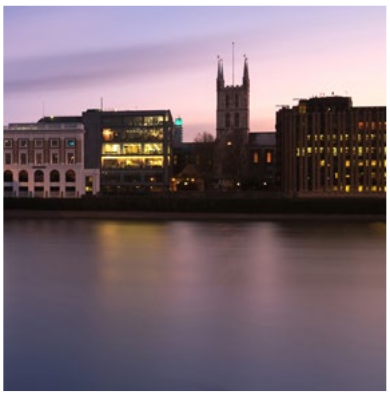
South East London Integrated Care System

NHS South East London

Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

2022/2023 ANNUAL REPORT



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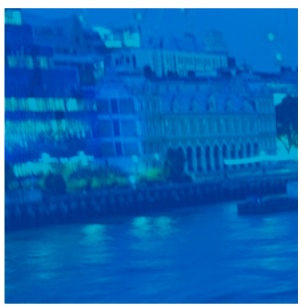
Acknowledgments

The South East London (SEL) LeDeR team would like to thank everyone who has contributed to the LeDeR reviews. We would particularly like to thank the families and carers of those who have lost someone dear to them. Your voice has been invaluable in helping us learn about your loved one's experience, and of your experience, of using local health and social care services. This has helped us to better understand what works well and identify areas that we need to improve on.

Thank you to the local service providers and local authorities who have given us information to help us complete the reviews and for giving the LeDeR programme the attention it requires.

Without this information we would not understand the care provided to each person. Lastly, thank you to the LeDeR Reviewers who have endeavoured to truly understand the people at the heart of the LeDeR reviews. Not only do the reviews show an understanding of each person as an individual, but they also reflect what was important to each person throughout their life.



Executive Summary

The South East London Integrated Care Board (SEL ICB) recruited and established the local LeDeR team in May 2022, with a Local Area Contact (LAC) and Programme Lead, Programme Support Officer, Senior Reviewer, and a Reviewer all in place by August 2022.

Upon inception the LeDeR team prioritised promoting awareness of LeDeR across South East London by sending out a LeDeR information communique and attending local service provider and partner meetings. Prior to the establishment of the LeDeR team, North of England Commissioning Service (NECs) were commissioned to complete South East London LeDeR reviews. The newly established LeDeR team liaised with NECs to ensure that the backlog reviews were completed and submitted to a high standard.

This annual report highlight's the work that the South East London (SEL) LeDeR team have taken to complete the LeDeR reviews for the deaths that were reported from 1st April 2022 to 31st March 2023. It will also show lessons learnt from any reviews completed and what has been done.

Introduction

South East London has a population of over two million people. Of those, around 9160 people have a learning disability and an estimated 21,000 are autistic people. The SEL LeDeR team reviews the deaths of people across South East London. South East London consists of 6 boroughs - Bexley, Bromley, Greenwich, Lambeth, Lewisham, and Southwark. The LeDeR programme supports the SEL Integrated Care System (ICS) to understand the experience of people with learning disabilities and autistic people when accessing health and social care services. It demonstrates what is working well and which areas need improvement.

All deaths of people with a learning disability and or autistic people aged 18 years and over are eligible for a LeDeR review, while deaths of children with a learning disability aged 4-17 are linked into the LeDeR programme through the national Child Death Overview Panel (CDOP) process. However, a change in policy initiated in June 2023 means that child deaths now follow a separate statutory review process overseen by the CDOP process. Therefore, child deaths will no longer be reported to LeDeR.

Foreword – Chief Nurse

Welcome to our latest annual report on the lives and deaths of people with learning disabilities and autistic people (LeDeR) in South East London. Our report highlights what we've learned about causes of death, themes around care and support, how we could do better, but also celebrating our successes.

The team continue to work hard and publicise the importance of notification of death on the LeDeR platform to inform learning and seek continuous improvement in the lives and care of people with a learning disability and those with autism.

In 2022, our LeDeR team was recruited, following the NHS England 2021 policy. This has enabled us to put in place a robust governance process that ensures our reviews are consistently and effectively quality assured, as well as ensuring effective learning across South East London amongst our ICS partners.

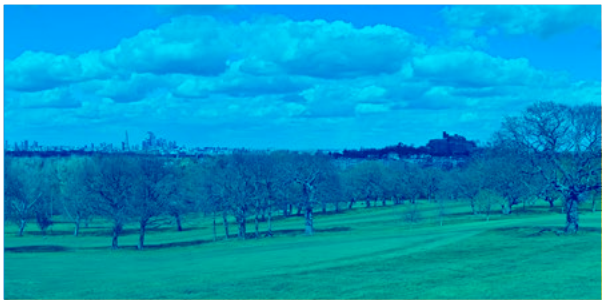
As an Integrated Care System, we aim to work in partnership to change things for the better for our citizens, and one of our core objectives is to tackle inequalities in outcomes, experience, and access. It's essential that we continue to understand and highlight good practice and learning from the lives and deaths of people with a learning disability and autistic people, so we can get health and care right for some of the most vulnerable members of our society.

Paul Larrisey
Acting Chief Nursing Officer

The LeDeR process

Anyone, for instance, a family member, a friend, doctor, nurse, or a social worker can report the death of an autistic person or someone with a learning disability by submitting a notification to LeDeR via the LeDeR website. The notification form includes basic demographic information about the person who died, such as their name, NHS number, address, date of birth, sex, and ethnicity. The person submitting the form is asked to provide information about the circumstances of death, including where the death occurred, cause of death if known, and whether they had any concerns around the care of the person. This process checks that the individual was a real person by checking their NHS number and personal information against the NHS Personal Demographic Service (PDS) database. The notification is also checked against the national data opt-out repository to ensure that any person that has opted out of sharing their information for purposes other than direct care is not included in LeDeR. This manual process currently takes around 10 days but can take longer resulting in delays. It is hoped the new automated system which is being launched in 2023/2024 will make this process quicker. During this process, it may also become apparent that the notification is not suitable for LeDeR, for example, on further examination the deceased person did not have a diagnosis of learning disability or autism in their clinical records. In these cases, a LeDeR review is not completed, and the notification is marked as out of scope. In 2022-2023, nine notifications were in this category and marked as out of scope.

Once confirmed that the death is within scope of LeDeR review, the LeDeR team starts to request health and social care records relating to the care received by the patient before death. The review is then allocated to a Reviewer with a target for this to be completed within six months from the date of notification. For some reviews, this will lead to a more comprehensive focused review, looking very closely at the person's life and circumstances of death.

