Southend Essex and Thurrock LeDeR Mortality Review End of Year Report 19-20

Executive summary

The LeDeR programme is now well established across Southend Essex and Thurrock (SET) and a local backlog of cases has been completed. The 2018 backlog of 98 cases is being managed by a CSU commissioned by NHSE.

Across SET, people with Learning Disability are still dying 20 years younger than the rest of the population and experience health inequalities because of their learning disability.

Pneumonia and respiratory issues are the leading direct cause of death, often as part of a pattern of frailty and deterioration.

There have been examples of excellent practise which show that it is possible to deliver outstanding care, but also instances where people did not get the care their required. In a few cases the poor care impacted directly on the cause of death of the individuals.

Some progress has been made against the 19-20 action plan including a review of DNACPR policy in acute hospitals, the establishment of Learning Disability Strategic Forums in CCGs, Easy Read resource pack for Annual Health Checks. However, in terms of delivering the whole action plan, complex engagement across a number of different footprints and organisations has been a challenge.

In 20-21 we are in a good position to achieve KPI compliance and will focus on 4 priority areas:

- Annual Health Checks
- Frailty
- Dynamic Support Register
- Case Management

Introduction to the LeDeR programme

The LeDeR programme aims to review all deaths of people with Learning Disability aged 4 years and upwards in order to identify health inequalities and issues which contributed to early or preventable deaths. The learning is to be used to change the system and raise the age at which people with Learning Disability are dying.

The LeDeR programme started in Southend Essex and Thurrock (SET) in September 2017 and since Jan 2019 has been managed through the Learning Disability Health Equalities Team, which works on behalf of the SET Collaborative Forum made up of 7 CCGs and 3 Local Authorities.

SET has almost a third (271/900) of the LD deaths in Eastern Region and LeDeR is therefore a resource intensive programme. SET has a relatively high population of people with LD (7134) because of
a) a history of long stay institutions such as Turner Village and South Ockenden. When these closed, people moved into the local community and supported living/residential provision clustered in those areas.
b) proximity to London and the relative low cost of housing and social care provision has meant that people with Learning Disability have moved into Essex.

More work is needed to fully understand the demographics of our Learning Disability community.

In addition to their funding of the whole LD Health Equalities Team, in the last year the Collaborative Forum funded 2.0 wte permanent reviewers, the Local Area Coordinator function and a Team Coordinator and this has made it possible for reviews to be completed and lessons learned. This made a significant impact on the year's performance and enabled us to achieve our local target. Processes are now embedded for operational running of the programme; quality assurance; governance and reporting; and liaison with other functions such as the Coroner's Office and Essex Safeguarding Board.

NHSE funding to SET for LeDeR 2019-20 was used to employ contractor reviewers to address backlog cases and to employ fixed term administrative support to request notes.

NHSE also commissioned NEC (a Clinical Support Unit in the North East of England) to clear 98 backlog cases from 2018.

Local Purpose
While much focus this year has been on establishing processes and capacity to complete reviews and bring the programme up to date, the learning from reviews has been considerable and gives a picture of both the common themes and the range of issues impacting on people's lives. The drive for the coming year has to be implementation of learning both at an organisational and CCG level and also in a more integrated system-wide approach to broader issues.

Involvement of the Local Learning Disability Community
All reviews are discussed at the Steering Group, which has representation from an Adult with Learning Disability, who is also a Health Access Champion, the Chair of Essex Family Carers Network and the Co-Chair of the HE Experts by Experience Forum.

