NHS
South East London
Clinical Commissioning Group

South East London Clinical Commissioning Group

Learning Disability Mortality Review (LeDeR)

Annual report 2020/2021

Title	South East London Clinical Commissioning Group Learning Disability Mortality Review (LeDeR) Annual report 2020/2021
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The authors would like to extend sincere gratitude to all family members or carers of people who have lived with learning disabilities and to all the reviewers who have contributed to the LeDeR programme. Particularly during the Covid-19 pandemic, which has overwhelmed health and social care systems in the United Kingdom (UK) and the world with immense impact and repercussions on those services. It should be noted undertaking these reviews is usually in addition to reviewer's day to day work. LeDeR reviews are not an investigation of a death but an analysis by reviewers to bring to life the circumstances leading up to the death and provide a portrait of the lives of the people they have reviewed. Families and friends also find it difficult and challenging to have conversations about their loved ones who have died. We would like to acknowledge their immense support and courage; we thank them for their contributions.

Summary

National Health Service England and Improvement (NHSEI) are committed to improving transparency and ensuring deaths of people with a learning disability are reviewed in a timely manner. This is to inform service improvements and honour the commitment made to bereaved families to review all deaths. In demonstrating this, the NHS operational planning and contracting guidance in 2020/21 has reiterated the responsibility of Clinical Commissioning Groups (CCGs) to implement actions from the LeDeR programme. CCGs must continue 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 NHSEI website.

This report from the South East London (SEL) LeDeR programme demonstrates the work covered in the six boroughs of SEL from April 2020 to March 2021. The six local areas or boroughs in SEL are Bexley, Bromley, Greenwich, Lewisham, Southwark, and Lambeth.

Introduction and Purpose

Welcome to the SEL CCG LeDeR report produced in collaboration with all six local boroughs in SEL. This is the second SEL-wide annual report on the reviews of deaths of people with a learning disability since the inception of the LeDeR programme in England. 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) 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 March 2017 (https://www.england.nhs.uk).

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 (MAR) or a Safeguarding Adult Review (SAR) 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 programme has been administered and managed from Bristol University on behalf of NHSEI from May 2015 to April 2021. A new LeDeR web-based platform for completing LeDeR reviews will be in place by 1st June 2021. This will be significantly different from the current platform held by the University of Bristol. There has been engagement with a wide

range of stakeholders and the LeDeR workforce to develop the new web platform to make sure it meets their needs and provide a more effective and efficient future process for completing LeDeR reviews.

1.1 The Governance Structure

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 City 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 City 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 the action plan, improvements, and challenges in completing and learning from reviews. Membership of steering groups varies and includes varying stakeholders to the programme including 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 local steering groups to 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. Due to workload pressures, and staff redeployment resulting from the Covid-19 pandemic however, steering groups in the six boroughs have not functioned at the same capacity in the last year. The impact this has had on delivering recommendations and learning from deaths has not yet been evaluated. In 2020, a LeDeR Coordinator with a clinical community nursing and research background was recruited to the SEL team due to increased service demand. This role supported areas where LACs were redeployed or were engaged in other service delivery during the Covid-19 pandemic. The LeDeR Coordinator role also includes contribution to the national research programme to improve care for individuals with a learning disability. Funded for two years, the SEL LeDeR Coordinator role supports the CCG LACs to deliver the LeDeR programme across the SEL footprint. The position involves submission of SEL data to the national LeDeR database and developing a system to record and track the programme work. The role also includes collating and presenting local,

regional, and national learning from the programme and business support to local steering and quality assurance groups across SEL.

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.

1.2 Child Deaths

All reviews of child deaths are undertaken by the child death overview panel (CDOP) who share their report on every child death with a learning disability with the local LeDeR programme. This report is added to LeDeR findings and recommendations; a separate review is not carried out for children. There have been two child deaths in 2020/21, both aged 16, one died in hospital and the other in an unknown place of death. One of these children were female and one male, their ethnicities British and one unknown.

1.3 Multi-Agency Reviews (MARs)

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 further enquiry. The statutory processes include MARs. Seven of the people's deaths notified to the LeDeR programme in 2020/21 required MARs.

1.4 Safeguarding Adults Reviews (SARs)

A safeguarding adult review is a multi-agency process to determine whether serious harm experienced by an adult at risk of abuse or neglect, could have been predicted or prevented. The process identifies learning to enable the partnership to improve services and prevent abuse and neglect in the future. One person's death notified to the LeDeR programme in 2020/21 required a SAR.

1.5 Coroner Cases

Reviews can also be put on hold if they have been referred to Coroners for inquest and findings or results have not been made. From the outset of the LeDeR programme to the time of writing this report, there have been four occasions where a person's death notified to the LeDeR programme were flagged as requiring a coroner's inquest.

1.6 SEL assessment of care received (completed reviews of adult deaths 2020-21)

This section demonstrates the quality of care given to people living with learning disabilities prior to their death. The standard of care graded represents all the care they had received found by the reviewers through their fact finding. Learning outlined and recommendations made by reviewers is forwarded to the borough LACs for implementation. The quality-of-care rate for four reviews are to be confirmed (TBC*) as data was not available on the National Platform at the time of writing due to transition to the systems. Those four reviews were not rated above 4 and did not required a MAR or were referred to a SAR. The grade key states how the care is described and the tables represent the grades allocated to the care. Care quality was rated as following below:

1. This was excellent care (it exceeded current good practice).
2. This was good care (it met current good practice in all areas).
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).
4. Care fell short of current best practice in one or more significant areas, bit 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.
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.
6. Care fell short of current best practice in one or more areas resulting in the potential for, or actual, adverse impact on the person.

