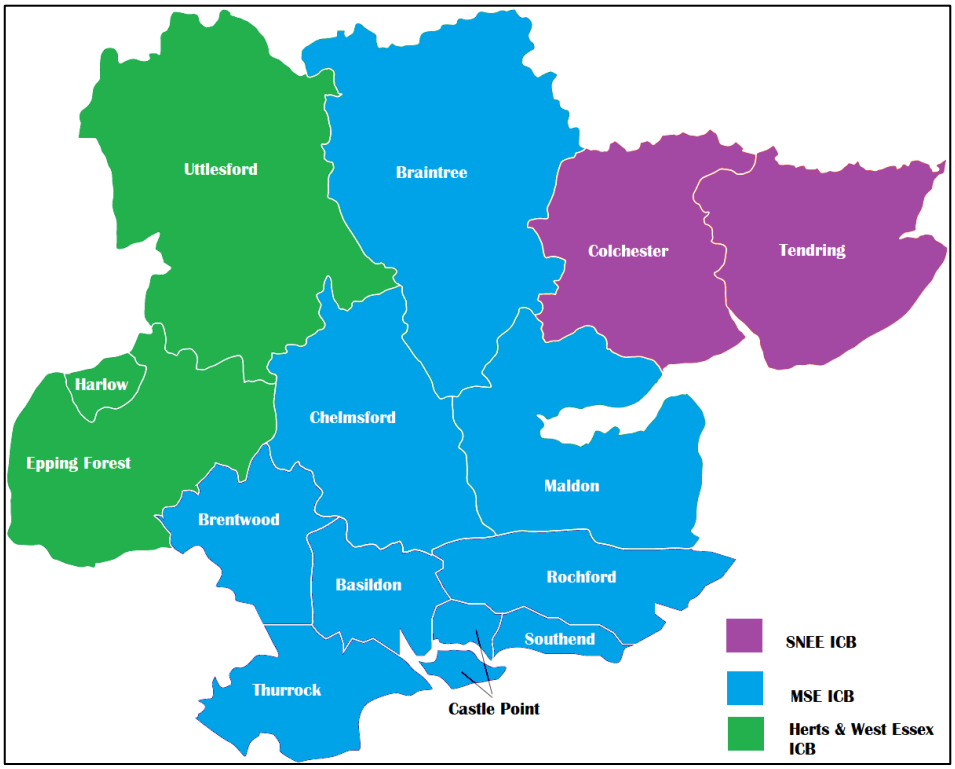
Southend, Essex and Thurrock (LeDeR) Annual Report 2022 - 2023

Learning from lives and deaths – People with a learning disability and autistic people



Version 2.3: August 2023

Contents

Foreword

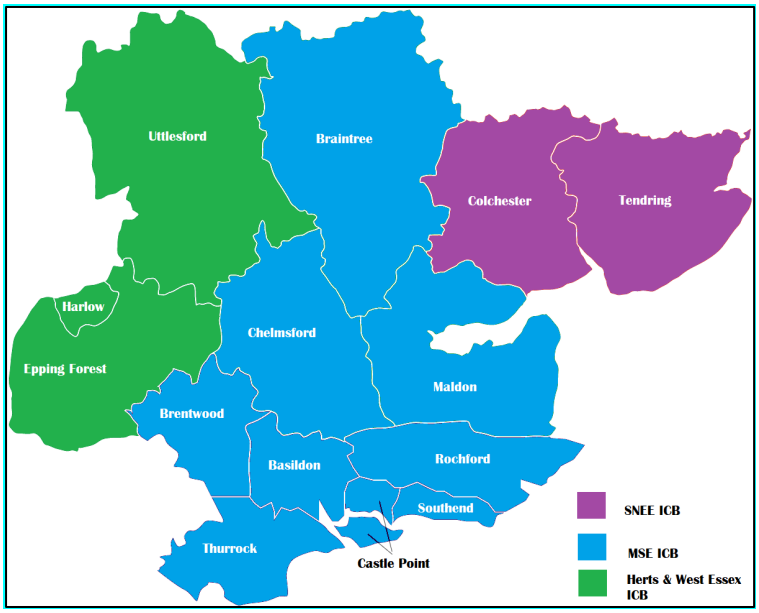
We welcome readers to the Southend, Essex and Thurrock (SET) LeDeR annual report for 2022-23. This report talks about the lives and deaths of people who lived in SET.

With the introduction of Integrated Care Boards (ICBs) from 1st July 2022, there are now three NHS boards working across SET;

Mid and South Essex (MSE)

Suffolk and North East Essex (SNEE)

Herts and West Essex (HWE)



Together as partners, we are committed to delivering the ambition set out in the Learning Disability and Autism NHS Long Term Plan to reduce health inequalities.

Throughout the report, we will sometimes split our information into three ICB areas to make it clear when we are talking about something which applies across all of SET, or whether there are differences across the County.

Since the last report, we have a shared Senior Reviewer working across SET and Suffolk, which has also helped us identify themes or concerns that are common across both counties

Throughout SET, we continue to work in partnership and remain committed to take the learning from LeDeR reviews, turning them into actions, and demonstrating change. This report will show the difference the programme has made to local people and their families and should give assurance of the ongoing commitment to service improvement.

The SET Transforming Care Partnership was set up do deliver the vision set out in Building the Right Support:

"Children, young people and adults with a learning disability and/or autism have the right to the same opportunities as anyone else to live satisfying and valued lives and to be treated with dignity and respect." (Department of Health and Social Care (2022) available at Building the Right Support Action Plan - GOV.UK (www.gov.uk)

The SET partnership Board continues to work across the three integrated care organisations and three Local Authorities which cover the County of Essex

Everyone's Essex sets out 5 commitments to Health for promoting health, care and wellbeing:

Healthy Lifestyles; promoting independence; place-based working (local partnerships); support for carers; levelling up health (Everyone's Essex: our plan for levelling up the county 2021-2025 available at Everyone's Essex: our plan for levelling up the county 2021 to 2025: Foreword from Kevin Bentley | Essex County Council)

Essex county Council published their 4 year strategy for disability in April 2023:

Essex_County_Council_Disability_Strategy_-_Meaningful_Lives_Matter.pdf

Essex County Council have an Ageing Well Programme

Ageing Well Programme

The 5 year all age autism strategy runs from 2020-2025:

All-age-autism-strategy-EasyRead-2020-2025.pdf (snapcharity.org)

The Relevant Strategies for Southend City Council are Ageing Well and Caring Well:

Ageing Well Strategy for Southend-on-Sea Borough Council 2022-2027
Caring Well Strategy for Southend-on-Sea Borough Council 2022-2027

Thurrock's Health and Wellbeing Strategy sets priorities for reducing inequalities in health and well-being, and for improving the health and well-being of the people of Thurrock:

Health and well-being strategy 2022-2026 | Health and well-being strategy | Thurrock Council

This Report will be made available in an Easy Read Format after having been approved by all relevant boards and adopted and published by MSE ICB

Acknowledgements

A special thanks to the LeDeR reviewers, health and social care providers, carers and families who have been central to supporting the LeDeR process and delivering the programme.

We acknowledge the ongoing support of Krishna Ramkhelawon Southend's Director of Public Health, who chairs the LeDeR steering group for SET.

We thank the dedicated members of the three LeDeR Quality Panels for their commitment, contribution and continued passion for improvement for people with a learning disability and autistic people.

We acknowledge our Health and Well Being Boards, the Learning Disability Health Equalities Board and the SET partnership for our ongoing governance and oversight arrangements, and a joint commitment for learning from the lives and deaths of people with a learning disability and autistic people.

We are grateful to the people from all agencies who make the notifications, our dedicated team of reviewers who work hard to make sure each review is carried out to the highest standard possible with the information available; we thank the family members and carers of people who have died for sharing the histories of their loved ones, and the Learning Disability Liaison Nurses for their dedicated input over the years.

We thank Rebekah Bailie at Essex County Council for laying the firm foundations of LeDeR in SET, and the wider Health Equalities Team at Essex County Council, the ongoing support from Essex Family Carers Network, our Suffolk and Hertfordshire colleagues, and LeDeR colleagues across the region for a commitment to collaborative working for better outcomes.

We remember Phil Brown, who transformed lives, and the people whose lives and deaths we have had the privilege to review and learn from, and in commitment to them we continue to strive for improvement across all aspects of health and care.

Executive Summary

The deaths of 113 people with learning disability and/or Autism were notified across SET between April 2022 and March 2023. This is a very similar number to the previous year when 116 deaths were notified. Since January 2022, the scope of LeDeR has been broadened to include reviews for people with Autism only (without a Learning Disability) and we are starting to see notifications for this group of people.

The average age of death has gone down somewhat this year, which we are monitoring. We believe that we are still seeing the impact of Covid-19 on our notifications and across health provision.

We remain compliant with the revised LeDeR policy in terms of team structure, and since January 2023 have shared a Senior Reviewer with Suffolk to achieve efficiencies and share learning.

We are committed to maintaining good performance in respect of allocation and completion KPIs and the expected split between initial and focused reviews. Although 2022-23 has been a challenging year in terms of staffing in the team, we have remained sighted on achieving the required number of completions in a timely manner whilst improving quality across reviews.

We have a 3-year deliverable plan which identifies where we need to a) prevent ill health b) improve management of health and c) remove inequalities and this reflects the commitment of all organisations, including public health. This is monitored by the LeDeR Steering group and is due to be reviewed this year.

Introduction

The aim of the Learning from Lives and Deaths (LeDeR) Programme is to reduce the health inequalities faced by people who have a learning disability.

The LeDeR programme to date has reported on deaths of people with learning disabilities aged 4 and above. The new LeDeR policy has brought the inclusion of those with a diagnosis of autism (aged 18 and over) into the programme from January 2022.

When somebody with a learning disability or autism dies, and their death is notified to LeDeR, we carry out a review of all aspects of the care and support they received – this might be Primary Care (from their GP Practice), care in Hospital, care and support from paid providers, or from family, or specialist services.

By reviewing all aspects of care and support, we are looking to improve quality by learning from what went well and making recommendations for change where things could have been better, to improve health outcomes for other people with learning disability and/or autism.

The LeDeR programme works alongside other quality improvement measures currently in place to reform services and improve health outcomes for people with a learning disability. If other reviews and enquiry processes need to take place, such as hospital structured judgement reviews (SJRs), serious incident reviews, safeguarding investigations, police investigations or a Coroner's report, the LeDeR review should be done after these are completed, so we can include the learning from their findings in our summaries.

The programme started in Essex in 2017. At that time, there were two things we wanted to see to show how LeDeR was making a difference:

1. We wanted the number of deaths notified to LeDeR to increase every year, as more people became aware of the programme, so that opportunities to learn were not missed
2. We wanted to see the average age of death of people with a learning disability increase, "to close the gap" as we knew that on average people with learning disability were dying up to 20+ years younger than the general population

We still want these things. However, the impact of Covid-19 throughout 2020 and 2021 had a significant impact on the numbers of deaths reported and the average age at death, and this is still seen across 2022 and 2023. Also, while we still have a steady increase in notifications for people with a learning disability, we have had very few for autistic people who didn't also have a learning disability.

