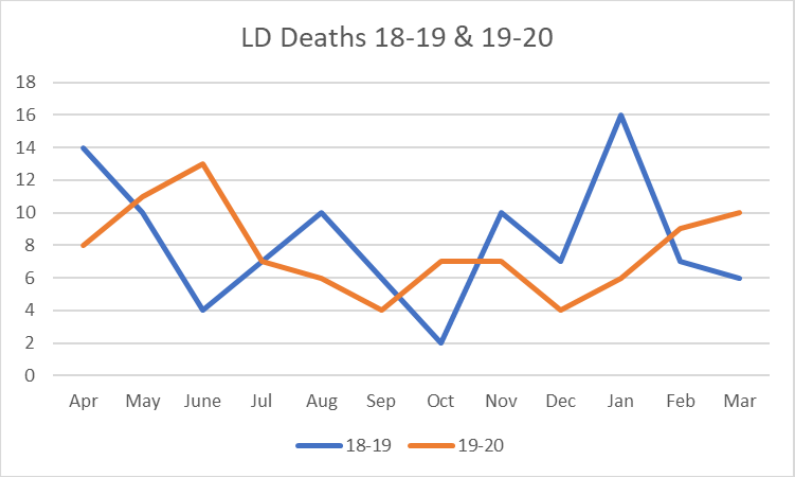
Appendix 1. LeDeR Supporting Data 2019-2020

LeDeR Notifications – comparison 2018 and 2019



	18-19	19-20
Apr	14	8
May	10	11
June	4	13
Jul	7	7
Aug	10	6
Sep	6	4
Oct	2	7
Nov	10	7
Dec	7	4
Jan	16	6
Feb	7	9
Mar	6	10
	99	92

With only two financial years to compare it is not possible to see any trends in notification.

Cause of Death

An official death certificate has the following sections:

I (a) Disease or condition leading directly to death
I (b) Other disease or condition, if any, leading to I(a)
I (c) Other disease or condition, if any, leading to I(b)

II Other significant conditions contributing to death but not related to the disease or condition causing it

1a must be filled in, but other sections are optional. A death certificate is not always available even on completion of report, particularly where GP records are not made available and not all sections are relevant for all certificates, so totals do not always relate to total number of deaths for the CCG.

Every death certificate is completed in the practitioner's own words (rather than a selected option) so that some grouping of causes of death has been done to make sense of the overall data. For instance "bronchopneumonia", "pneumonia" and "lower respiratory tract infection" would all be captured under "pneumonia/respiratory" but aspiration pneumonia is separate because it has a different cause.

This is not the case at the CCG level breakdown because the numbers are lower and so more easily read without significant categorisation. Codes might therefore not easily read across from the overall to the CCG data.

Cause of Death 1a, 1b, 1c and Pt II summarised for all ages Southend, Essex and Thurrock

COD1a

pneumonia/respiratory	44
aspiration pneumonia	22
cancer	12
sepsis/multi-organ failure	11
cardiac	9
cardio/respiratory	6
gastric	5
epilepsy	4
pulmonary embolism	3
other	3
syndromes	2
dementia	2
hypoxia	2
renal failure	1
liver failure	1
loss of blood	1
stroke	1

COD 1b

Heart	10
CP/LD/Downs	7
Bowel	6
pneumonia/embolism	5
COPD/respiratory LTC	4
Epilepsy	4
aspiration pneumonia	3
Frailty	3
Syndromes	3
Sepsis	2
Dementia	2
Cellulitis	2
DVT	2
Cancer	2
Stroke	2
chronic kidney	1
diabetic ketoacidosis	1
Cirrhosis	1
Immobility	1
infection in prosthesis	1
viral infection	1

COD P2	
Downs Syndrome/LD	11
cardiac	9
epilepsy	6
Cerebral palsy	5
multiple	4
syndromes	3
kidney	2
liver	2
cancer	2
diabetes	2
Autism	1
spastic paraplegia	1
gastric/bowel	1
anaemia	1
dysphagia	1
CD	1
hypotension	1
sepsis	1
UTI	1

COD 1c

Heart	4
Downs/LD/CP	3
Syndromes	3
Respiratory	3
Dementia	2
Diabetes	2
complications of surgery	2
Gastric	1
Epilepsy	1
Frailty	1
Dementia	1
Kidney	1
infected leg ulcer	1