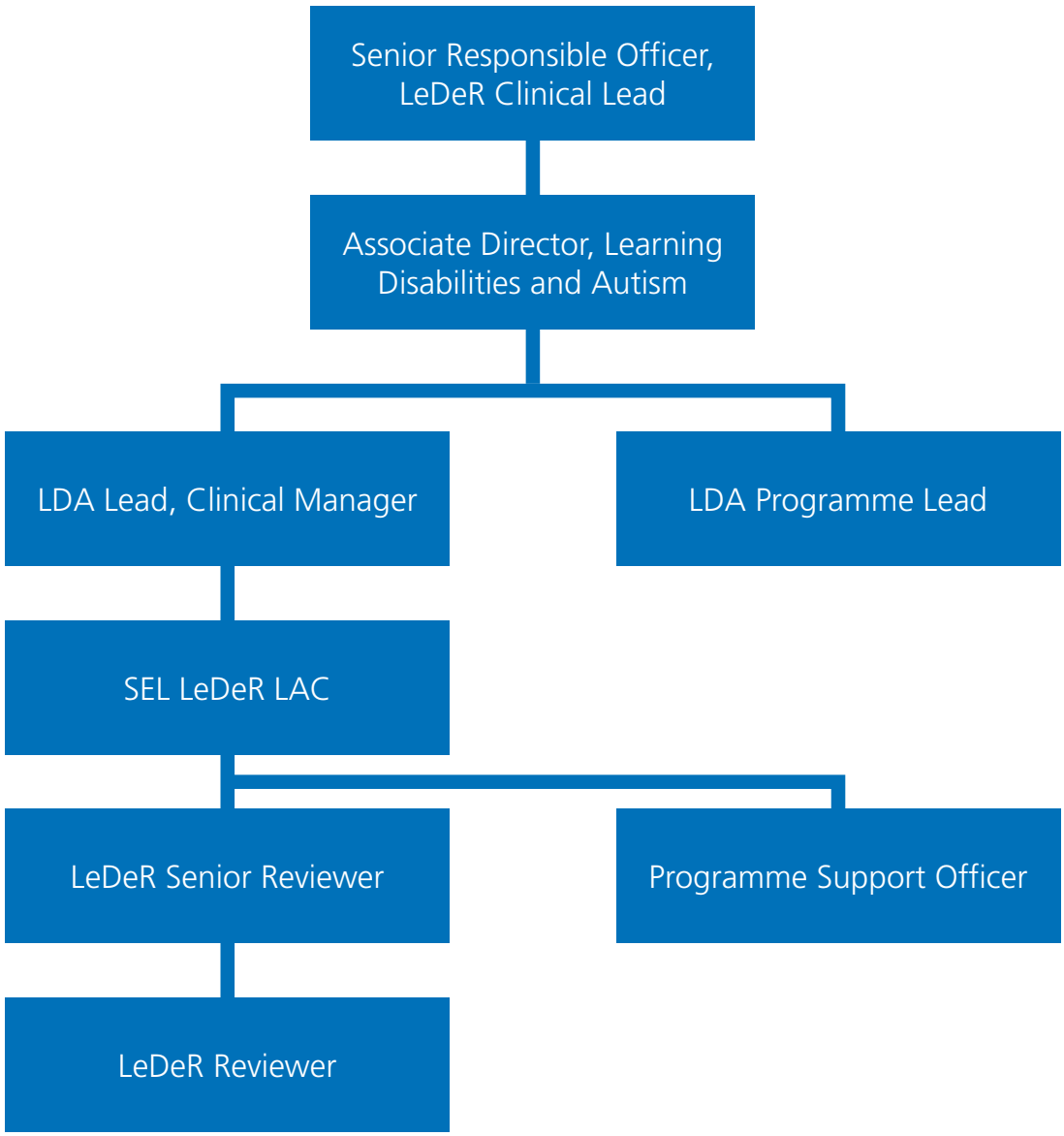


SEL Governance

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities, and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received. The 2021 LeDeR policy requires all NHS Integrated Care Systems to establish a clear governance process to support effective implementation of the LeDeR programme.

The SEL LeDeR programme sits within the Learning Disability and Autism Programme which in turn is part of the Quality and Nursing Directorate and led by the SEL ICB Chief Nursing Officer. The team consists of a Local Area Contact (LAC) and Programme Lead, Programme Support Officer, Senior Reviewer, and a Reviewer.

Figure 1.0 SEL LeDeR team



In response to the requirements of the LeDeR 2021 policy the monthly SEL ICS wide Focused Review Panel was initiated in October 2022. Focused reviews once completed, are presented by the Reviewer to the panel with areas of positive practice, areas of concern, and wider learning from the review being outlined, agreed, and shared.

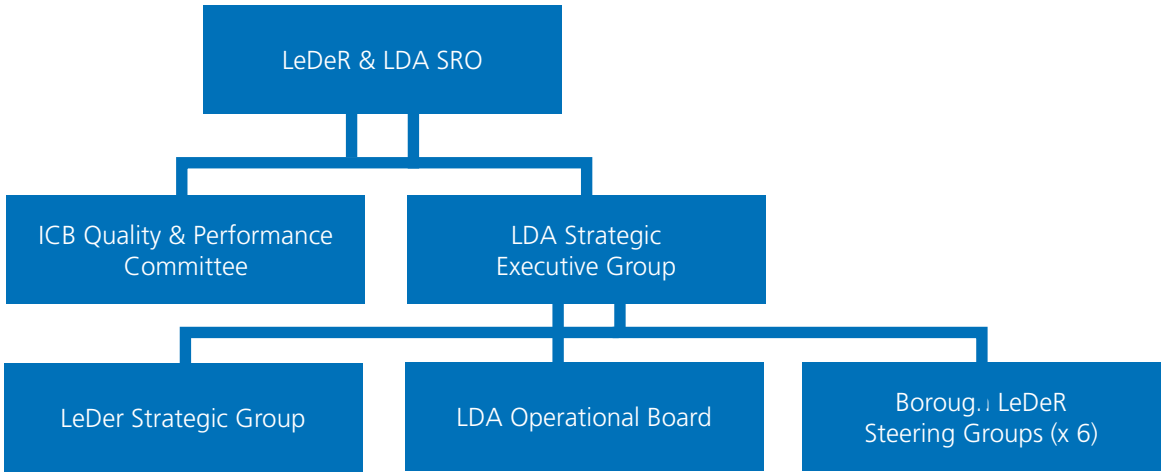
In February 2023 we held our first quarterly LeDeR Strategic Group. The purpose of the group to provide assurance to the South East London Learning Disability and Autism Executive Group and Governing Body that SEL ICS is complying with the national LeDeR requirements and to also:

- Have oversight of ongoing LeDeR themes from completed reviews.
- To share learning from themes arising across all SEL LeDeR reviews.
- Receive feedback from the six London boroughs on ongoing or planned actions on how learning and recommendations will be applied to improve care provision for people with a learning disability and autistic people in each borough.
- Identify and share positive practice across the ICS.
- Child Death Overview Panel (CDOP) reviews - feedback from the six boroughs on ongoing or planned actions on how learning from reviews is completed.

In addition to our LeDeR governance each South East London borough has been working towards developing a local LeDeR Steering Group. The purpose of these groups to:

- Support the work of the SEL LeDeR programme by looking at completed reviews and learning from the deaths of people with learning disabilities and or autistic people.
- Sharing wider SEL LeDeR learning at a local level.
- Increasing awareness of the experiences of people with learning disabilities and or autistic people. This includes good practice, and areas where change is needed.
- Using learning to lead changes needed across the borough in both health and social care and education.

Figure 1.1 SEL LeDeR Governance



South East London LeDeR Demographics

Total number of LeDeR notifications 2022-2023

A total of 82 LeDeR notifications were reported in 2022-2023, this is compared to 44 LeDeR notifications in 2021-2022.

