



North East London
Clinical Commissioning Group

NHS North East London ICB

LeDeR Programme: Annual Report 2021/22

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Executive summary

This is the third annual report of the NHS North East London (NHS NEL) LeDeR programme. It provides the progress of the LeDeR programme activities between 1st April 2021 and 31st March 2022.

This report covers summary activities from completed reviews from people with learning disabilities aged 4 to 89 years who have died during this reporting period.

The LeDeR programme was established following recommendations of the Confidential Inquiry into Premature Deaths of People with Learning disabilities (CIPOLD). In June 2017, the responsibility for LeDeR reviews was devolved to Clinical Commissioning Groups.

Research findings indicated that people with learning disabilities are four times more likely to die of preventable causes compared with the general population. People with learning disabilities and autistic people have greater and complex health needs than the general population. They experience higher levels of unrecognised and unmet physical and mental health needs. They are more likely face multiple barriers accessing health and social care services; including problems with communication, inadequate facilities, inflexible procedures and lack of accessible health promotion information.

The LeDeR Programme was established to understand and critically review the inequalities faced by people with learning disabilities and their families when accessing the health and care systems and to recommend ways to improve the quality of care for people with learning disabilities.

The LeDeR programme is a unique service improvement tool which aims to ensure that reviews of deaths lead to reflective learning which underpins health and social care service improvements.

The NHS Long Term Plan supports the continuation of the LeDeR programme: “action will be taken to tackle causes of morbidity and preventable deaths in people with a learning disability and for autistic people”

In March 2021 NHS England published a new LeDeR policy setting out future ways of working both in terms of scope and process. From January 2022, the LeDeR programme was extended to review death of autistic adults. None of the reviews used to inform this report is of a person known to have had an autistic diagnosis only, but it does include people who have had a diagnosis of both learning disability and autism. NHS NEL CCG had not had any death notifications of an autistic adult without a learning disability as at the time of preparing this report.

Since the start of the programme, in 2016 North East London has received 429 notifications, 96 of which were reported this year. The NEL LeDeR team has completed all the reviews within the required time frame achieving 100%, which has been a significant undertaking despite IT challenges with the new LeDeR platform at the start of year.

NHS North East London is committed to continuing our efforts to influence and advocate for improved quality of health and social care provision. We do this by learning from findings of completed reviews and ensuring people with learning disabilities and autistic people live healthy lives where health inequalities are reduced and avoidable or preventable deaths are prevented.

The ‘learning into action’ section in this report sets-out the priorities for quality improvement plans over the next year, which are based on the collective learning points from previous annual reports and the three-years LeDeR Strategy 2022-25.

Summary of key findings and recommendations

Eighty-eight (88) notifications were eligible for LeDeR Reviews, all of which were deaths of people with learning disabilities aged between 4 and 89 years old. Seventy (70) were adults and eighteen (18) were child deaths. Over half of these notifications were male (57%) and 43% were females.

As at 31st March 2022, 57 (65%) of 88 notifications had reviews completed- 47 were adults and 10 were child death reviews. The remaining 33 reviews, 20 were in progress and 11 were awaiting allocation.

The severity of learning disability was recorded as follows (from the 57 reviews): mild (19%), moderate (34%), severe (32%) and profound/multiple (11%), which showed no significant variation compared to last year's report.

Most common confirmed causes of deaths were: Covid-19, heart related problems, epilepsy, renal failure/acute kidney injury, pneumonia and aspiration pneumonia. These conditions were most frequently mentioned in Part 1a and 1b of the certificate of cause of death.

In this reporting period, there is minimal reference to Covid-19 as the common cause death compared to last year's report. NHS NEL has recorded six (13%) of the deaths which were linked to Covid-19 compared to 56 deaths recorded during the pandemic period 2020-2021.

Two main types of reviews were introduced this year-Initial and Focused. The new process applies to adult reviews only. Every person with a learning disability or autism whose death is notified to LeDeR will have an initial review of the health and social care they received prior to their death. Using their professional judgement and the evidence available to them, the reviewer will determine where a focused review is required. The person's family has the right to request a focused review. Focused reviews will or are completed for every person from a Black, Asian or Minority Ethnic background.

This report has revealed that 47% of completed focused reviews received good and excellent care, 37% received satisfactory care and in 10% care fell short of expected good practice, further analysis will be available in the body of this report.

Due to LeDeR platform technical issues, it is not known what the national or London LeDeR programme comparison is for this year.

Some of the recommendations made from this year's completed reviews are:

- GPs to ensure comprehensive annual health checks that can identify undetected health conditions early, refer appropriately and ensure appropriateness of ongoing treatments
- more efforts are needed to extend annual health checks to 14 years old
- more national health screening offers to be made to improve uptake
- provision of appropriate health education
- professionals to refer to other specialist services such as learning disability services for support and better engagement, particularly for those missing clinical appointments
- individuals who are deemed to have mental capacity, to be offered the opportunity to complete an end of life care plan so that their views and wishes are known. This should apply to all over 16 years old as per the principle 2 of the Mental Capacity Act (MCA) 2005
- more use of independent mental capacity advocate (IMCA) as a safeguard for people who lack capacity to get the support they need to make important decisions such as DNACPR and treatment
- more provision of reasonable adjustments in a timely manner.

Introduction

North East London population is almost 2 million and given the prevalence of learning disability in UK, approximately 2.6%, nearly 52,000 people with learning disability live-in North-East London. It is expected that these individuals will at one time receive health and social care from our local services.

This report uses the definition of learning disabilities provided in the 2001 White Paper "Valuing People. A person with learning disabilities will have:

- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development.”

In March 2021, NHS England published its first LeDeR policy setting out a number of changes to the LeDeR programme. The LeDeR Programme previously known as 'Learning Mortality Review Programme' is now referred to as Learning from lives and deaths for People with a learning disability and autistic adults (LeDeR).

The LeDeR programme focused on deaths of all people with learning disabilities aged 4 years and over; from January 2022 the LeDeR programme was extended to include autistic adults over 18years of age without a learning disability.

LeDeR reviews are not investigations of care but a review of care provision; the aim is to promote learning. **The expected outcomes of the LeDeR programme are to:**

- improve care, health and wellbeing and better-quality life for people with a learning disability and autism
- reduce health inequalities for people with a learning disability and autism and
- prevent people with a learning disability and autism from early deaths.

We can achieve this by identifying what factors may have contributed to these deaths, what works well, what does not work well and develop plans to make any necessary changes to health and social care services to make it better for others.

Until May 2021, the LeDeR programme was hosted by University of Bristol when their contract came to an end. The last annual report 2020-21, used data collected by University of Bristol which enabled performance to be compared across London and nationally.

This annual report covers 88 deaths notified to the programme between 1st April 2021 – 31st March 2022. This report contains real case studies, but they have been anonymised to protect the identity of individuals and families involved.

This report also outlines this year's LeDeR programme challenges, good practice and areas for improvements, which will be shared with relevant care providers and key stakeholders.

The purpose for this report is not only to provide updates on where we are as a programme, but to influence positive changes to service provision and mobilise further support to reduce health inequalities learning disabilities people continue to experience.

Acknowledgements

Following the World Health declaration of the Covid-19 pandemic on 11th March 2020, NHS England/ Improvement in conjunction with NHS NEL CCGs proactively developed a Covid-19 rapid review tool which was used following a death of a person with a learning disability due to Covid-19 or where Covid-19 is suspected to have contributed to the cause of death.

The success of this rapid response tool was due to the well-established and mature networks between the CCGs, care providers and community teams across North East London. A very special thank you to all those who contributed to ensure continuity of care for people with learning disabilities during an extraordinary two years facing the impacts of Covid-19.

Analysis of the Covid-19 rapid review reports further highlighted the significant health inequalities that people with learning disabilities encounter due to their complex health and social care needs. Despite the Covid-19 pandemic challenge, reviews continued, as did data collection and dissemination of the learning.

We would like to thank all the families and carers for their support which has ensured that every review undertaken enabled us to learn from the events their loved ones experienced and to identify local positive practice and/or areas for improvement.

Special thanks to all care providers, primary care teams, acute teams, key stakeholders and partners, who have provided information as requested under very difficult circumstances and above all for your continued support to reduce health inequalities for learning disabilities and autistic people.

Further thanks go to all the reviewers for the empathy shown when completing reviews, whilst keeping the person at the centre of the process, in order to identify learning and share good practice. Reviewers have continued to meet NHSEI review completion deadlines despite competing priorities, workforce challenges and ensured a person-centred approach even when adapting to virtual ways of working.

This report would not be what it is without the hard work, support and the contribution of our Local Area Contacts (LACs) who are NEL CCG Designated Safeguarding Adults Professionals and the NEL Strategic LD&A Lead, Rachel Penney and all those who in one way or the other contributed, a huge thank you to you all.

Quality Assurance and Governance arrangements

On 23 March 2021, the Learning from Lives and Deaths- People with learning disabilities and autistic adults (LeDeR) Policy version 1 was published. This policy set out the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the LeDeR programme from June 2021.

It is expected that from 1 April 2022 all requirements of this policy are implemented by the Integrated Care systems (ICSs). The ICSs and their partners need to ensure local governance is robust enough to bring about improvements in health and social care services, reducing health inequalities and reduce premature mortality for people with a learning disability and autism.

Integrated Care systems (ICSs) will be responsible for the delivery of the LeDeR programme and should set up a local governance panel to oversee the completion of reviews and delivery of the local action plan. The membership of the group will be guided by the ICS's own local geography, governance and quality assurance arrangements and by the issues that are important for health inequalities in that area.

Key responsibility for this group is to drive local service improvement plans as a result of completed LeDeR reviews. This governance group should ensure:

- LeDeR Governance is an integral part of ICS governance and quality reporting arrangements
- there are clear and robust reporting mechanisms including ownership by local quality governance systems.
- LeDeR values are embedded as part of quality assurance/mortality/ safeguarding work, primary care development/ownership, commissioning intentions, contract delivery to ensure service change is visible in our contracts
- ensure adequate resources are available for the delivery of the LeDeR programme
- hold local areas (CCGs) to account for their performance against the expectations set out in the new LeDeR policy.
- provide assurance around ICS LeDeR processes and report performance of the ICS every quarter as required.

LeDeR Governance panel

The LeDeR governance panel should be representative of key partners (care providers, commissioners and social care partners) and senior managers who should have the authority to affect change. Other groups that should be represented in this panel are:

- people with lived experience (service user representative) to ensure they are involved in the decision making about actions taken as a result of completed reviews.
- Black, Asian and Minority Ethnic (BAME) representative who will ensure that the challenges faced by people from these communities are considered and addressed as part of the LeDeR programme.

The role of the LeDeR Governance group will be:

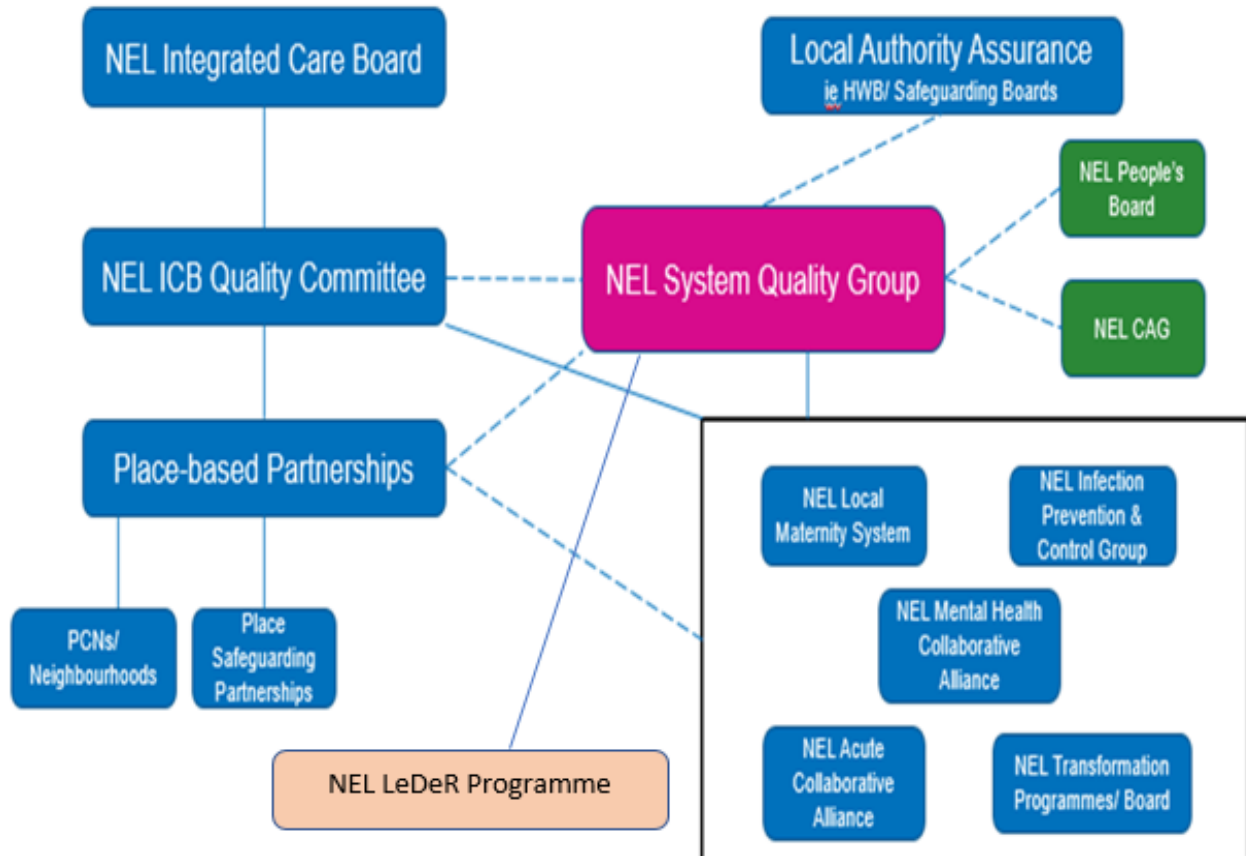
- oversee completion and final sign-off on focused reviews completed for the ICS and determine the actions to be taken
- develop and monitor the ICS LeDeR local action plan.
- provide expert professional and local knowledge in the interpretation of learning from reviews
- to support and enable meaningful system change against local action plans.

The first NEL-wide Governance Group meeting took place on 5th April 2022 and at this meeting members agreed on the terms of reference and a three years' LeDeR Strategy 2022-25.

Proposed NEL Governance structure

On 1 April 2021 the seven Clinical Commissioning Groups (CCGs) in North East London formally came together as a single organisation – the NHS North East London Clinical Commissioning Groups (NHS NEL CCG).

During this transition phase a new model of system quality improvement and assurance has been put in place. Below is the proposed NEL Quality governance structure.



The LeDeR Governance group will be part of NEL system quality group reporting to NEL ICB Quality Committee. The LeDeR group will feed into the system quality governance where learning will be heard and feedback. This will subsequently feed into regional and national accountability on quality and quality improvements.

