NHS
South East London
Clinical Commissioning Group

South East London Clinical Commissioning Group

Learning Disability Mortality Review (LeDeR)

Annual report

2019/20

Title	**South East London Clinical Commissioning Group** **Learning Disability Mortality Review (LeDeR) Annual report 2019/20**
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Authorisation		
Authorisers	**Please tick (☑)**	**Date**
South East London LeDeR Steering group	☑	09/10/2020
South East London LDA Strategic Board		

Contents

Acknowledgments

The authors would like to extend sincere thanks to all the reviewers who have contributed to the Learning Disability Mortality Review (LeDeR). It should be noted undertaking these reviews is usually in addition to their day to day work. The LeDeR reviews are not an investigation of deaths, but reflect a great deal of fact finding analysis by the reviewers, bringing to life the circumstances leading up to the death, and providing a portrait of the lives of the people they have reviewed.

Summary

NHS England and Improvement are committed to improving transparency and making sure the deaths of people with a learning disability are reviewed in a timely way, to inform service improvements and honour the commitment made to bereaved families to review all deaths. To demonstrate this, the NHS operational planning and contracting guidance for 2019/20 sets out clear requirements of Clinical Commissioning Groups (CCGs) in relation to the LeDeR programme. CCGs are now expected to publish local LeDeR annual reports describing their progress on completing reviews and the service improvements made from this learning. Data on the progress of review completion will be published regularly on the NHS England and Improvement website.

This report from the South East London (SEL) LeDeR programme demonstrates the work covered in the six boroughs of SEL from April 2019 to March 2020. The six local areas or boroughs in SEL are Bexley, Bromley, Greenwich, Lewisham, Southwark, and Lambeth.

1. Introduction

Welcome to the SEL CCG LeDeR report produced in collaboration with all six local areas. This is the first SEL wide annual report on the reviews of deaths of people with a learning disability. The LeDeR programme reports on deaths of people with a learning disability aged four years and over, the definition used is from 'Valuing people' (2001)[1] and includes:

"a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development."

The LeDeR programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It was implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017.

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; this includes deaths with any areas of concern relating to the care of the person who has died, or if it is felt further learning could be gained. Where there are areas of concern these deaths will receive either a full multi-agency review or a safeguarding adult review of the death as required.

The LeDeR programme aims to positively influence practice and policy by:

- Identifying potentially avoidable contributory factors related to deaths of people with learning disabilities.
- Identifying variation and best practice in preventing premature mortality of people with learning disabilities.
- Developing action plans to make any necessary changes to health and social care service delivery for people with learning disabilities.

The LeDeR programme is administered and managed from Bristol University on behalf of NHS England. Key processes to deliver mortality reviews of people with learning disabilities have been established. The SEL LeDeR steering group (appendix 1) is chaired by the SEL CCG Chief Nurse and the Director of Quality in the CCG with the Acting Strategic Director Adults and Health, Lambeth Council.

Appendix 1 also demonstrates the governance structure for the LeDeR programme for SEL CCG. The Chief Nurse and Director of Quality at SEL CCG and the Executive Director Adults and Health for Lambeth Council are the senior responsible officers for the SEL CCG learning disability and autism programme. There is an overarching LeDeR quarterly Steering group meeting bringing together all the Local Area Contacts (LACs) in SEL CCG together to discuss improvements and challenges in completing and learning from reviews. Membership of steering groups varies and includes the SEL CCG learning disability commissioning manager, learning disability and safeguarding leads, local authority, learning disability community health teams, primary care, acute hospital trusts, local advocacy groups, Healthwatch and people with a learning disability and their carers. There are also local steering groups in all six boroughs; these local steering groups discuss reviews for people from their local area and develop an action plan based on the findings, identifying good practice and areas requiring improvement. The local action plan contributes to the overarching action plan for SEL.

All reviews of child deaths are undertaken by the child death overview panel who share their report on every child with a learning disability with the local LeDeR programme. This report is

[1] Dept of Health (2001) valuing people: a new strategy for Learning Disabilities for the 21st Century

added to LeDeR findings and recommendations; a separate LeDeR review is not carried out for children. Where a LeDeR review of any person's death indicates significant concerns or failings in care and support, the review is referred to statutory safeguarding processes, and may be placed on hold within the LeDeR system pending the outcome for further enquiry.

Each borough in the partnership has a LAC responsible for managing the programme locally. This role involves:

- receiving notifications of deaths,
- identifying and organising the training of local reviewers with the national LeDeR team,
- allocating cases to local reviewers,
- providing advice and support for local reviewers as necessary,
- anonymising and collating learning points and recommendations, and
- sharing with health and social care providers.

1.1 Number of days SEL review has been at its current stage in the review process (adult deaths)

Stage of LeDeR process	Number of reviews	Number of days at current stage:		
	n	Mean	Min.	Max.
Reviews not yet allocated to a reviewer	32	116	1	252
Allocated - review in progress	33	263	32	792
Review complete, with LAC for approval	13	147	14	529

(Table 1 - Number of days SEL review has been at its current stage in the review process (adult deaths))

1.2 SEL assessment of care received (completed reviews of adult deaths)

		Last 12 months (Apr'19 - Mar'20)	This quarter
1	This was excellent care (it exceeded current good practice).	2	0
2	This was good care (it met current good practice in all areas).	20	4
3	This was satisfactory care (it fell short of current good practice in minor areas, and no significant learning would result from a fuller review of the death).	11	3
4	Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning would result from a fuller review of the death.	4	1
5	Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.	4	0
6	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	1	0
	Total	42	8

