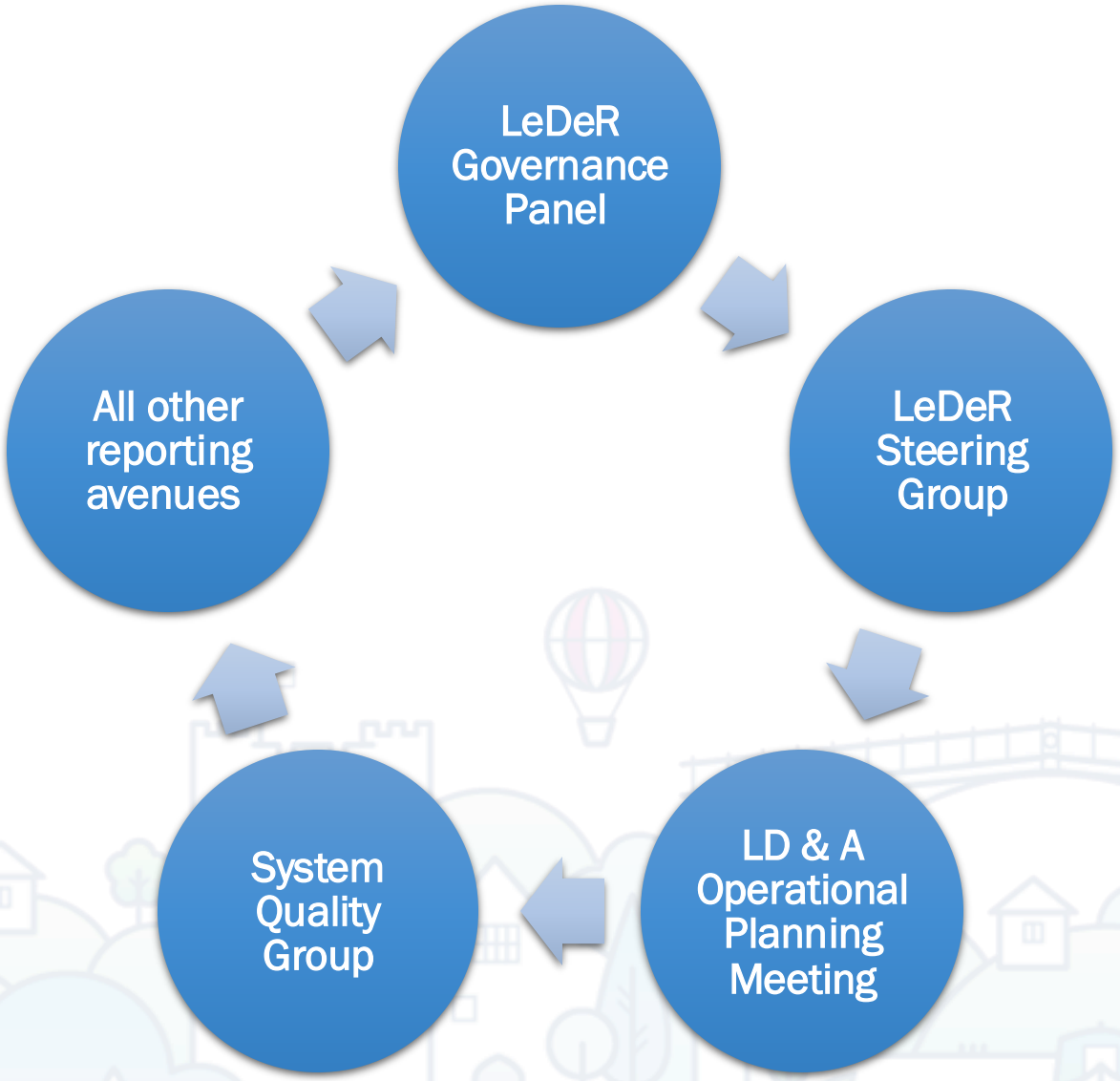
System partners who are members of both groups are expected to attend all meeting or to send a deputy who has decision making powers for the organisation they are representing.

Table 2 lists the 'as required' members who are invited to the LeDeR Governance panel should a case include the teams listed.

Table 2

As required
West Midlands Ambulance Service University NHS Foundation Trust (WMAS)
Screening Services
Police representative
Mental Health Team Providers
Senior Reviewers and respective reviewers as per the listed reviews on the agenda
Any other teams linked to specific cases

Governance Process



All focused reviews are presented at the LeDeR Governance Panel, who sign off the quality of the reviews and in discussion with the reviewer, agree specific, measurable, achievable, realistic and timebound (**SMART**) actions.

SMART actions feed into the system wide LeDeR Priorities Action Plan which is the responsibility of the LeDeR Steering Group.

Updates are reported to the:

- STW Learning Disabilities & Autism Operational Planning Meeting
- STW System Quality Group

Updates also feed into:

- STW Health Inequalities implementation plan
- NHS England quarterly reports

Child Deaths

From the 1st July 2023 the LeDeR policy regarding the review of deaths of children and young people aged 4 to 17 changed and there was no longer a requirement for deaths of children to be notified to the LeDeR programme.

This change was made because it was felt that the deaths of children with a learning disability and autistic children are reviewed by the national mandated processes that look at the deaths of all children.

Autism was also added to the national child mortality review child notification which will enable more in-depth analysis of the deaths of autistic children and young people for the first time.

The deputy LAC in NHS STW has close links into the CDOP process and attends panels when requested .

Equality impact and Demographic data

Table 3

According the office of national statistics following the 2021 census:	
Population of Shropshire Telford & Wrekin	509,100
Population of Shropshire	323,600
Population of Telford & Wrekin	185,500

Table 4

Data from the general practice registers shows:	
People aged 14 and over registered with a learning disability in STW.	2,684
People across STW with autism,	5,595 (2,384 of which are under the age of 18.)

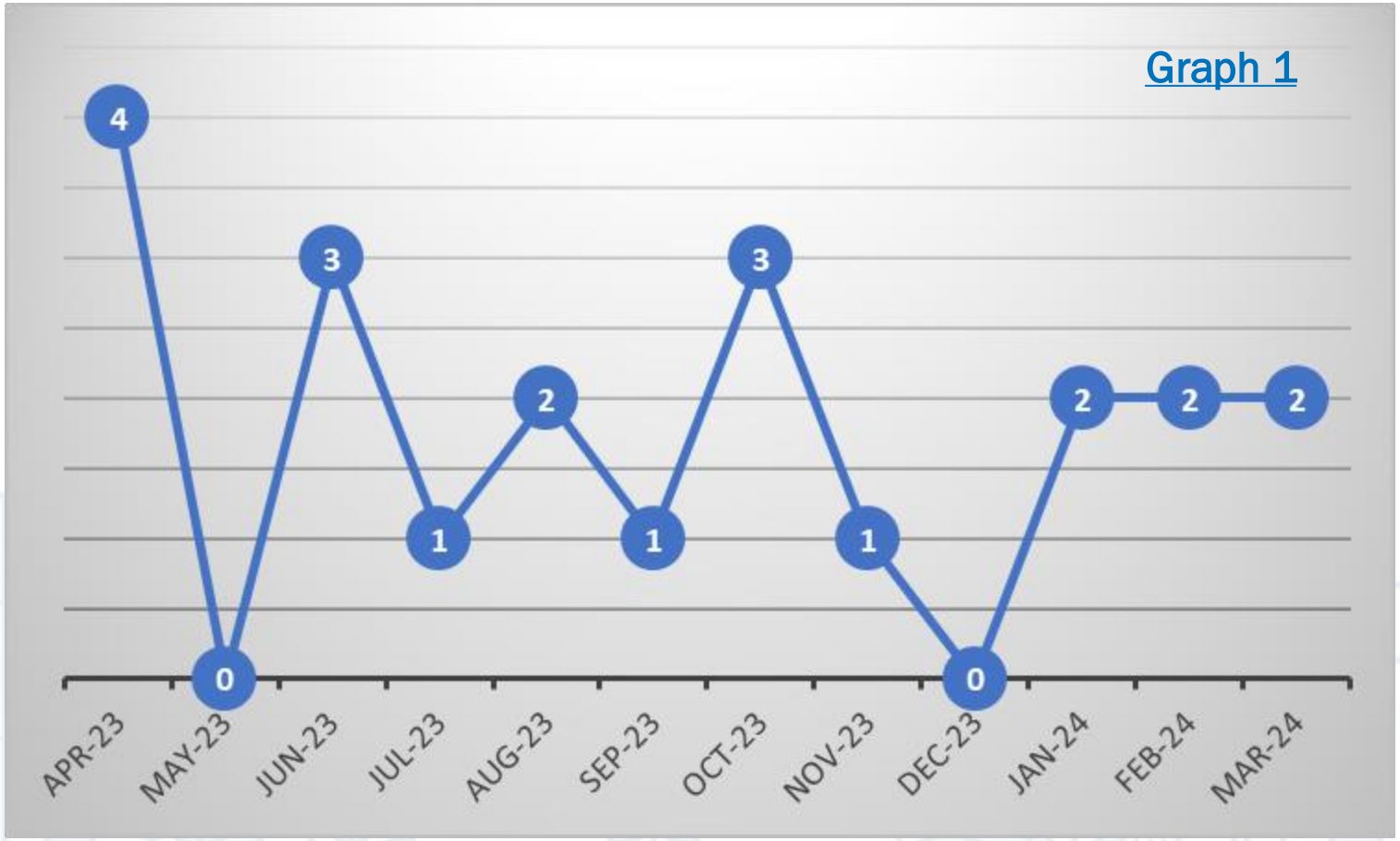
Summary of death notifications in 2023/24

Table 5

Total adult notifications 1st April 2023 – 31st March 2024	21
Total child death notifications 1st April 2023 – 31st March 2024	1
Completed reviews in 2023/24 (excluding child deaths) **please note some reviews completed in this period may have been carried forward from previous years.**	21
Number of initial reviews completed	6
Number of focused reviews completed	15
Number of reviews on hold	3

Notifications by month

The highest number of LeDeR notifications received for 2023-24 was in April 2023 (**4**), closely followed by June 2023 (**3**) and October 2023 (**3**). There were no notifications received in May 2023 or December 2023. As per slide 33, STW have seen a decline in notifications for 2023-24 compared to previous years.



