

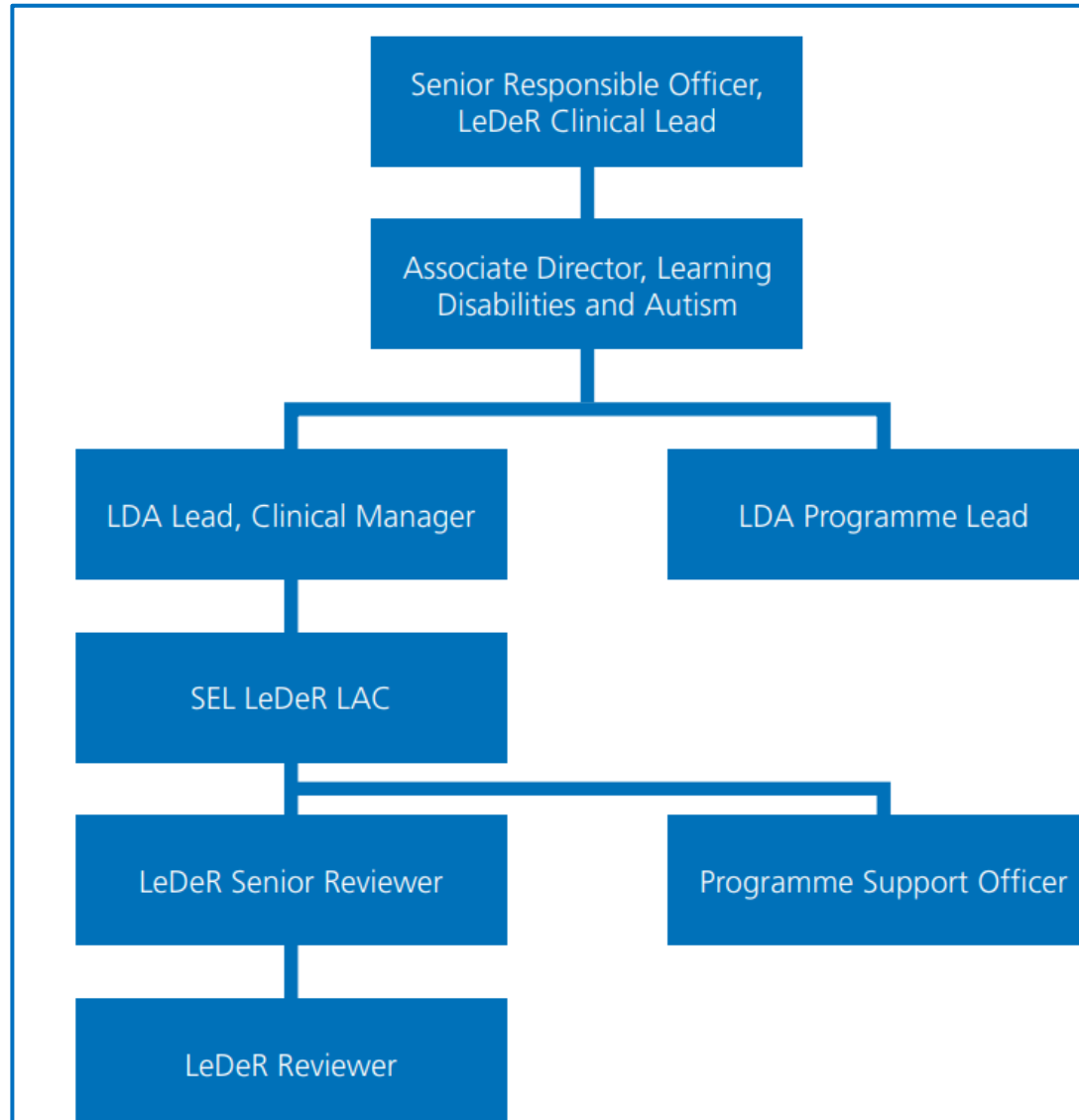
South East London Three Year LeDeR Strategy 2023-2026

Background and Rationale

- Learning from Lives and Deaths – People with a learning disability and autistic people, or LeDeR (formerly known as the Learning from Deaths Review Programme) started in April 2017.
- It grew out of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD) and was piloted in parts of the country in 2016. A commitment to continuing the LeDeR programme was made in the NHS Long Term Plan 2019.
- The LeDeR Policy was published in March 2021.
- Creation of the NHS England and NHS Improvement Autism Programme highlighted the need for reliable data on the health inequalities faced by autistic people. The changes to the LeDeR policy have provided the opportunity to address this and from February 2022 autistic people became eligible for a LeDeR review.
- 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 people received.
- Responsibility for ensuring the delivery of LeDeR reviews has now moved away from the Clinical Commissioning Groups (CCG's) and into the new NHS arrangements of the Local Integrated Care Systems (ICS).