Cause of Death – CCG Breakdown

BBW COD 1a	
Aspiration Pneumonia	1
Chest infection.	1
Pneumonia	3
Pulmonary Embolism	1
Respiratory and Cardiac Arrest	1
Septicaemia	1
	8

MID COD1a	
Bronchopneumonia	7
Cardio-respiratory failure	2
Aspiration pneumonia	2
Cancer of bowel	1
Chest Infection	1
Hypoxic Brain Injury & status epilepticus	1
Left ventricular failure	1
Congestive Cardiac Failure & COPD	1
Organ frailty	1
Right sided basal ganglia bleed. Bilateral basal ganglia lunar infarcts.	1
sepsis	1
Small Bowel Obstruction	1
	20

SOUTHEND COD1a	
Aspiration Pneumonia	3
BronchoPneumonia	3
Community acquired pneumonia	2
Cancer endometrial	1
Astrocytoma	1
Cardiomegaly	1
Dementia	1
Heart attack	1
Hospital acquired pneumonia	1
Juvenile Sandhoff Disease	1
Metastatic Hepatocellular Carcinoma	1
Peritonitis and Sepsis	1
Respiratory failure	1
	18

WEST COD 1a	
Aspiration pneumonia	6
Sepsis	2
Left lobe pneumonia with left lung collapse	1
Pneumonia	1
Respiratory Failure	1
Coalescing bronchopneumonia	1
Cerebral Palsey	1
Biventricular failure	1
Cause of death Liver disease from Alcohol ab	1
Hypothalamic Hamartoma	1
Protein Losing Enteropathy	1
Intestinal obstruction with peritonitis	1
seizure	1
	19

CPR COD 1a	
Aspiration Pneumonia	4
Bilateral Broncho Pneumonia	1
Myocardial Infarct	1
Multiple Organ Failure	1
Spontaneous retroperitoneal haemorrha	1
Vascular Dementia	1
	9

NORTH EAST COD 1a	
Bronchopneumonia	6
Cardiac Arrest	4
sepsis	3
Bronchopneumonia Pulmonary thrombo	2
Aspiration pneumonia with respiratory fa	2
Respiratory Failure	2
Community acquired pneumonia	2
Lung collapse	1
COPD	1
lower chest infection (LRTI)	1
Infective exacerbation of asthma.	1
malignant neoplasm of rectum	1
Liver cancer	1
Malignant Neoplasm of Female Breast	1
Perforated Duodenal Ulcer	1
Acute Renal Failure	1
Chronic Epilepsy	1
blood clot to the lung, causing cardiac arr	1
chest sepsis	1
Staphylococcus aureus Septicaemic. Complex Congenital Heart Disease with Eisenmenger Syndrome.	1
post operative blood loss	1
Natural causes	1
Old age	1

THURROCK COD 1a	
Multi -organ failure	1
Anaplastic astrocytoma of the brain	1
metastatic adenocarcinoma unknown pri	1
Aspiration Pneumonia	1
Bowel Cancer	1
Bronchopneumonia	1
Cardio Respiratory Arrest	1
Gastro Intestinal Bleed	1
Hypoxic Brain Injury	1
Laryngeal cancer	1
	10

Age and Gender

Average age is taken from GP registers and average age at death from LeDeR notifications.

CCG	Average Age	Av Age Death
NEE	44	58
Mid	36	65
Southend	47	62
BBW	41	64
West	40	57
Thurrock	41	65
CPR	35	52
	41	**60**

Southend and North East CCGs have significantly older populations whereas Mid and CPR are younger. The median age in the UK general population is 40 years.

In the UK general population, the average age of death is males 79.3 years and females 82.9 years (average 81.1). The average for people with LD is 60 years overall, 58 for females and 61 for males.

We know that a higher proportion of males die than females and that this is not explained by the gender split in the LD population.

There are different patterns across CCGs with Mid and West showing a more significant impact on males. In CPR the discrepancy is not so great.