Who is reporting deaths to LeDeR

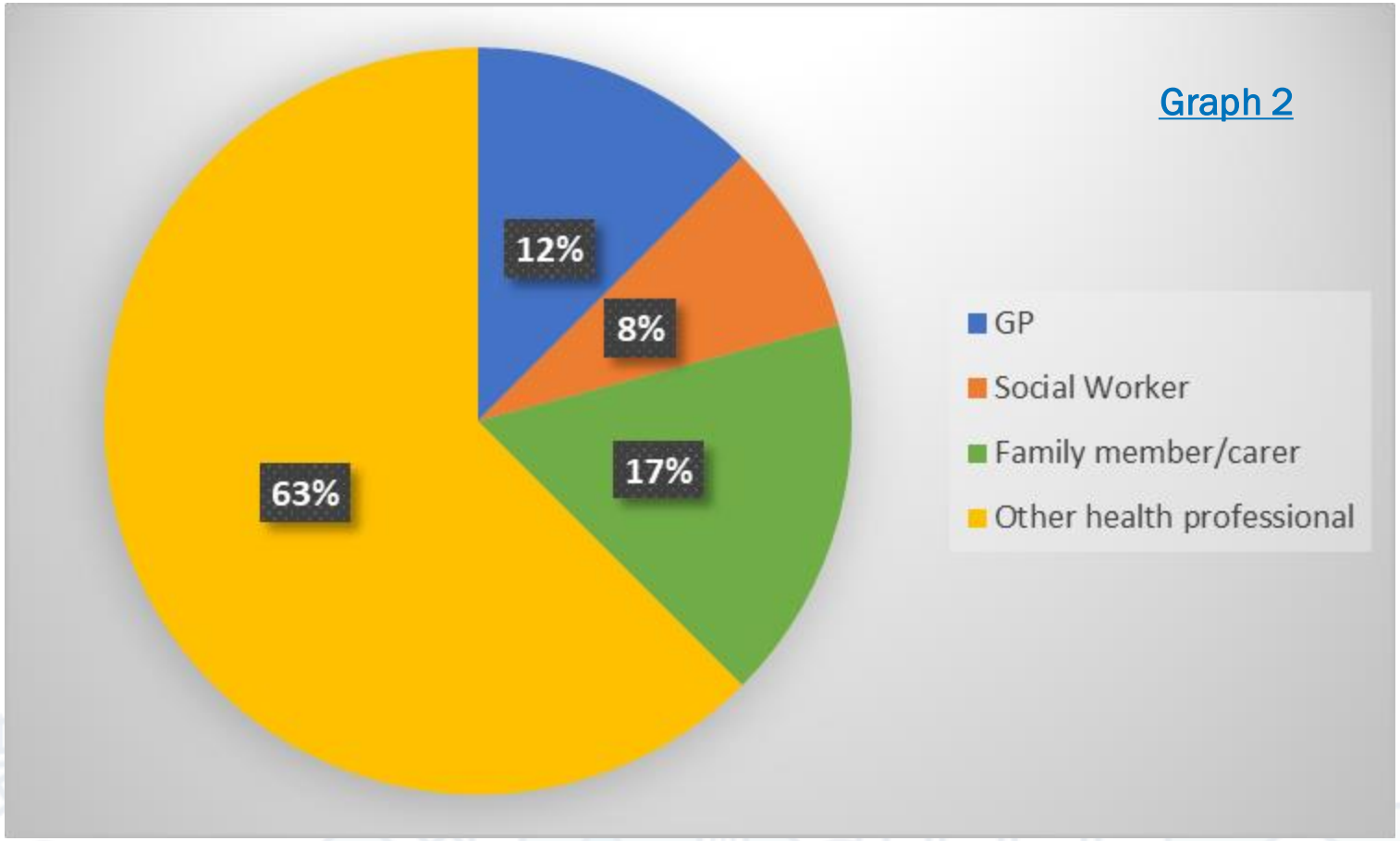
Table 6 Out of the 21 completed cases:

Notifier	No of notifications
GP's	3
Social Workers	2
Family members/carers	4
Other health professionals	15

Other health professionals could be:

- Clinical lead
- Nurse Specialist
- Mental Health Nurse
- Acute Liaison Nurse
- Assistant Psychologist
- Learning Disability Nurse
- Nurse Practitioner
- Speech and Language Therapist
- Learning from Deaths Lead

Graph 2



Please note the number of notifications will equal more than 21. This is due to more than 1 person submitting a notification to LeDeR for 4 of the cases.

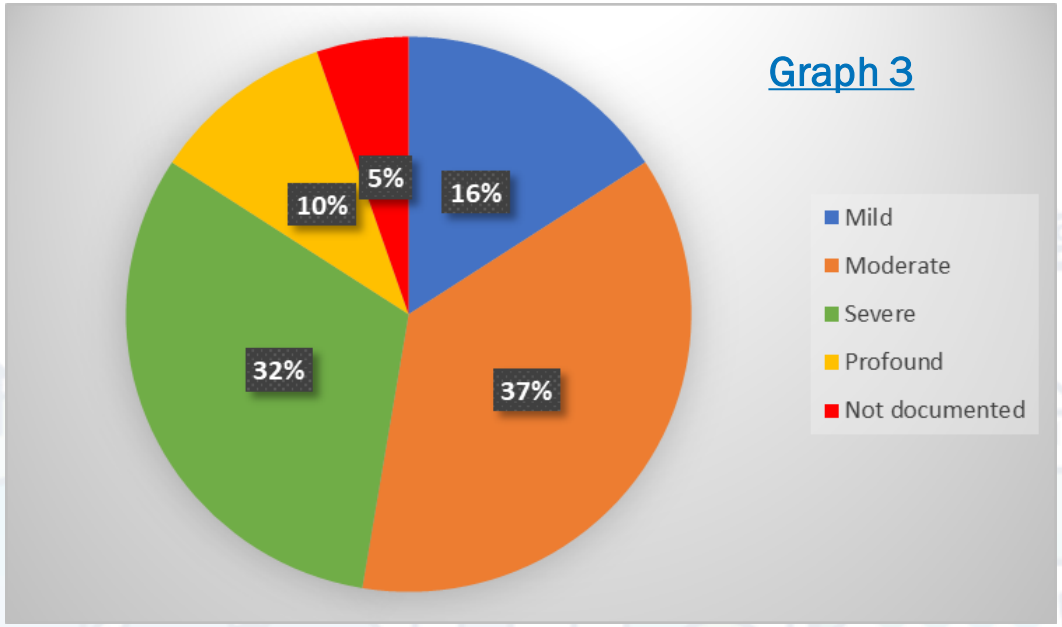
Level of Learning Disability

Table 7

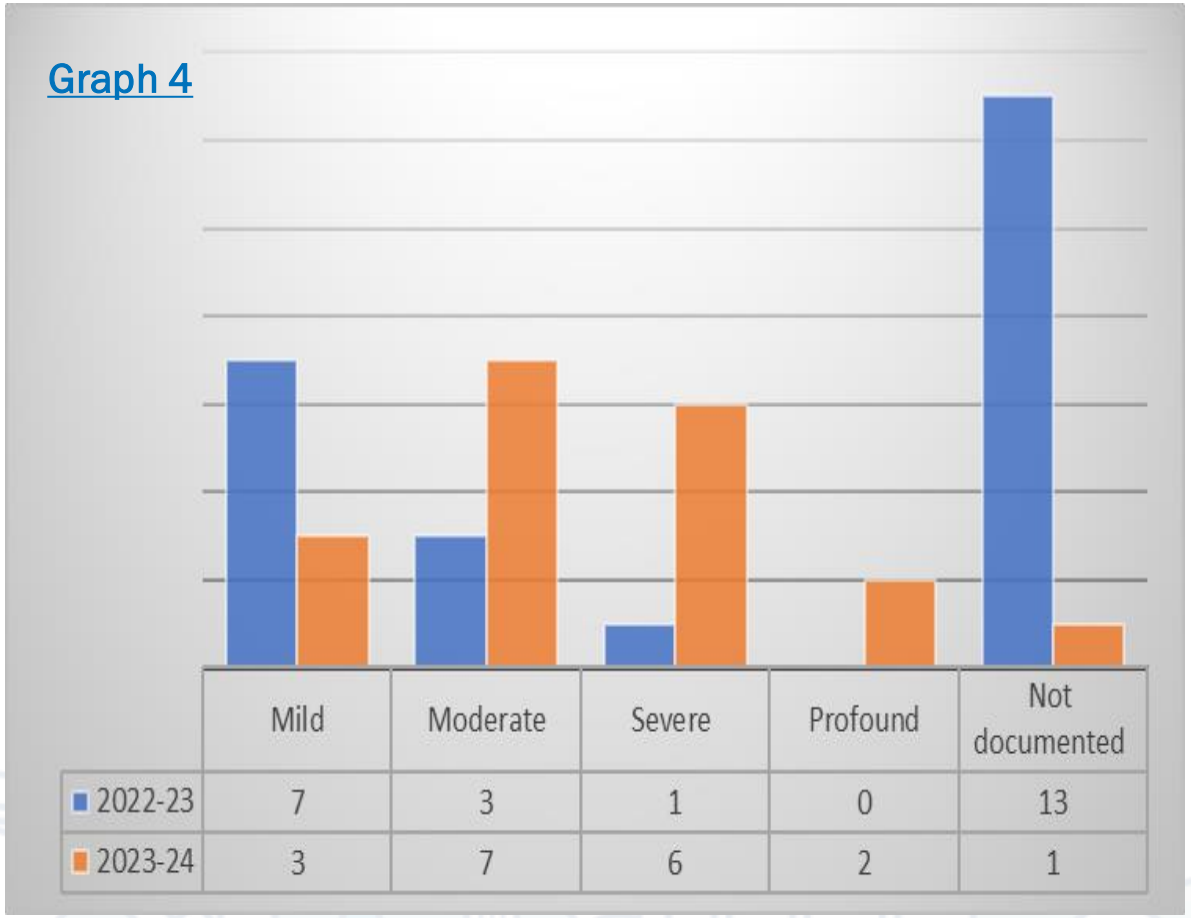
Level of learning disability	Number of people	Percentage
Mild	3	16%
Moderate	7	37%
Severe	6	32%
Profound	2	10%

1 case did not document the level of the learning disability.

Graph 3

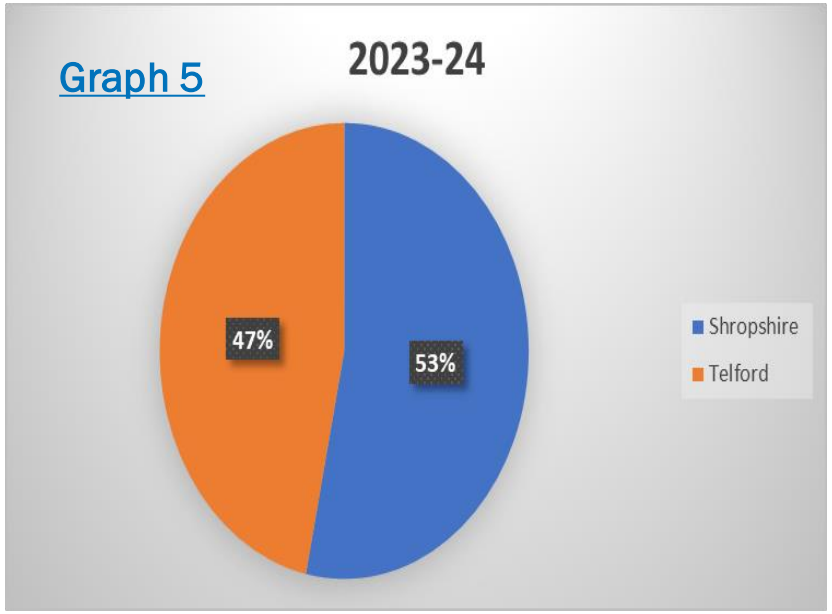


Graph 4



Graph 4 shows a comparison of this data to last year. This year's data is showing a significant improvement in the level of learning disability reporting.