It will take more time before we are confident that we are getting all the notifications we should, and we start to see an impact on the average age of death. However, in the meantime, this annual report provides an update on the achievements of the three Integrated Care Boards (ICBs) and Southend Essex and Thurrock (SET) Local Authorities and transforming care partnerships, and the changes already being seen.

The report will also report on the LeDeR learning from demographic data from notifications and reviews. It will provide an update on our progress since last year's report and then describe what we have learned from the reviews undertaken during this reporting year.

This report will also outline the governance arrangements for LeDeR across SET, and how partners are working together to promote improved outcomes and experiences for people with a learning disability and autistic people.

We will make the report available in 'easy read' format later in the year.

Involvement of people with a learning disability, experts by experience and families/carers

Across the SET footprint, there are many opportunities for people with Learning Disability and/or autism to be involved in the delivery of the programme. All Focussed reviews are overseen by a Quality Panel which is supported by an expert by experience from Essex Carer's Network. There is also Family carer representation on the LeDeR Steering Group, which monitors all recommendations and actions from reviews, and also the SET Partnership board.

The Learning Disability Health Equalities Board has maintained involvement from people with Learning Disability and Autism, but we recognise that there have been significant changes in ways of working, and this has potentially made it more difficult for people to be meaningfully engaged. This was due to changes in the ways we work which were the result of fewer face to face and more online meetings due to covid restrictions, plus the loss of some key personnel in Essex.

As a result, the Health Equalities team are recruiting associate commissioners with a Learning Disability plus dedicated support for them in the workplace, to ensure the voice of people with Learning disability does not become lost. We also have recruited a commissioner dedicated to Autism, as we are anticipating an increase in the number of "Autism only" reviews in 2023/24.

Delivery of the Programme

The LeDeR programme for SET is hosted by Essex County Council for the 7 Clinical Commissioning Groups (CCGs) in partnership with the three Local Authorities. This arrangement has continued under the newly formed ICBs in place of the old CCGs, and the SET reviewers are employed by Essex County Council. At the end of March 2023, the review team consisted of a Senior Reviewer covering both SET and Suffolk, one part time (0.6) permanent reviewer. This impacted on the capacity of the team to deliver the reviews in a timely way, although we were able to use the resource of some independent contracted reviewers. Since then, we have had a part time reviewer (0.6) return from a year's secondment, and we have recruited two additional part time reviewers (0.6 and 0.4), as well as a new commissioner who will be the SET LeDeR Local Area Contact (LAC) , freeing up additional time from the Senior Reviewer. We are also recruiting into a co-ordination and admin position to support all aspects of LeDeR.

We are monitoring the number of notifications being made to ensure that we now have sufficient capacity to deliver as many reviews as possible within the 6 months target.

Due to the historically lower numbers of notifications made in Suffolk County, the Senior Reviewer role is shared across SET and Suffolk, and two LD nurses are employed on a bank basis, with the Support of the Suffolk LAC and administrative support.

Governance arrangements

LeDeR is integral to the NHS 10 Year Plan, published in 2019, with the aim of improving the lives of people with learning disabilities nationally.

The Senior Responsible Officer Role is held by Nick Presmeg on behalf of Southend, Essex and Thurrock.

The Deputy Responsible Officer Role is held by Jeff Banks on behalf of Southend, Essex and Thurrock.

The ICB Chief Nurse is the Lead for the LeDeR programme in Mid and South Essex, and North East Essex and Herts. In West Essex, the ICB Lead is the Director of Strategy.

SET LeDeR Steering group – chaired by Southend's Director Of Public Health

This group has representation from senior leadership across Health and Social Care systems with the authority to affect change.

This group will review its original terms of reference in 2023 but will remain the key driver for change across all systems and be sighted on all reviews completed.

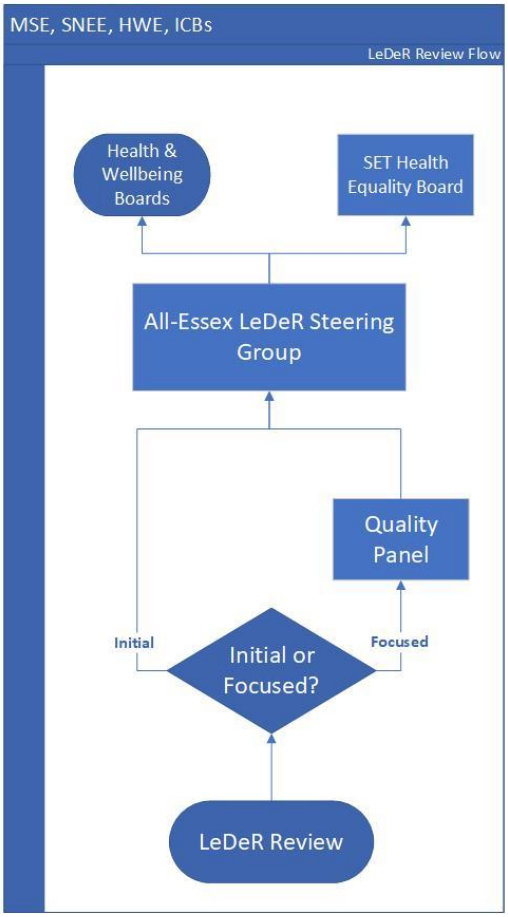
The Three Quality Panels

These groups convene separately for reviews from the MSE, NEE or WE areas. They are attended by an Expert by Experience from Essex Family Carers, with representation across the ICBs, Local Authorities, and the Learning Disability Specialist Health provider (ELDP – Essex Learning Disability Partnership). We are able to learn from practitioners who can help unpick anything tricky to understand or give a perspective on certain decisions.

In 2022/23 there were a number of changes to key personnel associated with the formation of the new ICBs, and so in 2023/24 we wish to identify a lead or leads across the three areas as a specialist to support reviews for people of any ethnic, racial or religious minority background.

We will also be investigating how we can involve colleagues from the Ambulance Trust to contribute to identified Quality Panels.

The image below represents how each group is involved in the Governance and oversight of LeDeR in SET.



Performance against national targets

The new LeDeR policy launched in March 2021 set out a plan for a 'lighter touch' initial review and it was expected that approximately 1/3 of reviews notified would move into the second focused review stage. Those focused reviews are guided by the reviewer and agreed by the Local Area Contact. The criteria for a focused review are:

- if it is believed there will be significant learning,
- when the family have requested a focused review,
- when the person has a diagnosis of Autism only,
- when the person is from a minority ethnic, racial, or religious background.

The key quality improvement measures which we continue to monitor across SET:

- 100% reviews to be completed within 6 months of notification (except where reviews are placed on hold for permitted reasons)
- At least 35% of reviews to be a focused review.
- Continued improvements to the quality of reviews to identify local learning.
- Progression of identified learning in a timely manner.

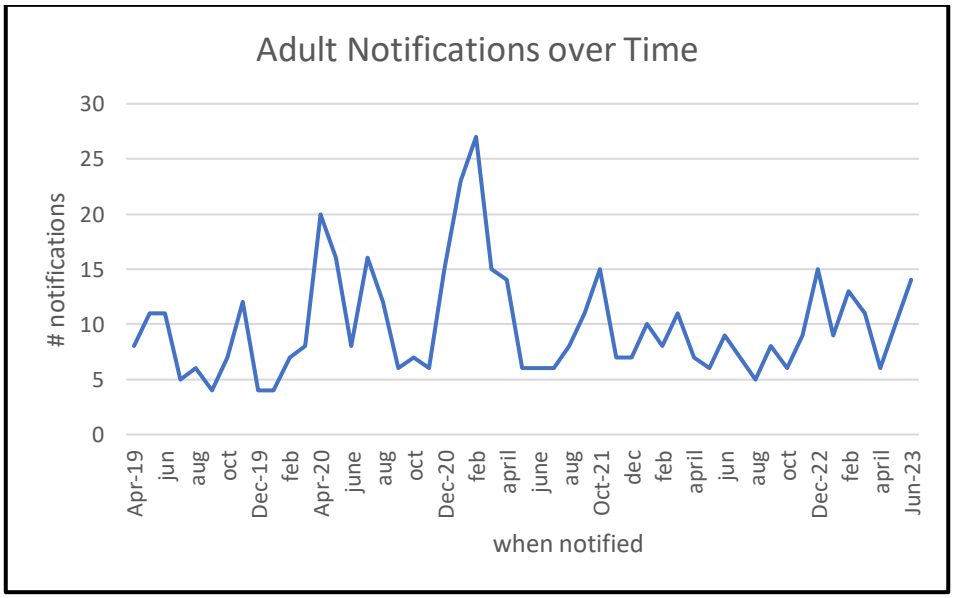
Our People, Performance, Themes and Trends

The data we are using

In this report, there are two sets of data we refer to.

The first is the set of **notifications.** This is the number of deaths notified to us at LeDeR in the year 22/23, meaning from 1st April 2022 to the 31st March 2023.

Since most notifications are made close to the day when the person died, this data is helpful for us to understand some of the trends around deaths as they occur. For example, this graphic:



is a clear indication of the impact on Covid-19, when notifications were at their highest, but also shows the impact of Winter on health.

Looking at notifications helps us to understand any changes on a year-by-year basis.

The second set of data we use is **completed reviews.** This would normally be for the same time period, from 1st April 2022 to 31st March 2023, but this year NHSE decided to extend the period by 10 weeks, as there was a problem in the online system which meant reviews could not be completed for a time, which meant there may not have been enough completed reviews to provide good data. We have decided for this report to mirror NHSE, so that our data will be in line with the National Annual report when it is published later this year. This does mean that our WE and NEE data covers a slightly different date range than the data being used in the HWE and SNEE reports, so there are slightly different numbers used in those areas. I will make it clear whether the data in the report relates to

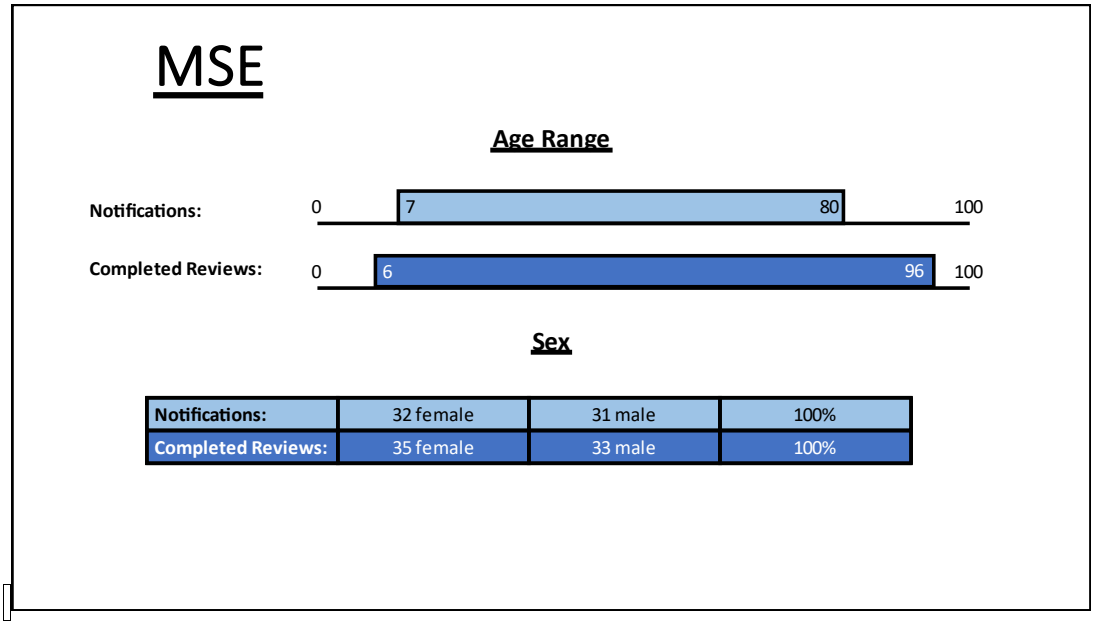
notifications in the year, which will nearly all be for people who died in that year, or completed reviews, some of which may be more than a year old.

