Southwest London Clinical Commissioning Group

"Learning from Lives and Deaths" People with a learning disability and autistic people.

Mortality Review (LeDeR) Annual Report 2021/2022

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

Author: SW London Local Area Contacts for LeDeR

Date: 31/08/22

Contents

i. Glossary

ASD	Autistic Spectrum Disorder
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 report is the second Learning Disability Mortality Review (LeDeR) annual report of the Southwest London Clinical Commissioning Group (SW London CCG). Since the first report was compiled in 2020/2021, some significant changes have been made to the LeDeR programme. The programme now includes not only people with a learning disability but those who have a diagnosis of being on the autistic spectrum. The LeDeR programme is now referred to as “Learning From lives and Deaths. People with a learning disability and autistic people”.

This report gives an overview of the reported numbers of deaths, the numbers of deaths per borough, main causes of death and learning from deaths of people with a learning disability.

The report also highlights some of the main areas of work that health care providers have been engaged in from each of the 6 South West London boroughs with the aim of reducing health inequalities for people with a learning disability and autism.

The Southwest London CCG and all partner organisations and commissioned services are committed to ensuring people with a learning disability and people with autism 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. Acknowledgement of the input and support from families and participants of the reviews

All those people involved with undertaking and supporting the LeDeR reviews, the Southwest London CCG and health and social care partners are extremely grateful to all the families, carers, and friends of the people with a learning disability and autism who have given their 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.

iv. Executive Summary

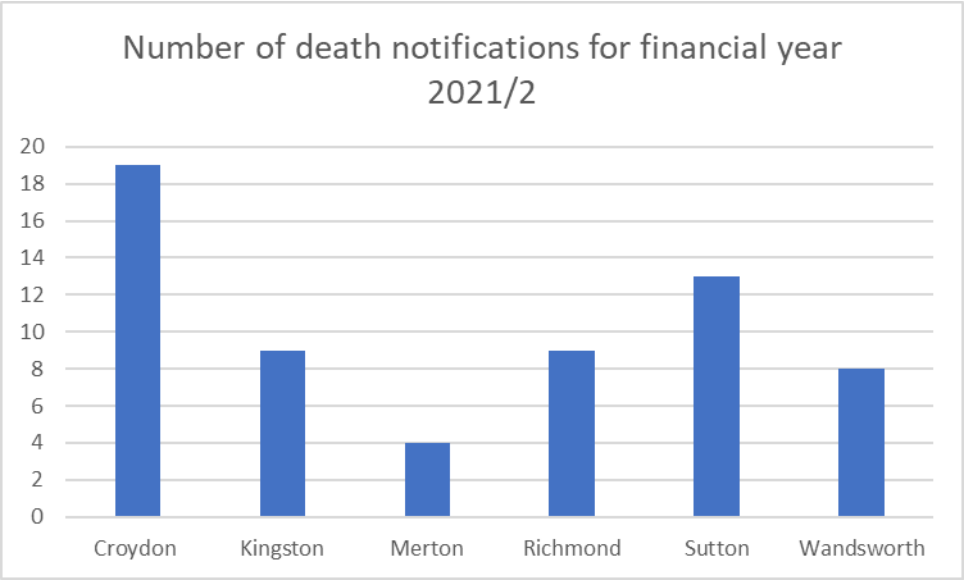
During the financial year 2021 to 2022 there have been 62 notifications made to the NHSE LeDeR platform on the deaths of people with a learning disability who have resided in the Southwest London CCG area which includes Croydon, Kingston, Merton, Richmond, Sutton, and Wandsworth boroughs.

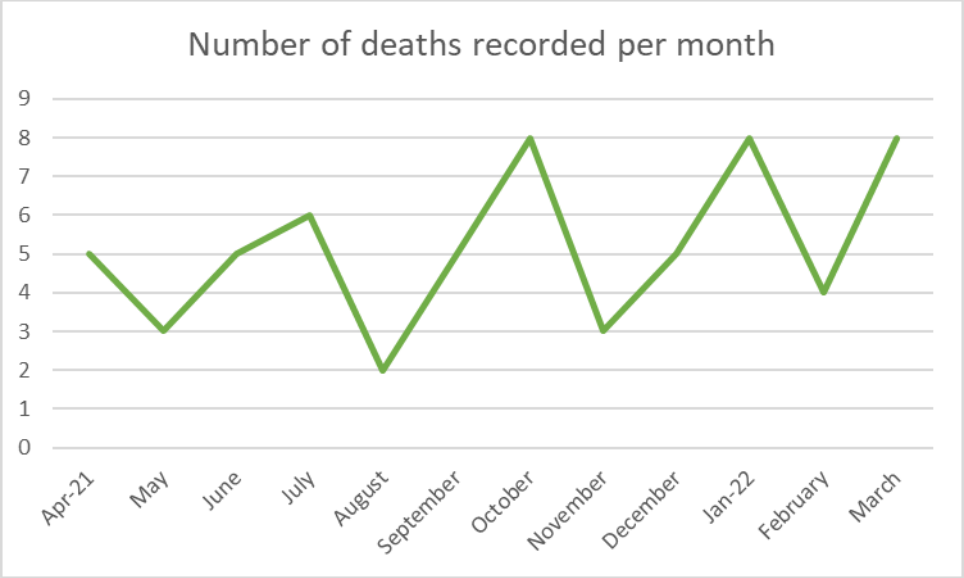
The new reporting system now includes autistic people whether they have been diagnosed with a learning disability. However, this change to recording on the system only came into being in January 2022 and so far, there have been no notifications of people solely with the diagnosis of autism.