- In response to the NHSE guidance in the new LeDeR 2021 policy a central LeDeR team was employed by South East London Integrated Care Board (ICB).
- The team comprises a Local Area Contact (LAC), Senior Reviewer, Reviewer and a Programme Support Officer. The LeDeR team will ensure timely completion of reviews, submission of good quality reviews and very importantly that learning and actions are implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality.
- Our 2021/2022 annual LeDeR report has been published, including an easy read version.

South East London LeDeR Team Structure



Executive Summary

- The Leder Policy (2021) stipulates in the local delivery expectations for each Integrated Care System (ICS) that a three-year LeDeR strategy is produced and updated annually in June each year.
- The strategy is expected to demonstrate how the ICS will act strategically to tackle those areas identified in aggregated and systematic analysis of LeDeR reviews and national findings, including how the ICS will reduce the health inequalities faced by people from Black, Asian and Minority Ethnic communities who live locally who have a learning disability and/or are autistic.
- The strategy will be approved within ICS governance and shared with the NHS England regional team and should contain a section to address difficulties faced by people with a learning disability from Black, Asian and Minority Ethnic backgrounds who have a learning disability and/or are autistic.
- There should be a clear plan of action for meaningful involvement of people with lived experience in LeDeR governance.
- The strategy will outline what changes will be made in the next three years as a result of the LeDeR programme. Furthermore, it will serve as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR.

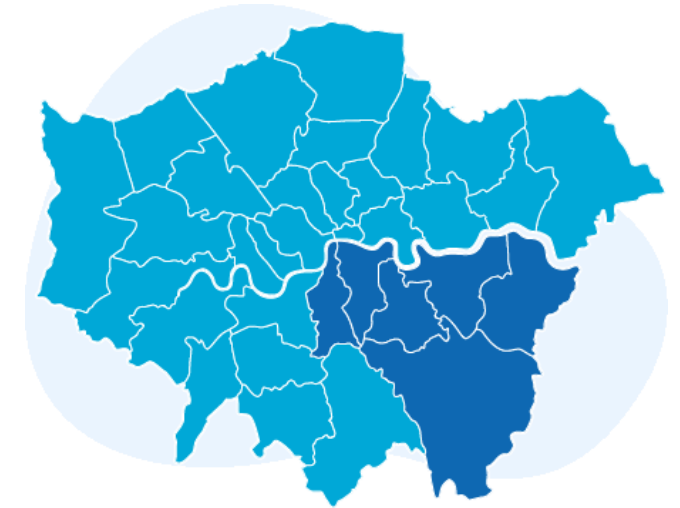
National Picture

- Approximately 2.16% of adults in the UK are believed to have a learning disability.
- Approximately 1% of the population is autistic.
- There is evidence from both before and during the pandemic that deaths for people with a learning disability and or autistic people are higher than they should be, and that they die earlier than the general population.
- Evidence shows that people with learning disability and autistic people experience health inequalities, leading to preventable mortality compared to the general population.

Local Picture: South East London

In 2022/2023 over 2 million people live in South East London:

Bexley:	253,891	LD Population 1228
Bromley:	356,203	LD Population 1280
Greenwich:	316,082	LD Population 1706
Lambeth:	444,851	LD Population 1680
Lewisham:	354,966	LD Population 1908
Southwark:	356,056	LD Population 1294
Total:	2,082,049	9096 (0.4%)



We currently do not have an accurate number of our autism population.

In 2022/2023 **6524 (71.7%)** learning disability patients had an annual health check completed.

Health Inequalities

- On average, the life expectancy of women with a learning disability is **18 years shorter** than for women in the general population (Mencap, 2023).
- The life expectancy of men with a learning disability is **14 years shorter** than for men in the general population (Mencap, 2023).

We know a little about themes of health inequalities experienced by Black, Asian and Minority Ethnic communities. However, we still do not know enough about the lives and deaths of people with autism and the health inequalities they face.