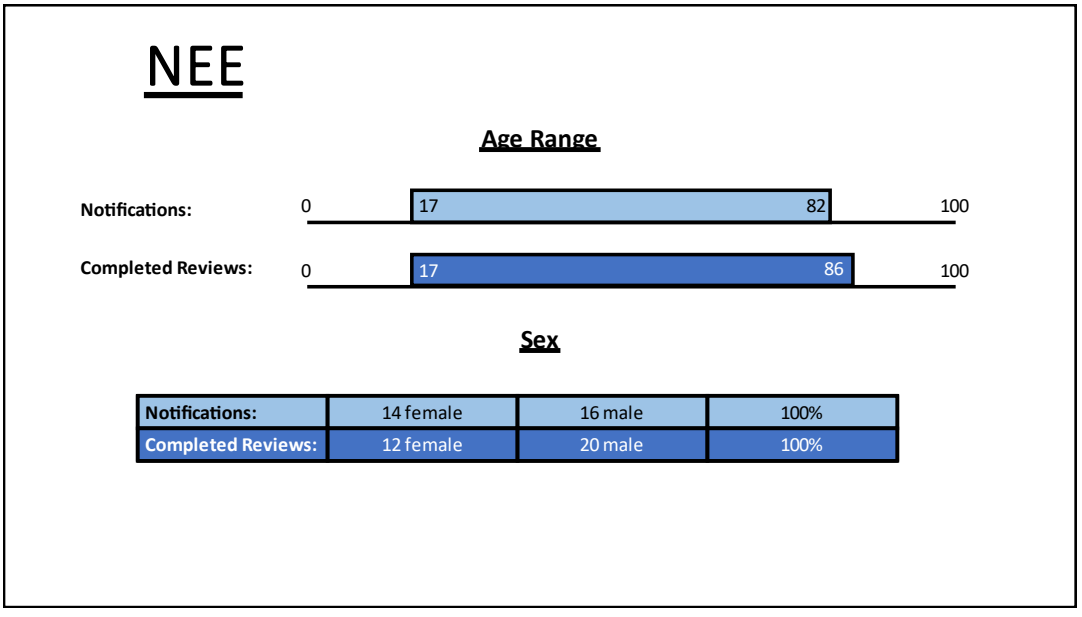
Notifications 2022-23

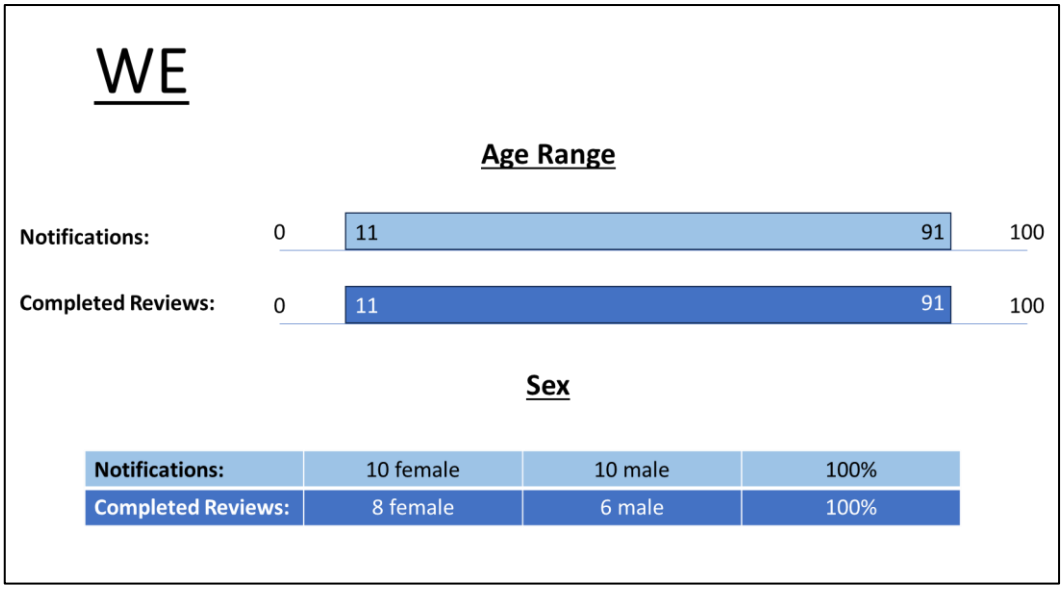
In 2022/23 we received a total of 113 notifications which included 7 child death notifications.

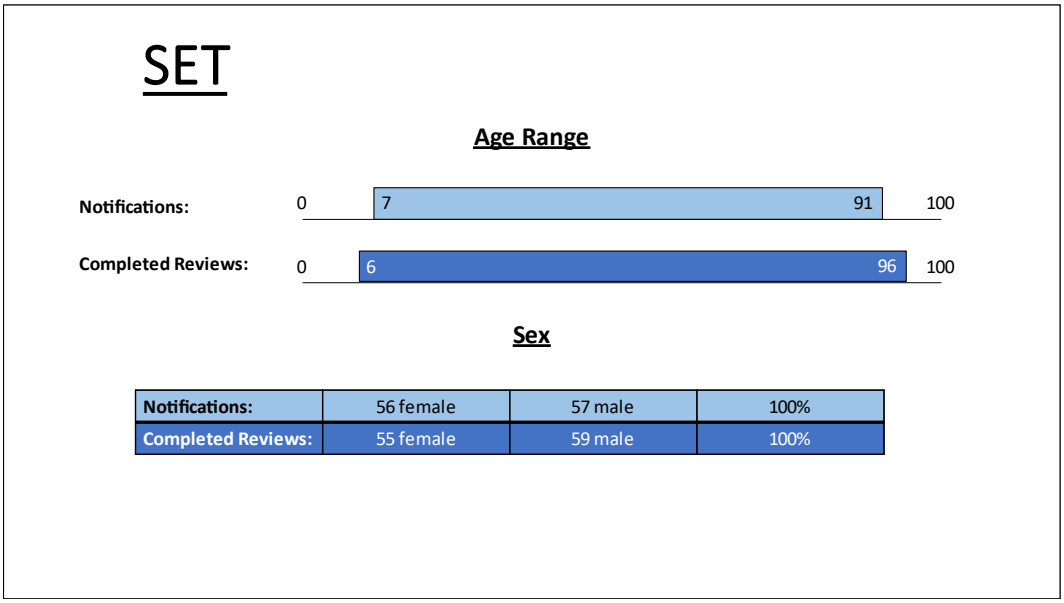
ICB	*April*	*May*	*June*	*July*	*August*	*Sept*	*Oct*	*Nov*	*Dec*	*January*	*February*	*March*	*Total*
MSE	4	4	7	5	3	3	3	3	9	5	6	11	63
WE	1	3	0	2	0	1	2	1	1	1	5	3	20
NEE	2	3	2	1	1	3	1	6	4	3	3	2	30
Essex total	7	10	9	8	4	7	6	10	14	8	14	16	113

Below is a comparison between notifications and completed reviews:









The number and nature of **completed reviews** in a year are broadly similar to the number of notifications, but they provide better data, as we know more about what happened once a review has been completed, and a number of reviews which were **notified** in 22/23 are not yet completed. The age range of completed reviews is broader than that of reviews notified in year by 6 years

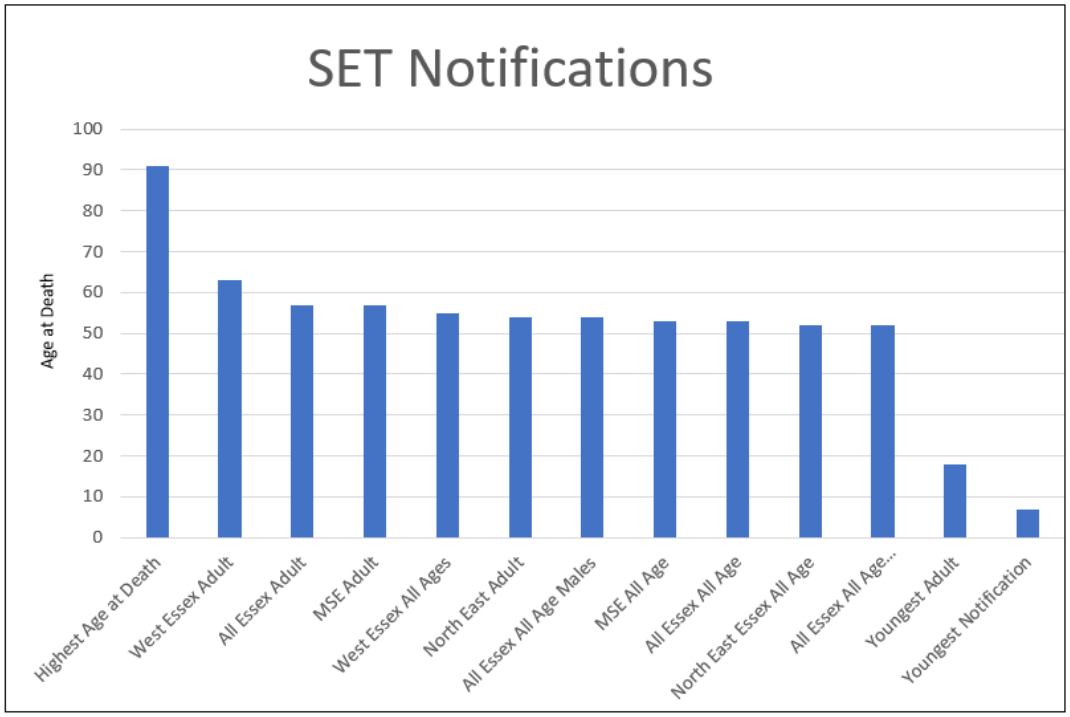
Age at death by notification

The King's College National LeDeR report 2021 leder-main-report-hyperlinked.pdf (kcl.ac.uk) highlighted that the median age at death was 61 for males and 60 for females based on notifications. Males with a Learning Disability died 22 years earlier than in the general population and females died 26 years younger than the general population.