Equality Analysis

There is clear evidence from studies that people with learning disabilities and autistic people are more likely to die of preventable causes compared with the general population.

This group of individuals has greater and complex health needs than the general population. They experience higher levels of unrecognised and unmet physical and mental health needs. They are more likely face multiple barriers accessing health and social care services; including problems with communication, inadequate facilities, rigid procedures (not user friendly) and lack of accessible health promotion information just to mention a few.

NHS North East London (NHS NEL) is committed to promoting equality and diversity amongst all our staff, stakeholders, service users and patients – fulfilling our obligations under the [Equality Act 2010](#) and the [Public Sector Equality Duty](#).

The LeDeR review programme has and will continue to positively impact on the quality of health and care services provided for people with a learning disability and autistic people. This annual report demonstrates the ICS's commitment to creating a positive culture of respect for all individuals, including staff, patients, their families and carers as well as community partners.

As required by the Equality Act 2010, the intention is to identify, remove or minimise discriminatory practice in the nine named protected characteristics of age, disability, sex, gender reassignment, pregnancy and maternity, race, sexual orientation, religion or belief, and marriage and civil partnership. It is also intended to use the Human Rights Act 1998 to promote positive practice and value the diversity of all individuals and communities.

New LeDeR Policy

The new LeDeR policy was published on 23 March 2021 setting out future ways of working. Reviews will no longer be referred to as 'mortality reviews' focusing at the circumstances around the person's death. It is expected that reviews will be looking at key episodes of health and social care provision throughout the person's life and how this has impacted on the person's overall health outcomes.

Since start of the LeDeR programme it focused on reviewing deaths for people with a learning disability aged 4 and above, however from 1st January 2022 this has been extended to include autistic adults, 18 years and over.

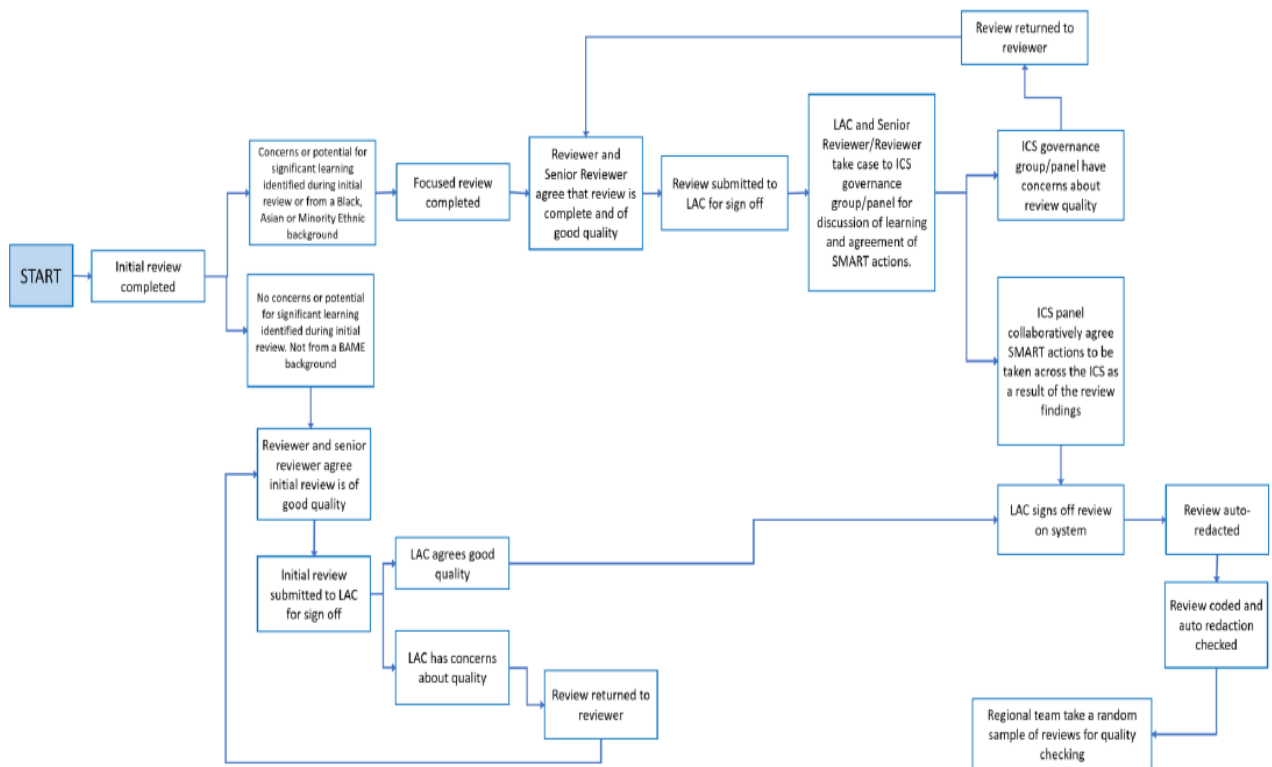
On 1st June 2021, the new web-based LeDeR platform was launched. New LeDeR training was also introduced for all LeDeR workforce and this will be refreshed annually.

The new platform introduced two reviewing processes- initial and focused reviews. An initial review will be carried out for all notifications. Using their professional judgement, reviewers will have the option to make recommendations to progress an initial review to a focused review.

All people from a Black, Asian and Minority Ethnic groups (BAME) background and autistic adults without a learning disability must have a focused review. Other groups that will have a focused review are: travellers/ gypsy and Roman communities; where findings indicate poor care and/or significant learning is likely and following a request from families.

Reviewers will no longer make recommendations; instead they will present areas of learning, good practice and concerns to Local Area Contacts (LACs) and to the local governance group for focused reviews.

LeDeR review process



LeDeR Challenges

The success of the NEL LeDeR Programme has not been without setbacks. There has been transition challenges during this year with the launch of the new web-based LeDeR platform which was delayed by a few months. The LeDeR review process changed and this required that all LeDeR reviewer workforce had to be trained on the new system before undertaking any reviews. This report recognises that it took some times for reviewers to do the training and learn about the new web-based platform.

Between March and July 2021, like many other regions, NEL CCG was unable to progress LeDeR reviewing. Despite teething problems with the new LeDeR IT platform, the new LeDeR Support team has continuously worked with local teams to improve on the system features as well as quality of information to be collected.

NHS North east London has been largely successful in overcoming many of these challenges, and be one of the top ICSs, nationally, to achieve 100% completion of all adults' reviews within six months of the notification date.

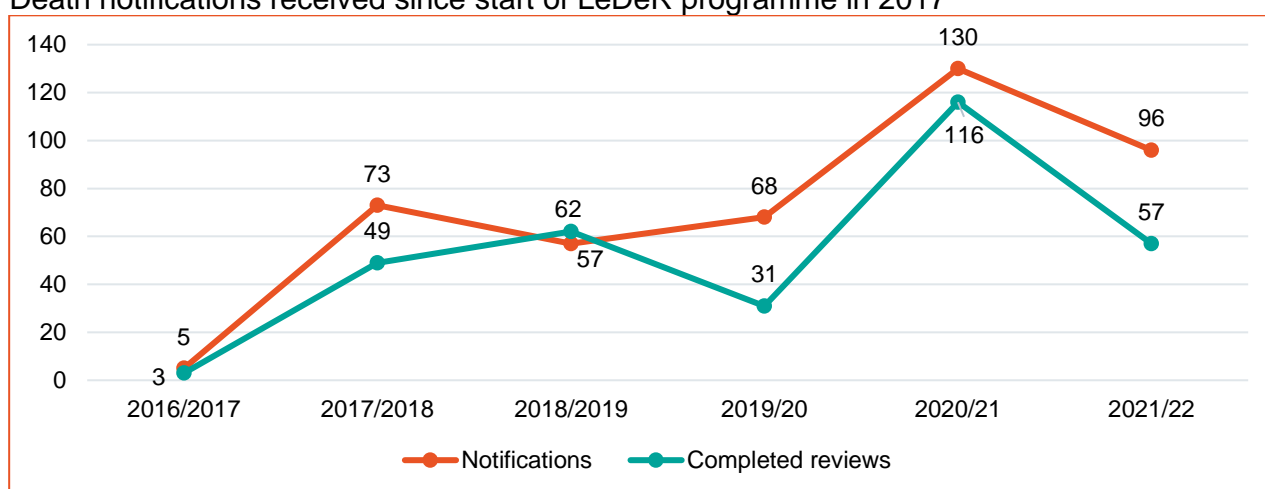
North East London LeDeR activity during 2021/22

The LeDeR review programme started reviewing deaths of people with a learning disability in 2015. NHS Tower Hamlets was the first NEL borough to participate in the national pilot project and recorded first reviews in 2016/17.

In December 2017, the LeDeR programme was devolved to Clinical Commission Groups (CCGs) and later to the ICS, and since then North East London has seen a steady number of death notifications to the LeDeR programme.

During the Covid-19 Pandemic, North East London recorded the highest number of deaths compared to previous years. As at the end of the year, March 2020 North East London carried forward review backlog due reduced reviewers' capacity as a result of the pandemic. Supported by NHS England, a recovery plan was put in place and NHS NEL managed to achieve a good performance of 86% in 2021.

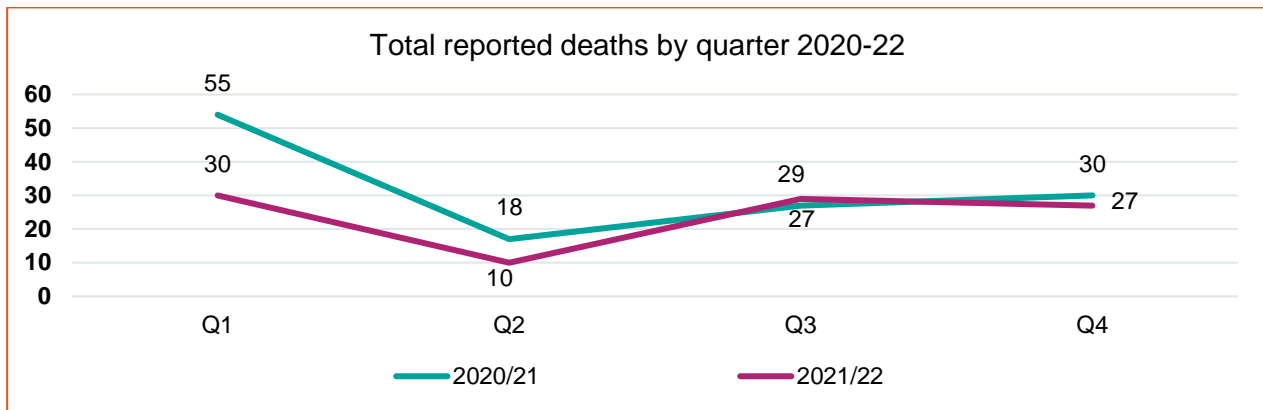
Death notifications received since start of LeDeR programme in 2017



Distribution by locality

Locality	2016/2017	2017/2018	2018/2019	2019/20	2020/21	2021/22
Barking & Dagenham	0	6	7	12	16	18
City & Hackney	0	9	5	7	16	18
Havering	0	15	8	8	27	11
Newham	0	10	9	14	25	16
Redbridge	0	10	12	12	22	15
Tower Hamlets	5	14	8	5	14	10
Waltham Forest	0	9	8	10	10	8
Total	5	73	57	68	130	96

During this year, NHS NEL received 96 death notifications; this is lower than last year's record, (during Covid-19 period) but notably higher than previous three years before the pandemic time.



The above graph shows a high number of deaths at the start of 2020 due to a backlog carried forward from the Covid-19 pandemic. Although we have seen a significant drop in the number of Covid-19 related deaths, Covid-19 has been reported as one of the top ten causes of death this year.

The LeDeR review process has a set criterion for progressing a review: one should have had a learning disability diagnosis before death, aged 4 years and above and no data opt out order in place. Eight out of the ninety-six reported deaths did not meet these criteria and were not progressed.

This report will focus on the 88 notification that met the criteria

Death notifications progressed to LeDeR reviews

	Reported deaths eligible for LeDeR review	Completed (%)	Allocated	Unallocated
2020/21	130	111 (86%)	14	5
2021/22	88	57 (65%)	20	11

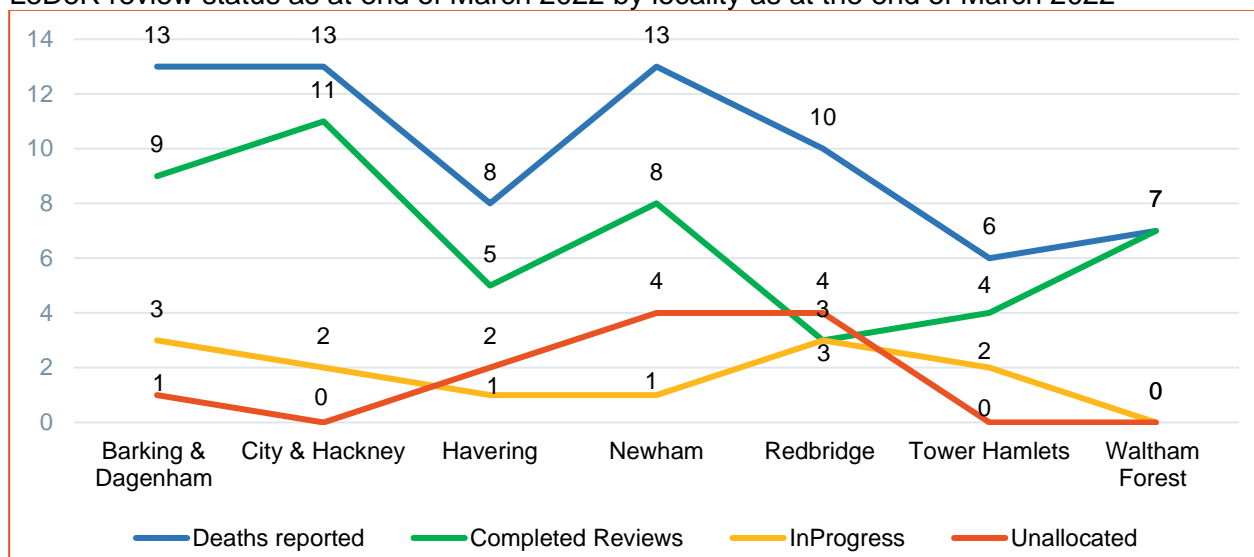
Out of the eighty-eight (88) notifications, 18 were children aged 4 years and above and 70 were adults with learning disability.

NEL has carried forwards 23 reviews from 2021-22 years compared to 19 last year. The unallocated reviews were notifications received between the months of January and March 2022 and were awaiting allocation as soon as reviewers become available.