All notifications were passed onto the local area contacts in each area for allocation for reviews.

There have been no delays or hold ups in allocation or undertaking of reviews in this time period.

The numbers of deaths notified for each borough are as follows:





- 19 Croydon
- 9 Kingston
- 4 Merton
- 9 Richmond
- 13 Sutton
- 8 Wandsworth

The overall average (mean) age at death for this group was 54 years and 9 months. The median was 60.

For comparison the median age at death among the general population is 81 years and ten months.

The main causes of death for people with a learning disability were attributed to aspiration pneumonia, other respiratory issues, and sepsis.

In particular, aspiration pneumonia was the cause of death for almost a third of the reported deaths and should continue to be an area of focus and training for support staff in caring for those at high risk from aspiration pneumonia.

The LeDeR Annual Report for 2019 notes that aspiration pneumonia is the single most common entry on death certificates of people with learning disabilities.

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'. Final counts of ethnicity were not available at the time of compiling this report due to some reviews not recording this information and some reviews not being fully complete.

The majority of the reported deaths (43, approximately 73%) died in hospital. This is a higher number than the reported figures from the national LeDeR program which was reported as 60% of people dying in hospital.

A further 16 people died at home recorded as their own home. There were no reports of deaths in hospices.

Changes to criteria for reviews

In the new review, introduced for deaths occurring after April 2021, significant changes have been made to the information collected. People with autism are now included (since January 2022) for the first time within the LeDeR remit.

Most significant is that most cases are dealt with in an 'Initial Review', a short questionnaire of limited scope while a selected group are subject to a 'Focussed Review' which is much longer and detailed.

Those requiring a Focussed Review include:

- Anyone diagnosed with autism
- Anyone from a Black or Minority Ethnic background and
- Anyone whose initial review has raised significant issues

v. Why is the LeDeR programme important?

Figures from the CIPOLD (2013) and more recently from the LeDeR annual report (2021) it is evidenced that people with a learning disability are dying much earlier than the general population. 6 out of 10 people with a learning disability die before the age of 65. On average people with a learning disability have a much shorter lifespan than the rest of the general population recorded as 22 years earlier for males and 26 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 and autistic people to live longer and healthier lives.

vi. Governance and monitoring of the progress of the local LeDeR programme at a strategic level and via local area steering groups

From July 2022 a new system "The Integrated Care System "or ICS will come into place which will take over from the previous Clinical Commissioning Group and brings together all health and care organisations that provide health and social care services across SW London.

Before the new ICS comes into being discussion have been held on how to ensure the continued governance and oversight of the "Learning from Lives and Deaths" programme and also on how the ICS will meet the recommendations from the NHS England LeDeR Policy (2021)

B0428-LeDeR-policy-2021.pdf

The policy recommends that each ICS sets up a team of dedicated reviewers and local area contact to have sole focus on conducting thorough reviews, ensuring all reviews are completed in a timely manner and that all learning and good practice that is identified from reviews is shared across the whole ICS as well as being shared with the national LeDeR team.

A business case and strategy had been developed in support of the recommendations and once the ICS comes into being we will work towards setting up this small team.

In the mean time we will continue to allocate and undertake reviews via our local area contacts in each borough and our dedicated team of contracted reviewers.

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.

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.

It has been agreed that local area steering groups will continue to function as they were set up previously, but they will be convened and chaired by the new LeDeR team once this is in place.

The governance of the LeDeR programme at a strategic level has been supported and overseen by the Director of Quality for SW London CCGs who is also the Deputy Senior Responsible Officer for Southwest London Transforming Care Partnership.

The director for quality has met on a quarterly basis with all the local area contacts, the lead transformation manager for learning disability and autism programme and the head of service for people with a learning disability and autism, to monitor and review key performance and

achievements of completed cases as well as to consider and plan how the governance oversight will continue once the ICS is in existence.

The future plan for the governance of the “Learning from Lives and Deaths” will make some changes to the current arrangement as there will be a dedicated team who will take responsibility for ensuring the programme is linked in with the wider ICS quality and governance oversight committees and processes.

It is envisaged that the team will set up and chair quarterly meetings with relevant senior people within the ICS to feedback on reporting and highlighting issues where learning into action is needed and to monitor this progress.