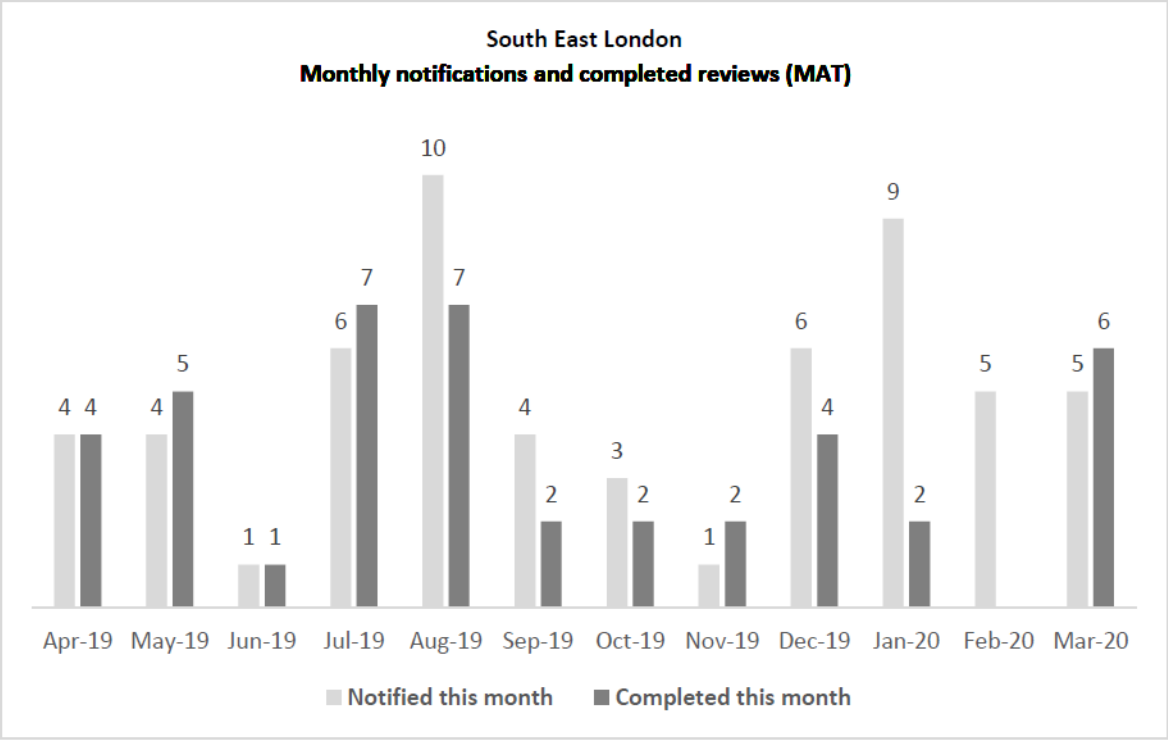
N.B. Information on individual reviews is available in the Local Area Contacts (LACs) weekly reports. (These reports can be accessed from the dashboard of the LeDeR online review system by clicking 'Sites' (top left), selecting 'LeDeR review system', then clicking on 'Document library' (top right).)

(Figure 1 - SEL assessment of care received (completed reviews of adult deaths))

2. South East London 2019/20 Performance and Demographics Overview

This section shows the number of deaths from the reviews completed in the 2019/20 reporting period, demonstrating the age and gender, place of death, ethnicity, and local areas people who have died. Data taken from the notification of deaths to the LeDeR programme is a voluntary reporting scheme and, therefore, may not capture all deaths in the reporting period.

2.1 Number of adult deaths notified to the LeDeR team and completed reviews (Moving Annual Total)



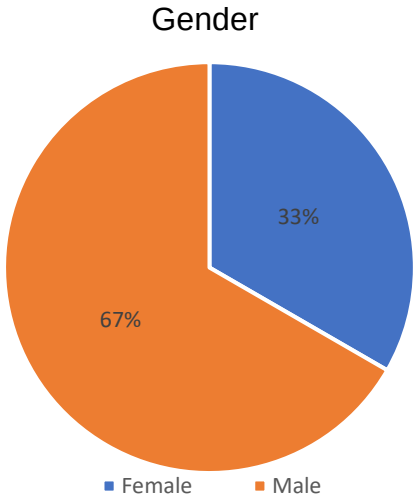
(Figure 2 - Number of adult deaths notified to the LeDeR team and completed reviews (Moving Annual Total))

2.2 Age at death and Gender

Table 3 demonstrates life expectancy in 2019/20 for people with learning disabilities in SEL was significantly lower for people below 50 years of age, higher in ages between 50-59 years at 19% and 25% for those between 70-79 years of age. The reason for this has not been established; this prevalence will be considered during future data analysis. The overall aim of the LeDeR programme is to use the information obtained from reviews of deaths to help reduce premature deaths. As this is the first combined annual report for SEL CCG, this data will be used to monitor performance across the six boroughs over the next reporting year. The pie chart below shows a significant proportion of reported deaths in SEL to be males. Nationally, LeDeR have previously reported a higher number of males to the programme at 58% for the 2018/19 reporting period.