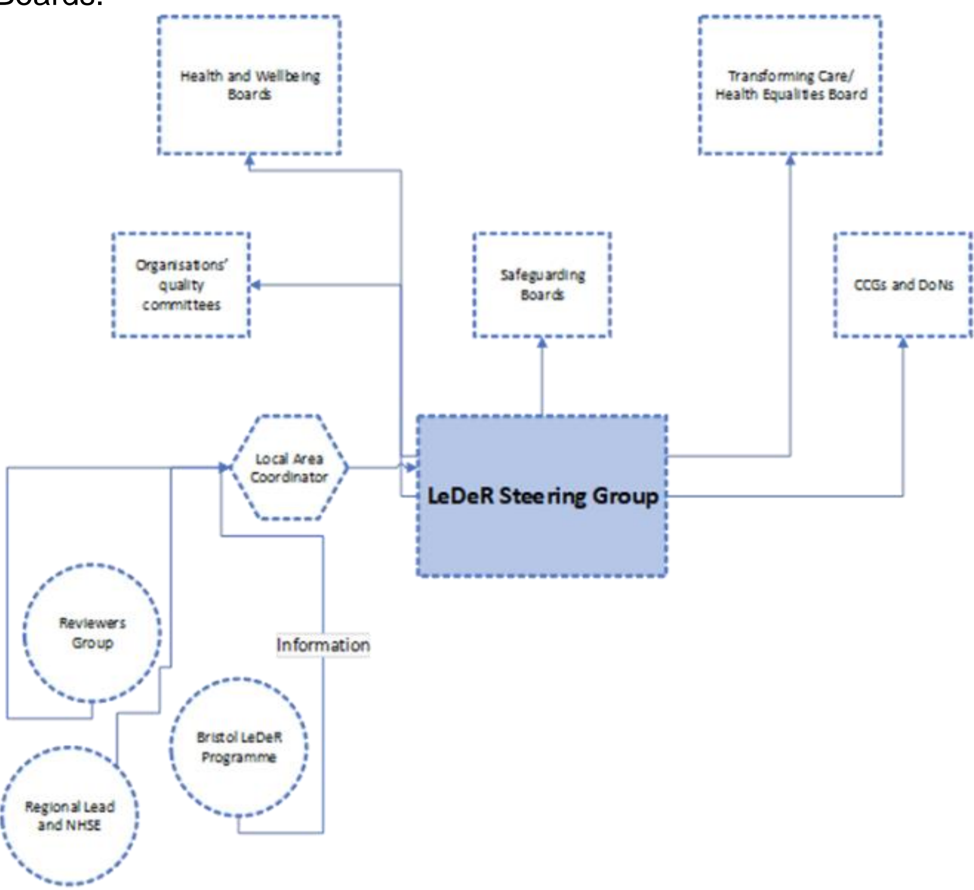
Working groups on AHC and STOMP have had intermittent representation from adults with learning disability, but recognising that this was insufficient, the LD Health Equalities Team had planned a structured approach to co-development, recruitment to a central EbyE group and involvement in key projects flowing from this. Unfortunately Corona virus halted this piece of work, but it will be re-started in 20-21.

A contract for EbyE representation in the coming year will enable representation of adults with Learning Disability and families at the Quality Panels.

Because of COVID and the inability to meet face to face, full engagement on the End of Year Report will not be possible before publication.

Governance arrangements

The LeDeR Steering Group provides oversight of the whole programme and reports to the Learning Disability Health Equalities Board and the Health and Wellbeing Boards.



Deaths in our local area[1]

Between 1st September 2017 and 31st March 2020, 272 people with Learning Disability died in the SET area. There are just under 100 deaths per year with around 10% of those children or young people. A comparison of year on year figures is available in Appendix 1.

[1] Please note local data is based on cumulative figures from September 2017. NHSE data is based on cases notified between Jan and Dec 2019.

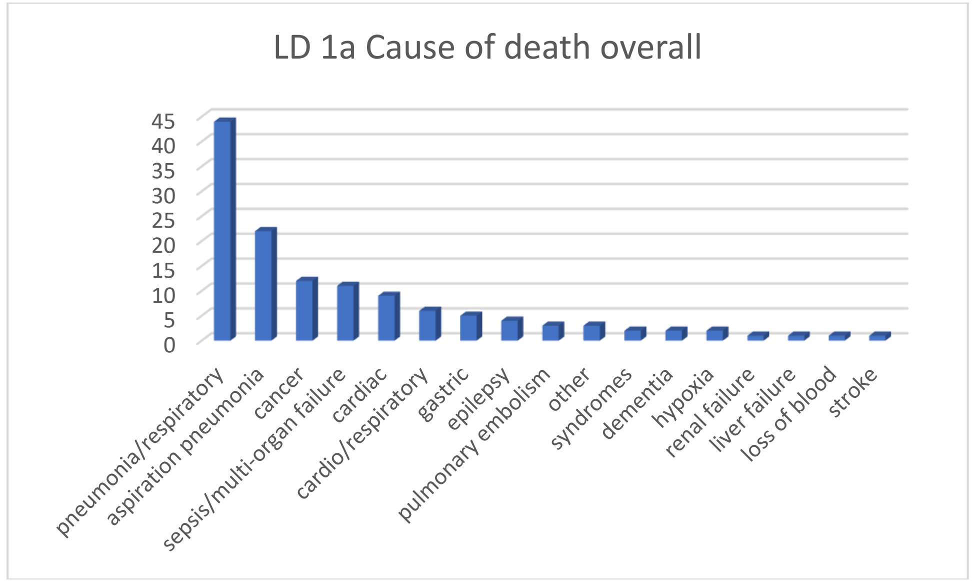
CCG	Total LD Reg	% of SET LD pop	No. deaths	% of deaths
NEE	1920	27%	85	31%
Mid	1374	19%	46	17%
Southend	1057	15%	38	14%
BBW	899	13%	25	9%
West	852	12%	35	13%
Thurrock	527	7%	21	8%
CPR	505	7%	22	8%
	7134		**272**	

