NHS
North Central London
Clinical Commissioning Group

North Central London CCG LeDeR annual report 2020-2021

Contents

1.0 Introduction

This is the second combined North Central London (NCL) Clinical Commissioning Group (CCG) Learning Disability Mortality Review (LeDeR) annual report on the reviews of deaths of people with a learning disability.

LeDeR has been established since 2016 to support local areas in reviewing the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement.

A full list of acronyms referred to in this report are available in **Appendix A.**

2.0 Governance

Until March 2021, the LeDeR programme was administered and managed by Bristol University on behalf of NHS England. From 1st June 2021 NHS South Central and West Commissioning Support Group has responsibility for delivery of the programme review system The NHS Long Term Plan[1] (January 2019) sets out the objective for people with a learning disability, autism or both to lead longer, happier and healthier lives. In North Central London (NCL), the LeDeR programme sits within the Learning Disabilities and Autism Programme (LDA), which, in line with the expectations set out in the Long Term Plan, also includes:

- The continued reduction of inpatient bed use and prevention of hospital admission
- Annual Health Checks in primary care for people with learning disabilities
- STOMP and STAMP (Stopping over medication of people with a learning disability, autism and Supporting Treatment and Appropriate Medication in Paediatrics)

In April 2020 a restructure of NCL CCG led to changes in the governance of the LeDeR Programme, which now includes a reporting line into the NCL Quality and Safety Directorate. This has further supported and strengthened the delivery of the LeDeR Programme which is well embedded within the five local NCL boroughs. The Senior Reporting Officer for the programme is Kay Matthews, Executive Director of Quality, NCL CCG. LeDeR reports to the CCG Quality and Safety Committee on learning from reviews. Local learning is fedback into Health and Wellbeing Boards as well as borough based Safeguarding Adults and Children Boards/Partnerships. An NCL LeDeR coordinator employed since January 2019 continues to support the delivery of the programme on an interim basis.

Each borough has a local LeDeR steering group chaired by a Local Area Contact (LAC) who is also part of the wider North Central London LeDeR Steering group.

Organisations represented within local LeDeR Steering groups include NHS North Central London Clinical Commissioning Group (Strategic Commissioning, Nursing, Safeguarding, Quality) all five local authorities (social care and learning disability teams) NHS University College London

[1] https://www.longtermplan.nhs.uk/

Hospital, NHS Royal Free London NHS Foundation Trust, Camden and Islington NHS Foundation Trust, Whittington Health NHS Trust, North Middlesex University Hospital and Barnet, Enfield and Haringey Mental Health Trust. Representatives from the voluntary and community sector are currently represented in some local steering groups such as Healthwatch, Mencap and hospice services with plans being scoped to have those with lived experience join each local steering group.

As the NHS head towards an Integrated Care System from April 2022, the governance of the programme and engagement across the sector will be central to the delivery of the programme and reduction in health inequalities for people with learning disabilities. Learning from LeDeR has continued to gain a prominent profile across the health and social care landscape and it is a priority of the CCG as the responsible body to continue to build upon this.

3.0 NCL Learning Disabilities & Autism Programme 2021-24 Delivery Plan

The LDA programme has devised a high-level delivery plan setting out a number of priorities to meet the objectives of the Long Term Plan, including reducing the use of inpatient settings for people with learning disabilities and/or autism and supporting improvements in health outcomes and quality of care.

LeDeR continues to be a key priority focussing on:

- Review of national LeDeR policy 2021 alongside engagement with Quality & Safety stakeholders to raise profile
- Ongoing management of reviews, including move to new LeDeR reporting system, and completion of reviews within target timescales
- Commission a sustainable model for completing high quality reviews, on time including implementing a reviewer Multidisciplinary team (MDT) in line with national policy
- Develop NCL-wide strategic priorities for improving quality of care and reducing premature mortality, e.g. Do Not Attempt Resuscitation (DNAR) Mental Capacity Act (MCA) decision-making
- Development of Black Ethnic Minority (BAME) focussed workstream to reduce health inequalities
- Link with digital flag [2]work to ensure deaths of people with Autism Spectrum Disorder (ASD) are notified

[2] https://digital.nhs.uk/services/reasonable-adjustment-flag

4.0 Deaths notified to North Central London CCG 2020/2021

4.1 Number of deaths

Year	Number of deaths notified	Completed
2016/2017*	6	6 (100%)
2017/2018	43	36 (84%)
2018/2019	51	34 (67%)
2019/2020	71	23 (32%)
2020/2021	74	58 (78%)
Total	**245**	

Table 1 – notifications to NCL

***Camden were the only borough receiving notifications in 2016/2017**

In 2020/21 74 notifications of death were received for people with learning disabilities who were registered with GP's across North Central London. This was a small increase from 19/20. 78% of these reviews have been completed which is a 46% increase in performance from 2019/2020. Of the reviews remaining, there are a number of reasons these have been unable to be progressed:

- Subject to Child Death Overview Process (CDOP)
- Awaiting safeguarding investigation conclusion
- Awaiting multiagency review panel meeting
- Coroner inquest
- Returned by quality assurance panel
- Awaiting further enquiries

Further work will be undertaken on all reviews when the programme restarts on the 1st June when the new secure LeDeR platform administered by NHS South Central and West Commissioning Support Group is launched.

Although mortality has risen by 67% over the 4 years of the programme from available data, and 2020-21 was 35% up on the previous 3-year average, it must be noted that NCL boroughs did not start reporting on the LeDeR programme at the same time. Reporting of deaths has increased due to awareness of the programme and we will continue to look at this data as a steering group.

4.2 Notifications by month

NCL Borough	Apr	May	Jun	July	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total
Barnet	4	4	2	1	0	2	0	1	1	2	2	0	19
Camden	3	0	0	1	1	0	0	0	1	0	0	1	7
Enfield	11	2	2	1	0	1	0	2	2	3	2	2	28
Haringey	0	2	0	0	0	0	0	0	2	2	0	1	7
Islington	0	2	0	1	0	3	1	1	1	2	1	1	13
Total	**18**	**10**	**4**	**4**	**1**	**6**	**1**	**4**	**7**	**9**	**5**	**5**	**74**

Table 2- notifications by month

It is notable most deaths occurred in quarters 1 and 4. This coincides with the peak waves of COVID-19. We can see that in wave 2 deaths were lower than in wave 1 and it is proposed that a

significant contributory factor to this was due to the work undertaken to keep those with learning disabilities safe combined with national social distancing restrictions- see section 5.0

Enfield's deaths are significantly higher than the other boroughs, with Barnet and Haringey having a small reduction.

Enfield accounted for 38% of deaths across NCL followed by Barnet with 26%. Enfield notified a significantly higher number of deaths in April 2020, and these were very concentrated over one particular weekend. A systematic review is underway to determine what factors could account for this- Appendix B

It should be noted that both Enfield and Barnet have a significantly larger number of individuals with a learning disability compared to other boroughs. This is in part due to the higher number of supported living providers and care homes for those with learning disabilities in these boroughs. Both are net importers of people with learning disabilities, the LeDeR programme reviews people at their place of death rather than where they originated from. Of note, 7% of deaths notified had a residing address outside of NCL in neighbouring boroughs. This is slightly higher than in previous years where this has been around 3%. From available regional data we can see that the number of NCL deaths is in keeping with other CCGs with a similar footprint.

4.3 Number of Deaths by Gender

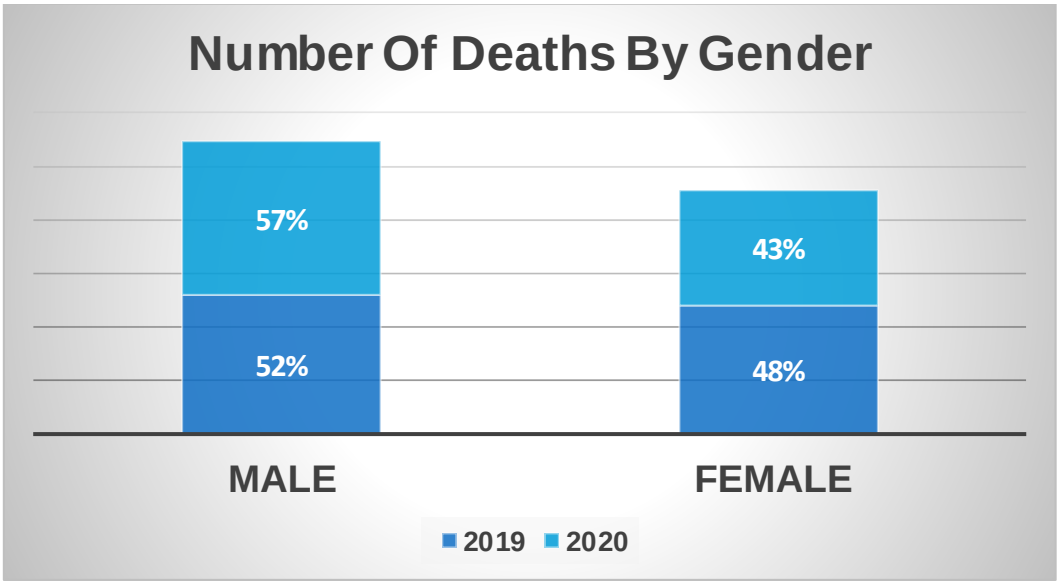


Figure 1- number of death by gender

Figure 1 indicates that male deaths accounted for a higher proportion of deaths than in 2019. This is keeping with national findings[3] where men made up almost 60% of deaths from COVID-19 and 70% of admissions to intensive care units.