We have:

Ensured Focused reviews are undertaken for all notified deaths of autistic people and people who have a minority ethnic background. This will provide more detailed data to support a greater understanding of need and inform our workstream for years two and three.

Health Inequalities

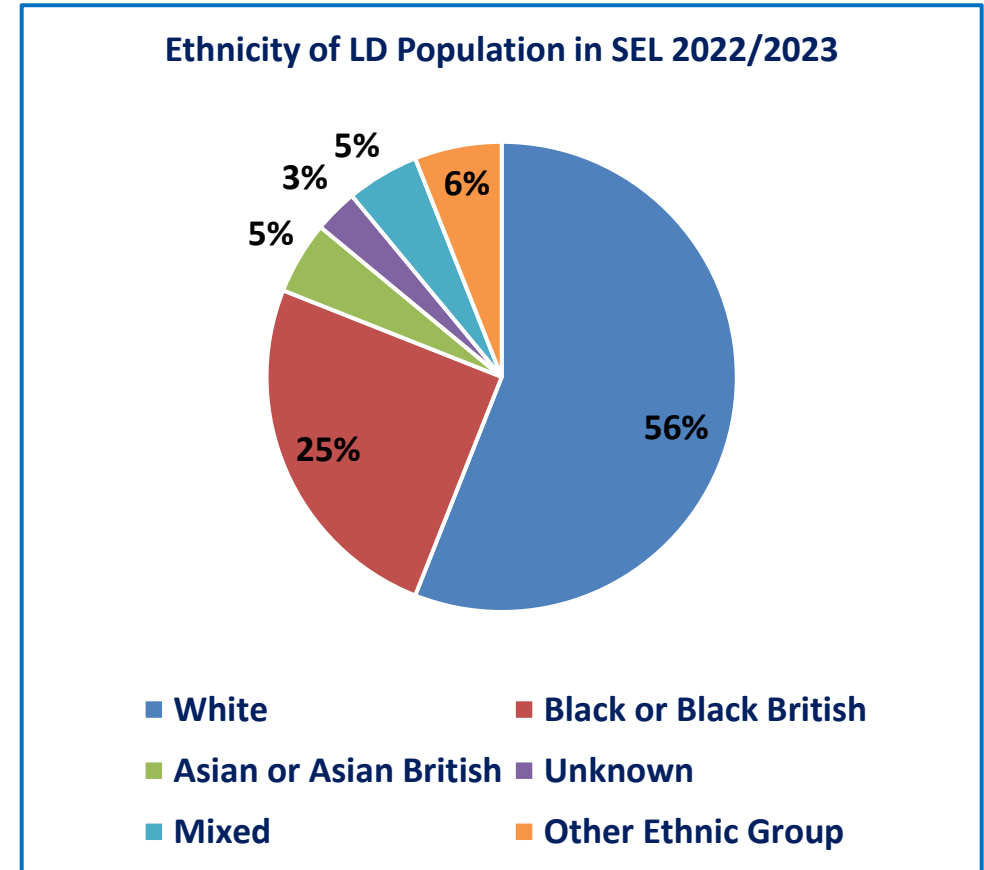
We know there is significant under reporting to the LeDeR programme of deaths from Black, Asian and Minority Ethnic (BAME) communities.

We have:

- Implemented a named lead with responsibility for Black, Asian and Minority Ethnic inequalities.

We plan to:

- Understand whether reporting of deaths of people from Black, Asian and Minority Ethnic communities, is comparable to white communities.
- Establish a communication and engagement plan for highlighting the LeDeR Programme with Black, Asian and Minority Ethnic communities.