Table 1: Care Quality in SEL for all people who died in 2020/21

Care Quality	Number of reviews						
	BEX	BRO	GRE	LAM	LEW	SOU	Total
1	0	1	1	1	0	0	**3**
2	2	2	3	1	4	2	**14**
3	4	3	3	2	2	0	**14**
4	3	2	0	0	1	0	**6**
5	1	2	1	1	2	1	**8**
6	0	0	0	0	0	0	**0**
CDOP	0	1	0	1	0	0	**2**
Reviews in progress	0	1	0	1	1	1	**4**
TBC*	0	1	1	0	0	2	**4**
Total	**10**	**13**	**9**	**7**	**10**	**6**	**55**

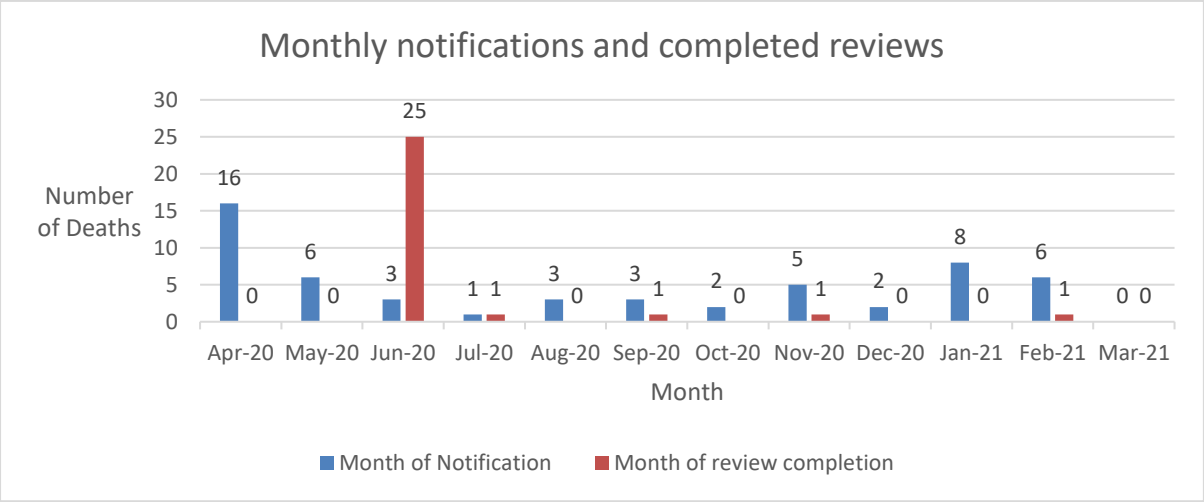
SEL 2020/21 Performance and Demographics Overview

This section shows the number of deaths from the reviews completed in the 2020/21 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.

Table 2: Number of Deaths in 2020-21.

Month	Number of notifications	Number of reviews completed
Apr-20	16	0
May-20	6	0
Jun-20	3	25
Jul-20	1	1
Aug-20	3	0
Sep-20	3	1
Oct-20	2	0
Nov-20	5	1
Dec-20	2	0
Jan-21	8	0
Feb-21	6	1
Mar-21	4	0
Unknown	-	26

2.1 Number of adult deaths notified to the LeDeR team and completed reviews.



(Figure 1: Number of adult deaths notified to the LeDeR team and completed reviews)

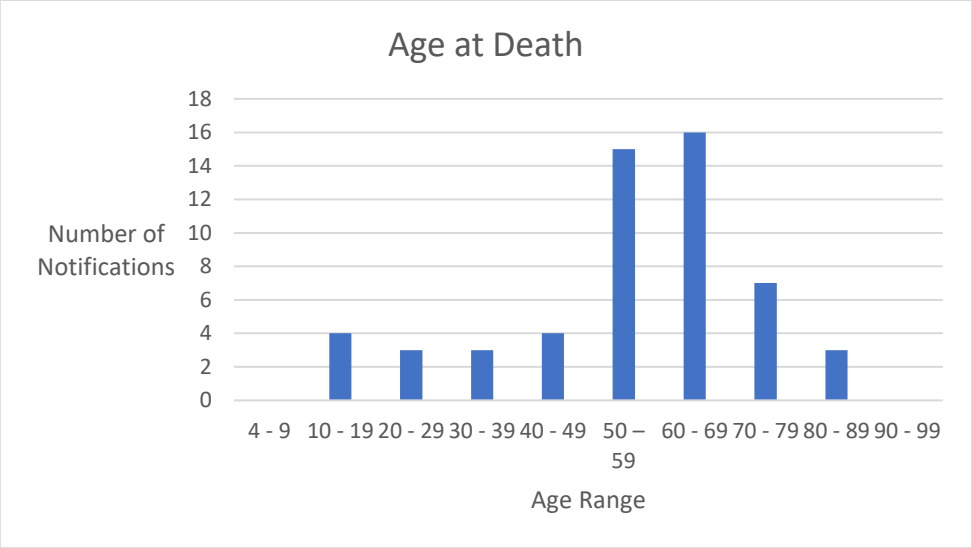
2.2 Age at death and Gender

Table 3 below demonstrates the age at which people with learning disabilities in SEL have died over the last year. Deaths were highest in ages between 50-59 years at 27% and 29% for those between 60-69 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. 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 57% for the 2018-20 reporting period.

