

Southend Essex and Thurrock LeDeR Annual Report 2021-22

Executive summary

The age at death of people with Learning Disability in Southend Essex and Thurrock (SET) is gradually improving, but is still far from the rest of the population.

116 people with learning disability died across SET between April 2021 and March 2022.

The SET LeDeR programme is fully compliant with the new national LeDeR policy and the recommendations from the Oliver McGowan review.

Our performance is good with allocation and completion KPIs met and an expected split between initial and focused reviews.

There is appropriate local representation at Quality Panels for focused reviews with local actions agreed, owned and largely implemented.

We have made excellent progress around aging and physical health and a wide range of local and SET-wide projects are in progress.

We are moving towards better data on the health of people with Learning Disability within Integrated Care Systems (ICSs) and towards sharing data where most needed to improve care.

Pneumonia and aspiration pneumonia remain the top causes of death and require ongoing work.

Much work is needed to prevent health conditions from developing

COVID showed us that infection control and shielding was insufficiently implemented across a range of settings and that we need to have better planning in place for any future pandemic or other crisis.

Recommendations have suggested different ways of tackling known issues (rather than identifying fresh themes) and there is already work in progress to address many of them.

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.

Primary care is the area we need to focus most support to make changes

Introduction

The LeDeR programme across Southend, Essex and Thurrock covers the footprints of 7 CCGs and 3 local authorities. The CCGs are moving into 3 Integrated Care Systems this year, but the LD Health Equalities Team (hosted by ECC) continues to deliver the LeDeR programme on behalf of the whole system, to commission specialist LD health services and to facilitate other national LD programmes (such as Stopping Over Medication of People with LD – STOMP and Transforming Care, which ensures people don't get stuck long term in LD Mental Health Beds) across the same footprint.

Child Death Reviews are carried out by the Child Death Review Team for the whole of SET alongside their usual processes.

The system is now open to reviews of people with diagnosed Autism but no learning disability, all of which will be focused reviews with appropriate Quality Panels. Reviewers are trained. We currently have 1 adult ASD notification

Collaboration through the LeDeR Steering Group, the local LD Forum and the Health Equalities Board has promoted a shared health, social care and third sector approach across the area.

Quarterly performance, reviews of action plans and End of Year Reporting are agreed at LeDeR Steering Group, shared with CCG/ICS Quality and Safeguarding Boards, The Learning Disability Health Equalities Board and Health and Wellbeing Boards. There is an MoU in place with Safeguarding Boards.

The Local Area Coordinator and Senior Reviewer meet regularly with regional NHSE to ensure shared learning and assurance.

Involvement of People with Lived Experience

Essex Carers Network and the Chair of the LD Experts by Experience Forum continue to sit on the LeDeR Steering Group. We now also have a parent carer on each Quality Panel in Essex and plan to expand this for Southend and Thurrock this year. We are also working with autism only forums to identify representatives for autism-only reviews.

Thurrock Lifestyle Solutions led engagement on the Action Plan for 2021-22 and produced the following infographic to summarise their feedback.



Thurrock LeDeR
infographic draft.pc

Summit ran engagement groups on cancer screening, aging well and dying well projects, all of which fed into the deliverables and outcomes of those groups.

ACE Anglia co-developed resources for the heart health project.

ICE produce Easy Read documents such as the summary of planning and end of year documents.

The three year deliverable plan is in the process of discussion and feedback through ECN and self advocacy groups.

Response to the Independent Review into Thomas Oliver McGowan's LeDeR Process

We are in compliance with the recommendations of the Oliver McGowan review. Reviews are independent with supervision, group support and development for reviewers who (either as permanent or consultant reviewers) have paid dedicated time for reviews. A representative of family carer and relevant local organisations are part of each Quality Panel. We comply with KPI of allocation within 3 months and completion within 6 months except where other processes or investigations must be completed first. We have robust governance and processes in place for assuring implementation and escalation.

We are also in compliance with the new LeDeR policy and have a Senior Reviewer in place.

Performance

The hiatus between the closing of the old LeDeR on line platform (31st March) and the new system (19th July) caused a backlog of cases, which have now been completed (unless they are on hold for other processes).