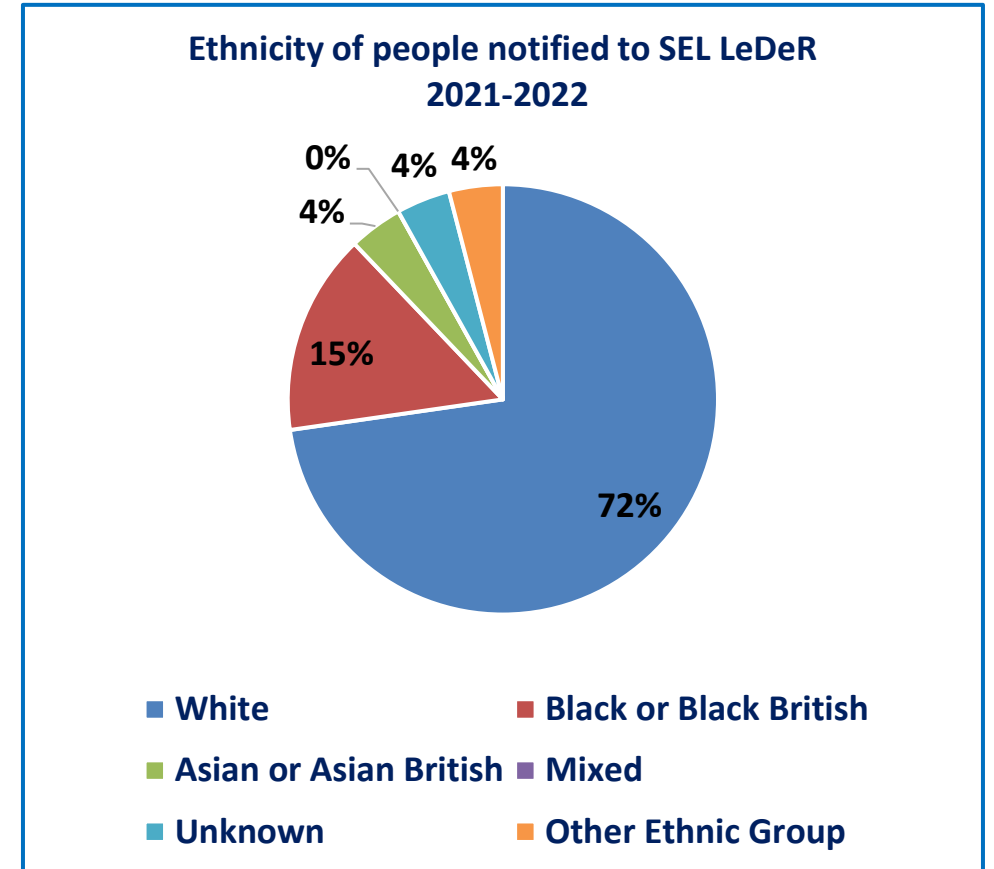
- In total 47 notifications:

