Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Essex County Council

Suffolk & North East Essex Integrated Care System

Southend-on-Sea City Council

Mid and South Essex Integrated Care System

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LeDeR Annual Report 2022/23 Summary Slides

Introduction

The Learning from Lives and Deaths (LeDeR) Programme started in 2017 with the aim to reduce the health inequalities faced by people who have a learning disability (LD).

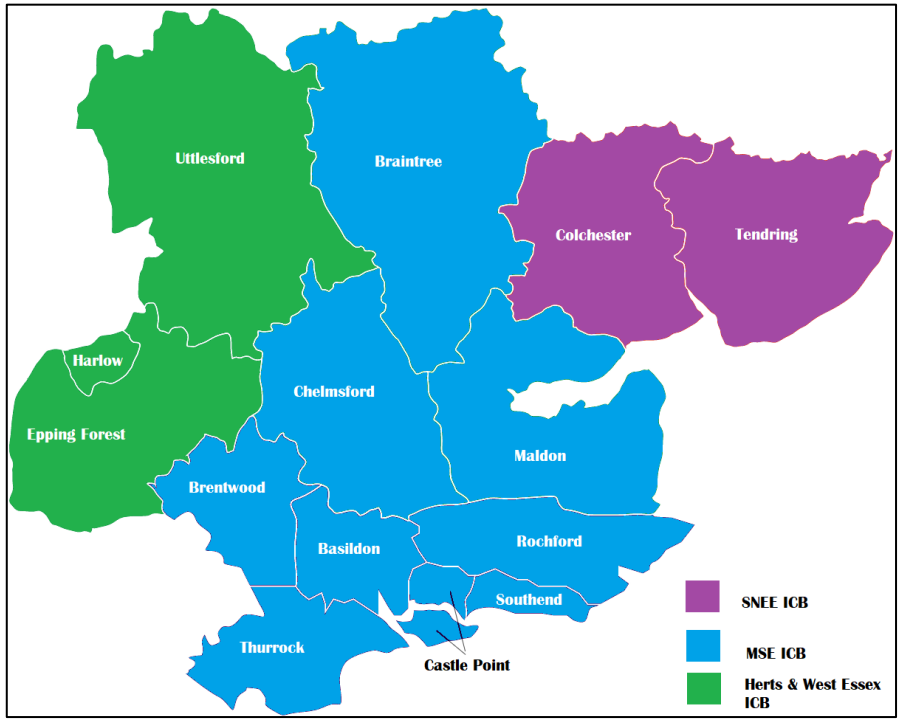
As of July 2023 LeDeR reports on deaths of people with LD and or Autism aged 18 and above. However, before July 2023 LeDeR reported on deaths of children aged 4 and over with LD and or Autism. When somebody with a learning disability or autism dies, their death should be notified to LeDeR.

LeDeR is a review of all aspects of the care and support a person received in their life and death. This is done to improve quality of care and support by learning from what went well, and making recommendations for changes.

The LeDeR programme works alongside other quality improvement measures currently in place to reform services and improve health outcomes. If other reviews and enquiry processes need to take place then the LeDeR review will be put on hold until after these are completed, to ensure we capture the learning from the findings in our reviews.

When the LeDeR programme started there were two things we wanted to achieve across SET:

1. We wanted the number of deaths notified to LeDeR to increase every year.
2. We wanted to see the average age of death of people with a learning disability increase, “to close the gap” as on average people with LD were dying up to 20+ years younger than the general population.



