Southwest London Clinical Commissioning Group Learning Disability Mortality Review (LeDeR) Annual Report 2020/2021

Incorporating Croydon, Kingston, Merton, Richmond, Sutton, and Wandsworth boroughs

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Contents

i. Glossary

LeDeR	Learning Disability Mortality Review
CCG	Clinical Commissioning Group
CIPOLD	Confidential Inquiry into Premature Death of People with a Learning Disability
CMC	Co-ordinate My Care (a patient record)
LAC	Local Area Contact
IPC	Infection Prevention and Control
ICS	Integrated Care System
MCCD	Medical Certificate of Cause of Death (sometimes called death certificate)
MCA	Mental Capacity Act
NHS	National Health Service
DNAPCR	Do Not Attempt Pulmonary Cardiac Resuscitation

ii. Introduction

This is the first Learning Disability Mortality Review (LeDeR) annual report of the Southwest London Clinical Commissioning Group (SW London CCG). Previous reports were compiled at local delivery unit level meaning that Croydon, Wandsworth and Merton, Kingston and Richmond and Sutton all compiled their own separate reports.

This annual report gives an overview of the work of that has been undertaken to reduce health inequalities for people with a learning disability across SW London, providing data on LeDeR notifications, learning from reviews and actions as well as the involvement of partner agencies in supporting the work of the LeDeR programme.

The Southwest London CCG is committed to ensuring people with a learning disability receive equal treatment in the care and services they receive.

There are around 1.5 million people living in Southwest London. The CCG is made up of 180 GP practices and six diverse boroughs: Croydon, Kingston, Merton, Richmond, Sutton, and Wandsworth. Many of our Boroughs have large populations of young people.

Southwest London Clinical Commissioning Group brings together the former Croydon, Kingston, Merton, Richmond, Sutton and Wandsworth CCG's.

SWL is served by eight acute and community providers: Central London Community Healthcare, Croydon Health Services NHS Trust, Epsom and St Helier University Hospitals NHS Trust, Hounslow and Richmond Community Healthcare, Kingston Hospital NHS Foundation Trust, The Royal Marsden Foundation Trust, St George's NHS Foundation Trust, and Your Healthcare.

Two NHS mental health trust providers serve South West London: South West London and St George's Mental Health NHS Trust and South London and the Maudsley (SLAM) NHS Foundation

Trust. The South London Mental Health and Community Partnership (SLP) is a collaboration between SLAM NHS Foundation Trust, Oxleas NHS Foundation Trust and South West London and St George's Mental Health NHS Trust

Across our six boroughs there are approximately 17,750 people in South West London living with a learning disability and / or autistic spectrum disorder. The number is expected to grow to approximately 19,700 people by 2030

iii. Executive Summary

In the year March 2020 to March 2021 there have been 109 notifications of deaths of people with a learning disability across the Southwest London CCG area which includes Croydon, Kingston, Merton, Richmond, Sutton and Wandsworth boroughs.

Out of these 109 deaths 44 were attributed to the COVID 19 virus. In March and April 2020, the highest number of deaths were reported, more than in any other time locally since the LeDeR programme started.

The average age at date of death was 57 years and 73 people were over the age of 50.

The most common cause of death was through COVID 19 followed by aspiration pneumonia and other respiratory disease.

Eleven of the people were described in the notifications as Black, eight as Asian and four as of mixed heritage. All but two of the white individuals were described as 'white, British'.

67% of people died in hospital as opposed to at home or in hospice.

The main issues identified for learning and action in the reviews relate to

- Aspiration pneumonia and other respiratory issues including COVID 19
- Health action plans
- Problems in the issuing of DNACPR notices.
- Provision of specialist liaison services in acute trusts
- Difficulties faced by care homes in accessing training on health-related issues.

In the financial year 2020 to 2021 SW London CCG delivered 99% of the LeDeR reviews within the required timescale – this performance was higher than both the London and the national average for timely completion of reviews.

iv. Why is the LeDeR programme important?

Figures from the CIPOLD (2013) and more recently from the LeDeR annual report (2020) it is evidenced that people with a learning disability are dying much earlier than the general population. The difference is 22 years earlier for males and 27 years earlier for females. These are highly concerning figures and indicate the significant inequalities across the health and social care systems which is unacceptable. The LeDeR programme is therefore important because it is looking in detail at all issues surrounding the deaths of people with a learning disability, picking out in more detail what is going wrong and giving recommendations on how things can improve. In the long run learning from the LeDeR should support people with a learning disability to live longer and healthier lives.

v. Acknowledgement of the input and support from families and participants of the reviews

Southwest London CCG and partners are very grateful to the families, carers and friends of all the people with a learning disability who have taken the time and effort to support the programme aims especially at such a distressing time for them. We would like to thank everyone who has been affected by the passing of their relative, friend or colleague for their input into the LeDeR reviews.

As part of the LeDeR work the Local Area Contacts share and update progress with our local community via steering groups, partnership boards and news updates via colleagues at Mencap.

We would also like to extend our thanks to local Mencap, Share, Generate and other voluntary sector partners.

vi. Local Steering Groups

As part of the LeDeR programme each local area was required to set up a steering group to include representation of people with a learning disability, family and careers, representatives from the local acute trusts, mental health services, community health services, local authority, and voluntary sectors.

Each of the six boroughs in Southwest London have set up their own steering groups. The steering groups are co-chaired by the Designated Safeguarding Adults Professional and representatives from Local Authorities.

The groups normally convene every quarter and have membership representation from families and carers, local Mencap staff, health and social care community and acute trusts, voluntary organisations, GP representatives and trained reviewers for the LeDeR programme.

The main purpose of the steering group is to review allocation of notifications of deaths ensuring any delays in progressing a review are addressed, to consider recommendations from local reviews, turn plans of action into learning from these recommendations and to support workstreams on action into learning.

vii. Local forums specifically dedicated to supporting the health needs of people with a learning disability.

Safeguarding Adults Boards

In the Southwest London area, the LeDeR programme is taken to be part of the overall safeguarding agenda. Each safeguarding adult's board receives a quarterly update from the LAC on the progress of reviews and updates on any work streams as part of the learning into action. The programme is always vigilant to ensure that if safeguarding concerns are identified that the appropriate type of review is undertaken. This could include the review being undertaken as a Safeguarding Adult Review rather than a LeDeR review.