Figure 1.2 Total number of LeDeR notifications received per month in 21/22 and 22/23

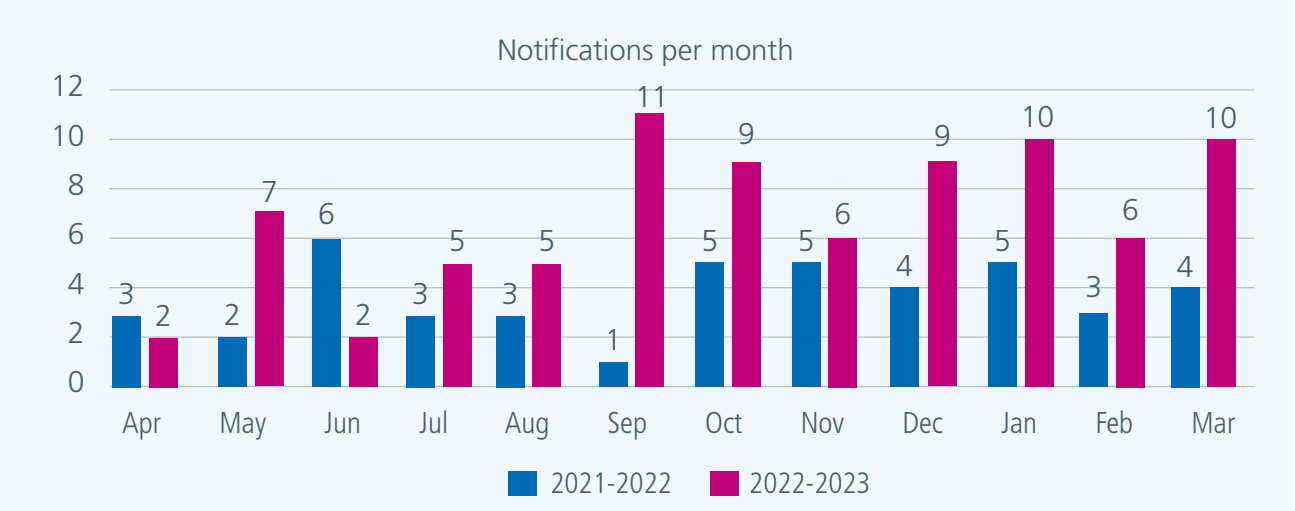
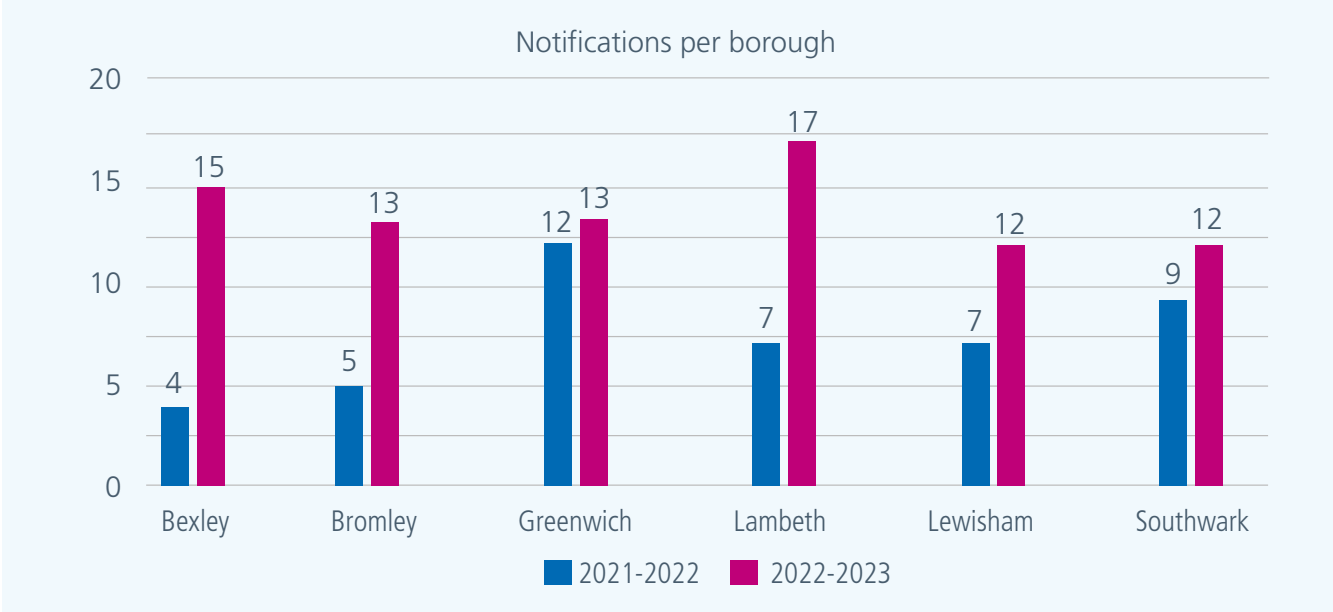


Figure 1.3 Total number of LeDeR notifications received per borough in 21/22 and 22/23



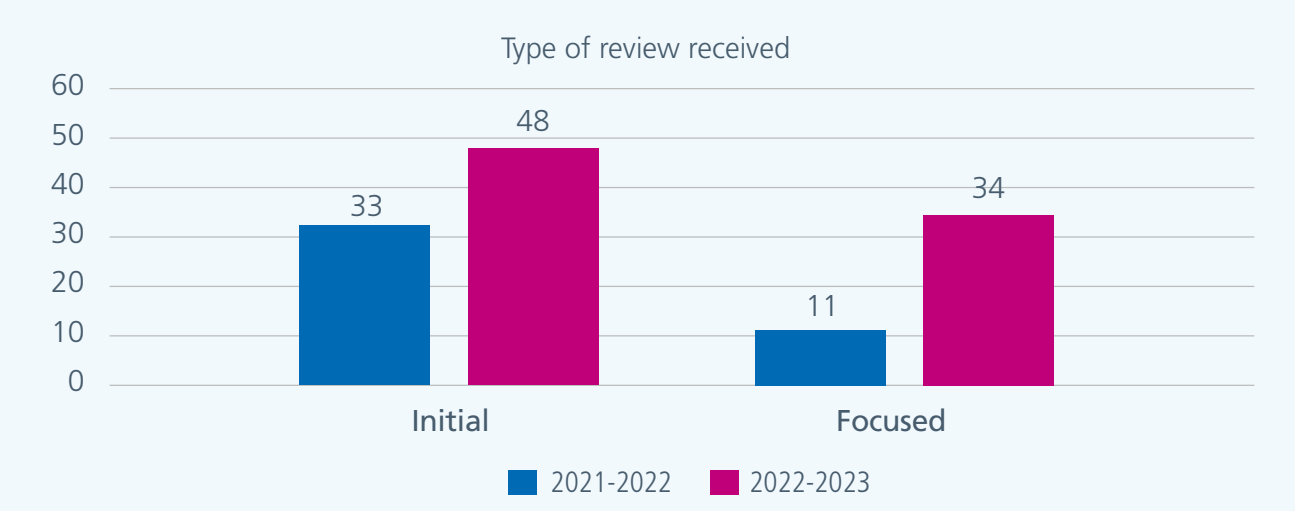
Type of review

There are two types of reviews: initial and focused. Focused reviews explore in more detail the life and death of the person and lessons that can be learnt from their care.

The current criteria for a focused review are:

- All autistic people who do not have a learning disability aged 18 and above.
- People from ethnic minority backgrounds, which includes Asian or Asian British, black, or black British, Caribbean, or African, mixed, or multiple ethnic backgrounds and other ethnic backgrounds.
- People who have been in a detained setting in the criminal justice system/or who have been under a Mental Health Act restriction within five years of death.
- Where there is likely to be significant learning from the life of the person to inform service improvements.
- Local priorities for focused reviews.
- Where the family have requested a focused review.
- Where there are any concerns about the care the person received.