[3] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf

4.4 Age at death

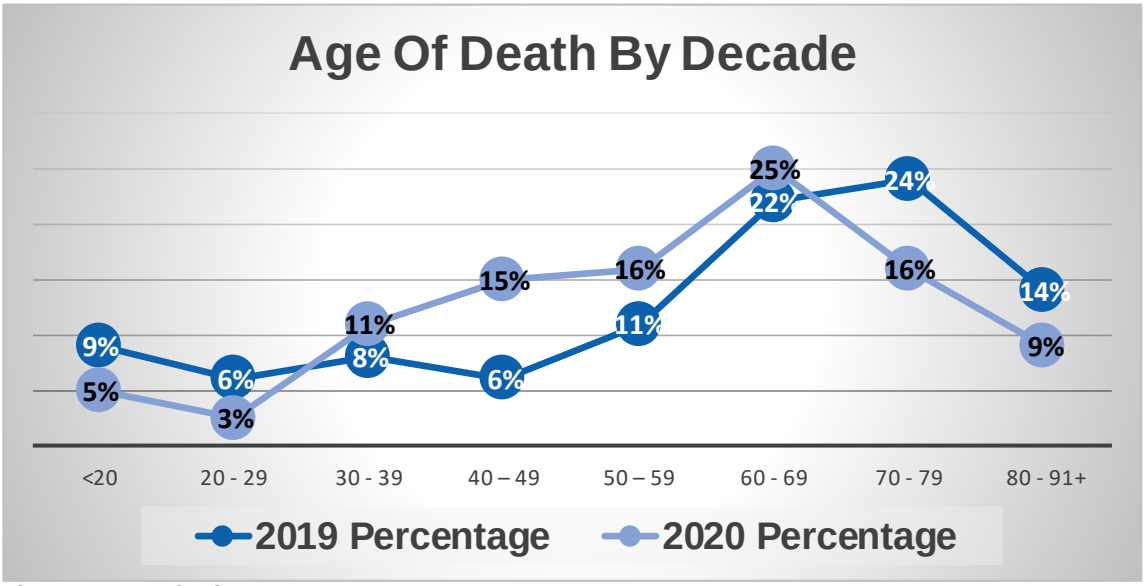


Figure 2- age at death

Data indicates that there has been an increase in deaths reported in the 40-49 and 50-59 age ranges in 20/21 with a decrease in the 70-79 age range. More data is needed nationally to examine whether comorbidities in these age groups was a greater risk factor to COVID-19 than last year. The over 60 age group still accounts for the largest proportion of deaths across NCL as it did in 2019. NCL's median age of death for those with learning disabilities was 56 years for males and 62 for females. These figures are lower than reported in 2019/20 however, as we have seen an increase in deaths in the 30s and 40s age range this year this is likely to account for the lower figure reported.

4.5 Place of Death

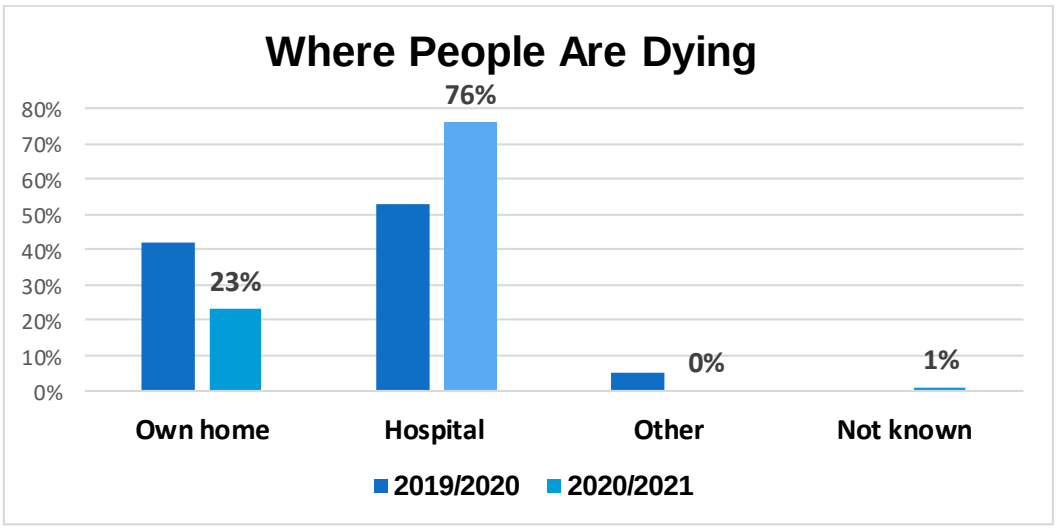


Table 3- place of death

The proportion of people with learning disabilities dying in hospital was significantly higher in 2020/2021 than in seen in the previous year. This reverses the recent trend of more people dying in their usual place of residence, which would be consistent with preferred places of care. The number being treated in hospital is expected given a pandemic, and reassuring that those needing acute care

were able to access it. The reverse in trend does not appear to be of concern given the higher numbers of deaths occurring in hospital was seen across the whole population, these figures would infact suggest that people with learning disabilities were being given full access to hospital services at a critical time rather than being denied access because of their learning disability.

4.6 Ethnicity

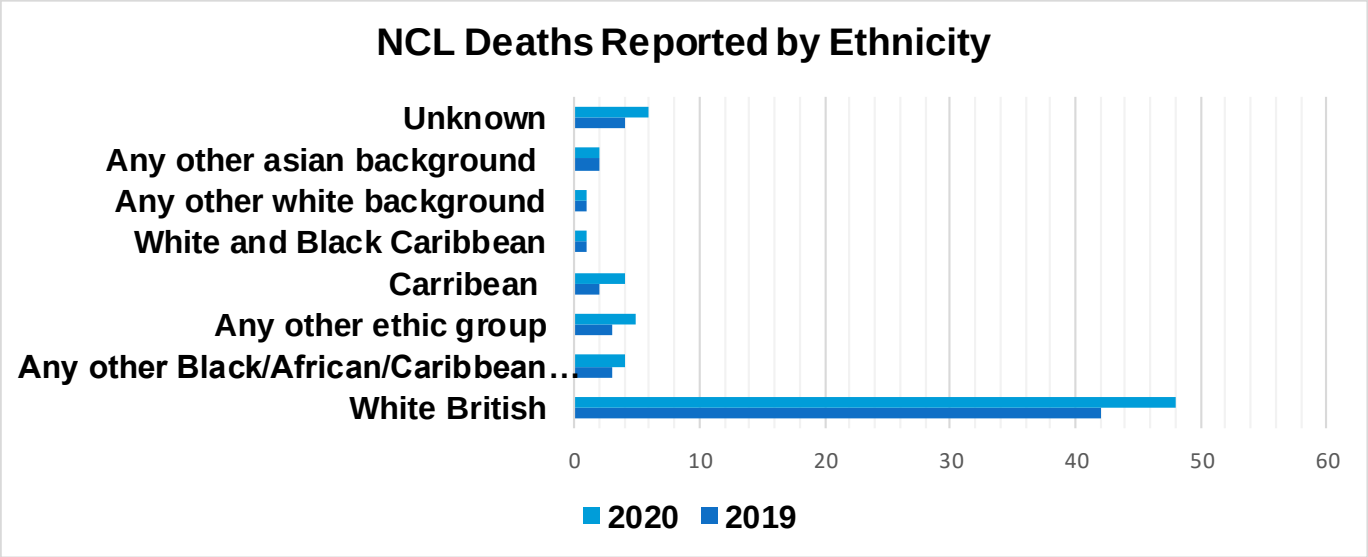


Table 4- Deaths Reported by Ethnicity

Ethnicity for 2020/2021 is consistent with 2019/2020 reporting. We continue to monitor this as a steering group.