Status of reviews at end March 2022 shows that we have sufficient reviewer capacity to quickly allocate reviews and that we are regularly completing within 6 months of notification unless other processes have to run their course first.

		Adults	Children	Total
Unallocated		2	0	2
In progress	>6mths	5	0	5
	<6mths	30	1	31
On Hold		15	9	24
Completed		112	12	124

Please note the 112 completed includes backlog cases of people who died in the previous year and whose analysis is not included in the data below.

Focused vs initial Reviews

The new system requires reviewers, in discussion with the senior reviewer, to identify reviews which can be completed after the initial stage processes, and reviews which are more suitable to progress to a Focused review, to be reviewed and graded by a Quality Panel before being presented to the Steering group. Whilst there is no performance measure against the number of reviews which are completed at the Initial Stage, and which are taken to the focused review, NHSE expects that 25-33% of reviews will be completed as focused. Although it is not possible to say how many reviews will be focussed until they have all been completed to initial stage:

1 – Of all the reviews completed last year (including reviews of deaths which fall outside this report), 25 % were Focussed; and

2 – Of all the reviews completed so far pertaining to deaths in the year 21/22, 22.2% were Focussed.

This indicates that our decision making is broadly in line with NHSE expectations. In 22/23 we expect to increase the numbers of reviews which are completed at a focussed level based on local priority areas and as more Autism only notifications are received.

Analysis of Data

This analysis is based on 116 deaths between 1st April 2021 and 31st March 2022 of which 106 were adults and 10 were children or young people under 18 years old.

Of these 54 adult reviews and 1 child review were completed in year. This does not relate to performance figures, which include reviews of deaths which occurred in the previous year.

We cannot report from the current LeDeR online system yet, so the following data is based on the LeDeR team spreadsheets. Data sets can be found in the supporting data document below:



SET LeDeR Report
2021-22 Supporting

Demographic Data

❑ Age at death

The Median average age at death of 65.5 for adults with a LD in SET who died in 21/22 compares unfavourably with the picture for the general population, which, prior to Covid-19 stood at 82.3 years for males and 85.8 years for females.¹

However, it compares more favourable with the average national age of death for people with LD which is 61 years.

Nationally, there has been only a slight increase in life expectancy for patients with a learning disability since 2014/15, but locally the average age at death has increased gradually.

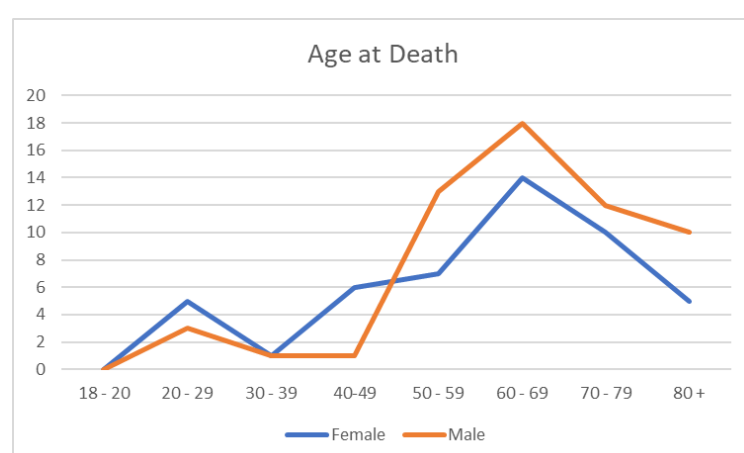
SET Median Age at Death:

2018: adults 61, children 10

2019: adults 61, children 11

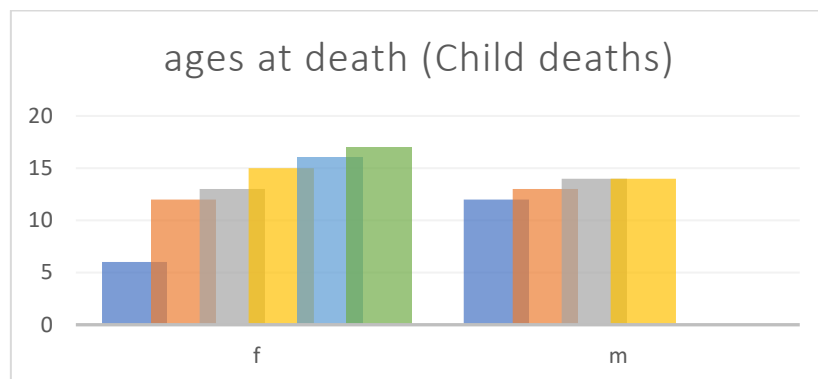
2020 adults 62, children 10.5

2021: adults 65, children 13.5



¹ The data sets are not “like for like”, as the LeDeR data starts from age 18+, and it is reasonable to expect that when ONS publish data for the years impacted by Covid-19 that average age at death will be impacted; nonetheless, a life-expectancy gap of 17 – 20 years for adults with LD represents a significant and ongoing health inequality.

There were 10 child deaths in the year, ranging from 6 to 17 years, with a median average age of 13.5 years. 9 of the 10 ages at death fall within the range 12-17.



Gender

There is no significant difference in gender, given the relatively small data set (48 women and 58 men). This breakdown by gender mirrors the ratio of people on GP registers nationally. 2 more females died in their 20s than males, and 5 more females died in their 40s.

For child deaths, 6 deaths were of female children, and 4 of male children.

So with the child and adult deaths combined: males 53% and females 47%

Ethnicity (number/percentage)

Of the 106 death notified, 4 were identified as being of a person of a minority ethnic background, and 3 were not stated.²

For child deaths, 2 of the 10 were for Black and Minority Ethnic children (as defined by the family or notifier) and 1 was a child of white non-British heritage.

We have a new BAME representative on the Steering Group, who will help us understand and action this further.

² These figures rely on the notifier recognising the ethnicity of the person and/or the reviewer identifying that a person is from a minority ethnic background, and therefore the number of BAME deaths notified could increase as the 52 reviews which have not been completed at time of writing, but which have KPIs which fall in reporting year 22/23, are completed.

☐ Level of learning disability

There is currently no consistent reporting on level of learning disability, but from a sample of 46 reviews where it was clearly recorded, the split was:

23: Mild LD reviews

10: Moderate LD reviews

13: Severe LD reviews

☐ Place of death

Place of Death	No.	
Hospital	63	59%
Usual Home	35	
Other/not known	4	
Temporary placement	3	
hospice	1	
Total	106	

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. In the general population, the proportion of people dying at their usual place of residence has been increasing (from 35% in 2004 to 52% in 2020) with a dip during the COVID pandemic where more people were in hospital.

Of the 106 adult deaths reviewed, only 35 (33%) of people with learning disability were able to die at their usual home, with 63 people (59%) dying in hospital. As a result of this statistic, the LeDeR review team will be bringing cases where there was not clear end of life planning to Focused review and Quality Panel scrutiny.

We do not have information on place of death for the children who died in year.

☐ Causes of death and long-term conditions

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.

COD 1a	No.
Pneumonia	14
Aspiration Pneumonia	14
Other respiratory	4
Sepsis/MOF	4
bowl obstruction/infarction/	3
Cancer	3
Heart Attack	2
Heart Failure	1
COVID	1
Down Syndrome	1
Pulmonary Embolism	1
Dementia	1
Uremia/Kidney	1 ³

In the general population Dementia and Alzheimer's Disease, Ischaemic Heart Diseases and Covid-19 were the most prevalent causes of death certificated in 2021, whereas for people with LD, Pneumonia, Aspiration Pneumonia and other respiratory conditions comprised 56% of direct causes of death in the completed reviews. There is a common pattern of early frailty ending in increased infections and death from pneumonia or sepsis. Aspiration pneumonia sometimes fits into this pattern (for instance where swallow deteriorates toward the final presentation of dementia and is not appropriate for PEG feeding) but is also sometimes a result of textured diet guidance not being adequately followed in the community. Lack of dental treatment also impacts here, and a significant number of reviews record that individuals have few or no teeth.

By contrast, only 7 reviews specified a dementia diagnosis, with a further 7 citing suspected or undiagnosed dementia (25% in total). This rate would be comparable to an older age-group in the general population, consistent with data which shows that people with LD are showing symptoms at a younger age.