Notifications in 22/23 for Essex show a drop in average age of death overall.

Last year the median average age of death was 65.5 years. This year we have broken down the average ages by sex and by ICB area.

Average Age at Death



The median average age at death for adults in Essex in 2022-23 was 57. In West Essex the average median age was a little higher at 63, but this is impacted by the small sample size and two 80+ notifications. In North East Essex the average age is lower at 54, but again this is influenced by the small sample size and two young adult deaths. The average age of death in MSE is 57, in line with the average age overall.

The reasons for this are not fully understood, and contrary to how it may first appear, not all negative. We have a few notifications for the deaths of very young adults who have outlived their initial prognoses, which is to say that they might have been expected to die in childhood, except for the very good care from family and professionals. This has the effect of decreasing our average age at death for adults, but not the average age at death overall.

Another reason we think the average age has gone down is because of the higher numbers of notifications we received during the peak of the covid-19 epidemic, when our average age at death actually increased. We think that some of the oldest adults died during covid, who might otherwise have died in 22/23, and therefore some of the oldest people are “missing” from this year’s numbers.

In the 2020/21 annual report there was 50 notifications for people between 60-69, 52 notifications for people between 70-79, 11 notifications for people above 80 years of age. In

the 2021/22 annual report there was 32 notifications for people between 60-69, 22 notifications for people between 70-79 and 15 notifications for people over 80 years of age.

As you can be seen from the evidence above, we lost a significant number of people above the age of 60 during covid. Especially when we consider that there are only 113 death notifications this year. Which is the same number as the number of adult's deaths that were over 60 when notified to LeDeR in 2020/21. Then in 2021/22 there were 69 people deaths notified of people over 60 which a significant number. It is important to note data shows the significant impact covid 19 had on our older adults with learning disabilities between 2020-2022 and therefore explains the lower average age of death in 2023.

We are determined not to allow the impacts of Covid-19 have a long-term impact on people's health and social care, and we are paying particular attention to some key areas in 23/24 and beyond to hopefully ensure that this is not a downward trend. This includes:

Monitoring uptake of Annual Health checks and completion of a Health Action Plan

Monitoring uptake of screening and vaccination working with Public Health colleagues to reduce un-necessary exclusions, including desensitisation work

Highlighting the importance of face-to-face appointments, especially where the patient is non-verbal or needs support with communication

Highlighting any variations from NICE guidelines, especially where this may result in late detection of cancer or late diagnoses

Working with Provider Quality Innovation to roll out training in key areas to care and support personnel in Essex.

For clarity the average age of death is calculated by omitting any notification under 18 years of age and then determining the average age of death amongst the adult notifications. This helps provide a realistic average age of death within the limitation of a small sample size.

Sex and Gender

During the LeDeR process, some aspects of healthcare we review is specific to the sex of the person who died, for example some of the screening offered.

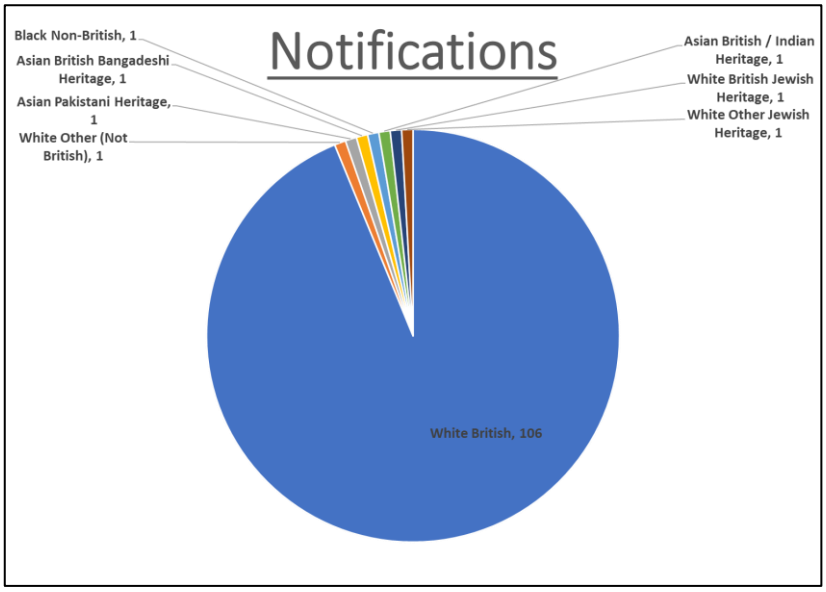
We received very similar number of notifications for women and men (56 female, 57 male), and also completed reviews for a similar number (55 female, 59 male).

We are able to record if a person who died identified as being a different gender to their biological sex, but so far we have not completed a review where that has been noted as the case. As conversations around sex and gender identity are becoming more normalised, we predict that this may change, and also if we start to be notified about more deaths of autistic people.

Ethnicity by completed reviews

The 2019 National LeDeR Report found that people from minority ethnic groups died at disproportionately younger ages than white British people. Nationally, of those who died in childhood (ages 4-17 years), 43% were from minority ethnic groups.

SET has a significantly lower number of deaths in people from minority ethnic backgrounds In 2022/23, only 7 LeDeR reviews were completed for people with a minority ethnic background and the rest were white British.



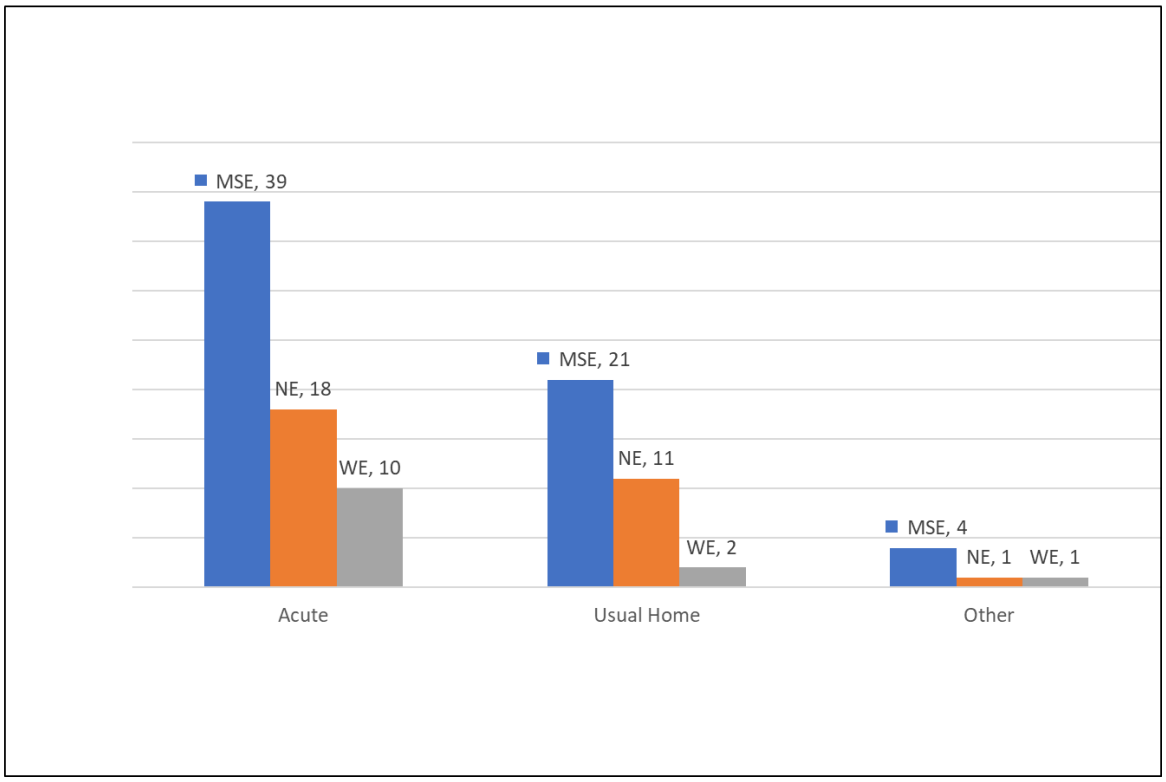
It seems likely that there is under-reporting of deaths across all minority groups. This is concerning, because it suggests that people from all minority ethnic backgrounds are less known to services for people with Learning Disability.

According to the latest 2021 census, the population in SET is predominantly white (90.4%), with non-white minorities representing the remaining 9.6% of the population. Asian people were the largest minority group in SET accounting for 3.7% of the population.

Place of death by notification

Nationally, the proportion of people with learning disabilities dying in hospital was 61% in 2021. We know that many people say that they would prefer to die at home. The NHS Long Term Plan identifies the ambition to avoid emergency admissions, and it is understood that dying at home in familiar surroundings is regarded as a preference by a majority in the general population

Place of Death



In 2022-23, 59% of people whose deaths were notified died in an Acute Hospital. That is the same percentage as last year.

The reviews have highlighted a number of reasons why people are not able to die at home, including:

When care providers do not feel able to take a person back home, as they do not offer the level of care and support the person needs at end of life.

When there is not a clear plan for a person to stay at home to die peacefully, and they are transported to hospital unnecessarily.

When a discharge from hospital is not well planned, and the person does not have the care, medication or equipment they need to remain at home.

We also know from reviews that where palliative care teams/hospice teams are involved at the end of someone's life, there is typically good planning, and care providers and families value this support.

One reason it might appear that more people die in their usual home than actually do, is that some people might classify a place as a "usual home" even if the person had lived there for a very short time, if being placed their effectively ended their previous living

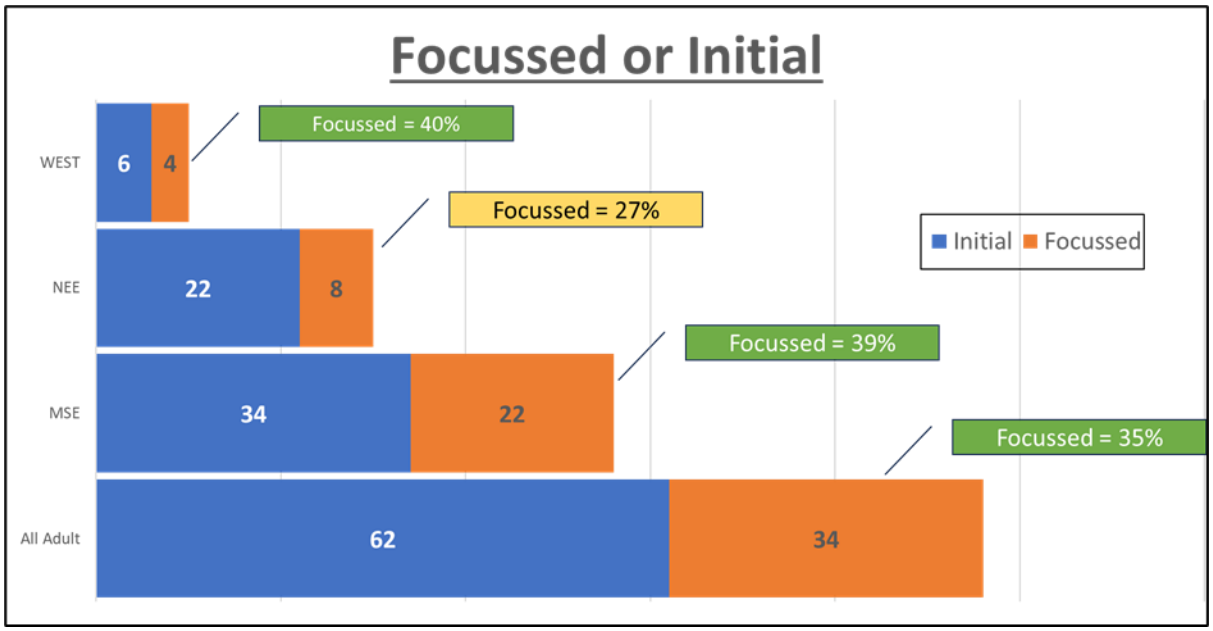
arrangement. The person with the Learning Disability may not have considered it their "usual home" and therefore it is likely that the number of people who died in the place they thought of as home is actually lower than 35.