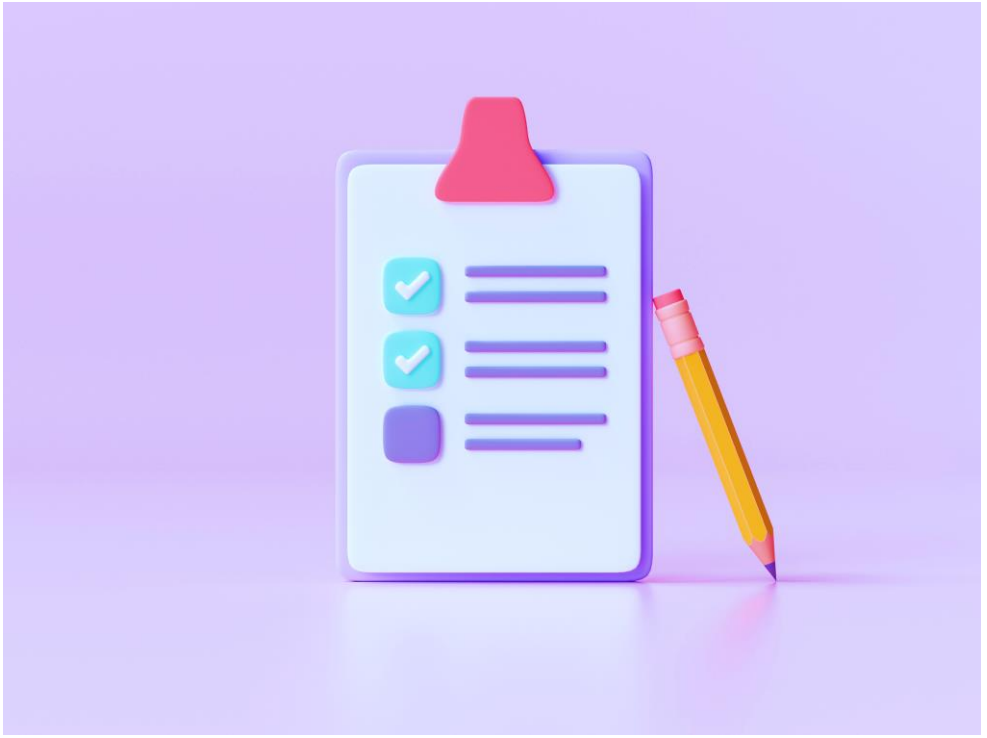
LeDeR Annual Report At A Glance

- Respiratory conditions remain the leading primary cause of death across all ages and all areas.
- Face to face contact matters, especially in respect of early identification of symptoms.
- Cerebral palsy and /or Down's Syndrome are experienced by a significant number of people whose deaths were notified to us, and we would do well to ensure all aspects of provision, specialist and mainstream, consider how their services can be adapted and adjusted to anticipate the needs of people with one or both of these diagnoses.
- Planning and professional curiosity is evidenced by multi-disciplinary working. Especially Quality Panels and also in the care of a person where there is some level of complexity.
- We continue to see a lack of representation of non-white British residents within our notifications, we believe this may be due to under reporting of deaths to LeDeR of our non-white British residents. This must be improved and we need to be open to the possibility there might be a link between notifications and access to services for these groups.

LeDeR Programme

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

This plan 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.

Trends: Notifications

Notifications

The deaths of 113 people with learning disability and/or Autism were notified across SET between April 2022 and March 2023.

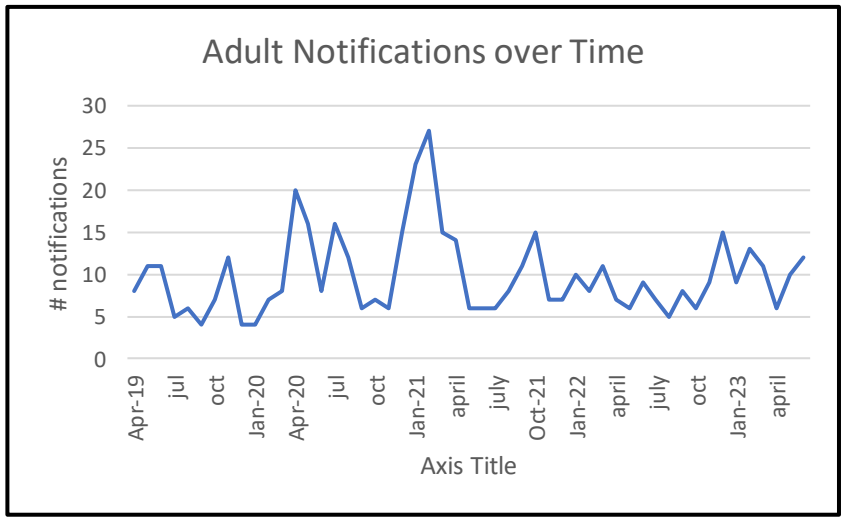
ICB	April	May	June	July	August	September	October	November	December	January	February	March	Total
MSE	4	4	7	5	3	3	3	3	9	5	6	11	63
WE	1	3	0	2	0	1	2	1	1	1	5	3	20
NEE	2	3	2	1	1	3	1	6	4	3	3	2	30
SET Total	7	10	9	8	4	7	6	10	14	8	14	16	113