CCG	Total LD Reg	Male	Male%	%male deaths	Fem	Fem%	%Fem deaths	No deaths
NEE	1920	1102	57%	64%	818	43%	36%	85
Mid	1374	820	60%	70%	554	40%	30%	46
Southend	1057	623	59%	61%	434	41%	39%	38
BBW	899	530	59%	64%	369	41%	36%	25
West	852	476	56%	66%	376	44%	34%	35
Thurrock	527	297	56%	67%	226	43%	33%	21
CPR	505	309	61%	55%	196	39%	45%	22
	7134	**4157**	**58%**	**64%**	**2973**	**42%**	**36%**	**272**

Children

24 children have died since the start of the programme across SET with age range from 5 – 16 years. The average age of death was 11 years and the median 7 years. 12 were male and 12 female. The breakdown by CCG is below:

CCG - Child Deaths	No.
MID ESSEX CCG	6
NORTH EAST ESSEX CCG	5
THURROCK CCG	5
WEST ESSEX CCG	4
SOUTHEND CCG	3
BASILDON AND BRENTWOOD CCG	1
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Grade of Care

The majority of care for children was good or satisfactory (83%) and 9% excellent. In 2 cases the care fell short of good practise and in one case this was contributory to the death. The CRDT board take forward all recommendations and actions.

Care Grade - Children	No.	%
This was good care (it met expected good practice)	15	65%
This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the persons wellbeing)	4	17%
This was excellent care (it exceeded expected good practice)	2	9%
Care fell far short of expected good practice and this contributed to the cause of death	1	4%
Care fell short of expected good practice but did not constribute to cause of death	1	4%
Grand Total	23	

Cause of Death

While not all children were on end of life pathways at the time of death, they tended to have more syndromes or complex health needs (than adults) which were contributory to or underlying the cause of death. All but one died in hospital or palliative care unit.

Not all reviews are complete, so cause of death is available for 18 children at time of writing.

N_COD_1a	N_COD_1b	N_COD_1c	N_COD_P2
Respiratory and Cardiac Arrest			
Pneumonia	POLG mutation mitochondrial cystopathy		
Cardio Respiratory Failure	Viral Illness	Edwards Syndrome	
Hypoxic Brain Injury	Epileptic Seizure	Gaucher Disease	
Pneumonia			
seizure	Lennox-Gastaut Syndrome	Trisomy 5p	
Cardiac Arrest	Catecholamine Polymorphic Ventricular Tachycardia		
Hypothalamic Hamartoma			
	Long QT Syndrome		Acute Colitis
Multi -organ failure	1b. Systemic inflammatory response syndrome (SIRS) septic shock		
Anaplastic astrocytoma of the brain			
Ia. Protein Losing Enteropathy	Ib. Failing Fontan with circulation failure.	Ic. Unbalanced Atrioventricular Septal defect (operated with total cava-pulmonary connection 2009).	Autism
Bronchopneumonia			Myopathy and learning difficulties
Pneumonia	Cerebral Palsy	Epilepsy	
Juvenile Sandhoff Disease			
Acute Renal Failure			Severe Global Delay, Cerebral Palsy, Epileptic Encephalophy.
I (a) Cardio-respiratory failure	I (b) Atrial and ventricular septal defects, pulmonary hypoplasia and lung abscess		II Multiple congenital abnormalities
Peritonitis and Sepsis	Gastric Fundus Necrosis and Perforation	Superior Mesenteric Artery Syndrome following corrective spinal surgery for progressive neuromuscular	

Ethnicity

The following table shows the ethnicity of all people with LD who have died in SET since Sept 17

Ethnicity	No.	%
British	237	87.13%
Any other ethic group	3	1.10%
Any other White background	3	1.10%
Irish	3	1.10%
African	2	0.74%
Pakistani	2	0.74%
Any other Black/African/Caribbean background	1	0.37%
Bangladeshi	1	0.37%
Chinese	1	0.37%
(blank)	19	6.99%
Grand Total	272	

We do not currently have data on ethnicity of our local LD population or whether it is representative of the general population in SET, but the data from deaths looks to be in line:

Ethnicity of Essex

White British	90.80%
Other white	3.60%
Asian	2.50%
Black	1.30%
Mixed	1.50%
Other	0.30%

Children and Ethnicity

Ethnicity Children	No.	%
British	16	67%
African	2	8%
Any other White background	2	8%
Bangladeshi	1	4%
Chinese	1	4%
Pakistani	1	4%
unknown	1	4%
	24	

When the figures for child deaths are split out it becomes clear that the deaths of Black and Minority Ethnic people are almost entirely those of children.

Place of Death – all age

Place of Death	No.
Hospice/palliative care unit	10
Hospital	149
Not known	9
Residential / nursing home that was not usual address	12
Usual place of residence	88
(blank)	4
Grand Total	**272**

55% of people with LD who died since Sept 17 died in hospital. This is lower than the national average for people with LD but higher than the average for the rest of the population.

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