45 LeDeR

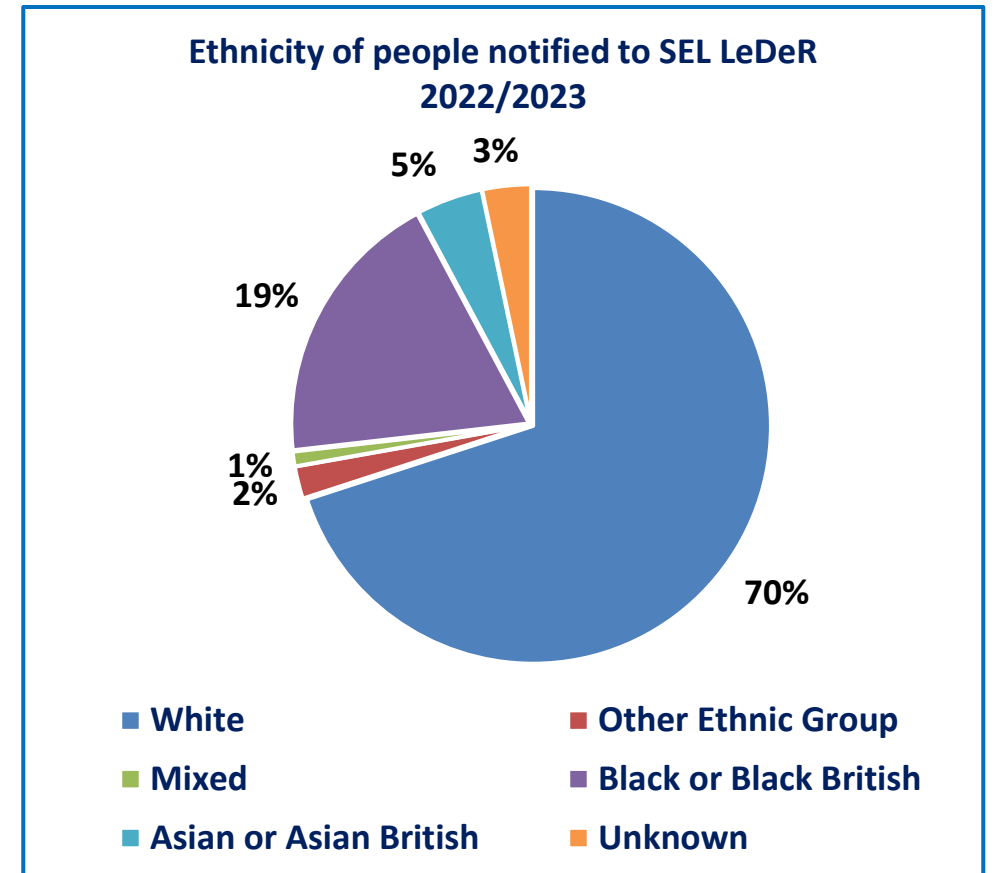
3 CDOP

11 Focused and 36 Initial

- Deaths highest in ages between 60-69 years at 24% and 22% for those between 50-69 years of age.
- 54% of notifications received were female and 46% male.
- People who identified as white made up the highest proportion of deaths (72%).
- In 2021/2022 there was a clear indication that the main cause of death was respiratory diseases/illnesses. This will be reviewed and made an area of local priority for Focused reviews.



- In total 89 notifications:
 - 81 LeDeR
 - 8 CDOP
 - 37 Focused and 52 Initial
- Average age of death: 55 years.
- At time of notification 57% were reported as male, 42% female and 1% preferring not to say.
- People who identified as white made the highest proportion of deaths (70%) notified to the SEL LeDeR Team.



Vision and Aims

Vision:

An Integrated Care System that will be responsible for ensuring that actions are implemented to improve the quality of services for people with learning disabilities and autistic people to reduce health inequalities and premature mortality.

Aims:

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

Objectives

- Deliver a comprehensive LeDeR review programme across South East London ICS.
- To ensure timely completion of reviews.
- Deliver local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.
- Drive local service improvements based on themes emerging from LeDeR reviews at a regional and national level. Influence national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.
- Identify good practice as well as where improvements in the provision of care could be made.
- Local actions are taken to address the issues identified in reviews.
- Recurrent themes and significant issues are identified and addressed at a more systematic level, regionally and nationally.
- To develop excellent pathways with primary, secondary, and tertiary providers.

Please see examples of ongoing projects to improve care provision for people with a learning disability and autistic people in South East London. Please note this is not an exhaustive list and shows just some of the projects taking place/planned.



BEXLEY

A new Epilepsy pathway is being implemented. The Learning Disability nurses within the Bexley Learning Disability Community Teams have received training on the tool and are currently identifying any patient who has epilepsy and requires an epilepsy risk assessment.

A review of the pathway implementation will be carried out by the Oxleas Epilepsy Specialist Nurse via a combination of collecting information and also a survey.

Local Areas of Focus

BROMLEY

Learning Disability Annual Health Coordinator: a pilot project to improve the number of people with a learning disability and autism having an Annual Health Check in Bromley. This will facilitate and ensure the effective delivery of Learning Disability and Autism Annual Health Checks, monitoring progress and reporting outcomes, contributing to quality improvement.

Work is underway to increase awareness of the Annual Health Check in one of the special schools where all students will be eligible. There is also a new parent and carer information leaflet and a postcard that parents/carers can take to their GP to be added to the learning disability register. The plan is that these resources are shared and discussed at the student's annual review of their Education, Health and Care plan at year 9 (aged 14).



Local Areas of Focus

GREENWICH

The LeDeR local borough steering group including its membership and Terms of Reference is currently under review.

A new Epilepsy pathway is being implemented. The Learning Disability nurses within the Greenwich Learning Disability Community Teams have received training on the tool and are currently identifying any patient who has epilepsy and requires an epilepsy risk assessment.

A review of the pathway implementation will be carried out by the Oxleas Epilepsy Specialist Nurse via a combination of collecting information and also a survey.



Local Areas of Focus

LAMBETH

The Learning Disability Steering group and LeDeR/Autism Action Group have identified several key areas/projects of focus for example:

- Making healthcare personalised for people with a learning disability or autism.

Covid vaccination clinic at the Crescent November 2022, GSTT sedation pathway to support those with needle phobia, anxiety etc to be able to access vaccinations and other health care (e.g. dental work) and Reasonable adjustments: ongoing work with GP practices to ensure they have the tools to make reasonable adjustments.

- Application of the Mental Capacity Act (MCA).

LeDeR workshop at MCA group March 2022 (understanding MCA patterns in peer reviews) and MCA week in March 2023 – practice focus, across partners.