4.7 Ensuring the needs of people with a learning disability from black, Asian and minorities ethnic communities are a focus for local action

A systematic review[4] of health and health care of children and adults with learning disabilities from BAME communities in the UK suggested that people with learning disabilities from BAME groups are more likely than others to face barriers in accessing services, less likely to receive specialist services, and more likely to have poor knowledge about those services available to them. All of the borough LeDeR groups maintain vigilance on the ethnicity of all deaths reported

NCL will identify a BAME lead as a priority in 21/22 for the NCL LeDeR steering group in order to:

- Establish links with local organisations which represent people from BAME communities, especially those with a learning disability and raising the profile of LeDeR within those communities
- Further understand the local BAME profile across our boroughs and expected prevalence of people with a learning disability who are from BAME communities
- Understand and ensure action on local factors relating to people who are from BAME communities and their access to services

[4] [4] https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12630

4.8 Stopping over medication of people with a learning disability, autism or both (STOMP)[5]

As part of the review process reviewers are asked whether an individual had been prescribed an antipsychotic and /or antidepressant medication, the number of years prescribed, and whether there had been active attempts to withdraw the medication. Public Health England (PHE) state that every day between 30,000 and 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for.

2020/2021	Yes	No	Not Known
% prescribed antipsychotic medication at time of death	22	32	4
% prescribed antidepressant medication at time of death	24	31	3

Table 7- Causes of death reported 2020/2021

NCL reviews indicate that the number not taking any of these medications is higher than those that are. It is hoped that the change of a new IT platform will enable more detailed reporting around the prescribing and management of psychotropic and mood stabilising medications in the future.

A priority within the LDA delivery plan is to work closely with Medicines Management colleagues to devise an approach to STOMP/STAMP in preparation for a national audit in 2022/23.

4.9 Degree of Learning Disability

The degree of a person's learning disabilities was reported for 58 completed reviews. Of these, 30% were known to have had mild learning disabilities; 35% had moderate learning disabilities; 27% severe learning disabilities; and 8% profound and multiple learning disabilities.

4.10 Causes of Death

Cause Of Death	%
COVID 19	52%
Respiratory related- including aspiration pneumonia	29%
Cancer	5%
Cardiovascular related	2%
Hepatic failure	2%
Sepsis	2%
Hypoxic Brian Injury	2%
Multiple Organ Failure	2%
Sudden Unexpected Death in Epilepsy (SUDEP)	2%
Pulmonary Thromboembolism with infarction	2%

Table 8- Causes of death reported 2020/2021

It is notable that COVID 19 and respiratory related illnesses were the most frequently listed cause of death across NCL. Reviews highlighted that many of those who died from COVID-19 were vulnerable to chest infections, pneumonia and other respiratory risks.

[5] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

Of note; there were no recorded flu related deaths over the Winter 2020/2021 period which may have been a result of social distancing restrictions (the low incidence of flu is also noted across the general population). There was a concerted effort across NCL to vaccinate those with learning disabilities against influenza in autumn 2020. Cancer and cardiovascular related causes of death are lower this year than reported previously.

4.11 Multimorbidity

The NICE Guideline 5614[6] clinical assessment and management of multimorbidity defines multimorbidity as the presence of two or more long-term health conditions.

All completed reviews indicated the presence of at least one long term health condition. The majority (60%) had three or more long term health conditions. The most common conditions were respiratory related including Dysphagia/chronic/recurrent chest infections followed by neurological disorders such as Epilepsy.

4.12 Annual Health Checks

Learning disability Annual Health Checks (AHCs) which are offered to all those over the age of 14; can identify undiagnosed health conditions early, should include a physical check, medication review, a mental health check and there should be an opportunity to discuss any health issues or concerns.

Reviews indicted that of the reviews undertaken, a large proportion did have a formal annual check but remains lower than the national target rate for the learning disability population as a whole, which is currently 75%.

% who had a formal AHC in 12 months prior to death	**64%**
% who had **NOT** a formal AHC in 12 months prior to death	**36%**

Table 9- Annual health checks LeDeR reviews

Where reviews indicated an AHC check had **NOT** taken place there was in many cases evidence that GP reviewed the person's care and treatment regularly as part of management of long-term health conditions. Reviews also indicated AHCs were of varying quality and health action plans were not always generated when an identified issue was detected.

The LDA programme has an oversight/support role in delivering AHCs liaising with learning disability teams and commissioners who work with GPs to support delivery via primary care commissioning. Work has been undertaken in order to increase those on the learning disability register with further improvement work planned.

[6] https://www.nice.org.uk/guidance/ng56

		2019/20					2020/21		
		Q1	Q2	Q3	Q4	19/20 Full Year	Q1	Q2	Q3
NCL	Number of Health Checks	565	790	1,051	1,471	3,877	515	1,119	1,188
	Number on LD Register (>14)	4,712	5,052	5,025	5,115	4,976	4,969	4,633	5,533
	%	12%	16%	21%	29%	78%	10%	24%	21%

Table 10- NCL annual health check data 19/20 20/21

4.13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

The use of DNACPR decisions came into focus at the beginning of the COVID-19 pandemic. The Care Quality Commission (CQC) was commissioned by the Department of Health and Social Care (DHSC) to conduct a special review of DNACPR decisions. The report noted it was particularly concerning that some people across a range of equality groups, including those with a learning disability; felt they were not supported to the extent they needed to be in advance care planning conversations, or given the information they needed in an accessible way. The report concluded that while many of the concerns raised are not new, the pandemic has enhanced the need for training support and awareness. NCL will focus on DNARCPRs as an area for improvement in 2021/2022

4.14 HealthIntent

Learning disabilities is a selected registry for the HealthIntent[7] platform that will allow health and care professionals across NCL to be more proactive in the care of those with a learning disability by linking elements of their health and care information from different sources. The registry is making significant progress in phase one with consultation and collaboration taking place across the system to ensure that the right agreed measures associated with particular conditions e.g. constipation are included. Subsequent phases are also planned as the system continues to develop. Phase one is expected to be rolled out in autumn 2021.

[7] https://www.northlondonpartners.org.uk/ourplan/Areas-of-work/Digital/healtheintent.htm

4.15 Grading of Care

46 % of cases this year were graded 1 or 2, considered 'good' or 'excellent' care. Reviewers stated that lack of evidence an AHC has been completed or issues around communication prevented more cases being graded as excellent.

Grading	Percentage
1= Excellent care	4%
2 =Good care	42%
3=Satisfactory care	25%
4=Care fell short of current best practice in one or more significant areas	13%
5=Care fell short of current best practice significantly impacting on the persons wellbeing and had the potential to contribute to cause of death	16%
6=Care fell short of best practice resulting in Potential for or actual adverse impact on the person and this contributed to the cause of death	0%

Table 10- Grading of Care

5.0 COVID 19

In March 2020 COVID 19 had an unprecedented impact across society and health and social care. Those with comorbidities were quickly identified as more vulnerable to becoming more ill or dying as result of the disease.

During this period the LeDeR coordinator communicated updates across the system to ensure that awareness was raised of how COVID was affecting those with learning disabilities reflected through LeDeR notifications.

Rapid reviews were conducted for people with learning disabilities who died during wave 1 of in March and April 2020 to ascertain any urgent learning to be gained.

NCL were asked to complete 8 sample reviews over a 6 week period in July 2020 to contribute to the national LeDeR report[8] relating to 50 people with learning disabilities whose death has been attributed to COVID19.

It is important to record that whilst there was an increase in mortality during the pandemic we also have many examples of people being supported in hospital and making a full recovering and returning to the community. For example during Wave 1 Whittington Health went above and beyond a distressed individual with a learning disability who was acutely unwell with Covid and ensured that their principal carer was with them for the duration of their admission to provide support to the individual and to the carer, this was despite an unprecedented pressure on their service.