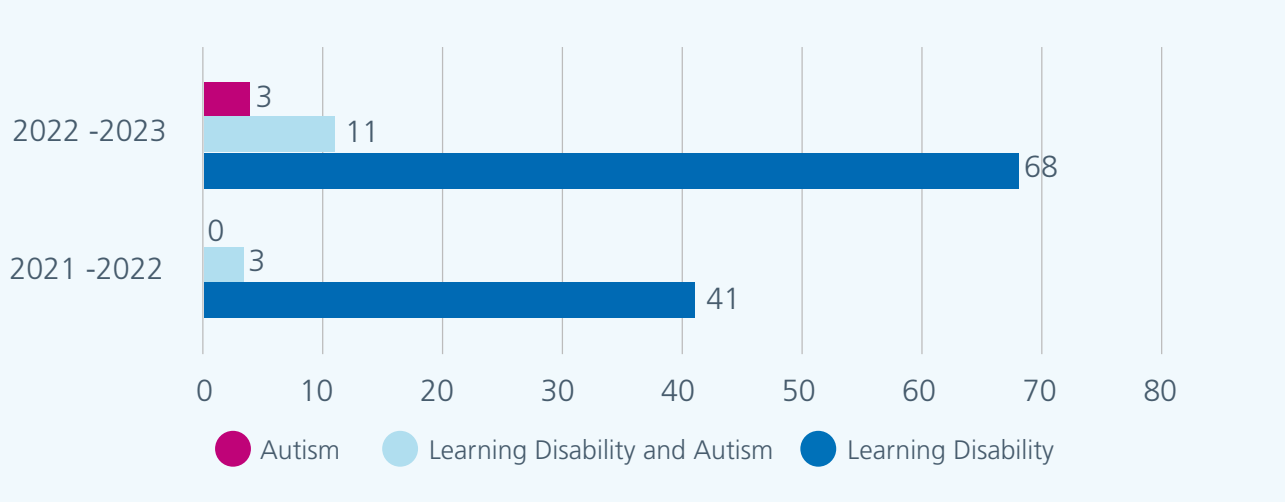
Figure 1.4 Number of LeDeR initial and focused reviews received in 21/22 and 22/23



Type of patient

Type of patient includes people with a learning disability, autistic people with a learning disability and autistic adults. Figure 1.5 indicates the number of autistic reviews received is still very small but perhaps this is to be expected as the inclusion of autistic adults' deaths in LeDeR only started in January 2022. As a team we are working with local partners, to raise awareness of the fact that the deaths of autistic adults can be notified to LeDeR.

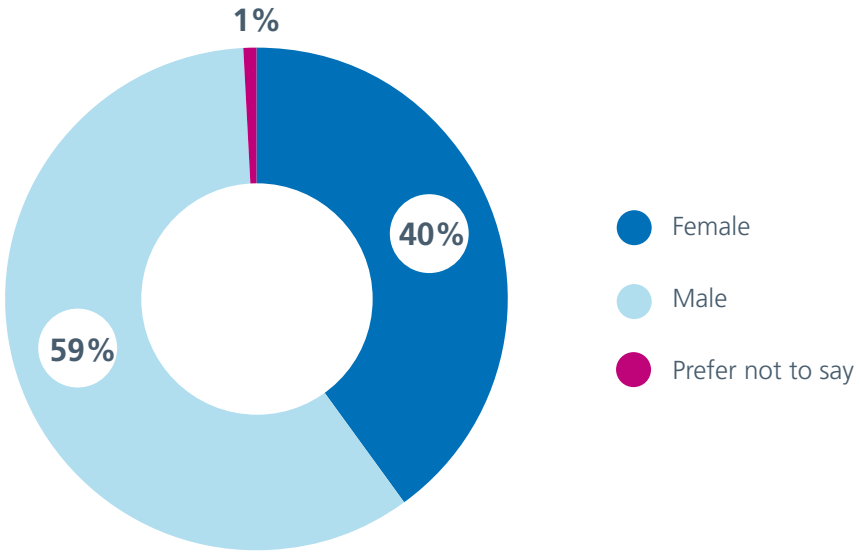
Figure 1.5 Type of patient



Gender

Of the 82 LeDeR notifications received males accounted for 59% of deaths, females 40% and 1% were denoted at the time of notification as preferring not to say.

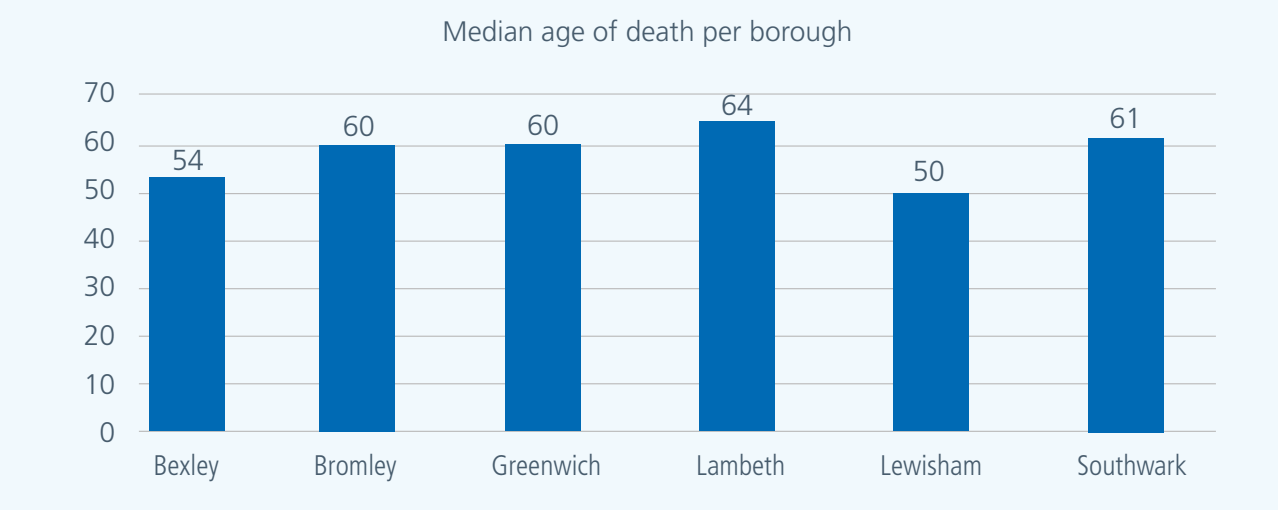
Figure 1.6 Gender of the 82 LeDeR notifications received in the reporting year 22/23



Age at death

Across South East London the median age at death for those with a learning disability and or autism was 61 for males, 21 years lower than the national general population and 57 for females, 28 years lower than the national general population. Figure 1.7 shows the median age of death for each borough.

Figure 1.7 Median age of death in each borough for LeDeR notifications



Ethnicity

The vast majority (71%) of adults with a learning disability and autistic people who died in 2022-2023 were denoted as white at the time of notification. This is only slightly higher than 2021-2022 (70%).