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 LeDeR studies and annual 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 Borough 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:

- Be notified by the LeDeR platform that a death in your area has been notified
- 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. Notifications of deaths of people with a learning disability across SW London from March 2021 to March 2022

From June 2021 a new system/ Web based platform for reporting, monitoring, and training was set up by NHS England taking over from the previous system based at Bristol University. This web-based platform is now the hub for anyone either family, friends, members of the public or people from health and social care organisations to report on deaths of people with a learning disability and people with autism. NB reporting on a death for someone with a learning disability or an autistic person is not mandatory for this programme it is voluntary.

This platform will be accessible to Local Area Contacts and trained and approved reviewers who will be able to allocate and monitor reviews, gain understanding of any issues in care and find out about learning from reviews and keep up to date with training and any other issues regarding the LeDeR programme.

This platform has had some initial access and development issues which are being addressed by the national LeDeR team. A working party has been set up to engage representatives from each locality across the country to gather direct information from users on what issues are being experienced and also what suggestions for improvements to the platform can be made.

The on-line platform for reporting and for information on the "Learning from Lives and Deaths" can be accessed at https://www.leder.nhs.uk/

xi. Reviewers and completion of reviews

Under the current system 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.

In previous years each area has had their own pool of reviewers which were normally drawn from the community learning disability services, social workers from the local authority and specialist learning disability nurses from the acute trusts.

However due to increasing pressures of these people's everyday roles they were not able to continue to provide support and since then the CCG has been able to use a small, contracted bank of trained reviewers.

It is envisioned that once the new ICS has come into being and is fully functioning then a new full time permanent team of 2 reviewers and a local area contact will take over from the current system and will be responsible for all work and issues related to the "Learning from Lives and Deaths" programme.

Timely completion of reviews

From March 2021 to March 2022 the SW London CCG has managed, with support from local reviewers and local area contacts, to ensure all notified deaths of people with a learning disability and/ or autism have been undertaken and completed in a timely manner with no back log of reviews awaiting to be allocated or undertaken.

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

xii. Statistical analysis of SW London LeDeR data from March 2021 to March 2022.

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
- the causes of death

SW London CCG serves a population of approximately 1.6 million people. The area it covers includes 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 Table 2.

In the twelve months prior to 31st March 2022 there were 62 notifications of deaths made to the NHSE LeDeR platform for SW London CCG area.

This is a much smaller number than were notified in the previous year which was recorded as 101 notified deaths of people with a learning disability. Out of the 101 notifications 44 were recorded as COVID 19 being the cause of death with the highest death rate being recorded as 24 within the month of April 2020 and another peak in numbers in December 2020 and January 2021 where the figures were recorded at 10 and 12 respectively.

In comparison with other years the numbers of notifications of deaths of people with a learning disability who died from causes other than COVID 19 are of a similar number.

However, the addition of reviews for people diagnosed as being on the autistic spectrum have not yet been realised as this addition to the programme has just come into being.

Figures in next years report should be able to identify any increase in reports for this group of people and also to identify any trends in cause of death and other demographics.

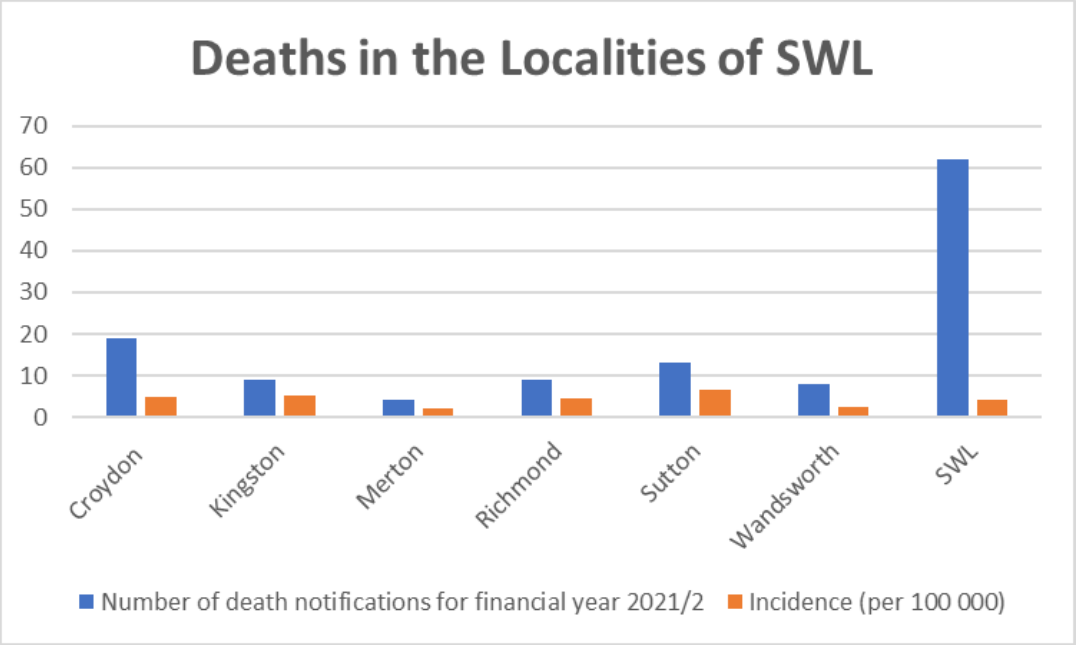
Table 1 shows the total number of deaths recorded in SWL for each month between April 2021 and March 2022.

