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NHS Somerset

LEDER ANNUAL REPORT 2022 - 2023

LEARNING FROM THE LIVES AND DEATHS OF PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE

6th July 2023

LeDeR Annual Report 2022-23

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1 EXECUTIVE SUMMARY

This report covers the period April 2022 – March 2023. There is an easy read summary of the report which can be found in Appendix 1. Additionally a Makaton signed summary is available on our website.

Learning from the lives and deaths of people with Learning Disabilities and Autistic People (LeDeR) is a national service improvement programme that was set up with the aim of reducing health inequalities and preventing premature mortality by making changes to services both locally and nationally.

The aim of this report is to share learning from the LeDeR programme in Somerset in order to promote change across the health and social care system. This report will summarise what we have found out from the LeDeR reviews carried out in the reporting period, highlighting good practice and areas for improvement. It will discuss key themes that have emerged from reviews and highlight work the LeDeR team have already done with system partners to promote change and improve outcomes for people with learning disabilities and autistic people. Lastly the report will identify key improvement priorities for the next year.

The report has been written by Dr Rachel Donne-Davis, Local Area Contact for the LeDeR Team, with contributions from a number of system partners. The LeDeR Team have provided case studies for the report and discussions by the LeDeR Governance and Improvement Group have also been incorporated.

2 INTRODUCTION

2.1 NATIONAL

LeDeR is a national service improvement programme looking at deaths of people with learning disabilities and autistic people. The programme was established in 2017 and is funded by NHS England (NHSE).

The LeDeR programme aims to achieve the following:

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

Everyone with a Learning Disability aged four and above who dies, and every adult (aged 18 and over) with a diagnosis of autism, is eligible for a LeDeR review. Notifications of a death of someone with a Learning Disability or Autistic People can be made by anyone through the LeDeR website *https://leder.nhs.uk/*

A LeDeR review takes a holistic approach looking at key episodes of health and social care the person received that may have impacted on overall health outcomes. Key areas of improvement as well as good practice is identified for sharing across the system locally and nationally. Involving people who knew the person well is a key part of the process and care is taken to involve family members or others who knew the person so a pen portrait can be developed

Every person with a learning disability that LeDeR are notified of will have an Initial Review. Reviewers will then use their professional judgement to determine whether a Focused Review (a more in-depth level of review) is required. Focused Reviews can also be requested by the family of the person who has died.

In certain situations a Focused Review will automatically be carried out:

- Where the person is from a black, Asian or Minority ethnic group
- Where the person has a clinical diagnosis of autism but not a learning disability. This is being piloted while the reviews for Autistic People are introduced.
- Where a local priority area has been identified. For example in Somerset, where dysphagia or choking is identified as a possible cause of death, a Focused Review will automatically be carried out.

In 2022 King's College London published a report summarising learning from LeDeR reviews nationally. This was based on data from 2021. In addition, a national Learning into Action report was produced in 2022 detailing service improvements from across the country made in 2021/22. At the time of writing this is the most current contextual information available to us in terms of LeDeR nationally and we will reflect on local learning in the light of this.

2.2 LOCAL

Within NHS Somerset the LeDeR Team sits within the Quality, Safety and Improvement Directorate. The LeDeR Team consists of a Local Area Contact (LAC), Deputy Local Area Contact, one Senior Reviewer, two Reviewers and a Team Administrator. The Chief Nursing Officer for NHS Somerset is the Senior Responsible Officer (SRO) for LeDeR.

In 2021-22 we identified the following improvement priority areas:

- **Improvement Priority 1:** ***The Annual Health Check (AHC) Programme***.
- **Improvement Priority 2:** ***Mental Capacity Act (MCA)***
- **Improvement Priority 3:** ***Effective Joint Commissioning***
- **Improvement Priority 4:** ***Meaningful Engagement of people with learning disabilities and autistic people***

This report will update on service improvement work related to these priorities and identify new priority areas as highlighted in LeDeR reviews in 2022-23.

In 2022-23 we facilitated increased engagement from people across the health and social care system with the LeDeR process. This has seen more people involved at every level of our Governance processes and enabled learning into action to happen in a much more effective way. The following are some comments from people in the Somerset system about their involvement in the LeDeR programme:

"I have been delighted to take on the role of SRO for this really important area of work. The LeDeR process enables us to learn continually as a system, implementing actions where improvement is required, learning from areas of good practice and monitoring the effectiveness of the improvements we make.

"Improving the care and support we provide and the outcomes for people in our population is so important and requires continued focus and attention."

Shelagh Meldrum, LeDeR SRO and Chief Nursing Officer, NHS Somerset.

"The LeDeR process is central to supporting learning across the health and care system. It raises the profile of the needs of the LD population across the region and in all care settings. LeDeR has been instrumental in supporting wider services in identifying health inequalities and driving learning and service development to address this.

"The multidisciplinary nature of the LeDeR group really supports the learning process which is always conducted in an empathic manner. In my experience there has never been a focus on seeking blame but the panel approaches cases with curiosity and a desire to learn as much from good practice as it does from challenges in care delivery."

Tom Clifford, Operational Service Manager for Learning Disabilities, Autistic Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

"The LeDeR programme is an important part of NHS Somerset's plan to reduce health inequalities and promote access to health care for all Somerset residents. LeDeR allows us to celebrate good practice by highlighting where organisations are working effectively together and also highlights where we can make improvements because people's needs are not being met in the most effective way. It has been positive to see a further improvement, this year, in the engagement of a wider range of health and social care partners in this important work and I am confident we can continue to work together to improve outcomes for people with learning disabilities and autistic people."

Jonathan Higman, Chief Executive, NHS Somerset

2.3 PATIENT ENGAGEMENT

Meaningful engagement of people with learning disabilities, and autistic people is key to LeDeR being effective as a service improvement tool. In last year's annual report we identified this as an area that we wanted to improve upon locally.

In order to achieve this we have been working with Biggerhouse Film and OpenStoryTellers to better understand people's experiences and to help us to think about how we can ensure LeDeR is an accessible and meaningful process for people. Further information on this work can be found in the Learning into action section

It is important to remember that this report is about the deaths of people with learning disabilities and autistic people. Whilst the case studies and data are anonymised these are real people's stories. Their lives were important and of significant value and the impact their deaths have had on their family and loved ones will doubtless be substantial.

We would like to thank families and carers who have taken the time to speak to us at what has often been a really difficult time in their lives. Their contribution to this process has been invaluable and we feel privileged to share part of their story.

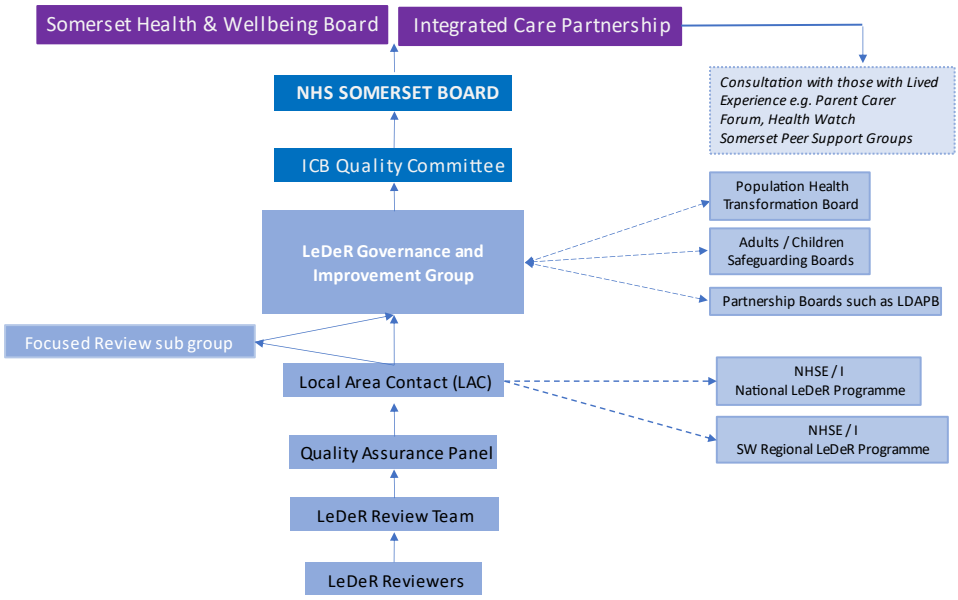
2.4 QUALITY ASSURANCE AND GOVERNANCE

All LeDeR reviews in Somerset are quality assured via peer review as well as by a Quality Assurance Panel. The Quality Assurance Panel is made up of key stakeholders from across the Integrated Care System. Additionally Focused Reviews are further approved by a Focused Review Panel which is a subgroup of the LeDeR Governance and Improvement Group.