Age at death	Number of notifications	Percentage
4 - 9	3	~4%
10 - 19	8	~12%
20 - 29	2	~3%
30 - 39	3	~4%
40 – 49	4	~6%
50 – 59	12	~19%
60 - 69	16	~25%
70 - 79	13	~20%
80 - 89	2	~3%

(Table 2 - Age at death for people with learning disabilities in 2019/20 in SEL)

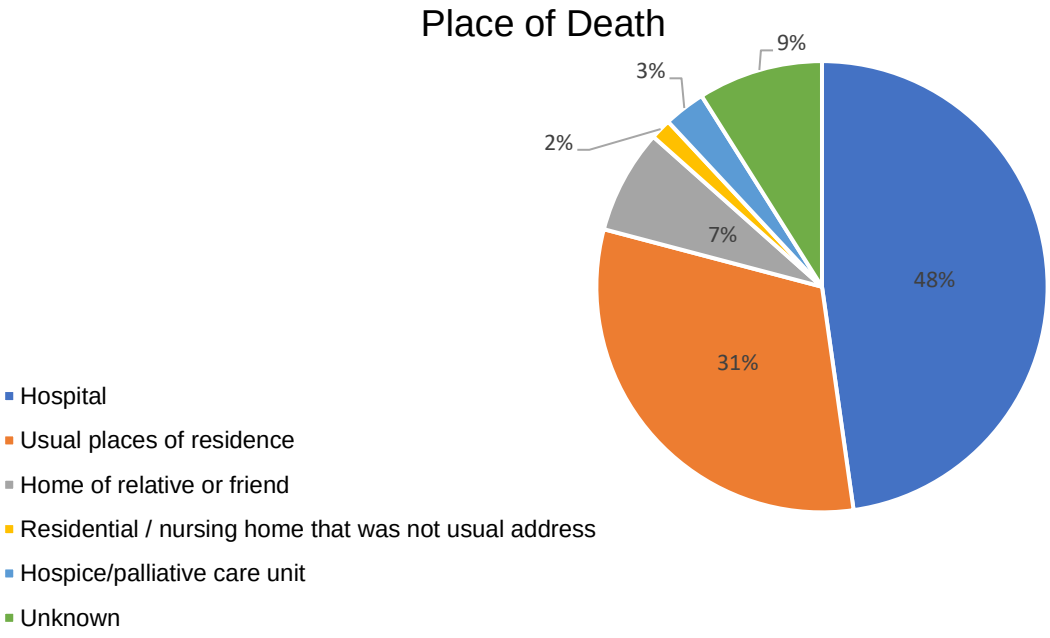


(Figure 3 – Gender of people reported to LeDeR in 2019/20 in SEL)

2.3 Place of Death

Some challenges have been found within the LeDeR reporting system when using data to establish where a person with a learning disability has died. Notifications to the programme record “usual place of residency” whether a person died at home, in supported living or care home. Although the living arrangements and place of death may be detailed later in a review, this is not always clearly identified in the data set.

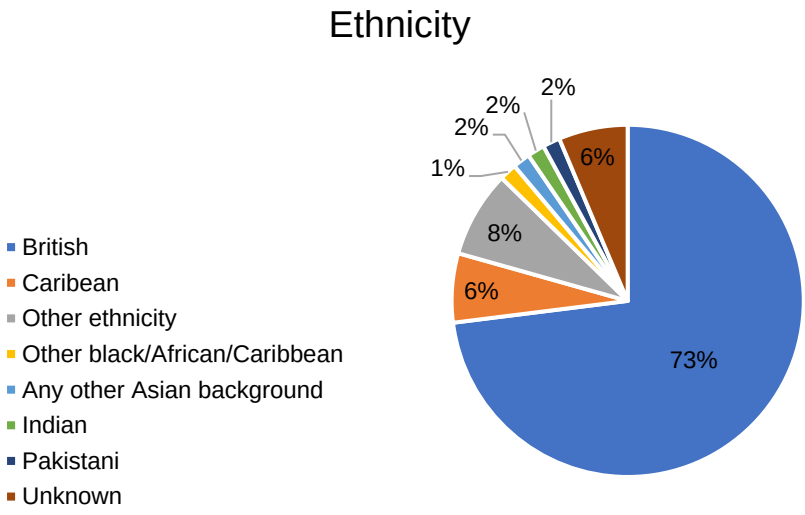
The pie chart below indicates more people died in hospital than in their usual place of residence, in congruence with the national LeDeR findings. The LeDeR steering groups will explore ways of closer working between hospitals and community services to improve end of life care planning and increase the number of people supported to die at their usual place of residence. The LeDeR coordinator will work closely with the local area contacts to ensure full information is captured for performance reporting.



(Figure 4 – place of death of people reported to LeDeR in 2019/20 in SEL)

2.4 Ethnicity

The figure below shows the ethnicity of people with learning disability whose deaths were reported into the programme in 2019/20, as set out in the categories on the LeDeR reporting form. The reporting shows people who identify as British make up the highest proportion of deaths for this reporting year, more specific ethnicity data further than British has not been available at the time of reporting in the system. National LeDeR findings show the proportion of deaths notified from people from Black, Asian, and Minority Ethnic (BAME) groups are lower than the population in England as a whole (14%). In SEL, this data has yet to be determined and with the experience of Covid-19, further work will be undertaken to understand the proportion of deaths within the BAME community.



(Figure 5 – Ethnicity of people reported to LeDeR in 2019/20 in SEL)

2.5 COVID-19 Related Deaths

During quarter four of this year, SEL was significantly affected by the Covid-19 pandemic, the impact of which will be analysed over the next reporting year and beyond. The initial response to deaths of people with a learning disability with suspected or confirmed Covid-19 included two full LeDeR reviews and five rapid reviews to capture and share learning back into the system swiftly. This included reissuing the "Stop and Watch guidance" to all providers.