Guys and St Thomas NHS Foundation Trust: Community Learning Disability Team and Tier 3 Weight Management Psychologist are developing a reasonably adjusted pathway for people with learning disabilities with a BMI 40+.



Local Areas of Focus

LEWISHAM

The Lewisham Learning Disability Health Stakeholder Group is represented by all partnerships and meet regularly to oversee the work across the borough in order to improve health outcomes for people with learning disabilities.

Learning Disability and Autism Specialist Prescribing Advisors are creating and facilitating training sessions to address gaps in knowledge amongst primary care teams borough wide as well as within Primary Care Networks.

The aim is to raise awareness and increase confidence in clinicians which helps to increase uptake and improve the quality of annual health checks.



Local Areas of Focus

SOUTHWARK

All service users at a local day service provider are being offered pre-assessments and additional support to attend annual health checks, along with liaison with social prescribers.

Health Ambassador's undertook quality checks at GP practices.

Learning Disability and Autism Specialist Prescribers are working with GP practices on learning disability register accuracy.

Guys and St Thomas NHS Foundation Trust: Community Learning Disability Team and Tier 3 Weight Management Psychologist are developing a reasonably adjusted pathway for people with learning disabilities with a BMI 40+.



South East London Projects

- **Reasonable Adjustment Digital Flag:** This will inform health and social care staff that a person has indicated that they need reasonable adjustments to access care. Early identification of this should result in improved health and social care outcomes. Piloting commences - June 2023. GSTT and NHSE working with advocacy group of people with learning disabilities in Lambeth, Southwark and Lewisham. From this pilot recommendations will be made as to how the flag can be effectively implemented across all services.
- **Cancer Screening Project:** Enabling fair and equitable access to NHS screening programmes for people with a learning disability. Oxleas and NHSE working across SEL to understand what's in place, identify gaps and develop improvement plan.

Working together with people with Lived Experience

We plan to ensure meaningful involvement of people with lived experience in LeDeR governance by:

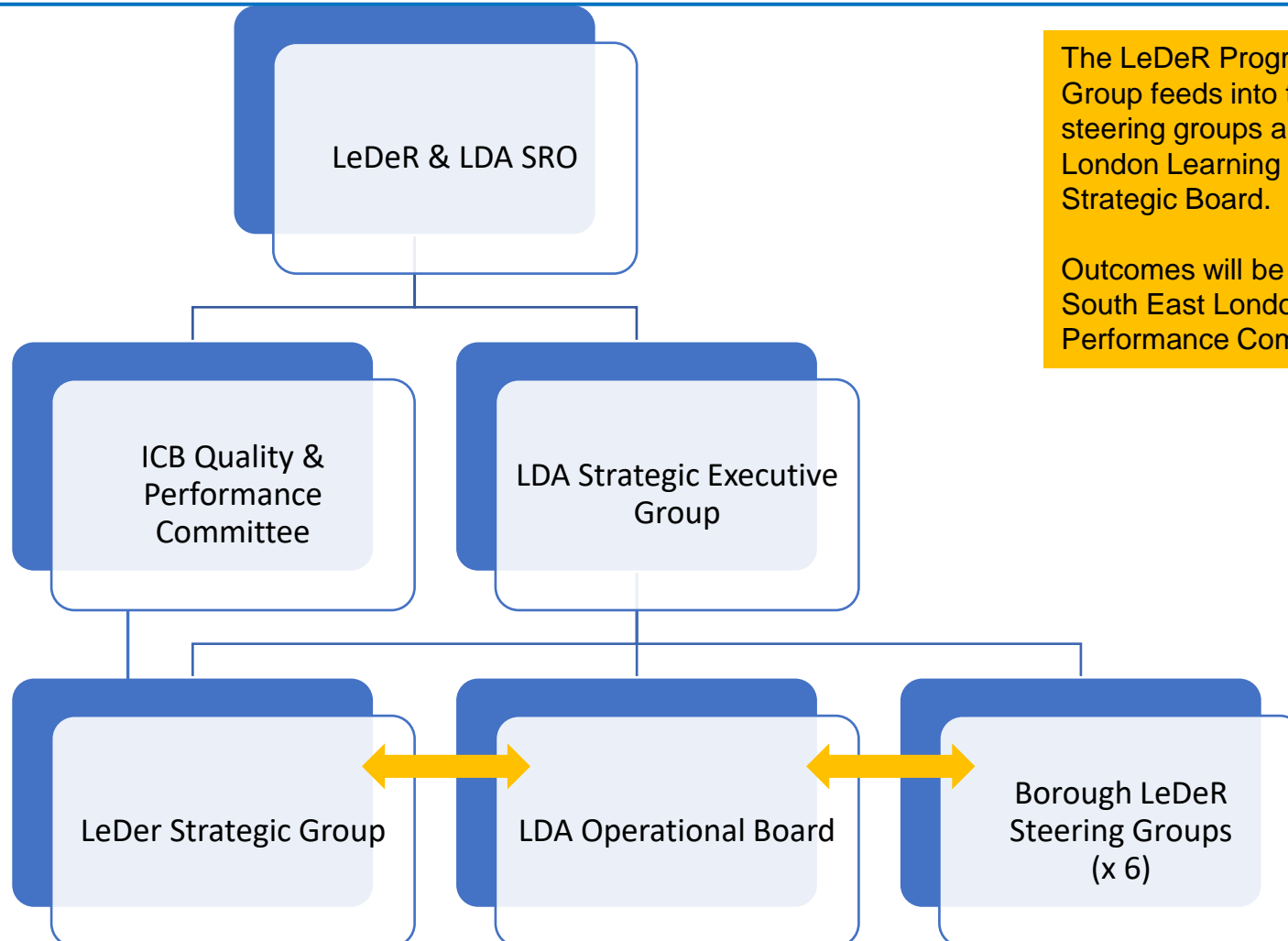
- Determining key roles for people with lived experience within local steering groups and forums to shape action and embed culture shift.
- Ensure support is provided to enable the person with Lived Experience to attend steering groups/forums.
- Utilise easy read resources/invitations.