North East Essex CCG continues to be the area with the highest population of people with learning disabilities, but an even higher proportion of deaths. A deep dive in mid 2019 showed no direct cause or correlation associated with this. Potentially the long stay institutions in the history of the area and the age of the local population had an impact.

i) Causes of death

With the larger number of completed reviews we can see that pneumonia (34% of all COD 1a)and aspiration pneumonia (17%) are the major clinical cause of death showing on 1a of death certificates and outweigh sepsis (9%), whereas last year, using a smaller data set, sepsis seemed a more significant issue (19%).

We still see a very 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.



Cancer continues to be the third largest cause of death. People with Learning Disability are sometimes dying before they are eligible for screening.

If we look at the secondary causes of death, cardiac issues are the leading underlying cause with chronic heart disease, cardiomegaly or hypertension are represented in 1b, 1c and Part 2 of the death certificates also (see appendix 1 for definitions and detail).

Worryingly terms such as "learning Disability", "Cerebral Palsy", "Downs Syndrome" also appear throughout all sections of the death certificates and training is needed in this regard.

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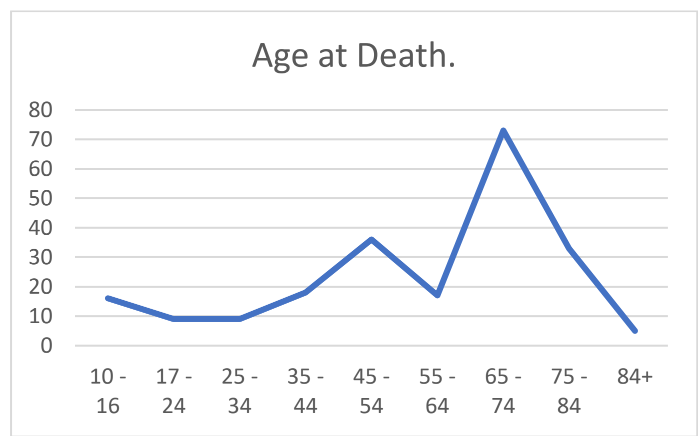
ii) Gender

Men with LD die at a higher rate than can be explained by gender split in the local LD population: 64% of deaths were of males whereas 58% of the LD population are male (as shown by GP Registers) and 58% of the national deaths are of males. Some CCGs show a more significant impact than others (details in Appendix 1). We need to explore further the underlying causes of our local gender difference.

iii) Age

In the UK general population, the average age of death for males is 79.3 years and for females 82.9 years (average 81.1). The average age of death for people with LD in SET is 60.4 years overall with a spike in deaths at 65 – 74 years. This continues to be well under the life expectancy in the general population but in line with the national average for people with LD (60 years). The LeDeR themes document highlights the systemic problems underlying this.



Children's deaths are reviewed by the Child Death Review Team (CDRT) as part of their established process and more detail is available in Appendix 1.

iv) Ethnicity

People with Learning Disability across SET identify predominantly as British (87%) and this is broadly in line with the population of Essex (90% white British). Nationally

90% of people with LD identify as white British. All but one of the people who died and were registered as from a Black or Minority Ethnic background were children.

We do not currently understand the ethnic mix of people registered with LD on GP registers and have much work to do to understand the issues of race and ethnicity, particularly for children. We are seeking BAME representation on our SteeringGroup.

v) Place of Death

More people with Learning Disability in SET died in hospital (55%) than in the general population (46%). The figure is higher at the national average for people with LD (60%). LeDeR themes indicate a need for earlier and better End of Life planning so that people can be supported to die in the place of their choosing.

vi) Grading of Care

Grade of Care	No.
This was good care (it met expected good practice)	69
This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the persons wellbeing)	35
Care fell short of expected good practice but did not constribute to cause of death	17
This was excellent care (it exceeded expected good practice)	8
Care fell short of expected good practice and this significantly impacted on the persons wellbeing and/or had the potential to contribute to the cause of death	6
Care fell far short of expected good practice and this contributed to the cause of death	3
Grand Total	**138**

Care could refer to any organisation or combination of organisations which were involved in the person's life. 75% of cases reviewed showed good or satisfactory care. 6% gave examples of excellent care. 6.5% found care so poor that it either impacted directly on the death or had the potential to do so Cases where care fell short and contributed to the cause of death or had the potential to do so. This level of grading results in a Multi-Agency review and a referral to Essex Safeguarding Board for further scrutiny. We expect to see the full impact of this in the coming year.