Borough	COVID-19 death	Date of death	Age at death	Place of death	Review Progress
Bromley	Suspected	23/03/2020	62	Hospital	With LAC for allocation
Lambeth	Suspected	31/03/2020	58	Hospital	With LAC for allocation
Bromley	Confirmed	02/03/2020	57	Hospital	Completed (Archived)
Southwark	Confirmed	28/03/2020	18	Unknown	Completed (Archived)
Lambeth	Confirmed	30/03/2020	13	Hospital	With LAC for allocation

(Table 3 - Covid-19 deaths)

Rapid reviews are not part of the LeDeR programme, they were completed using a template provided by NHS England as an interim method to capture immediate learning until a full LeDeR review could be carried out. The data from March 2020 shown in the table above at the beginning of the outbreak shows four of the five confirmed Covid-19 deaths of people with a learning disability occurred in a hospital setting. The rapid reviews undertaken found Covid-19 was not always recorded as cause or contributing factor of death.

3. Borough 2019/20 Notifications Overview

The six boroughs in SEL are covered by LACs with direct access to provider services in their local areas. This provides access to knowledge about the services provided and links to stakeholders in the service provision area and allows value in their experiences. This section includes the yearly report the LACs present pertinent to the six Boroughs in SEL.

3.1 Bexley

In 2019/20 there was a total of eight notifications in **Bexley**, where the average age of death was 51.4 years old. Of those notifications:

- **Ethnicity**: 1 Indian (~13%), 6 British (75%) and 1 White British (~13%).
- **Place of death**: 3 Hospital (~38%) and 5 Usual places of residence (~63%).
- **Gender**: 4 Females (50%) and 4 Males (50%).

3.2 Bromley

In 2019/20 there was a total of 11 notifications in **Bromley**, where the average age of death was 45.2 years old. Of those notifications:

- **Ethnicity**: 1 Any other ethnic group (~9%), 8 British (~73%), 1 Any other Mixed background (~9%) and 1 White and Black Caribbean (~9%).
- **Place of death**: 6 Hospital (~55%), 3 Usual places of residence (~27%) and 2 Unknown (~18%)
- **Gender**: 2 Females (~18%) and 9 Males (~82%).

3.3 Greenwich

In 2019/20 there was a total of 10 notifications in **Greenwich**, where the average age of death was 61.6 years old. Of those notifications:

- **Ethnicity**: 1 Any other ethnic group (10%), 8 British (80%) and 1 Unknown (10%).
- **Place of death**: 6 Hospital (60%), 3 Usual places of residence (30%) and 1 Home of relative or friend (10%).
- **Gender**: 2 Females (20%) and 8 Males (80%).

3.4 Lambeth

In 2019/20 there was a total of 10 notifications in **Lambeth**, where the average age of death was 50.9 years old. Of those notifications:

- **Ethnicity**: 2 Any other ethnic group (20%), 4 British (40%) and 1 Unknown (10%), 2 Caribbean (20%), 1 Any other Asian background (10%).
- **Place of death**: 6 Hospital (60%), 2 Usual places of residence (20%), 1 Home of relative or friend (10%) and 1 Residential / nursing home that was not usual address (10%).
- **Gender**: 6 Females (60%) and 4 Males (40%).

3.5 Lewisham

In 2019/20 there was a total of 16 notifications in **Lewisham**, where the average age of death was 55.9 years old. Of those notifications:

- **Ethnicity**: 1 Unknown (~6%), 1 Pakistani (~6%), 13 British (~81%) and 1 Caribbean (~6%).
- **Place of death**: 5 Hospital (~31%), 6 Usual places of residence (~38%), 3 Unknown (~19%), 2 Hospice/palliative care unit (~13%).
- **Gender**: 6 Females (~38%) and 10 Males (~62%).

The LeDeR programme in Lewisham has been hampered by the shortage of available reviewers in local provider services. Only one of the deaths notified during the year had been reviewed by the end of the year. Plans in place across SEL in 2020/21 should see the outstanding reviews in Lewisham completed before April 2021.

3.6 Southwark

In 2019/20 there was a total of 9 notifications in **Southwark**, where the average age of death was 49.9 years old. Of those notifications:

- **Ethnicity**: 1 Any other Black/African/Caribbean background (~11%), 7 British (~78%) and 1 Caribbean (~11%).
- **Place of death**: 6 Hospital (~67%), 3 Usual places of residence (~33%)
- **Gender**: 2 Females (~22%) and 7 Males (~78%).

4. 2019/20 SEL Themes, learning points and recommendations from reviews

Across several cases there were incidents where the learning disability annual health check had not taken place, though there was a great deal of alternative input from primary care services in some of these cases. People with learning disability are frequently supported by multiple services and individuals who provide person-centred care, aiding support in the persons preferred place of death. Reviewers of LeDeR deaths in SEL found many examples of good and excellent practices as depicted below in this excerpt from one reviewer.

> *"Mental Capacity Assessments were completed using reasonable adjustments such as Easy Read documentation, taking time to provide extended appointments to ensure ZZ had all information and time to consider and weigh the range of choices available to her and the consequences of her decision making."*

4.1 Learning from reviews

- Service users should be given additional support to take part in annual health checks.
- Extra work is required to improve communication regarding health promotion, e.g. screening and requests to attend appointments should be provided in a more accessible format.
- Using genealogy services enabled contact with family who had lost contact many years ago. This could be used to support contact with families where contact has been lost.
- End of life planning should be discussed as early as possible, supported by active conversations about death and dying.
- Further work is required on assessing capacity and recording best interest's decision making.
- The wider health and social care workforce should be educated about what learning disabilities are.
- Pathways to direct care to the appropriate clinician/s should be put in place.
- Reviewers should be supported to obtain information regarding timelines in death in a timely fashion.
- Attention should be paid to available training for the general workforce on recognising deteriorating patients including education on sepsis bundles, and the National Early Warning signs.
- Training on diagnosis of learning disabilities should be offered to relevant workforce who make diagnosis, but also for clinicians who may encounter learning disability patients.
- To consider training in national health and social care curriculums for understanding learning disability and autism.
- Ensure hospital passports are used when patients are admitted to the acute sector or elsewhere.
- Close collaboration and integration amongst health and care teams regarding people living with learning disabilities and autism.