A visual summary of LeDeR Governance structures and reporting mechanisms can be found in Figure 1.

Figure 1

Somerset LeDeR Governance Pathway

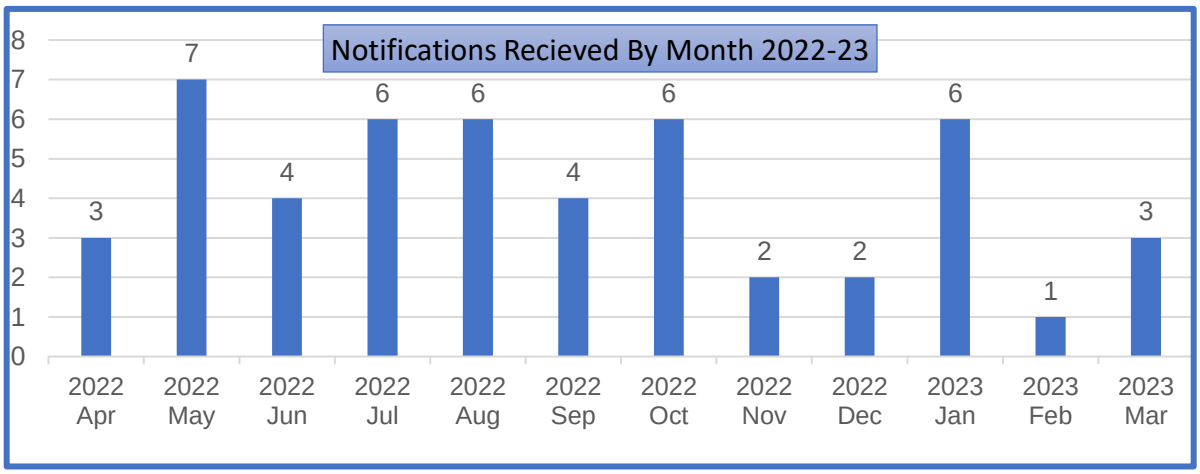


3 LEARNING FROM DEATHS IN SOMERSET

3.1 NOTIFICATIONS

In 2022-23 50 notifications were received by the LeDeR Team in Somerset. Chart 1 details notifications received per month. Of these 50 notifications 5 were deemed to be out of scope of the LeDeR programme, due to the individuals concerned not having a Learning Disability.

Chart 1



Autism Reviews

We only received one autism review within the reporting period. This review is currently on hold while we await the outcome of other statutory processes. Whilst the number of autism only notifications have been low across the region we recognise that we could do some more proactive work locally to increase awareness of autism now being included within the LeDeR process. We plan to work with key stakeholders, including experts by experience over the next year to do this.

3.2 COMPLETIONS IN 2022-23

44 reviews were completed by the LeDeR team in this reporting period. Chart 2 details completion by month. There were no reviews completed in November due to the significant number of reviews signed off the previous month.

Chart 2

3.3 KEY PERFORMANCE INDICATORS

NHSE set two key performance indicators (KPI) for LeDeR teams:

- that all notifications will be allocated within three months of receipt, and
- all reviews will be completed within six months of notification.

Our performance against these two key performance indicators is set out in charts 3 and 4. We were only non-compliant on two occasions. In December 2022 (Chart 3) this was due to a delay in the notification being received. In August 2022 (Chart 4) this was due to a safeguarding issue coming to light at a late stage which meant we delayed sign off of the review until this had been clarified.

Chart 3

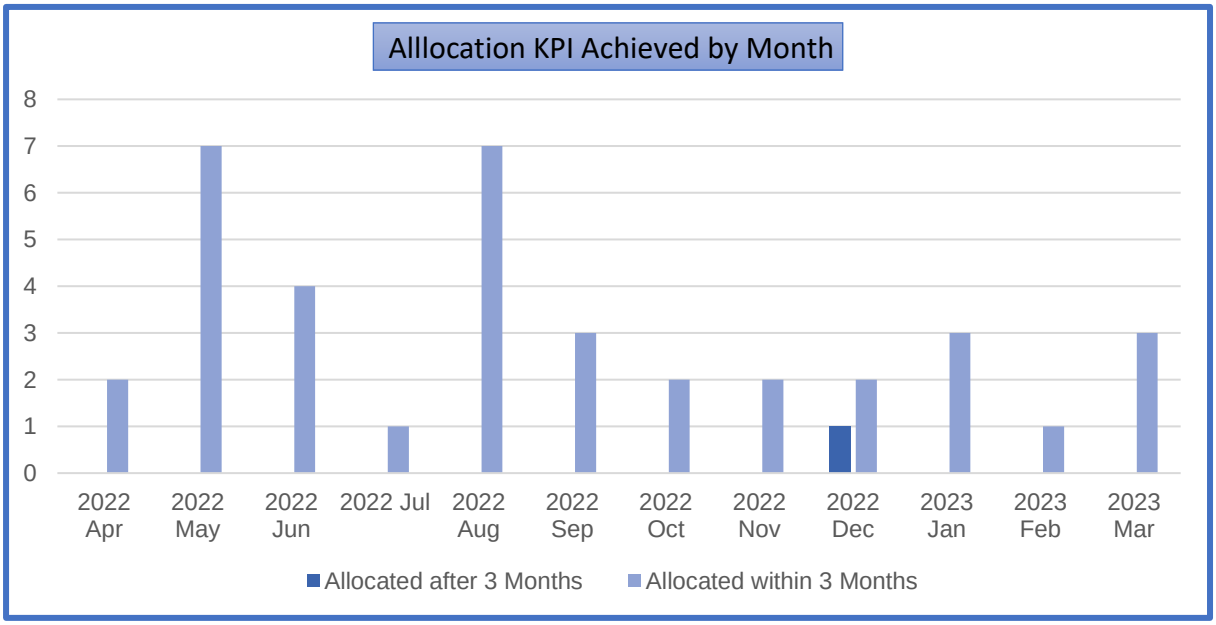
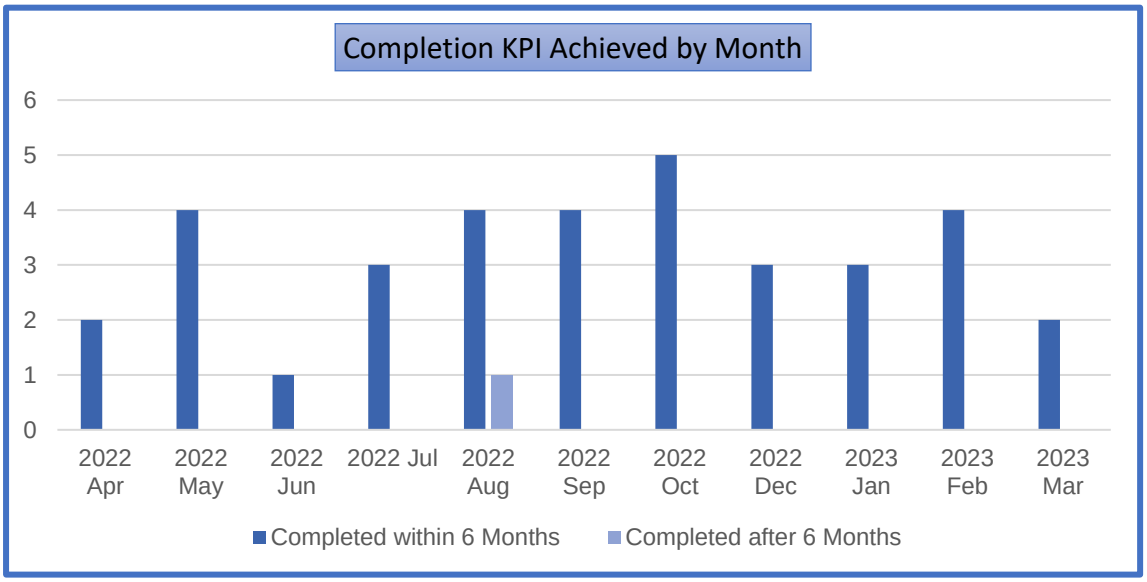


