



LeDeR Southend Essex and Thurrock End of Year Report 18-19

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1. National Context

The LeDeR National Annual Report has been released and action into learning sets have reported. Where we have comparable data, SET compares to national findings as follows:

	SET LeDeR	National LeDeR	Comment
Gender Split	57% male 43% female	58% male 42% female	
Age at death	Median 61 years (55-64 years 23%; 65-74 years 28%)	Median 59 years Males 60 years Females 59 years	National population median 2015-17: Male 83 years Female 86 years
Ethnicity	3% BAME	10% BAME	National population 14% BAME
Cause of death (Pt 1 Certificate)	Chest/Respiratory/pneumonia 37% (aspiration pneumonia a further 7%) Sepsis 19% (multiple organ failure a further 11%) Cancer 15% (note total = 27 redacted reviews – small sample)	Pneumonia 25% Aspiration pneumonia 16% Sepsis 7% Dementia 6% Ischaemic heart disease 6% Epilepsy 5%	
% falling short of best practice with potential or actual adverse impact	7%	8%	
Place of death	Hospital 53% Usual residence 38% Other 9%	Hospital 62% Usual residence 30% Other 8%	National population Hospital 46%

The national findings indicate that people from Black and Minority Ethnic (BAME) groups (particularly children) and those with profound and multiple learning disability are more at risk of dying younger than other people with LD. As the percentages of SET notifications are small for both these groups (BAME 3% and Children 8%), not enough relevant reviews have been completed to make any statements or comparisons at this point.

The general information for SET does not highlight any specific area which stands out as more problematic than the national picture, but neither are we providing any better outcomes. For discussion of local learning and actions compared to national themes, see sections below.

NHSE have requested an audit, which has been carried out for SET by the LAC in order to clearly establish the baseline of outstanding reviews and this will enable NHS England to allocate £5million national funding to address the backlog up to December 2018. This

could be resourced through CSUs or through local management (dependent on submission of a successful trajectory and bid).

2. Performance/KPIs

1. Each CCG must be a member of a learning disabilities mortality review (LeDeR) steering group, and have a named person with lead responsibility.

Each CCG has a named person who is invited to each Steering Group meeting and receives all information, minutes and resources relevant to the group. Patricia D’Orsi is the Director of Nursing with lead responsibility.

2. There must be a robust CCG plan in place to ensure that a LeDeR review is undertaken within six months of the notification of a death in its area.

SET does not currently have reviewer capacity to comply with this KPI, but has a robust plan to achieve this (see “Trajectory” below). There are currently 98 incomplete reviews which were notified more than 6 months ago (63% of all incomplete reviews) There are 7 reviews with a reviewer for more than 12 months, which require support from Senior Managers to free up time to conclude these.

NHS ENGLAND LONDON REGION	All Notifications (in scope)	% unassigned	% complete	% in progress	With LAC for allocation	With reviewer for completion	With LAC for approval	Completed	Incomplete reviews:		Those with a reviewer	
									> 6 months since notification	% active reviews >6m.	> 6 weeks since allocation	% allocated > 6 wks ago
Steering Group & CCG												
Essex steering group	188	61%	18%	22%	114	34	7	33	98	63%	30	88%
NHS BASILDON AND BRENTWOOD CCG	12	42%	8%	50%	5	5	1	1	8	73%	5	100%
NHS CASTLE POINT AND ROCHFORD CCG	15	73%	13%	13%	11	1	1	2	9	69%	1	100%
NHS MID ESSEX CCG	38	68%	13%	18%	26	3	4	5	23	70%	2	67%
NHS NORTH EAST ESSEX CCG	58	64%	17%	19%	37	10	1	10	28	58%	10	100%
NHS SOUTHEND CCG	25	48%	28%	24%	12	6	0	7	10	56%	4	67%
NHS THURROCK CCG	16	56%	25%	19%	9	3	0	4	8	67%	3	100%
NHS WEST ESSEX CCG	24	58%	17%	25%	14	6	0	4	12	60%	5	83%

Progress towards an improved position has been broadly as predicted

	Notifications				Status			
	No.	% unassigned	% complete	% in progress	With LAC for allocation	With Reviewer for Completion	With LAC for Approval	Completed
Sep 2018	137	61%	11%	28%	84	34	4	15
Dec 2018	152	57%	13%	30%	86	45	1	20
Mar 2019	188	61%	18%	22%	114	34	7	33

Predicted Position	Actual
<ul style="list-style-type: none"> 187 Notifications 	188 Notifications
<ul style="list-style-type: none"> 35 Reviews completed 	33 Reviews completed

<ul style="list-style-type: none"> 114 outstanding of which 85 will be outstanding for over 6 months 	114 outstanding of which 98 are for over 6 months.

The main cause of discrepancy has been reviewers leaving their posts without completing expected reviews or not completing long outstanding reviews within expected timescales. The actions identified to address these are as follows:

- a) Additional funding committed to provider additional fixed term reviewer capacity
- b) Request through TCPB to prioritise long outstanding reviews in reviewer roles.

Trajectory

The trajectory has been updated to show how additional resource (on top of two full time permanent reviewer posts) will be used to address the backlog and enable two permanent reviewers to sustain the system within KPI targets. Additional funding has been agreed through the Collaborative Agreement across SET and will be used to recruit

- a) Part time consultant reviewers starting in June 2019 until end March 2020 or when interim posts offer sufficient capacity at a lower cost
- b) Interim reviewer posts up to 2 x full time

Additional funding from NHSE has not yet been confirmed and so has not been applied to this trajectory, but would further shorten the timescale to remove the backlog.