4.2 Recommendations for 2020/21

SEL local areas will continue to develop LeDeR review performance and system improvement in alignment with the themes for the whole system model across health and social care, as set out in the SEL Integrated Care System Plan in May 2020. The SEL

LeDeR meeting is developing a steering group approach to continue to develop standardised working practices such as action plan formats and collaborative approaches to improvements such as annual health check quality and performance.

SEL 2020 Long Term Recommendations	LeDeR Priorities 2020/21
Transformed 'out-of-hospital care' and fully integrated community-based care	To demonstrate closer working between hospital and community teams to improve end of life planning and care.
Population health	To work with local areas and partner agencies across SEL to deliver the LeDeR programme and embed learning, ensuring resources are improving outcomes for people with learning disabilities.
Giving people more control over their own health and more personalised care	To provide opportunities for the workforce to improve knowledge and skills in supporting people with learning disabilities and their careers. To increase the use of hospital/care passports to facilitate person-centred care
Prevention	To develop a SEL Steering Group to improve quality and performance in relation to annual health checks. To develop a standardised LeDeR action plan template to support the steering groups in identifying improvements and sharing them with relevant clinical and social care pathways.

(Table 4 - SEL LeDeR Recommendations for 2020/21)

5. SEL Thematic Review

A learning development summary tool has been developed to collate the learning from LeDeR reviews in SEL. This tool reveals areas of improvement and will allow monitoring of improvement and progress. The planned functions include monitoring frequency of reviews and progress of improvement.

5.1 Methodology

The thematic review process consolidates information from LeDeR review summaries, extracts issues and actions from the summaries, assigns common themes and areas of learning, analyses information attributed to cases, and provides actionable data to improve care. Data was obtained from reviews using qualitative methodology, and thematic analysis was employed to analyse the data. Summaries of themes can be found below.

Case ID	Learning points	Recommendations/actions taken
DON 11/07/2017	1) Importance of having regular annual health checks and access to Health Facilitators (incl. Health Action Plan). 2) Timely access to mental health or psychology services, particularly in cases where people with a LD self-harm. 3) Inclusion and independence: i.e. Accessible/User-friendly communication with adults with a LD. 4) Transfers between hospitals	1) Support to be given to GPS to improve the quality of annual health checks – program in place. 2) Assurance gained that there is timely access and that a prioritization system is in place. 3) All providers to ensure that information is available and is being offered in easy read form - Ongoing 4) To remind services that all relevant information is shared when patients are transferred between hospitals and LD Liaison nurses have direct communication in these circumstances – Discussed in steering group with acute trust leads.

(Table 5 – Example summary of a LeDeR review)

Borough	Key Themes	Key area/lessons learned	Specific Issue	Actions: Description
Bexley	Communications	Annual Health Checks	Access to regular, quality AHCs and Health Facilitators (incl. Health Action Plan).	Support to be given to GPs to improve the coverage and quality of AHCs – program in place.
Bexley	Communications	Discharge Planning	Transfers between hospitals	Remind services to share all relevant information during hospital transfer and ensure LD liaison nurses have direct communication in these circumstances
Bexley	Communications	Reasonable Adjustment	Inclusion and independence: i.e. accessible/ user-friendly communication with adults with LD.	Ensure information is available and is being offered in easy read form - Ongoing
Bexley	Referrals/Access	Referrals: CTLD	Timely access to mental health or psychology services, particularly in cases of self-harm.	Seek assurance of timely access to service and confirm a prioritization system is in place.

(Figure 6. Example case separated into issues/actions in tool)

As of writing this report, the reviews identified 266 issues which were translated into eight overarching themes including:

- clinical care,
- communication,
- documentation,
- knowledge and skills,
- no learning,
- referrals/access,
- safeguarding
- social care.

These overarching themes were found on review of the case summaries by a group of health and social care colleagues; they are presented and elaborated on in 5.3 using demonstrations with graphs. There were some limitations in the exercise, they include:

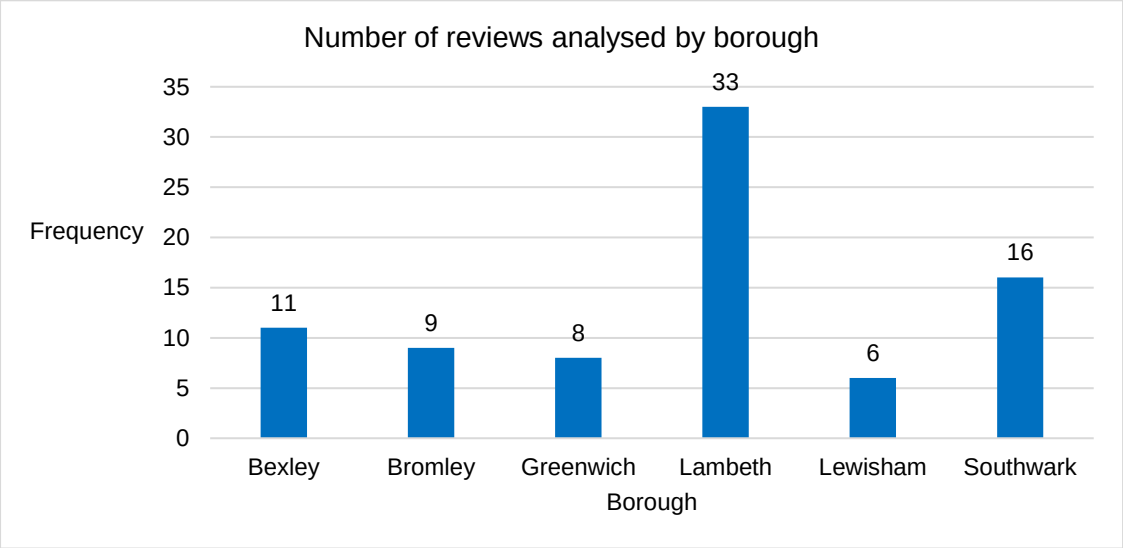
- The summaries used as data sources were not written in a standardised way, it was unclear if there were varying degrees of complexity in the cases or more detail included in some summaries.
- The source material was from varying dates, it was unclear whether the recommended actions had been taken from these and completed.
- Subjectivity of the theming process was challenging

- The limited number of summaries available may not allow many significant themes to emerge.