Focused reviews 2023/24

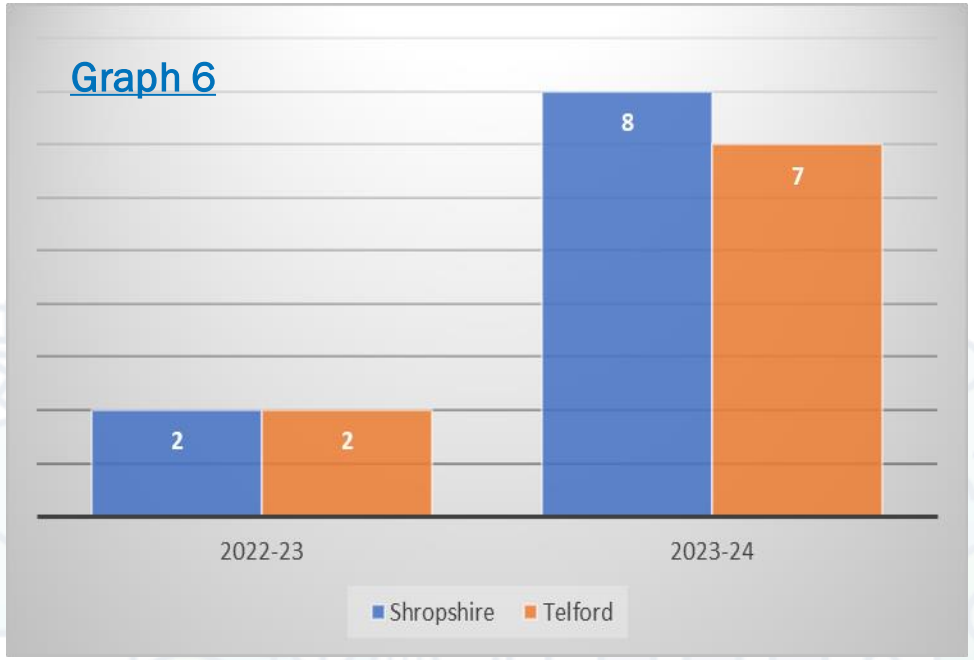


The number of focused reviews completed in 2023-24 was **15**.

Compared to last year where only **4** of the reviews completed were focused reviews.

Graph 5 shows that, 8 of the 15 reviews were from Shropshire (**53%**) and 7 of the 15 reviews were from Telford & Wrekin (**47%**).

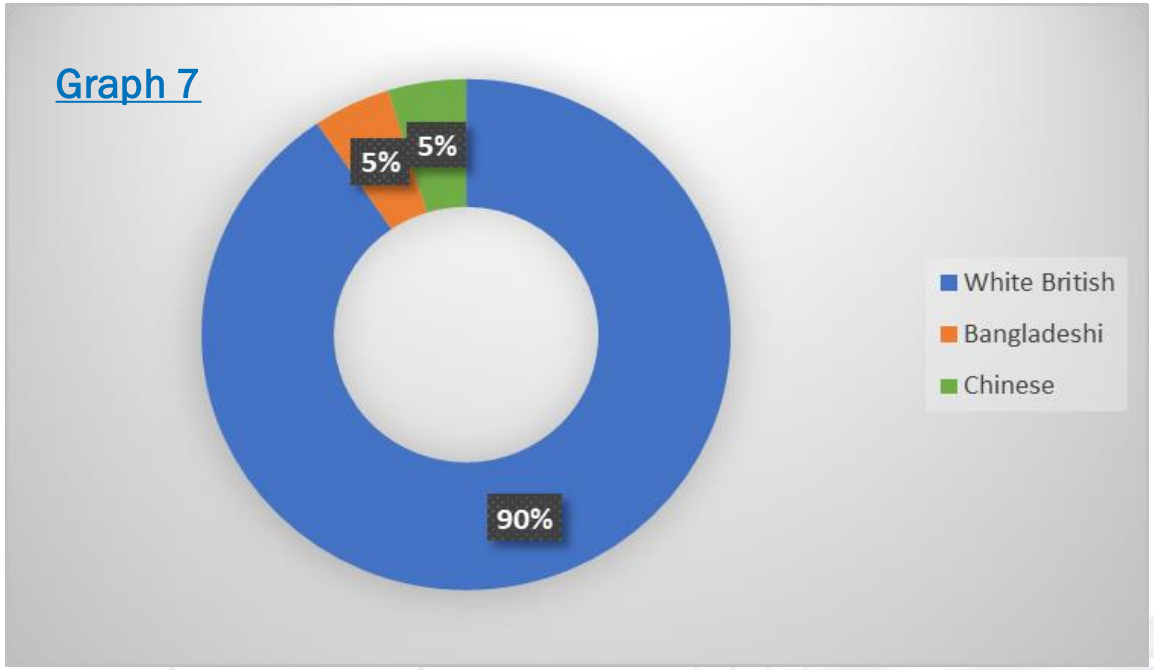
Graph 6 shows last year's data was a **50-50** ratio of reviews per locality with **2** linked to Telford & Wrekin and **2** to Shropshire.



Ethnicity

As per graph 7, of the 21 completed reviews, 19 (90%) were white British. 1 was Bangladeshi and 1 was Chinese.

Graph 7



As an ICS we need to do more to ensure we are receiving notifications for our whole community to try to understand more about the potential impact of ethnicity on health inequalities of people with a learning disability or autistic people.

Table 8

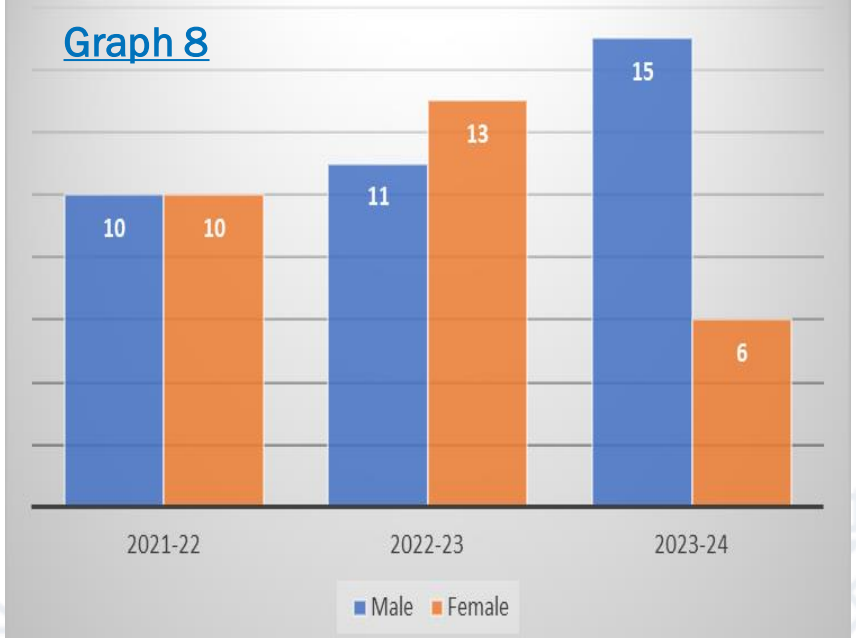
Ethnicity	2021-22	2022-23	2023-24
White British	14	22	19
Other	5	2	2

An individual's ethnicity was not recorded as part of the LeDeR review until 2021, therefore we do not have this data prior to then. In 2021 a platform development occurred for this data. The ethnicity from a majority of LeDeR cases from 2021 was recorded as white British, where the table states other, this could mean another ethnicity, the information was not available or not disclosed.

Gender

Nationally there are more deaths of males than females. As shown in graph 9, across Shropshire Telford & Wrekin there are significantly more male deaths (**71%**) than female deaths (**29%**) compared to last year where there were slightly more female deaths than male deaths.

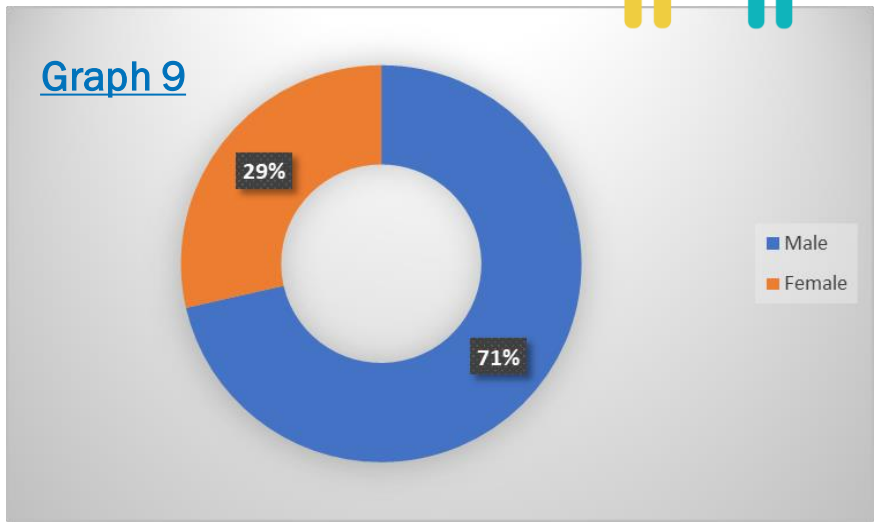
Graph 8



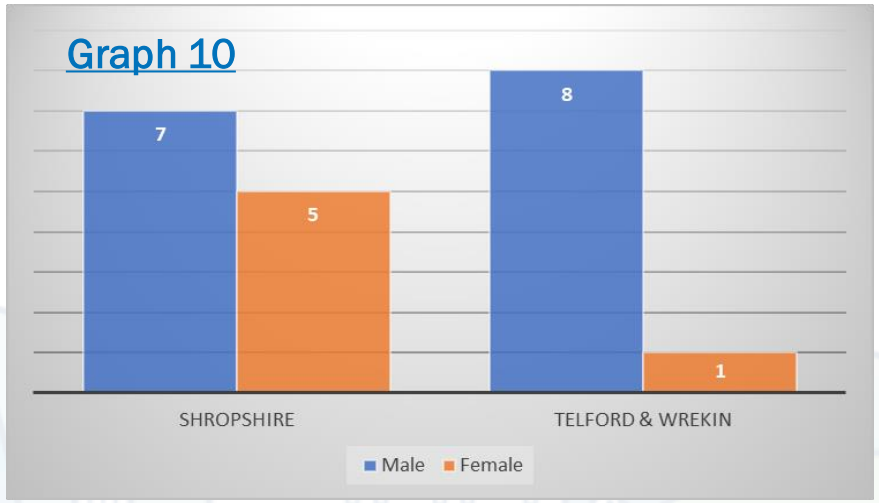
A breakdown of gender was not recorded as part of the LeDeR review until 2021, therefore we do not have this data prior to then. As a comparison from 2021, there has been an increase in male deaths as shown in graph 8.

With a further breakdown of region, more females died in Shropshire than in Telford & Wrekin and slightly more men died in Telford & Wrekin than Shropshire as shown in graph 10.