Of the completed reviews 25 had cardiac involvement. If we look at the overall causes of death, Heart attack and Heart Failure are the most named condition, with hypertension significantly represented in 1b, and 1c of the death certificates. This was recognised in last year's report as an issue, and throughout 21/22 work has been underway to understand and influence heart health for people with LD. Both the child death reviews which currently have death certificates includes cardiac conditions as a cause of death.

21 reviews indicate an ongoing mental health issue, and 6 of these (29%) include a mental health response to trauma/bereavement. Although the sample size is small, this appears a significant number within the set, and the Steering group and STOMP Oversight Group should consider increasing access to therapeutic treatment, including talking therapies, where patients have a Learning Disability, as notably this was not offered in any of the 6 cases.

13 reviews identify Chronic Kidney disease as an issue, especially in older aged people; 12 reviews identify people experiencing chronic UTIs with potential Kidney disease. One potential outcome would be more training for care-providers in prevention through healthy lifestyles and early recognition of kidney issues, to achieve better outcomes.

Worryingly terms such as "learning Disability", "Cerebral Palsy", "Downs Syndrome" continue to appear throughout all sections of the death certificates, as well as on DNACPR paperwork

³ MOF = Multi Organ Failure, often part of sepsis

and ongoing training is needed in this regard and remains a regular item for updating at the LeDeR Steering Groups.

As outlined above, only two of the child deaths in year have death certificates, but of the 12 reviews completed of deaths in the preceding year the majority had complex or life limiting health conditions

☐ Quality of Care

Unlike the previous platform, the New LeDeR System does not grade the care in all the reviews; instead, grades are given in Focussed reviews for the Quality of Care and availability of services. As a result, analysis of the grades given does not give a picture of the range of provision, as typically the cases reviewed at panel are cases where there have been significant issues.

After discussion with the regional team, there is consensus that we will score and capture the grades of all reviews locally for deaths occurring in 22/23

Child Death reviews are not graded in LeDeR.

☐ DNACPR

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR or DNAR) is a medical decision that resuscitation will not be successful, will only delay death or will deprive someone of dignity at end of life. It does not imply a withdrawal of other treatment. Although the system does not capture data on issues relating to DNACPR decisions across all reviews, this has been a common theme from the recommendations made to the Local LeDeR Steering group. There have been examples of good practice of DNACPRs sensitively and appropriately applied in the acute setting, typically when the Specialist LD nurse is involved. However, poorly completed paperwork, which does not evidence how capacity was considered, lack of family involvement and/or the involvement of an advocate is still too common.

☐ Role of cancer screening

Where cancers have been diagnosed, the primary sites identified are comparable to the general population. The sample size is too small (15 reviews) to draw any strong conclusions from the slight difference, but from these reviews we can see a higher level of oesophageal cancer (captured as “other”) and a lower incidence/diagnosis of prostate cancer.

There is no National Screening programme for Prostate cancer, but PSA tests are available to over 50s, and this should be considered as part of the Annual Health Check for men of that age.

Of the 15 reviews where cancer was diagnosed, in 9 cases the cancer was considered untreatable, which indicates late detection.

It is noted in a number of reviews that individuals had opted out of screening, or would not be able to tolerate the procedure. As we progress to reviewers having access to full Health Records via Systm1, we will expect to see that the capacity of an individual to understand

the implications of “opting out” has been considered, and reasonable adjustments such as acclimatisation and additional time are evidenced to encourage screening.

☐ Annual Health Checks

Completed reviews mirrors the local target of approximately 75% of people having had an Annual Health check. However there is evidence that some reviews were cancelled, delayed or carried out remotely due to Covid. It remains a concern within the programme that not all Health Checks are of equal quality, and not all translate into a robust Health Action Plan.

AHCs are available for children from 14 years upwards, but they are usually primarily under the care of a paediatrician rather than GP. The children who died mostly had complex and multiple health conditions and were known to specialist consultants. We do not have data on their Annual Health Checks.

Children 2020-21

The reviews of 11 deaths of all children with learning disability in 2020-21 were not all available in April 2021, but were completed in this year.

The age ranged from 5 to 16 years with an average of 10.5years.

4 died at home and 7 in hospital

All the children who died had significantly impacted health with multiple conditions. 7 had life limiting conditions, 5 were born very prematurely and had complex health needs from birth.