Further development options for the tool, such as adding dates of reviews, have been discussed.

5.2 Learning Summaries Available

The number of case summaries and the number of issues or actions per borough has been counted. The average number of issues found per case has also been calculated.



(Figure 7 – Number of reviews analysed per borough)

5.3 Overarching Themes in SEL

Clinical Care
'Many concerns expressed service users were isolated inside rooms, not regularly checked and found without pressure area boots on etc.' (Bromley, Clinical Care, End of Life)

Communications
'Limited engagement with learning disability (LD) safeguarding team on admission' (Southwark, Communications, LD Awareness)

Documentations
'The electronic patient record didn't flag a flu vaccine should be offered. The AHC action plan supplied by the practice details flu vaccines and screening, but a copy was not kept for their records.' (Bexley, Documentations, Annual Health Checks)

Knowledge and Skills
'Poor MCA practice. Family could have had deputyship which would have aided them to have more control over decisions.' (Lambeth, Knowledge and Skills, End of Life)

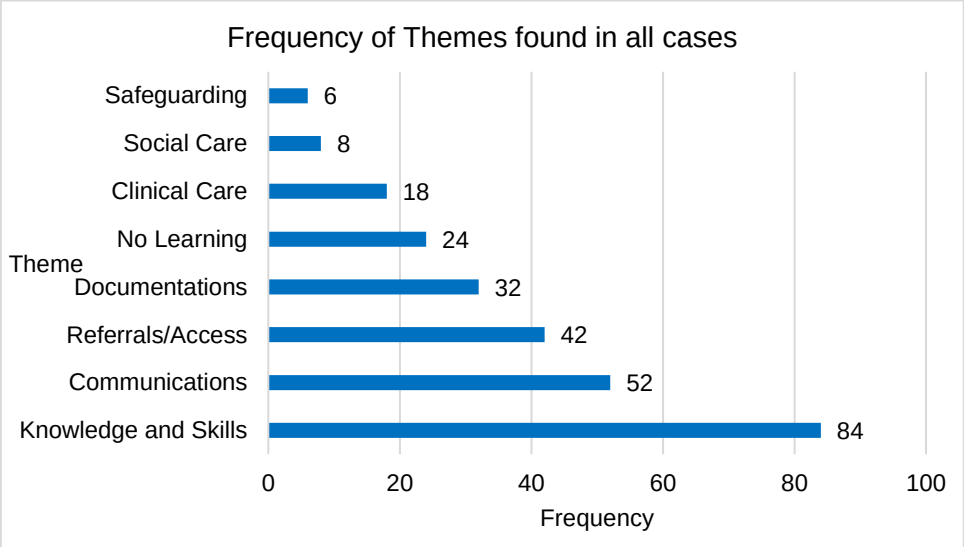
Good Practice (No Learning)
'Received a high standard of care, no gaps in service provision or care delivery could have changed the outcome or improved experience.' (Lewisham, No Learning).

Referrals/Access

'GP follow up following an A&E visit may have in this case identified the patients deteriorating condition.' (Bexley, Referrals/Access, Referrals: Other)

Safeguarding
'Patient developed a grade 3 pressure sore, but District Nurses did not raise a safeguarding alert to Bexley or present to the Tissue Viability Panel' (Bexley, Safeguarding, Referrals: Specialist Services)

Social Care
'Difficulty securing care from LA suiting family. Reported to be a relatively common issue even when families have an appropriate care package, it can be difficult to secure appropriate and sustained carers. The learning point is about personalisation of care.' (Lewisham, Social, Reasonable Adjustments).



(Figure 8 – Frequency of identified themes in cases analysed)