Graph 9

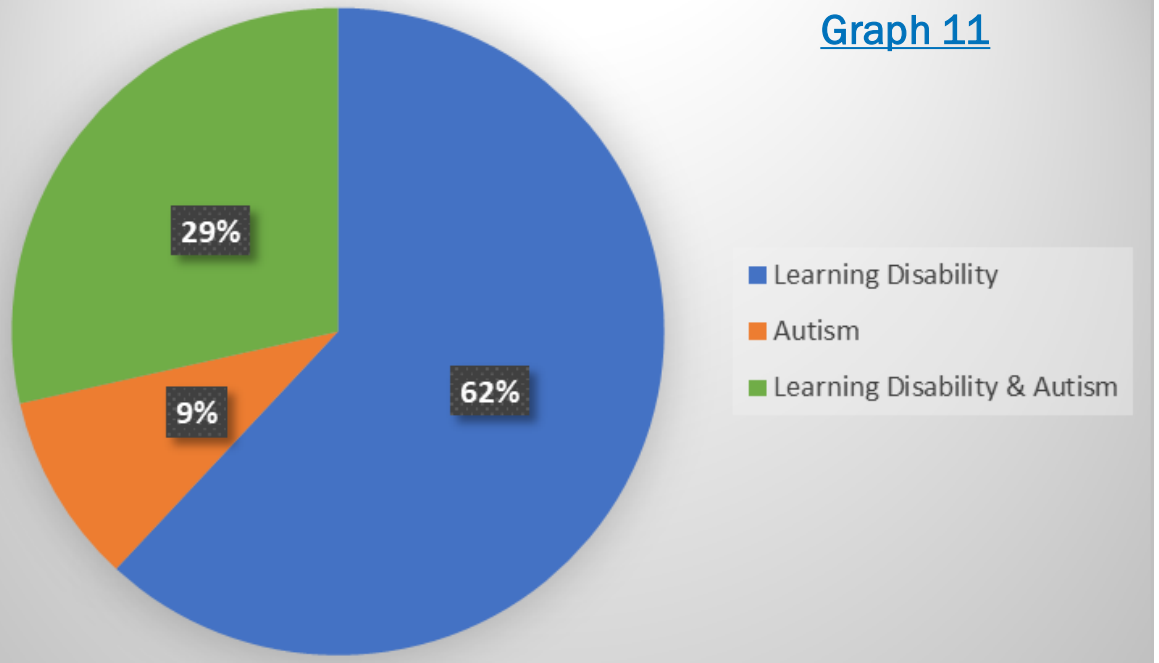


Graph 10



Diagnoses

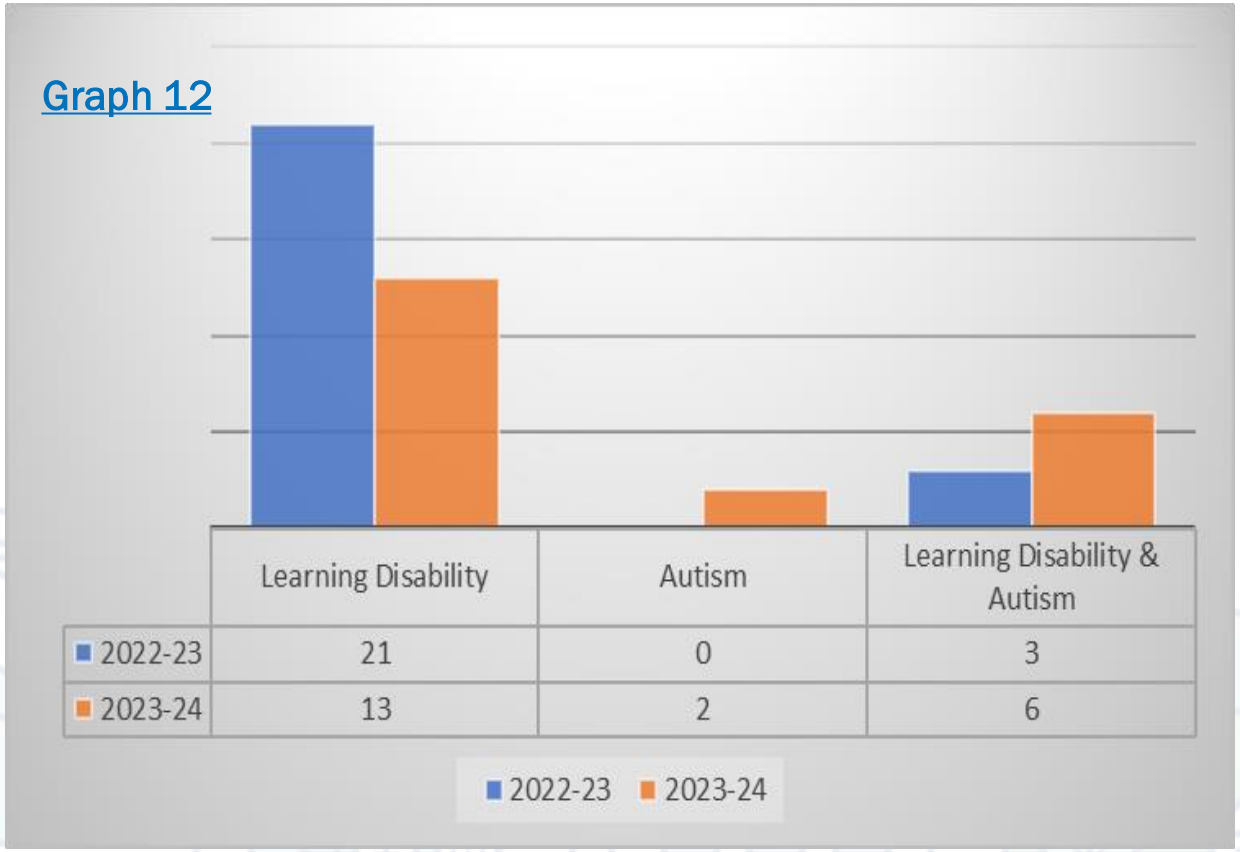
Graph 11



As per graph 11, 13 people (**62%**) had a learning disability only diagnosis, 6 people (**29%**) a diagnosis of both a learning disability and autism and 2 people (**9%**) had a diagnosis of autism only.

Graph 12 shows a comparison from 2022-23, this data was not reported for the period of 2021-22.

Graph 12

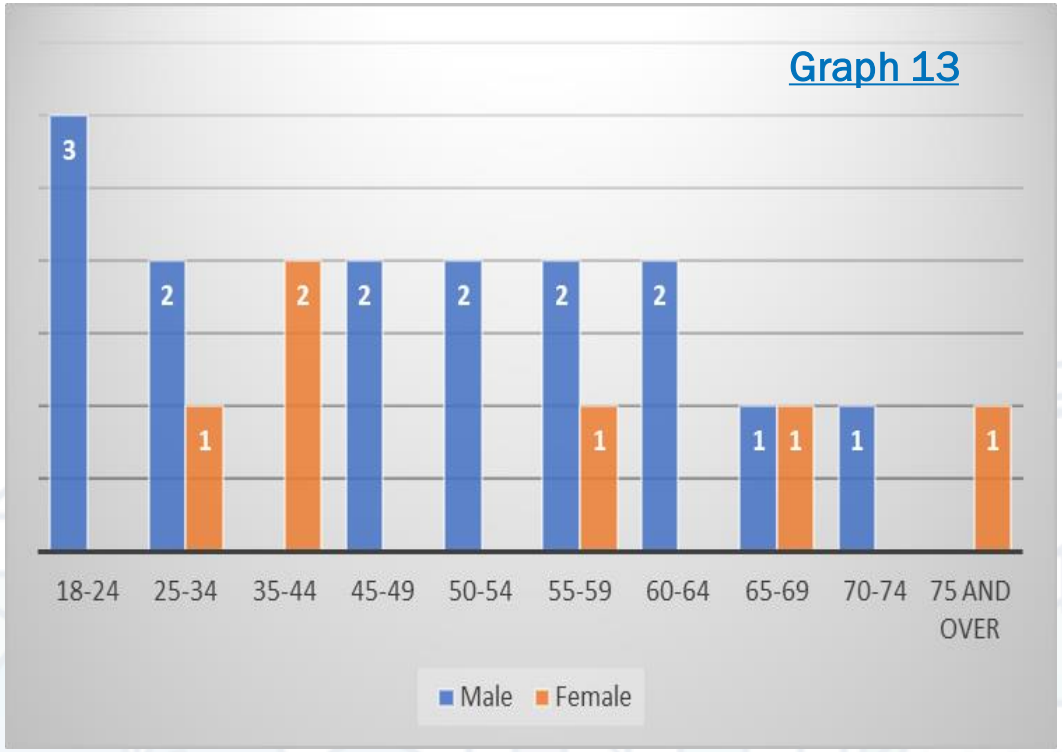


	Learning Disability	Autism	Learning Disability & Autism
2022-23	21	0	3
2023-24	13	2	6

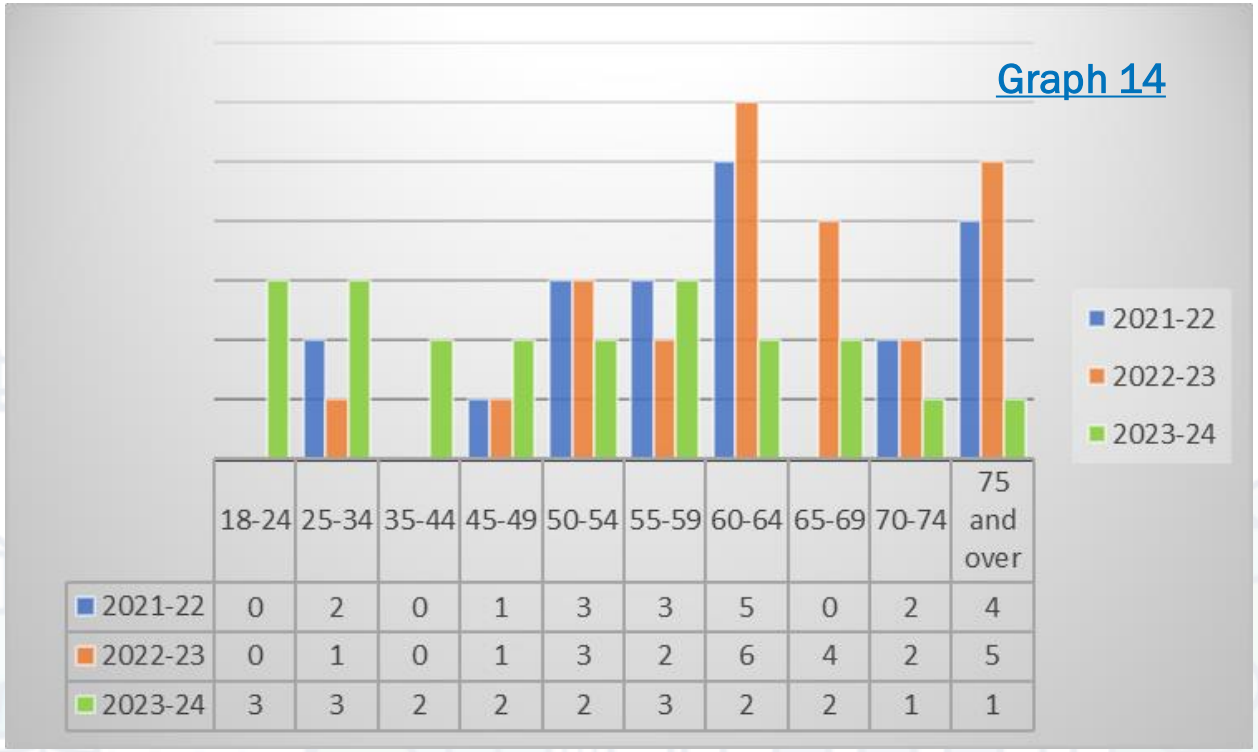
Age at death

Graph 13 shows the age range of all 21 reviews that were completed. The age of death was not recorded for completed LeDeR reviews until 2021, therefore we do not have this data prior to then. Graph 14 shows a comparison from 2021, which shows an increase in individuals dying younger in STW.