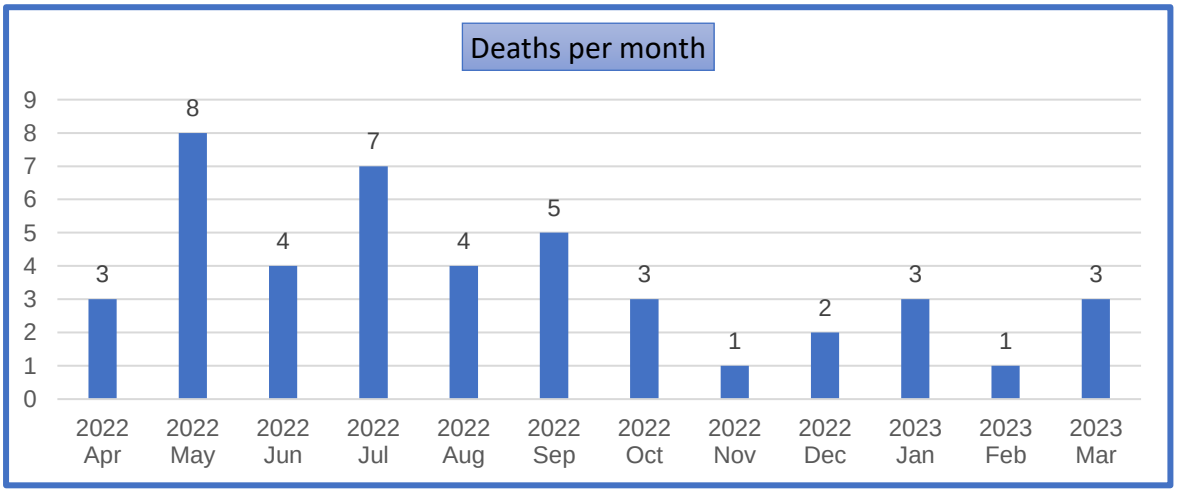
Chart 4



3.4 ABOUT THE PEOPLE WHO DIED

The following demographic information is based on date of death as opposed to date of review completion or date notification was received. This brings our reporting in line with national data analysis and allows for more timely learning from deaths. 44 reported deaths occurred during the reporting period and these are detailed in Chart 5.

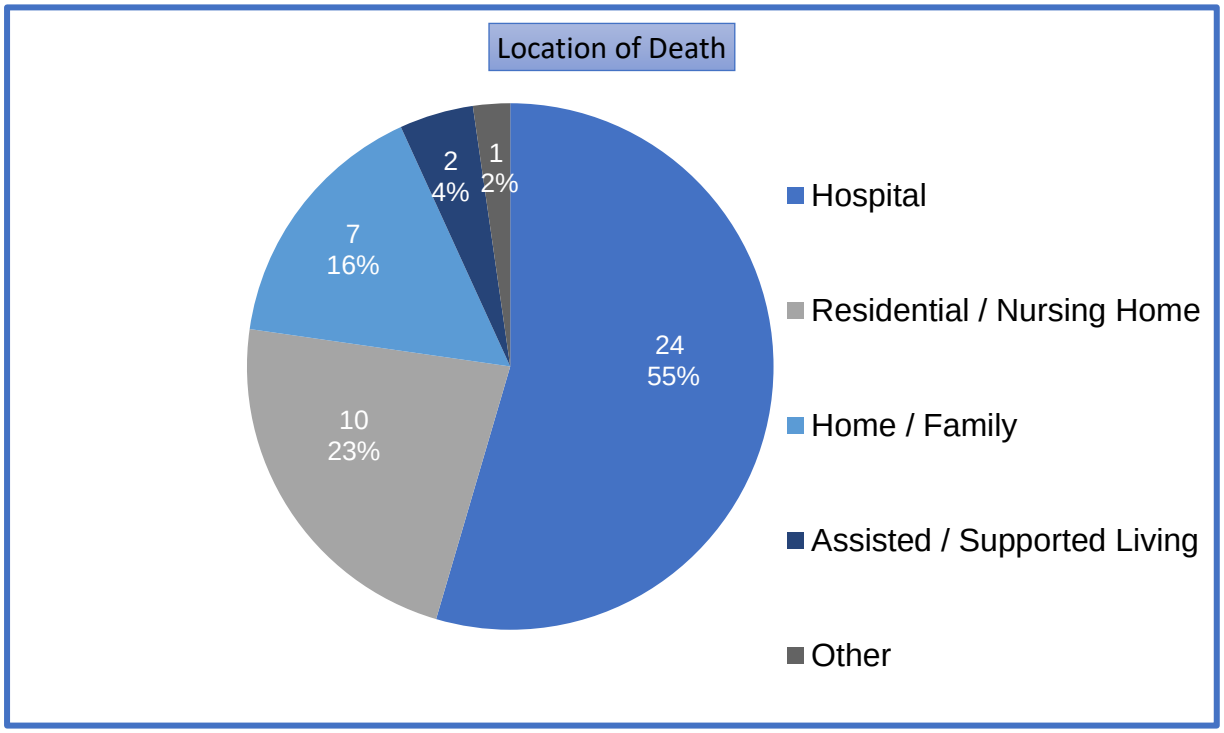
Chart 5



3.4.1 Location of Death

Of the 44 deaths the highest proportion of people died in a hospital setting. This figure is slightly lower than what has been reported nationally, the King's College London LeDeR Report (2022) (1) . finding that 61% of deaths in 2021 occurred in a hospital setting. Chart 6 presents the detailed breakdown of Location of Death

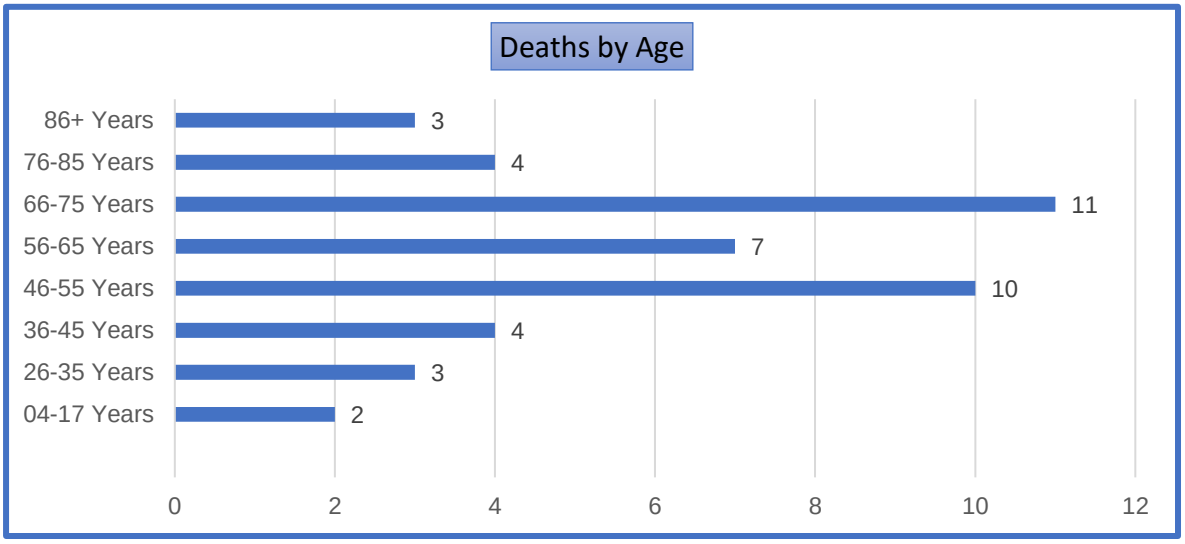
Chart 6



3.4.2 Age at Death

The highest proportion of deaths were in the 66-75 age range, followed by the 46-55 age range. This indicates a change from the 2021/22 data where the highest proportion of deaths in Somerset were in the 56-65 age range.