This year summary report for adult reviews by borough/locality as at the end of March 2022

Locality	Adults deaths (70)	Completed reviews (47)	Allocated/ InProgress (12)	Unallocated (11)
Barking & Dagenham	13	9	3	1
City & Hackney	13	11	2	0
Havering	8	5	1	2
Newham	13	8	1	4
Redbridge	10	3	3	4
Tower Hamlets	6	4	2	0
Waltham Forest	7	7	0	0

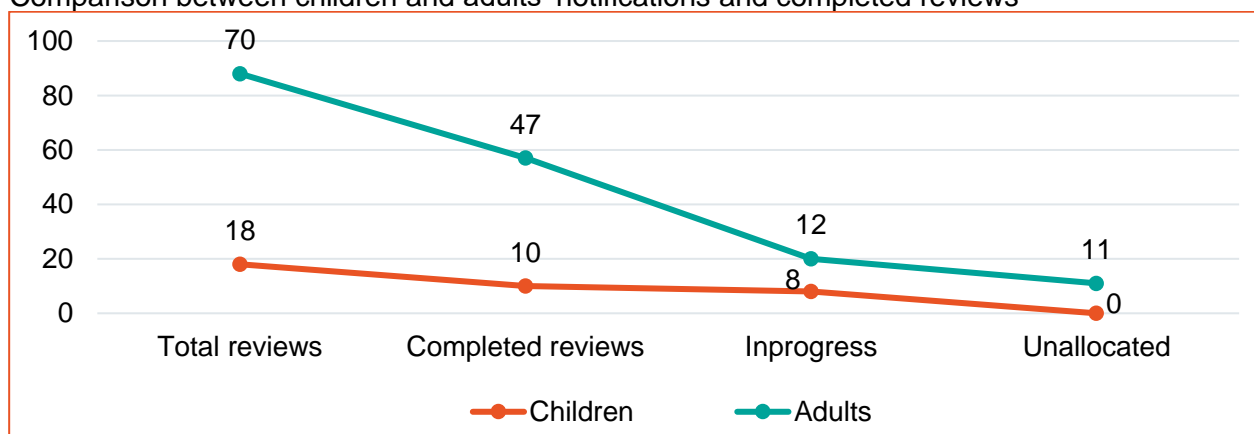
LeDeR review status as at end of March 2022 by locality as at the end of March 2022



Summary report for children reviews by borough/locality

Locality	CDOP reviews (18)	Completed (10)	InProgress (8)
Barking & Dagenham	2	1	1
City & Hackney	4	4	0
Havering	3	1	2
Newham	2	1	1
Redbridge	3	1	2
Tower Hamlets	3	2	1
Waltham Forest	1	0	1

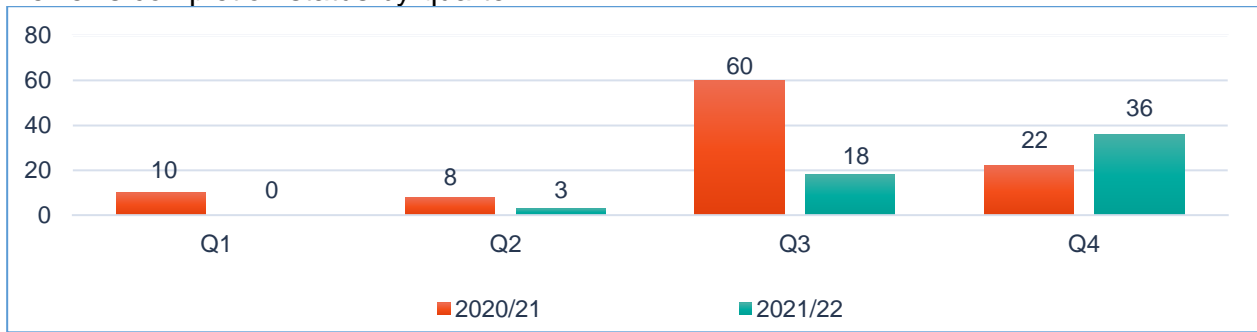
Comparison between children and adults' notifications and completed reviews



All children deaths were reviewed under the Child Death Overview panel (CDOP) review process. Ten (55%) of the LeDeR CDOP reviews were completed during this reporting period and all necessary information provided to the LeDeR programme team for reporting.

Overall, 65% of all notification had reviews completed as at 31st March 2022.

Reviews completion status by quarter



During the first quarter of this year, NHS NEL, like most other ICSs were not able to progress reviews due to the delay with the new LeDeR platform. The three reviews completed during quarter 1 were Child Death Reviews (CDRs). It was not until quarter two when allocations started and NEL recorded the first adults completed review in October 2021.

Types of completed reviews

The LeDeR process of reviewing deaths in adults and children is not the same. A standard proforma is completed for all adult deaths. All adult LeDeR reviews are undertaken by trained LeDeR reviewers.

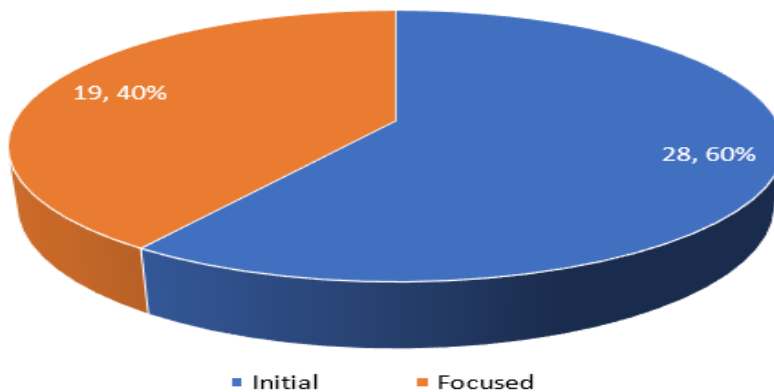
CDOP reviews

The statutory Child Death Review (CDR) remains the primary review process for children's deaths (aged 4-17 years) with a learning disability, the LeDeR programme is not required to review each of these cases separately.

There is a legal requirement that Child Death Overview Panels (CDOP) conduct reviews for all deaths of children under 17 years within their locality. The timescales for completion of reviews is entirely depended on the CDOP schedule. Following completion of all investigation the results are then shared with LeDeR programme by way of a LeDeR representative participating in CDOP review meetings and copies of analysis reports (copies of Forms B and C) attached on the system.

Adult reviews: Initial and focused reviews

The new LeDeR platform introduced a new reviewing process for all adult reviews- initial and focused reviews. 47 adult reviews were completed this year; all (100%) had an initial review and 40% (19) had focused reviews.



The focused reviews were based on the new LeDeR review process set criteria which requires that the following groups should have a focused review:

- Black, Asian, Ethnic Minority (BAME) background
- autistic adult without a learning disability
- where findings from an initial review indicate poor care or more learning is likely with a focused review
- if requested by families
- travellers/ gypsy and Roman communities.

79% (15 out of 19) of focused reviews were of BAME background whilst 21% (4) were as a result of the initial review not providing enough information to rule out poor care. The four focused reviews were discussed and agreed between the relevant LAC and reviewer following an initial review which indicated that a full focused review could result in more learning.

No focused review was completed as a result of a request from families or of travellers/ gypsy and Roman communities nor a person known to be autistic without a learning disability.

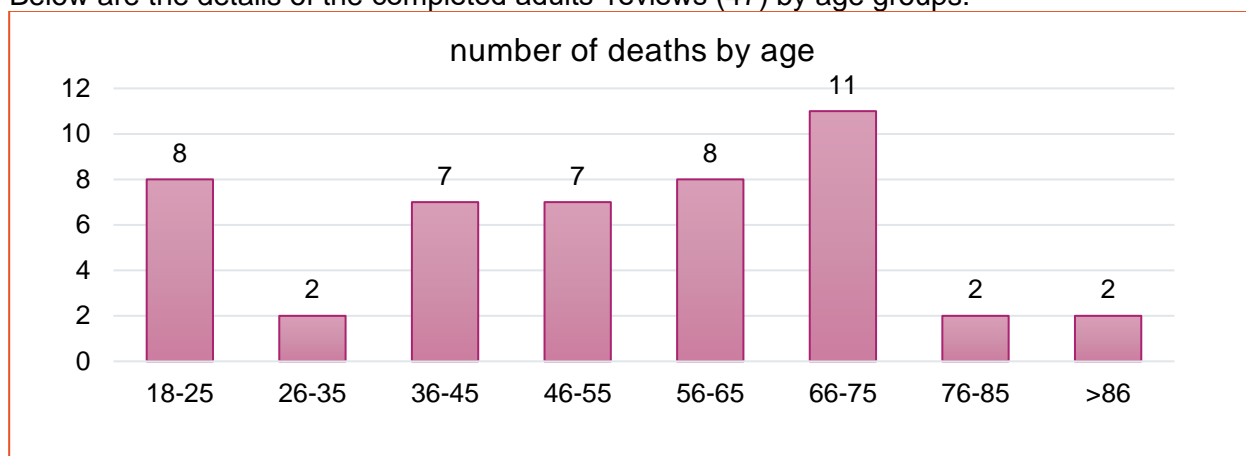
Demographics

The next part of this report focuses on the analysis of the 57 completed during this year. There is no London or national data available for comparison due to the absence of a reporting function in the new LeDeR platform to help generate reports.

Age

Eight-eight (88) deaths qualified for LeDeR review process; 70 were adults and eighteen (18) were children deaths aged 4-17 period. Forty-seven adult reviews were completed.

Below are the details of the completed adults' reviews (47) by age groups:



There were fewer younger people aged 18-35 years and the numbers increased in each age band, then declines after 75 years.

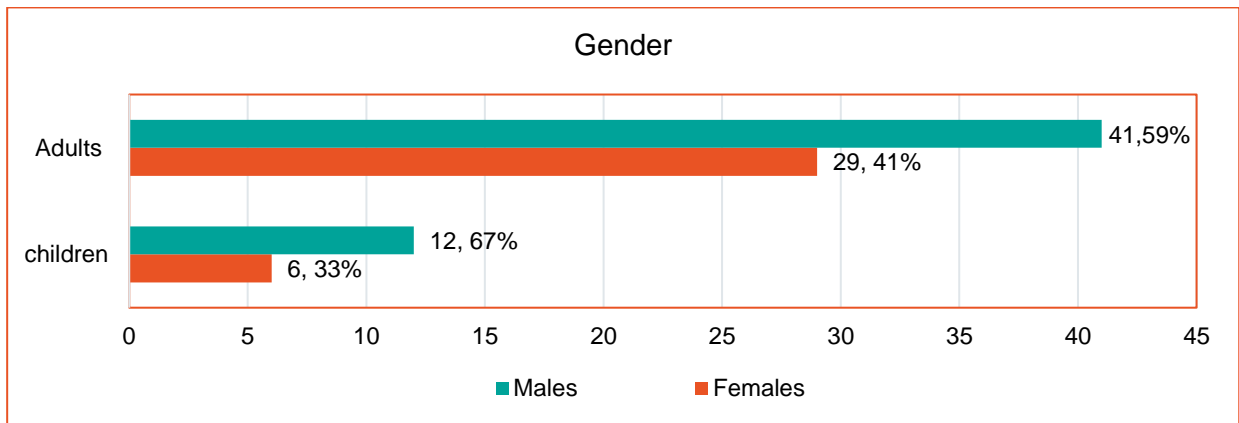
- age range, 4- 89
- average age was 56 and
- the median 52 years

In the 2021 annual report, the maximum age was 97 and median was 58, a decrease in both has been recorded this year.

Gender

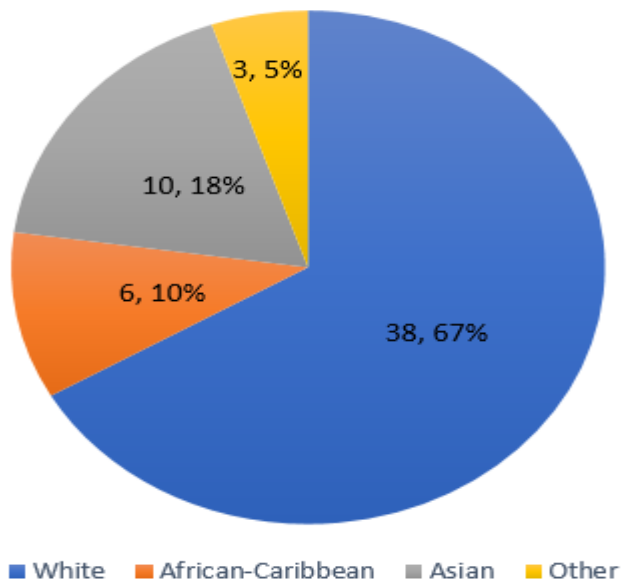
There were more deaths for males than females within data reviewed; 57% (50) of the completed reviews were males while females were 43% (38). This information is in line with our last years' data which shows that there were fewer female deaths than males in 2021, (56% males and 44% females).

The below graph shows gender analysis from completed reviews both children and adults, which indicates that more males died compared to females.



Ethnicity

North East London has a very diverse community. It was noted that some of the notification forms completed did not provide full details of the person who had died, most likely that this information was not known to the reporters at the time of completing the notification forms. The analysis of the ethnicity data has been compiled from the fifty-seven (57) completed reviews for accuracy.

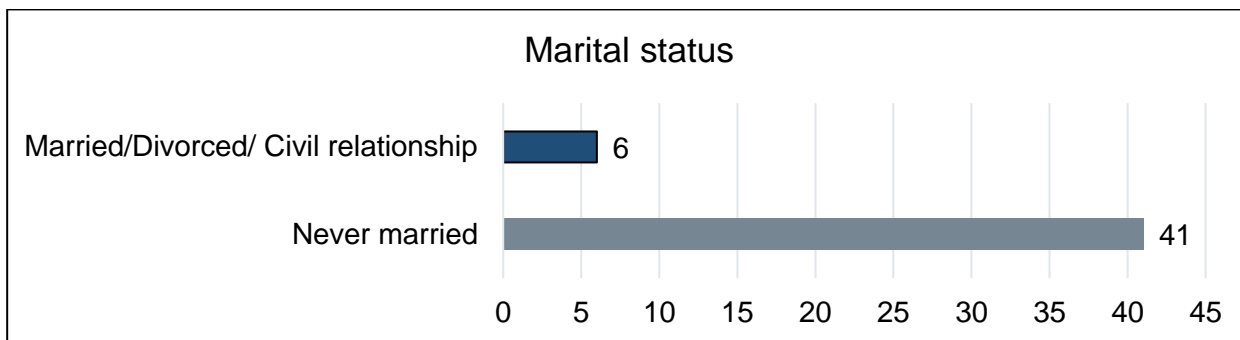


The proportion of adults and children described as 'white' was higher than other ethnic groups. 67% were white while 33% were of Black Asian Minority Ethnic background.

This year's report shows similar statistics in terms of the ethnic groups compared to last year's report 2021 which showed 65% white, 23% Asian and 10% black African-Caribbean groups.