[8] https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary

NCL Identified learning	Actions taken
Effectiveness of 111 triage – not asking if an individual had a learning disability. In line with national findings	National NHS Learning Disability and Autism programme worked with the national NHS 111 team to ensure that those with learning disabilities were not experiencing 'diagnostic overshadowing'
Symptoms - silent hypoxia (person has low oxygen levels but is not observed to be struggling for breath)	Oximeters were rolled out across NCL in all settings including supported living as a joint piece of work by learning disability teams/Commissioners/Primary Care Networks.
Information sharing	Pandemic meant more joined up working. Learning disability teams shared lists of those known to their teams with the local acute trust who placed alerts on their record system in the form of a 'digital flag'- in keeping with national findings
COVID Grab and Go hospital passport	This document was encouraged to be completed to aid front line clinical staff if a person with a learning disability was admitted to hospital with COVID-19
Reasonable adjustments	Reviews indicated these varied with some families and carers being unable to visit even though this would have aided communication and were a reasonable adjustments for the person in hospital – this was in line with national findings
Limited staff testing and access to PPE	This was communicated to Public Health England and commissioners across NCL

6.0 Backlog project

The full LeDeR review process slowed due to capacity across teams being reduced as a result of COVID-19 with business critical only work being focused upon. Many LeDeR reviewers were redeployed, and information became more difficult to obtain due to system wide capacity reduction.

In September 2020 NHS England asked CCGs to complete all learning disability mortality reviews notified by 30th June 2020 by 31st December 2020. NCL had 61 reviews meeting the backlog project criteria. This number excluded reviews that were on hold due to safeguarding outcomes, Coroner inquests or reviews subject to CDOP processes.

Each borough had a recovery plan in place and aimed to complete all outstanding reviews notified prior to June 2020 by 30th November 2020. A LeDeR backlog project group was established in early September chaired by the LDA Programme manager purpose of which was to:

- establish resources needed
- unblock issues in the system around records
- plot a clear weekly trajectory
- agree timely quality assurance process of reviews

This group met weekly with Enfield and Barnet local area contacts (LACs) whose areas had the most outstanding reviews due to large footprint, providing assurance alongside the NCL LeDeR coordinator on progression of individual reviews and raising issues that needed escalating.

The number of trained active local reviewers in each NCL borough differs greatly. Due to ongoing pressures many were unable to be allocated new reviews. As reviews must be undertaken within 6 months of notifications; a group of six independent reviewers were utilised to complete reviews. This was funded using LDA programme funds as well as specific COVID-19 recovery funding made available by the CCG.

By 31st December 2020 NCL achieved 90% of backlog reviews completed against a target of 100%

7.0 North of England Commissioning Support Unit (NECS)

In January 2021 NHS England offered NCL an opportunity to outsource 14 reviews to North of England Commissioning Support Unit (NECS) to complete by the 31st March. 4 reviews assigned to NECs remain outstanding due to multiagency review meetings, delays in family involvement and outstanding information.

8.0 Structured Judgement Reviews and Medical Examiner role

In 2018 NHS England published guidance on behalf of the National Quality Board (NQB) on learning from deaths[9] to assist trusts on how they should support, communicate and engage with families following a death of someone in their care. Part of the guidance highlighted that all deaths of people with a learning disability should be subject to Structured Judgement Review (SJR). Learning from a review of the care provided to patients who die should be integral to a provider's clinical governance. It is also especially pertinent that those with learning disabilities have their care reviewed to enable learning to form quality improvement work with providers. Currently the quality and timely sharing of SJRs to assist LeDeR reviews varies widely across Trusts. During 20/21 many SJRs have been delayed due to the large number of deaths and this has significantly impacted on review completion.

An example of where this process is working well and is best practice is the Royal Free London NHS Trust:

"Once a patient with learning disabilities dies in the Trust, the learning disability nurse completes a LeDeR notification and a Learning from deaths/Structured Judgement Review which are reviewed with a senior consultant and then presented at Mortality Review meetings"

The Royal Free's SJR process has increased the quality of reviews produced and enabled Barnet in particular to achieve key programme KPI's. It has also reduced the need for reviewers to request separate records freeing up capacity of the Learning Disability Acute Liaison Nurse and medical records administrators. The process also enables the Trust to promptly review where care and treatment can be improved. An example of the SJR template can be seen in **Appendix C**

NCL will continue to emphasise the importance of a robust and effective SJR process across our acute trusts to support LeDeR reviews.

[9] https://www.england.nhs.uk/wp-content/uploads/2018/08/learning-from-deaths-working-with-families-v2.pdf

The establishment of the medical examiner (ME) system in England will offer further opportunity for learning from deaths. ME offices are being established in acute trusts in England, to provide independent scrutiny of all non-coronial deaths. They will also act as a contact point for the bereaved; with families and carers having opportunity to raise concerns where they feel there has been unsatisfactory interactions with health services.

We have already taken steps to form links with the medical examiners offices in acute trusts and plan to extend these links as further offices become established across NCL.

We expect guidance from NHS England on how the LeDeR workforce and medical examiner offices can work together. Although it is expected that all organisations are expected to undertake separate processes relating to deaths; it is imperative that good working relationships are established to ensure appropriate information is shared and that responses are co-ordinated between agencies and partners where required with consideration given to the sensitivity and needs of families and others affected.

9.0 NCL response to Oliver McGowan Independent Review

The NCL LeDeR Steering group reviewed the findings of the Oliver McGowan Independent Review and examined recommendations by Fiona Ritchie OBE, Independent Consultant against aspects of our current programme delivery- **Appendix D**

We await further information from Health Education England (HEE) on the Oliver McGowan Training in Learning Disability Autism[10] mandatory training once the Department for Health and Social Care have evaluated it's trial period.

10.0 Areas for developments

10.1 New LeDeR policy

A new LeDeR Policy published in March 2021; Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021 goes live from 1st June 2021.

Key changes to the policy include:

- Introduction of a 2 stage LeDeR review system where most cases will receive a basic review, with only a proportion of cases moving to a full review where required or where families request this
- A new IT platform that goes live on 1st June 2021
- LeDeR reviews will be the responsibility of health and social care services/ICSs
- LeDeR reviewer capacity will be commissioned across ICS areas or on a regional footprint
- LeDeR reviewers will use SMART cards to access health records to decrease the administration burden of getting hold of records.
- LeDeR review recommendations will be agreed by a local governance panel not the reviewer.

[10] https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism?_cldee=cmltaS5tYXRoYXJ1QHNraWxsc2ZvcmNhcmUub3JnLnVr&recipientid=contact-cd0c68958c42ea1180e0005056877cb9-55b88632f67d4c7f9f796b67d6a506cd&esid=a4e83445-1592-eb11-b1ac-000d3a87020b

There are a number of key deliverables the CCG/ ICS much achieve under the new policy and work is underway to plan and implement within the required timescales.

11.0 Safeguarding Adult Boards (SABs)

During 2020/2021 a Safeguarding Adults Review (SAR[11]) was published following a Camden LeDeR review. Several acute trusts produced 7 minute briefings to supporting learning for staff and it has been shared widely across the system.

11.1 LeDeR/SAB

An area requiring further strengthening across NCL is the interface between LeDeR and safeguarding adult's processes.

Following the referral of three LeDeR cases to the safeguarding adults review (SAR) subgroup in Haringey, it was identified that there was a gap between the LeDeR and SAR processes. A meeting was held with representatives from the two groups and it was quickly identified were areas that could be improved and actions agreed:

Some of the issues identified were:

- LeDeR reviews are not statutory therefore, there is limited authority to obtain information from partner agencies. This can result in incomplete information being available to reviewers, which may lead to safeguarding concerns being identified incorrectly due to limited information being available, whereas this information is more accessible via the SAR route.
- Lack of understanding of how the two processes can work together
- LeDeR review recommendations not being implemented by partner agencies due to it not being a statutory process.

Agreed actions:

- SAR chair to attend LeDeR steering group meeting to explain the SAR criteria and SAR process to all the group members.
- The LeDeR coordinator to liaise with the SAR coordinator in cases where information is not being easily made available to the LeDeR reviewers to help determine if the LeDeR review meets the SAR threshold for referral.
- Themes identified during the year by the LeDeR steering group should be discussed at the SAR Subgroup for a joint discussion.
- LeDeR review recommendations should be highlighted in the annual report to SAB to reinforce the drive for improvement. It is possible that some priorities could be incorporated in the SAB's Strategic Plan, if relevant to the safeguarding agenda and priorities.

[11] https://www.camden.gov.uk/documents/20142/0/UU+SAR+Report+-+FINAL.pdf/357a3641-1fda-6da3-71d5-762b085e00a1?t=1579865672773

- LeDeR annual report to continue being shared at the joint SAB/Safeguarding Children's Partnership meetings.
- LeDeR steering group to be invited to SAR learning events

It is a clear within the new LeDeR policy that LeDeR is a service improvement programme therefore, where appropriate, the LeDeR review may arrive at differing learning and recommendations to other reviews or investigatory processes. It is pertinent to note that the governance of LeDeR must sit within the quality mainstream assurance and surveillance of the ICS and not be isolated from it. Local governance arrangements are expected to ensure that LeDeR is embedded as part of quality assurance/mortality/safeguarding work, primary care development/ownership, commissioning intentions, and contract delivery to ensure that service change is written into contracts.