Of the three whose death was unexpected, one had Duchenne’s Muscular Dystrophy with cardiac issues, one had a neurological disorder plus epilepsy and had removed own tracheostomy and one had cerebral palsy and epilepsy.

The two children who died aged 8 years of COVID 19 also had other significant health conditions and were referred to hospice or palliative care.

Our thoughts are with all their families.

There was only one piece of learning, that the excellent practise and GP, hospice, PCN’s and Evelina Centre all worked together to support family during the pandemic and ensure that the child could die at home with her family as wished.

Please see attached summary



Child Deaths
20-21.xlsx

Summary of Local Learning

The SET Themes document 21-22 outlines the key areas highlighted by recommendations from deaths with completed reviews in 2021-22 and indicates where actions are already in progress.

Broad themes are already well known and are largely covered in the 3-year deliverable plan, which outlines the work already agreed to address this learning across a complex system and a wide range of issues.

Primary care remains the most challenging area to make change because of the high number of surgeries, the pressures on capacity and the turn over of members of staff. However there is an agreement for CCG's Learning Disability lead GPs to run a cross-SET forum and develop a network of LD champions to engage and find solutions.

Below please see the SET LeDeR Themes 2021-22



3. SET LeDeR
Themes 2021-2.docx

Statement of purpose and progress from the last Annual report

Since the last report much progress has been made in a) implementing specific local actions and b) larger integrated workstreams:

1. Aging, frailty and physical health deterioration.

This will be presented to NHSE as part of the deep dive into response to LeDeR.

There is a Dynamic Support Register for risk of physical health deterioration and admission to acute hospital

We now have joint training between ECC and specialist LD Health for social care providers to ensure they identify frailty and health deterioration as part of an early aging process and access the right help at the right time

There is now a specialist frailty assessment tool relevant to people with Learning Disability and a comprehensive Toolkit for Social Workers and Social Care Providers – an accessible version for families and adults with LD is in development.

Training on the presentation of frailty in people with LD is available to GPs, adults with LD, their families and social care providers

2. Health coordination

This need is also identified as part of the DSR and excellent outcomes have been established for those with whom the new coordination approach has been implemented. This approach is now being broadened and shared across mainstream health services

3. Annual Health Checks.

The majority of areas achieved the 75% target in 21-22 with an integrated approach from Local Authorities, ELDP Specialist Health and community organisations becoming business as usual. In the next two years we will increase our focus on quality of the check and well understood and thorough Health Action Plans being produced.

4. Data

We have made progress towards integrated data sets for people with learning disability within the 3 ICSs. We will continue developing this and using it to focus support and intervention. The central LD Health Equalities SystemOne Unit is now in place and we are working with each GP surgery to share cases to provide us with access for LeDeR reviews and for population health overview.

5. Local projects

- There has been a project on Diabetes in Southend with representation adults with LD and independent advocate, which is developing a network of LD Diabetes Champions.
- The NHSE funded heart health project has identified gaps and actions to improve heart health and has produced Easy Read leaflets and Posters to support primary care in working with adults with LD and heart health.
- West Essex cancer screening project has identified people who have not returned bowel screening kits and will target them with specialist support and Easy Read instructions.
- West Essex hospice has run study days on end of life care for people with learning disability and ECC run End of Life training for social care providers in conjunction with local hospices
- ELDP specialist Health service has started offering enhanced physical health checks for people on caseload and at high risk of health deterioration – results are sent to GP and social prescribers with a 6 month follow up of the health action plan.
- Acute LD hospital nurses have raised recommendations within their acute trust governance structures and have workstreams in progress (see Themes document)
- There is a protocol in place to ensure people can have support from a familiar carer in hospital if they need it.
- Specialist LD Health Care Assistants have been funded to add to the LD Hospital Liaison Nurse capacity and work with community services to improve admission and discharge processes

There is still much work to be done, but there is commitment across the health and social care system both to address internal issues and to work together.

The challenge in 22-3 will be to re-establish networks and responsibilities at the ICSs and ICBs form to ensure this good work continues at pace.

COVID 19

In the past year we completed all but one of the reviews relating to Wave 2 of the LD COVID deaths and will have the full analysis and report in June.

A significant proportion (24%) of people who died had Downs Syndrome.