Learning Disability Partnership Board

Some boroughs also have a learning disability partnership board with a broad membership that includes people with a learning disability, families and carers, local councillors, health and social care representation, employment, and housing. The partnership board includes a specific health subgroup which focuses on the health needs and services of the local population. The LeDeR programme is a main focus for these groups and progress on work is monitored here too.

Acute Trusts and Mental Health Trusts

All acute trusts in London and the Mental Health Trust now have a lead professional for people with a learning disability. Local acute trusts, as part of the safeguarding agenda, have a specific quarterly meeting that focuses on the needs and issues of people with a learning disability that use the services they provide. The membership of these meetings differs slightly between acute trusts but usually have in attendance representation from people with a learning disability, families and carers, community health trusts, mental health trust and voluntary sector. These meetings are normally chaired by the safeguarding lead or learning disability liaison person. The meetings are part of the process for assurance and feed back to the trust boards.

viii. People with a learning disability from Black, Asian and minority Ethnic backgrounds

According to the most recent LeDeR studies and reports people with a learning disability from Black Asian and minority Ethnic backgrounds are more at risk of early mortality than people with a learning disability from White backgrounds.

The new LeDeR policy states that in future, all notifications of deaths of people with a learning disability from Black Asian and minority Ethnic groups must always have a full in-depth focused review conducted.

This is because the LeDeR programme has identified that there is underreporting of deaths for these groups of people. More detailed information is needed to better understand what the issues and health inequalities are and to support plans on how to tackle these health inequalities.

Each local area is in future required to have a lead who will champion and provide focus for people with a learning disability from Black, Asian and minority Ethnic backgrounds.

The role of these leads will be to monitor notifications, link with local cultural associations, ensure specific actions relating to these people are being implemented and to act as support and advice to families and carers and to link them with specialist services.

For Southwest London CCG there are currently nominated leads in Croydon, Wandsworth, and Merton with work being undertaken in the other 3 boroughs to identify leads via the local steering groups.

Also due to the changes with CCG's being transformed into an ICS in the coming year, for Southwest London plans are being developed to establish a panel of experts who will monitor and oversee all work related to notifications of deaths of people with a learning disability from Black, Asian and minority Ethnic backgrounds.

ix. Local Area Contact Role

Each CCG is required by the LeDeR programme to have a local area contact.

The role of Local Area Contact (LAC) is the link between the LeDeR Programme team and the Local Steering Group. This role is normally fulfilled by the Designated Safeguarding Adults lead from the CCG. The role includes the following:

- Receive deaths notification from Bristol University
- Assess availability of trained reviewers and allocate a case where there is capacity
- Monitor the progress of the review
- Provide advice and support for reviewers
- Receive completed reviews, documents and action plans and quality check these
- A member and chair of the Steering Group with strategic level oversight
- Provide advice and guidance to the steering group in order that appropriate action is taken to improve the care of people with learning disabilities and to reduce premature mortality

In Southwest London, there is a LAC for each Borough identified (Designated Safeguarding Adults lead and LeDeR specialist for Croydon) providing a strong level of resilience and partnership across the CCG.

x. Governance and monitoring of the progress of the local LeDeR programme at a strategic level and local levels.

The Director of Quality for SW London CCGs is the Deputy Senior Responsible Officer for Southwest London Transforming Care Partnership and oversees the LeDeR programme.

During 2020/2021, Southwest London Local Area Contacts (LACs) from all 6 SW London boroughs have met up with the CCG Director Lead for the LeDeR programme to monitor and review key performance and achievements of completed cases ensuring that lessons learnt are widely disseminated to improve learning and sustain improvement in Learning Disabilities services.

This meeting is held usually on a quarterly basis and allows opportunity for all CCG LACS to take a SW London wide view of issues and trends and to plan work on action into learning across all areas if appropriate.

The LAC's take a lead role in ensuring that all information and issues relating to the LeDeR programme are disseminated through local networks.

The main forums for information dissemination are via the local steering groups, safeguarding adults' boards, learning disability partnership boards and acute trust learning disability focus meetings.

The SWL CCG annual report will be presented at the Quality and Performance Oversight Committee in August 2021.

xi. Notifications of deaths of people with a learning disability across SW London from March 2020 to March 2021

When someone with a learning disability who was resident in any of the SW London boroughs passed away a notification was sent to Bristol University as the commissioned body which collated NHS England LeDeR data.

Notifications were usually made by health professionals involved in the deceased persons care and treatment as well as social care agencies and families and carers.

Once a notification was received by Bristol University, this notification is forwarded onto the CCG LAC for the relevant locality.

From June 2021 a new system/ Web based platform for reporting, monitoring and training will be set up and managed by NHS England. Going forward this platform will be the hub for reporting deaths and will be the place where LACS and reviewers can monitor reviews, find out about learning from reviews and keep up to date with training and any other issues regarding the LeDeR programme.

This can be accessed at https://www.leder.nhs.uk/

xii. Reviewers and completion of reviews

All people who conduct reviews of the deaths of people with a learning disability have had specific training on how to undertake mortality reviews by the LeDeR programme NHSE team as well as being supported and supervised by the CCG local area contacts.

All reviewers come from a health or social care professional background which includes social workers, occupational therapist, speech and language therapist, learning disability nurses and general trained nurses. Usually, each professional will have a special interest and/or specific experience of working with people with a learning disability so that they have insight from a perspective of learning disability issues.

To support newly trained reviewers, an experienced buddy reviewer can be allocated to a case to support a newly trained reviewer on their first few reviews.

The CCG LACs are also on hand to provide support and advice as all CCG LACS have also had reviewer training.

When a review is completed, it is forwarded to each area LAC for quality checking and oversight. This involves assessing the full review, measuring it against set standards from the LeDeR programme and ensuring that the learning and any recommendations are appropriate.

Each area has had their own pool of reviewers normally drawn from the community learning disability services, social workers from the local authority and specialist learning disability nurses from the acute trusts.