Table 1: Deaths from all causes by month April 2021 – March 2022

Month	Number of deaths recorded
April 2021	5
May	3
June	5
July	6
August	2
September	5
October	8
November	3
December	5
January 2022	8
February	4
March	8

Table 2: Deaths in the Localities of SWL

Locality	Number of deaths recorded	Incidence (per 100 000)
Croydon	19	4.9
Kingston	9	5.1
Merton	4	2
Richmond	9	4.5
Sutton	13	6.5
Wandsworth	8	2.4
SWL	62	4.1



Ethnicity

Of the 62 notifications, thirty-five people were described as white, one person was described as Asian, one person was described as black and a further two people described as mixed heritage. As stated previously in the report some reviews did not record ethnicity and some reviews have not been completed at the time of reporting. The lack of reporting of ethnicity is an area that needs addressing and improving upon and has been reported up to the national team for LeDeR.

Gender and marital status

The group consists of 45 men (72%) and 17 women (28%). In the national LeDeR data, there are typically more men than women, though the reason for this is unclear. However, this is typically in the region of 60/40 so the difference in the current data is higher and unexplained.
None of the 53 for whom information was recorded was married or in a partnership.

There are four questions in the new questionnaire relating to gender identity, mainly related to changes in preferred gender since birth, preferred terms etc. However, no-one in this group is recorded as having changed their gender.

Within the new questionnaire there is a question on gender identity but currently there is no mention of sexual preference or sexual orientation. Non-normative sexual orientations are considerably more prevalent than gender dysphoria and there is widespread evidence that asserting an LGBTQ identity affects access to and quality of healthcare. This is an issue that has been raised with the LeDeR national team.

Place of death

Most of the group (43, about 73%) died in hospital. This is rather higher than the proportion (60%) reported for the national LeDeR Programme.

A further 16 died at home, mostly in their own homes. None was recorded as having died in a hospice though elsewhere in the review, hospices are recorded as providing care at home (and sometimes in hospital). Unfortunately, it is impossible to put a figure on that involvement as it is not systematically recorded.

Age at the time of death

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

The oldest was an 84-year-old gentleman from Wandsworth who died at home.

Table 3 shows the number of deaths for different age cohorts.

Table 3: Decade of death

Age Range	Number (%)
<18	5 (8.1)
18 - 19	2 (3.2)
20 – 29	5 (8.1)
30 – 39	6 (9.7)
40 – 49	0 (0.0)
50 – 59	10 (16.1)
60 – 69	16 (25.9)
70 – 79	16 (25.9)
> 79	2 (3.2)

The overall average (mean) age at death for this group was 54 years and 9 months. The median was 60. When the children (under 18) are excluded, the mean rises to 59 years and seven months and the median to 63.

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

Table 4 shows the differences in age distribution of deaths since 2018.

Table 4: Mean and median ages at death 2018 - 2022

	April 2018 – March 2019	April 2019 – March 2020	April 2020 – March 2021	April 2021 – March 2022
All cases Mean (median)	58.9 (64)	58.4 (61)	57 (59)	54.8 (60)
>18 only mean (median)	61.2 (61)	62 (63)	59.5 (61)	59.6 (63)

Adult women in the group died rather later, on average, at just less than 56 years than the adult men, who died on average at 54 years and five months.

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).

Degree of learning disability

On the previous system there was an opportunity to report on the persons level of learning disability to indicate if they had a severe and profound learning disability or a more moderate learning disability. The new reviewing system does not have this question included and therefore it is more challenging to report on numbers of people from these different groups currently.

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). 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 5: Causes of Death noted in Part 1a of the MCCD

Cause	
Aspiration pneumonia[1]	9
Other respiratory conditions	6
Cardiac conditions	6
Cancer	2
Sepsis	6
Stroke	4
Dementia	2
Other[2]	3
Missing or undetermined	26

As in previous years, 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[3].

In particular, aspiration pneumonia claims nearly a third of the lives in this group and must remain a continued focus of attention.

The LeDeR Annual Report for 2019 notes that aspiration pneumonia is the single most common entry on death certificates of people with learning disabilities.

[1] Includes one entry multi-organ failure after Aspiration pneumonia
[2] Tuberous sclerosis, Hypoxia, Mesenteric ischaemia,
[3] As reported by the LeDeR Annual Report, 2019, p. 36. Other calculations suggest it is the fourth most common.

Grading

Until 2021, reviewers were asked to give an overall grading to the care received by the person who died. In the new questionnaire this grading is only made for those for whom a Focussed Review is done.