Figure 1.8 Ethnicity of the 82 SEL LeDeR notifications received in 22/23

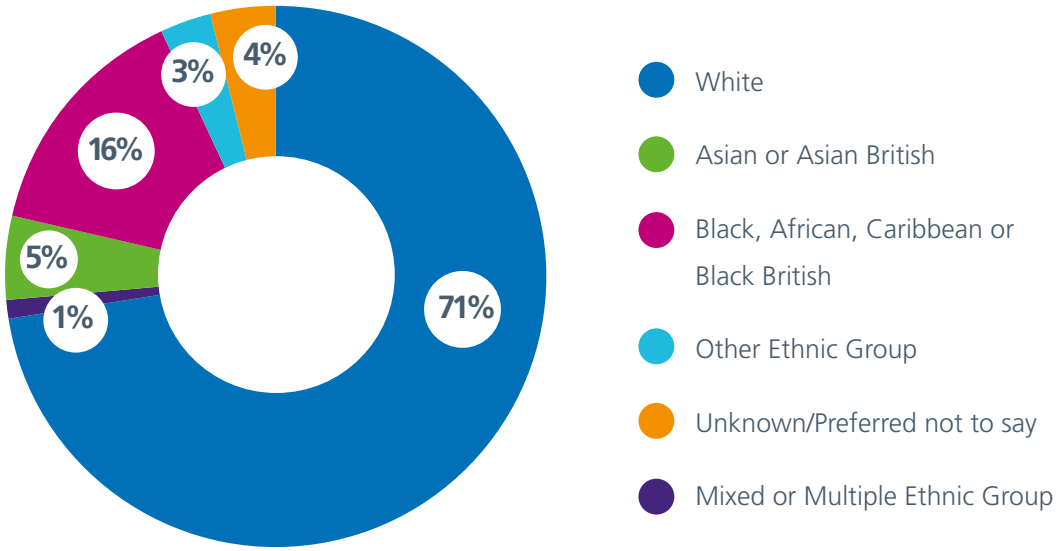
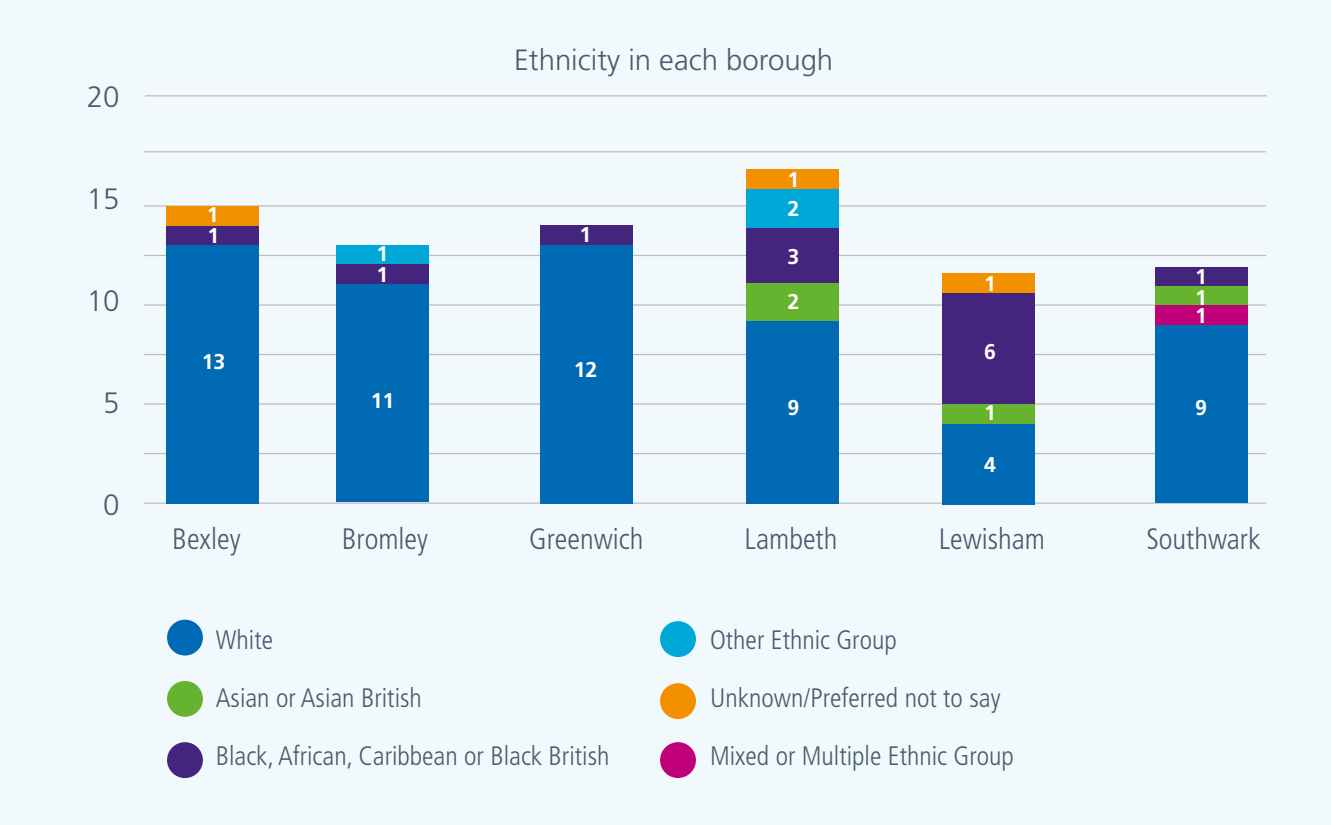


Figure 1.9 Ethnicity of the LeDeR notifications received for each London borough



South East London CDOP Demographics

The Child Death Overview Panel (CDOP) is responsible for reviewing all child deaths (people under the age of 18) to identify learning to help prevent future child deaths. Data from the CDOPs of children and young people with a learning disability and or autism is then shared with the SEL LeDeR team. Due to no CDOP reviews being completed between April 2022 and March 2023 our dataset is small and therefore unable to identify if there are any significant differences on cause of death when compared to CDOP reviews where a child did not have a diagnosis of learning disability or autism.

Number of CDOP deaths notified to SEL LeDeR in 2022-2023

Between April 2022 and March 2023 8 CDOP deaths were reported to the SEL LeDeR team.

Type of review

Of the 8 CDOP reviews received 4 were marked as Initial and 4 as Focused.

Gender

We received 4 male notifications and 4 female notifications.

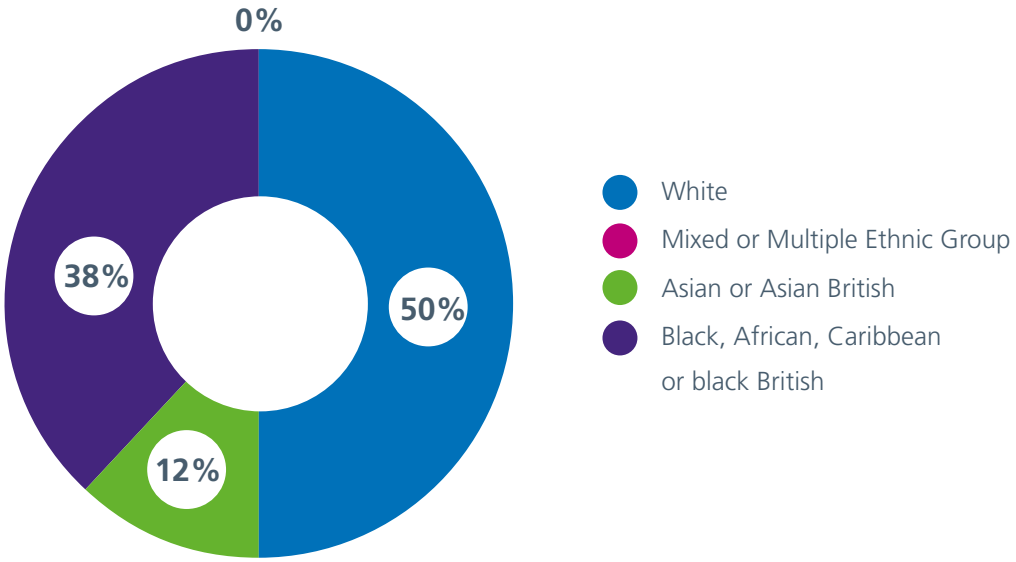
Age at death

The median age at death for the 8 CDOP reviews received was 11. The median age at death for males was 13 and 9 for females.

Ethnicity

50% of the notifications received were donated as white.