The number of reviewers fluctuates quite frequently as people leave their posts and new people are employed and undertake the reviewer training.

Occasionally this has caused challenges for the timely allocation of reviews should the reviewer on the LAC list be unable to take on reviews, for example due to their routine work taking priority. To overcome these issues a small number of external contracted reviewers have been employed to take on unallocated reviews.

Overall, across SW London there were 19 reviewers that were active and able to undertake reviews. Borough specific reviewer numbers were:

- 6 for Croydon
- 3 for Sutton
- 5 for Merton and Wandsworth
- 3 for Richmond and Kingston
- 2 contracted reviewers that were available to all SW London CCG's

Timely completion of reviews

Overall, from March 2020 to March 2021 the SW London CCG has kept up timely completion of reviews without having a backlog.

Reviews have also been completed within the set target and time limit of the LeDeR programme.

SW London CCG had a 99% completion rate of reviews in December 2020 when all outstanding reviews were requested to be completed before the shutting down of the system linked to Bristol University.

SW London CCG were commended by the London LeDeR lead on their performance overall in allocating and completing reviews in 2019/2020 on target.

xiii. Statistical analysis of SW London LeDeR data from March 2020 to March 2021 including COVID 19 figures.

This section of the report presents the record of the following:

- overall numbers of deaths of people with a learning disability by month
- their age at time of death
- their gender
- their ethnicity
- the place of death
- their diagnosed level of learning disability
- the grading of care
- the causes of death
- Numbers of deaths from COVID-19 infection

SW London CCG serves a population of approximately 1.6 million people. It's area is coterminous with the London Boroughs of Croydon, Kingston upon Thames, Merton, Richmond upon Thames, Sutton and Wandsworth. Numbers and rates for the whole of SWL are given in the main body of the text. Variations between the localities are given in appendix 1.

In the twelve months prior to 31st March 2021, one hundred and one notifications of deaths occurring in the SWL were made to the LeDeR programme.

From these and notifications made early in April 2021, it was possible to identify 97 deaths occurring between April 1st 2020 and March 31st 2021.

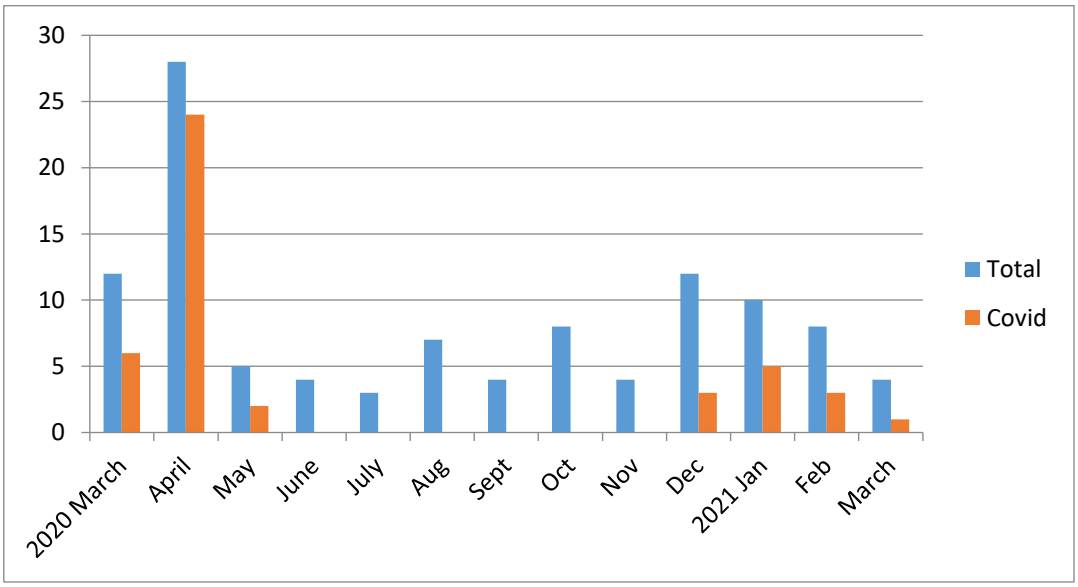
Table 1 shows the total number of deaths recorded in SWL for each month between March 2020 and March 2021, as well as the number of deaths from COVID-19. The March 2020 figure is included to illustrate the impact of COVID-19, the first deaths from which were recorded in that month. The first death from COVID-19 in SWL is recorded by LeDeR in March 2020. Between then and March 31st 2021, 44 deaths were recorded as having been caused by the virus.

Table 1: Deaths from all causes and from COVID-19 by month March 2020 – March 2021

	All deaths recorded	Deaths from COVID-19
March 2020	12	6
April	28	24
May	5	2
June	4	0
July	3	0
August	7	0
September	4	0
October	8	0
November	4	0
December	12	3
January 2021	10	5
February	8	3
March	4	1
Total	109	44
Total exc. March 2020	97	38

The same information is presented graphically in Figure 1.

Figure 1: Deaths from all causes and deaths from COVID-19 by month March 2020 – March 2021



Of the 44 deaths from COVID-19 in this thirteen-month period, eighteen were allocated to Croydon, six to Kingston, three to Merton, five to Richmond, five to Sutton and seven to Wandsworth. (Please refer to Appendix 1 to see summary of differences between localities).

In the first wave of COVID-19, between March and May 2020 32 deaths were recorded. In the second wave, from September 2020, which nationally was both longer and more lethal, far fewer deaths are recorded in this population (twelve until the end of March).

A preliminary statistical analysis shows no significant differences in terms of age, ethnicity, gender and severity of diagnosis between either those dying in 2020 compared to those in earlier years or those dying from COVID-19 in 2020-21 compared to those dying from other causes.

Gender and marital status

The group consists of 58 men and 39 women. The over representation of men (60%) is essentially the same as the 58% reported in the latest LeDeR annual report[1]

Only two of the 84 for whom information was available were recorded as having been married.

Ethnicity

Of the 97, eleven were described in the notification as black, eight as Asian and four as of mixed heritage. All but two of the white individuals were described as 'white, British'.