12.0 Learning from LeDeR reviews

12.1 Positive practice

Examples of this good practice are frequently shared across the system and feedback from families is regularly communicated to those involved in the person's care;

Camden: Day centre services provided a wide range of activities positively impacting on the person and their carer
Barnet: Supported living manager and staff treated person as if they were a family member
Islington: GPs have demonstrated high quality personalised care. Whittington hospital NHS Trust actively working with community teams ro ensure that information is rapidly shared to support admitted patients
Haringey: North Middlesex Hospital provided reasonable adjustments by facilitating walk around of radiotherapy services
Enfield: A number of professionals worked effectively together to ensure person's end of life plan was supported

Reviews have identified a number of areas of positive practice:

- **Pulse oximeters:** were used to inform decisions about escalation of care
- **Coordinate My Care (CMC)**: digital record enabled professionals involved in person's care to access their personalised urgent care plan
- **Advanced Care Planning (ACP):** completed with the family in advance of hospital admission meant a clear plan was in place
- **Acute Liaison Learning Disability nurse:** was an invaluable link between the family and the person whilst they were inpatient at a time when the family could not visit
- **Accessibility and flexibility:** primary care video consultations enabled concerns and potential diagnosis to be identified quickly
- **Listening to those who know the person best:** Carers' concerns were taken seriously by the GP who fully investigated any possible causes of changed behaviour
- **End of Life planning:** coordinated end of life care plan included a hospice referral
- **Person Centred Planning:** monthly meetings in the care home ensured that person was fully included in decisions made about them

- **Personalised Care:** personal items were collected from supported living by hospital staff to make person feel more comfortable whilst in hospital
- **Reasonable adjustments**: clinical staff facilitated a walk around of radiotherapy services
- **Hospice services:** were involved at the earliest opportunity to support person and the supported living provider to provide the best possible care

Reviews indicate a number of recurrent themes and form priority areas for improvements for 2021/2022:

- **Mental Capacity Act (MCA) and best interest decision making- application and recording**

Action being taken:

  - NCL LeDeR steering group are looking at training and resources

- **Use of hospital passport- not having one or it not being brought when presenting to hospital**

Action being taken:

  - Reminders cascaded to all providers that hospital passports must be completed and updated as necessary as part of contract monitoring
  - Enfield have produced an Easy Read 'Top Tips on drafting a Hospital Passport' guide. This will be taken to the Partnership Board Health Subgroup in June 2021 for agreement. Once completed this will be posted on the internet with the Hospital Passport template and shared with CCG's and acute trusts.

- **Recognition of early warning signs of ill health/acute deterioration**

Action being taken:

  - Camden has successfully rolled out the Significant 7 early warning signs
  - Enfield reviewing Restore2 [12]too
  - Steering group considering a uniform early warning signs tool

- **Annual Health Checks (AHC)- whilst we see evidence there is good access to primary care:**

  - in some cases no 'formal' annual health checks takes place
  - inaccurate coding on GP registers continues to be flagged
  - AHCs are of varying quality, health actions plans are not always being generated where there is an identified area of concern

Action being taken:

  - Healthintent population management work stream
  - Develop a joint delivery plan across Primary Care Networks and LD Commissioning, including incorporating learning from exemplar sites (SEL), where appropriate

[12] RESTORE2 (wessexahsn.org.uk)

- Quarterly review of local data to improve performance, including engagement at practice level, where required
- Deliver training to GPs to increase confidence in delivering AHCs

- **Accessibility- continued work is required to improve communication regarding health promotion, e.g. screening. Requests to attend appointments should be provided in an accessible format**

  - Acute providers to update or create a 'was not brought' policy

- **Lack of Care coordination and communication between services**

Action being taken:

- Easy read discharge pack developed by the London A2A (Access to Acute) learning disability liaison nurse network is used for those with learning disabilities discharged from the Royal Free Hospital Trust. A quality improvement project is planned for 2020/2021 to further embed this
- Consideration of Haringey Learning Disability Partnership providing a list to local acute Trusts of those living alone or with a parent/carer to alert if outpatient appointment is not attended

- **Consideration should also be given to an NCL/ICS wide piece of work on training and implementation of DNAR**

Action being taken:

- Whittington Health NHS Trust undertook an audit examining a range of treatment escalation decisions in patients with learning disability admitted to the Whittington and the learning from this was presented to the medical colleagues in the hospital as part of their 'Grand Round'
- North Middlesex NHS Trust's Safeguarding Lead and Acute Liaison Nurse will revisit the work they have done on use of DNACPR and Mental Capacity and Best Interest processes to make sure they are fully embedded.
- Enfield Safeguarding Adults Board have commissioned an independent audit of community DNACPR's. The LeDeR local area coordinator has arranged a meeting with the audit team to see if specific issues relating to people with learning disabilities can be included
- Camden Learning Disability Service is looking at an NCL piece of work around DNAR In CLDS we would like to work with other partners to think about how as a system we can ensure DNARs are always used appropriately and what safeguards we could agree to reduce the risk of poor practice
- Promotion of Respect council form ReSPECT[13] is already widely used by health and social care organisations across England to support healthcare professionals and patients having important conversations in advance about their realistic emergency care choices, including whether cardiopulmonary resuscitation (CPR) should be attempted in a future emergency

[13] https://www.resus.org.uk/respect

13.0 Individual borough learning

13.1 Camden

Recommendation/Learning from reviews	Action taken to date/suggested action
Staff recognising possible silent hypoxia	Supported living has now been given oximeters across Camden
Improve evidencing of MCA implementation in acute Trusts	MCA champion model developed and embedded in one acute Trust. Role is to support and promote robust MCA practice across the Trust. MCA leads incorporated learning from Safeguarding Adults Review (SAR) into MCA training.
Increase uptake of AHCs	Presentation to, and consultation with Camden GP practice nurses. AHC toolkit promoted widely across Camden. One page profile toolkit developed and uploaded to Camden GP intranet site. Camden AHC Steering Group progressing with increased communication to GPs, and a summary letter to support use of toolkit.
Hospital Passports to be reviewed by providers	Consultation with supported living providers and directive given to regularly review passports
Vulnerable adults requiring support to attend appointments should routinely be identified as 'Was Not Brought' rather than 'Did Not Attend'	Health and social care providers to develop a 'Was Not Brought' policy in their organisation
Improved identification of, and response to, early signs of deterioration of ill health by carers	Roll out of Significant 7- Tool aims to help carers both at home and in care home settings to identify the signs of deterioration
Developed effective care coordination and communication between services for patients with complex needs	Coordinate My Care (CMC) roll out- envisaged that everyone on complex care pathway will have a CMC record. Further work needs to take place on who owns the rights to the care plan- still a pilot project

13.2 Haringey

Recommendation/Learning from reviews	Action taken to date/suggested action
Develop effective care coordination and communication between services for patients with complex needs	Nominated named individual from Haringey and Enfield integrated learning disability team to have weekly care coordination meeting with learning disability nurse at North Middlesex hospital. Complex Physical Health Pathway (ComPHy) Protocol and 'at risk' register has been developed as a central point for sharing and recording information for those whose physical needs are so complex that they are at risk of unplanned acute hospital admission
Continued focus needed on promotion of annual health checks and additional support to take part in annual health checks	GPs have been supported to continue to prioritise annual health checks for people with learning disabilities, as part of the response to the pandemic. This has included: engaging with GPs at a local level to promote annual health checks; providing GPs with a health check toolkit (developed by NHSE London); joint working between Community Learning Disability Teams and Primary Care Networks to align the completion of annual health checks with appointments for flu vaccinations and further promotion to GPs via the CCG GP webinar
Need to ensure reasonable adjustments are made within services accessed by people with a learning disability	Learning Disabilities and Adult Safeguarding Team at North Middlesex hospital were successful in a 'dragon's den' style bid to design a 'pop up' sensory trolley with sensory equipment suitcases for complex learning disability and autism clients whilst inpatient. This will improve patient experience by creating a calm and therapeutic environment, it will also ensure their care is person-centred and play a crucial role in improving health outcomes for those with learning disabilities in Haringey and Enfield. Speech and language therapy team have adapted their dysphagia training to a MS Teams version. We have provided this training to 22 support workers, parents and carers during the last year
Recognition of early warning signs of ill health	Steering group to take forward
Need for a consistent Multi-disciplinary (MDT) approach to managing a patient's risk due to complex physical and mental health	Steering group to take forward
End of life planning should be discussed as early as possible, supported by active conversations about death and dying	Steering group plan to take this forward and look at rolling out ''starting the conversation" project developed by Barnet. Palliative care doctors are working with the learning disability team meeting to consider developing a joint pathway
Developed effective care coordination and communication between services for patients with complex needs	Haringey Learning Disability Partnership are liaising with Whittington Health to access 'coordinate my care' system to enable essential information and care plans to be easier to access and available when needed