Completed reviews

In 22/23 we completed:
10 Adult reviews for West Essex
30 Adult reviews for North East Essex
56 Adult reviews for Mid and South Essex

Adult reviews are either completed after the **Initial** review, or are selected for a more in-depth **Focussed** review

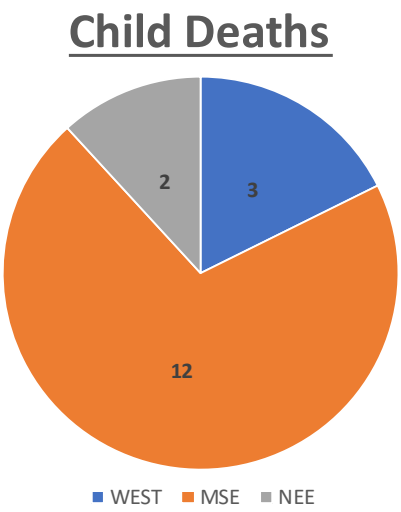
NHSE expects at least 35% of reviews to be focussed, which is in line with what we have done this year. Although the chart below shows that we are a little under 35% for NEE, that will balance out as we sign off the next Focussed reviews for completion in 23/24, which are mainly NEE reviews



The criteria for a focussed review are:

- if it is believed there will be significant or new learning,
- when the family have requested a focussed review,
- when the person has a diagnosis of Autism only,
  when the person is from a minority background.

We also completed 17 reviews of child deaths across the SET.



Total SET Deaths: 17

The child deaths are not reviewed by the LeDeR reviewers, as they are passed to the Child Death Overview Panels (CDOP), who will carry out a thorough inquiry. The Senior Reviewer will attend the CDOP if there is a LeDeR case being discussed and will receive copies of the completed review and will receive a copy of a Form C, which has details of the completed review by CDOP. Relevant learning from the Panel will be reported back to the LeDeR Steering Group.

From 1st July 2023, Child Deaths will no longer be considered under LeDeR, but the information and learning from the Child Death Reviews will be shared with the LeDeR Steering Group and analysed alongside LeDeR Data at a National Level.

Primary causes of death from completed reviews

The cause of death is described in 4 parts on death certificates:

1a disease or condition directly leading to death

1b other disease or condition (if any) leading to 1a

1c other disease or condition (if any) leading to 1b

Part 2 other significant conditions contributing to the death, but not related to the disease or condition causing it.

There are some marked differences in the leading causes of death for the general population and the individuals whose deaths were notified to LeDeR.

The most common causes of deaths in Essex recorded on people's death certificate at 1a as the primary cause of death are set out below in the table, which shows where there were three or more deaths of a single primary cause (listed at 1a on the death certificate) , or

where there were three or more deaths which are strongly related (for example Pneumonia, Community Acquired Pneumonia (CAP), and Hospital Acquired Pneumonia (HAP) are all shown, even though there was only one death recorded as HAP.

Primary Cause of Death	ICD codes		MSE	NEE	HWE	SET
Respiratory Conditions	J00-J99	Aspiration Pneumonia	14	4	1	19
		Bronchopneumonia	2	2		4
		Lower Respiratory Tract Infection/Chest Infection	3	1		4
		Respiratory Failure	2	2	1	5
		Pneumonia	12	4		16
		Hospital Acquired Pneumonia			1	1
		Community Acquired Pneumonia	1	2		3
		Covid-Pneumonia/ Pneumonitis/Covid-19	4		2	6
		Pulmonary Embolism/fibrosis	3			3
		Total Respiratory	**41**	**15**	**5**	**61**
Sepsis/ Septicaemia	A40-A41	Sepsis	2			2
		Urosepsis	1			1
		Septicaemia		1		1
		Septic Shock	1			1
		Total Sepsis	**4**	**1**		**5**
Cardiac/ circulatory system	I00-I99	Congestive heart Disease		1		1
		Congestive Cardiac Failure/ Cardiac Failure/Heart failure	4			4
		Intercerebral Haemorrhage	1			1
		Cardiac Arrest	2	3	1	6
		Obstructive Coronary Artery Disease/Atherosclerosis	1	1		2
		Dilated Cardiomyopathy	1			1
		Myocardial Infarction	1			1
		Myocarditis	1			1
		Other Cardiac	1		2	3
		Total Cardiac	**12**	**5**	**3**	**20**
Neoplasm/ Cancer	C00-D48	Metastatic Cancer	3		1	4
		Neoplasm		1		1
		Cancer of the Bowel	1			1
		Acute Myeloid Leukaemia		1		1
		Carcinomatosis		1		1
		Carcinoma	1		1	2
		Cancer of the Pancreas	1	1		2
		Total Neoplasm/Cancer	**6**	**4**	**2**	**11**
Dementia/ Alzheimer's	F01, F03, G30	Dementia	2	2		4
		Alzheimer's	1	2		3
		Total Dementia/Alzheimer's	**3**	**4**		**7**
Epilepsy	G40	Epilepsy	1			1
		Status Epilepticus	1			1
		Epilepsy Seizure			1	1
		Total Epilepsy			**1**	**3**

This shows that Respiratory conditions are by far the leading primary cause of death for people with a Learning Disability (61) , followed by Cardiac deaths (20), Cancers (11), Dementia (7) Sepsis (5) and Epilepsy (3)

For comparison, if we had reviewed a sample of deaths of people from the general population, we would expect to find the leading cause of death to be Dementia and Alzheimers (around 12 people) , followed by heart diseases (around 10 people) and chronic lower respiratory diseases (around 6 people).

Clearly there is a very great difference in the leading casues of death for people in the general population and people with a learning disability, and this continues to inform the work of the SET Health Equalities team and partners. In particular, there has been a focus on respiratory illness throughout 2022 and into 2023.

For more detail on the causes of death in the general population against the relevant ICD10 codes, the ONS website is helpful:

Deaths registered summary statistics, England and Wales - Office for National Statistics (ons.gov.uk) (accessed June 2023)

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

Some deaths resulting from Sepsis, Cancers, Epilepsy and Diseases of the Circulatory or Respiratory system are classified as Avoidable Deaths in adults under 75, which make up the majority of deaths notified and reviews completed.

(for further detail, please see: Avoidable mortality in the UK QMI - Office for National Statistics (ons.gov.uk) accessed July 2023)

Genetic and Long-Term Conditions (LTCs)

The online LeDeR Platform did not collect data about people's genetic or long-term conditions in a uniform way across all reviews until January 2023. This means there is not a full year's data available, however by the time of the next annual report for 23/24, this data will be available.

For this year, we have done a manual count of all genetic and long term conditions mentioned in the reviews, which may not have captured every individual case, but nonetheless this has shown us some interesting trends which we can use to shape our reviews in 23/24, and will provide a useful comparison with the data available next year. We have identified 7 areas where we want to continue to work with agencies to make improvements; these are:

Down's Syndrome

Cerebral Palsy

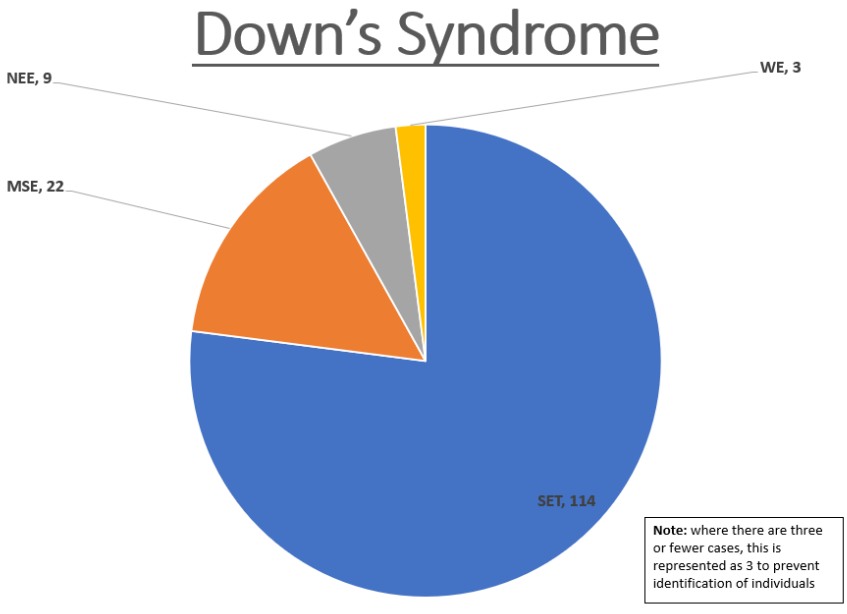
Epilepsy

Scoliosis

Dysphagia and PEG feeding

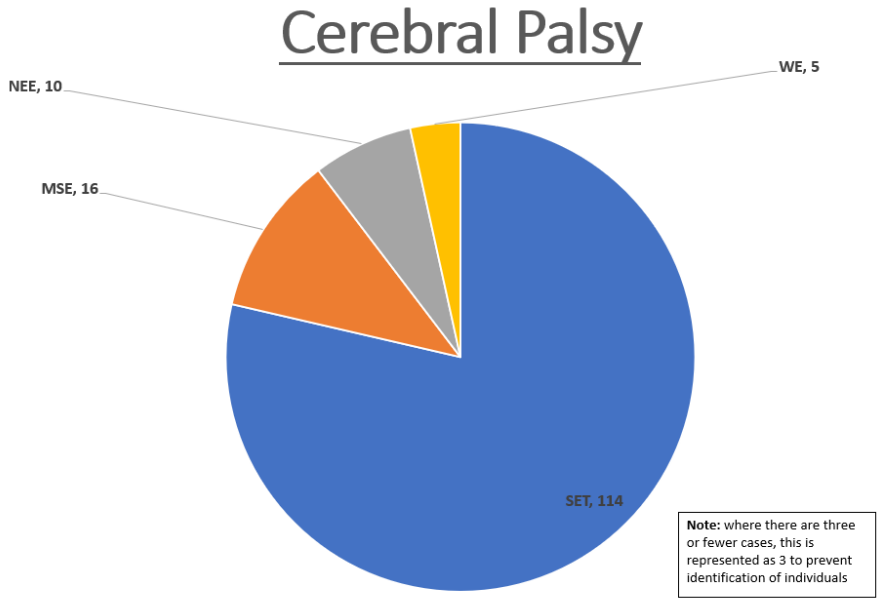
Constipation

Visual impairment

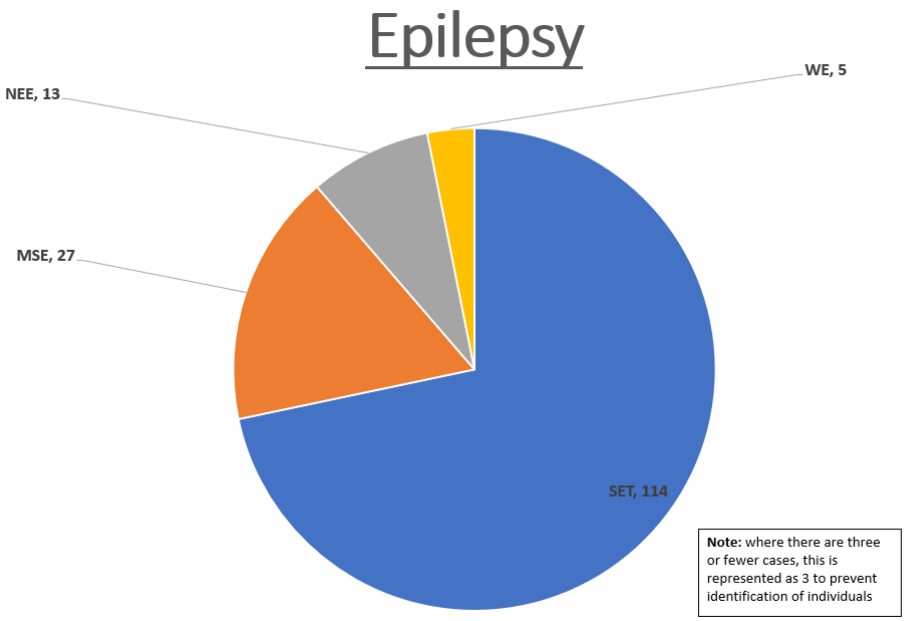


At least 34 (30%) of the completed reviews were for people with Down's syndrome. This genetic condition is associated with some other health conditions, and we should look at what reasonable adjustments we can make across health and social care to improve services for people with Down's syndrome.

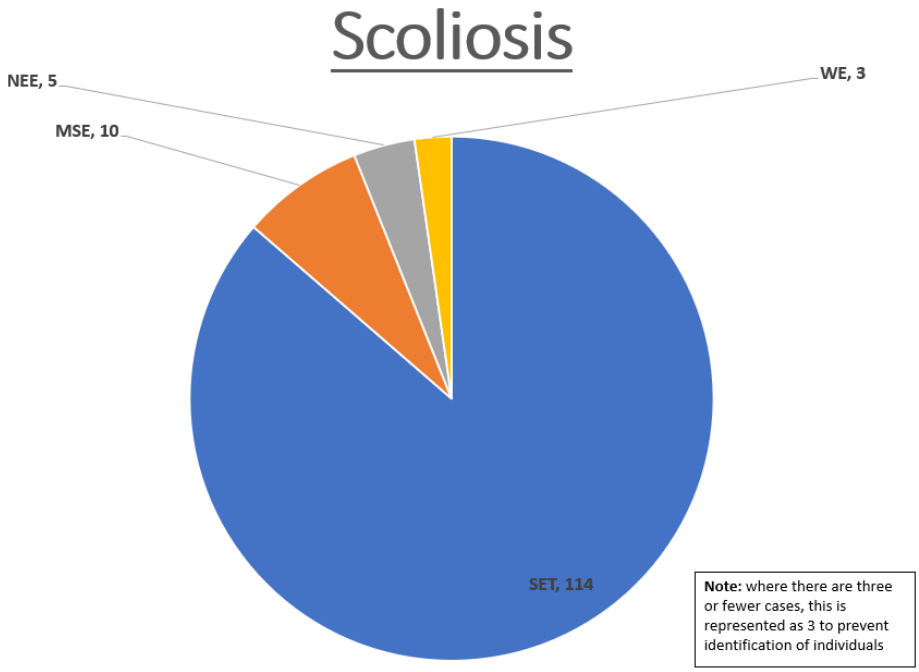
An example of this relates to dementia. Although everyone's health needs are unique, we do know that people with Down's syndrome typically experience symptoms of dementia at a younger age. We need to make sure that care providers are alert to the early symptoms, and that dementia assessment and support services do not exclude people with Down's Syndrome unnecessarily.



At least 31 (27%) of the completed reviews were for people living with Cerebral Palsy. We have noted in reviews that this group are most likely to have different perceptions of the level of their learning disability by professionals, and in particular where a person has communication needs which are not understood.



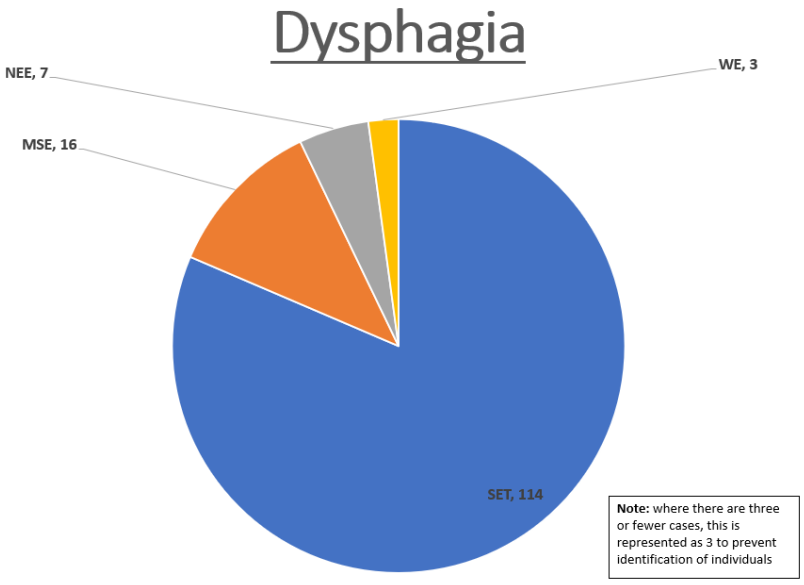
At least 45 (40%) of the completed reviews were for people with epilepsy. Many of those had well-managed epilepsy, managed through medication, with oversight from a Neurologist and or epilepsy nurse. In reviews, we are looking to ensure that care providers are appropriately trained, and that there are emergency plans and risk assessments in place. If someone has a seizure who doesn't have epilepsy, they should be referred to the First Fit clinics and fully assessed.

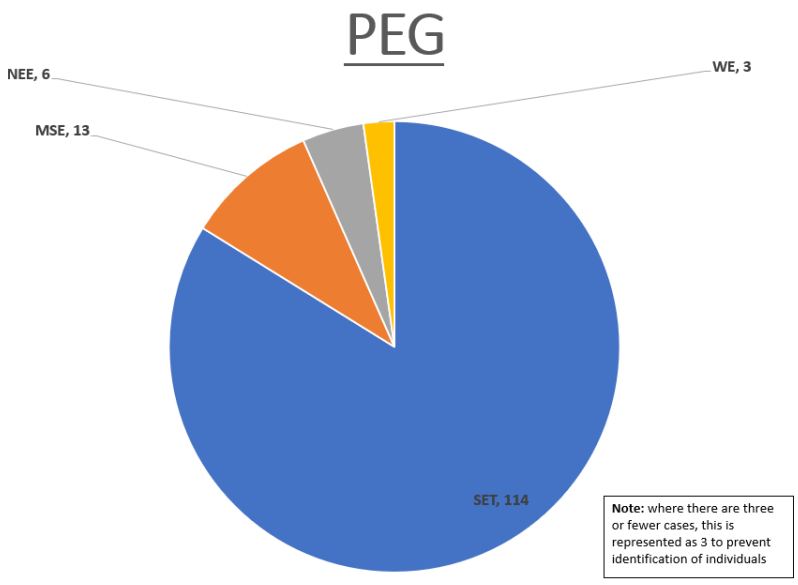


At least 18 (16%) of people had scoliosis, and we think the number could be much higher, as some reviews use different language such as "postural difficulties". Posture is extremely

important to consider when people are eating and drinking, because good posturing can reduce the risk of a person aspirating, and also important to understand how to support people with postural difference to mobilise/keep mobile, as this can also have an impact on their overall health.

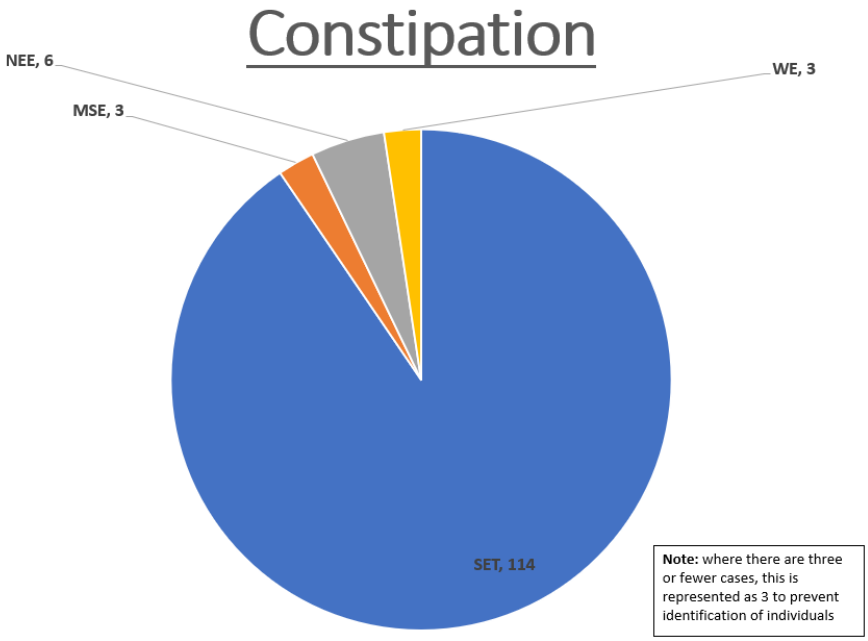
Reviews have shown us the positive influence of Speech and Language Teams (SALT) in training and supporting care providers to encourage good posture for eating and drinking, and there is evidence of good working between SALT, Occupational therapy teams, and equipment services. However, a number of reviews highlight delays in people being able to access equipment which will meet their needs, which creates a risk of health deterioration.