Learning disability annual health check

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

Nationally, LeDeR has called for these checks to be made mandatory. However currently there are no questions in the review system currently that ask about people having an annual health check and when the most recent one was. This issues will be picked up and raised with the national team.

xiii. 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 been going on to address these issues.

Respiratory conditions

Data from the past years LeDeR reviews for SW London as well as data from the LeDeR national team and most recent annual report indicate that aspiration pneumonia and other respiratory conditions are the leading cause of death for people with a learning disability. As mentioned previously in this report there are differing reasons why this maybe, including certain conditions that are often associated with people having a learning disability and which cause compromised breathing.

Some description of the work to date that has been ongoing across SW London to address this issue is given below.

Maximising the accessibility of vaccination programmes for people with learning disability and autistic people in Southwest London

Special arrangements / support available in Southwest London for people with a learning disability and autistic people through targeted engagement, support, and reasonable adjustments include:

- Use of easy read materials, targeted engagement, and outreach sessions
- Produced easy read materials and slides as part of our engagement activity as well as signposting to and circulating easy read materials as part of our communication and engagement work.
- Delivered engagement sessions for people with a learning disability
- Co produced video with Share featuring a visual "walk through" of what happens when you come for a jab in a soothing environment.
- Created a video which documents a sensory session: Pilot sensory Covid-19 vaccination clinic - YouTube

- Made a “meet the nurse and GP” video featuring a Zoom Q and A to provide accessible facts about the vaccination
- Community learning disability teams and Mencap and local learning disability organisations being invited to support clinics
- Involving staff with specialist knowledge of learning disability within vaccination roll out - include community learning disability teams supporting the booster programme for people with a learning disability and complex needs through home visits or supporting GPs where needed. The vaccination team at Merton Health have employed an learning disability specialist nurse to support with vaccinations.
- Dedicated clinic times to allow for quieter times
- Home visits available if required
- Roving teams going out to care homes from this week for those clients who live in care homes
- Pop up sensory friendly clinics - Sensory Covid vaccination and flu jab clinic in December in partnership with Battersea Primary Care Networks and Share. Merton in collaboration with Sense.
- Proactive contact of people on the learning disability register
- Vaccination centres – when a person with a learning disability / autistic person / person with additional needs is identified in the queue they are taken to one of the quiet spaces rather than having to go through the full vaccination process

DNACPR notices

The DNACPR notice (Do Not Attempt Cardio-Pulmonary Resuscitation) is a feature of advance care planning that has been used for many years but attracted some notoriety during the COVID-19 emergency when there was widespread concern that orders were being issued to groups of people rather than individuals.

From the reviews conducted between March 2021 and March 2022 twenty-five people had a DNACPR notice in place at the time of their death. A further fourteen are recorded as definitely not having one and the remainder of the notifications there was no information given.

The group with notices are significantly older than the average at just under 68 years of age and assumptions can be made that this related to their physical condition.

Most orders were described as correctly completed and followed by a small number (six) were described as incorrect, mostly because there was no recorded discussion with next of kin. While this is of concern, it is worth noting that the DNACPR order itself is rarely available to the LeDeR reviewer as it is not provided as part of the electronic note’s hospitals are now using.

Mental Capacity Assessment

It is difficult to quantify the use of mental capacity assessments (MCA) in this group because

- Records are often not made available and
- The information is not recorded consistently and
- The review does not require detail on any assessment.

Twenty-five people in this group were recorded as having had an MCA and six definitely not to have done so. Information is not available on the remainder. As this is such an important part in supporting many people with a learning disability who do not have mental capacity this is another

area where learning into action needs to focus and will be addressed via local steering groups and professional leads for people with a learning disability at the acute trusts.

Current ongoing work to support LeDeR recommendations

Across the SW London area there are ongoing work streams that have been initiated to support better health access and better health outcomes for the local population of people with a learning disability. Many of these work streams are local initiatives sited within each borough, linked to the community learning disability teams, local acute trusts and the mental health trust. There is joint working and sharing of information across the learning disability directorates at local and strategic levels. With the implementation of the new Integrated Care Service the sharing of knowledge and resources will develop further and support learning into action across the whole of the SW London health and social care economy.

Below are some examples of work that has been put in place since the last LeDeR report by community teams, the mental health trust, and the local acute trusts.

Work across SW London Acute Trusts

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 now all 4 trusts have a full time learning disability liaison professional employed within them.

Some Trusts have one or more liaison post depending on the size of the Trust and its location. These posts are normally filled by a health professional who has a specific background, experience or training in the area of learning disability.

These posts are normally linked to the acute trusts safeguarding team and they work across the whole trust to ensure staff at all levels are aware of the needs of people with a learning disability. Amongst many other areas of work, they support and facilitate hospital acute and planned admissions for people with a learning disability especially when the person has complex physical health issues.