Table 3: Ages of people with LD who died in SEL in 2020/21

Age at death	Number of notifications	Percentage
4 - 9	0	0%
10 - 19	4	7%
20 - 29	3	5%
30 - 39	3	5%
40 – 49	4	7%
50 – 59	15	27%
60 - 69	16	29%
70 - 79	7	13%

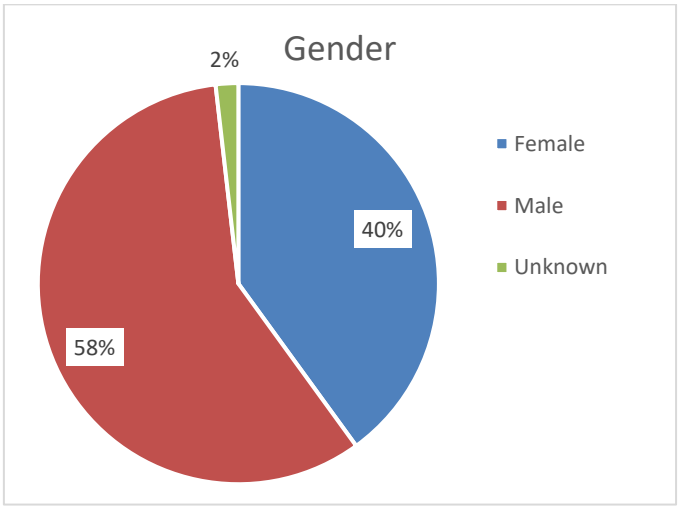
80 - 89	3	5%
90 - 99	0	0%



(Figure 2: Ages of people with LD who died in SEL in 2020/21)

Table 4: Gender of people with LD who died in SEL in 2020/21

Gender	Number	Percentage
Female	22	40%
Male	32	58%
Not shown on platform	1	2%



(Figure 3: Gender of people reported to LeDeR in 2020/21 in SEL)

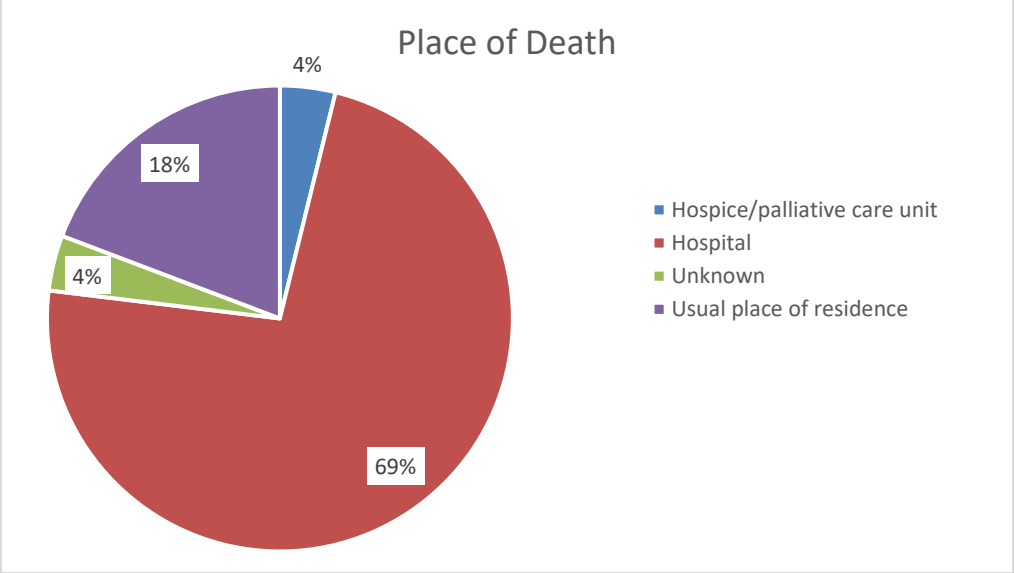
2.3 Place of Death

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. It should be noted the figures below may have been exacerbated by the Covid-19 pandemic, all 17 people’s deaths confirmed to be related to Covid-19 has been in hospital. 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 LACs to ensure full information is captured for performance reporting.

Table 5: Place of death of people in SEL in 2020/21

Place of Death	Number	Percentage
Hospice/palliative care unit	2	4%
Hospital	38	69%
Unknown	2	4%
Usual place of residence	10	18%



(Figure 4: Place of death of people reported to LeDeR in 2020/21 in SEL)

2.4 Ethnicity

The 2020 national annual LeDeR report found while most people who died from 2018-2020 were of white British ethnicity, there was a much lower proportion of children for which this was the case. Of those who died in childhood (ages 4-17 years) in 2018-2020, 41-46% were from BAME groups. The lowest median age at death was also male people from Black Asian Minority Ethnic (BAME) groups.

A systematic review of health care of children and adults with learning disabilities from BAME communities in the UK suggested people with learning disabilities from BAME groups are more likely than others to face barriers in accessing services. BAME learning disabled people are less likely to receive specialist services, and more likely to have poor knowledge about those services available to them. Considering this disproportion, the following recommendation was made by the University of Bristol:

"Integrated Care Systems (ICS), and their commissioned Primary Care Networks to take actions to reduce any disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families."