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.

Notifications Since April 2019

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.

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

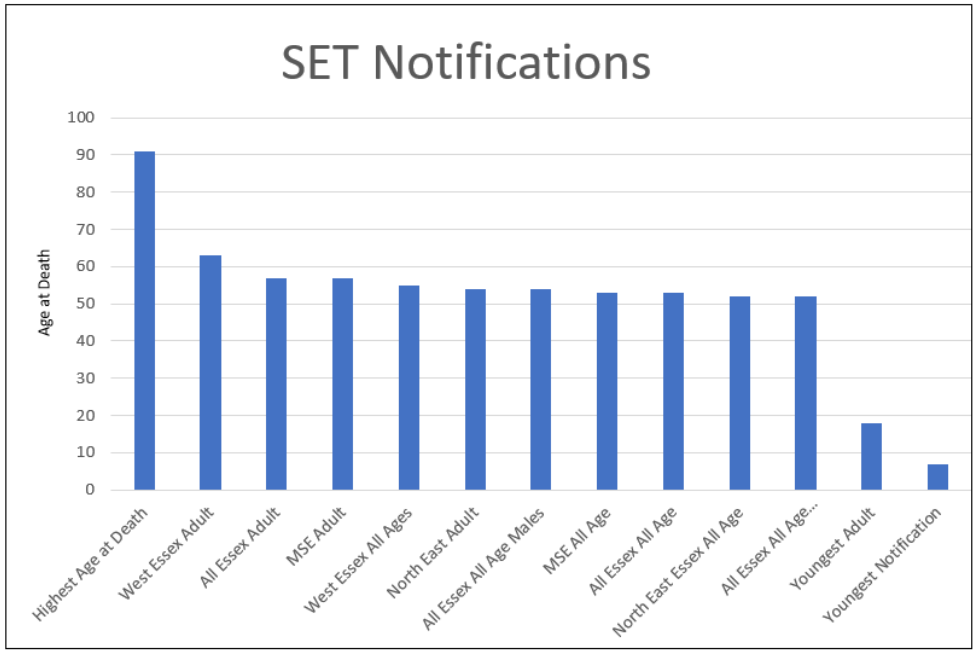


Trends: Age Of Death Of Those Reviewed

Deaths Of Those Reviewed

This has resulted in the average age of death going down slightly 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.

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. This impact continues to be seen across 2022 and 2023.



Average Age Of Death

The median average age at death for adults across SET in 2022/23 was 57. This down from last years median average age of death across SET for 2021/22 which was 65.5 years.

- **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 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.