Some of the work that has been going on in the acute trusts over the past year which supports the recommendations from the LeDeR reviews is

Kingston Hospital

- 295 referrals to date
- Set up a pathway with community pharmacist to refer patient for a STOMP review of medications on discharge
- Delivered over 20 hours of training on how to support people with a learning disability across the trust
- Funding application to make specialist nurse band 6 secondment into a permanent post
- Created an electronic flag for reasonable adjustments that shows in clinical electronic patient records
- Learning disability liaison practitioner recognised by the trust winning trust award

Croydon University Hospital

- The learning disability liaison nurse has collaborated with the palliative care team and devised EOL pathway for patients with a learning disability when leaving the hospital back into the community to continue with their EOL support.
- Currently devising elective admission Post Covid pathway for patients with a learning disability when they require surgery.
- Completed Learning Disability DNACPR checklist together with pathway which is currently going to be included within the trust policy
- Successfully devised a learning disability checklist within the hospital with the aim to improve patients with a learning disability experience within the hospital.

Epsom and St Helier Hospitals

Have developed and implemented

- a check list for staff to ensure they are getting the right information for the person with a learning disability including mental capacity and best interest check list
- a guide for staff on what it means when someone has a learning disability
- A poster that guides staff on action they should take when someone with a learning disability is admitted to the hospital and who to contact for specialist support
- An easy read guide for DNARCPR

St Georges University Hospitals NHS Trust

- Have received 1,322 referrals were received, a 15% increase on the previous year.
- Have participated in the learning disability benchmarking survey and look forward to receiving the results to check performance and feedback on areas for further development.
- Staff report feeling confident to implement Reasonable Adjustments (draft Benchmarking Report).
- The learning disability Patient Engagement Group created accessible information relating to Vagal Nerve Stimulation. The group is being reviewed with the new Senior Practitioner now that people can revert to face-to-face meetings.
- Reporting on patients with a learning disability 'flag' is refreshed daily, enabling the learning disability team to make proactive contact with patients who may not have been referred to them on admission.
- Learning Disability Open Sessions are run monthly for staff.

Health improvement work reported on from community services

Croydon

The community learning disability nurse team have been working with the vaccination team in supporting the Covid vaccine programme particularly for people with a learning disability who may present challenges, who are unable to attend the hub or surgery for their vaccinations. Therefore, these vaccinations have been carried out within the persons own homes as part of reasonable adjustments and has proved to be very successful

The bowel screening project is under way and working closely with care homes who have taken part in the pilot study.

The Croydon community team is currently in the process for recruiting for a Health facilitator for all Croydon care homes that support people with a learning disability.

This is a NHSE pilot scheme to upskill care home staff to address health inequalities for People with a learning disability living in residential care. The scheme is part to the Ageing Well project – Enhanced Health in Care Homes.

This role will involve promoting the importance of and supporting the implementation of annual health checks, health action plans, urgent care plans and educative work around best interests and the Mental Capacity Act.

Community learning disability nurses have been busy reviewing as many clients as possible from the Croydon Health Action Plan database as following Covid the team are trying to ensure that our known clients have received health checks and access to health care.

Kingston and Richmond

The boroughs of Kingston and Richmond are serviced by the Neurodevelopmental Team attached to Your Health Care.

The service has launched Project 2020. This is a nurse-led initiative which aims to reduce the health inequalities faced by our service users. Each service user who consents to take part in the project will be supported to ensure that they have a hospital passport, annual health check, a health action plan, a Red Bag, a coordinate my care (CMC) record and are up to date on with their immunizations and relevant health screenings. This will ensure that we close any gaps where they exist in each service user's portfolio of health tools. Project 2020 is initially being rolled out in all residential homes in the borough of Richmond but eventually, we will establish this approach as part of the standard nursing process

Nurses from Yourhealthcare Neurodevelopmental Service (NDS) offer specialised bowel management support to adults with learning disabilities living in the Boroughs of Kingston and Richmond. Following a learning disability based comprehensive bowel assessment, NDS nurses work in collaboration with General Practitioners to identify required management intervention and where necessary, agree on an appropriate laxative regime for each person and develop person centred bowel management guidelines and bowel monitoring charts to offer an enhanced bowel management support for the people they support.

Prevention or minimising constipation problems among these people have shown an increase in their community participation and quality of life. It further highlights reduction in the bowel related hospital admissions/associated behaviour problems and urgent interventions needed from GPs, district nurses and the carers. In overall, this intervention has made a difference to lives of many people with Learning Disabilities supported by the NDS nursing team.

Merton

Kick off – Merton and Wandsworth development of sustainable and bespoke community care packages to support autistic adults – through development of network approach [Improving autism support]

Commenced Merton adult Autistic Spectrum diagnostic service pilot and post diagnostic support

Development plan for Merton autism spectrum condition and learning disability service (adults).

Merton Kids First (parents) provided feedback and were involved in redesigning diagnostic letters for children and young people from SW London and St Georges mental health trusts.

The vaccination team at Merton Health Centre have employed a learning disability specialist nurse to support with vaccinations.