Supporting data for i) to vi) can be found in Appendix 1.

Performance against national targets

1. Compliance with Key Performance Indicators

Of the 271 deaths at the end of March 2020 we have reviewed 51% with a further 33% in progress. This splits into two cohorts:

	Total	Unallocated	In progress	Completed
Local	173	18	23	132
NEC	98	2	91	5
	271	20	114	137

Because of the focus on backlog work to the end March 2020, we were not showing compliance with KPIs of

a) Allocation of reviews within 3 months of notification
b) Completion of reviews within 6 months of notification

However, we are now in a good position to achieve regular compliance in 20-21 now that our local backlog is complete.[2] We have more completed reviews than any other area in the Eastern Region and have sufficient capacity to manage our cases.

Allocations are made centrally by date of notification (not based on CCG area) and the availability of records. Access to GP records continues to be the major block to timely completion but as the programme has become familiar to primary care we have been able to build relationships with surgeries and use an agreed escalation route for significant problems.

	DEATHS OF PEOPLE AGED 18 AND OVER - excluding those on hold					DEATHS OF PEOPLE AGED 18 AND OVER: REVIEWS CURRENTLY 'ON HOLD'			CHILD DEATHS			
	Reviews assigned within 3 months of notification (notifications			Reviews completed within 6 months of notification		Waiting for coroner's inquest	Waiting for other investigation	Delays with family involvement	Total notifications to date:	progress	Completed	Completed
Region, steering group & CCG	No.	%	No. notified >6m	No.	%	No.	No.	No.	No.	No.	No.	%
England total	**2449**	**38%**	**5843**	**728**	**12%**	**38**	**69**	**19**	**588**	**274**	**314**	**53%**
EAST OF ENGLAND	**107**	**15%**	**675**	**28**	**4%**	**4**	**22**	**1**	**61**	**26**	**35**	**57%**
NHS BASILDON AND BRENTWOOD	6	30%	15	0	0%	0	0	0	1	1	0	0%
NHS CASTLE POINT AND ROCHFORD	5	25%	17	2	12%	0	0	0	0	0	0	0%
NHS MID ESSEX CCG	9	23%	37	1	3%	0	0	0	6	4	2	33%
NHS NORTH EAST ESSEX CCG	12	18%	67	0	0%	1	3	0	5	0	5	100%
NHS SOUTHEND CCG	9	28%	30	4	13%	0	0	0	3	1	2	67%
NHS THURROCK CCG	4	31%	12	2	17%	0	1	0	5	1	4	80%
NHS WEST ESSEX CCG	5	18%	26	0	0%	0	1	0	4	0	4	100%
	50		**204**	**9**		**1**	**5**	**0**	**24**	**7**	**17**	

A review may be put on hold if a safeguarding, coroner or police investigation is still in progress.

2&3 Representation of CCGs in LeDeR programme

All CCGs have membership of the LeDeR Steering Group and have a lead representative from Southend/CP&R. Thanks goes out all the organisations across Southend Essex and Thurrock who have consistently attended, contributed and engaged strategically to ensure improvements in the lives of people with Learning Disability.

4. Production of Annual Report

[2] After the end of year, the temporary suspension of LeDeR Reviewing during COVID pandemic caused a further local backlog, but a fresh NHSE target of KPI compliance by Dec 31st is achievable and a trajectory is under regular monitoring.

This report will be made public through presentation to Health and Wellbeing Boards in September and subsequent inclusion of minutes and supporting papers on their public facing webpages.

Recommendations made by reviewers for local actions.

The 19-20 Action Plan identified priorities as described below, but it was not possible at the time for Lead CCGs in the plan to take responsibility for wider strategic decisions outside their own areas.

Other items from the wider action plan were implemented locally and at single organisational level for instance, in Mid and South STP the acute hospital trusts reviewed their Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) policy and paperwork to ensure that learning disability or assumptions about the physical health or quality of life of a person with learning disability could not be used to inform DNACPR decisions. A paper on this went to NHSE as an example of good local work.