Almost all (96%) had multiple health conditions with a typical presentation of both heart and respiratory issues, epilepsy or mental health conditions for which they were on medication and also often presenting with dementia.

Ward based treatment (oxygen, IV antibiotics and fluids) remained the most common treatment, but with dexamethasone or other steroid treatment not seen in the first wave. A number (5%) of people were discharged with antibiotics and steroids and later died at home.

6 people were put on Intensive Care Unit, which was an increase from 1 in the first wave.

3 people (5%) were treated at home, sometimes for additional/other conditions a further 3 people on palliative care at home and 1 died at home with no request for treatment. 5 people had multiple admissions.

Southend was the most significantly impacted CCG area

Some of the people who died had their first COVID vaccine, but none had more than one.

Since the end of wave 2, the COVID vaccination programme has had a clear effect and we are seeing only very few cases where COVID is thought to be the direct cause of death.

We continue to see a high level of respiratory involvement in deaths (as described above), often after survival of COVID. Identification and support for people with LD and long COVID now needs attention.

Transforming Care

The Integrated LD Health Commissioning Team continues to manage admissions to LD inpatient mental health beds and to facilitate discharges to the community in collaboration with health and local authority colleagues. Numbers of adults in CCG and Specialist Commissioned beds is consistently below the upper limit. Numbers of children significantly and regularly exceed the limit, which reflects the need for community resources to prevent and manage crises. There is significant NHSE funded commissioning in progress to address much of this.

The new Mental Health Act will impact further on the community focus and should further reduce admissions.

STOMP (Stopping the Over Medication of People with LD&A)

There is an ongoing STOMP Oversight group, which has:

- Identified LD data sets for STOMP cohorts and medication reviews by GP surgery/PCN and care home.
- Explored S1 coding, Eclipse Live and PCN pharmacy forums to ensure specialist LD Health STOMP clinics can inform primary care of medication optimisation and share care effectively.
- Shared data with social care records to ensure a joined up approach to behaviour and medication
- Plans to align specialist STOMP clinic approaches across north and south Essex
- The integrated STOMP protocol will be reviewed and updated in late 2022 to reflect progress

Action Plans

The three year deliverable plan was agreed this year with contribution from every organisation across the SET health and social care system. This outlines how we will address all the learning to date from LeDeR reviews.

Please see below the full plan colour coded by organisation plus a summary.



SET 3 Year
Deliverables Plan 1.0



SET LeDeR 3 year
deliverable plan - Su

This plan and its outcomes will be reviewed and reported through LeDeR Steering Group and LD Health Equalities Board, with updates to the three Health and Wellbeing Boards at end of each year.

Rebekah Bailie
LeDeR Local Area Co-ordinator

Suzanna Edey
Senior Reviewer

May 2022

GLOSSARY

LeDeR = Learning Disability Life and Death Review Programme. Everyone with Learning Disability who dies has a review to find where care could have been better or where early death could be stopped.

LD = Learning Disability. This means someone has difficulty learning new information and carrying out daily activities since they were a child.

ASD= Autism Spectrum Disorder/Autism.

SET = Southend Essex and Thurrock

KPI = Key Performance Indicator. This is how we know if we are working efficiently

QP = Quality Panel. This is a group of people who meet and discuss focused LeDeR reviews for their local area and agree what should be done to make improvements.

CCG = Clinical Commissioning Group. This is an organisation which buys healthservices for the local area. There are 7 across Southend Essex and Thurrock

LA = Local Authority. This is the organisation that buys services such as social care

ICs = Integrated Care System. The CCGs are joining together to form bigger organisations. There are three across Southend Essex and Thurrock. (1. Mid and South Essex 2. North East Essex is part of Suffolk and North East Essex. 3. West Essex is part of Herts and West Essex)

ICB = Integrated Care Board. These are boards for each of the ICs.

CRDT= Child Death Review Team. This team reviews the deaths of all children. They write LeDeR reports for children with learning disability and/or autism.

STOMP/STOMP Cohort = Stopping Over Medication of People with Learning Disability/Autism. This makes sure people are not put on medication they don't need to control their behaviour. Someone who is in a "STOMP cohort" means they are a group of people on medicines for psychosis when they are not psychotic or medicines for epilepsy when they do not have epilepsy.