As a result, LeDeR steering groups are being asked to identify a BAME lead for the steering group to:

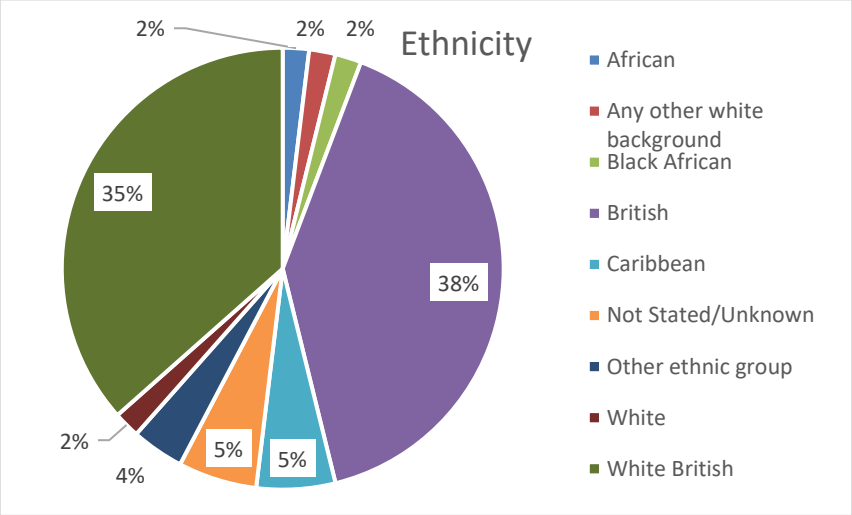
- Establish links with local organisations which represent people from BAME communities, especially those with a learning disability and raising the profile of LeDeR within those communities.
- Understand the local BAME profile and expected prevalence of people with a learning disability who are from BAME communities in their local area.
- Understand and ensure action on local factors relating to people who are from BAME communities and their access to services. Carol-Ann Murray Strategic Commissioning Lead from SEL Learning Disability and Autism Programme has agreed to facilitate the BAME course in SEL on an interim basis.

The figures below show the ethnicity of people with learning disability whose deaths were reported into the programme in 2020/21, 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 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.

Table 6: Ethnicity of people reported to LeDeR in SEL in 2020/21

Ethnicity	Number	Percentage
African	1	2%
Any other white background	1	2%
Black African	1	2%
British	21	38%
Caribbean	3	5%
Not Stated/Unknown	3	5%
Other ethnic group	2	4%
White	1	2%
White British	19	35%



(Figure 5: Ethnicity of people reported to LeDeR in SEL in 2020/21)

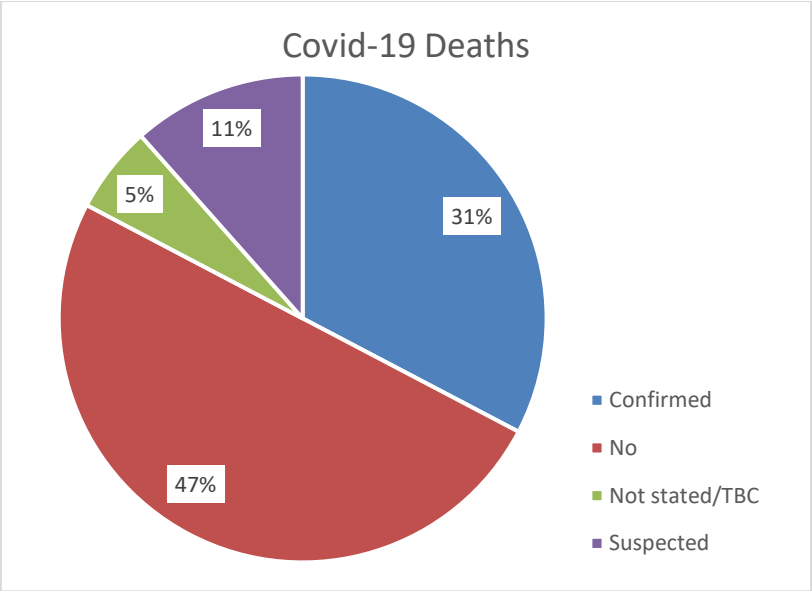
2.5 Covid-19 Related Deaths

Our SEL London Learning Disability and Autism (LDA) programme remains committed to addressing the heath inequalities and improve outcomes for people with a learning disability. In the Winter of 2020/21 and the Covid-19 pandemic's second wave in the UK, the SEL LDA programme prioritised the work around annual health checks and flu vaccines. As the vaccination to protect against Covid-19 is rolled out in the UK and in England, a full report of how Covid-19 pandemic affected the lives of people living with learning disabilities is described and demonstrated in this 2020/21 LeDeR annual report for SEL CCG.

People with learning disabilities have been disproportionately impacted by Covid-19 pandemic which is consistent with respiratory conditions being the leading cause of death amongst this population. Across London, there was a 355% increase in the number of reported deaths of people with learning disabilities during the peak of the pandemic in April 2020 compared to April 2019. At the time of writing this report, there have been 23 confirmed or suspected Covid-19 related deaths notified to LeDeR in Bristol amongst people living with Learning Disabilities in SEL since April 2020. The vast majority of the 23 people died in hospital. There was also three confirmed and two suspected Covid-19 deaths in the previous financial year. During 2020-21 there have been 12 deaths confirmed or suspected to be related to Covid-19 in the first quarter, one death in the second quarter of the year, one in the third and ten Covid-19-related deaths in the fourth quarter of the year. This was likely to signify the emergence of a new variant in the Winter of 2021.