Civil partnership/ marital status

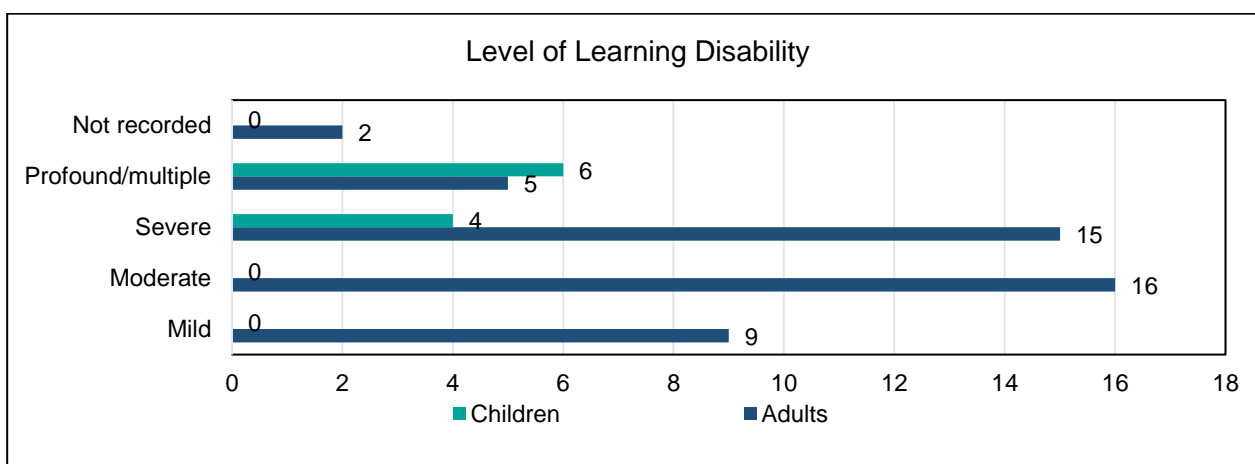
87% were single (never married) while 13% were recorded to have had civil partnerships, married or divorced. No data available from previous reports for comparison



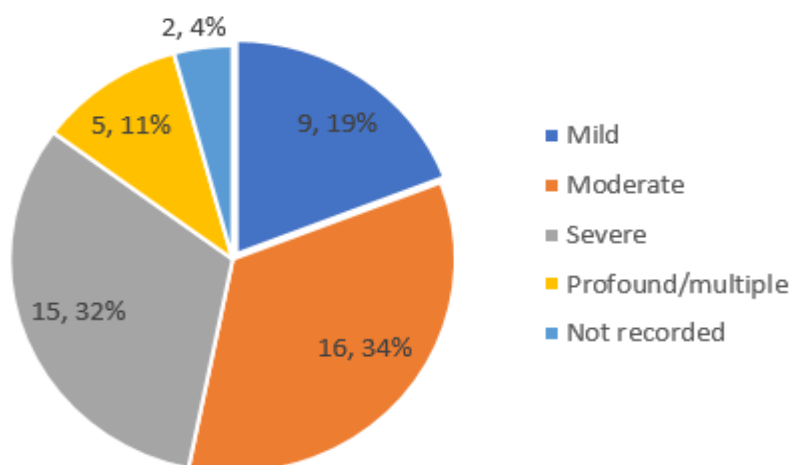
Level of Learning Disability

The LeDeR programme uses four main categories to describe the level of severity of a learning disability. These groupings are mild, moderate, severe and profound/ multiple learning disability.

Most of the children who died were known to have had a life limiting conditions and complex health needs. Most of them had lived longer than expected. They were all recorded as have had either severe and profound-multiple learning disabilities.



There were more deaths for children with profound/multiple learning disabilities than in adults. No children were recorded as having had mild or moderate learning disabilities.



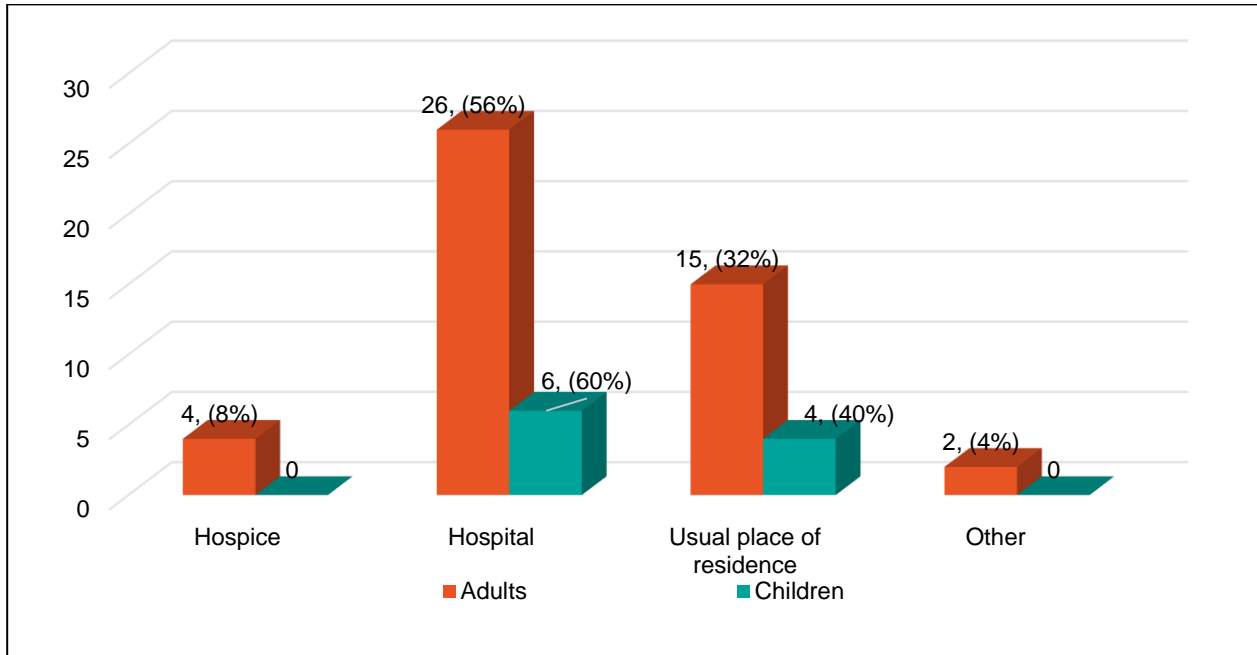
Analysis of completed adults' reviews above indicate an insignificant variation from data recorded last year which indicated mild (25%), moderate (32%), severe 26%) and profound/multiple (17%).

Place of death

60% of all child deaths happened in the hospital while 40% died at their family homes. Most of them were on palliative care pathways; in two reviews discussions had taken place about advanced care planning but were not yet implemented at the time of death.

Fifty-six percent (56%) of all adults' death occurred in hospitals, thirty two percent (32%) in their usual place of residence while under ten percent in hospice care units. From data collected, it was not possible to know whether people died in their preferred places or not.

Place of death



In the previous reporting period 2020-21 data showed that more people died in hospital (62%) while 27% in their usual place of residence. This was lower than data collected during the last two years. Although no explanation to support this reduction in people dying in a hospital setting, this report recognises that during the Covid-19 pandemic people were reluctant to visit hospital due to fear of contracting Covid-19.

Pre-existing Health conditions

Findings from all reviews, indicated that all people with a learning disability who had died were known to have had pre-existing physical health conditions. Most had two or more of the below listed health conditions.

List of common physical health conditions, number of patients and percentage

Health Condition at the time of death	Percentage (%)
Impaired mobility	18 (95%)
Falls (risk of falls)	17 (89%)
Skin conditions and prescribed medication	16 (84%)
Respiratory conditions/problems (incl. CoPD/ asthma)	15 (75%)
Obesity	14 (75%)
Epilepsy/seizures	13 (68%)
High blood pressure (hypertension)	13 (68%)
Constipation/ prescribed laxatives medicines regularly	12 (65%)
Diabetes (Type 1 & Type 11)	11 (58%)
Mental health needs (Paranoid Schizophrenia, psychotic episodes, depression, bipolar affective disorder/personality disorder, challenging behaviour, anxiety, agitation/irritability behaviour and hallucinations)	10 (52%)
Incontinence	8 (42%)
Dental problems (patient advised to see community dentist)	8 (42%)
Renal/ Chronic kidney disease	8 (42%)
Known heart conditions/ Cardiac problems	8 (42%)
Sensory impairment e.g. hearing or visual problems	7 (36%)
Dysphagia, (aspiration risk)	6 (32%)
Iron, Vitamin D and B12 deficiency	6 (32%)
Impaired hand use (e.g. unable to move hands to feed self or push away something)	4 (21%)
Cancers	4 (21%)
Dementia/ Alzheimer's	3 (16%)
Hyperthyroidism & Hypothyroidism	3 (16%)
Osteoporosis	2 (11%)

Most initial reviews did not provide details of pre-existing health conditions and this was due to limitations with the new initial review template.

The above list has been collated from nineteen (19) focused reviews, (15% of 57 completed), the majority of whom are of Black, Asian, Minority Ethnic (BAME) background.

Comparing data from this year's report with the previous year's would be inaccurate as this year's data focuses on a small set of completed reviews, mainly of BAME background, while previous data was based on all completed reviews.

Most common causes of death

Research findings by Mencap UK, indicate that people with a learning disability are four times more likely to die of avoidable causes compared to the general population. Source: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>.

It is estimated that approximate 11%, six (out of 57) of reviews completed during this reporting period were conceivably preventable deaths. These individuals died from hospital acquired pneumonia, perforation of the bowel, sepsis and asphyxia (suffocation) as recorded under 1a on the certificate of death as the main causes of death.

In one review, the person died suddenly due to perforation of the bowel with no previous medical history or health concerns; no history of ill health however, the person had been complaining of constipation as evident on GP record. In another review, the person died of brain cancer which was diagnosed during their last admission.

Causes of deaths such as sepsis, infection, pneumonia, aspiration pneumonia, perforated bowel/obstructive bowel and suffocation are potentially treatable and/or preventable if caught in time.

Adult reviews

The most frequent causes of deaths reported causes of death as recorded on death certificates were:

- Respiratory problems: pneumonia/ bronchopneumonia, asthma
- Renal problems: Acute kidney injury/ renal failure/chronic kidney disease
- Cancers: prostate, breast, brain, tumours, carcinoma, metastatic cancers
- Heart related problems: cardiac arrest/ heart failure/migration of a shunt
- Epilepsy
- Asphyxia (suffocation)
- Diabetes
- Sepsis
- Covid-19/ Covid-pneumonia
- Aspiration pneumonia
- Multi-organ failure
- Liver related problems
- Perforated bowel/obstructive bowel
- Frailty
- Obesity

For this reporting period, LeDeR reviews identified the most common causes of death were linked to cardiac problems, respiratory, renal failure, cancers and epilepsy.

Common secondary causes or disease impacting on deaths: epilepsy, diabetes, sepsis, aspiration pneumonia and heart failure.

Most common causes of death in children were:

- Sepsis
- Cardiac arrest
- Epilepsy/ Sudden Unexpected Death in Epilepsy (SUDEP)
- Chromosomal, genetic or congenital anomaly
- Infection (undefined)
- Respiratory failure

Coroners Inquests and post mortems

All home deaths were subject to a post mortem to determine cause of death, except for four, which were expected deaths and GPs certified these deaths. There was evidence that some professionals including coroner's office were recording learning disability as a cause of death.

Three reviews had coroner's inquests (for patients from Waltham Forest, Redbridge, and Barking & Dagenham). The Waltham Forest and Redbridge inquests have concluded.

In one of the reviews, the person sadly suffered a fatal, unwitnessed accidental injury in a residential setting; the coroner's conclusions were that the patient died from asphyxia (suffocation). Failings were identified and recommendation made to the residential care unit where the patient lived around staff adhering to regular checks as required and regular review of risks to ensure risk assessments reflect individual's needs.

In the second inquest the patient had died from cardiac tamponade (meaning extra fluid build-up in the space around the heart. This fluid puts pressure on the heart and prevents it from pumping effectively. The person had had a shunt inserted. The coroner reported that a sequence of events caused by migration of a shunt is exceptionally rare. The suspected diagnosis of a pulmonary embolism was found to be reasonable based on the clinical history and presentation at the time and the treating team did everything they could. The conclusion was that this cause of death could not have been reasonably foreseen by the treating team.

Analysis of the key aspect of care provided to people with a learning disability

This chapter focuses on the findings from the main aspects of care provided to people with learning disabilities specific to reviews and screening programmes and how this data compares with last year's and the national data where appropriate.

a) Annual Health Checks from completed reviews

All people with learning disabilities over the age of 14 are entitled to an annual health check. Regular health checks help identify unmet and unrecognised health conditions, leading to early actions to address and treat these health conditions.

Since March 2020, annual health checks have been disrupted by the Covid-19 pandemic and public health guidelines and government restrictions. Although annual health checks have been fully restored for some time, there is evidence a lower percentage of the LeDeR cohort accessed their annual health checks this year compared with the previous years.

Out of the 57 completed reviews, 52 were aged 14 years and over and were eligible for annual health checks. Five were children aged between 14-17 years old, reviews show that annual health checks had not been completed at the time of death. There was no evidence to indicate that these children were not on the learning disability register.

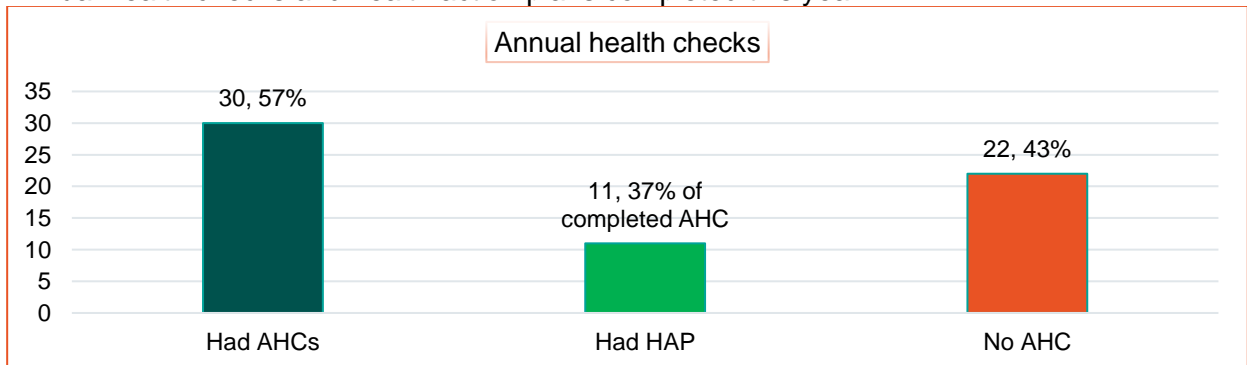
57% (30) adults had their annual health checks completed during the last 12 months while 43% there was no record of annual health check or had had annual health checks in over 3 years. The quality of completed annual health checks varied from person to person and information collected was not consistent.

Eleven (37%), of those people who had their annual health checks had their health action plan completed or updated.

NEL Commissioning data on annual health checks reported a performance of 82% as at end of March 2022; this was above the national target which is 75%. However, LeDeR report 2021/22 recorded 60%, which is 22% lower than overall performance. Clearly, there is more to be done to establish barriers to accessing annual health checks and encourage all those that have not had annual health checks in the previous year(s) to come forward and have their annual health checks completed.