Graph 13



Graph 14



	18-24	25-34	35-44	45-49	50-54	55-59	60-64	65-69	70-74	75 and over
2021-22	0	2	0	1	3	3	5	0	2	4
2022-23	0	1	0	1	3	2	6	4	2	5
2023-24	3	3	2	2	2	3	2	2	1	1

Median age at death

Table 9

No	Age ranges
1	18
2	21
3	22
4	27
5	32
6	33
7	35
8	43
9	45
10	49
11	50
12	54
13	55
14	55
15	55
16	62
17	62
18	68
19	69
20	70
21	79

Nationally the median age of death for the reporting period 2022-23 for a person with a learning disability is **62.9** years. Data for 2023-24 is not yet available, the median age for STW for 2022-23 was **62**.

As shown in table 9, In 2023-24 the median age of death in STW is **50.** This shows a significant decline compared to 2022-23.

Table 10

Male ages	Female ages
18	27
21	35
22	43
32	55
33	69
45	79
49	
50	
54	
55	
55	
62	
62	
68	
70	

Median age for males in STW = **50** years of age

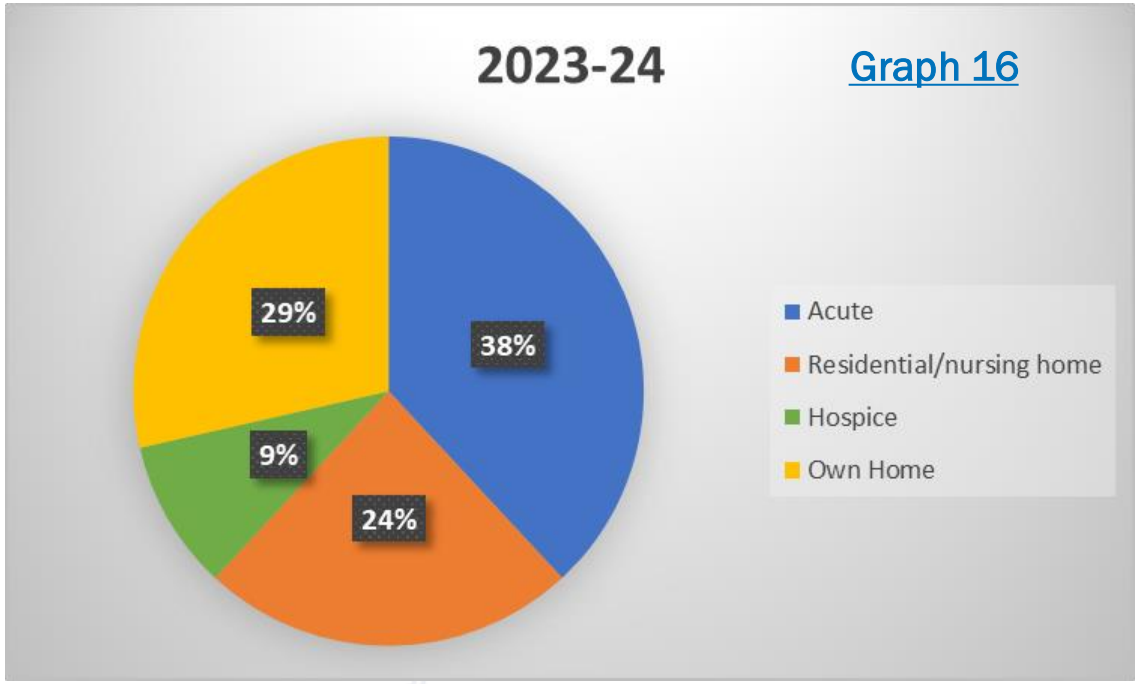
Median age for females in STW = **49** years (43+55 = 98/2)

8 out of the 15 male deaths (**53%**) in STW were ages **50** and under

3 out of the 6 female deaths (**50%**) in STW were aged **50** and under

Place of death

Eleven people (**53%**) died in their usual place of residence, i.e., either their own home (including supported living) or a residential/nursing home. This an increase to 2022-23 where **42%** died in their usual place of residence.



Graph 15

	Acute	Residential/nursing home	Hospice	Own Home
2021-22	4	8	2	5
2022-23	11	10	0	3
2023-24	8	5	2	6

2021-22 2022-23 2023-24

The place of death was not recorded for completed LeDeR reviews until 2021, therefore we do not have this data prior to then. The table to the left shows a comparison from 2021.

Lead cause of death

Table 11 shows the lead causes of death for STW since the start of LeDeR. This highlights that Pneumonia and Dementia have been the lead causes of death since the start of LeDeR.

Table 11

Year	2018-19	2019-20	2020-21	2021-22	2022-23	2023-24
Cause of Death	Generalised Pneumonia	Pneumonia	Pneumonia	Dementia	Dementia	Aspiration Pneumonia

Table 12

Cause of Death		No. of cases
Aspiration Pneumonia		4
Epilepsy		2
Cancer		2
Sepsis		0
Dementia		0

Table 12 highlights the local priorities for 2023-24 for STW. These were decided based on previous years leading causes of death. As shown for this reporting period the cause of death for **4** cases was Aspiration Pneumonia, **2** cases was epilepsy and **2** was cancer.

Table 13 shows the leading causes of death for this reporting period were **4** as Aspiration Pneumonia and **3** Bronchopneumonia.

Table 13 - Lead cause of deaths 2023-24

Cause of Death	No. of cases
Aspiration pneumonia	4
Bronchopneumonia	3

Long term conditions

Tables 14 & 15 show information taken from the LeDeR platform regarding long-term conditions had reported in the 21 reviews completed.

Table 14

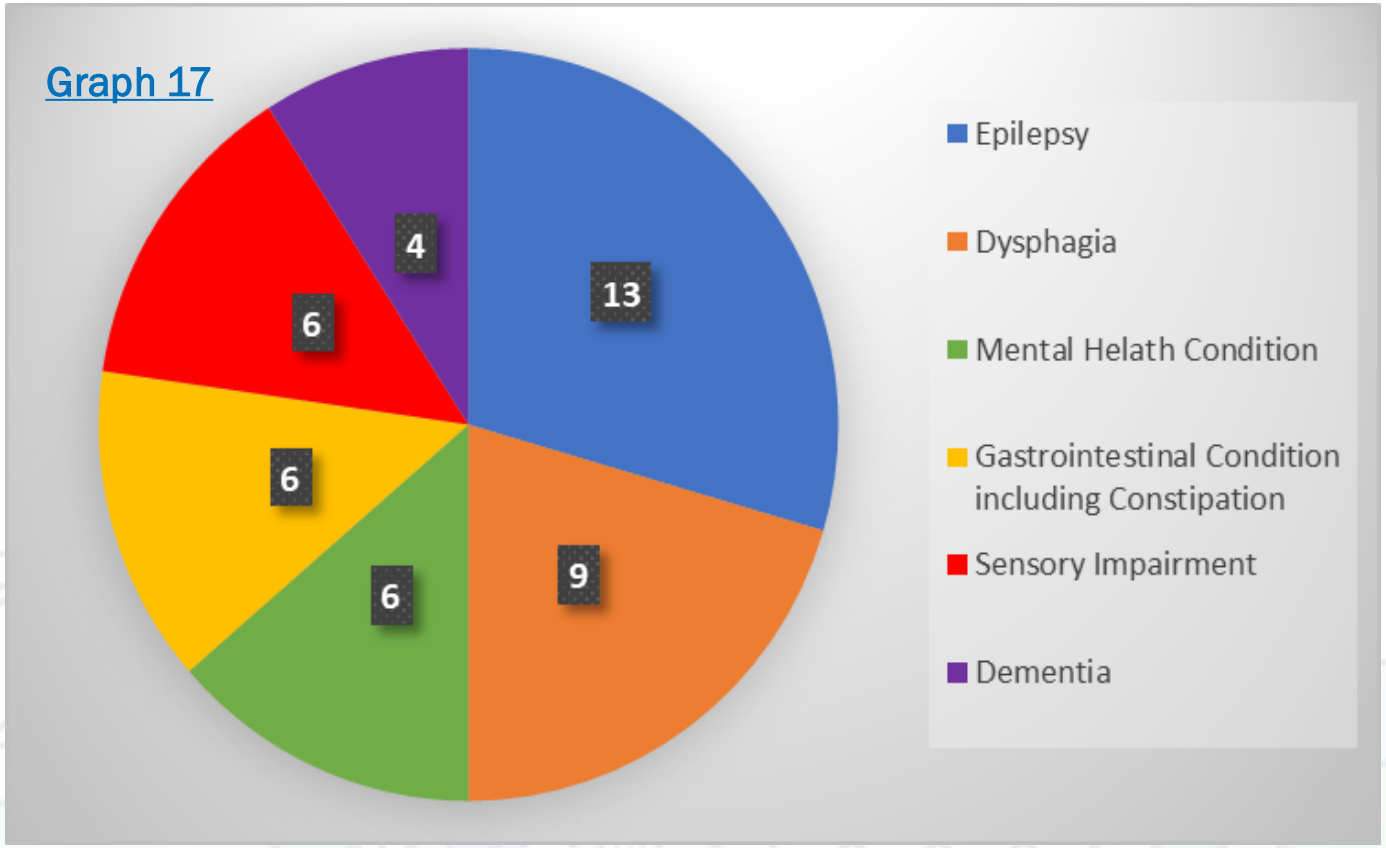
Long term condition	No of cases
Epilepsy	13
Dysphagia	9
Mental Health Conditions	6
Gastrointestinal conditions including constipation	6
Sensory impairment (vision or hearing	6
Dementia	4
BMI over 30	3
Cerebral Palsy	3
Hypertension	3
Asthma/COPD	2
Cancer	2

Table 15

Long term condition	No of cases
Cardiovascular Disease	2
Significant Scoliosis	2
BMI under 18.5	1
Hirschsprung Disease	1
Stroke	1
Hirschhorn Syndrome	1
Chronic Kidney Disease	1
Disorder of Glycoprotein	1
Non-diabetic Hyperglycaemia	1

With Graph 17 showing the most prevalent long-term conditions reported.