This means that the proportion of Black, Asian and minority Ethnic group of people is around 30%, roughly equivalent to the proportion in the population of SWL as a whole (but see Appendix 1 for variations between localities).

Place of death

Most of the group (65, around 67%) died in hospital. This is slightly higher than the proportion (60%) reported for the national LeDeR Programme.

[1] University of Bristol (2020) *LeDeR Programme Annual Report 2019*, p. 21

A further thirty people died at home, mostly in their own homes. Two people died in hospices. Hospices provided care for other patients who died at home (and sometimes in hospital) but it is impossible to put a figure on that involvement.

Age at death

Five of this group were seventeen or younger when they died, four boys and one girl. Their ages were eight, nine, ten, fifteen and seventeen.

The oldest was an 86-year-old gentleman from Wandsworth who died at home.

The overall average (mean) age at death for this group was just over 57 years. The median was 59. When the children (under 18) are excluded, the mean rises slightly to 59 years and six months and the median to 61.

By contrast, the median age at death among the general population is 81 years and ten months (mean = 79 and one month).

Adult women in the group died rather earlier, at 57 years and eight months, (med 57) than the adult men, at 60 years and nine months (median 61).

In the general population, women die some three years later than men (medians women: 85 years and four months; men 82 years and nine months; means women 82 and five months, men 79 years and one month).

Table 2 shows the number of deaths for different age cohorts.

Table 2: Decade of death

Age Range	Number (%)
< 20	5 (5.1)
20 – 29	6 (6.2)
30 – 39	4 (4.1)
40 – 49	10 (10.3)
50 – 59	22 (22.7)
60 – 69	23 (23.8)
70 – 79	20 (20.6)
> 79	7 (7.3)

Level of learning disability

Learning disability is classified into four broad categories: mild, moderate, severe and profound/multiple. In this group, 27 were classified as 'mild', 20 as 'moderate', 28 as 'severe' and five as having 'profound or multiple' disabilities. Data on the remaining 17 were missing. The proportion of men and women in each of these categories is the same as the group as a whole.

It is apparent from the data that those people with the most serious level of impairment died at a younger age, most likely due to the co-morbidities of their condition causing significant physical health problems. Those people diagnosed as having a mild learning disability lived, on average, to 62 years and seven months. Those people diagnosed as having a moderate learning disability died on average at 62 and two months. Those people diagnosed as having a severe learning disability died on average at 59 and seven months. However, those people diagnosed with profound and multiple learning disabilities diagnoses died much earlier on average at 42 years of age.

Cause of death

Table 3 shows the cause of death as noted in part 1a of the death certificate (properly, the Medical Certificate of Cause of Death, MCCD). Within the certificate part 1a records the condition leading directly to death, parts 1b and 1c, conditions that contributed to 1a and section 2, other conditions not directly related to death.

Table 3: Causes of Death noted in Part 1a of the MCCD

Cause	Number
COVID-19[2]	28
Aspiration pneumonia[3]	9
Other respiratory conditions[4]	12
Cardiac conditions[5]	5
Cancer	4
Septicaemia[6]	2
Urinary Tract Infection	2
Other[7]	7
Missing or undetermined	28

The figure given here for deaths from COVID-19 is lower than that given in above as it records only those deaths with COVID-19 specified in section 1a. The earlier figure includes deaths where COVID-19 is given in other parts of the MCCD and, where the certificate is not available, information from the referral or timeline leading to death.

Even without COVID-19, respiratory disease is by far and away the most common cause of death among this group. In the general population, it is the third most common cause[8].

The LeDeR Annual Report notes that aspiration pneumonia is the single most common entry on death certificates of people with learning disabilities.

Learning disability on the death certificate

The fact that the person who died had a learning disability was mentioned on just twenty of the 68 death certificates for which that information was available. Learning disability should be noted in part 2 of the certificate.

This may seem a trivial point but influential analyses of causes of death, which in turn inform decisions about funding, rely on information on the death certificate. If the persons condition is not recorded, it means that people with a learning disabilities become invisible to commissioners and policy makers[9].

[2] Includes one entry Multi-organ failure after COVID-19

[3] Includes one entry Multi-organ failure after Aspiration pneumonia

[4] Includes one entry Sepsis after CAP

[5] Heart Disease 972; Ischaemic Heart Disease; Cardiac Arrest (x2); Cardiopulmonary arrest

[6] One records E Coli septicaemia and the other lists 'infected sacral pressure ulcer under 1b

[7] Dementia, DVT, Epilepsy, Multi-organ failure, UGI bleed, Hypoxia, Ischaemia,

[8] As reported by the LeDeR Annual Report, 2019, p. 36. Other calculations suggest it is the fourth most common.

[9] For a fuller discussion see the LeDeR Annual Report 2020, p. 28

Grading

Reviewers, at the end of the review process, are asked to give an overall grading for the care received by the person who died. These are given in table 4.

Table 4: Overall Grading of Care Received

Criterion	SWL 2020-21 No (%)	LeDeR 2019[10] %
Care given met or exceeded good practice	48 (61)	56
Care fell short in minor areas	18 (23)	38
Care fell short in significant areas	9 (12)	10
Care fell short with significant impact	3 (4)	4
Care fell short and contributed to death	0 (0)	3
Missing	19	

It would be misleading to place too much emphasis on differences based on such small numbers in the SWL group, but the smaller proportion in SWL recording care falling short in minor areas should be noted.

The fact that no reviews were recorded as contributing to death should also be noted.

Multiagency reviews

There were no instances from reviews requiring a multi-agency review which are recommended by the LeDeR programme as a means of addressing shortcomings or problems identified in the review process.

Instead, problems which were identified in the reviews appear to have been dealt with by the reviewer, LAC liaison with the Trust, the Serious Incident process and the Rapid Response Review and Complaints processes. These were monitored by the four locality steering groups (Croydon, Wandsworth and Merton, Sutton, Kingston, and Richmond). Learning into action discussed later in this report address these issues.

Learning disability annual health check

The annual health check is seen as a key means to improve and maintain the health of people with learning disabilities. It is available to anyone over the age of fourteen and on their GP's learning disability register. It should be routinely offered by GP practices. Checks are classed as 'enhanced services' offered by GP practices.