Figure 2.0 Ethnicity of the CDOP reviews received in 22/23



Reviews completed in 2022-2023

Between April 2022 and March 2023, the SEL LeDeR team completed 40 LeDeR reviews (24 initial and 16 focused), no CDOP reviews were completed during this reporting period. During 2022-2023 we encountered delays with the completion of LeDeR reviews. This was due to a number of factors such as the national update to the LeDeR platform, notifications being received late on the platform due to a longer screening period of passing through the NHS Personal Demographic Service (PDS) database and reduced staff capacity.

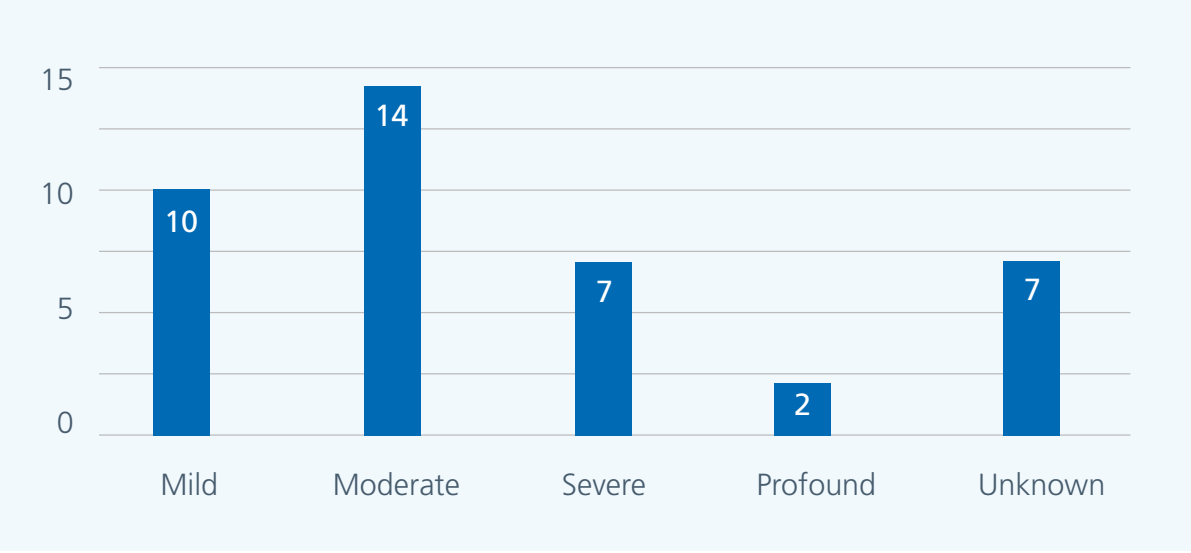
Autism LeDeR Reviews:

In January 2022, the LeDeR 2021 Policy introduced the inclusion of review for autistic adults for the first time. We completed one autism review in 2022/2023. This review is not representative of all autistic adults without a learning disability, and therefore very limited conclusions can be made. Increased reporting is needed to be able to better determine areas for improvement in the care of autistic adults without a learning disability. To maintain the confidentiality of this person we will not discuss details of this review in this report, but it is hoped that with increased awareness of the inclusion of autistic adults within LeDeR, future annual reports will be able to offer some analysis of issues relating to this cohort.

Level of learning disability

Of the 40 reviews completed, Figure 2.1 shows the level of learning disability recorded by the reviewer.

Figure 2.1 Level of learning disability



Annual Health Checks/Learning Disability Register

Of the 40 LeDeR reviews completed 78% of people had received an annual health check and 73% were recorded as being on the GP Learning Disability Register. Table 1.0 shows the number of learning disability health checks completed in each London borough; the annual target is 75%.

Table 1.0 Number of health checks completed (aged 14 and above) per borough in 22/23

Borough	LD Population	LD Annual Health Check	% with Annual Health Check
Bexley	1119	850	76%
Bromley	1176	893	75.9%
Greenwich	1512	1202	79.5%
Lambeth	1555	1322	85%
Lewisham	1728	1273	73.7%
Southwark	1174	986	84%

Transitions

Two reviews completed were within the age of 18-25. To maintain the confidentiality of these people it is not possible to go into detail about their reviews within this report. However, it is worth noting that despite one of these people having a severe learning disability, they were not on the GP learning disability register and did not have an annual health check completed.

Next of Kin involvement in care and LeDeR review process

Of the 40 reviews completed, 33 had an identified next of kin involved in their care while seven did not have a known next of kin. All 33 identified next of kin were contacted by letter informing them of the LeDeR review and invited to contribute to the review process. 20 next of kin responded and contributed to the review; of which two of these who contributed to the review lived abroad, although it was clear in discussion that they were very involved in the welfare of their relative, maintaining regular communications with them or the professionals involved.

Six next of kin did not respond to the LeDeR communication and the remaining next of kin responded but declined to take part in the review process; two of whom declined to take part in the review because of their distress in talking about their relative.

Circumstances and Causes of Death

Place of death

The majority of people who died in hospital had been admitted acutely via A&E with the exception of one who had attended an outpatient clinic. Six people had previous hospital admissions within 30 days of the last admission. Concerns had been expressed about how lack of investigation and/or discharge planning may have contributed to re-admission. Admissions where there was learning disability liaison nurses involvement tended to have better outcomes.

Table 1.1 Place of death

Place	Percentage
Hospital	51%
Usual Place of Residence	41%
Hospice	4%
Other	3%
Mental Health Unit	1%

Deaths reported to Coroner

Deaths are reported to a coroner in certain circumstances. These can include suspicious deaths, those with an unknown cause, or deaths which have occurred under state detention. It is important to note that a death reported to a coroner is not an indication of the quality of care a person received. Of the 82 LeDeR notifications received in 2022-2023 18 were referred to the coroner.

Deaths with DNACPR

A do not attempt cardiopulmonary resuscitation (DNACPR) decision is put in place to protect people from unnecessary suffering by receiving cardiopulmonary resuscitation (CPR) that they don't want, that won't work or where the harm to them outweighs the benefits. According to the National Institute for Health and Care Excellence (NICE) guidelines, DNACPR decision must be made on an individual basis.

Of the 40 LeDeR reviews completed 52% of people had a DNACPR in place at the time of death. In all but one of the situations where there was a DNACPR in place it is recorded that this was discussed with the next of kin.

End of Life Care

A good End-of-life care plan should include priorities and preferences for care and treatment, decisions about resuscitation, views about how and where they would like to be looked after in their last days of life, who they would like to have with them and any spiritual or religious beliefs they would like to be considered. 20 reviews completed had an End-of-Life Care plan in place. 11 of these had community or hospital palliative care provision.

Cause of death

Table 1.2 shows the most common cause of death for people whose LeDeR review was completed between April 2022 and March 2023. This is comparable to 2021-2022 where the main cause of death was respiratory diseases/illnesses.

Table 1.2 Cause of death

Cause of death	Percentage
Pneumonia (Aspiration, Broncho and Pneumococcal)	37.5%
Heart disease	12.5%
Cancer (Duodenal tumour, Oesophageal cancer, Metastatic renal cell carcinoma and malignancy of unknown origin)	12.5%
Sepsis	7.5%
COVID 19	5%
Respiratory Failure	5%
Frailty, old age	5%
Chest Infection	2.5%
Brain Stem Death	2.5%
Hypoxic Brain Injury	2.5%
Bowel Ischaemia	2.5%
Alzheimer's	2.5%
Postural Asphyxia associated with Epilepsy	2.5%

Long Term Health Conditions

When a death is reviewed by a LeDeR Reviewer, information is collected about whether the person had any long-term health conditions. However, information about long-term health conditions is not always accessible to Reviewers as it depends on what type of health records they can obtain. A total of 40 LeDeR reviews were completed in 2022-2023 the table below shows the percentage breakdown of each long-term health condition recorded.