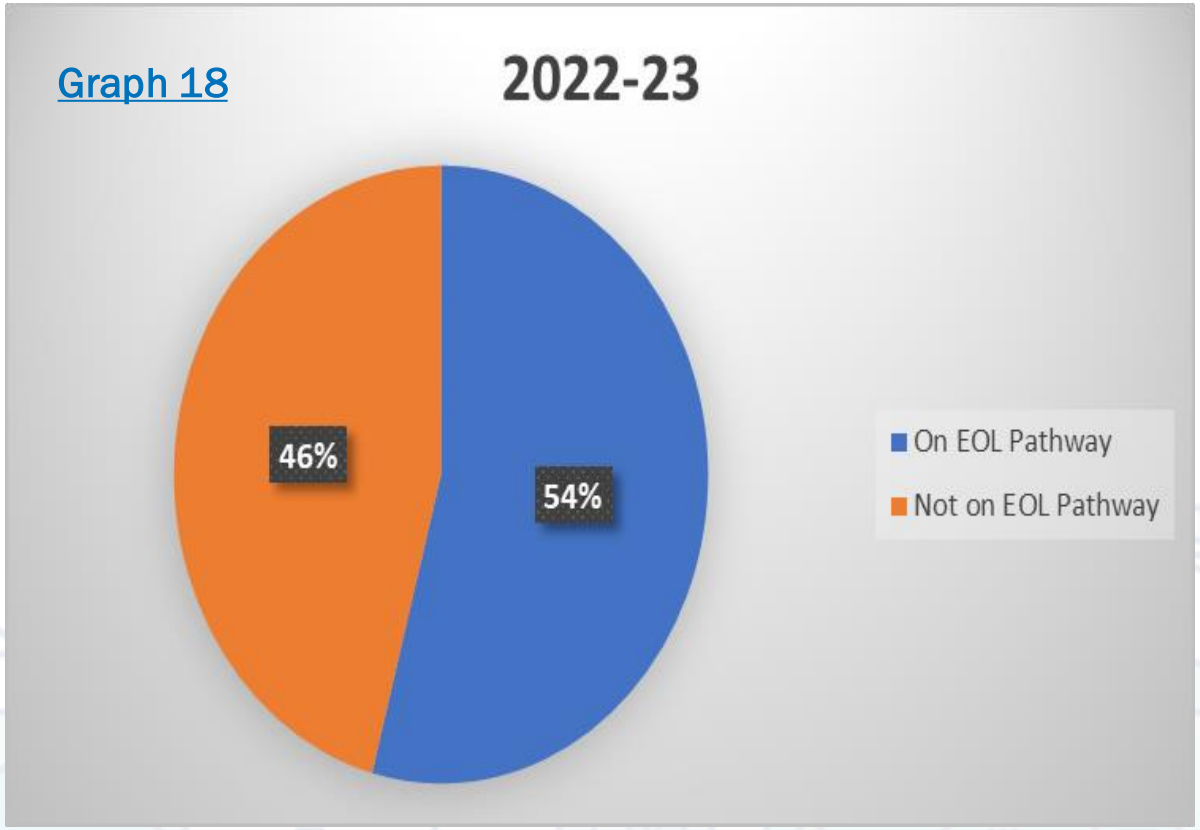
Graph 17



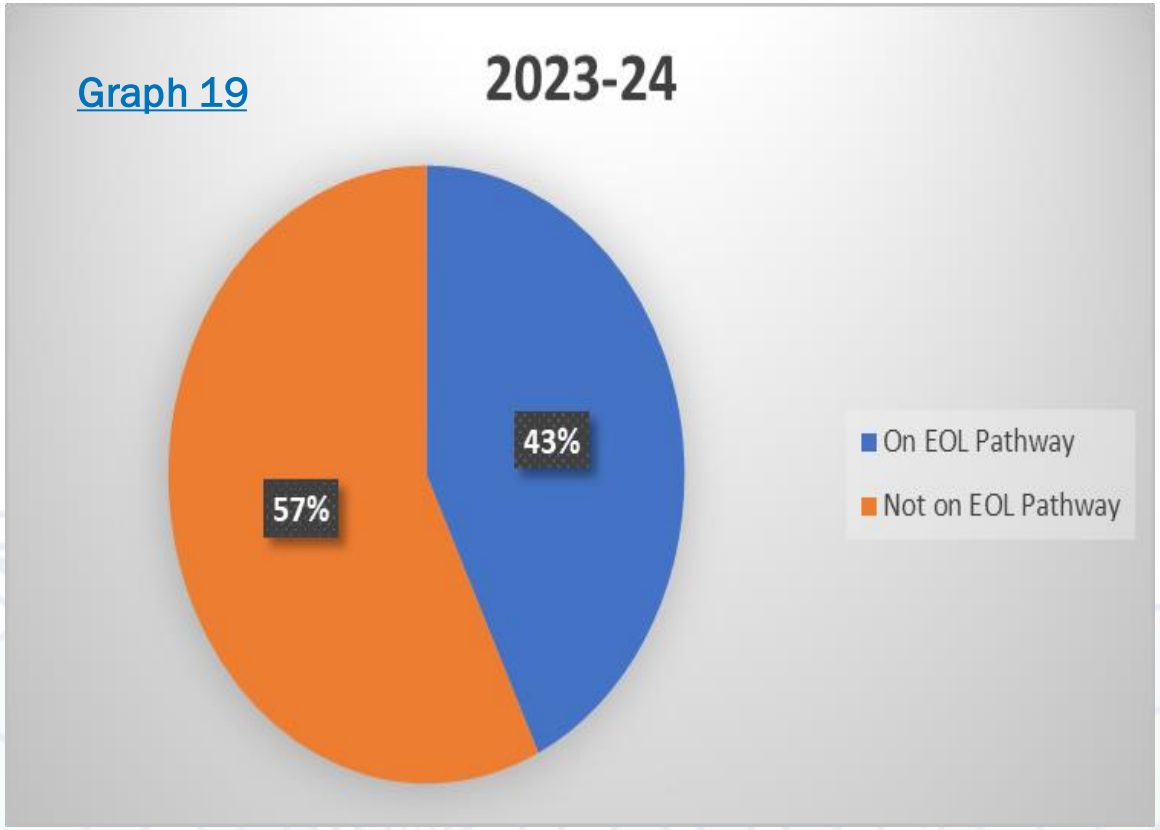
End Of Life Care (EOL)

9 (**43%**) of the individuals out of the 21 completed reviews were on the End-of-Life Pathway, compared to last year where 13 (**54%**) of the individuals out of the 24 completed reviews were on the End-of-Life Pathway.

Graph 18

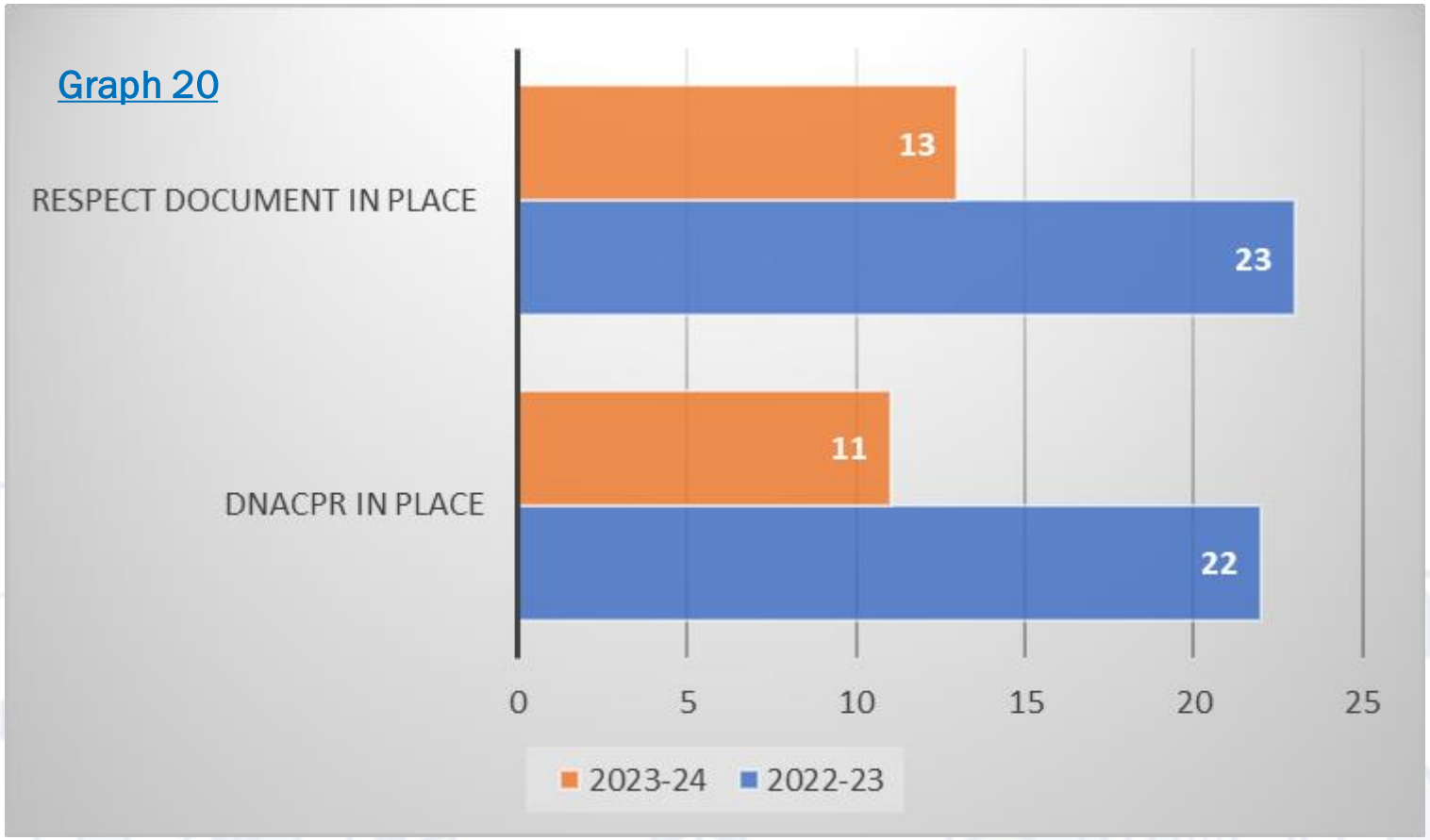


Graph 19



DNACPR/ReSPECT

For 2023-24, 13 (62%) individuals out of the 21 completed reviews had a ReSPECT document in place and 11 (52%) of the individuals had a DNACPR in place, which shows a decline from last year 2022-23, where 23 (96%) individuals out of the 24 completed reviews had a ReSPECT document in place and 22 (92%) of the individuals had a DNACPR in place.



Poor use of MCA/BI/ReSPECT

Below demonstrates concerns raised from some of the 21 completed reviews.

- Individual had no ReSPECT/DNACPR in place, family/carer felt one would have been beneficial to highlight the individuals care and treatment preferences.
- Recommendations within the ReSPECT document not always followed by healthcare professionals.
- Mental capacity assessment not utilised accordingly when individual was deemed as not having capacity.
- No consideration of completion of ReSPECT document when individual was presenting as well.
- No evidence of appropriate MCA/BI when ReSPECT form completed
- No family/carer awareness of ReSPECT document
- Evidence of poor example of a ReSPECT document, not signed or reviewed by clinicians
- Best interest decisions not regularly reviewed
- Evidence of limited knowledge around the mental capacity act with health professionals
- Inappropriate ReSPECT document completed with no physical health reason
- Mental capacity assessments not always completed properly and or task specific.

Comparison of notifications and median of age since the start of LeDeR.