We have robust governance structures to ensure the delivery of the LeDeR programme in South East London is currently being implemented. This will ensure learning from the reviews of deaths of people with a learning disability and autistic people takes place with the aim of bringing about improvements in health and social care, reducing health inequalities and premature mortality.

Our governance structure includes:

- LeDeR Strategic Group – Quarterly – overview of strategic impact of LeDeR programme and service improvement. Feeding back themes and identifying local actions to address areas of learning to SEL ICB Quality and Performance Committee and LDA Strategic Executive Group and LDA Operational Board.
- LeDeR Focused Review Panel - four weekly – multi-stakeholder oversight of focussed reviews of individual cases.
- Borough steering groups x 6 (Bexley, Bromley, Greenwich, Lambeth, Lewisham, Southwark) to drive forward the implementation of key actions and embedding learning from reviews into improving local services.

LeDeR Governance



The LeDeR Programme Strategic Group feeds into the local borough steering groups and South East London Learning Disability and Autism Strategic Board.

Outcomes will be reported to the South East London Quality and Performance Committee (SEL QPC).

Workstream 2023-2026

Key Priorities	Delivery for Year 1	Delivery for Year 2	Delivery for Year 3	How will we demonstrate delivery?
<p>Robust quality and governance structures.</p>	<ul style="list-style-type: none"> ○ Establish and embed a clear and effective pathway with the Quality Team/PSIRF (Patient Safety Incident Response Framework) and Safeguarding team to ensure quality and safeguarding concerns are raised in a timely manner in the correct forums. ○ Review TORs, aims and objectives of the SEL ICS LeDeR Focused Review Panel and the Strategic Group – TOR, aims and objectives being met. ○ Complete quality audit of reviews completed in 2022/2023. 	<ul style="list-style-type: none"> ○ Review SEL LeDeR Programme Team input and support provided to borough LeDeR steering groups. ○ Review pathway with the Quality Team/PSIRF (Patient Safety Incident Response Framework) to ensure quality issues have been acted upon. 	<ul style="list-style-type: none"> ○ Review outcomes of concerns raised with Quality and Safeguarding teams. 	<ul style="list-style-type: none"> ○ Quality and safeguarding pathways agreed, and shared with relevant stakeholders. ○ Concerns raised with Quality and Safeguarding teams are addressed, resulting in service improvement.