Table 7: Number of deaths confirmed or suspected to be related to Covid-19 in 2020/21

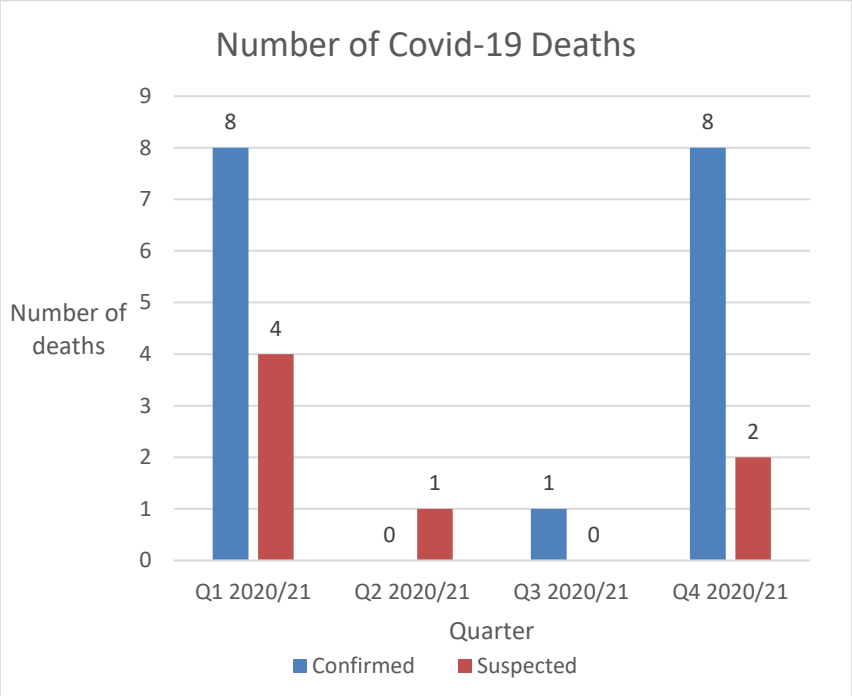
COVID-19 death	Number	Percentage
Confirmed	17	31%
Suspected	6	11%
Not stated/TBC	3	5%



(Figure 6: Number of deaths confirmed or suspected to be related to Covid-19 in 2020/21)

Table 8: Number of deaths related to Covid-19 in SEL during the pandemic

Quarter	Confirmed	Suspected
Q4 2019/20	3	2
Q1 2020/21	8	4
Q2 2020/21	0	1
Q3 2020/21	1	0
Q4 2020/21	8	2
TOTAL	20	9



(Figure 7: Number of deaths related to Covid-19 in SEL during the pandemic)

Table 9: LeDeR Covid-19 January 2020-March 2021 Deaths in SEL Boroughs

Borough	Covid-19 Status	Date of death	Age at death	Place of death	Review Progress
Lewisham	Confirmed	2020	86	Hospital	Complete
Lewisham	Suspected	2020	63	Usual place of residence	Complete
Lewisham	Confirmed	2021	62	Hospital	Complete
Lewisham	Confirmed	2021	65	Hospital	Complete
Bexley	Suspected	2020	55	Hospital	Complete
Bexley	Confirmed	2020	85	Hospital	Complete
Bexley	Confirmed	2020	73	Hospital	Complete
Bexley	Suspected	2020	39	Hospital	Complete

Bexley	Confirmed	2020	77	Hospital	Complete
Bexley	Confirmed	2020	66	Hospital	Complete
Bromley	Suspected	2019	79	Usual place of residence	Complete
Bromley	Confirmed	2020	57	Hospital	Complete
Bromley	Confirmed	2020	71	Hospital	Complete
Bromley	Confirmed	2020	65	Hospital	MAR
Bromley	Confirmed	2021	69	Hospital	MAR
Bromley	Confirmed	2021	83	Hospital	Complete
Bromley	Confirmed	2021	66	Hospital	Complete
Greenwich	Confirmed	2020	19	Hospital	Complete
Greenwich	Suspected	2020	64	Hospital	Complete
Greenwich	Confirmed	2021	24	Hospital	Complete
Greenwich	Confirmed	2021	46	Hospital	Complete
Lambeth	Suspected	2020	58	Hospital	Complete
Lambeth	Confirmed	2020	13	Hospital	Complete
Lambeth	Confirmed	2020	54	Hospital	Complete
Lambeth	Confirmed	2021	27	Hospital	Complete
Lambeth	Confirmed	2021	56	Hospital	Complete
Southwark	Confirmed	2020	18	Not known	Complete
Southwark	Suspected	2020	39	Usual place of residence	Complete
Southwark	Suspected	2021	49	Usual place of residence.	In progress

Borough 2020/21 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 demographic report pertinent to the six boroughs in SEL. It should be noted an analysis has not taken place to understand the variations in population sizes and demographics in each local area and whether the differing numbers between local areas are proportionate to these differences.

3.1 Bexley

In 2020-21 there were a total of 10 notifications on the LeDeR notification system.
The average age of death was 60.3 years old. The notifications included:

- Ethnicity: 1 person from any other white background (10%), 5 British (50%), 2 other ethnic group or not stated (20%) and 2 white British (20%).
- Gender: 2 (20%) of the people were female and 8 male (67%).
- Place of death: 9 people (90%) died in hospital and 1 (8%) in their usual place of residence.

3.2 Bromley

In 2020-21 there was a total of 13 notifications on the LeDeR notification system. The average age of death was 59 years old. The notifications included:

- Ethnicity: 7 of the people were British (54%) and 6 (46%) white British.
- Gender: 6 (46%) of the people were female and 7 male (54%).
- Place of death: 9 people (69%) died in hospital and 4 (31%) in their usual places of residence.