13.3 Barnet

Recommendation/Learning from reviews	Action taken to date
Mental capacity and best interest training/recording (in acute trust and providers)	Steering group to consider further promotion and awareness – focus on recording of decisions. Consider links to safeguarding training.
Training - Community CPR and DNAR	Steering group to consider alongside MCA training (see above)
Need to ensure reasonable adjustments are made within services accessed by people with a learning disability	Awareness raising of health inequalities and need to return to the data in contract monitoring and when considering new services - regular discussions in CCG forums, and provider meetings / forums.
Recognition of early warning signs of ill health including constipation awareness	Roll out and training of 'Stop and Watch' guidance to identify the early signs of ill health in those with a learning disability. Vital signs monitoring equipment and support rolled out to all care and support providers – summer 2020 including supported living. Refreshed in February 21
Need for a consistent Multi-disciplinary (MDT) approach to managing a patient's risk due to complex physical and mental health	Complex needs pathway has been established within the Barnet LD service. Increase in AHC in Barnet to 75% (from 63%) 21/22 priorities include further work to improve numbers and quality of AHCs (see operational plan)
End of life planning should be discussed as early as possible, supported by active conversations about death and dying	Starting the Conversation: End of Life information pack was created for family and / or care providers including how to talk about death and dying with people with learning disabilities.
Did not attend / Was not brought to appointments	Agreed as a quality improvement project across NCL CCG (update needed)
Record keeping Care and support planning	Steering group to consider – links to care co-ordination and complex care pathway. Best practice in review processes.
Training - Safeguarding training (learning event in process)	Learning event completed 15.04.21 Recommendations to be considered by end of May 2021 and will be reported to SAB.
Improved joint working (multi agency)	Steering group to consider further - links to care co-ordination and complex care pathway. Best practice in review processes.
Carer involvement in decision making - recognition of roles and responsibilities. Awareness of advocacy	Steering group to consider further with Carer's leads and Barnet Mencap
Ensuring person centred care plans are used	Steering group to consider – links to care co-ordination and complex care pathway. Best practice in review processes.
Provider policies - emergency plans and training	JCU highlighting through provider contract monitoring and new procurements. Also links to client reviews.

13.4 Islington

Recommendation/Learning from reviews	Action taken to date
Staff recognising possible silent hypoxia	Supported living and care homes have now been given oximeters across Islington
Hospital passports should be regularly reviewed by providers	Community team is prompting reviews of these wherever they are able
Updating to speech and language guidance	Dysphagia alert introduced to notify learning disability team staff of dysphagia on admission to hospital
Improving communication between care homes and hospital	Hospital and community team worked together to actively address any issues between partners
Supporting carers/families to be involved in End Of Life care including visiting	Community team have designed a template for advanced care planning and it being shared across the borough. Whittington Health have been actively supporting carers (with many examples) to visit their loved ones throughout the pandemic
Need to ensure that carers understand information being given to them when English is not their first language	Dysphagia training has been recorded in Turkish to help families understand how to support their adult with learning disabilities with their compliance with eating, drinking and swallowing instructions for that individual. It's aim is to reduce the likelihood of ill health related to aspiration/choking, less GP appointments, less antibiotics required, less hospital admissions and more preventable deaths
Developed effective care coordination and communication between services for patients with complex needs	Islington are in discussion to develop Complex Physical Health Pathway (ComPHy) Protocol model created by Haringey and 'at risk' register as a central point for sharing and recording information for those whose physical needs are so complex that they are at risk of unplanned acute hospital admission
Improve joint working	Throughout the pandemic continued with LeDeR programme expanding the group. Problem solved issues between hospital and community.
Mental Capacity	On behalf of NCL produced guidance for community teams and primary care on assessing capacity and best interest decisions in relation to the covid vaccine
Need to ensure reasonable adjustments are made within services accessed by people with a learning disability	Whittington Health introduced BOB 'a box of bits' full of sensory equipment to aid and calm those with learning disabilities and improve their patient experience

13.5 Enfield

Recommendation/Learning from reviews	Action taken to date/Suggested action
When the next of kin / contact person has a learning disability they may find complex information difficult to understand- any communication needs of next of kin should be clear to professional	There could be significant information governance and data issues around this
Some people who have been independent throughout their lives may be reluctant to accept care when their needs change. ILDS takes an individual approach to this, looking at how to engage with the person and manage risks	The Enfield Steering Group and NCL mortality steering group will think about any guidance they could produce on how to manage these situations consistently
Lack of understanding and properly applying the Mental Capacity Act 2005	Mental Capacity Assessment should be completed properly and documented with evidence of the diagnostic and functional part of the test. Organisations should create a template which has all the elements of the test and sections to document evidence for each section of the test. More training needed on applying the MCA in practice and documenting it correctly. Organisations should regularly audit MCA records in order to identify areas where more teaching and support is needed and to address these.
Staff in acute settings need more awareness of hospital passport	All staff should be trained on the importance and use of the Hospital Passport. Hospital Passport should be one of the mandatory information collected during clerking by doctors and assessment by nurse on the ward for all learning disability patients. The care/treatment plans should demonstrate that relevant information from the Hospital Passport has informed the plan
Discharge planning process for people with learning disability should commence on the day the patient is admitted into hospital. It could start just by identifying the discharge options and who needs to be involved in the discharge planning process. Consideration for discharge should be discussed at every doctor's ward rounds and the discussions clearly documented	Steering group to discuss and take forward
There was no evidence that an IMCA/advocate was appointed	An IMCA/advocate should always be considered for people aged 16 years or older, who have no one able to support and represent them, and who lack capacity to make a decision Steering group to take forward and discuss how to make this a SMART recommendation
Vulnerable patients needing hospital care during the pandemic may not be admitted	Consideration should be made for GP's to refer directly the hospital at home teams where admission presents prohibitive risks

due to higher risks of coronavirus infections in hospital	Hospital at home teams have proved effective for these vulnerable patients
Lack of referral to a community physiotherapist leading to an over reliance on wheelchair use	Community services to be more joined up in their thinking to coordinate care. More funding required to support community services. Input from a keyworker needed. GP practices to make referrals to the learning disability team
No recent referral to a dietitian. Weight continued to be gained. Person was not supported adequately to lose weight. This became a risk factor for the outcome of a Covid-19infection	The importance of a dietitian was required to give the whole family advice. Community teams/ commissioners to consider monitoring the provision of healthy lifestyles for those in receipt of services as part of the contract monitoring process and take any necessary actions. GP practices should be involved in this process as well.
Family were not allowed to visit the hospital and there is no documented evidence that they were contacted	Hospital staff to ensure they have the correct contact details for next of kin
No referral after annual check to the integrated learning disability service	GP services need to be more proactive in addressing wider health issues and referring to the Integrated Learning disability team in a timely manner. More work needs to be done by the integrated learning disability team to educated providers on the role of the team, how they support those with learning disabilities and how to refer them to their service.
Family was called at midnight to discuss a DNACPR order this caused great distress as the family had always been very clear that person should receive continuing care and treatment as necessary	Staff must be prepared to treat patient's loved ones with respect and minimise distress even when working under exceptional pressure (due to COVID-19). Consider a wider NCL piece of work around DNAR
Lack of community testing for COVID-19- those with the disease and protected residents and staff from transmission	This a wider system issue where (recognising the needs of vulnerable people in supported living) community testing and PPE should be made widely available
Lack of clarity within government guideline on what care homes should do when admitting new residents into their service during a pandemic Care homes do not routinely train staff on managing pandemic which is far more in-depth that just a level 1or 2 infection prevention training	Basic principles of public health perspective of disease control should be included in all infection control training regardless of the level of training being delivered. Recommendations from this review and other pandemic related death reviews should be fed to any government review on the pandemic.
There was a heightened threshold for escalation to hospital in April 2020 Vulnerable people are at higher risk of contracting SARS-CoV-2 in hospital during an outbreak. Balancing the risk between admitting and monitoring at home will be challenging for some time, particularly as infection rates are changing	Consider some Learning Disability specific guidelines about escalating during the pandemic