Chart 7



3.4.3 Gender

Chart 8 shows that 57% of people who died in the reporting period identified as male and 43% identified as female. This is consistent with what was reported in the national LeDeR annual report (1) which stated that in 2021 people identifying as male accounted for 56% of deaths, and people identifying as female for 44%.

Chart 8

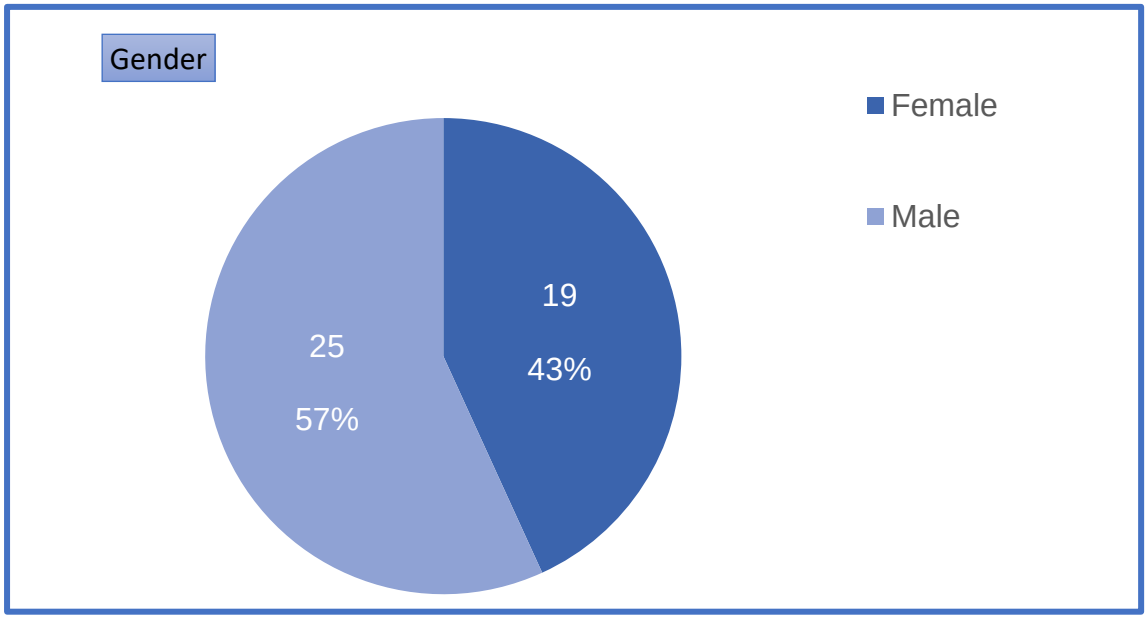
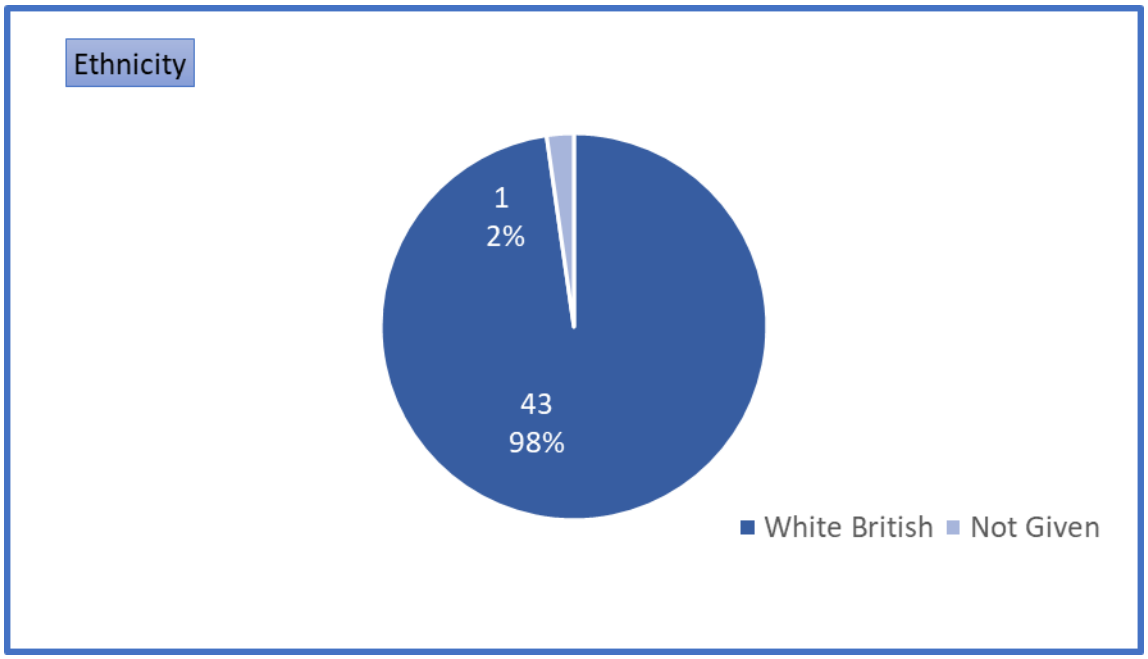


Chart 9



3.4.4 Ethnicity

Chart 9 shows our ethnicity data for this reporting period. A majority of people who died were reported to be white British (98%). 2% of people did not have a recorded ethnicity.

There are concerns nationally about under reporting to LeDeR of deaths from ethnic minority groups (King's College London 2022) (*1) and this is something that needs to be given further consideration in Somerset. The 2021 census (*2) indicates that in Somerset 91.3% of the general population describe themselves as White British. Whilst our LeDeR data doesn't differ significantly from this, we recognise that we could be doing more to make the work of LeDeR more accessible to those from all ethnic groups.