Trends: Primary Cause Of Death

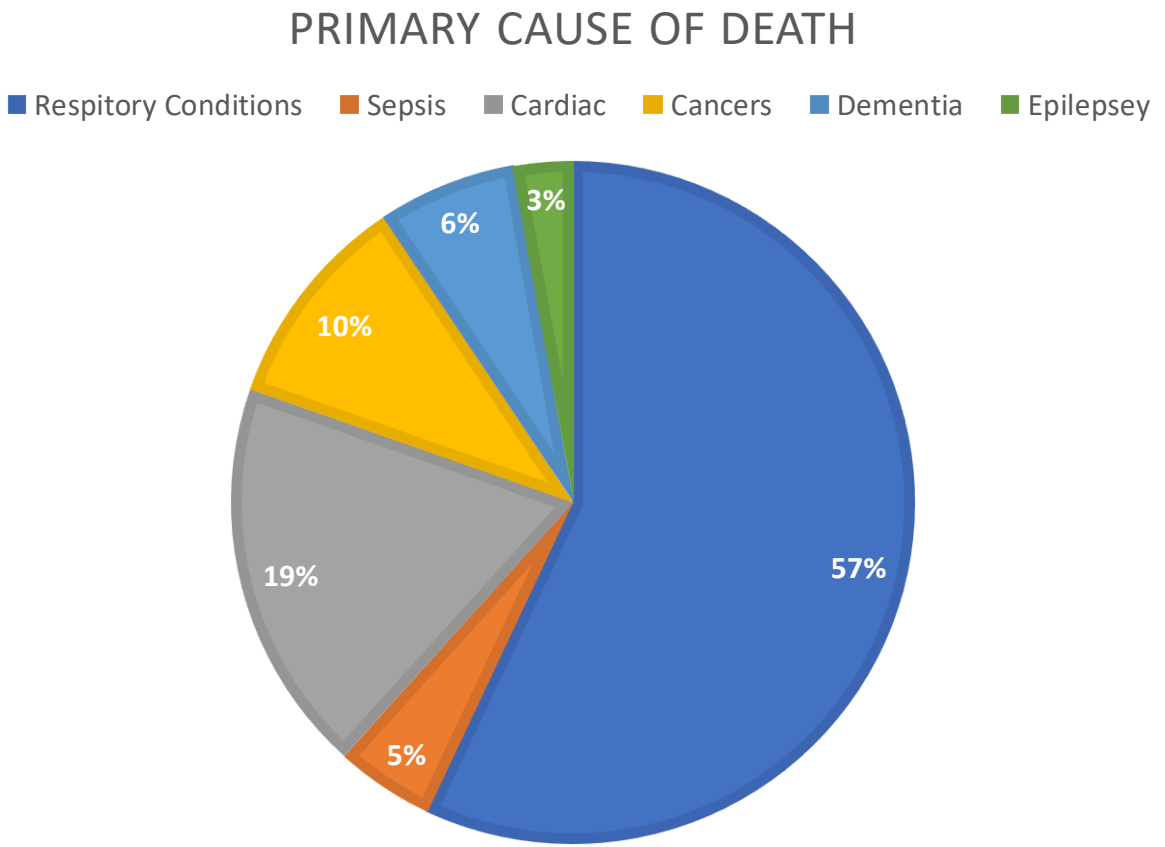
From those reviewed respiratory conditions are by far the leading primary cause of death for people with a Learning Disability totalling (61), followed by Cardiac deaths (20) and Cancers (11).

The pie chart on the right shows the split between the six primary causes of death which impact 107 out of the 113 notified deaths we received.

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 Alzheimer's (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 causes of death for people in the general population and people with a learning disability.

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.



Trends: Annual Health Checks & Health Action Plans

NHSE data for March 2023 shows Annual Health Checks have risen in comparison to March 2022. We know there has been significant work across SET to ensure that more people over 14 years of age are receiving their checks. Unfortunately from the NHSE data we can see that not every annual health check results in an accompanying action plan being drafted.