Table 1.3 Long-term health conditions

Long Term Health Conditions	Percentage
Mobility Difficulties (Including mobility aids and frequent falls)	63%
Continence (Including Urinary Tract Infection (UTI) and Incontinence)	53%
Epilepsy	50%
Dysphagia	43%
Gastro-intestinal (Including Constipation)	38%
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	30%
Cardiovascular Disease (excluding Hypertension/Stroke)	30%
Diabetes	28%
Hypertension	28%
Sensory Difficulties	28%
Mental Health Condition	25%
Dementia	23%
Cancer	18%
Chronic Kidney Disease (Renal)	15%
Body Mass Index (BMI) over 30	10%
Stroke	10%
Body Mass Index (BMI) Under 18	8%
Deep Vein Thrombosis (DVT)	3%

Epilepsy

Of the 40 reviews completed, 50% had epilepsy. Findings indicated varying access to specialist epilepsy care. In cases where epilepsy specialist nurses, (including learning disability epilepsy specialist nurses) were involved, there were positive working relationships with both the individual and their families. In several cases, an increase in seizure activities were linked to infections (including lower respiratory tract infection and urinary tract infections) as well as deteriorating conditions (including dementia). Care plans and risk assessments were not always completed, which left potential epilepsy risks unmanaged. To address this Oxleas Community Learning Disability Nursing Team reviewed their epilepsy pathway to ensure that an epilepsy risk assessment and a full nursing assessment are completed.

National Cancer Screening Programme

Cervical Screening:

The NHS cervical screening programme in England is offered to people with a cervix aged from 25 to 64. Routine screening is offered every three years up to 49 years of age and every five years from 50 to 64 years of age.

Breast Screening:

Breast screening is offered to women aged 50 to their 71st birthday in England.

Bowel Screening:

NHS bowel cancer screening checks for bowel cancer. It is available to everyone aged 60 to 74 years. The bowel programme is slowly expanding to ensure everyone aged 50 years and above will be eligible to receive bowel screening home-test kit by 2025.

The number of reviews completed that had a diagnosis of Cancer was small and as such we cannot provide a detailed analysis for de-identification reasons. However, it is possible that some of these people would have been affected by the COVID Pandemic and therefore some of the annual health checks or consultations would have been done by telephone possibly resulting in the GP or nurse being unable to pick up on signs that can guide investigations/ earlier screening.

It was not always clear why a person did not attend their annual health check or cancer screening. For example, it was found that some patients attended bowel screening but no other screenings. Most of the records available to the Reviewer had minimal details about screening tests undertaken. For some at the time of diagnosis their disease was quite advanced and could be presented as missed opportunities for early diagnosis. The reviewer noted that red flag symptoms were not always followed up or abnormal results not acted on appropriately. However, there were cases that were presented extremely late, and it is unclear if there were any symptoms leading up to their diagnosis. The late presentation of some of these patients suggest that symptoms at an earlier stage must have been missed, not reported, or not acted on.

In some of these cases their experience of end-of-life care was poor with emergency admissions and poor pain control. However, there were positive practices identified including good multi-disciplinary working and good communication involving the individual, carers, and relatives as well as the services involved.

Ethnic Minority Communities

Of the 40 reviews completed 11 reviews were from an ethnic minority background. These reviews were all completed as focused reviews. Median age at death for those with a learning disability and or autism is 48 years when compared to the white population which is 63 years.

Figure 2.2 Ethnic minority notifications

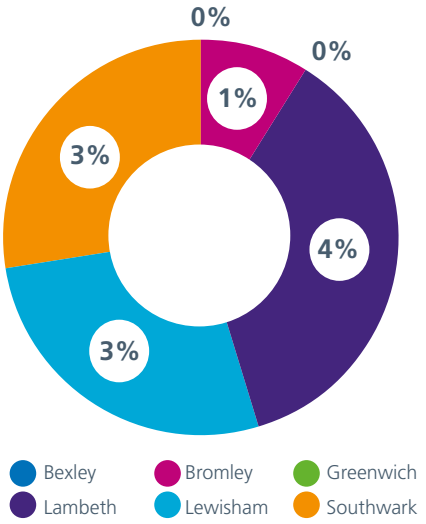
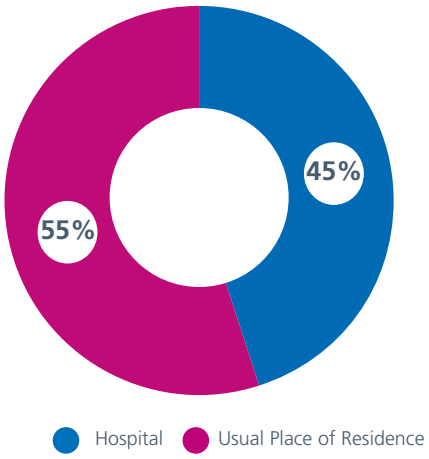


Figure 2.3 Place of death



Cause of death

Cause of death within the ethnic minority community was found to be similar when compared to the white population with pneumonia being the most recorded cause of death. 18% of those from an ethnic minority background died from COVID 19 whilst there were no reported COVID 19 deaths within the white population.

Table 1.4 Cause of death

Ethnic Minorities: Cause of death	Percentage
Pneumonia; including Aspiration, Broncho and Pneumococcal	28%
COVID 19	18%
Respiratory Failure	18%
Heart Disease	9%
Duodenal Tumour	9%
Bowel Ischaemia	9%
Sepsis	9%

Table 1.5 Clinical processes

Ethnic minority communities: Clinical processes	Percentage
Mental Capacity Assessment completed	81%
Best Interest Decisions made appropriately	81%
Annual Health Check	63%
Do Not Attempt Resuscitation – DNACPR	45%
DNACPR discussed with family	45%

Long term conditions

Mobility difficulties were found to be the most prevalent long-term condition in both white and ethnic minority communities. However, it was noted that, people from an ethnic minority background had a higher percentage of both Epilepsy and Diabetes.

Table 1.6 Long term conditions

Ethnic Minorities: Long term health conditions	Percentage
Mobility difficulties (Including mobility aids and frequent falls)	63%
Epilepsy	54%
Continence (Including Urinary Tract Infection (UTI) and Incontinence)	45%
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	36%
Diabetes	36%
Cardiovascular Disease (excluding Hypertension/Stroke)	36%
Dysphagia	36%
Gastro-intestinal (Including Constipation)	36%
Sensory difficulties	27%
Mental Health Condition	27%
Body Mass Index (BMI) over 30	27%
Chronic Kidney Disease (Renal)	18%
Hypertension	18%
Cancer	9%
Dementia	9%
Body Mass Index (BMI) Under 18	9%
Stroke	0%
Deep Vein Thrombosis (DVT)	0%

Quality of Care and Effectiveness of Services: Focused reviews

Within the focused review's completed an additional question asks the reviewers to grade both the quality of care and availability and effectiveness of services the person received. This is rated on a six-point scale as shown below. 25% of the 16 completed focused reviews received good care with availability and effectiveness of services being good and meeting the expected standard for 37.5% of reviews.