TCP = Transforming Care Partnership. "Transforming Care" makes sure people with Learning Disability and/or Autism do not stay in mental health hospitals for years when they do not need to. It runs across Southend Essex and Thurrock. We now talk about "Health Equalities" when we mean Transforming Care and all the other work going on for people with LD.

SET LD Forum – This group meets to discuss work to make improvements for people with LD

LD HE Board – The Learning Disability Health Equality Board. This meeting has senior representatives from all health and social care organisations. They oversee the work of Transforming Care, LeDeR STOMP and all the NHSE funded work across SET.

HWB – Health and Wellbeing Boards. There are three HWBs across Southend Essex and Thurrock. They are led by elected Councillors and oversee the work of health and social care for their area.

MoU – Memorandum of Understanding. This is a written agreement which explains how two organisations or groups will work together.

LAC – Local Area Coordinator. This person is responsible for the LeDeR Programme across SET and reports to all the Boards and NHSE.

Senior Reviewer – This person works closely with the LeDeR reviewers, coordinators and LAC to make sure LeDeR processes work properly and we meet our KPIs.

ECN – Essex Carers Network. This organisation represents family carers across Essex.

EbyE Forum – The LD HE Team have a group of adults with learning disability and family carers who co-produce the work of the team.

TLS – Thurrock Lifestyle Solutions. This organisation is led by adults with learning disability and advocates on behalf of people with learning disability

ACEAnglia – this is an advocacy group based in Suffolk. They work with us on co-production and Easy Read.

Summit – this is a group based in North Essex who work on behalf of people with learning disability. They partner with Batias who do the same in the south of Essex.

Healthwatch

ICE – Inclusive Communication Essex – this group now work within specialist health services to produce Easy Read materials.

Oliver McGowan Review – this review looked at the death of a young man (not in our area) who was wrongly medicated and how the original LeDeR review was not adequate. It made recommendations for how LeDeR should be delivered. Further information can be found at:

Clive Treacey Review – this review looked at the death of a man (not in our area) with epilepsy and made recommendations for improving approaches to epilepsy in people with LD. More information can be found at

LeDeR Policy – a new LeDeR web-based system and a new policy were put in place on 19th July 2021. More information can be found at:

Governance – this means how people can be sure the system is working effectively and independently.

Median – if the numbers were set out in a list, the median number is the one in the middle

Average – if the numbers are added up and then divided this gives us an average

BAME – Black Asian and Minority Ethnic Groups.

NHSE – National Health England

PEG - percutaneous endoscopic gastrostomy. This is a feeding tube put into the stomach so that a person is not at risk of choking and does not have to swallow food.

Dysphagia – difficulty swallowing food or drink

Aspiration Pneumonia – infection that inflames the lungs when liquid or food has passed into them.

Pneumonia – infection that inflames the lungs

Hypertension – blood is moving under too much pressure around the body. This can lead to heart attack.

Cardiac – this means to do with the heart. Many conditions can involve the heart, so we just say “cardiac” to cover all of them.

Cerebral palsy – there are different types of cerebral palsy, but they all affect a person’s ability to move and balance

PSA – Prostate Specific Antigen. This is a test to see if prostate cancer is present.

SystemOne – a computer system commonly used by GPs to keep records

Muscular Dystrophy – this is a condition which makes muscles get weaker over time. It is inherited.

Epilepsy – a problem with electrical activity in the brain, which can cause people to shake and fall over.

Tracheostomy – an opening at the front of the neck with a tube inserted to help breathing.

GP – your local doctor

Hospice – a place where people can go to be looked after as they are dying

PCN – Primary Care Network. Doctors surgeries join together to form groups so they can work better together.

Evalina Centre – a specialist children’s hospital in London

DSR – Dynamic Support Register. This is a list of people with information about their health risks so we can see who needs the most urgent help.

Diabetes – a condition where sugar in the blood is too high and causes problems in the body. There are two types and can be controlled with insulin and/or diet

Downs Syndrome – a condition which affects how a baby grows and develops. People with Down’s Syndrome have some level of learning disability.

ICU/ITU – Intensive Care Unit or Intensive Treatment Unit – a special ward in hospitals where people often have supported breathing and need a very high level of support and monitoring.