3.3 Greenwich

In 2020-21 there were 9 notifications for Greenwich received on the LeDeR notification system. The average age of death was 49.4 years old. The notifications included:

- Ethnicity: 5 of the people were British (55.6%), 1 not stated (11%), 1 white (11%), 2 white British (22%).
- Gender: 2 (22%) of the people were female and 7 male (78%).
- Place of death: 8 people (89%) died in hospital, and 1 (11%) in their usual place of residence.

3.4 Lambeth

In 2020-21 there were a total of 7 notifications for Lambeth on the LeDeR notification system. The average age of death was 40.9 years old. The notifications included:

- Ethnicity: 1 person was African (14%), 1 black African (14%), 2 Caribbean (28%), 2 not stated (28%) and one white British (14%).
- Gender: 2 (28%) of the people were female and 5 male (71%).
- Place of death: 1 person (11%) died in a hospice/palliative care unit, 4 (67%) in Hospital, 1 unknown- abroad in Africa (11%), 1 unknown – CDOP case (11%).

3.5 Lewisham

In 2020-21 there were a total of 10 notifications made to the LeDeR system for Lewisham. The average age of death was 65.9 years of age. The notifications included:

- Ethnicity: 1 person (10%) is listed as any other ethnic group, 2 (20%) as British and 7 white British (70%).
- Gender: 5 (50%) of the people were female and 5 (50%) male.
- Place of death: 1 person (10%) died in a hospice/palliative care unit, 6 (60%) in hospital and 3 (30%) in their normal place of residence.

3.6 Southwark

In 2020-21 there were a total of 6 notifications made to the LeDeR notification system for Southwark. The average age of death was 48.2 years of age. The notifications included:

- Ethnicity: 1 (17%) as black African/British, 2 people (33%) were British, 1 (17%) Caribbean and 2 (33%) White British.
- Gender: 4 (67%) people were female, 1 (17%) male, 1 (17%) is unknown.
- Place of death: 2 people (33%) died in hospital and 4 (67%) in their usual place of residence.

2020/21 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.

> ‘’Good MDT approach to his care including a specific GP service which supports patients in residential care homes. There was good documentation of the care and MDT meetings which took place in the care home in the GP records. The care appears to have been holistic and to have fully considered and met his needs’’.

4.1 Learning from reviews

The points below are some examples to demonstrate the varying recommendations made by the reviewers as part of the LeDeR process in 2020/21. These will provide us with local improvement solutions, a thematic analysis is also being completed to outline the most common issues and areas of learning across SEL which can be used to make improvements

at a strategic level and prioritise intervention as appropriate. The findings of the thematic analysis will be made separately to this report.

- 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.
- Genealogy services have enabled contact with family who had lost contact many years prior and could be used to support more families to regain contact.
- End of life planning should be discussed as soon as appropriate, supported by active conversations about death and dying.
- Further work is required on assessing capacity and recording best interest decision making.
- The wider health and social care workforce should be educated about learning disabilities.
- 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 2021/22

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 (ICS) Plan in May 2020. ICSs will

be responsible for ensuring LeDeR reviews are completed of the health and social care received by people with a learning disability and autistic people (aged four years and over) who have died, using the standardised review process. This enables the ICS to identify good practice and what has worked well, and 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 (NHSEI 2021). The SEL LeDeR team is developing strategies through developing business cases to meet the requirements of the LeDeR policy 2021. The main points from the LeDeR policy (NHSEI 2021) are as follows:

- The most important focus of the new policy is that there is a stronger emphasis on the delivery of the actions coming out of the reviews and holding local systems to account for delivery, ensuring there is evidence of service improvement locally. NHS England and Improvement regional teams will hold ICS' to account for the delivery of the actions they identify, and ICS' will report to them every quarter on their progress.
- From the 1st of June 2021, there will be a new process for reviewers to follow, including a new computer system ('web-based platform'), and new training for the LeDeR workforce. Over the next year the workforce will change, and reviewers will work in teams so no reviewer will work alone, everyone will have the time they need to do reviews and support to do them. This is important and was identified as part of the recommendations for the Oliver McGowan review (2020) carried out by Fiona Ritchie.
- For the first time we will be reviewing the deaths of adults who have a diagnosis of autism but no learning disability.
- All notifications of a person's death will receive an initial review including talking to their family or people who knew them well, talking to their GP or looking at the GP records, and talking to at least one other person involved in the person's care. If the reviewer feels a more detailed review is needed, a focused review will follow. Families can say if they think a focused review is needed.
- All people from BAME communities will get a focussed review because the evidence so far shows that the health inequalities experienced by people from these communities are significant. There is also significant under reporting of deaths from BAME communities.
- We are beginning to collect data from the deaths of people who are autistic. It is therefore important we can learn as much as possible from every one of these

reviews to give us as robust a base line as possible at this time. Therefore, all reviews of people who are autistic without a learning disability will be focussed reviews initially.

- In response to this change and stakeholder engagement the new name for the LeDeR programme is 'Learning from Life and Death Reviews – people with a learning disability and autistic people'. We will still use the name LeDeR (NHSEI).

4.3 LeDeR in local areas

In November 2020, a 'Big Health Week' was held to improve the quality of health and lives of those with LD. The task included supporting families, important others, and care staff. Health checks/screening was conducted at this event and at Covid-19 vaccination hubs as an opportunity for screening discussions. At health checks, consent was sought to enter patient information on for example the bowel screening website for community services in LD to support the process for screening. Cancer screening workshops were held in this week, including bowel and cervical cancer screening. Additional work has been completed on easy read literature for example for breast cancer. 'Talk Cancer' weeks have been held in the community to support community engagement around the subject of cancer. The People's Parliament was used as an opportunity for question-and-answer sessions on health especially considering Covid-19.