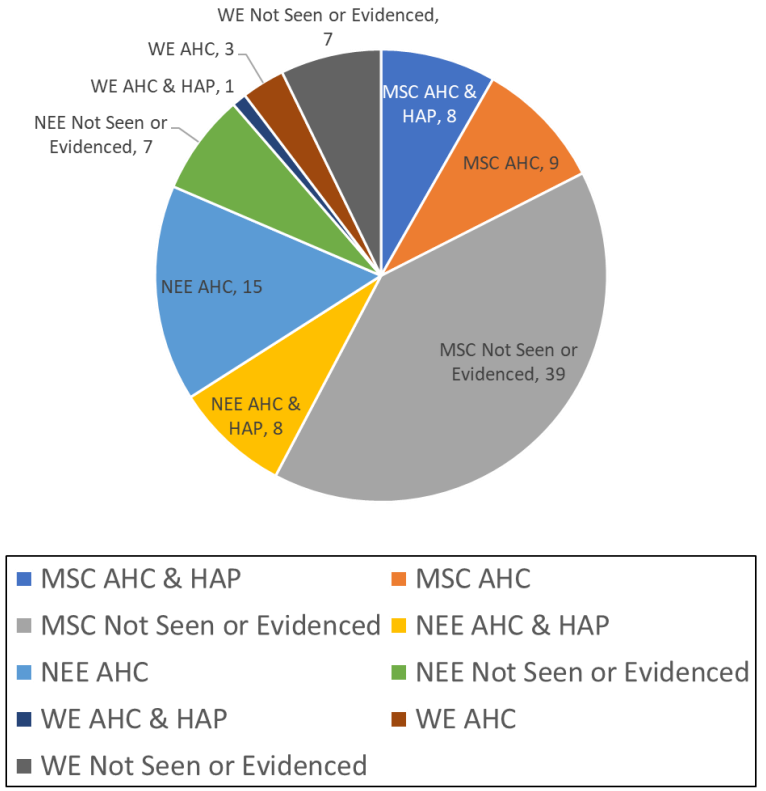
There were 97 reviews that we were able to analyse to determine if an Annual Health Check had been carried out for 22/23.

In 54.6% of the reviews Annual Health Checks had not been seen or evidenced. This shows there is more work to be done in improving access to health checks and action plans for those who could benefit from them most.

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 of the checks and action plans.

Over the next 12 months we would want to see the number of Annual Health Checks and Health Action Plans continue to rise and the quality of these also improve.

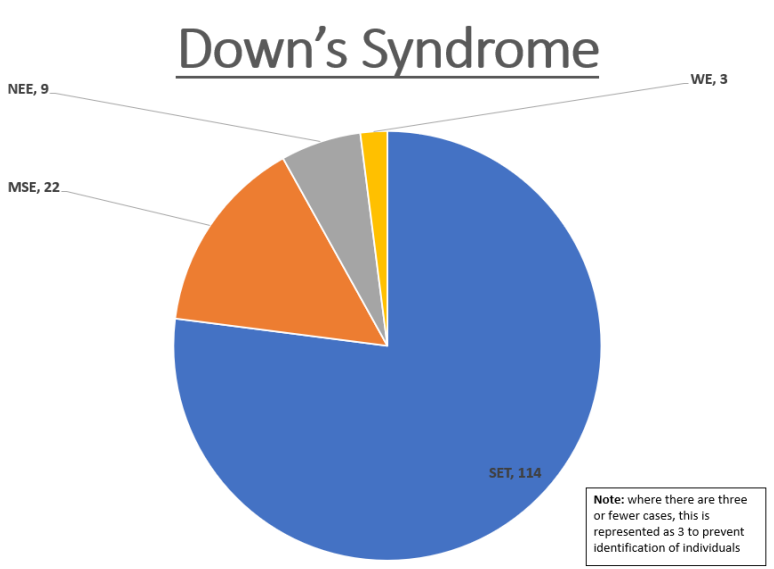
Annual Health Checks & Health Action Plans