Table 16

Year	Notification No	Difference	Median Age	Difference
2018-19	29	-	58	-
2019-20	20	9 less	50	Minus 8 years
2020-21	25	5 more	55	Plus 5 years
2021-22	28	3 more	60	Plus 5 years
2022-23	30	2 more	62	Plus 2 years
2023-24	21	9 less	50	Minus 12 years

The low numbers of notifications means that the outcome of, should be taken as trends over time on which to initiate quality improvement rather than an absolute number. Age is tracked to guarantee that we ensure we are paying attention to all parts of our population. As a system we are only aware of the deaths that are notified to LeDeR, which is why it is important that all deaths are notified to LeDeR by anyone to ensure we get a true picture for Shropshire, Telford & Wrekin.

Quality of Care from reviews (see appendix 2)

Table 17 highlights the grading of the quality of care from all 15 completed focused reviews in 2023-24 and table 18 highlights this for 2022-23. Grading is discussed and decided by all members of the LeDeR Governance Panel, prior to approval and closure of any case on the LeDeR platform.

Table 17

2023-24	
Grading	No of cases (15)
6	0
5	6
4	3
3	3
2	1
1	2

40% of the cases in 2023-24 were graded as a 5 (good care) 20% of cases were graded as a 4 (satisfactory care) and as a 3 (fell short of expected good practice). 7% of the cases were graded as a 2 (fell short of expected good practice and may have contributed to cause of death) and 13% of the cases were graded as a 1 (fell short of expected good practice and contributed to the cause of death)

In 2022-23 75% of the 4 completed focused reviews were graded as a 5 (good care) and 25% were graded as a 4 (satisfactory care).

Table 18

2022-23	
Grading	No of cases (4)
6	0
5	3
4	1
3	0
2	0
1	0

Availability & Effectiveness of services from reviews (see appendix 2)

Table 19 highlights the availability & effectiveness of services from all 15 completed focused reviews in 2023-24 and table 20 highlights this for 2022-23.

Table 19

2023-24	
Grading	No of cases (15)
6	3
5	4
4	2
3	3
2	1
1	2

20% of the cases in 2023-24 were graded as a 6 (excellent) **27%** were graded as a 5 (good) **13%** of cases were graded as a 4 (fell short of the expected standards in some areas). **20%** were graded as a 3 (fell short of the expected standards which impacted on the persons wellbeing). **7%** of the cases were graded as a 2 (fell short of the expected standards which impacted on the persons wellbeing & or had the potential to contribute to cause of death) and **13%** of the cases were graded as a 1 (fell far short of the expected standard & this contributed to the cause of death)

In 2022-23 **75%** of the 4 completed focused reviews were graded as a 5 (good) and **25%** were graded as a 4 (fell short of the expected standards in some areas).

Table 20

2022-23	
Grading	No of cases (4)
6	0
5	3
4	1
3	0
2	0
1	0

Improving Care

From reviews where care fell short, it was identified that in these cases:

- Illnesses were not recognised until the individual became so unwell, admission to hospital was required.
- There were significant safeguarding concerns relating to drug errors or omissions.
- Despite clear guidance in place and the individuals' presentation/symptoms (indicating deterioration) no medical attention was sought.
- Due to individuals decline to be examined, their worsening condition was not identified in a timely manner resulting in fatality.

To improve the care for people with a learning disability and or autistic people we need to ensure the quality of services is of the best standard.

To do this as a system we need to:

- Understand the uptake of effective education and training available to all care providers
- Ensure regular and consistent monitoring and oversight by commissioners
- Promote the importance and raise awareness of reporting significant concerns in a timely manner to ensure individual are receiving the input required effectively.

Learning opportunities from local reviews 2023/2024

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

To ensure ReSPECT documents are regularly reviewed	Further education with care providers around the importance of Annual Health Checks.	Any reasonable adjustments should be identified, flagged and implemented within all systems.	Further support for family's & implementation of family support forums locally within STW.	To ensure the completion of Health Action Plans following all Annual Health Check.	Autism training to be provided for family carers	Annual Health Checks to always be completed face to face
Health professionals to always utilise and refer to supporting documents such as hospital passport and pain profiles	Clear guidance, further and up to date training and education around MCA/BI and ReSPECT documents including family carers and all health and care professionals.	Quality assurance processes need to be shared widely (including family and carers) to incorporate the triangle of care principle	Care providers to have processes in place to ensure staff members are familiar with all person specific documentation	To ensure everyone is aware of the differences between a learning disability and a learning difficulty	More information and support to be provided to family carers around power of attorney, appointee and deputyship.	The right skills and training to be provided for all team members who care for individuals with learning disabilities and or autism
Learning Disability and or autism not to be used as cause of death on a death certificate	To ensure the correct terminology is always used for individuals	More LeDeR awareness amongst wider organisations	Joint working amongst system partners to support specific pathways to support individuals with a leanring disability and or autism	The benefits of vaccinations and age appropriate screenings to always be discussed with individuals using accessible information	All Mental Capacity Assessments to be task specific and appropriate paper work to always be completed	To promote the importance of discussions and completion of ReSPECT forms when an individual is presenting as well.

Positive Practice from local reviews 2023/2024

Some evidence of good health and social care support throughout individuals' lives.	Indication of individuals social and emotional needs being met with a good Multidisciplinary team approach.	Transition from child to adult services well planned and effective to support individuals	Examples of good post diagnosis multidisciplinary team working to support individual emotionally and physically	Some evidence of good communication and advice offered to support individuals and their families.	Indication that appropriate and timely specialist medical and social referrals made.
Effective use of system partners adapting their communication strategies to support individuals.	Some evidence of Individuals' quality of life being the main focus following best interest meetings.	Some evidence of the inclusion of family members who were fully informed throughout.	Indication of care package provisions considering individuals personality and preferences.	Some good examples of consistent and appropriate reasonable adjustments	Some effective referral pathways made to specialists in a timely manner

Key themes from reviews

Table 21

Theme	Actions to be taken	No of cases linked to.
ReSPECT Document	• Promotion of appropriate completion of ReSPECT documents, raising awareness amongst key organisations of the benefits of proactive use of RESPECT documents. • Education and training to be completed by all health and social care professionals, carers and family members and to remain up to date.	6
Learning Disability as cause of death	• Promote and raise awreness that learning disability/learning difficulty to never be included in part 1 as cause of death, on death certificates.	2
Reasonable Adjustments	• Any reasonable adjustments to always be identified, flagged and implemented amongst all organisations including incorporation into individual support/care plans	2
MCA/BI/DoLS	• Mental capacity cssessments and best interest decisions to always be task specific • Inclusive of individuals, family members/carers • Paperwork to always be appropriately completed • Guidance to always be followed • Training and education to be completed and in date.	9
Supporting documentation	• To ensure all supporting documentation is in place including hospital passports, pain profiles and utilised to easily identify any changes in presentation to ensure appropriate actions are taken to support individual needs in all key organisations.	5
Annual Health Checks	• To always be completed on time and face to face. • To ensure enough time is given to include discussions around vaccinations, age-appropriate screenings, social prescribing. • To include provision of accessible information and if any declines to be documented as to why. • A health action plan to always be completed following an annual health check for individuals, family members carers to follow. • The importance of Annual Health Checks shared with carers/care providers.	7
Learning Disabilities & Autism	• To ensure anyone supporting individuals with a learning disability and or autistic person have the right skill set, training and education to support individual needs fully.	5
Quality of Care	• To have oversight of the quality of care supported individuals are receiving and more accountability to be established • Processes for this oversight to be in place including the triangle of care.	5

STW System Wide: LeDeR Priorities Action Plan

ReSPECT
Recommended Summary Plan for Emergency Care and Treatment

STW currently have 11 priorities on the LeDeR Priorities Action Plan. Using the data we are seeing from our LeDeR reviews as a baseline for 2024-25 we want to focus on specific priorities to enable us as a system to make a tangible change and really drive this forward.

Hospital passport 	Mental Capacity Assessment (MCA), Best Interest (BI) Decisions and Deprivations of Liberties (DoLs)	Training & education
Reasonable adjustments	Healthy Lifestyles	Inclusion of family members/carers
EOL, Palliative Care, ReSPECT & DNACPR	Reduce health inequalities for those with LD&A from ethnic diverse groups	Care act reviews 
Epilepsy Management	Managing deteriorations and early detection of deterioration	

Clive Treacey

Following the death of Clive in 2017, his care and treatment was the subject of an independent review commissioned by NHS England, in line with the principles of the LeDeR programme methodology. From this review, 10 key findings were found and 52 recommendations to drive systemic change.

Update: For STW, there is now a system wide action plan in place, highlighting all recommendations following the Clive Treacey independent review. The system have come together and met face to face to discuss how to move forward with this action plan. The recommendations are also linked to a number of priorities on the LeDeR Priorities Plan. Nationally, SUDEP Action developed a commissioning checklist and guidance to provide a concise but comprehensive tool to help deliver safe, effective epilepsy care for people with a learning disability and/or autism. NHS England are also in the process of implementing a conscience manual to support the next steps linked to the key findings and recommendations. STW are committed to attending any events linked to Clive Treacey to drive tangible change locally.

Challenges: Variable commitment system wide has resulted in delays linked to recommendations updates. Each system partner will have their own Clive Treacey Action Plan, which means each system will be at different stages regarding specific recommendations, making it difficult to to deliver informed system wide updates.

<u>It is important to work together as a system to ensure systemic change occurs.</u>

Oliver McGowan

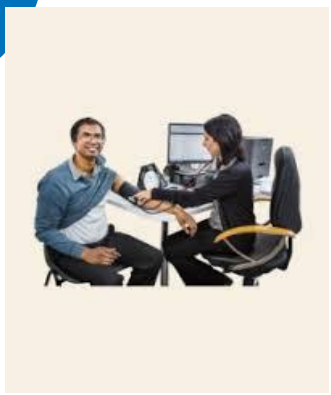
The Health and Care Act 2022 introduced a requirement that providers registered with the CQC must ensure their staff receive learning disability and autism training appropriate to their role. Staff working in health and social care need to understand the needs of autistic people and people with learning disabilities, to provide improved services, reduce health inequalities and eliminate avoidable deaths.

Update: System partners within in STW continue to complete the e-learning element of this training. Guidance has been circulated on who should be completing which tier The Oliver McGowan Mandatory Training on Learning Disability and Autism: Tier guidance for employers (hee.nhs.uk) (the second part of this training) tier 1 is a 1-hour webinar following the completion of the e-learning and tier 2 is a full day face to face training session following the completion of the e-learning. The deputy LAC for the LeDeR programme sits within the stakeholder group who meet monthly for any updates linked to Oliver McGowan.

Challenges: The amount of people in STW who are required to complete the tier 2 face to face training outnumbers the number of sessions available for people to attend. The training team continue to work hard to put on more training sessions and work closely with national partners to support the roll out of this training.

The Oliver McGowen training programme plays a pivotal role in our commitment as a system to provide the highest quality care and support to individuals with learning disabilities and autism.

Annual Health Checks



The aim is for the uptake of Annual Health checks (AHC's) for any individual with a learning disability aged 14+ is at least 75%.