Information gathered revealed that most of these annual health checks were done virtually due to Covid-19 restrictions. Twenty one percent (8 AHCs) had face to face consultation session as part of home visits. Two had a mix of virtual and face to face consultations.

Annual health checks and health action plans completed this year



Findings from AHC and HAP were recorded around:

- Covid-19 restrictions made it difficult for people to attend face to face annual health checks
- No annual health checks completed on children and young people aged between 14-17 years
- while virtual annual health checks worked for some, it was felt that virtual checks were inadequate as GPs could not carry out physical examinations and depended on carers to provide this information.
- a significant number of patients didn't have health action plans completed following AHCs
- Annual Health Checks were not consistent however, using the same best practice toolkits across the footprint could be one way to ensure high quality checks
- No evidence indicating that GPs were seeking support from Community Learning Disability Teams to help with those hard to reach patients and those not attending appointments.

Reviewers made recommendations to enable conversations with GPs to identify areas for improvement. GPs to ensure they carry out comprehensive annual health checks that can identify undetected health conditions early, refer appropriately and to use existing best practice toolkits to ensure consistency across the area. Closer working relationships between the Community Learning disability teams and GP is needed.

**It is worth noting that since the government announced an end to all covid-19 restrictions, GPs are no longer expected to offer virtual annual health checks.*

b) Weight Management for people with learning disabilities

People with a learning disability are more likely to have be overweight or obese. Some people may be underweight because they have difficulties with eating or swallowing. Others may be overweight because they have a condition that increases their risk of obesity, such as Down's syndrome.

Body mass index (BMI) is the commonly used measure of whether someone is within a healthy weight for their height. This report acknowledges that there may be challenges around using BMI as a tool and measure for healthy weight, particularly for learning disability people who may have short stature or anomalies in body structure, in this situation, BMI readings could be misleading.

	Unknown	Underweight	Normal weight	Overweight	Obese
2020/21	17 (36%)	7 (7%)	23 (25%)	13 (14%)	32 (35%)
2021/22	17 (36%)	5 (11%)	9 (19%)	5 (11%)	11 (23%)

From the above table, there is evidence of reduced percentage of the people recorded as overweight and obese this year compared to last year. A higher proportion of the people who died were recorded as underweight. Findings show that there were fewer people recorded as overweight and obese compared to last year's report, however the data set used for this report is small and not representative of all the reported death notifications.

Evidence from records indicated that GPs provided healthy eating information for weight management (eat well guide) as well as advice on regular physical activities. There was no evidence of follow-ups or outcome from these programmes recorded.

Reviewers recommendations use of alternative methods to check patient weights or health measurements such as using mid-upper arm circumference (MUAC) assessment if weighing scales unavailable. GPs to monitor these referrals and involve teams such as community learning disability teams for support to support those that are hard to engage with these activities.

c) Mental Capacity Assessment

Mental Capacity Act 2005 recognises that people with learning disabilities can be encouraged to make whatever decisions they have the capacity to make, and that if they are unable to make a particular decision someone will make it for them in their best interest.

It was clear that all people who died needed a mental capacity assessment to determine which areas they can make decisions on and areas that they need support with.

85% of all focused reviews found evidence of mental capacity assessments and 15% held no information to indicate if they had it completed or not. Due to limitations with the data, it was not possible to tell why these assessments were not completed.

In some reviews there was good evidence of the application of the MCA. Some clearly demonstrated that the person lacked capacity to make decisions and best interest decision making processes were implemented appropriately and relevant support put in place.

However, in some reviews, gaps were found around understanding and application of MCA. Suggestions were made around strengthening MCA training to promote awareness and appropriate application of MCA and best interest decision making across health and social care providers.

Deprivation of Liberty Safeguards (DoLS)

The Deprivation of Liberty Safeguards can only be used if a person is in hospital or a care home. If a person is living in another setting, including supported living or their own home, it is still possible to deprive the person of their liberty in their best interests. This can be done via an application to the Court of Protection only if one lacks capacity to make the decision themselves.

Three of the reviews showed that the persons had DoLs applied for the purpose of receiving care and treatment. Records indicate that these individuals lacked capacity to consent to their care and treatment and they were subject to continuous supervision and control. The care and treatment being received was deemed necessary and decisions made in their best interest.

Mental Health Condition

Seven people, (37%) out of the nineteen who had focused reviews had a known mental health condition. Common health conditions recorded were: depression, bipolar affective disorder, personality disorder, challenging behaviour, anxiety, agitation/irritability behaviour and dementia/Alzheimer's. They were all on psychotropic medicines and there was evidence of regular reviews by the relevant teams. Due to limitations with the data sets, no information was available on medications prescribed and prevalence.

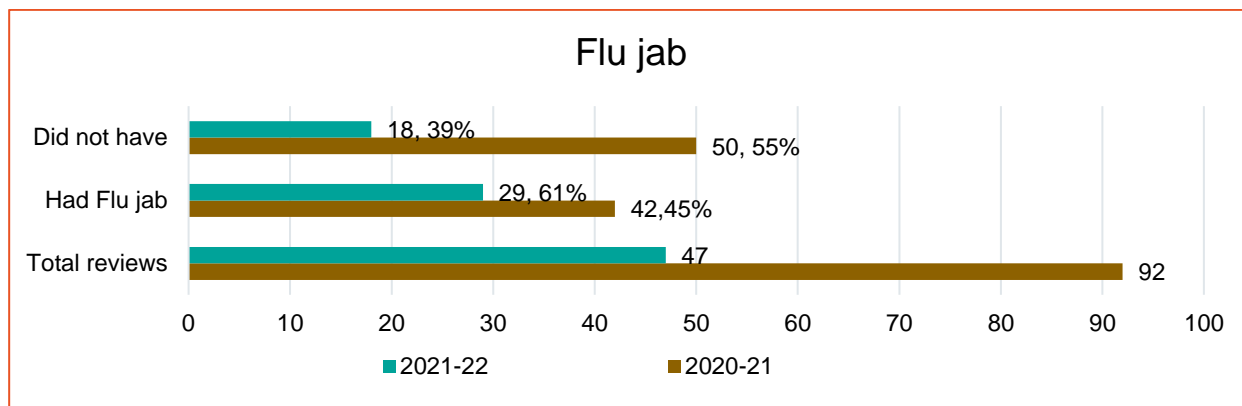
It is not possible to compare this data with last year's data as the current data set relates to BAME reviews while last year's data was based on all ethnic groups.

Reviewers found no record indicating that any of these patients had been considered for social prescribing service. Since April 2021 NEL Learning Disability and Autism programme commissioned two specialist LD Pharmacists (to support people with learning disabilities reduce and/stop overmedication with antipsychotic medications, where this is appropriate). Due to restrictions in the data collected, it was not possible to know if any of these seven persons who died had had support to reduce or stop antipsychotic medicines through this project.

d) Flu jabs and Covid vaccinations

Flu jabs

Flu jabs are offered every year to all vulnerable patients to protect them from severe side effects of the influenza virus and to reduce the risks of pneumonia.



According to national statistics, as of March 2022, 52% of those aged under 65 years and in a clinical risk group had the flu jab, while 85.1% of those aged 65 years old and over and in a clinical risk group had the flu jab.

61% (of 57 reviews) completed showed that the person had had the flu jab during this reporting period, which is higher compared with 45% last year. It is not clear from information gathered how many of these individuals declined or missed appointments, or were not offered the jab at all.

Although there are signs of good progress, this remains a focus of ongoing improvement work.

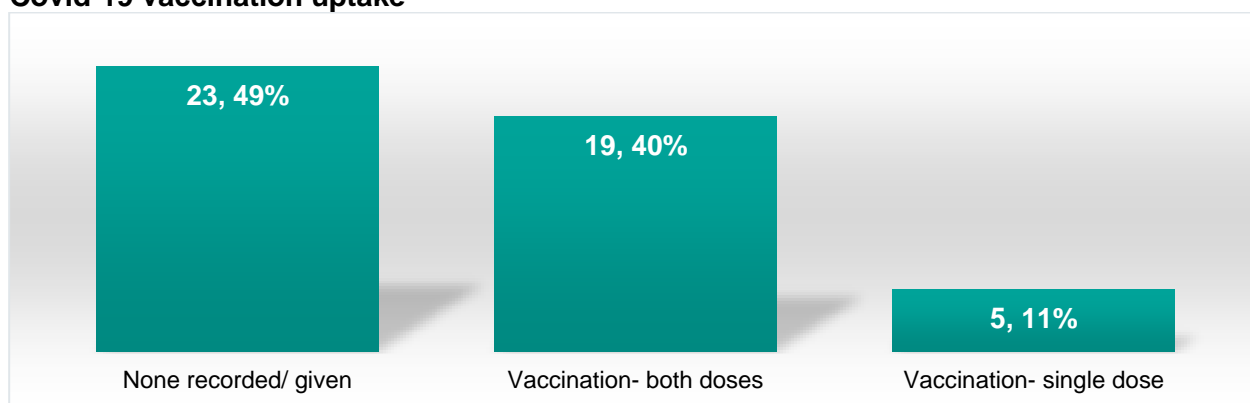
Covid-19 Vaccinations

Following the pandemic, an independent body of experts was set up to advise the government on the prioritisation of the Covid-19 vaccination. An approach was agreed that prioritised those in care homes first, then those aged 80 and older and front-line health and social care staff. Beyond these groups, prioritisation was done in a mix of age groups (in 5-year intervals) and younger people who are clinically vulnerable.

People with a learning disability were not included in these phase1 priority groups. However, in February 2021 a decision was made to prioritise everybody with a learning disability for the vaccine. At this time, statistics had emerged indicating that people with learning disabilities were six times more likely to die from Covid-19 compared to those without a learning disability due to underlying health issues.

Out of completed 47 adult reviews, 19 (40%) had had both Covid vaccination doses while 5 (11%) had had one dose. Under 50% of the reviews showed no evidence of covid vaccinations. Common reasons recorded were, covid lockdown restrictions, limited GP face to face appointments, carers declining vaccination offers on behalf of their loved ones and needle phobia.

Covid-19 vaccination uptake



National data released in March 2022 showed that 69.5% of the general population had had one dose, 65% had two doses and 51% had booster dose. 63% of male had both doses compared to 68% females; 67% males had single dose compared to 71% females were recorded as having had single dose.

Out of the 19 reviews recorded as having had both doses, seven (37%) were male and twelve (63%) were female. None had had a booster vaccination. Three females and two males had one dose. There was evidence of slightly better uptake in females compared to males. These statistics are in line with national data.

Reviewers recommendations were made as follows:

- health education to all and especially carers to understand the importance of vaccination programmes in preventing infections and serious ill-health
- tailored communications to address concerns about the impact of vaccinations in long term conditions
- GPs to refer to community learning disability teams for support with individuals missing health appointments and improve vaccination uptake

e) National cancer screening programmes

Review findings were that cancer screening is not always taken up in a timely manner potentially leading to late diagnosis. Diagnostic overshadowing is sometimes an issue, access to investigations can be poor due to lack of reasonable adjustments and assumptions about ability or willingness to tolerate tests. Improving access to screening and diagnosis for people with a learning disability and autistic people is critical in extending their life.

Data collected from 47 completed adult reviews showed that five people had had bowel cancer screening, three had cervical screening and one had breast screening (mammogram test). This information was gathered from GP records covering the last 3-5years of the individual's life.

Type of screening programme	Those eligible this year	Had screening this year	% screened last year, 2020-21
Bowel (both Females & Males 60-74)	16	5 (31%)	49%
Cervical (Females- 25-64)	16	3 (18%)	17%
Breast cancer (Females- 50-71)	14	1 (7%)	26%

From April 2021, NHS reduced the age for bowel screening from 60 years to 55 years. Bowel screening is now being offered to both male of female aged between 55-74 years old. National statistics reported in March 2022 show that in the last 30 months, 66.8% of eligible groups had bowel screening done and the uptake seems to have gone up over the last 6 months to 70.1%. This is significantly high compared to 31% recorded by NEL LeDeR programme this year.

Cervical cancer screening is offered to all females aged between 25-64 years old and occurs once every three to five years. Nationally 68% of all those aged 25-49 years had cervical screening while 74% was recorded in the over 50s. An average of 71% was recorded compared to 18% of those females who died in North east London.

Both practical and emotional barriers contributed to low uptake in cervical screening. The most common reasons were anxiety, fear, embarrassment, shame, and fear of pain. Some carers expressed lack of confidence in the benefits of screening and low perceived risk of cervical cancer for this group of patients, often due to believing they were not sexually active.

All females aged between 50-71 years old and registered with a GP are invited for NHS breast screening every 3 years (source: <https://www.nhs.uk/conditions/breast-screening-mammogram>).

Only one person (7%) out of 14 eligible persons attended breast screening during the last 3 years. This was significantly low compared to last year's report (which was 26% and the national record of 64.1%).

There is evidence that care providers are taking steps to address inequalities and access to screening services such as; more accessible clinics, longer appointments, additional assistance during appointments and provision of appropriate information in easy read format.

From the above, more efforts are needed to improve uptake of national health screening programmes. More offers and conversations need to happen during routine appointments and provision of reasonable adjustments. GPs must ensure appropriate health education targeting people with learning disabilities and their carers to improve their understanding and importance of accessing timely cancer screening programmes. They should be working closely with other specialists such as community learning disability services for support and better engagement.

f) Advanced care planning

Advanced care planning is also referred to as end of life care. This refers to health care for a person nearing the end of their life or in the advanced stage of a terminal illness.

Advanced care planning and DNACPR are decisions that do not exist in isolation but as part of a broader range of care planning for long terms conditions, and emergency treatment escalation plans. Having a comprehensive care plan in place helps reduce unnecessary acute admissions. It is important to have open discussions and advanced care planning to help improve choice, symptoms control and dignity near end of life.

In children, it was noted that most of them were known and cared for by palliative care teams for several years especially those who were known to have had a short life expectancy due to a life limiting condition.

53% (25 of completed reviews) had end of care plans in place. The duration varied from a few hours to a year in adults. In all 25 reviews, families, carers and relevant people close to the person who died were involved in their end of life care planning and their views considered where appropriate.

There is no evidence to indicate that the person who died was involved or invited to share their thinking and wishes for how they would like to be cared for in the final months and days of their life.

In six of the reviews, advanced care planning had been discussed with family but the person died before this could be put in place due to sudden unexpected deterioration.

End of life care	2021/2022	2020/2021
Those who had End of life care in place	25 (53%)	39 (42%)
End of care considered by not effected before the person's death	6 (13%)	---
Have no advanced planning	16 (34%)	53 (68%)

Recommendations were made around continued staff training on recognising deterioration and acting in a timelier manner; efforts to be made to involve individuals in advanced care planning and their wishes recorded.

g) Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders were in place for 72% of the persons who died. This was noted to be higher than the numbers recorded last year which was 65%. They were all known to have had long term conditions which contributed to their cause of death.