Table 1.7 Quality of care grading

Grade	Quality of Care	Number	Percentage
1	Care fell far short of expected good practice and this contributed to the cause of death.	1	6.25%
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	2	12.5%
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.	2	12.5%
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	7	43.75%
5	This was good care (it met expected good practice).	4	25.0%
6	This was excellent care (it exceeded expected good practice).	0	0%

Table 1.8 Grading of quality of care versus severity of learning disability

Grading	Mild	Moderate	Severe	Profound	Unknown	Total
1	1	0	0	0	0	1
2	1	0	1	0	0	2
3	1	1	0	0	0	2
4	2	1	1	1	2	7
5	0	1	2	0	1	4
6	0	0	0	0	0	0

Table 1.9 Availability and effectiveness of services

Grade		Number	Percentage
1	Availability and effectiveness of services fell far short of the expected standard, and this contributed to the cause of death.	1	6.25%
2	Availability and effectiveness of services fell short of the expected standard, and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	2	12.5%
3	Availability and effectiveness of services fell short of the expected standard, and this did impact on the person's wellbeing but did not contribute to the cause of death.	1	6.25%
4	Availability and effectiveness of services fell short of the expected standard in some areas, but this did not significantly impact on the person's wellbeing.	6	37.5%
5	Availability and effectiveness of services was good and met the expected standard.	6	37.5%
6	Availability and effectiveness of services was excellent and exceeded the expected standard.	0	0%

Table 2.0 Grading of availability and effectiveness of care versus severity of learning disability

Grading	Mild	Moderate	Severe	Profound	Unknown	Total
1	1	0	0	0	0	1
2	1	0	1	0	0	2
3	0	1	0	0	0	1
4	3	0	1	1	1	6
5	0	2	2	0	2	6
6	0	0	0	0	0	0

Good practice gathered: completed reviews

- Good collaborative working between the Learning Disability Epilepsy Nurse and Social Worker.
- Community Learning Disability Team formed an excellent relationship with patient and their family.
- GP offered annual health check virtually and in person to promote engagement, and liaised with carers over the phone to ensure the right support was offered.
- Family had good communication with the GP.
- GP flagged learning disability and indicated need for additional time on records.
- Family were involved in decision making – particularly end of life care plans.

Reviewers recommendations on areas needing change

- Improved quality of Annual Health Checks to pick up unidentified problems and if required ensure reasonable adjustments are in place.
- DNACPR correctly completed.
- Improved accuracy of hospital passports.
- More targeted and proactive campaigns to increase uptake of cancer screening programmes.
- Improved early diagnosis of cancer - improved understanding of missed opportunities for early diagnosis of cancer.
- Increased reporting of deaths for autistic people.

Learning into action

SEL LeDeR programme has recorded a number of local initiatives and projects. These initiatives were aimed at creating awareness of the LeDeR/Learning Disability and Autism programme while addressing gaps identified in this LeDeR report and previous reports. Working closely with key partners/services and our LeDeR Local Leads, below are just some of the activities documented.

South East London ICB Learning Disability and Autism Specialist Prescribing Team:

The Specialist Prescribing Team has implemented several initiatives in response to insights from previous LeDeR reports. This includes a proactive approach to raise awareness on all aspects of learning disability and autism and to provide training across the region, such as through SEL wide educational sessions focused on Stopping over medication of people with a learning disability, autism, or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP). The emphasis is on promoting patient safety, reducing the potential side effects of medications, and minimizing unnecessary medications.

Efforts have been directed towards improving the uptake and quality of Annual Health Checks (AHCs). By enabling the primary care workforce, the team aims to facilitate the proactive management of avoidable complications and the effective management of co-morbidities such as asthma and epilepsy, either through comprehensive AHC provisions or appropriate onward referrals to specialised services. Additionally, the team is actively involved in supporting the management of vaccinations, aligning with LeDeR recommendations, to prevent premature deaths caused by diseases like pneumonia and flu.

The team has also contributed to enhancing the review process by strengthening data collection, particularly regarding medication usage and physical examinations. This step has been crucial in providing a comprehensive understanding of patient health. The team has taken the opportunity to raise awareness about proactive screening, aiming to facilitate informed decision-making for better patient outcomes and reduce health inequalities. Efforts have also been made to educate people with learning disabilities and their caregivers through engagement events, empowering them to take more ownership of their health.

Recognising the critical implications of medication administration errors, the team has actively engaged in educating care agency staff and those working in residential home. This involvement stems from identified quality concerns and safeguarding issues. The team is committed to increasing awareness and providing necessary support to care homes, especially in addressing specific medication-related issues and training needs.

Learning Disability and Autism Programme:

The Learning Disability and Autism Big Health Week took place between the 7-11 November 2022. Events included what does a good annual health check look like and reasonable adjustments in healthcare.

South East London Local Initiatives/Projects:

- Commissioned support for Bexley GP surgeries in contacting and visiting those hard-to-reach patients to increase attendance at health checks.
- RESTORE 2 training to support care staff to recognise early signs of deterioration has been delivered to Lambeth providers. 80 staff have been trained from different care homes throughout Lambeth who then cascade the training within their organisations.
- LeDeR awareness session held with Lewisham learning disability providers through learning disability provider forum with LeDeR outcomes shared.
- Bexley Community Learning Disability team and the local Learning Disability Liaison nurses are working on a process to triangulate and share information of individuals who have a diagnosis of learning disability so they can be flagged appropriately on the electronic record system.
- Awareness of the LeDeR programme and requirements for learning disability annual health checks, and annual reviews of epilepsy and dementia care have been shared via the Lambeth GP bulletin. A pathway is also in development for feeding back learning and actions from LeDeR reviews to primary care.
- Annual Health Check Co-ordinator (pilot) in place working with a Lewisham Primary Care Network to model approach with aim to roll out across borough.
- Annual Webinar for primary care clinicians to create awareness of the importance of annual health checks and how a good health check is done.
- During the Learning Disability and Autism Big Health Week Oxleas Community Learning Disability Team have re-launched their Black Books (a book where all health-related information is kept).
- Work is underway with the education setting and community paediatricians as well as planned talks with Bromley council colleagues to see how we can improve our learning disability register size.

Evaluating the Impact

It is the responsibility of SEL ICB to monitor and review service improvement plans to ensure that they are implemented and effective in improving the quality of care provided to people with learning disability and autism, reducing inequalities and saving lives.

In order to achieve this, SEL ICB has put in place the following:

- A strong governance arrangement to not only oversee the completion of the reviews but to ensure actions are taken forward into service improvement and to hold services and stakeholders to account.
- Implemented a three-year SEL LeDeR strategy 2023-2026 which sets out our commitment to service improvement in relation to the LeDeR findings. This includes an implementation and monitoring plan for the strategy. This plan will be reviewed annually to ensure improvements are captured and any challenges mitigated in good time.

Looking Forward

In future years we seek to enhance our annual report further, as our LeDeR dataset grows, so will the opportunities for further statistical analysis. This will allow us to record change over time, understand where initiatives have been effective, and target areas where more needs to be done. Areas of work to be continued is as follows:

- Continue to raise awareness of the LeDeR Programme in particular the inclusion of autism across South East London to ensure all individuals with a learning disability and autistic individuals who sadly die are notified to the programme and their death reviewed in a timely manner.
- Continue to build and strengthen our links between key partners, care providers and NHS health services to ensure all findings and recommendations from reviews are shared and reflected in transformation work streams to further improve the lives of individuals with a learning disability and autistic adults living within South East London.

How will we evidence that service improvements are making a difference to people with a learning disability and autism and their families?

- The SEL LeDeR Governance Group will monitor the themes and trends from completed reviews within their meetings.
- Reviewers will continue to monitor and report improvement in grading of care and effectiveness of services.