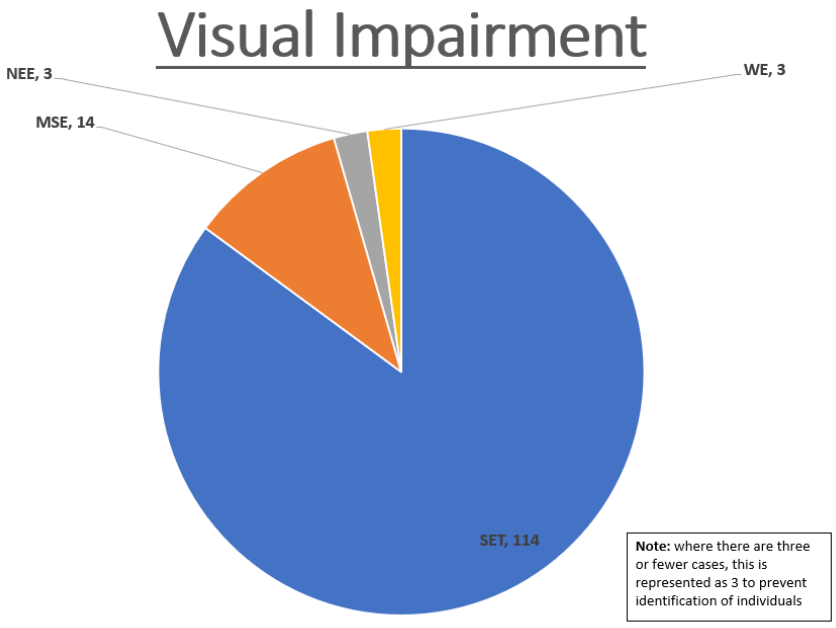
At least 26 (23%) of reviews directly talk about dysphagia, and we think the number of people affected is higher, as some reviews use terms such as swallowing difficulties. 22

reviews were for people who were PEG fed. Dysphagia is a very significant condition given the high numbers of people who die from Aspiration Pneumonia. Again, where SALT teams are involved in a person's care, they are able to support care providers to manage the condition.



12 (10%) of the reviews directly talk about the effects of constipation, and we understand how dangerous this condition can be if unresolved, and how painful. We will ensure all learning from the case of Richard Handley is carried forward into reviews where constipation is a feature.

Richard Handley: 'Gross failures' in constipation death - BBC News (accessed Jun 2023)



20 (17%) of reviews were for people with significant visual impairment. To date, we have not

made many recommendations around improving services for this group of people, and so for 23/24 we will make it a priority to consider how services made reasonable adjustments to accommodate their needs.

DNACPR numbers

Before January 2023, the LeDeR online platform did not routinely capture whether a person had a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation – sometimes called a DNR or DNAR). Again, we have manually counted and captured those reviews where reviewers explicitly state they have seen confirmation that a DNACPR is in place.

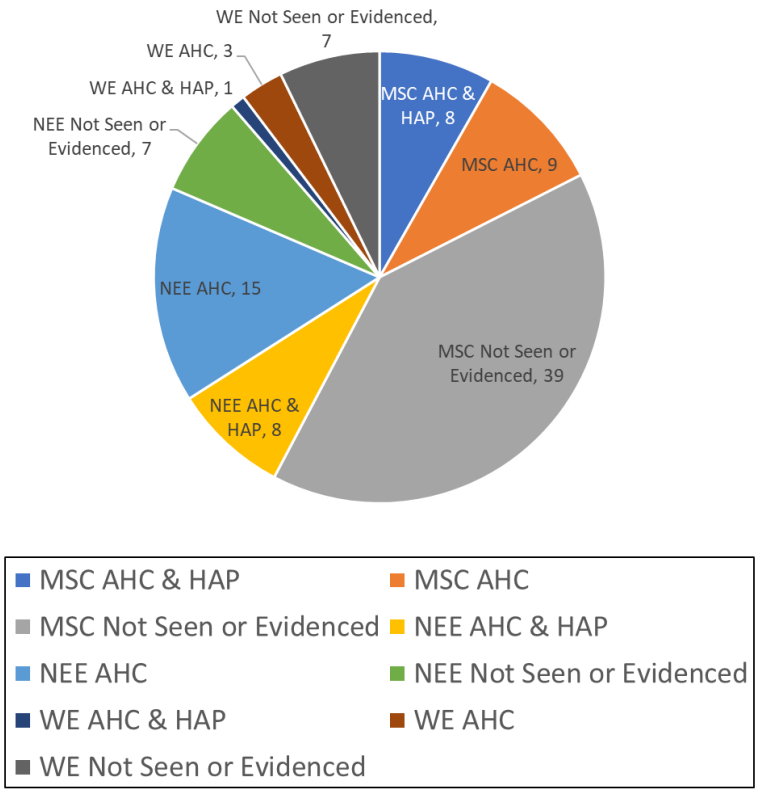
	DNACPR confirmed
MSE	55%
NEE	70%
WE	76%

The majority of reviews did have DNACPRs in place, and as part of the review process we are asked to consider whether they were correctly completed and followed. One area where we have seen improvement is that DNACPR documents sometimes used to cite Learning Disability as a clinical reason not to resuscitate. However, our Learning Disability Liaison Nurses and have been proactive at challenging this, and this is now an infrequent occurrence. We do wish to continue to see improvements in respect of consultation with the person concerned, family, carers, and the involvement of advocates. We want to see better evidence that Capacity Assessments are carried out and clear best interests decisions with rationale where appropriate, and also the involvement of an IMCA (independent Mental Capacity Advocate) especially in hospitals.

Annual Health Checks

For most of 2022/23, the LeDeR system didn't specifically ask for annual health check information to be recorded in initial reviews, although in older reviews, it is often included in the narrative. The Pie-chart below shows only the reviews where the Annual Health Check and/or Health Action Plan has been confirmed by the reviewer – we are confident that in reality a much higher proportion of Annual Health Checks are carried out, and there is targeted work ongoing to improve uptake and quality in this area.

Annual Health Checks & Health Action Plans

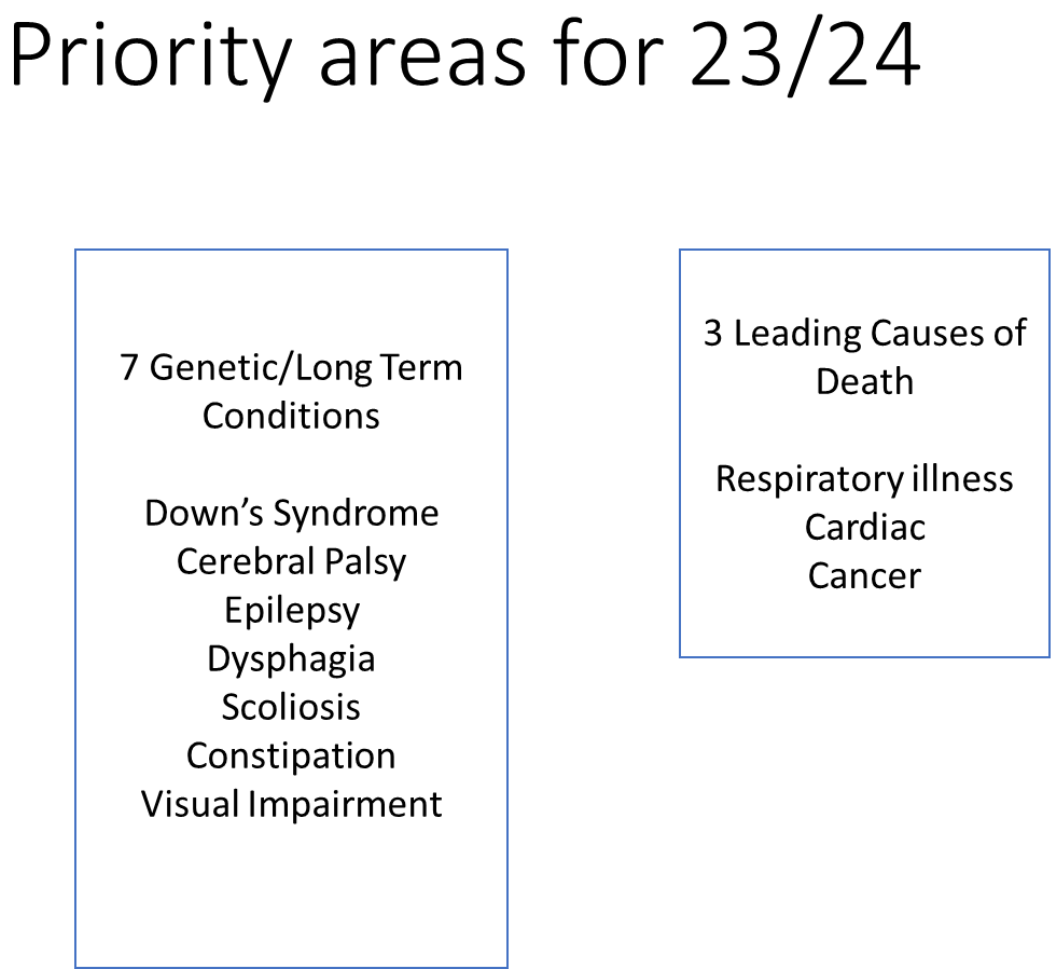


(Note – only those 14+ are eligible to receive an annual health check)

Whilst there is evidence that annual health checks and Health Action Plans are being carried out, there are also concerns raised about the quality of some annual health checks and health action plans, and improving quality is the focus of the Annual Health Check working group. We also secured additional funding from NHSE to support people who had previously missed out on a health check to attend.

Themes and learning from 22-23

Analysis of the leading causes of death and prevalent genetic and long term conditions identifies a “Top Ten” for 2023/34, to better understand the landscape and to identify areas for improvement and reduce the impact of living with these conditions.



There are also a number of consistent themes, and some new emerging themes from 22-23, including the following:

Emerging Themes from 22-23 reviews

- Systemwide need for increased focus on preventative health care
  - Weight management
  - Public health screening uptake
- Lack of advocacy
- Need for transparency around Best Interest Decisions, especially decisions not to treat
- Improved quality of Annual Health Checks, and a clear Health Action Plan
- Missed or late diagnoses
- Oral Health, access to dentistry
- Mental health, access to appropriate services
- Timely and appropriate referrals
- Planning for ageing (people with LD and their carers)
- Lack of clear pathways
- People's histories becoming "lost", family history not considered
- MCAs being carried out appropriately and correctly recorded

Autism Reviews

Although we have been able to carry out a LeDeR Review following the notification of a death of a person with Autism only (no Learning Disability), there have been very few notifications, nationally and locally in SET.

To date we have had three or fewer notifications for an individual with Autism Only. However, we have had a small additional number of notifications where Autism was the primary need, but the person had also been given a diagnosis of a mild Learning Disability. We have also been made aware of an out-of-scope death of an autistic person who did not have a formal diagnosis, which is one of the criteria of eligibility for a LeDeR Review.

In 23/24, we will make sure that every reviewer has access to Autism Training, and work with NHSE to promote LeDeR to Mental health and other professionals and supporters of people with Autism, to encourage in-scope notifications.