Sutton

Sutton learning disability Health Facilitation project

Commissioners have been very concerned that the uptake of annual health checks were so low in such a vulnerable patient group during COVID and therefore funded the Sutton Learning Disability Health Facilitation Project with the aim to:

- Increase the uptake of annual health checks to 67% for 20/21 and 75% for 21/22
- Assess the use and quality of Health Action Plans
- Investigate patient barriers to getting Learning Disability Annual Health Check

Initial feedback from people with a learning disability was one of the biggest barriers to attending the GP practice was anxiety around COVID and going to GP practices which respondents felt lots of sick people were attending so didn't want to go there themselves. Sutton team decided to set up a service where nurses would carry out the majority of the AHC (excluding medication review) on behalf of the practices. They set up 2 clinics and offered a home service. Practices could refer 20% of the learning disability register.

The nurses have now completed over 200 annual health checks with fantastic patient feedback and a common theme is that the nurses are kind, understanding and patient. Patients have been referred on to other services including Speech and Language therapy for dysphagia, dietitian for weight management, unintentional weight poor fluid intake or constipation. To talking therapies, psychology or the learning disability mental health team

<u>Bowel screening in Sutton</u>

Sutton learning disability health facilitation team, the learning disability care home team, GPs and other staff from the practices are working together in Sutton to increase the uptake of bowel cancer screening among people with a learning disability. An estimated 9 in 10 people will survive bowel cancer if it is diagnosed at the earliest stage. Evidence shows that eligible people with a learning disability are less likely to take part in bowel cancer screening compared to those without a learning disability. This leaves them at risk of undetected cancer.

Southwest London and St Georges Mental Health Trust

The children and adolescent mental health service (CAMHS) learning disability team, who previously covered 1 borough, has now become a learning disability service covering all 5 boroughs of Southwest London and have successfully recruited to the new posts.
The service is now able to offer consultation and assessment to all boroughs with treatment services available to 3 of these boroughs
The team also has additional resource with the employment of behavioural specialist in Wandsworth that covers the learning disability service and tier 3 supporting young people without learning disability but are likely to be diagnosed as autistic. The service has embedded the two special school posts in Merton ensuring specialist advice, support, and supervision as a multidisciplinary team.
CAMHS learning disability service have produced their first webinar about working with children and young people with learning disabilities
The mental health trust is supporting the training of an Advanced Clinical Practitioner in learning disabilities/Autism (one of the first to receive this credential in this field).

The mental health trust is the creating a new full time lead learning disability nurse post. The post holder will be focusing on quality improvement across the service line and improving the mental and physical health outcomes for people with a learning disability that may be admitted to an inpatient ward or to any of the services provided by the mental health trust.

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

As noted previously in the report, there have been changes to the review process which previously asked questions specifically about positive and negative aspects of care and the grading of care. This is now only applicable when there is a focused review. Currently it is also not possible to retrieve reviewer's comments on quality of care from reviews that have been completed.

However, it has been possible to take direct comments from families and carers that have been part of the reviews and some examples of these quotes have been given below.

Positive comments regarding the acute trusts

"Care team was involved immediately at the hospital, and s/he was moved to a quiet area and died with dignity but not alone."

"Clinical team worked closely with the family and supported living team who were able to get the best possible care."

"S/he was assessed in hospital by the Star team and a detailed escalation plan was put in place."

"Long discussions with learning disability liaison team to decide on DNACPR."

" The learning disability liaison team had daily catch ups with the family which helped as well as video calls."

"The team sent a sympathy card to the family after the death"

“He was admitted to ICU, family praised his care.”

“Residential home staff were able to stay on the ward to support the patient and clinical staff.”

“Mother wanted to praise the learning disability liaison team for the tremendous support they gave her son and to her and her family. In particular, she said, learning disability liaison R/N Padraic Costello was outstanding and he was especially helpful when there was a delay in obtaining the death certificate.”

“Specialist teams were involved in his hospital care and of good documentation.”

“DNACPR was a difficult decision and had been explored and agreed with family.
Record with learning disability liaison team to have decision in place. Was appropriate to have this discussion with family to explore in more detail. “

“Learning disability liaison practitioner sat with patient and explained planned procedures using visual aids.”

“Next of kin praised junior Dr on the ward for support and excellent communication skills at time of death.”

“The carer from the residential care home was able to be with him at all time in hospital which improves communication with clinical staff and made him feel safe and secure.”

“Family described exceptional care in hospital.”

Positive comments from reviews about community care

“There was significant hospice input to care at home.”

“The person died at their residential home with hospice support. They had an escalation plan, coordinate my care advanced plan and DNACPR input from Neuro Developmental Services – physio, SALT, psychiatry. Annual LD health check done at home as a reasonable adjustment.”
Family was supported with discussions and decision making by the community care team.

“Good communication with professionals; home manager was effective with family and professionals. Overall, very good.”

“Positive practice expressed by the sister and home manager. Excellent team working, primary and acute care facilitated a good death taking into account the persons wishes.”

“GP acted quickly on home assessment and sent her to emergency department without delay.

“He was on an integrated care pathway that stated his preferred place of death as the Nursing Home He also had a collaborative crisis plan in place that was followed by his care and support team.”