Where cross-organisational working groups were facilitated this was effective, but capacity for this was limited. For instance two working groups were held with representation across all 10 partners, resulting in:

a) an integrated pathway for STOMP “Stop Over Medication of People with LD/Autism”. The aim of this is to ensure a joined-up approach to removing or optimising medication used to control behaviour.

b) a pack of Easy Read Resources was formed to empower people with Learning Disability and their families to understand what they should expect from Annual Health Checks, get on their local GP register and prepare well for a check. A paper was submitted to NHSE as an example of good local work.

LeDeR Areas of Priority and Action 2019-2020					
Outcome	**Deliverable**	**Actions**	**Who**	**Existing Resources/Good Practise**	**Timescale**
Carers/family understand how to support and maintain the health of someone with LD	Widely available Information on healthy lifestyles, common health issues for people with LD, available services	Identify (develop if necessary) and agree resources - information leaflets, videos,	Thurrock CCG Lead	\\chesfs50\ euchomedirs\ rebekah.baillie\My	End Sept 19
		identify and agree key routes for sharing information (networks, organisations, venues etc)	Thurrock CCG Lead		Oct-19
		ensure families and carers understand and request an annual health check and support adults to be well prepared for it	Mid and West CCG leading AHC oversight group	AHC working group has action plan	Dec-19
		agree as part of comms plan, budget if required	LAC and CP&R Comms Lead		Jan-19
Adults understand their own health and how to maintain it, when to ask for help.	Widely available Easy read information on healthy lifestyles, common health problems for people with LD and how to get help.	Identify (develop if necessary) and agree Easy Read resources - information leaflets, videos, local services etc	B&B CCG lead		End Sept 1
		identify and agree key routes for sharing information (networks, organisations, venues etc)	B&B CCG lead		Oct-19
		develop and pilot adult held record including Health Action Plan	Southend to pilot	\\chesfs50\ euchomedirs\ rebekah.baillie\My	Mar-20
		ensure adults understand and request their annual health check and are well prepared for it.	Mid and West CCG leading AHC oversight group	AHC working group has action plan	Dec-19
		agree as part of comms plan, budget if required	LAC and CP&R Comms Lead		Jan-19
Adults/ arers/family can identify changes in health and know what to do to get the relevant help and prevent	Information on sepsis, pneumonia and their place in frailty/deterioriation.	identify and agree existing resources and develop local information as part of overarching health plan and comms plan using routes as above	NEE CCG lead	\\chesfs50\ euchomedirs\ rebekah.baillie\My	Sep-19
The health and social care system understands individuals health needs, identifies, intervenes early and manages risks to health collaboratively	Training for Primary Care on Sepsis, Pneumonia and their place in deterioration/frailty, how to support people with LD to access healthcare	Scoping of existing training and resources Identify where adaptations need to be made to make relevant for LD and support implementation Identify gaps and routes to commissioning/delivery of needed training and information Health and Wellbeing Strategy for LD to be established covering social prescribing, care navigation, and accessible information	LD Integrated Health Commissioning with Public Health and CP&R	ELDP offer training to GPs and capacity is detailed in LD Place Plans for each CCG Some Primary Care Engagement leads in CCGs are rolling out training on sepsis to Primary Care (West)	Oct-19
	Training on Sepsis, Pneumonia and their place in deterioration/frailty, how to keep healthy and get the right help - for social care providers	training on LD awareness to be devised/national resources used	ECC Lead	PROSPER offers training on sepsis to social care providers in ECC footprint	Jan-20
	Early intervention, extended Dynamic Risk Register to include those at risk of escalation to acute admission	ELDP to form cross-organisational working group	Inder Sawnhey Clinical Lead	ELDP contracted to deliver this in 2020.	Jan-20
	Training on LD Awareness	to be rolled out and made mandatory nationally	Integrated Commissioning	in development nationally	as advised

Local priorities and the evidence base that supports them

At the end of March 2020 we had 318 recommendations from completed reviews. These were grouped into themes and identified as:

a) Relevant to specific organisation
b) Cross-system issues

Organisations will report back to the Steering Group the progress towards their specific recommendations.

Of the cross-system issues, the following four priorities will be taken forward through commissioning of the LD specialist healthcare function and engagement with relevant STP or CCG level forums:

1. Delivery of effective Annual Health Checks
2. A clear understanding of early frailty in people with LD and an integrated offer to address it
3. A dynamic health support register to identify and support those at risk of acute admission
4. Case Management

The action plan and a more detailed document outlining themes accompanies this report.

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25/06/20