Workstream 2023-2026

Key Priorities	Delivery for Year 1	Delivery for Year 2	Delivery for Year 3	How will we demonstrate delivery?
<p>Co-produced strategy for meaningful involvement of people with lived experience in LeDeR governance and development.</p>	<ul style="list-style-type: none"> ○ Identify a broader range of people with lived experience, including people with learning disability, autistic people, and the carers/families of people with learning disabilities and autistic people who want to be partners in LeDeR Programme. ○ Co-production of agreed outcomes. 	<ul style="list-style-type: none"> ○ Produce and publish co-produced strategy for meaningful involvement of people with learning disabilities, autistic people and their families/carers in the LeDeR Programme. 	<ul style="list-style-type: none"> ○ Review co-produced strategy for meaningful involvement of people with learning disabilities, autistic people and their families/carers in the LeDeR Programme. 	<ul style="list-style-type: none"> ○ Published strategy for meaningful involvement of people with learning disabilities, autistic people and their families/carers in the LeDeR Programme.

Key Priorities	Delivery for Year 1	Delivery for Year 2	Delivery for Year 3	How will we demonstrate delivery?
<p>Reduce mortality rates of people with learning disability and autistic people from Black, Asian and Minority Ethnic communities.</p> <p>Understand mortality causation and key themes for the wider autistic population.</p>	<ul style="list-style-type: none"> ○ Understand whether reporting of deaths of people from Black, Asian and Minority Ethnic communities, is comparable to white communities. ○ Establish a communication and engagement plan for highlighting LeDeR Programme with Black, Asian and Minority Ethnic communities. ○ Identify recurring themes from learning from reviews undertaken of people with Black, Asian and Minority Ethnic background and those from the wider autistic community, to identify priority areas for improvement. 	<ul style="list-style-type: none"> ○ Achieve increased ethnicity recording in order to understand true figures of people from Black, Asian and Minority Ethnic communities with a learning Disability or who are autistic. ○ Ensure relevant commissioners (working with borough leads and SEL programmes) are sighted on gaps in health and social care services – working with borough leads; for example late cancer diagnosis, reduced engagement with families. ○ Deep dive identification of key themes and conditions affecting Black, Asian and Minority Ethnic populations and wider autistic population. 	<ul style="list-style-type: none"> ○ Work with partners to measure the impact of LeDeR in service delivery: <ul style="list-style-type: none"> • For people with learning disability and autistic people from Black, Asian and Minority Ethnic communities. • For the wider autistic community. 	<ul style="list-style-type: none"> ○ Increased understanding of reasons for deaths of: <ul style="list-style-type: none"> • People from Black, Asian and Minority Ethnic communities. • The wider autistic community. ○ Reduction in frequency or significant actions to address common themes emerging from completion of Focused reviews. ○ Reduction in treatment gap and improved equity of health and social care delivery, and preventable deaths based on themes identified.

Workstream 2023-2026

Key Priorities	Delivery for Year 1	Delivery for Year 2	Delivery for Year 3	How will we demonstrate delivery?
<p>Embedding LeDeR within ongoing action groups.</p>	<ul style="list-style-type: none"> ○ Joint working with the South East London Annual Health Check Steering Group. ○ Joint working with the Medicines Management team to achieve STOMP goals. 	<ul style="list-style-type: none"> ○ Joint working with the South East London Annual Health Check Steering Group. ○ Joint working with the Medicines Management team about to achieve STOMP goals. 	<ul style="list-style-type: none"> ○ Joint working with the South East London Annual Health Check Steering Group. ○ Joint working with the Medicines Management team about to achieve STOMP goals. 	<ul style="list-style-type: none"> ○ Contribution of the LeDeR team towards achieving identified goals.

Workstream 2023-2026

Key Priorities	Delivery for Year 1	Delivery for Year 2	Delivery for Year 3	How will we demonstrate delivery?
<p>Communications and Engagement.</p>	<ul style="list-style-type: none"> ○ Promote the LeDeR programme in South East London, including creating more awareness of the inclusion of autism, including promotional event, inclusion on Big Health Week, and connecting with stakeholders. ○ Support Autism Strategy nationally and at borough level across South East London. ○ Identify forums for engaging with autistic people, and their families/carers. 	<ul style="list-style-type: none"> ○ Identify focused areas and groups for targeted communications and engagement, including autistic people, people from a black, Asian or minority Ethnic background. ○ Engage with Provider and borough events to provide overview of LeDeR programme, and how to notify. ○ Big Health Week. 	<ul style="list-style-type: none"> ○ Event with local partners demonstrating learning and outcomes from learning for first three years of LeDeR programme. ○ Big Health Week. 	<ul style="list-style-type: none"> ○ Increased awareness of the LeDeR programme across South East London. ○ Increase in notifications in LeDeR autism reviews. ○ Decrease in common themes and preventable deaths of people with learning disabilities and autistic people in South East London.