Summary Of Recommendations

Our key recommendations based on the themes identified within this report are:

1. **Continue to increase the number of Annual Health Checks that people over 14 with Learning Disabilities receive** to proactively identify any additional support needs they may have.
2. **A Health Action Plan should be created when an Annual Health Check is completed** to improve the health of the individual and prevent / reduce / delay the need for crisis care.
3. **Promote overall awareness of LeDeR** to increase notifications for those who have died who had a Learning Disabilities and / or Autism.
4. **Target awareness of LeDeR to those that work with individuals / communities that are Non-White British** as there is a lack of representation in notifications. Investigate if there is a connection with notifications to access to health care for these groups.
5. **Utilise reasonable adjustments to allow for face to face appointments** for those with a Learning Disability and / or Autism to enable early diagnosis of health issues and cancers.
6. **Continue to support targeted work to address respiratory conditions** that are by far the leading primary cause of death in LeDeR.
7. **Encourage use of Healthcare Passports** to make accessing services as positive as possible and to avoid histories being lost.
8. **There should be increased access to dental services both mainstream and specialist.** To achieve this, we will promote existing oral health training available for provides and unpaid carers. Alongside working with the Meaning Lives Matters Programme and other aligned projects to promote access to dental health across SET.
9. **Plans for ageing should be discussed with individuals and their carers.** To ensure there is a clear plan for a person's future and enhance the opportunity for individuals to die peacefully in their place of choosing. This will be achieved by linking with the Essex County Council Ageing Well Programme and the Southend Ageing Well Strategy. Along with other aligned work across SET.
10. **Support the training of the workforce across SET on Mental Capacity Assessments and promote the use of Mental Capacity Assessments (where appropriate)** along with best practice of how to record them.
11. **Analyse pathways of support for those with Cerebral palsy and /or Down's Syndrome** as a priority these conditions are experienced by a significant number of people whose deaths were notified to us.
12. **Raise awareness of the other most common genetic and long term conditions** that are experienced by those whose deaths were notified to LeDeR as well as how to access appropriate support. This includes Epilepsy, Dysphasia, Scoliosis, Constipation and Visual Impairment.
13. **Promote the importance of advocacy to people with Learning Disabilities and / or Autism across the health and social care system.** Work with commissioners across SET to understand the existing as well as future offer, the eligibility and promote the

use of advocacy. Use of a formal or informal advocate to be flagged in future reviews.

NHS England LeDeR Annual Report

The themes identified in this report mirror a number of the recommendations made in last year's National Report (2021 LeDeR report into the avoidable deaths of people with learning disabilities - King's College London (kcl.ac.uk)). However, this Southend, Essex and Thurrock LeDeR Annual report 22/23 was written and published in advance of the 2022 NHS England LeDeR Annual Report which is due in the Autumn of 2023. Once the national report is published the local themes, trends and findings will be compared against the national context. Any similarities or differences between the national and local report will be reported via governance.

It is also important to note that the period the national report analyses is different to the local report as the national report analyses notifications between 1st January 2022 – 31st December 2022. Whereas the SET LeDeR Annual Report along with the majority other reports within the East of England colleagues has analysed the notifications from April 2022 to March 2023.

Highlights of Progress since Last Annual Report

Aspiration pneumonia conference – having highlighted the prevalence of Aspiration Pneumonia in the Learning Disability Cohort, as a direct result of recommendations from the LeDeR Quality panels, Provider Quality Innovation in partnership with the HE team are presenting an Aspiration Pneumonia conference for learning and sharing good practice – Autumn 2023

Ageing Well Program – is now in its second year which has been driven forward by the Provider Quality Innovation Team in partnership with Essex County Council colleagues.

End Of Life Programme – this is being led by the Provider Quality Innovation and delivered in partnership with Essex Hospices.

Health Equalities team representation on working groups for : Aspiration Pneumonia, Pneumonia, Dementia, Frailty, STOMP oversight group, AHCs

AHCs – having secured funding for additional support for people who had "missed" an annual health check, this project has delivered additional health-checks, and in particular this is shown in the AHC data collected for NEE

Digital Hospital Passports – following recommendations from the LeDeR Quality Panels, MSE Hospitals are working on a digital hospital passport which can be easily updated

Gold Standard review for Autism /Suicide – The Health Equalities team supported the development of a "Gold Standard" approach to this specialist area of reviews, and this has already been shared with SNEE ICB and is available to all reviewers

Care co-ordination and Dynamic Support register and shaping of new ELDP contract – as a result of LeDeR Recommendations, the Essex Learning Disability Partnership (Specialist health) has adapted the provision to include a care-co-ordination role, and in addition the dynamic support register is in place, and key personnel actively involved in LeDeR will be involved in shaping the next contract

ReSPECT is currently being rolled out**.** ReSPECT is a process that supports meaningful conversations between one or more healthcare professionals and people, their carers/family on how they want their future care to be given. The ReSPECT form is a summary of personalised choices for a person's clinical care in the event of an emergency when that person may not have the capacity to express those choices themselves.

The process reflects both patient preferences and clinical judgement, including a recommendation on whether CPR should be attempted if a person's heart and breathing stops. This Supports the DNACPR process and is an excellent opportunity to ensure the wishes and feelings of people with a learning disability and autistic people are captured.

Oliver McGowan Mandatory Training has commenced roll out across the three ICBs. All the LeDeR Team will eventually have received all tiers of the training

Access to sytsm1 – Laptops have been procured to allow the review team access to released flagged GP records, which should assist in the quality and timeliness of reviews being completed.

Report Origin & Endorsements

This Southend, Essex and Thurrock LeDeR Annual report 22/23 was written in accordance with the requirement from the NHS. The report is commissioned by the Learning Disability Health Equality Board and formally signed off by the SET LeDeR Steering Group.

This report is endorsed by the Learning Disability / Autism Health Equality Board which is led by:

Nick Presmeg	(LD HE Board SRO)
Jeff Banks	(LD HE Board Vice SRO)

The report is formally signed off by SET LeDeR Steering Group which is led by:

Krishna Ramkhelawon	(SET LeDeR Steering Group Chair)

This year's report was produced by the SET LeDeR Team, the lead author was:

Suzanna Edey	(SET Senior Reviewer)

Local LeDeR contacts

If you would like any further information on the work that is happening in SET please contact:

Andrew Graham
LeDeR Programme Local Area Contact (LAC)
Email: Andrew.Graham@essex.gov.uk

Suzanna Edey
Senior Reviewer
Email: Suzanna.edey@essex.gov.uk

Appendix 1 case study – Adam

Adam's health started to deteriorate in September 2021 when his mum took him to hospital with pain in his back. She explained to the hospital staff that Adam had a very high pain threshold and that he was in a lot of pain.

They were kept waiting from 10.00pm in the evening, they were told he needed a scan as there was inflammation in his body; they were moved to another area at 4.00 and at 4.45am were told that "they didn't do scans at night" and to go home and see their GP.

Whilst in hospital Adam had been given two doses of Morphine for the pain, but was discharged with no pain relief. Adam's mum felt he had been discriminated against she said that they saw a person with a learning disability, who was overweight and who was difficult to deal with.

No information about Adam's visit to the hospital was received by his GP. Adam's mum said that Adam was angry, that they didn't help him.

Adam would find hospital's stressful due to his autism, he found being kept waiting caused him frustration and anger and this could lead to behaviours which could be seen as challenging.

Mum wrote a letter of complaint as she felt Adam had been discriminated against. She received a reply that said the doctor didn't feel he had discriminated against Adam, but he agreed a letter was not sent to inform doctor of hospital admission to A&E.

Mum took Adam to GP as she felt there was something seriously wrong. At that time, she was supporting her husband who had terminal bowel cancer. The Doctor listened to her and Adam's concerns and arranged an ultrasound. The GP referred him to liver specialist after the ultrasound for a colonoscopy

Staff at (different) hospital were brilliant, they talked to Adam and made him comfortable. They made reasonable adjustments and allowed Adam to have his Phone so he could talk to his mum through-out the procedure. After the procedure the Consultant spoke to Adam's mum and told her that it was likely that Adam had bowel cancer.

Adam was referred for a PET scan, mum spoke about how they really helped Adam through the procedure that she was allowed to be present though from a distance due to Adam being radioactive. Adam was diagnosed with terminal cancer, ring tumours, disease in nodes and liver.

She said that the learning disability liaison nurse was with them at as many hospital appointments as possible. However, the staff all took on board that Adam could exhibit behaviours that could be challenging.

Adam's oncologist was very good. She explained that though Adam's cancer was not curable it was treatable, and that immunotherapy would help. Adam also received good support from his Mental health team.

The hospice become involved in Adam's care and support.

Appointments were usually well managed, as Adam needed that the appointments happened on time. Adam would become angry if he was kept waiting.
Whilst undergoing treatment Adam was supported 24-hour care in his own home. He had a good team of support staff who mum said were more like family.

During this time the care provider business was sold, but Adam was able to keep the staff who had good knowledge of his needs.

Adam's health continued to deteriorate and becoming less aware of the people around him, and there were plans to start him on chemotherapy.

Adam and his mum wanted to arrange for Adam to come home to live. It was important that this happened whilst maintaining the same staff team. There were meetings arranged but no one from social services came and the meetings were cancelled.

All staff around Adam worked to secure a meeting with social services and his support package was changed to ensure he was able to move home to mum's house with support in place. His support staff had been helping mum while the transition was being arranged, they would bring Adam home to visit and would be on call if needed.

By the end of August 2022 Adam moves home with support in place. Mum had arranged GP transfer, hospice support transfer.

When Adam is admitted to hospital Mum stayed with him 24 hours a day. His support staff are with him in the hospital. At first, he is placed on a ward but is moved to a side ward. Adam's mum said the staff were wonderful; she was very clear that this was all staff, inclusive of Porters, catering staff, nurses, and doctors. Adam's mum remembered that Adam didn't like the noise that the drinks trolley made. The woman who pushed it would always apologise to Adam and ask if it was ok to give mum a cup of tea.

Adam's medication was explained to him and even at end of life he was given options about when to take certain medication. When Adam died the nursing staff and Adam's mum prepared his body together.

Adam's mum said that at Adam's funeral there were lots of people from the hospital who had cared for Adam and that it was very special to her that they came.

This review was taken to a focussed review, and subsequently Adam's mum has agreed to be videoed to share her experience and Adam's story, and this will be used as training within the ICB

ICS	all notifications from sep 2017 to (31/3/23)	% ics split	no (from total notifications) who are CYP	% of child deaths of ICS total deaths	No. awaiting allocation	in progress	% in progress	No. Complete	% complete	percentage of reviews completed as initial	percentage of reviews completed as focussed target >35%	
North East	209	30%	11	5%	2	27	13%	180	86%	75	25	
West	78	11%	10	13%	2	11	14%	65	83%	64	36	
MSE	403	58%	36	9%	10	45	11%	348	86%	67	33	
Total	690		57		14	83		593	86%			

KPI completion within 6 months	Number of adult deaths notifed this year from April 22	Complete within 6 months	complete outside 6 months	in progress and under 6 months old	in progress and over 6 months old	still to allocate	reviews from before April 22 (on hold or DSCRO)	No of child deaths notified this year from April	complete within 6 months	in progress over 6 months old	still to allocate	child reviews on hold from 21-22
NEE	28	3	4	13	6	2	4	2	0	1	0	0
WEST	15	4	1	7	1	2	1	3	0	1	0	0
MSE	60	14	4	26	6	10	5	7	0	3	0	0
Total	103	21	9	46	13	14	10	12	0	5	0	0