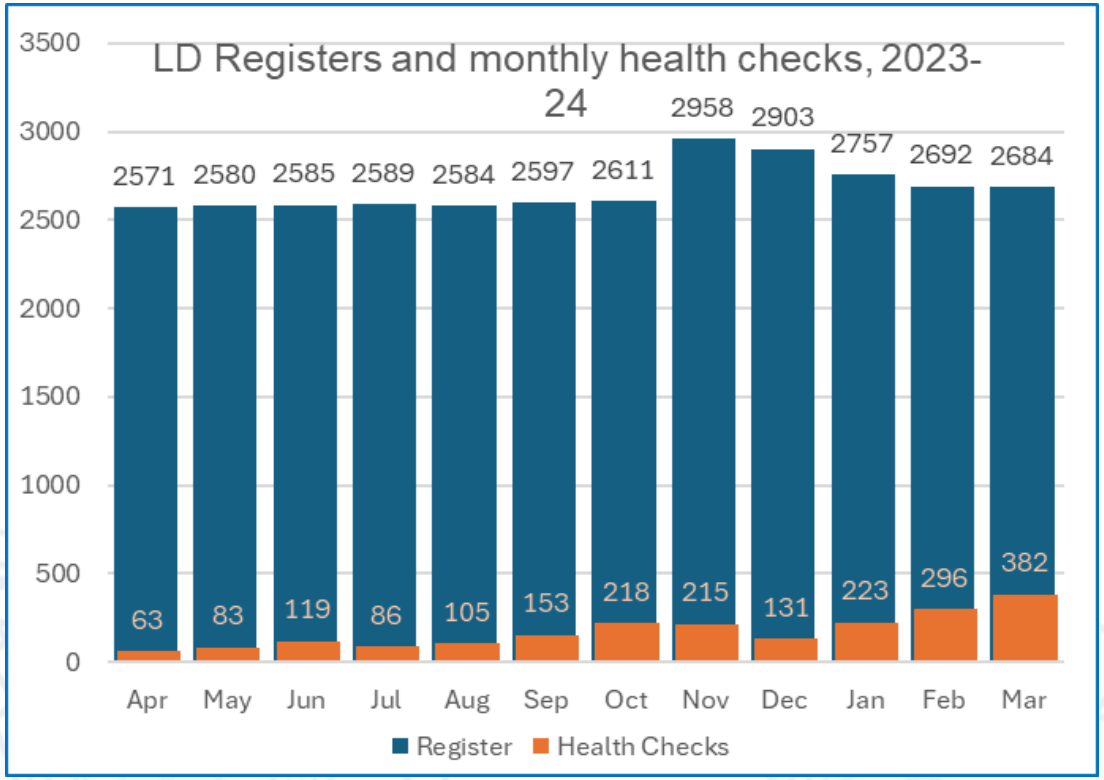
Update: This year the uptake of Annual health Checks (AHC's) reached within Shropshire Telford & Wrekin was **77.3%**, which is over the target set by NHS England.

Challenges: From LeDeR reviews in some cases there is evidence that some AHCs are outdated for individuals, no Health Action Plans are in place following the AHC and in some cases the AHC was completed over the phone with a family member/carer.

We need to ensure that all AHCs should be completed face to face, and any reasonable adjustments required to support an individual's needs should be identified, flagged and implemented.

The system relies heavily on the learning disability register to be correct to ensure all individuals receive all support available to them, this highlights the importance of coding within GP practices together with the correct use of terminology.

Graph 21



Review of 2022-23 recommendations	Updates and key progress
Strengthen links with and reduce inequalities for people from minority ethnic communities.	One of our LeDeR panel members feeds into the EDI working group
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.	New LeDeR panel member with lived experience and representation linked to out EDI population.
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.	A one-minute brief is produced monthly and shared system with a LeDeR specific topic linked to themes from LeDeR reviews. Established Aspiration Pneumonia working group to complete a quality improvement project around this. .
To ensure that we continue to focus on delivering the recommendations from the Oliver McGowan and Clive Treacey reports.	This is linked to slides 39 & 40 within this report
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.	All systems have a responsibility to flag reasonable adjustments ready for implementation of the reasonable adjustment digital flag nationally.
Increase the training around reasonable adjustments and healthy living across the STW system partners that incorporates Healthwatch/Treat me well.	There has been an Increase in joint working across the system and e-learning is in place to support the roll out of the reasonable adjustment digital flag.
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.	GPs have a coding list to refer to support this from NHS England.
NHS STW to carry out an audit on the adherence of mental capacity act and DoLS and the use of DNACPR and ReSPECT documents.	New ReSPECT lead in post and the policies and processes are being reviewed to include system partners.
To explore and develop a regional interlinked system to identify people with a learning disability and autism when accessing health and social care services.	The introduction of electronic systems within our acute system partners will support with this.
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.	There is now an established LeDeR task & finish group to look at a quality improvement project around hospital passports and the previous point is also linked to this recommendation.
Improve opportunities for personalised end of life care.	Established end of life working group led by Shropshire Community Health team.

Challenges

1. Postponement of new electronic systems within one of our system providers leading to delays in improving processes for individuals with learning disabilities and or autism such as flagging of reasonable adjustments & relevant documents such as health passports.
2. Balance of responsibilities due to resources, capacity and at times changing priorities resulting in a variable commitment and core membership system wide linked to the LeDeR Programme and Clive Treacey Action Plan.
3. Capacity to work proactively and preventively when all services are overstretched and firefighting
4. Not all system partners have dedicated learning disability and or autism teams
5. Some services being disparate and separate risking duplication and gaps system partners are unaware of
6. Too many goals/targets in the context of the current capacity pressures
7. As a system we have faced challenges and barriers including breaching and quality of reviews and extracting learning from reviews in a timely manner. We sought a remedial action plan from our provider to improve the performance as seen above. The contract with our current provider ended on 31.03.2024 and STW changed the provider undertaking the reviews from 01.04.2024.
8. At points throughout this reporting period the LeDeR platform was inaccessible to the LAC/deputy LAC delaying quality assurance and closure of LeDeR cases.

Shropshire Telford & Wrekin Priorities for 2023/24

The local priorities for STW for 2023-24 were:

- Aspiration Pneumonia
- Epilepsy
- Cancer
- Dementia
- Sepsis

If the cause of death was linked to any of the above, then it would be reviewed as a focused review. This resulted in a higher rate of focused reviews compared to previous years.

Plan for 2024-25

Given that Aspiration Pneumonia is our lead of cause of death during 2023-24 in STW, it will remain a priority moving forward. All other LeDeR cases with be reviewed on a case-by-case basis by the LAC and deputy LAC to determine if the case should be a focused review. This will be considered if there would be significant learning from a review, there are quality of care concerns, evidence of lack of reasonable adjustments and any gaps in any education and training.

Recommendations and Next Steps for 2024-25

- Target the promotion of LeDeR to increase the number of LeDeR notifications utilising our LeDeR Steering Group members.
- To promote the appropriate completion of DNACPR's and ReSPECT documents, liaising with the ReSPECT Lead for SaTH.
- Improve joint working to achieve priority health/social care goals for example Clive Treacey
- Agree a smaller number of high priority goals to deliver on in 2024/25 and discuss and receive informed updates for all at The LeDeR Steering Group monthly.
- Continue to utilise the learning management system to promote learning from all LeDeR reviews with monthly one-minute briefs.
- Continue to utilise opportunities to promote learning from all LeDeR reviews.
- The implementation of a communications plan and user friendly ICB website incorporating resources and links associated with LeDeR and the learning disability and autism programme.
- Putting learning from reviews into action and undertake quality improvement projects linked to our LeDeR priorities to ensure we make tangible change for individuals with a learning disability and autistic people across Shropshire, Telford & Wrekin.

Conclusion

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. We have identified a number of areas where there are opportunities for quality improvement, and we continue to see examples of good practice within our reviews which demonstrate positive learning and our drive to improve at all times.

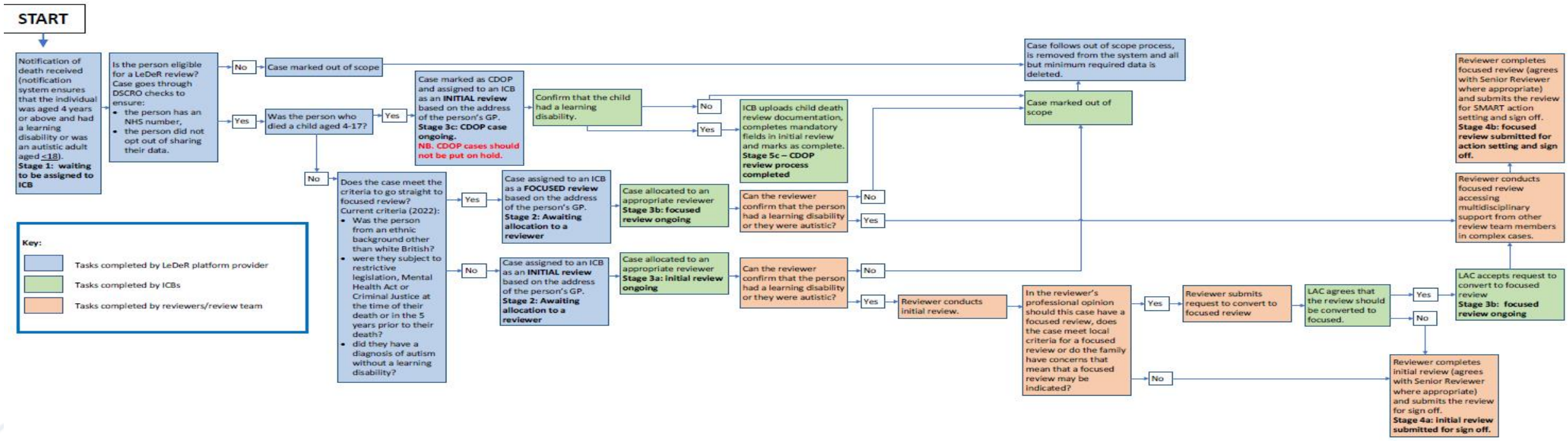
This year has seen the age of death decrease but this is against a backdrop of lower notifications. Previous years have been comparable to nationally published data which is available each September. We will commit to driving up the profile of LeDeR to get as many notifications as possible to strengthen our data and drive our improvements.

Appendices

- Appendix 1: LeDeR process chart
- Appendix 2: Grading of care table

Appendix 1

Overview of review process



Appendix 2

Grading care (4)

Grade	Quality of care – overall, on balance…..	Availability and effectiveness of services – overall, on balance…..
6	This was excellent care (it exceeded expected good practice). Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.	Availability and effectiveness of services was excellent and exceeded the expected standard
5	This was good care (it met expected good practice). Please identify in the review learning and recommendations any features of care that current practice could learn from.	Availability and effectiveness of services was good and met the expected standard
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing). Please address these issues in your recommendations for service improvement, and identify in learning and recommendations any features of care that current practice could learn from	Availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement, and identify any features of care that current practice could learn from.	Availability and effectiveness of services fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death.
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	Availability and effectiveness of services fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
1	Care fell far short of expected good practice and this contributed to the cause of death.	Availability and effectiveness of services fell far short of the expected standard and this contributed to the cause of death.

Resources

- easyreadfullreport.pdf (bristol.ac.uk)
- The Triangle of Care explained (youtube.com)
- Clive-Treacey-Independent-Review-Final-Report-9.12.21.pdf (england.nhs.uk))
- NHS England-funded project is lasting legacy to Clive | SUDEP Action
- (Oliver McGowan | Oliver's Campaign |)
- The difference between Learning Disability and Learning Difficulty (youtube.com)
- Resources for Healthcare Professionals | Mencap