3.5 CAUSE OF DEATH

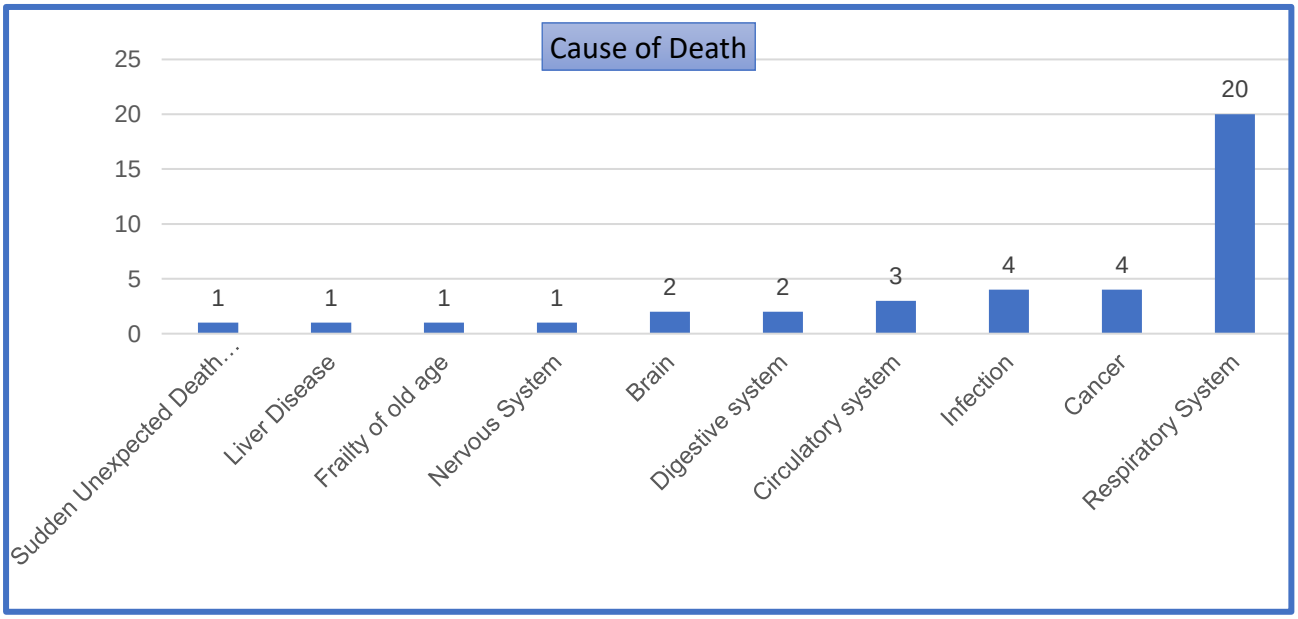
Chart 10 details the main Cause of Death for each death in the reporting period. Please note this only includes information for 39 deaths as we are awaiting information for the remaining 5 deaths due to other statutory processes which are ongoing at the time of reporting.

This data is drawn from the Medical Certificate of Cause of Death (MCCD). However some causes are grouped together into one overall category to enable ease of analysis as the numbers involved are so small e.g. brain to include all references to brain, cerebral stroke, cerebral haemorrhage/infarction, cerebrovascular accident.

The definitions of each of these categories can be found in this locally developed document:

Definitions of Cause of Death .doc

Chart 10



Please note as per the last reporting period we are using locally agreed definitions, however in preparation for the next annual report we will be using nationally agreed criteria as used in the King's College London report which will allow for closer comparison with national data.

Similarly to 2021-22 the most common cause of death recorded related to the respiratory system with 20 deaths being included within this category. Of these deaths

- five related to aspiration pneumonia
- six to bronchopneumonia (including one with a query Covid-19 infection)
- one lobar pneumonia
- two type 2 respiratory failure
- one aspiration
- one acute respiratory infection
- one Klebsiella bacterial pneumonia and
- three pneumonia (including one recurrent pneumonia).

Whilst direct comparisons are not possible due to the difference in numbers, timeframes and definitions used it is worth noting that in the national data (*1) Diseases of the Respiratory System was the third most common cause of death, behind Codes for Special Purposes (e.g. Covid-19) and Diseases of the Circulatory System. This combined with a slight increase in the numbers of deaths where the respiratory system is cited as a cause highlights the need for a local focus on this area in 2023/24.

Consequently we propose to:

- carry out a ‘deep dive’ into the 20 deaths identified in 2022-23 to ensure any thematic learning has been captured and followed up appropriately.
- carry out a Focused Review for all deaths where the cause of death relates to the respiratory system.

4. PEOPLE'S STORIES

At the heart of LeDeR are people, real people with real stories and we are uniquely privileged to be able to hear these stories and learn from them as we conduct LeDeR reviews. Spending time with family members and other people important to the person who died gives us a unique insight into that person and we are so grateful to all the people who have given their time to speak to us. Here are just a few examples of some of the stories we have had the privilege of sharing as a team. Names and other identifiable details have been changed to enable the stories to be shared anonymously.

4.1 CELEBRATING GOOD PRACTICE

Laura's Story

Laura was a lady with a mild learning disability and autism. She was diagnosed with breast cancer, which sadly was a life limiting diagnosis. At the time of diagnosis the oncology team had concerns that she would not have the capacity to consent to further investigations and treatment. However working alongside Community Nurses in the LD Specialist Health Team and Acute Liaison Nurses within the hospital setting they were able to ensure that Laura was presented with information in a way that she understood and appropriately involved in decisions. This meant that Laura was able to choose to access treatments that would slow the growth and spread of the cancer. The reasonable adjustments that were championed by the LD Specialist Health Team and put in place to support Laura were key to her remaining in control of her treatment choices and experiencing a better quality of life in the lead up to her death.

David's Story

David was a young man with severe learning disabilities, as well as a number of other physical health conditions. He used an adapted electric wheelchair to maintain mobility and independence. David communicated with sounds and expressions and people who knew him well could understand what he was communicating, despite him not being able to use words.

The complexity of David's presentation meant that from a young age his parents new that his life expectancy was poor.

His family worked with medical professionals to ensure that he had appropriate health and social care as his needs changed and health declined further. Primary Care worked together with Palliative Care Consultants to plan his care at end of life. A Treatment Escalation Plan was written by the GP with involvement from his carers and family. The aim had been for David to die at home in a setting he was familiar with. However sadly this was not possible due to the decline in his presentation. The Acute Liaison Nurses at the hospital worked with David, his family and other professionals to ensure that his experience at end of life was as positive as it could be. His family spoke very highly of the Acute Liaison Nurses and the support they had provided at this and previous hospital admissions.

4.2 AREAS FOR IMPROVEMENT

Shaun's Story

Shaun was a gentleman with severe learning disabilities who lived at home with family, prior to moving to a residential setting where he lived in his own self-contained flat. Shaun had limited speech and would use short sentences, but sometimes his speech was thought to be echolalic in nature. Shaun could become anxious however people who knew Shaun well could understand his emotional experience and anticipate his needs, even when speech was limited.

Prior to his death Shaun experienced a seizure. This was a first seizure but Shaun was not referred for specialist input at this time, despite this being recommended in NICE guidance. Following a number of additional seizures Shaun was referred to neurology and a CT scan was ordered. The CT scan was of poor quality but was not repeated. Both these things may have contributed to a delay in a brain tumour being identified.

Martin's Story

Martin was a gentleman with mild learning disabilities who had lived independently in his own home for all his adult life with minimal support from social care and his family. He was very proud of all he had done for himself over the years but as he grew older and his health needs increased he found he needed more help to stay well.

He had several respiratory conditions including chronic obstructive pulmonary disease (COPD) and asthma, as well as heart failure, dysphagia and type 1 diabetes. At times Martin felt overwhelmed by trying to manage his health conditions and by the numbers of health professionals involved in his care.

Martin had frequent hospital admissions related to him experiencing shortness of breath. During one hospital admission it was noticed by staff that Martin was unable to independently use his inhalers effectively. He was assessed by the respiratory clinical nurse specialist as benefitting from a nebuliser to use at home to help manage his respiratory conditions. Martin took the nebuliser home however medication for this was not included in his hospital discharge summary and there was some confusion in the community about whether this should have been prescribed. Following consultation with the hospital, community staff were advised that Martin did not use a nebuliser and asked for it to be returned to the hospital. Martin had signed a consent form while he was in the hospital for taking the nebuliser home and he was keen to use it; he was disappointed when it had to be returned.