	DNACPR applications in place (numbers and %) 2022	DNACPR applications in place (numbers and %) 2021
DNACPR in place	34 (72%)	60 (65%)
None	13 (28%)	32 (40%)

Evidence recorded showed that all recorded DNACPR were correctly completed and appropriately applied. Families and professionals were involved in the decision-making process and families supported.

In one review, the carer did not wish the person know they were dying. The individual was at the end of life stage and evidence indicated that numerous teams were involved and provided excellent care. The family wish not to let the individual know was respected by all professional involved. A recommendation was made around more efforts to support families and professionals to communicate and involve individuals in key decisions about themselves, such as DNACPR and end of life care plans.

All professionals have a legal obligation under 'principle 2 of the Mental Capacity Act 2005 to help a person, over 16 years, to make their own decision before deciding that they are unable to make a decision'. Reviewers felt that all individuals deemed to have capacity should be offered the opportunity to complete an end of life care plan so that their views and wishes are known.

l) Social Care assessments

All completed focused reviews showed that the person had had a social care assessment to determine the type of care package. The type of social care package was based on individual needs and this varied from few hours a week to 24/7 residential or nursing care packages.

Three had Deprivation of Liberty safeguards (DoLs) approved and applied at the time of death (see mental capacity assessment section page 30). None of the completed focused reviews had Mental Capacity Act sections applied on them.

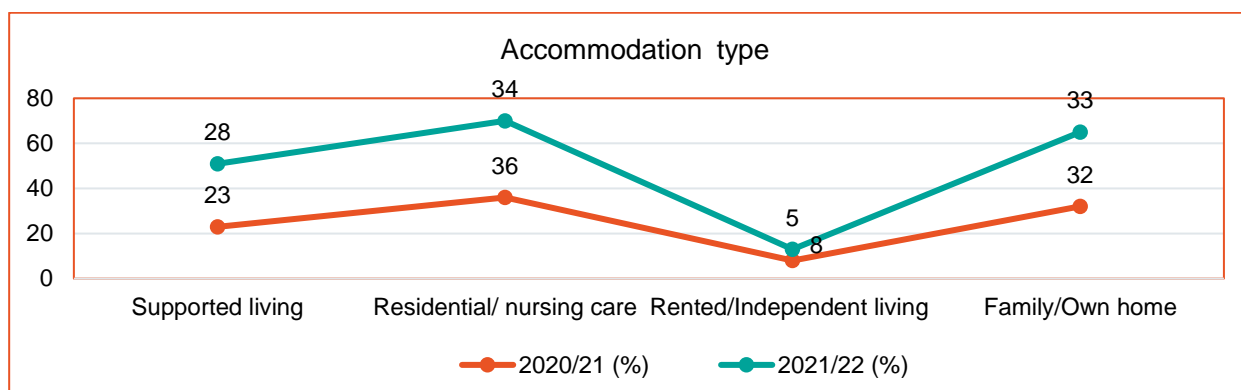
All nineteen individuals had formal carers or family paid via direct payments. Fourteen were local authority funded and three were health care funded via continuing health care.

In two reviews the persons were not know to local authority and no care package was in place. Findings from one of these reviews indicated that there were significant failings. According to the reviewer, the individual’s quality of health and wellbeing was graded as poor. This review has been referred for a safeguarding adults review consideration.

Overall, there were no major concerns noted about social care provision, however there were some issues identified around delayed home adaptations, examples of poor communication between agencies when handing over care; high care staff turnover and delayed social care reviews particularly during the Covid-19 pandemic.

Accommodation arrangements

All children lived with their families. Evidence showed that there were more people with a learning disability living in both their own homes and supported living than in both residential and nursing care homes.



Few people with learning disability lived in rented or independent accommodation and were all recorded to have had a mild learning disability.

Out of borough placements

All adults had accommodation placements arranged- 91% (43) were placed within their own borough and 8% (4) were out of borough placements. Two were placed by Barnet council and Essex while the other two were within north east London locality (these were Newham residents placed in Barking & Dagenham and Redbridge boroughs)

J) Reasonable adjustments

People with learning disabilities and autistic people have the same rights as the rest of the population to live purposeful lives as active members of families and communities. Reasonable adjustments should be routinely made for patients with learning disability and autistic patients as part of core service delivery.

NEL ICS has made a commitment to working with primary care, community and hospital providers to ensure that reasonable adjustments for people with learning disability is properly understood as a holistic approach and that there is an agreed minimum standard of knowledge and awareness of the needs of people with learning disability and autistic people across all staff. Mandatory learning disability training is now being offered to all staff working with learning disability people, with the Oliver McGowan training expected to be introduced later this year.

Provision of reasonable adjustments ensures that people have full access to services and this will help increase uptake of reviews and screening programmes. Learning from Covid-19, use of technology, blended virtual and face to face consultations has ensured continuity of care during very difficult circumstances.

Analysis of completed reviews indicated that reasonable adjustments were provided as required. The type of equipment or assistive technology and support varied from person to person based on needs assessment.

In all of the focused reviews there was evidence of provision of individual care equipment, adjustments to the environment and bespoke reasonable adjustments. There was evidence of provision of accessible information suited to individual needs (format or specific contact method and communications support via carers) and in one review information provided required communications via professionals (interpretation and translation services).

There was no data from all initial reviews to indicate if the individuals had reasonable adjustments provided or not.

Summary findings from Child death reviews

CDOP reports revealed that all ten children who died lived with their families and relied mainly on their parents for care. They were known to have life limiting conditions and complex health needs- developmental delays, neuro degenerative conditions and developmental regression requiring high level of care and for some, their needs were getting more complex as they grew older.

Due to the complexity of their need, they were all known to Great Ormond Street Hospital. There was evidence that a number of specialist teams were involved with the child and they were accessing the necessary care. They were well known to the community paediatricians, their GPs, community development centres and the relevant community teams. They had their childhood immunisations completed.

40% (4) of them were fed via the PEG (PEG stands for percutaneous endoscopic gastrostomy) or nasogastric tube (NG tube) and their families had been completely trained and supported to manage this safely at home.

80% (8) had DNACPR and palliative care package in place. In one review the family declined to sign DNACPR. The family was noted to have been carrying an emergency defibrillator with her all the time. There is evidence that all the families/ carers were fully informed and involved in these key decisions and were offered appropriate counselling services and support. The application of DNACPR guidelines were followed and its implementation was appropriate.

Most CDOP reports indicate regular joint health and social care assessments designed to meet the person's aims and objectives and ensuring extra support was put in place to avoid unnecessary pressure on families. Feedback obtained from care plans show good quality care plans and all had appropriate referrals to transfer to SEND (Disabled Children's Service) for assessments and packages of care agreed.

Records show all these children had limited use of their limbs and provision of bespoke reasonable adjustments was evident (such as adapted prams/ buggies/ wheelchairs, home adaptation) suited to their needs.

There were no safeguarding concerns reported regarding families' capacity or ability to meet the needs of their children, except in one review whereby a sibling reported 'abuse'; investigation into this allegation found no evidence to support it and the case was closed.

Overall grading of care provided to these children was recorded as excellent or good. They were all known to have been well kept and supported to attend health appointments and reviews.

i. Housing

There was evidence of long waits for social care housing, particularly for families who had not been in the country for more than five years and whose migration status was not indicative of long stay. In one review, the child stayed in hospital for over a year. At some stage this child was clinically well and ready for discharge but this was not possible due to a lack of suitable housing for the local teams to put in adaptations for this child to go home. This child died in hospital due to infection. In a second case, the family could not be added on the housing waiting list due to their immigration status, they lived with relatives.

ii. Consanguinity

Consanguinity refers to relationships between blood relatives. Consanguinity increases the risk of congenital anomalies and autosomal recessive diseases; the closer the relationship, the higher the risk. LeDeR findings indicate that two of the child deaths were known to have had multiple chromosomal-genetic or congenital anomalies linked to consanguinity. The parents were blood relatives and were referred for genetic counselling.

According to CDOP review process, consanguinity is classed as a modifiable factor in some cases. Recommendations were made around Newham, Waltham Forest and Redbridge health and social care teams to undertake some work to understand societal impact and working with already existing teams to do some work on consanguinity awareness.

iii. Covid 19 pandemic

Care provision in children, as was the case for adults, was disrupted during the pandemic. Due to lockdown restrictions and social distancing guidelines, it was difficult for professionals to undertake their regular visits to families in a timely manner for reviews and supply of equipment and home adaptations. There was absence of timely planning which caused delays in decision-making and gaps in care provision.

Evidence shows that families were supported to use alternative ways of communication (video and telephone consultation) to ensure continuity of care and support. Although this shift in the delivery of care may have resulted in some delays, there is no record to indicate that this change contributed to any of the child's death.

iv. Transition

Five of the completed child death reviews were aged 14 and above. While most of the records showed commitment to the concept of 'integrated care planning' transition process there was little evidence that this was happening and this had a negative impact on the young person and their families as they move to adulthood and transfer to adult services. It is recommended that transition planning start as early as 14 years of age.

In two of the adult reviews completed, the individuals turned 18 without a transition plan in place; in one review the planning had started but the person died before this could be completed and put in place. This individual was on end of life care and had DNACPR in place and the family had not discussed these key decisions with the person.

Recorded conversations with professionals indicated that this individual was able to understand his health was deteriorating however efforts to get health and social care teams to openly discuss this with him were unsuccessful. The family had requested professionals not to inform the person of the bad news. The person died without having had her end of life wishes known.

Recommendations were made around:

- good planning and assessments to be carried out in a timely manner (from 14-17 years subject to complexity of needs) to ensure smooth transition,
- families to be supported to communicate difficult decisions such as end of life care and DNACPR decisions.
- Improved documentation during transition to ensure routine offer of advocacy during transition
- All individuals deemed to have capacity/ability to consent to be given opportunity to participate in key decisions and their final wishes recorded.
- improved communication/information sharing between all teams involved with the patient, close working relationship with families and carers, professionals to liaise with CLDT teams for support with this process,
- patient assessment records to be concise, accurate and to include all patient conditions and their management processes
- Strengthen links with carers' centers to ensure carers are receiving appropriate support and information to support them in their caring roles.
- joint agreements between families and professionals on what is best for their relatives, and the use of advocates to be promoted.

Grading of care

On completion of each focused review, the quality of care is graded based on information provided. Grading of care is based on six domains, numbered 1-6; six being excellent and one very poor care. Nineteen reviews were graded and the outcomes were as shown below:

Grade	Explanation of the grade	No.s & % (19) 2021/2022	No.s & % (92) 2020/21
1	Care fell far short of expected good practice and this contributed to the cause of death	0, 0%	1, less than 1%
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	1, 5%	2, 2%
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.	2, 11%	7, 7%
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's well-being)	7, 37%	30, 30%
5	This was good care (it met expected good practice)	8, 42%	57, 55%
6	This was excellent care (it exceeded expected good practice)	1, 5%	6, 6%

All initial reviews were not graded and it is most likely that the care was good or excellent, as there were no obvious areas of concern.

47% of completed focused reviews received good and excellent care, 47% received satisfactory care indicating care. It should be noted that in satisfactory reviews, the care is generally good with a few areas where improvements could be made.

In one review (5%), the care fell short of expected practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death. This review was referred for a safeguarding adult review consideration. Areas needing improvements have been identified and this has been captured on learning into action section. No review was recorded as having received poor care.

According to last year's annual report 61% of all completed reviews were graded as having received excellent and good care, 30% received satisfactory care while less than 3% received poor care.

Although, the percentage for good and excellent care has dropped this year, we acknowledge that the numbers completed last year were significantly higher than this year and the data related to a small set of focused reviews of BAME background, compared to last years.

Grading of care and level of disability

Level of severity	Grade 6	Grade 5	Grade 4	Grade 3	Grade 2	Grade 1
Mild	0	1	0	2	0	0
Moderate	0	3	1	0	1	0
Severe	0	3	3	1	1	0
Profound multiple	1	4	5	1	0	0

People who were known to have severe and profound learning disabilities were more likely to receive good and excellent care compared to those with mild and moderate learning disabilities. No review was graded as having received poor care (Grade 1) during this reporting period.

ICS Performance and matrix scoring against National targets

NHS England has set key performance indicators (KPIs) which will be used to measure ICSs performance. This is based on percentage of reviews allocated and completed within specified times detailed in the LeDeR policy.

ICS are expected to allocate reviews within three months of notification and complete them within the next three months. A review will be termed as ‘a breach’ if it is not completed within six months from notification date. This excludes reviews delayed due to other statutory investigations such as serious incidents, safeguarding reviews and/or coroners’ inquests

NHS NEL performance as at end of March 2022

Despite delays with the launch and ongoing IT issues with the new LeDeR platform, NEL has achieved 100% completion of all reviews notified within six months.

Performance analysis for adults’ reviews

Metric Description	Frequency of data collection	* Scoring Matrix		
		Red	Amber	Green
% notifications assigned within 3 months	Monthly	0%	Amber: 0%	100%
% of notifications completed within 6 months	Monthly	0%	Amber: 0%	100%

Performance analysis- Child death reviews

Metric Description	Frequency of data collection	* Scoring Matrix		
		Red	Amber	Green
% notifications assigned within 3 months	Monthly	0%	Amber: 0%	100%
% of notifications completed within 6 months	Monthly	11% (>12months)	Amber: 33% (>6months)	55%

There have been two breaches with the children’s death reviews. . These two reviews have been open for over twelve months (red) while three (amber) are over six months but less than 12 months since notification date. 55% have been completed.

According to the office of national statistics, there was an increase (6.9%) in the number of child deaths reported during the COVID-19 pandemic. This resulted in significant backlog of reviews as reported by child death review panels across England as well as North east London CDOP teams.

Lived experience- case studies

Good practices leading to good care

SP was a 56-year with Downs syndrome, Alzheimer's disease and epilepsy. In adulthood he moved from his family home into a care home. SP enjoyed spending time outdoors, playing football with staff, going for long walks and meeting new people at a local café and going out to for short drives

SP was later moved to a new supported living. Until when his dementia progressed, he had had an active life and enjoyed getting out for trips. His family comments were that his carers were fantastic. He had consistent care f provided, accompanied to appointments and engaged with specialists to create and share care plans.

When SP was admitted to hospital his care support staff continued to provide 24/7 personal care for his whole hospital stay. The family were able to be with him while he was in hospital.

There was evidence within the health care records received of good shared care planning between specialist services and his care staff. He had regular reviews with the SALT team and a plan was agreed with the Palliative Care Team before his death. Comments from a carer "I felt comforted and supported during what was a very difficult time, I could not ask for more."

EB was 46-year-old with Downs syndrome and other physical health needs; wheelchair bound and later became bed-bound. EB had significant disabilities towards the end of her life and unfortunately this greatly reduced her ability communicate and to engage in social activities.

According to records, ED carers were quick to identify her changing health needs and referred her to her GP when required. There was appropriate use of annual reviews and her best interests were clearly documented.