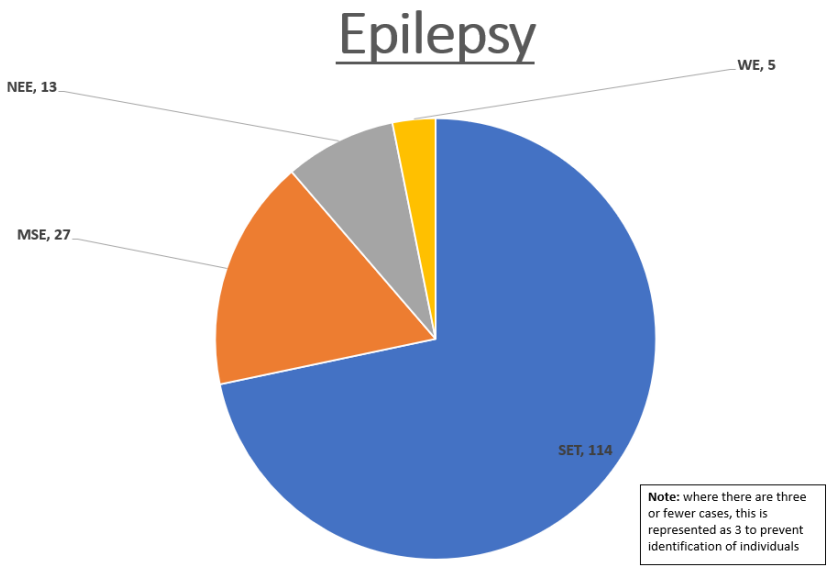


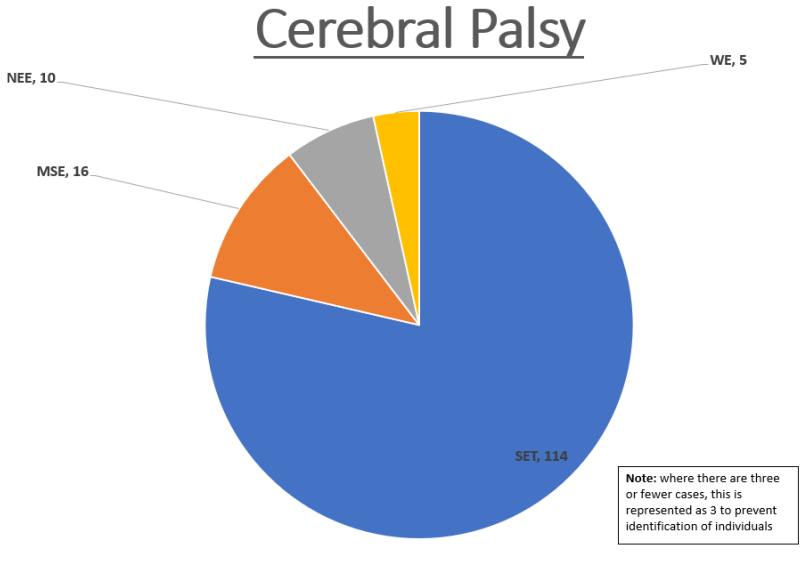
Trends: Genetic & Long Term Conditions

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. Therefore, we must consider the genetic and long term conditions that people with a Learning Disability and or Autism have and how it is manged.

The three most common genetic & long term conditions that people had in the reviews were:







Trends: Genetic & Long Term Conditions

The seven genetic / long term conditions that should be considered a priority based on this years reviews are:

- Down's Syndrome.
- Cerebral Palsy.
- Epilepsy.
- Dysphasia.
- Scoliosis.
- Constipation.
- Visual Impairment.

Themes Identified From The Reviews

- Systemwide Need For Increased Focus On Preventive Health.
- Improved Quality Of Annual Health Checks With A Clear Action Plan.
- Mental Health, Access To Appropriate Services.
- Lack Of Advocacy.
- Missed Or Late Diagnosis.
- Timely and Appropriate Referrals.
- Need For Transparency Around Best Interest Decisions, Especially Decisions Not To Treat.
- Oral Health, Access To Dentistry.
- Planning For Ageing
- Lack Of Clear Pathways.
- People's Histories Becoming "Lost".
- MCA's Being Carried Out Appropriately And Correctly Recorded.

Recommendations

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 Passp**orts to make accessing services as positive as possible and to avoid histories being lost.

Recommendations Continued

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.