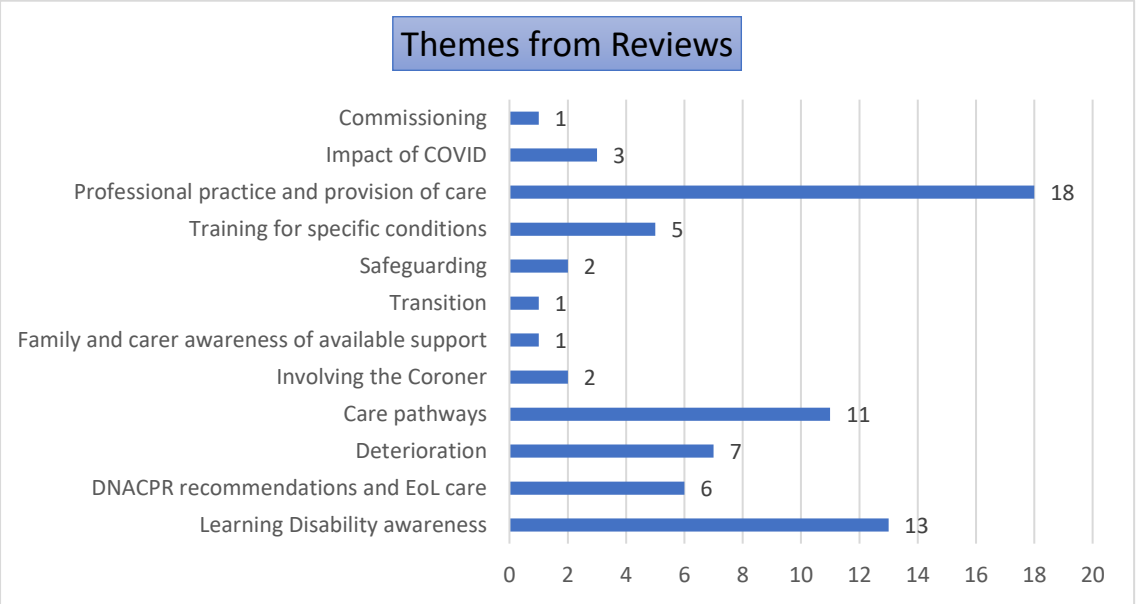
5 LEARNING INTO ACTION

LeDeR is a service improvement programme so ensuring that learning from the reviews leads to changes in practice locally is at the core of what the programme is trying to deliver in Somerset.

5.1 THEMES FROM REVIEWS

All learning generated from reviews is grouped into themes to allow us to pick up on patterns. Chart 11 highlights which themes have most commonly been identified during 2022-23. It should be noted that this data is taken from reviews completed in the period and not deaths in the period as we only establish themes at the end of the review process.

Chart 11



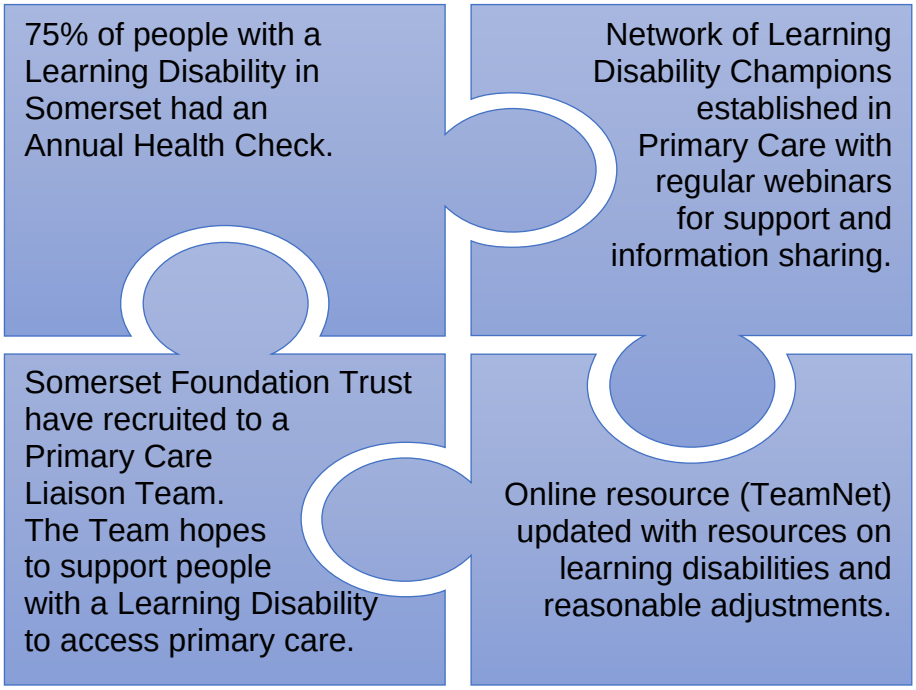
Similarly to last year the most common theme in the reporting period is Professional Practice and Provision of Care. This is quite a broad theme and encapsulates learning related to processes not appropriately being followed or effectively meeting people's needs. A common example of this is misapplication of the Mental Capacity Act.

Learning Disability Awareness and Care Pathways are the next two most frequent themes. The two themes are very related and linked by communication which is a thread that runs through a lot of the themes. Martin's story clearly highlights challenges, not only with care pathways but also with the need for clear communication for people with learning disabilities.

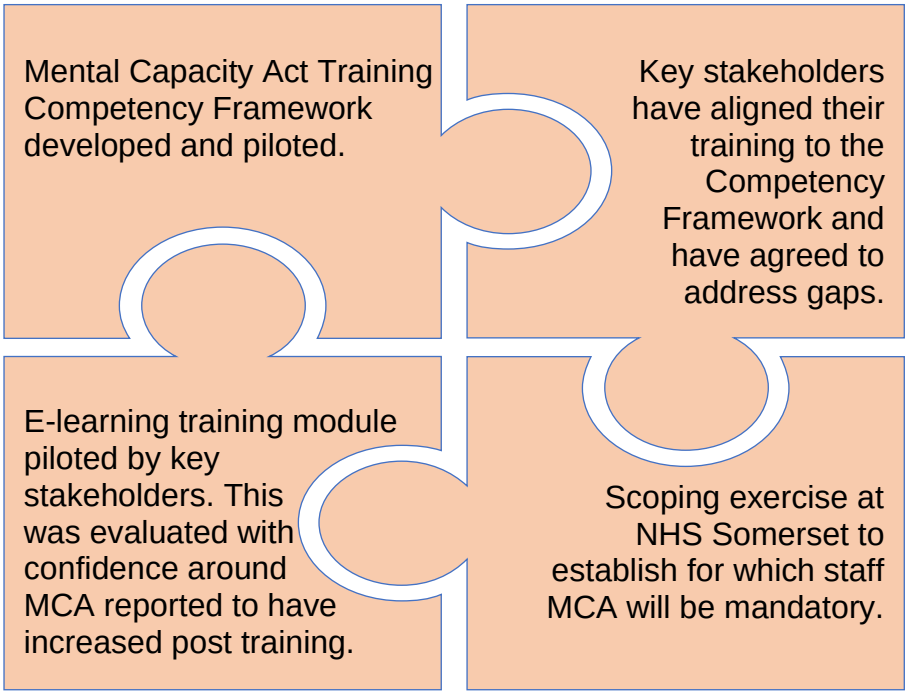
5.2 UPDATE ON LEARNING INTO ACTION

Based on learning from reviews in 2021-22 the following is a summary of what has been achieved across the Somerset system against our stated service development aims. We have used the image of jigsaw puzzle pieces as it is only when these developments work together that they are truly effective in improving outcomes for people with a learning disability and autistic people.