Seventy-eight (roughly 80%) of the 97 people in this study were recorded as having had a check in the twelve months before their death. Nationally the LeDeR programme has called for Annual Health Checks for People with a learning disability to be mandatory. Further information regarding learning into action around annual health checks is presented later in this report.

Breakdown of local reporting data

SWL CCG consists of six localities, coterminous with the London Boroughs of Croydon, Kingston-upon-Thames, Merton, Richmond-upon-Thames, Sutton and Wandsworth. It serves a population estimated at 1.6 million. Table 5 shows the numbers of deaths recorded in the six localities.

[10] LeDeR Annual Report 2019, p. 46

Table 5: Actual and Expected Deaths and Incidence in the Six Localities April 2020 – March 2021

	Pop (000s, rounded)	Actual No. of deaths	Incidence (per 100 000)
Croydon	387	32	8.2
Kingston	178	8	4.5
Merton	207	8	3.9
Richmond	198	11	5.6
Sutton	206	22	10.7
Wandsworth	330	16	4.8
SW London CCG	1506	97	6.4

The table shows:

- the population of the locality [11], rounded to the nearest 1 000;
- the actual number of deaths recorded.
- the rate of deaths per 100 000 population.

Therefore, Sutton had recorded around twice as many deaths per head of population than Richmond; two and a half times as many as Kingston and Merton (see appendix 2). This may be as a result of the number of providers and residents in Sutton (and Croydon) being higher than other Boroughs.

Table 6 shows differences between the localities in terms of deaths from COVID-19, home deaths, gender balance, mean age and numbers from black and Asian populations. Entries are shown as: actual number (expected number). Actual and expected figures may not add to the same total due to rounding.

Table 6: Demographic Variations between Localities

	Deaths from COVID-19	Deaths at Home	No. Of Women	Black, Asian and Ethnic minorities	Mean Age (difference)
Croydon	18 (15)	10 (11)	12 (13)	6 (12)	54 (-3)
Kingston	6 (4)	2 (3)	4 (3)	2 (4)	53 (-4)
Merton	3 (4)	1 (3)	3 (3)	2 (3)	64 (+7)
Richmond	5 (5)	4 (4)	5 (5)	1 (0)	61 (+4)
Sutton	5 (10)	9[12] (7)	8 (9)	6 (3)	59 (+2)
Wandsworth	7 (7)	6[13] (5)	7 (7)	8 (4)	56 (-1)
SWL	44[14]	32	39	25	57

It is as well not to place too great an emphasis on any differences in this table as the numbers involved are small.

There is no difference in the actual and expected number of deaths at home or in the gender mix.

[11] Population is ONS mid 2019 estimate from 2011 Census data, found in 'ukmidyearestimates20192020ladcodes.xls' and rounded to the nearest 1 000.
[12] Includes one hospice death
[13] Includes one hospice death
[14] Figures for March 2020 to March 2021

Covid: Croydon and Kingston had a higher rate of deaths attributed to COVID-19 than expected, where in Sutton the rate was lower.

Ethnicity: Black, Asian and Ethnic minority populations of Croydon and Kingston are slightly underrepresented in the actual figures.

Age: Residents of Merton, Richmond and Sutton were reported as living longer than those in other localities.

xiv. Intervention to reduce mortality from COVID 19

It is obvious from the reporting figures that COVID 19 had an impact on the increased early mortality of people with a learning disability.

In order to reduce mortality and hospital admissions various projects were engaged to support people where possible to have their COVID 19 vaccine.

Some of the work that went on was the establishment of local borough steering groups to look at best ways to support people with a learning disability to have the COVID 19 vaccine. The steering groups included representation from COVID vaccine programme lead, primary care networks, Mencap and CCG primary care representation.

Outcomes from these groups were to support primary care networks to make reasonable adjustments at vaccination centres with support from local community learning disability teams and learning disability nurses. Time slots were set aside specifically for people with a learning disability and specialist such as learning disability nurses were on hand to support patients.

The community learning disability teams also worked with the with primary care networks and GPs to provide practical support to attend appointments, including support related to needle phobia.

Community teams have engaged with the learning disability and autism population and their families and carers to raise awareness of the benefits of vaccination.

All decliners of the vaccine have been re-contacted at intervals and offered support and individual conversation to understand the reasons for declining the vaccine.

Other work that has been undertaken to support the vaccination programme.

- Community Learning Disabilities Team nurses have completed vaccinator training and offer accessible information and advice to clients/families/carers regarding covid vaccination.
- Community Learning Disabilities Team nurses have been supporting the group 6 vaccination programme by ‘buddying’ with district nurses when vaccinating the homebound including Learning Disabilities clients.
- Community Learning Disabilities Team are currently receiving referrals from GPs to support consent/Mental Capacity Assessments and ‘hard to reach’ clients with vaccinations.
- Community learning disability nurses gave “drive through” vaccinations to people who found accessing vaccination centres difficult.
- Croydon community learning disabilities team set up a vulnerable people’s database to identify everyone on their case load with a confirmed learning disability who has a carer of 70-75 years old or who belonged to a vulnerable household.

- NHS England easy read guidance on how to manage during the pandemic was disseminated by community learning disability teams and followed up with practical support and telephone conversations.
- Community learning disability nurses to joint work with Croydon Health Service vaccination hub at Croydon University Hospital to set up 'pop up' clinic to support Pfizer vaccination to under 40yr old cohort.
- In Croydon there are 70 people known to community learning disabilities team who have not received the vaccination following the group 6 roll-out. The community learning disability nurses are engaged in a programme to work with these people to support them in having the vaccine.

xv. Learning into action

In this section, we will look at the main issues that were identified from local reviews, where care and support of people with a learning disability did not go as well as expected, and we will look at what work has gone on to address these issues.

Over the past year, despite the COVID 19 pandemic, specialist health services and acute trusts have made significant progress in making improvements in access to health for people with a learning disability across Southwest London.

Most of the issues identified locally also reflect those reported on nationally in the LeDeR annual report but some appear to be unique to the SW London area.