There was evidence of use of the Proactive Elderly Advance Care Plan (PEACE) was a particular example of good practice and there were weekly multi-disciplinary team (MDT) meetings led by her GP.

The records demonstrate that ED received a good level of service and received weekly GP reviews as part of the GP Practice's Multi-Disciplinary-Team Ward Round at the home.

EB reviews included an Annual Dementia Review, an Annual Health Check and medical Review and an Admission Avoidance and Dementia Annual Review. ED had a 'Proactive Elderly Advance Care Plan' (PEACE) in place. Appropriate referrals were made to District Nursing, the Community LD team and Speech and Language Therapy team. The Community LD team also produced a care plan to manage her dysphagia.

EB carers completed a hospital passport and also placed her on the LD Hospital Alert System to ensure here needs were identified and supported appropriately in case hospital admission was required.

The reviewer noted appropriate application of Mental Capacity Act (MCA) 2005 and Deprivation of Liberty Safeguards (DoLS) and Mental Capacity assessment were appropriately documented. All interventions were provided in Best Interests and in collaboration with the carers and next of kin.

FD was over 70 years-old known to have had mild learning disability and Asperger's syndrome. After his parents died, he was found isolated and self-neglected.

During his last few years he had a couple of hospital admissions to mental health facilities and lived in various supported accommodations facilities. FD could communicate and was independent with most aspects of his personal care with some prompting. He chose his own clothes and dressed independently with minimum assistance. He made his own breakfast and staff supported him to ensure healthy eating. He had history of refusing staff support. He had no sight or hearing problems.

Towards the end of his life he was admitted to hospital where he contracted Covid-19. He became bedbound and his condition deteriorated suddenly and he was placed on an end of life care pathway. His carers were allowed to be with FD at the hospital when he passed away.

Episode of poor care

DD was over 60 years old non-verbal and lived in a 24hrs residential care setting. DD was known to varied services psychology dementia, physiotherapy, gastroenterology team, and falls services; no annual health checks over the last 12 months; the last annual health check was completed in 2018 and no record of health action plans shared with the care home. Bespoke reasonable adjustments put in place as per care plan.

DD was known to Community Learning disability team. Blood tests were evident from GP records and results were recorded as unremarkable. No record indicating that DD took part in cancer screening, GP record state 'refused cervical test.'

Last seen by Physiotherapist in December 2018, risk assessment completed and risk plan put in place and no record of review by the physiotherapist. No mental health issues however he had had an assessment with the dementia team in 2019 no follow up evident in records.

DD was seen at the emergency department in 2020, presented with unusual behaviours, looking distressed, suffered unexplained seizure and no history of epilepsy. Head scan was suggested but, this did not happen. Blood tests done, results unremarkable. DD was discharged with a message to return should symptoms persist and a letter to GP to monitor and refer to neurologist. However, records show that DD could not be reached by the consultant neurologist for an appointment due to a wrong phone number on the referral letter.

A few months later, DD was discharged back to his GP with advice to prescribe medication which could also be used as a mood stabiliser. According to the consultant, behavioural changes could have been due to learning disability and Down Syndrome.

During DD's last few months, Carers reported behavioural changes, not eating and sleeping well. DD returned to A&E in August 2021 by ambulance, unaccompanied, complaint- fitting; admitted and a scan revealed a brain tumour which was inoperable. DD passed away a week after admission.

Learning into Action

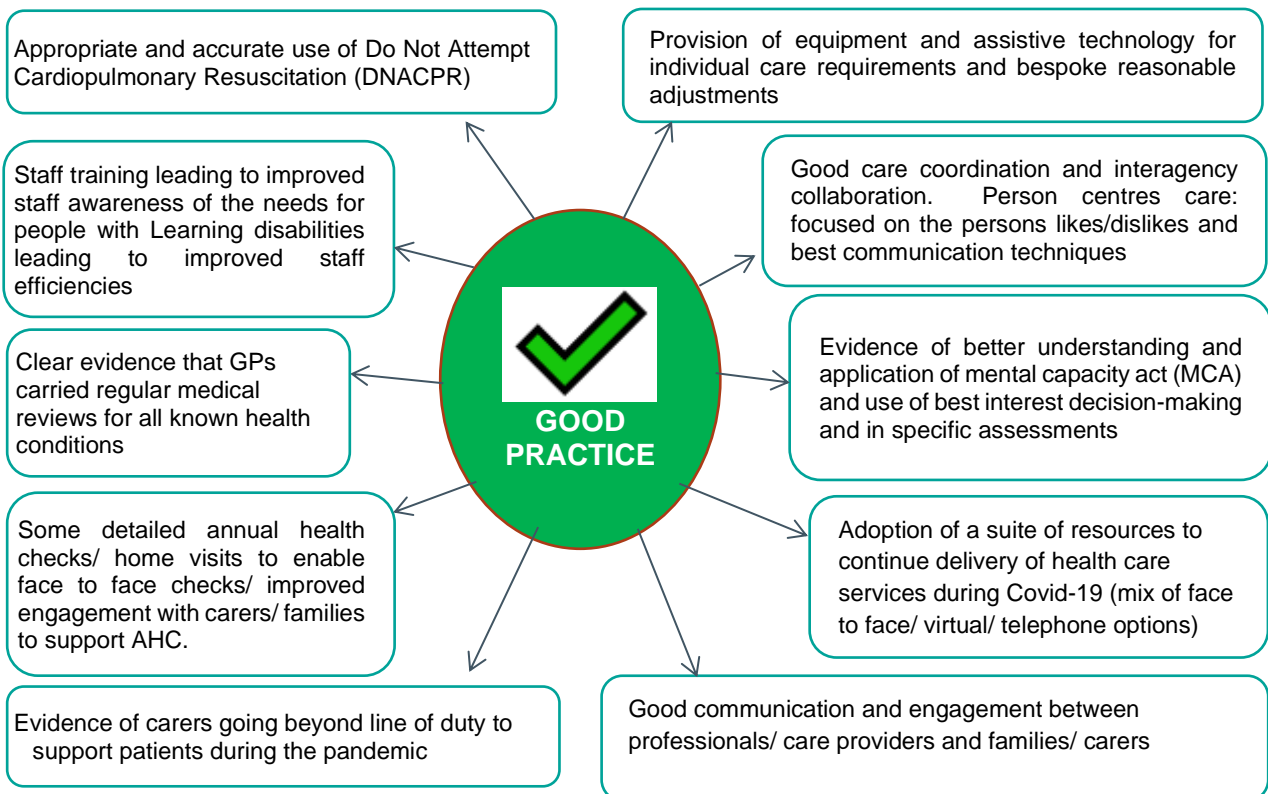
Work has begun on identifying trends and recommendations from completed reviews. Local working groups have been established at local levels and with our care providers to discuss completed reviews, share good practices and agree how learning can be actioned and used to improve care for people with learning disabilities and autistic people.

Of the 47 adult reviews completed, 60% (28) were initial reviews and they did not explicitly identify any learning. Most of the learning and recommendations in this report were gathered from 19 focused reviews completed majority of whom were of BAME background.

Summary of good practice

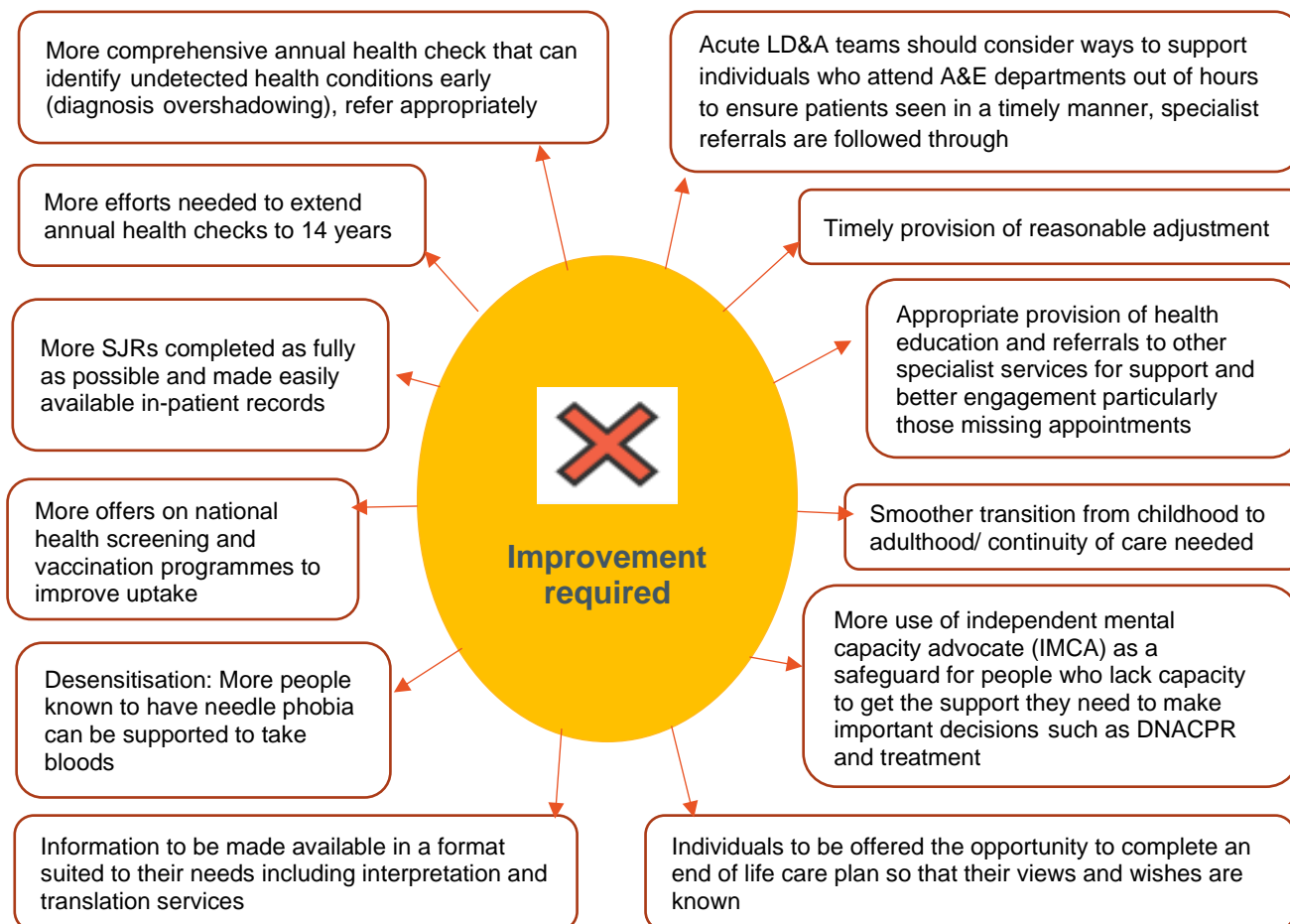
There were evidence of good practice providing services and teams an opportunity for learning from positive experiences captured from completed reviews.

Some of the good practice recorded were:



Areas requiring improvements

A range of recommendations were made in relation to annual health checks and improved awareness of the needs for people with learning disabilities and autistic adults. These will be taken forward as part of wider improvement work across the ICS and progress will be reported in future reports.



From the above areas needing improvement, a number of areas have been identified and these have been developed into key priorities that the LeDeR programme will be focusing on over the coming year. These priorities have been incorporated into the three years LeDeR Strategy 2022-25 and NEL Learning Disability and Autism Delivery Plan 2021-23.

These are:

Priority 1: maintaining performance for reviews and demonstrating the embedding of learning in response to the new LeDeR policy

Outcomes:

- maintain focus on LeDeR reviewing priorities during this time of changing landscapes as we transition from NEL Clinical Commissioning Group into Integrated Care System (ICS).
- explore the opportunities across the ICS/ICP for developing the future operating model in light of the new national LeDeR policy requirements
- establish the LeDeR team as part of the ICS

- ensure training of new reviewers and administrative roles on the new LeDeR system
- embed learning into provider business practice through regular sharing of findings and recommendations with the members of the wider NEL stakeholder, partners and care providers.
- strengthen local ICS LeDeR forums to support local learning from completed reviews
- support NEL LeDeR Governance panel which is now charged with the responsibility to oversee the delivery of the LeDeR Programme across NEL locality
- collate data sets which will help understand the local population and their needs and
- establish any underreporting of deaths in the locality

Priority 2: Quality Annual Health Checks and Health Action Plans

Aim: ensuring that these checks identify undetected health conditions, ensure early interventions and appropriateness of ongoing treatments.

Outcomes

- ensure annual health checks are delivered in a consistent manner across NEL using same toolkit/ template
- increase the numbers of annual health checks, starting 14years old
- ensure GP registers of persons with a learning disability are kept accurate and up to date
- increase the number of health action plans completed or created and shared with all those involved with the care of the person.
- annual health checks to include health living and mental health conversations
- follow ups on DNAs and where appropriate sign post/ refer individual to other specialist services such as learning disability services for support and better engagement (aimed to reduced DNAs)
- improve cancer screening offers, this can be done during annual health checks

Priority 3: Mental capacity Act (MCA)

Key aim: to ensure effective understanding and interpretation of the MCA and its application for people with learning disability and autism in key decision-making processes such as DNACPR, care and treatment. Individuals deemed to lack capacity, decisions should be made in their best interest decision making.

Outcome:

- ensure legal compliance and improving informed decision making and application of best interest- ensure that the Mental Capacity Act (MCA) is followed when decisions are being made for those who lack capacity
- all individual known to have a learning disability to have regular MCA assessments to identify unmet needs and new areas of support
- More use of independent mental capacity advocates (IMCA) to support patients with key making decisions (such as DNACPR, treatment procedures, finances and personal care), in line with the Mental Capacity Act

Priority 4: Provision of reasonable adjustments

Key aim: to ensure equity in accessing health and social care services hence improved health outcomes and reduced health inequalities.

Outcomes

- improved (shorter) waiting times and provision of individualised reasonable adjustment for learning disability people when accessing both primary and secondary care (less waiting times) to ensure comfort and encourage engagement
- professionals to demonstrate more provision of health information in appropriate format suited to the person's needs; improved communication to ensure fair access to routine health appointments and screening programmes
- improved accurate recording of health needs to enable consistent, appropriate and patient centred approaches for people unable to express their needs such as more use of hospital passports and coordinate my care plans
- improved ways of supporting individuals who attend emergency departments out of hours and/or follow-up these individuals to ensure their need are met when they attended hospital
- regular social care assessments to ensure any changes in care needs are captured and action taken in a timely manner
- provision of support to ensure patients do not miss their and screening programmes
- improved information sharing across professionals about people with learning disability and autism.

Priority 5: Transition from children to adult services

Aim: is to ensure smooth and timely transfer of young people from children services to adult services in a timely manner.

Outcomes

- improved planning and assessments carried out in a timely manner (subject to complexity of needs) to ensure smooth transfer to adult services
- improved communication/information sharing between all teams involved with the patient, close working relationship with families and carers; professionals to liaise with CDLT teams for support as needed
- more persons with learning disabilities participating in key decisions about their care and treatment
- provision of appropriate information to carers to ensure they are receiving the support they need to carry out their caring roles.