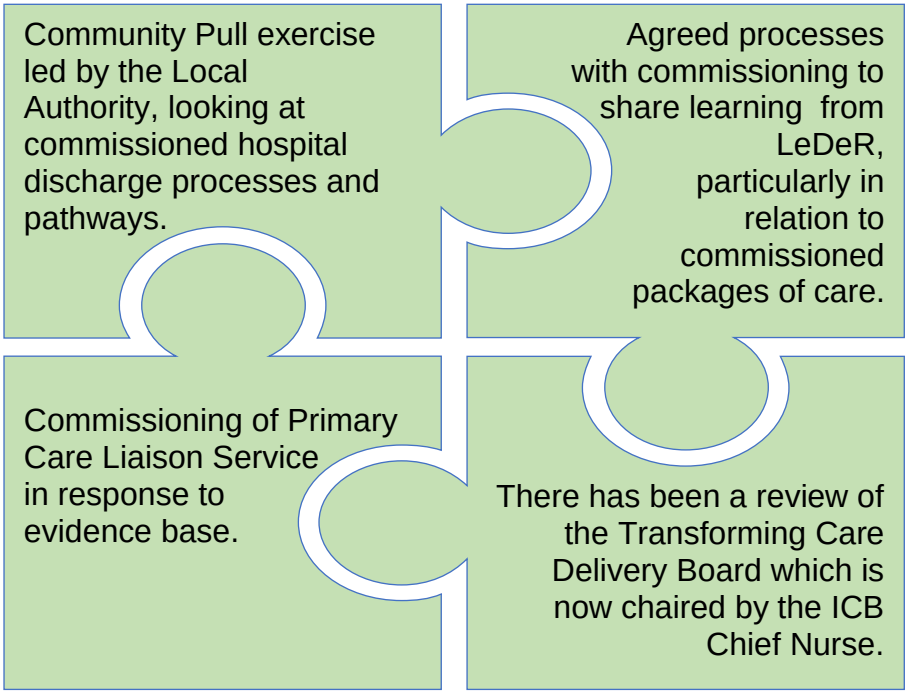
Improvement Priority 1: ***The Annual Health Check (AHC) Programme***.



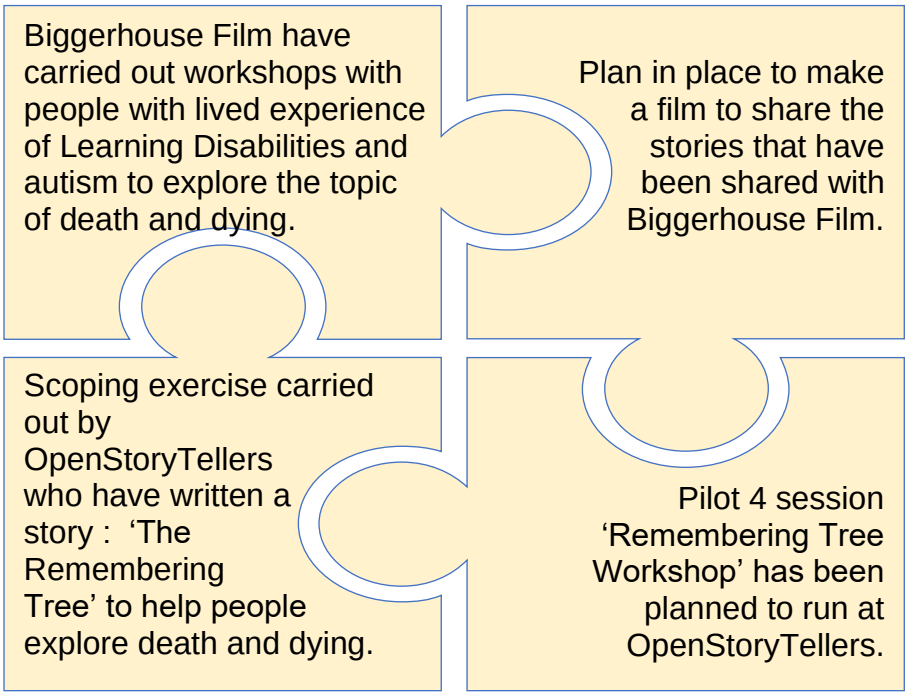
Improvement Priority 2: ***Mental Capacity Act (MCA)***



Improvement Priority 3: ***Effective Joint Commissioning***



Improvement Priority 4: ***Meaningful Engagement of people with learning disabilities and autistic people***



As well as work linked to specific improvement priorities we have also achieved the following:

- Circulated LeDeR Learning Briefs on a range of topics including dysphagia and oral health.
- Quality Improvement Project, led by the Quality Lead for LD, Mental Health and Community Services, focusing on the experiences of people with a learning disability in an Emergency Department setting.
- Finalised a Children and Young Person's version of the pre-health check questionnaire.
- Agreed the use of a consistent patient deterioration tool in Somerset.
- Agreed an approach to introductory dysphagia training.
- Established an Oliver McGowan Training Steering group to drive forward the implementation of this training locally. More detail on the training implementation can be found in Appendix II.

5.3 LEARNING INTO ACTION: PLANS FOR THE FUTURE

Our Improvement priorities have been helpful in providing a focus as the LeDeR Team has become established in Somerset and these will remain ongoing areas of work. However going forward we believe our service development work will naturally evolve from the reviews themselves.

Based on the key themes coming out of reviews in 2022-23 and specific learning presented at the LeDeR Governance Group we intend to focus on the following areas of work in 2023-24.

Professional Practice and Provision of Care

- Automatically carry out Focused Reviews, unless clearly not indicated, for all respiratory deaths.
- Automatically carry out Focused Reviews, unless clearly not indicated, for all epilepsy related deaths.
- Carry out a deep dive of all respiratory deaths in 2022-23.
- Continue to share LeDeR Learning Briefs on key topic areas.
- To identify Transforming Care workstream leads to address specific issues of inpatient support, community support and long term provision in respect of housing and workforce.

Care Pathways

- Work with system partners to ensure LeDeR learning is fed into planned Learning Disability Pathway Review Workshops.
- Support colleagues across the system to ensure LeDeR learning is fed into the development of new services e.g. Cancer Screening Liaison Team.
- Work with system partners to develop an online resource of accessible information about diabetes.
- Complete Learning Disability Advanced Care Planning Audit and associated action plan.
- Pilot Advanced Care Planning clinic for people with Learning Disabilities with colleagues at Somerset Foundation Trust.

Learning Disability Awareness

- Share outcomes of OpenStoryTellers work and the Death and Dying Film from Biggerhouse film once available to raise the profile of LeDeR and the importance of talking about death.
- Implementation of Tier 1 and Tier 2 Oliver McGowan Training.

Autism Reviews

- Work with colleagues in the Somerset Autism Service and those with lived experience to raise the profile of LeDeR locally and increase the number of autism only referrals.

6 CONCLUSIONS

2022-23 has been a time of consolidation for the LeDeR Programme in Somerset. In a landscape of significant system change it has been positive to have an established LeDeR team to work with system partners to take forward learning and change practice. We have seen increased sign up from across the health and social care system which has been significant in promoting changes in practice. Importantly we have also increased our engagement with people with Learning Disabilities and Autistic People and look forward to continuing this work going forward so we can ensure the work of LeDeR is meaningful and accessible to those it effects the most.

Whilst we have seen examples of excellent collaborative working, reasonable adjustments and other examples of good practice in clinical care, we are still sadly seeing too many examples where services did not effectively meet the needs of people.
We want to continue to use learning from LeDeR as a tool to galvanise the system to make positive changes that will improve outcomes for people with learning disabilities and autistic people. We have an exciting programme of work planned in 2023-24 and look forward to sharing the outcomes from this.

References

1) King's College London (2022) Learning from Lives and Deaths – people with a learning disability and autistic people.