In Lewisham, the Learning Ambassador programme has increased the funding for cancer awareness, the Cancer Alliance, and the importance of early diagnosis. There will also be additional sessions will be held at the weekly lunch and learn events for Lewisham GP practices to raise awareness of the LeDeR programme and processes. The Community LD services, and Mental Health will also be requested to input at these meetings. Sessions will be put on for the safeguarding leads and input from LeDeR reviewers. LeDeR will also be placed as an agenda item regularly on the Lewisham LD Stakeholder Meetings monthly.

Table 10: Key points of new LeDeR policy (NHSEI 2021)

Key Points from the new policy.	Where we are at in SEL.
Roles and Responsibilities 1. Senior executive as Senior Responsible Officers for delivery of LeDeR across ICS 2. Local Governance Panel	1. SEL has a Senior Responsible Officer in place for the programme. 2. There is a Black and Minority Champion nominated

3. Black and ethnic minority champion 4. Ensure funding and sufficient directly employed or commissioned staffing to complete the reviews - must be at least 0.5 wte posts. Have at least one LAC. Teams of reviewers led by a Senior, including administration support.	3. Business case and plans are in progress starting from receipt of the new LeDeR Policy in 2021.
Quality Assurance ICS should have a clear plan for Quality Assurance/Governance by 30th September and operation by April 22. To support Quality Assurance there will be: • An improved review templates. • Training on what good looks like • Reviewers work with senior reviewers who will check work. • Local Governance Panels will have oversight of quality of reviews. • NHSEI will sample to assure quality. Put data sharing agreements in place including information governance.	Quality Assurance • SEL ICS Quality Assurance/ Governance will be ready by April 2022 to include all stated.
1. LeDeR Includes people with autism for the first time. 2. Responsibility moves from CCGs to ICS - focus on implementing change. 3. ICS must develop a LeDeR governance group/panel from people across the ICS who have responsibility for quality/quality improvements.	1. Training is offered by the National LeDeR Team on the new platform. 2. Responsibility for move from CCGs to ICSs will be planned and implemented at strategic level by Responsible Officer and Senior Executives. 3. Governance panel to be led by quality teams across the ICS.
Governance Panel 1. ICS to develop the governance group/ panel from people across the ICS who have responsibility for quality/quality improvements. 2. Governance Panel must include people with lived experience.	Governance panel 1. Governance panel will be determined in 2021-2022. 2. June 2021. Other changes, such as staffing models and local governance arrangements will need to change in line with the development of ICS' and

3. Governance Panel must not be separate from ICS quality governance. 4. Make strong links with Medical Examiners.	relevant human resources processes. It will be the responsibility of SEL ICS to ensure appropriate communications are in place for these in collaboration with their regional colleagues. Action plan towards this will act as an appendix to the business case stated above.
Review Process Initial Review (shortened) 1. Local Area Contact role to assign reviews will in time move to the Senior Reviewer. a. Web based template driven review b. Discussion with family or carer 2. Discussion with General Practice (GP) a. Review of GP records using Smart Card. 3. Discussion with at least one other person i.e., SJR reviewer at hospital or other family member. a. Initial reviewer recommends if a second level focussed review is required. b. Reviewers will no longer make recommendations but will present areas of good / poor practice and learning to the local governance group / panel. 4. Focussed Reviews 5. Criteria a. For all deaths in ethnic minorities b. Where there is potential for learning. c. Where there are concerns about quality of care.	Review Process. 1. Standards to be formulated by April 2022 to include all recommendations. From 2021, adults who have a diagnosis of autism without a learning disability will also be eligible for a LeDeR review; further advice will be published in coming months. By 1st April 2022, all changes within this policy will be implemented by SEL ICS, subject to legislative changes relating to ICS' being passed in coming months. 2. SEL ICS will benchmark to identify effective best practices from other areas where smart cards have been used and consider information governance practices/policies to implement the use of smart cards but work collaboratively with stakeholders including General Practice/adult services to affect the use of smart cards across different health, social care/third sector organisations/cultures. Risk assessments will be done with plans to mitigate any potential risks, with the development of a risk register.