Aspiration pneumonia and other respiratory issues

From the national LeDeR programme and from information gathered from local reviews aspiration pneumonia and other respiratory issues have been identified as the leading cause of death for people with a learning disability.

There are many reasons why this is more prevalent in the learning-disabled population but often these people are more susceptible due to having other physical health issues and co-morbidities.

However, it is important that health and social care staff are aware of this vulnerability and are equipped to identify and support those people who have this vulnerability. Some of the work that has been progressed so far in Southwest London.

There was a successful roll out of flu and COVID vaccination programmes for people with a learning disability through targeted engagement, support, and reasonable adjustments. A successful specially designed sensory Covid vaccination clinic in Wandsworth was set up and was aimed at helping young people with learning disabilities conquer their fear of needles. The pilot sensory clinic was set up by the charity Wandsworth Share Community working with the NHS.

Further work has been undertaken by the Croydon community learning disability team to support desensitisation of service users who have needle phobia as well as providing practical advice and support and supplying easy read leaflets to inform service users and carers of symptoms of Covid 19.

Three community learning disability nurses completed the vaccination training and practical competency to support the covid19 vaccination programme.

Other areas across the SW London area have produced and disseminated easy read leaflets on social distancing/shielding measures and advice on uptake of Covid 19 vaccines.

In all the SW London boroughs COVID 19 vaccinations were offered at specialist sites which were run by the primary care networks in each area. These sites were supported by the local community learning disability teams and community learning disability nurses to engage and support people with a learning disability and their families when they attended. Also, times were set aside that were specifically allocated for people with a learning disability.

The Merton team provided a service for clients who had issues with social interactions that enabled them to be driven up to the vaccine site and get their vaccine whilst staying in the car.

In Kingston and Richmond after discussions with the local community and health services, a pop-up flu vaccination clinic was set up in late autumn specifically for people with a learning disability their families and carers. This was set up and enabled by Mencap Kingston, Mencap Richmond, community pharmacy and CCG LAC.

Dysphagia (swallowing difficulties) often results in people being susceptible to aspiration pneumonia. To combat this community learning disability team's speech and language therapists and dieticians are undertaking timely dysphagia assessments and dietetics input to support early recognition of this problem and are able to give specialist advice on supporting the individual at risk as part of the persons care plan.

Annual Health Checks

The NHS Long Term Plan sets an ambition that by 2023/24, at least 75 per cent of people aged 14 and over on the learning disability register receive an annual health check, in a drive to tackle health inequalities for people with a learning disability. Once people have received their annual health check, they can then work with clinicians to develop a personal health action plan, which sets out advice, treatment, and support for addressing any health concerns which may have been identified through the check.

Annual health check training was developed and delivered by SWL GPs in partnership with local charity Generate, co facilitated by a person with a learning disability. The training was presented by webinar and delivered to GP's and to practice staff. The webinar was recorded and is available to watch.

The clinical lead GP for learning disability for Kingston and Richmond has been working with GP colleagues, local Mencap and the community learning disability team to improve the quality and numbers undertaken for annual health checks. Kingston borough now have completed annual health checks for 78% of people that are registered with learning disability, Richmond borough have 69 % and Croydon borough have 81%.

SW London achieved the health check target set by NHSE this year (NHSE target set 67% of people on the LD register).

A health facilitator pilot project commenced in Sutton to increase uptake of annual health checks for people with a learning disability and personalised support following their annual health check by raising awareness, providing additional support to reach those people with a learning disability who are not attending for their annual health check and identify the barriers to AHC's for both people with a learning disability and GPs.

Problems in the issuing of DNACPR notices.

Since the beginning of the pandemic, it has been reported nationally that DNACPR notices have been used incorrectly.

The CQC reported that since the start of the COVID 19 pandemic DNACPR notices were being given as a blanket decision for people with a learning disability without the involvement of their families, carers and those close to them. Decisions were being applied to groups of people when they should actually be taking into account an individual's personal circumstances regardless of them having a learning disability.

A small number of reviews in the SW London sector has also picked up similar issues.

To address this, work has gone on via the learning disability liaison professionals in each trust and supported by the local community learning disability teams, to audit DNACPR that were applied to all patients with learning disability and to develop DNACPR pathways.

Community learning disabilities team staff have also been working directly with GPs to raise awareness of this issues and to facilitate conversations on ways to best support patients who may have complex health needs and multiple co morbidities.

Differences between local hospital trusts in the provision of learning disability liaison.

There are 4 acute trusts that cover the footprint of SW London CCG. Each Trust manages its learning disability liaison services on an individual basis and not all Trusts have had a specialist learning disability liaison role that is employed by the trust.

Some Trusts have one or more liaison post depending on the size of the Trust and its location. Those Trusts that don't employ a liaison role have contracted support for the local learning disability team on a sessional basis to meet the needs of the learning disability patient population.

Kingston hospital has recently employed a full-time liaison professional for people with a learning disability. Some of the work that has been undertaken by the liaison professional to date includes:

- Taken and managed 70 referrals for people with a learning disability in the past 4 months.
- Implementation of early adopter site for NHSE reasonable adjustments flag for people with a learning disability working jointly with the SW London CCG to implement this system.
- Update of information on the trust intranet and upload of easy read information for patients, families, and carers.
- Undertaking of a DNACPR audit between March 2020 to March 2021
- Successfully gained funding from the trust charity for Photo symbols login – gold standard for producing Easy Read information

Difficulties faced by care homes in accessing training on health-related issues.

Local reviews have identified that some care homes across SW London have had problems with access to training especially around how to identify the soft signs that someone is becoming acutely unwell as well as problems in accessing training on routine clinical procedures.

The SW London CCG and partners has been engaged in work to remedy this and has been working towards improvements in some of the following ways.

Enhanced care in care homes - Nearly every care home now has an identified GP clinical lead, who is offering weekly support to care home staff and residents via the PCN Network Direct Enhanced Service (DES). Clinical pharmacy support carrying out medication reviews.

Care homes have been provided with and trained in the use of observation equipment, such as sphygmomanometers, thermometers, and pulse oximeters.

Southwest London CCG has appointed a project manager and has obtained funding to work with the care home support team to train all care homes to take vital signs and to recognise early signs of deterioration, communicating any concerns to healthcare professionals.