Practice in the early stages of the pandemic to place people in care homes without testing for coronavirus	Provider has conducted a management review of deaths in the service. They would be willing to share their findings with LeDeR or the government as part of a wider review
Unable to ascertain whether person had been flagged on the LD system to alert the acute liaison nurse the person had been admitted	All people with LD need to be flagged on the system so they can get specialist care whilst admitted to hospital Note: there is a national piece of work led by NHS digital around flagging of those with LD on hospital systems
Recognition of early warning signs of ill health	Pulse oximeters were rolled out to inform escalation. Consideration is being given to implementing Restore2 tool

Other actions being taken:

- The Enfield Mortality Steering Group is currently meeting monthly to coordinate the action plan and check progress. Membership of the group will be reviewed to make sure the right people are involved.
- Actions are appropriately allocated to groups with the right expertise, such as Partnership Board Subgroups including the Health Subgroup and Nutrition and Exercise Group.
- Maintain the role of named learning disability clinician at the North Middlesex Hospital, which had had a very positive effect on people's care.

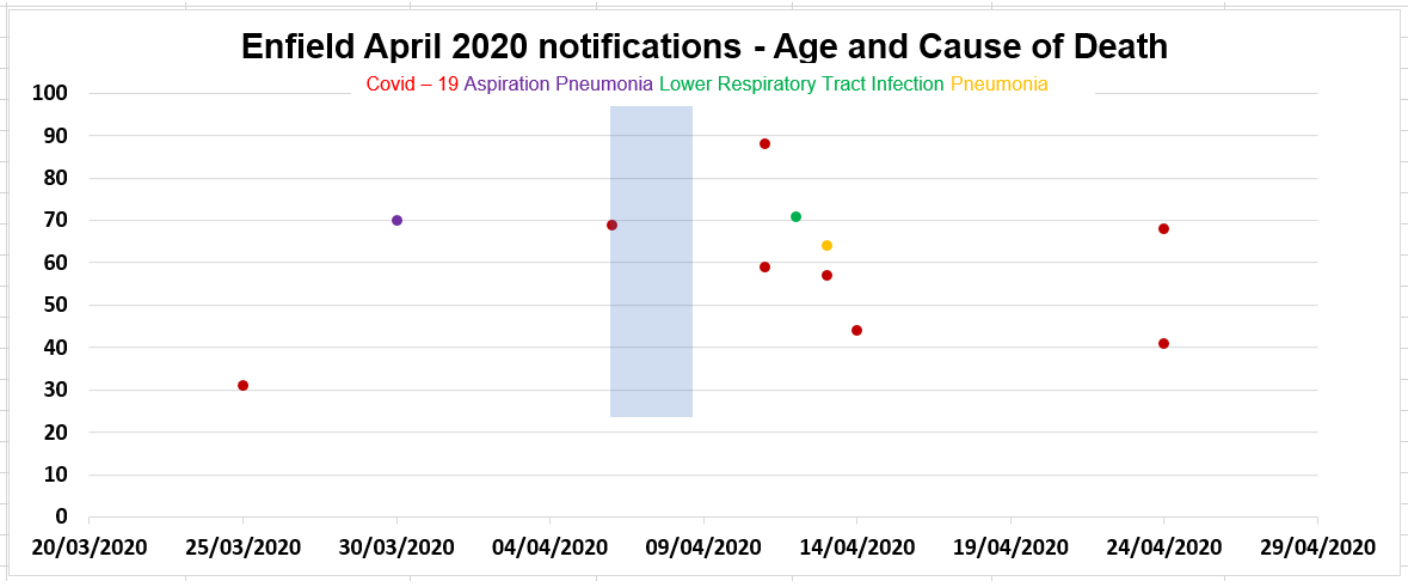
The past 12 months has seen a significant change in the LeDeR programme across NCL. These changes have brought about key successes in clearing a back log of reviews and now being in a position where we can confidently meet national target for completion of reviews.

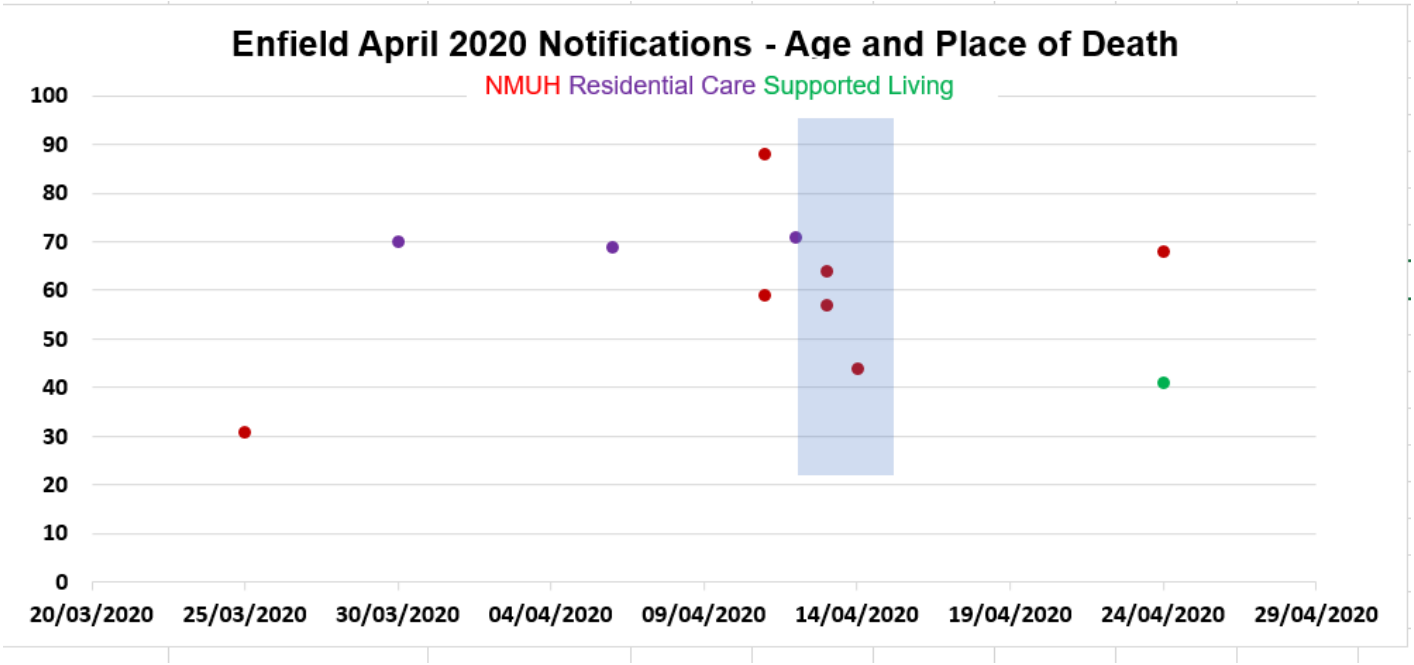
NCL LeDeR steering group has positively worked together to share common themes as we have merged as one CCG and is committed to working collaboratively across the footprint to actively addressed the service improvement requirements highlighted by completed reviews. The COVID-19 pandemic delayed some service improvement however, the pandemic has also had a positive impact as evidenced through positive practice.