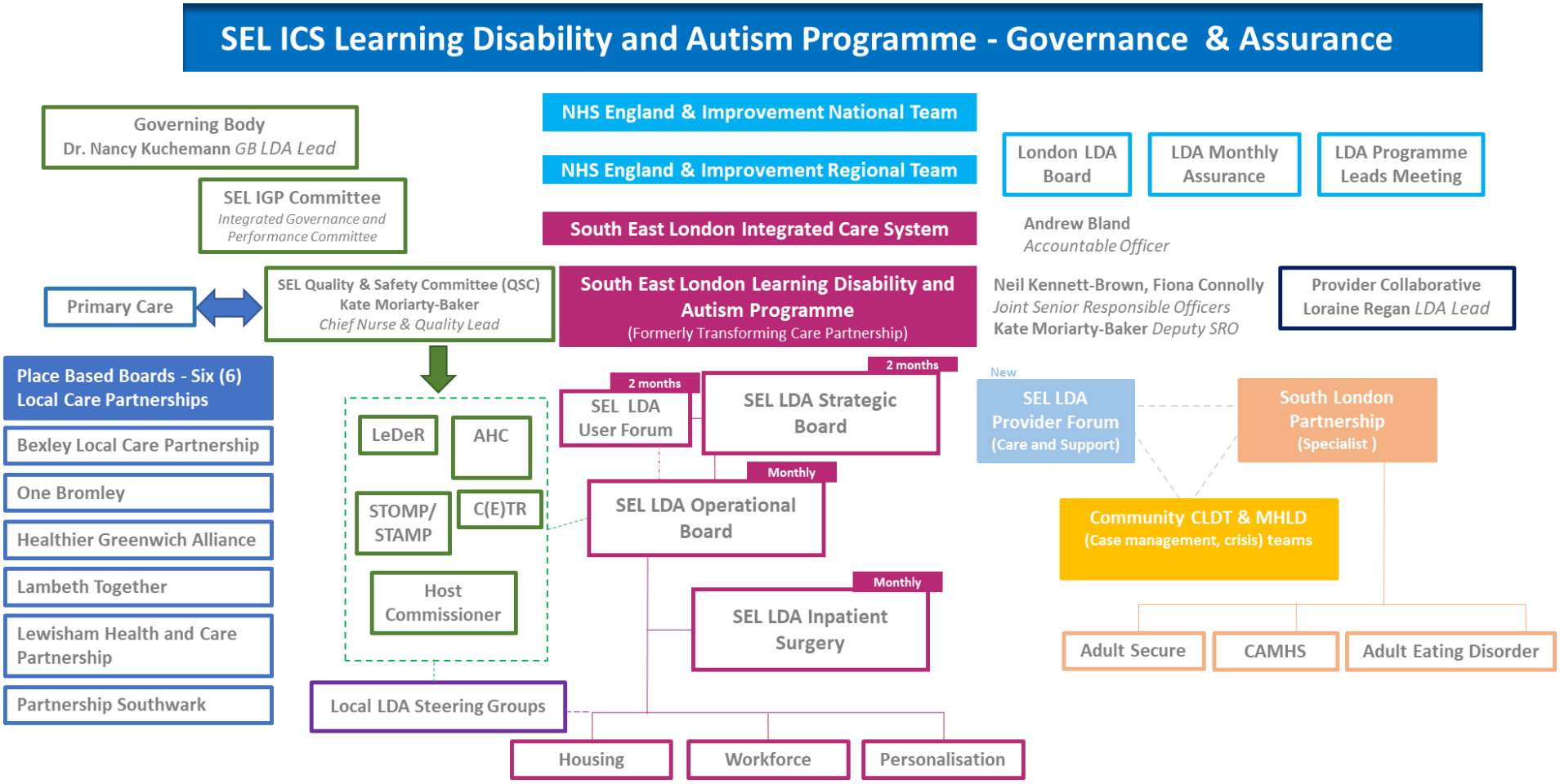
d. Between 2021 and 2023 all deaths where person had autism but not a LD.	3. SEL CCG will formulate a care pathway as guidance to support this process to allow standardisation and clarity but also consider subjectivity as per patient requirements. Pathway training and sharing will be made available to all stakeholders.
Transfer of responsibility from CCG to ICS • NHSEI will hold ICSs to account for making service improvements. • Reviewers to have smart card access to clinical records. • Reviewers will work in larger teams with admin support and supervision. • NHSEI will require quarterly reports on performance against the actions agreed for all reviews completed.	Transfers of responsibility from CCG to ICS Strategic planning to be implemented by Senior Responsible Officer and executives at strategic level. Consultative stage may include task and finish groups to include relevant stakeholders. Options appraisals and terms of references will be employed to achieve collaborative decision making. The involvement of a four-step problem solving project management strategy such as 'plan, do, study and act' cycles and model to manage the change, develop a plan or the use of 'Kaizen' three pillars to improve productivity, efficiency and business, reduce waste and encourage standardisation.
A new two stage review process: 1. an "initial review" for all deaths and a "focussed review" where required. A new simplified web-based template driven review process: 2. ICS' must employ or commission a MDT for completing the reviews comprising a Senior Reviewer; Reviewers and admin support. These must be at least 0.5 wte posts. Plus, a Local Area Contact. ICS must have an implementation plan by 30th Sept 2021 and must be in place by 1st April 2022.	1. Training offered by national LeDeR Team. 2. Please see above.

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. The impact of Covid-19 on health and Adult Service care systems in SEL as stipulated in the introduction of this annual report has not been evaluated. The programme has worked collaboratively to meet the needs of people with learning disability across SEL. To date, as the analysis in this report demonstrates we have been able to achieve required standards as stipulated by NHSEI. Reviews on hold include MARs, SARs, CDOPs, and those reviews awaiting Coroner inquiry/inquiries. Recommendations and learning from all reviews including Covid-19 cases and BAME reviews in SEL CCG is currently being allocated to local steering groups for action when they recommence operation. The SEL 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 LeDeR Coordinator will remain active in her support of all processes to effect learning and sharing of best practice within teams, between teams in health, social care and the third sector.

In this report the NHSEI future (2021, LeDeR policy, 2021) has been featured briefly, suggesting the possible plans for SEL CCG. The plans demonstrated in this report are not ratified and are by no means definitive of the SEL arrangements but are indicative of our considerations towards NHSEI proposals. The SEL LeDeR team welcome the new policy and the recommendations proposed. There have been some questions regarding additions in the policy and these have been raised with NHSEI. In SEL CCG we strive to meet the needs of our local population, we will continue to dedicate hard work in achieving excellence and high standards for our local population.

Appendix 1 – SEL LeDeR programme governance



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