A super trainer and the care home support team have delivered the national infection, prevention, and control training virtually and face to face to all care homes, training over 1,100 care home staff. A team of specialist IPC nurses are available to support issues that care homes may still be experiencing.

NHS mail shared mailboxes and Microsoft Teams have been rolled out to all care homes to support confidential information sharing and collaboration, and to support the weekly GP clinical contacts. The care homes have been followed up by support calls by the SWL CCG team to support the use of NHS mail where needed.

The Capacity Tracker tool has been rolled out across all care homes to give a daily position on bed availability, suspected Covid-19 cases, outbreaks in care homes, staffing levels, availability of personal protective equipment and flu/ Covid immunisation uptake. This system is being replied upon by local teams to respond to issues raised by care homes.

Facebook Video Portals have been piloted for some Care Homes residents to connect with their family and friends and supporting the workforce in care homes by offering additional staff via the NHS Workforce Hub and the Princes Trust.

Southwest London CCG is continuing to run care home information sharing webinars which explain changes in guidance, best IPC practice and other issues. There are opportunities for care homes to ask questions and to share experiences. A weekly Frequently Asked Questions (FAQ) pack is sent to every care home in Southwest London on a weekly basis.

Covid Vaccinations - As at 17th May, 91.6% of the 1,152 residents in CQC Registered Mental Health and Learning Disability (MH&LD) care homes have received the 1st dose of the Covid Vaccine, and 83.5% have received the 2nd dose. 74.5% of MH&LD care home staff members have received the 1st dose, and 53.8% of staff have received the 2nd dose. These numbers are comparable to the older people's care homes in Southwest London. Work is continuing to support vaccine hesitancy in staff members and residents.

RESTORE2 (identifying the soft signs of deterioration):

135 of the 195 MH&LD Care Homes in Southwest London have been trained in the use of RESTORE2, and the remaining Care Homes are being approached for training dates. A remote monitoring pilot is being trialled in Southwest London and will include the use of a digital remote monitoring solution in around 120 care homes across the boroughs, which will include CQC-registered MH&LD homes. This will be rolled out during the summer.

The incompatibility of the Learning Disability Hospital Passport with electronic records increasingly used by Hospital Trusts.

Some local reviews have identified problems with access, use and update of hospital passports.

Currently most hospital passports are held in paper form which poses several issues.

Often information is not current, passports get lost or damaged and when they are taken with the person to hospital they do not get used as they are not immediately accessible, and most hospital and health notes and records are now in electronic format.

To combat this issue new ways of producing and storing hospital passports in electronic formats are being investigated.

One of the ways is to use the Co-ordinate My Care (CMC) record which is widely in use across Southwest London and other areas across London. Initially set up as a care plan to support people at the end of life the record has been found to be easily adaptable for use as an electronic care record for people with a learning disability which can be linked into health action plans and used to form a hospital passport.

CMC records are easily accessed by GP's community health services and mental health and acute trusts as well as being accessible to emergency services which is extremely useful when current up to date important information is needed. The CMC record also supports appropriate DNACPR notices. There is now the following project ongoing to enable the use of the CMC record.

In Croydon, all community learning disability nurses including acute trust liaison nurses and community mental health nurses have been trained in the use of the CMC record system. The CCG has been promoting this work with the community placement providers and is also monitoring the numbers of records being put in place. CMC training for all care homes in Croydon is currently being implemented.

Your Health Care community learning disability services who cover Richmond and Kingston are also involved in local work to support and embed the CMC project.

The GP lead for people with a learning disability in Kingston and Richmond is involved in bidding for money to support a wider implementation of the CMC record as well as supporting and promoting the use of CMC with GP colleagues and care providers.

Other initiatives that have been raised from learning in the national LeDeR reports:

STOMP/STAMP - (Stopping overprescribing of psychiatric medication for people with a learning disability). A pilot was delivered in Southwest London for pharmacists to undertake and complete medication reviews for people with a learning disability in care homes. Part of the pilot was for pharmacist to undertake holistic review of medication within a person's treatment review. The pilot was nominated for a Health Service Journal and patient safety award and was a finalist in the Learning Disabilities Initiative of the Year category.

Specialist Bowel Screening Clinic - Considering the reports of higher levels of constipation for people with a learning disability and the serious health issues this can lead to if not identified, Your Health Care community learning disability service has now set up a specialist bowel clinic to assess and monitor those people who are at high risk of constipation and other bowel issues.

xvi. Examples of how the programme has made a difference for local people with a learning disability and their families

We can see from our local reviews that there is more or less a similar pattern of issues that are reported on nationally although as discussed previously there are some issues that have been highlighted locally.

The main causes of death of people with a learning disability in SW London are from respiratory problems followed by cardiac problems.

There have been some highlighted issues around the incorrect use of DNACPR notices in spring 2020 due to the spike in deaths of people with a learning disability due to COVID 19 and also issues for care homes in regard to accessing training on health care for service users.

Although LeDeR reviews often highlight concerns with a person's care and with the system there are also some positive stories that are reported on in reviews and which we would like to include here in this report.

Some quotes from completed local reviews.

From acute trusts

"To me and to X it was life giving, as simple as that. I was able to see X and see how they responded in a way the doctors and nurses can't see. X wanted to say please give me something by mouth, I am hungry…thanks to you I could get my voice heard"

"X was brilliant...it was a huge difference. What was extraordinary to me was that despite the distance we had for nearly a year...with the tip of my glove I touched their hand and their legs, they just smiled…they heard my voice and they knew her mother was there and all would be alright"

"XX's brother and sister-in-law noted the kindness and compassion of the staff on the ward where XX died, both to them and XX. "

"Thank you nurse for everything you and nurse A do and all your kind, loving team have done for XX, you have looked after him as though he was one of your own family. We are truly grateful."

"An SJR reviewer noted "very person-centred care for a lady at the end of life in ITU during Covid"

"Family members expressed that they had positive experiences in hospitals as they have been kept informed, being involved in decision making and had flexible visiting at the hospital."