2) Census (2021) TSO30

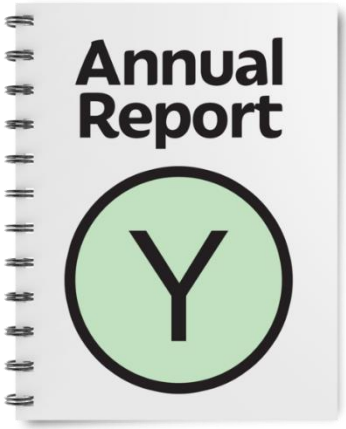
Proud to be part of Somerset Integrated Care System

NHS Somerset

Appendix I – Easy Read Summary

LEDER ANNUAL REPORT 2022 - 2023

LEARNING FROM THE LIVES AND DEATHS OF PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE



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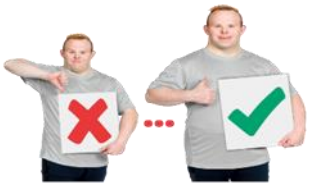
4	What we have done to improve services	
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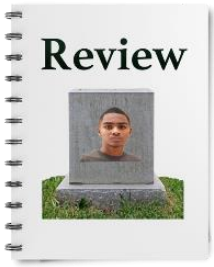
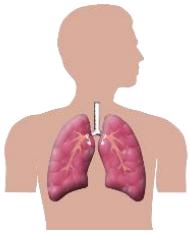
1. Introduction

	All adults with a learning disability and autistic people who die in Somerset have a review. This is called a LeDeR review. This report is about people who died between April 2022 and March 2023.
	A LeDeR review looks at what health and care services worked well for the person who died. The review also looks at what could have been done better. All reviews are checked to make sure they are written well and focus on the person.
	In the review we like to talk to the people who knew the dead person well, like their family and carers.
	We want to say a big thank you to all families and carers who have taken part in our reviews. Sometimes it is really difficult to talk about the death of someone you have cared for.

	We have been talking to people with learning disabilities and autistic people to find out from them how we can involve them more in the work of LeDeR.

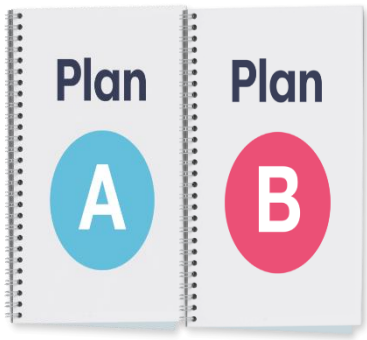
2. Learning from Deaths

	44 LeDeR reviews have been completed this year for people with learning disabilities. There is the death of 1 autistic person waiting to be reviewed.
	Most people died in hospital.
	Young and old people died but most people who died were over 56 years of age.
	Just over half of the people who died identified as being male.

	There were different reasons that people died. Difficulties with breathing were the most common cause of death.

3. People's Stories

 **When support was good**	Some reviews show there was good support for the person who has died. Here are Laura and David's stories :
 **Laura's story**	Laura had cancer. Health professionals helped her to understand all the information from the doctors. Laura was happier because she was able to make her own choices about her treatment. With support she could make her own decisions at the end of her life.



David's story

David's health was not always good.

His family, his GP and the hospital doctors all worked together to make a plan for when David was very poorly. The plan was for David to die at home if possible.

Unfortunately, David became very poorly.
He had to go to hospital.
He was supported to die peacefully and comfortably there.

The family said the Learning Disability nurses at the hospital had always helped to give good support for David.

When support could have been better

Some reviews have shown that support for the person who has died could have been better.

Here are Shaun and Martin's stories:

Shaun's story

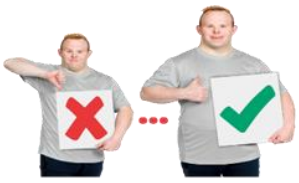
Shaun was an older man.
He had a seizure for the first time.
He should have been referred to the specialist epilepsy service straightaway, but he wasn't.

Shaun had some more seizures.
Then he was referred to the specialist epilepsy service.
He had a picture taken of his brain.
The picture wasn't good.
It didn't show everything clearly in Shaun's brain.

These things may have delayed Shaun being diagnosed with a brain tumour.

 **Martin's story**	Martin lived independently all his life. He always liked to do as much for himself as he could. When Martin was older he was often unwell and had to go to hospital. He had problems with his breathing. When Martin went home from the hospital it wasn't made clear what medication or equipment he should have to help his breathing. Martin was upset when some of his equipment was sent back to the hospital.

4. What we have done to improve services

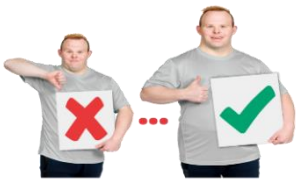


 **Annual Health Checks**	We are supporting people to have annual health checks. We are working more closely with Learning Disability champions in GP practices. There are new nurses to help people with learning disabilities and autistic people to get good health services in Somerset. We have online information and advice for professionals and carers about health and care for people with learning disabilities and autistic people.

 **Mental Capacity Act**	People with learning disabilities and autistic people must be supported to make their own decisions whenever they can. We have been helping professionals to understand more about the Mental Capacity Act.
 **Joint Commissioning**	We have been working more closely with commissioning to make sure they hear about learning from LeDeR. We want to make sure that people are supported in a way that works for them.
 **Listening to service users**	We have been working with Biggerhouse Films and Open Storytellers. They are talking and listening to people with learning disabilities and autistic people about death and dying. They will run workshops and make a film for service users.
 **Eating, drinking and Swallowing**	We have produced an information sheet for carers about why it's so important to support people safely with eating and drinking. Basic training for all carers in Somerset has also been agreed.

 **Emergency department**	We have been looking at what it is like for people with learning disabilities and autistic people when they are in the emergency department in a hospital. We want to make it as good as possible for everyone.
 **Oliver McGowan Training**	Oliver McGowan Training is special training to help health and social care workers provide the best care to people with learning disabilities and autistic people. Somerset have set up a group, including people with learning disabilities and autistic people to look at how to deliver the training. There will be online training starting in May. There will be in-person training starting in July.

5. What we are going to improve next



 	We will look more closely at all deaths to do with breathing. We will look more closely at all deaths to do with epilepsy. We will carry on providing information for professionals and carers about learning disabilities and autism.

	We will carry on working with health and care professionals and service users. We want to make sure services for people with learning disabilities and autistic people are as good as they can be.
	We will carry on listening and talking to service users about death and dying. We will tell people about service user's work with Biggerhouse films and Open Storytellers. All health and care professionals working in Somerset will have special training about learning disabilities and autism. This is called Oliver McGowan Training.
	It is important that LeDeR reviews the deaths of autistic people. We will work with autistic people in Somerset and the Somerset Autism service to tell them about LeDeR.

- If you would like to see this report using Makaton signs, click here:

Signed report

- If you would like any more information on this report please contact the LeDeR team:

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Appendix II – Oliver McGowan Training Update

From 1 July 2022 the Health and Care Act 2022 included a duty for ICB and Local Authority regulated service providers "to ensure that each person working for the purpose of the regulated activities carried out by them receives training on learning disability and autism which is appropriate to the person's role". A two tier model of training has been developed to meet this duty, named after Oliver McGowan whose death and a subsequent campaign by his family highlighted the need for health and social care staff to be better trained in the needs of people with a learning disability and autism. This is a theme which has been raised consistently through the LeDeR reviews.

Health Education England has been tasked with facilitating the implementation of the Oliver McGowan Mandatory Training, (OMMT), across ICSs in England. In the South West region this has been supported by South, Central and West Commissioning Support Unit, (SCW CSU). Health Education England originally tasked each ICB with the job of rolling the training out to all NHS Health providers but have since revised this to include Social Care staff too. In Somerset there are around 30,000 staff, (headcount), who will be required to complete OMMT. Eighty per cent, (24,000), will require Tier 2 training, including public facing and certain commissioning roles. The remaining 20% will require the shorter Tier 1 training.

A Somerset Delivery Group has been formed, chaired by the ICB Associate Director of Safeguarding, Mental Health, Learning Disability and Autism. Group membership includes Experts with Lived Experience, the ICB Quality Lead for Mental Health and Learning Disability, and Workforce Programme Lead, and both clinical and workforce representatives from Somerset NHS Foundation Trust, Somerset Council, and third sector providers Discovery and Autism Somerset

Tier 1 training is scheduled to be available from May 2023 and Tier 2 from July 2023.