5.4 Areas of Learning found in SEL

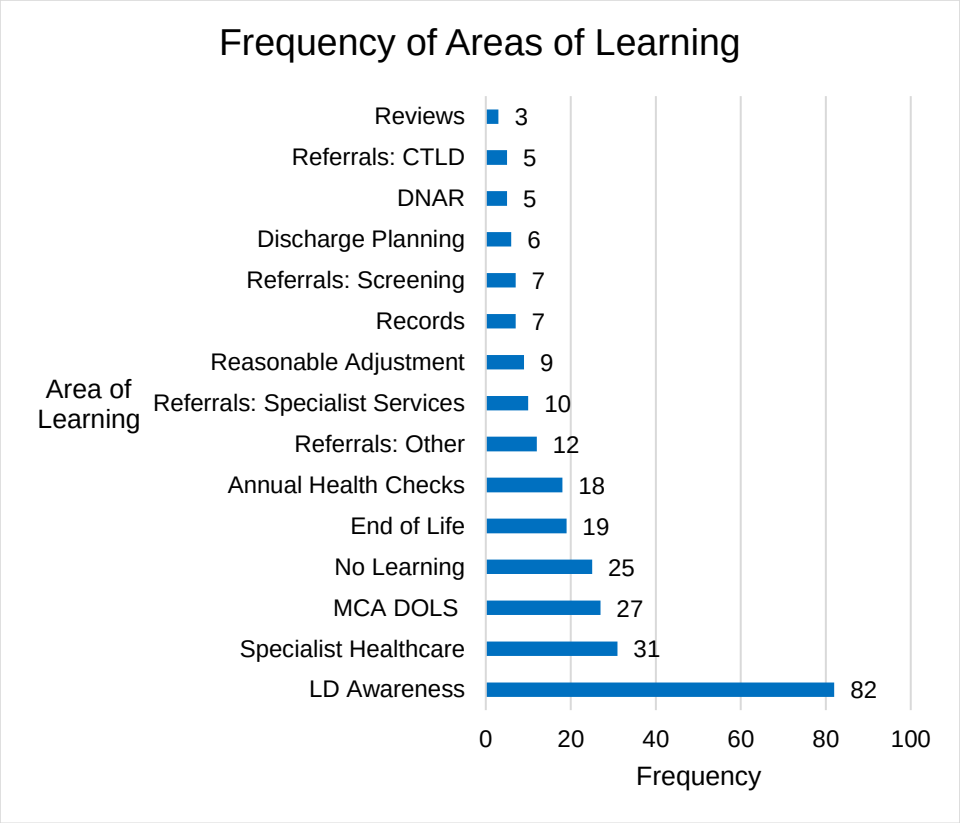
Areas of learning were decided on review of the case summaries and added as necessary to reflect the content of the reviews. Most Common Areas of Learning:

LD Awareness
'Staff on the ward reportedly relied too much on the mother to provide care. Mother reported receiving little or no support with care, particularly with administering medication and nutrition on the ward.' (Southwark, Knowledge and Skills, LD Awareness)

MCA DOLS
'Heart failure -under review. Frequent admissions decisions on possible preventative surgery made by medical team without following formal capacity process.' (Bromley, Clinical Care, MCA DOLS).

Good Practice (No Learning)
'Care Home staff visited patient in hospital -excellent. Good MDT service, MHLD, SLT, GP.' (Lambeth, No Learning, No Learning)

End of Life
'Lack of effective communication about the death. The adult CLDT were only notified of the death by patient's girlfriend, so only very limited information was submitted to LeDeR.' (Southwark, Communication, End of Life).



(Figure 9 – Frequency of identified areas of learning in cases analysed)

5.5 Analysis of theme by borough

The tool's Analysis by borough allows extraction of the themes emerging most frequently in each local area.

Data shows:

- Issues with Knowledge and Skills is the most common theme in Bexley, Bromley and Lambeth.
- Greenwich had high levels of issues in three areas Knowledge and Skills, Communication and Referrals/Access.
- Issues in Lewisham are more evenly spread with all themes emerging at least once. Referrals/Access by a small margin is the most common.
- Issues emerging in Southwark are in four key areas: Communication, Documentation, Knowledge and Skills and No Learning, as many summaries found the care to be reflective of best practice.

Examples of the issue
'Increased frequency of visits to GP with weight loss and constipation and other symptoms. Red flag alert did not appear to come up related to increased number of visits with same symptom presentation.' (Bromley, Knowledge and Skills, LD Awareness)

Examples of the action
'Single integrated medical records would ensure increase in GP contacts is easily identified.'

5.6 Most Common Areas of Learning by borough

The tool's Analysis by Borough allows extraction of the Areas of Learning emerging most frequently in each local area.

Data shows:

- Issues involving LD awareness and MCA DOLS are most frequent in Bexley and Bromley
- Most issues in Greenwich involved LD awareness or Specialist Healthcare
- Issues in Lambeth and Lewisham are more evenly spread with low numbers in all areas
- Southwark have the most prominent issue of LD awareness, making up 31% of the issues found.

Examples of the issue
'Increased frequency of visits to GP with weight loss and constipation and other symptoms. Red flag alert did not appear to come up related to increased number of visits with same symptom presentation.' (Bromley, Knowledge and Skills, LD Awareness)