	April	May	June	July	August	September	October	November	December	January	February	March
Outstanding Reviews	135	143	151	153	147	141	123	105	87	65	43	21
Reviews over 6 months	106	114	122	124	118	112	94	76	58	36	14	-8
Notifications	10	10	10	10	10	10	10	10	10	10	10	10
Reviews (LeDer Reviewers)	0	0	0	6	14	14	26	26	26	30	30	30
Reviews (Pool)	2	2	2	2	2	2	2	2	2	2	2	2
Total Reviews Complete	2	2	2	8	16	16	28	28	28	32	32	32
LeDeR Reviews Completed	39	41	43	51	67	84	112	140	168	200	232	264

3. CCGs must have systems in place to analyse and address the issues and recommendations arising from completed LeDeR reviews.

The Local Area Coordinator analyses the learning from reviews on behalf of the CCGs and presents this to the Steering Group, who collectively form the action plan to address the issues. These themes and actions are reported to:

Health and Wellbeing Boards, Safeguarding Boards, Transforming Care Partnership Board, Quality Committees within all organisations represented on the Steering Group, Expert by Experience Forum.

4. An annual report, detailing the findings of local LeDeR reviews and the actions taken, must be submitted to the appropriate board/committee for all statutory

partners, and shared amongst other local health and social care boards as appropriate.

This report forms the annual summary and will be updated quarterly to the relevant boards and partners.

3. Themes and Learning

The proportion of notification by CCG broadly reflects the proportion of social care provision across the County, but there is a need for thorough analysis of population, mortality and notification against a number of factors. Clarification of GP LD registers and comparison of notifications with ONS data are two pieces of work being carried out by LD Integrated Health Commissioners, but resource is required to carry out a more detailed project.

CCG	No. deaths	%
NHS NORTH EAST ESSEX CCG	58	31%
NHS MID ESSEX CCG	38	20%
NHS SOUTHEND CCG	25	13%
NHS WEST ESSEX CCG	24	13%
NHS THURROCK CCG	16	9%
NHS CASTLE POINT AND ROCHFORD CCG	15	8%
NHS BASILDON AND BRENTWOOD CCG	12	6%
SET steering group total	188	

Local Learning from Completed Reviews

This is an abbreviated form of a more detailed paper with redacted examples from 27 completed and redacted reviews (21 adult, 6 children), which have been presented to the Steering Group and form the basis of the action plan.

1. Early frailty and deterioration

Sepsis and pneumonia are commonly identified as the clinical causes of death (both nationally and locally), but they are often the end in a period of deterioration following common features of frailty. This pattern typically occurs earlier the life of a person with Learning Disability i.e. in their 50's for a number of reasons:

- a) Falls and mobility
- b) Long term conditions
- c) Deterioration

2. Dysphagia

Pneumonia, respiratory failure or chest infection was shown as a cause or contributory factor in 12 cases but only 2 of these were identified as aspiration pneumonia. It is not clear whether swallowing issues were involved as an underlying cause in the others.

3. DNACPR/Decision not to treat

Do not Attempt Cardio-Pulmonary Resuscitation (DNACPRs) are almost always in place at the time of death and are marked as correctly completed. However the reasoning behind the decision is rarely clear from the review. Quality of life is referenced but available information on the person's quality of life before they became ill is not robust.

4. Mental Capacity Act/Health Insight

Assessments may be lacking or queried by later assessments. It is not clear what work has been done to support an adult understand the implications of health conditions or the consequences of choices (health insight).

5. End of Life

A number of recommendations referenced the need to plan early to support people with LD to identify where they would like to die and how they would like to be supported

6. Not known to services

Sometimes adults are not known to specialist health or social care services and only occasionally attend GP. They then are known only in crisis and shortly before death. At other times people were known to one service, but not referred to others which could have usefully intervened.

Cancer is a significant cause of death (relative to the small sample size of redacted reviews) and while no formal recommendations were yet made by reviewers, the members of the Steering group identified local issues which will be held on the action plan.

Actions

The LeDeR National Annual Report has been released and action into learning sets have reported. There are 12 national recommendations and 5 key areas for national action, which will be implemented across SET:

- Pneumonia – efforts will focus on increasing the uptake of the flu vaccine among people with a learning disability alongside other at risk groups through a targeted awareness campaign.
- Respiratory – The NHS will commission an independent review into the deaths of people with a learning disability due to respiratory conditions to address inequalities amongst this patient group.
- Constipation – the NHS will launch a national campaign to promote awareness around the risk of constipation including how it can be prevented, recognised and treated to better support families, carers and staff who work with people with a learning disability.

- Sepsis and deterioration – Earlier this year NHS England took action to help ensure hospital staff spot and treat the killer blood condition within an hour to save thousands more lives.
- Cancer – the uptake of screening to ensure early diagnosis of cancer is a priority for the NHS with a focus on people with a learning disability in the national screening review. The NHS is prioritising making reasonable adjustments for screening including the roll out of easy read information.

SET Action Plan

The SET action plan is based on the 27 completed reviews accepted and returned from Bristol, which have been presented to the Steering Group, but will also take account of National actions and guidance from the Action Learning Sets. Further reviews will be presented to the Steering Group at bi-monthly meetings and the action plan will continuously be updated. Actions will need to be taken at different levels:

- a) Systems Level:
 - Single record of information (adult held)
 - Shared understanding and escalation of risks to health
 - Reasonable adjustments
 - Best practice pathways
 - Integrated and multi-disciplinary working including case management
- b) Individuals
 - Availability of accessible information on health and resources
 - Support for decision making
 - Support to plan End of Life
- c) Families and Carers
 - Information on health and resources
 - Involvement in decision making
 - Training on health issues

It is clear that health and wellbeing are everybody's responsibility and that all parts of the health and social care system need to work together. There will be a need to prioritise key areas for implementation this year and commitment from all partners will be needed.



LeDeR Action Plan
1.0.xlsx

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