"One of the doctors rang and asked about how they can tell if she is in pain. I told them that she loves Elton John Yellow Brick Road – if she doesn't respond then you know she is unwell. The doctor played this and she held her hands together in prayer position signalling she was relaxed"

"Family members commented about the Learning Disabilities Nurses as "wonderful" as the team has given the family members good advice about care and treatment whilst in hospital, clear communication and additional specialised nursing care was provided."

"Family reported that during the pandemic open visiting by arrangement with the ward manager was very helpful"

"Virtual visits were arranged and appreciated"

From a person using the pop up flu vaccine clinic held at Mencap

"I was quite anxious about having the flu vaccine but going to the Searchlight centre where I know people made me feel better about having it. They let mum come into the room with me which also helped. "

Positive feedback about GPs

- Making home visits during lockdown.
- Making timely referrals to hospitals and other agencies.

xvii. The Future of the Learning Disability Mortality Review Programme

As we move forward into a new organisation the current form of the CCG will no longer exist however it is important that the work already undertaken as out comes from the LeDeR programme is continued. The CCG will continue to explore in partnership with each borough and local voluntary and third sector organisations the delivery of improved engagement with and support to people with a learning disability and / or autism and their families to improve health inequalities and address areas of inequality highlighted by the LeDeR programme.

There are a range of new elements to the LeDeR programme which the CCG (and then ICS) will need to ensure are progressed during this transition year for the NHS, with delivery through the LeDeR Steering Group. This work forms part of the wider Southwest London Learning Disability and Autism Programme. Overarching ambitions of the programme are:

- Improving health inequalities
- Support and strengthen community services for people with complex needs and reduce reliance on inpatient care
- Ensuring people with a learning disability and / or autism can live their best lives
- Improving quality of Services

Specific to the LeDeR Programme is a new NHS England Policy, which has come into being from March 2021 which describes new changes to the way the reviews will be undertaken, as well as describing what is expected of the ICS to support reviews, implement learning and service improvements from these. By 1 April 2022 all changes within this policy must be implemented by ICSs, subject to legislative changes relating to ICSs being passed in coming months.

- The new policy also includes reviews of deaths of all people diagnosed with autism whether they have a diagnosis of a learning disability or not.
- A new web-based platform will now be the central point of information and reporting for all reviews and death notifications as well as holding information on training and support for reviewers and others involved in the LeDeR process.

Main changes to the review process are:

- Every notification of a death will have an initial review but not all will have a focused review. Families can request a focused review.
- The need for a focused review will be determined by the initial reviewer.
- All deaths of people with a learning disability who come from a Black, Asian or minority ethnic background will have a focused review.
- Completed reviews will no longer make recommendations but will present areas of good practice, learning and areas of concern to be presented at local governance groups.
- All people with a learning disability aged 4 and above and every adult over 18 years diagnosed with autism is eligible for a LeDeR.

- Improved reviewer training with yearly refresher training.
- Reviewers will work in larger teams across areas and have regular supervision and admin support.
- All completed reviews will be checked by a senior reviewer and local governance groups will have quality oversight of reviews.

During the year the CGC will need to progress the development of a Southwest London LeDeR strategy – and through this, meet the requirements of the programme and ensure this is embedded in the ICS governance processes.

In summary, the LeDeR programme will remain a service improvement programme and become part of the quality and service improvement frameworks within the ICS. Greater responsibility and accountability will now be placed on ICSs to deliver the objectives of the LeDeR Programme and holding local systems accountable for actions coming out of the reviews. A report on this will need to come to the Quality and Performance Oversight Committee in early 2021/2022.

Ahead of that time, the CCG will need to consider the local implementation of the new workforce model required, essentially including a workforce dedicated to the LeDeR programme. Current modelling suggests 2 to 2.5 WTE staff would be needed for the current rate of notifications. The CCG will be required to ensure that staffing arrangements are in place through commissioning or employment of a dedicated, independent, larger, multi-disciplinary team of reviewers supervised by a senior reviewer and supported by administrative staff. The team of reviewers will be supported through training, peer support and professional supervision. At present, the national team are recommending that reviewers are employed on at least a 0.5 whole time equivalent basis to ensure activity levels and maintain timeliness of reviews. Southwest London should ensure that reviewers are representative of their local population and should ensure that they understand the local communities they work within including ensuring an appropriate understanding of culture, and belief, bereavement and death and learning disability and autism in those communities. This should be monitored and reviewed over time.

xviii. Southwest London CCG LeDeR Strategy

During the coming year, the CCG will need to produce a three-year LeDeR strategy demonstrating 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. Whilst Southwest London has previously delivered timely reviews and produced excellent local plans, going forwards this work will need to be embedded in the work of Quality Surveillance Groups for example. Collaborations between partners across health, care services, public health and the community and voluntary sector will be key to help to address health inequalities, improve outcomes and deliver joined up, efficient services for people with a learning disability and autistic people.

xix. Conclusion

Due to the COVID 19 Pandemic the past year has been a great challenge for everyone, not least for people with a learning disability who have been more susceptible to the effects of the virus and have had a higher mortality rate than the rest of the general population.

Hospital admissions normally for this group of people can often be a scary and frightening experience, but in the last year many people have had to endure hospitals stays without the direct support and comfort from family friends and carers, being distanced due to infection control measures and social distancing.

Local reviews have described tragic experiences of people in the last moments of their life due to becoming seriously unwell in a very short space of time caused by the virus and how families have been unable to be with their loved ones in their last moments.

Not all of these situations have been avoidable but what has been highlighted in reviews is the compassion and support that health and social care professionals have given in times of need and great stress.

The importance of and need for specialist learning disability liaison practitioners in the community and in acute and mental health trusts has been raised and reported on and they have been praised for their work by families and other professionals.

The work of keeping up with the LeDeR reviews and supporting the learning into action has also been a challenge over the past year but because of the dedicated team of reviewers, LACS and health and social care colleagues across SW London we have been able to be on target with performance and implement recommendations and changes that support better health care for our local population of people with a learning disability.

We would again like to give an extra big thank you to all those family members, friends and carers of the people who have passed away and to colleagues for all your support and hard work over the past year, we are extremely grateful.