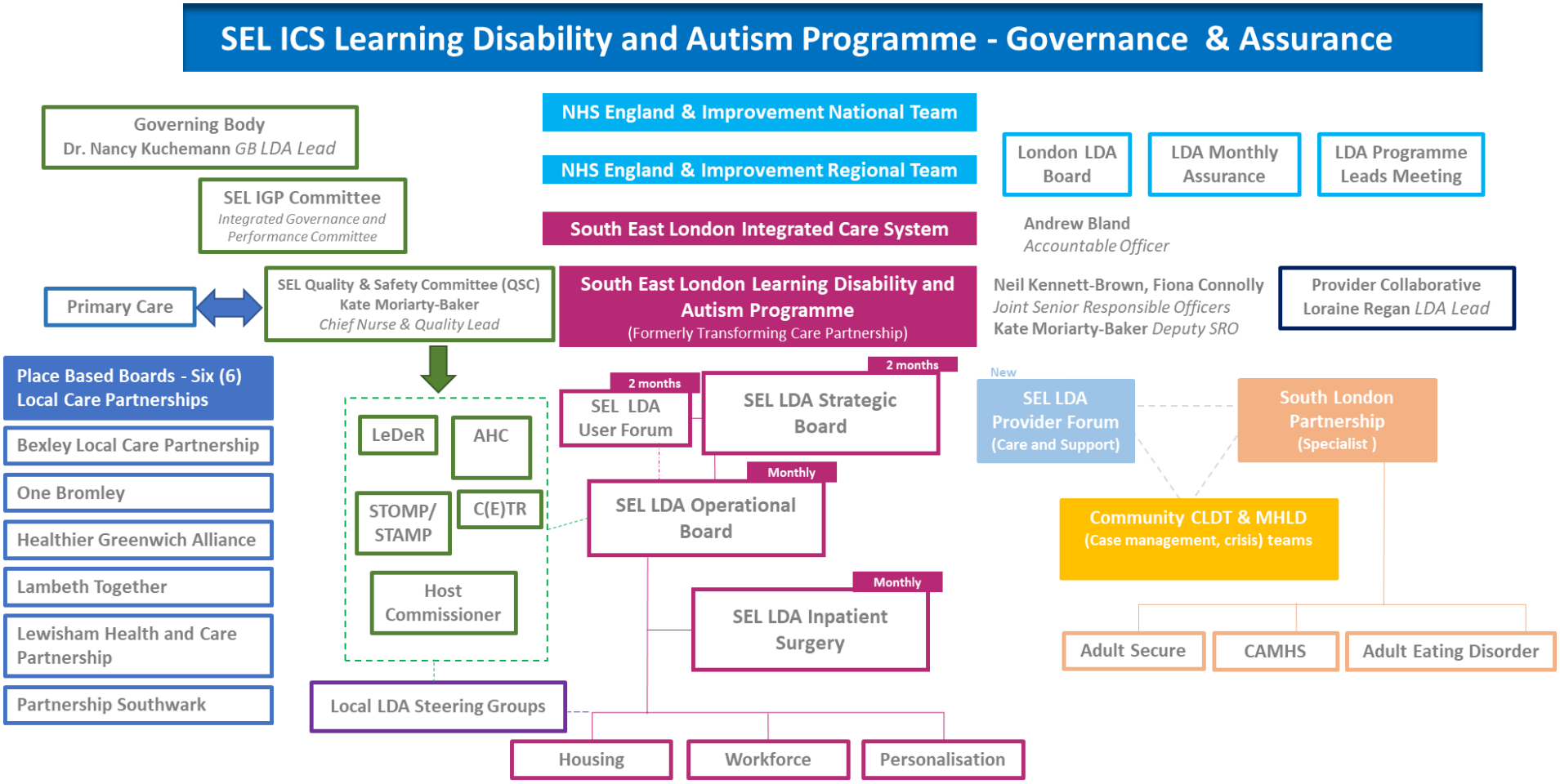
Examples of the action
'Single integrated medical records would ensure increase in GP contacts is easily identified.'

6. Conclusion and Next Steps

SEL CCG continues to be committed to deliver the LeDeR programme. During the past year, our reviewers have managed competing priorities to deliver thorough reviews. There are still several reviews to be completed, the SEL CCG LeDeR team will continue to monitor progress and the actions arising from these reviews with a view to positively impacting on care and service delivery for people living with learning disability.

The CCG LeDeR steering group is dedicated to leading learning disability learning locally in health, and social care or the third sector, and will support more people to train to become reviewers delivering very high standard reviews. The LeDeR team will raise the profile of LeDeR reviews to attract more quality reviewers by engaging with SEL CCG communications team and NHS England and Improvement quality team. The team will proactively engage in identifying effective ways of enhancing timely quality reviews by researching effective models and ways of working. Learning from LeDeR reviews will be shared with SEL CCG executive teams and Health and Wellbeing board.

Appendix 1 – SEL LeDeR programme governance



Appendix 2 - University of Bristol Third annual report overview

The latest LeDeR annual report for 2018 published by the University of Bristol in May 2019[2] indicates from 1st July 2016 to 31st December 2018, 4302 deaths were notified to the programme. In 2018 this was approximately 85% of the estimated number of deaths of people with learning disabilities in England each year. This year's report details policies relating to the care and support of people with learning disabilities still require strengthening. The report has 12 recommendations.

The national report notes the median age at death was 59 years, 60 for males and 59 years for females. In the general population of England, the median age of death (for people of all ages including 0-4 years) was 83 years for males and 86 for females.

Nationally the proportion of people with learning disabilities reviewed by the LeDeR programme who has died in hospital was 62%. The LeDeR 2017/18 annual report reports the proportion of deaths in hospital of people with learning disabilities at 64%. Within SEL the place of death is like the general population with % of death in hospital, most people die in their usual place of residence.

England data shows in people diagnosed with Learning Disability the medical conditions most frequently cited anywhere in Part I of the Medical Certificate of Cause of Death were: pneumonia (25%), aspiration pneumonia (16%), sepsis (7%), dementia (syndrome) (6%), ischaemic heart disease (6%) and epilepsy (5%). Across the general population more frequently die from cancer and diseases of the circulatory system than people with learning disabilities.

The report contains information and recommendations and the intended actions shared by the reviewers. There are key recommendations from the report listed in table 3.

1	Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme.
2	NHS England to support CCGs to ensure the timely completion of mortality reviews to the recognised standard.
3	There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, health and social care so that ‘learning disability’ has a common understanding across each of the sectors and between children’s and adults’ services.
4	CCGs and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian, and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action.
5	The Department of Health and Social Care and NHS England to support national mortality review programmes to work with ‘Ask, Listen, Do’ and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative’s death.

[2] LEDER annual report 2018 published May 2019 bristol.ac.uk/sps/leder

6	The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia.
7	Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.
8	Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability Code of Practice in relation to identifying and sharing information about people with learning disabilities approaching transition, transition planning and care coordination must be addressed.
9	The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children to adults' health services.
10	The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death.
11	Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording 'learning disabilities' as the rationale for DNACPR orders or where it is described as the cause of death.
12	The Care Quality Commission to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution.

Table 3 - Key recommendations Uni Bristol LeDeR annual report 2018.