Conclusion

Within and across the NEL Integrated Care System, the LeDeR programme continues to have a substantial role as a lever and catalyst for change and improvement for people with learning disabilities and autistic people.

Since the last NEL LeDeR report, we have seen improvements in the delivery of quality care; we have noted evidence of some high-quality annual health checks, provision of bespoke reasonable adjustments, application of DNACPR guidelines and processes and more equitable access to Covid-19 vaccination, just to mention a few areas.

The LeDeR Programme Team has participated in a number of local initiatives aimed to improve health and social care provision such as:

- annual health check webinars
- positive support behaviour (PBS) trainings for carers and professionals
- obesity management project and provision of appropriate weighing equipment
- webinar to create awareness of LeDeR programme being extended to autistic adults
- pharmacy STOMP project aimed to review patients on psychotropic medicines and support stopping and/or reduce overmedication
- training of care staff on recognising deterioration and acting in a timely manner
- service user engagement events to gather service user views about our annual reports and action plans

More robust links have been achieved with primary care, acute settings and community services in acknowledging and working to address inequalities for people with learning disabilities, and the importance of LeDeR in better understanding the health care needs of people with learning disabilities has been evident.

The NHS Long Term Plan, published during 2019, and the NHS Oversight Framework for 2019/2020, provided a welcome spotlight on reducing the health inequalities experienced by people with a learning disability and autistic people.

NHS North East London is a key partner and system leader and during 2022/23 we will continue to support partnership working to deliver the LeDeR programme. We will continue involving our partners, learning disability people, autistic adults, their families and carers. We will seek better ways working, listening more and coproduce learning from the LeDeR programme and from service user experiences to keep on improving and make changes for learning disability people and autistic adults.

The three-year LeDeR strategy 2022-25 and NEL Learning Disability and Autism Delivery Plan 2021-23 will become the critical mechanism by which the Integrated Care System will hold care providers and localities to account for progress in helping to reduce premature mortality.

We look forward to another successful year of improving outcomes so that learning disability and autistic people can live longer, happier and healthier lives.

Appendix 1: Proposed Action Plan

Priority Areas/ Objectives	Rationale	Actions	Outcomes	Evidence of improvement	Action led by
LeDeR performance and implementation of the LeDeR policy new LeDeR policy	To ensure continuity for LeDeR reviewing and embedding of learning in response to completed reviews	Continuity of LeDeR Reviewing process	<ul style="list-style-type: none"> Maintain focus on LeDeR reviewing priorities during this time of transition from NEL Clinical Commissioning Group into Integrated Care System (ICS). 	Ensure capacity/ resources to undertake reviews	ICS
		Recruitment of LeDeR Programme Team	<ul style="list-style-type: none"> Establish LeDeR team in accordance with the new LeDeR policy. Ensure training of new reviewers and administrative roles on the new LeDeR system 	Ongoing	LeDeR Programme Team
		Engagement with key partners and create awareness of the LeDeR programme (LeDeR Promotion with all health and care Agencies)	<ul style="list-style-type: none"> Explore the opportunities across the ICS/ICP for developing the future operating model in light of the new national LeDeR policy requirements Supporting ICS/ICB in building relationships with key partners/ICPs More awareness of the LeDeR programme and reporting a death of PWLDA (e.g. webinars, annual events/ seminar on LeDeR) 	Ongoing	ICS/ NEL LDA & LeDeR programme Team
		Continue data collections as part of LeDeR reviewing process	<ul style="list-style-type: none"> Collate data sets which will help understand reporting status of the LDA deaths across the locality (establish if underreporting of deaths in the locality) 	Ongoing	LeDeR programme Team
		Provide support to the NHS NEL LeDeR Governance panel	<ul style="list-style-type: none"> Ensure robust Governance Panel is in place to oversee the delivery of the LeDeR Programme across NEL locality Ensure the NEL Gov. panel is representative of the local population 	Regular panel minutes Ongoing	ICS/LeDeR programme Team

		Regular Feedback sessions with care providers, carers, service users to share learning from completed reviews (through meetings/forums/ webinars)	<ul style="list-style-type: none"> Embed learning into provider business practice through regular sharing of findings and recommendations with the members of the wider NEL stakeholder, partners and care providers. 	Regular feedback sessions/meetings	LeDeR programme team
		Strengthen local LeDeR forums/groups to include all key stakeholders and partners	Ensure local learning LeDeR forums (at borough level, CCG forums, ELFT and NELFT LeDeR forums) are representative of local services and support them to embed local learning from completed reviews	Regular meeting/membership	LeDeR programme team/ NEL Governance Panel
Annual Health Checks and health action plans	Ensuring high quality AHC that can detect health conditions early and ensure appropriate interventions	CCG LD commissioners to review direct enhanced service (DES) to establish agreed validation process and strengthen agreed quality assurance measures.	Ensure improved uptake of AHC starting 14 years of age	Evidence of 14-17 years having AHC	GPs/ Commissioners
		<p>Specific actions:</p> <ul style="list-style-type: none"> Commissioners to strengthen use of existing best practice Annual Health Check toolkits (Cardiff model) to ensure consistency in AHC and HAPs across NEL area. Cardiff model is the recommended template by NHSE Local commissioning teams to consider recruitment of LDA Teams (<i>this is working well in Newham</i>) to work with GPs and community services with view to strengthen quality of AHCs and ensure necessary support is provided as required to improve uptake. 	<p>Adopting the recommended annual health checks toolkit will ensure:</p> <ul style="list-style-type: none"> quality annual health checks are delivered in a consistent manner across NEL Increase the number of health action plans (HAP) completed or created and shared with all those involved with the care of the person. Annual health checks to include health living, mental health conversations and promote cancer screening programmes Ensure GP registers of persons with a learning disability are kept accurate and up to date. This would help improve the data and ensure people with learning difficulties are not coded as learning disabilities. GPs offer face to face appointments to ensure improved quality of annual health checks (AHCs) Improved GPs referrals and sign posting to other services especially those that may not meet the LD team's eligibility criteria GP register cleansing 	Comprehensive annual health checks/ early diagnosis and referrals for treatment	

	<ul style="list-style-type: none"> - Care coordination for complex cases (severe and profound LD cohort) <p>Suggestion: LDA nurses will play a key role in improving awareness of the needs of PWLDA; Equality act and provision of reasonable adjustments; improved awareness on the health appointments and screening programmes. <i>This is working well in Newham.</i></p>	<ul style="list-style-type: none"> - Improved care coordination for complex cases/more MDTs 		
	<p>GP training to improve awareness of the needs of PWLDA, provision of reasonable adjustments and MCA (<i>Newham has commissioned similar training</i>)</p> <p>Liaise with safeguarding GPs to incorporate LeDeR updates within their regular GP training.</p>	<ul style="list-style-type: none"> - improved awareness about the needs of people with LDA - Appropriate use and application of MCA - Improved understanding and provision of individualised reasonable adjustments - Increase AHC numbers/ uptake - More referrals to CLDT teams and other services - Accurate coding of Disability & Autism patients on clinical notes 	Evidence of less learning difficulty service users coded as learning disability users	GPs/ Commissioners
	<p>Commissioners to ensure audit on time allocations for people with LD&A (double or appropriate appointments)</p>	<ul style="list-style-type: none"> - Evidence of double appointments; appropriate appointment times and timeslots; suited to individual situation (longer slots for people with complex health needs/ behaviours that are challenging) - less waiting times provided to PWLDA for comfort and to encourage engagement - Ensure quiet / LDA friendly spaces in clinics/ waiting areas where long waits are unavoidable or protected LDA time slots 	Longer consultation times for PWLDA on GP records/ positive service user experience feedback	GPs/ Commissioners

		GPs/ health care professionals to follow up on missed appointments	Fewer DNAs/ missed health appointments and where appropriate sign post/ refer individuals to other specialist services such as learning disability services for support and better engagement (aimed to reduced DNAs).	Fewer DNAs	GPs/ Commissioners/ /Safeguarding GPs
		Regular audits of cancer screening programmes by GPs, Cancer Screening Programme Teams to establish what the barriers are and come up with ways to mitigate these barriers For example, request annual figures from health analytics for the last 5 years to use pre covid as a baseline. This will also show the impact of covid.	<ul style="list-style-type: none"> - Improved cancer screening offers during annual health checks and more support provided to ensure patients do not miss their and screening programmes - Evidence of more conversations between GPs and service users/ carers around what reasonable adjustments are best suited to support access & engagement - Evidence of positive service user/ carers experience /feedback from patient surveys 	Increased screening numbers for PWLDA	GPs/ Commissioners/ Safeguarding GPs
Mental Capacity Act (MCA)	To ensure effective understanding and interpretation of the MCA and its application for people with learning disability and autism in	Mental Capacity Act (MCA) training: Targeted awareness of professionals' knowledge of application and use of MCA, IMCA and BIA	<ul style="list-style-type: none"> - Improved awareness of the needs of PWLDA - Professionals to demonstrate competency in understanding and application of MCA; ensure MCA is effectively implemented and best interest decisions are being made for those who lack capacity - Ensure PWLDA being supported to specify preferred and/or required care and treatment. - Ensure individual known to decline care and treatment to have MCA assessment to identify level of capacity and areas where support may be required 	Informed decision making and application of best interest	All health and social care professionals



	key decision-making processes	Health and social care team professionals to refer individuals to IMCA as may be indicated	Evidence of use of independent mental capacity advocates (IMCA) to support patients with key making decisions (such as DNACPR, treatment procedures, finances and personal care), in line with the Mental Capacity Act	Family feedback/ patient surveys	All health and social care Professionals involved
Provision of reasonable adjustments	To ensure equity in accessing health and social care services. Ensure legal compliance with Equality Act 2010	Education/ training (targeted): Health and social care professionals training to improve awareness of the needs of PWLDA, provision of reasonable adjustments and MCA (<i>Newham has commissioned GP training on MCA</i>)	<ul style="list-style-type: none"> - improved awareness of the needs of PWLDA - evidence of individualised provision of reasonable adjustments suited to individual situation - less waiting times during health appointments - ensure quiet / LDA friendly spaces in clinics/ waiting areas where long waits are unavoidable or protected LDA time slots 		All health and social care Professionals involved with patient
			Improved monitoring of waiting times for learning disability and autism people when accessing services such as emergency departments/ out of hours and/or outpatient follow-up appointments. Provision of quiet spaces/ LDA friendly environment where long waiting times are unavoidable	Family feedback/patient surveys	Acute LD Team
	GPs/ CLDT Teams: Promote use of electronic CMC plans/ Urgent Care plans (UCP) being implemented for PWLDA Audit of number of people with a hospital passport/ urgent care passport and if they are using them <i>*Paper hospital passport are not easily updated/ amended and easily forgotten at home in case of hospital and emergency visits.</i>	Improved accurate recording of health needs to enable consistent, appropriate and patient centred approaches for those that are non-verbal and/or unable to express their needs such as more use of hospital passports and coordinate my care plans. Improved information sharing across professionals about people with learning disability and autism-Examples of more urgent care plans/ health passports that are updated regularly to reflect individual circumstances but also accessible to wider teams		GPs/ CLDT Teams	



		<p>Regular Health and social care reviews to identify any changing needs.</p> <p>Close working relationships (integrated care settings) between health and social care teams to understand the challenges/ hindrances to provision of reasonable adjustments and working together to provide a solution</p>	<ul style="list-style-type: none"> - Evidence of consistency in carrying out social care assessments to ensure any changes in individuals' circumstances are captured and care plans are reflective of individual needs. - Evidence of regular review on mobility and assisted technology equipment to ensure they are fit for purpose. - Improved provision of appropriate reasonable adjustments and/or improved communication to ensure fair access to routine health appointments and screening programmes 	Service user/carers feedback/ surveys	GPs/ Commissioners/ health and social care teams
		<p>Audit of accessible information- provision of information in varied formats suited to individual needs</p>	<ul style="list-style-type: none"> - Evidence of improved access to information in a format suited to individual needs. - More use of easy read, audio formats, interpretation and translation services to those who need these services, - Positive patient/ carer feedback; about the care they receive: less number and reoccurrence of SIs/ complaints patient surveys 	Family feedback/ patient surveys	GPs/ All health and social care Professionals involved
			<ul style="list-style-type: none"> - Improved awareness/ health education on the importance of preventive health programmes - improved service users/ carers participation in their care and treatment - improved uptake on annual health checks and screening programmes as a result of provision of appropriate information 	Family feedback/ patient surveys/ improved uptake of health programmes	GPs/ All care professional involved



Transition from Children to adult services	To ensure seamless transfer of young people from children services to adult services in a timely manner.	Professionals to review transition pathways and strengthen guidelines on planning and assessments for children transitioning to adult services esp. those with complex health needs.	<ul style="list-style-type: none"> – improved planning and assessments carried out in a timely manner (subject to complexity of needs) to ensure smooth transfer to adult services – improved communication and information sharing between all teams involved with the patient, close working relationship with families and carers and care provider; more liaison with CDLT teams for support as needed 		GPs/ Children's commissioner / Social care Teams
		Provision of information to carers/ regular carers reviews	Improved carers' reviews and provision of appropriate information to carers to ensure they are well informed and are receiving the support they need to carry out their caring roles		Social care Teams/ Children's commissioner
		Applications of MCA: Consent and Best Interest	Evidence of young people participating in key decision about their care and treatment if individuals are deemed to have capacity to participate; more use of IMCAS for those deemed to lack capacity, as may be indicated.		All professional

References

Annual Health Checks: <https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

Annual Flu Programme- <https://www.gov.uk/government/collections/annual-flu-programme>

End of Life Care: <https://www.nhs.uk/conditions/end-of-life-care/>

Equality Act 2010: <https://www.legislation.gov.uk/ukpga/2010/15/contents>

Equality Act and Reasonable adjustments:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/138118/Equality_Act_2010_-_Duty_on_employers_to_make_reasonable_adjustments_for....pdf

Mencap: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>.

NHS Cancer Screening Programmes: <https://www.nhs.uk/conditions/breast-screening-mammogram>

NHS Breast Cancer Screening: <https://www.nhs.uk/conditions/breast-screening-mammogram>)

Mental Capacity Act and Mental Capacity Assessments: <https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/>

More information about Covid-19 vaccination Programme:

<https://www.gov.uk/government/collections/covid-19-vaccination-programme>

NHS guidance on DNACPR: <https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>; NICE Guidelines <https://www.nice.org.uk/sharedlearning/talk-cpr-project-talkcpr>

Public Sector Equality Duty: <https://www.wvl.nhs.uk/public-sector-equality-duty>

NHS LeDeR Programme: <https://leder.nhs.uk/>

Transition from children to adults' services: <https://www.nice.org.uk/guidance/qs140>

Contact and information

For more information related to this report please email Beatrice Kivengea via Beatrice.kivengea@nhs.net

To find out more about the work of the LeDeR Programme team in north east London, please send an email addressed to: nelondonicb.lederprogramme@nhs.net