“Clinical team involved with the Royal Trinity Hospice. “

Comments from reviews when things didn't go so well

"This person did not have a recent learning disability annual health check. Last check was with previous provider, in November 2018. Home manager was not aware of the need for annual LD health check."

"Sent back and forth from home and hospital on medication for pneumonia."

"No independent interpreter available so had to rely on family to translate."

"Poor communication from ward staff with family and care home staff. They were not updated as the condition deteriorated."

"End of life care – this person was nursed in a six bedded bay that was noisy. This upset the niece. Ward staff did not offer a side room or discuss this option with her."

"Staff were not aware of basic Makaton signs "

"Hospital records refer to 'Learning Difficulty' throughout the past medical history section."

Some personal quotes on local acute trusts work

"I just wanted to drop you a quick email to pass on some very positive feedback. One of my clients visited the hospital recently with a hospital passport and the family reported a really positive experience for the client and family. The passport was used really well and as result his (and their) anxiety was very well managed!" Psychologist

"Just a huge THANK YOU for your amazing work today!! Really appreciate it. And it really is fantastic having people who know David so well being involved in such important decisions" Parent

"Just wanted to thank you for your support with S R yesterday. Feedback from the team was very positive at this morning's huddle and they really appreciated your input." – Cath, Service Manager

"Hi Jessica. Thanks for organising B's visit to the Albany Unit today. Everything went really smoothly from the moment we arrived. There was someone ready waiting for B, a room had been set aside for him, the consultant came to B (no waiting) and was very kind and accommodating, moving bed etc. so that B would be most comfortable, talking to him gently and slowly so he could understand as much as possible. B remained calm and relax throughout even during the examination. Thank you all for making this experience the best it could be." -

xv. Continuation of the Learning from Lives and Death of People with a Learning Disability and Autistic People in SW London ICS

From July 2022 the CCG will no longer exist and will become part of the SW London Integrated Care Service (ICS). The work that has been ongoing in SW London for the LeDeR programme since its inception and being one of the first pilot sites must continue within this new organisation.

The NHSE LeDeR policy (2021) recommendations are in the process of being implemented within the ICS taking into consideration changes in how systems are now working and how resources are being allocated across the whole system.

The proposed strategy moving forward is to set up a small team of full time permanently employed staff to work across all 6 boroughs of SW London to allocate and undertake reviews, to identify and highlight where care has gone well and where things have not gone so well for the person. With this information the team will work together with the wider health and social care economy to highlight these issues and to provide support in planning and development of necessary changes in practice as well as showcasing where care and support has gone well.

The team will need to continue close working with families and carers of those people who have sadly passed away as well as maintaining close links and partnership working with the local authorities and the private and voluntary sector service providers.

The team will be linked in with the Southwest London Learning Disability and Autism Programme to provide information and guidance from reviews to influence and support its aims of

- 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

To re cap on some of the changes to the new “Learning from Lives and Death of People with a Learning Disability and Autistic People (LeDeR)”

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.

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

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.

xvi. Southwest London CCG LeDeR Strategy

2021 was a year of transitions and change in the LeDeR programme, with the introduction midway of a new reporting interface and review template. As the CCG structure ends and the emergent ICS structure embeds, it is welcome that the ICS will renew its focus and frameworks to 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 both the local PLACE structures and also through the SWL level partnerships. 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.

xvii. Conclusion

Every death of a person is a huge loss, having a lasting effect on those who were part of their life.

The LeDeR programme was set up to highlight inequalities in care for people with a learning disability and to support and advise on ways of addressing these inequalities and to make a positive difference to the lives of people with a learning disability and autistic people.

The programme over time has evolved, as it should, and has grown to become a stronger advocate for people with a learning disability enabling them to have bigger voice in an area where there are so many other competing issues. Mencap started the phrase " If you get it right for people with a

learning disability then you can get it right for everyone" This still stands true as people with a learning disability have all the same health issues as anyone else but these can often be compounded with their learning disability and other conditions that are linked.

The SW London CCG and partners have strived to ensure all reviews from notifications have been allocated and undertaken in a timely manner. However, the programme is not just about ensuring reviews are taken on and completed, there is meaning to every person's life and the reviews are designed to pick up on where things have gone well and not so well for that person in the last months, weeks, and days of their life.

The most important thing to gain from the reviews is understanding and learning, sharing good practice and shining a spotlight on areas where there is concern.

Our local populations of people with a learning disability and their families and carers, the specialist community learning disability teams, acute hospital liaison professionals and other people who are part of the wider SW London learning disability network have made stronger links over the past few years, working on the same goals in improving health care access and understanding the specific needs of people with a learning disability and autistic people.

The information provided in this report on the work that is ongoing is only a small snap shot of what is going on across SW London to improve access and to support people to live longer, healthier lives.

On a final note, we would like to re emphasise our gratitude to all families, carers and those involved with reviews and health and care services in supporting the programme and for all their hard work and dedication.