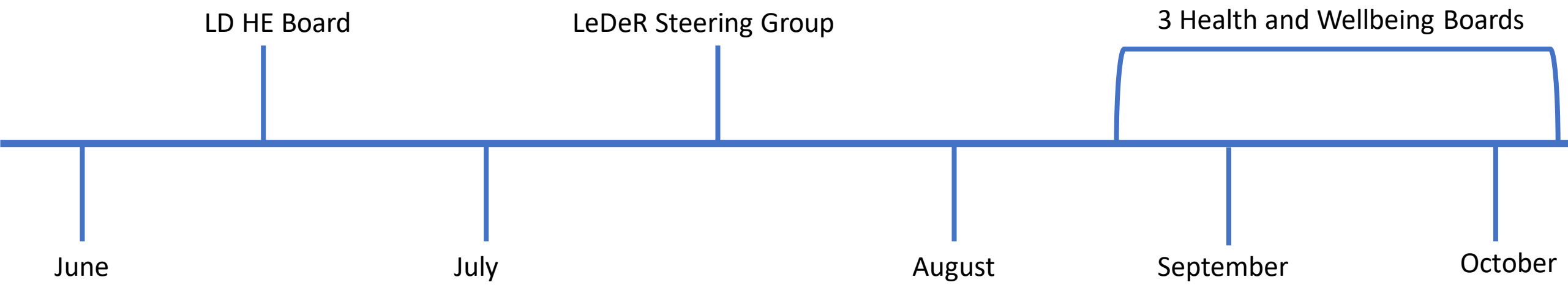
12. **Raise awareness of the other most common genetic and long term conditions** that are experienced by those whose deaths were notified to LeDeR as well as how to access appropriate support. This includes Epilepsy, Dysphasia, Scoliosis, Constipation and Visual Impairment.

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.

Governance Process

- The LeDeR report will be taken to the LeDeR Steering Group for formal sign off.
- Then it will progress to the three Health and Wellbeing Boards across the SET footprint by the end of October and published in September in compliance with NHSE timelines.
- After it has completed this governance journey the report will be published and be available for wider sharing.

Timeline



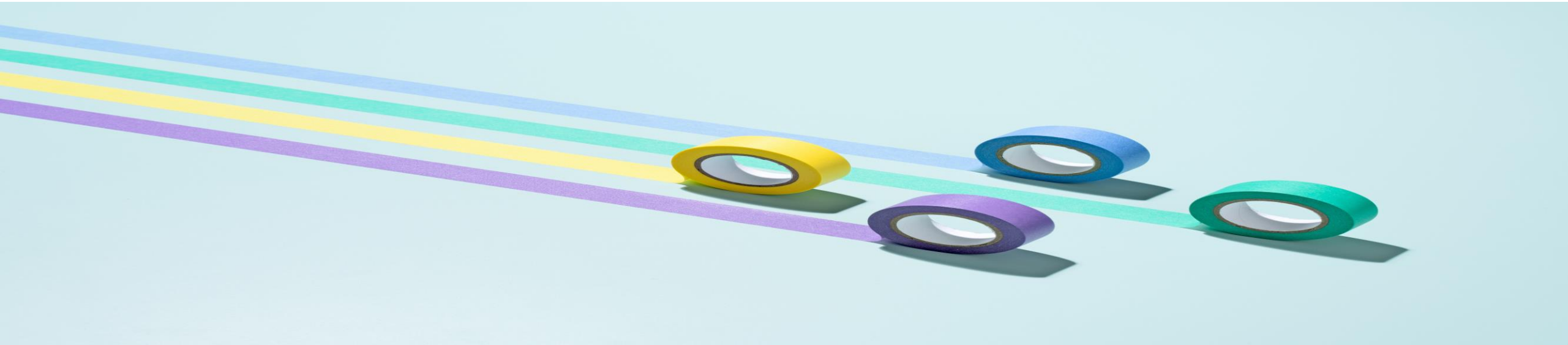
Next Steps

1. Take the LeDeR Annual Report through the governance process.

2. Promote the learning and recommendations from the LeDeR Annual Report to ensure the insight is embedded across SET.

3. Once the report has completed the governance process an ‘easy read’ version of the report will be created and made available later in the year.

4. The SET LeDeR Annual report 22/23 was written before the 2022 NHS England LeDeR Annual Report was published. The national report 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.



Thank you

If you would like any further information on LeDeR in SET please contact:

Andrew Graham

LeDeR Programme Local Area Contact (LAC)

Email: Andrew.Graham@essex.gov.uk