Appendix A: Acronyms

Acronym	Meaning
ACP	Advanced Care Planning
AHC	Annual Health Check
ASD	Autism Spectrum Disorder
BAME	Black, Asian and Minority Ethnic
NCL CCG	North Central London Clinical Commissioning Group
CDOP	Child Death Overview Panel
CQC	Care Quality Commission
CSU	Commissioning Support Unit
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
DHSC	Department of Health & Social Care
EOL	End of Life
HQIP	Healthcare Quality Improvement Partnership
ICS	Integrated Care System
KPI	Key Performance Indicator
LAC	Local Area Contact
LeDeR	Learning Disability Mortality Review Programme
LD	Learning Disability
LDAP	Learning Disability and Autism Programme
MAR	Multi-Agency Review
MDT	Multidisciplinary Team
MCA	Mental Capacity Act
MEO	Medical Examiner's Office
NQB	National Quality Board
NECS	North of England Commissioning Support
PCN	Primary Care Network
PHE	Public Health England
QA	Quality Assurance
SAB	Safeguarding Adults Board
STOMP	Stopping Over Medication Of People With A Learning Disability
STAMP	Supporting Treatment and Appropriate Medication in Paediatrics

Appendix B


Enfield April 2020 notifications - Age and Cause of Death
Covid – 19 Aspiration Pneumonia Lower Respiratory Tract Infection Pneumonia
100
90
80
70
60
50
40
30
20
10
0
20/03/2020
25/03/2020
30/03/2020
04/04/2020
09/04/2020
14/04/2020
19/04/2020
24/04/2020
29/04/2020


Enfield April 2020 Notifications - Age and Place of Death
NMUH Residential Care Supported Living
100
90
80
70
60
50
40
30
20
10
0
20/03/2020
25/03/2020
30/03/2020
04/04/2020
09/04/2020
14/04/2020
19/04/2020
24/04/2020
29/04/2020

Appendix C

NCL Response to the Oliver McGowan review recommendations

No	Recommendation	Action to be taken by:	What are NCL doing currently?
1	Reporting a person's death to the LeDeR programme should be mandatory, with the responsibility placed on clinical commissioning groups (CCGs) to ensure this happens in their locality	DHSC	Awareness of how to report as death to LeDeR has been shared widely across the system through a variety of resources
2	Clear guidance should be produced to enable CCGs to effectively 'triage' individual deaths, to ensure that the most appropriate governance methodology is used to review them (based on circumstances and complexity	National LeDeR programme team	All reviews are triaged by LACs for complexity
3	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process	CCGs	If no buddy is available the LeDeR coordinator takes this role and escalates any concerns to the LAC
4	There should be clear guidance on the roles of buddy and second reviewers	National LeDeR programme team	Reviewers/buddys are linked in together where their skills and expertise compliment each other's to produce a thorough, high quality review
5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeR	CCGs	LeDeR coordinator is in place to assist both LACs and reviewers with complex reviews
6	There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes	CCGs	Each NCL borough steering group has their own governance process with plans to streamline this from April 2022
7	Governance of LeDeR should be appropriately embedded into emerging new structures, such as sustainability and transformation partnerships (STPs) and integrated care systems (ICSs), from the onset	NHS England and NHS Improvement	CCG is currently developing a delivery plan in line with new LeDeR policy for implementation by April 2022

No	Recommendation	Action to be taken by:	What are NCL doing currently?
8	Additional guidance should be produced that supports and advises LeDeR reviewers and LACs in situations where there are local disputes regarding the process or outcome of a LeDeR. This must include an independent escalation procedure to be used where there is a difficulty or impasse that cannot be resolved locally	National LeDeR programme team	Guidance will be developed in line with the new LeDeR policy
9	The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case)	LACs and Lead reviewers	All reviewers are supported by LeDeR coordinator and LAC
10	Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress	CCGs	NCL Executive Director of Quality & Safeguarding is SRO for the LeDeR programme
11	Experienced reviewers should be used when circumstances are intricate or challenging. The national LeDeR team should hold a national database of such reviewers to aid this process	National LeDeR programme team	Complex reviews are allocated to experienced reviewers (undertaken at least two or more reviews) or an experienced independent reviewer
12	The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies	CCGs	Regular meetings are held to highlight and escalate any issues with obtaining information
13	When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does	LeDeR reviewers and LACs	MARs are chaired by LACs who have had previous experience and/or safeguarding experience. An area for improvement is timescales for follow up actions to be completed where reviews have been on hold with no progression for a long period of time
14	One of the requirements for a MAR is determined by an initial scoring system of 1–6, with a score of 6 indicating that 'care fell short of current best practice in one or more significant areas resulting in the potential for or actual adverse impact on the person'. Currently, this scoring is not carried forward into the main report. It is recommended that there is a review of this scoring process and that the initial score is retained as a record in the main report	National LeDeR programme team	Review scores are not amended on reviews

No	Recommendation	Action to be taken by:	What are NCL doing currently?
15	In regard to the MAR meeting itself, it is recommended that there is action taken to: ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish • review the purpose of the MAR with specific reference to the function of Question 8 (now Question 9 in version R05) and, should this question be retained, provide clear guidance for MAR participants; also, to think through whether this question should be asked in confidence if it is a particularly difficult situation • provide specific guidance and training for MAR chairs delivered by the national LeDeR team and families to include key topics such as the Mental Health Act, Mental Capacity Act and best interest decision making • maintain a national list of experienced, trained people who could be called on to chair complex or contentious MARs.	CCGs	Families are invited to be part of process and where they feel unable to attend, feedback is given and documented.
16	There should be a review of the LeDeR methodology against similar processes, such as child death reviews, in order to garner the learning and include any improvements as appropriate	National LeDeR programme team	NCL CDOP lead is also a member of the LeDeR steering group
17	A system process chart should be developed to enable reviewers to ensure they are undertaking the review correctly. This should include standard templates and a self-assessment tool that reviewers can use, to ensure consistency across the country	National LeDeR programme team	All reviewers have access to LeDeR process flow chart, quality assurance template and a meeting is organised with the LeDeR coordinator to devise a work plan ensuring all relevant records are requested. Regular contact is maintained.
18	There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers	CCGs	Reviewers are always offered peer support sessions, some feel this is not needed. Regular contact is maintained and review meetings organised. A supervision template will be discussed as part of implementation of new LeDeR policy
19	The LeDeR guidance must make explicit (to all parties) that it is completely acceptable for LeDeR reviews, where appropriate, to arrive at differing conclusions to other reviews or inquests. This is on condition that they have the evidence to support this determination and that the LeDeR itself was subject to correct governance process	National LeDeR programme team	LeDeR is a service improvement programme and as such identifies learning and recommendations to help reduce health inequalities and reduce premature mortality. These may differ from the outcomes of other reviews as LeDeR is not an investigation

No	Recommendation	Action to be taken by:	What are NCL doing currently?
20	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally	CCGs	NCL overarching action plan and local borough actions plans are in place and reviewed/updated regularly
21	Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review	CCGs and ICSs	This new national policy re writes the way LeDeR reviews are to be undertaken including governance, production of recommendations and monitoring of actions therefore it is not necessary for CCGs to do this at this time
	This review and the accompanying action plan must be submitted to, and monitored by, the local integrated care system (ICS), giving feedback to the national LeDeR team around progress. The panel wishes for a senior, single point of contact from NHS England and NHS Improvement to ensure all actions are taken and progress monitored	NHS England and NHS Improvement	The national LeDeR team will monitor performance of ICSs in delivery of the new policy through its usual assurance routes supported by its regional teams.

Appendix D

Royal Free London NHS Foundation Trust

Confidential Document: Contains personal and sensitive information

Learning from Deaths (LfD) Mortality Review
Please return completed forms to <rf.riskandsafety@nhs.net>

Please note that this is a clinical and technical form, as it is intended for use by the clinical teams to identify areas of good practice and learning in relation to patient deaths. Therefore, this review is not intended to be used as a primary resource to share with patient families and carers. However, when requests are made by families and carers this form will be shared with them, so please consider this when completing the form and try to include explanations for acronyms and medical terminology used.

This document contains 2 parts as described below:

- **Part 1 Details of death – this is an information pack compiled to assist with the learning from death review and includes information supplied by the Bereavement & Mortuary services.**
- **Part 2 Learning from death review – this section is to be completed by the reviewer.**

To complete the review electronically in Datix please copy and paste the below address into your web browser – if you do not have Datix log in details, email rf.riskandsafety@nhs.net:
*https://royalfree.datix.thirdparty.nhs.uk/Live/index.php?*action=record&module=PAL&fromsearch=1&recordid=71404

Part 1: Details of death (record ID:)	
Date of death:	Patient's hospital ID:
Site of death:	Patient's NHS ID:
Location of death:	Patient's age:
Speciality admitted:	Patient's DOB:
Date of admission:	Admitting Consultant:
Cause of death	
Cause of death 1a:	
Cause of death 1b:	
Cause of death 1c:	
Cause of death 2:	
MCCD completed by: Contact details:	
H.M Coroner referral	Has the patient's death been referred to the coroner:
	Inquest:
	Date of inquest (if required):
Has the GP been notified:	
Learning from deaths supporting information	
Has the family raised concerns regarding the death: Detail of concern:	
Has a safeguarding alert been raised:	Did the deceased have a learning disability:
Learning from death criteria:	SI reference *(if applicable)*:
Are there linked records on Datix: Linked record Datix ID: *(Please note you will need to access the Datix LFD record to view the ID/detail of each linked record*	