

**NHS North East London ICB**  
Learning from Lives and deaths of People  
with a Learning disability and Autistic adults  
**(LeDeR)**  
Annual Report 2023-24

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## Document Revision History

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## **Executive summary**

We know, people with learning disability and autism or both are more likely to experience poor health outcomes and die much younger from avoidable causes compared to their peers in the general population.

All people with a learning disability and autism including those with complex health needs, deserve meaningful and fulfilled lives including making life choices on where they live as well as the services they receive.

The LeDeR programme reviews the circumstances of deaths for everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a formal diagnosis of autism. The aim is to identify areas of learning and to suggest solutions that care providers can put in place to enable people with learning disabilities and autism access services they need to live better longer.

In June 2023, North East London Integrated Care System (ICS) approved a Joint Forward Plan.

This plan describes the challenges that NEL, as a system, face in meeting the health and care needs of our local people. Six areas were identified with a greater focus upstream on population health and tackling inequalities. These are:

- Tackling health inequalities
- Greater focus on prevention
- Holistic and personalised care
- Co-production with local people
- Creating a 'high trust environment' that supports integration and collaboration
- Operating as a learning system driven by research and innovation

NHS NEL LeDeR Programme is committed to working with NEL partners, care providers, families and service users in delivering the above. A NEL-wide LeDeR Governance Group has been established to oversee the delivery of LeDeR programme requirements and to hold care providers to account.

The LeDeR Governance group is attended by key persons in health and social care who can influence change and ensure findings from completed LeDeR reviews are shared, with the view that improvements will be made to support people with learning disabilities and autism to live good quality lives like any other person without a disability.

Listening to and working with people with a learning disability and autism and their families is important in making sure that services are tailored to meet their needs.

## **Challenges**

The main challenges this year were high numbers of reported adult deaths (similar to 2020, during the pandemic), and delayed recruitment due to NHS consultation process leading to reduced LeDeR workforce.

## Introduction

This is NHS NEL ICB's 5<sup>th</sup> Annual Report. It consists of two main parts: adults and children's sections. It provides an overview of the North East London (NEL) ICB LeDeR activities between April 2023 to March 2024.

NEL localities are Barking & Dagenham, City and Hackney, Havering, Newham, Redbridge, Tower Hamlets and Waltham Forest boroughs. NEL data use in this report includes persons placed in NEL boroughs from other localities, who are registered with a NEL ICB GP. This does not cover NEL residents placed outside of the NEL locality and registered with a GP outside NEL footprint.

In this report 'learning disability' will be used to refer to people known to have had a learning disability and or both a learning disability and autism. The age groups covered will be 4 years and over for those with a learning disability and adults (over 18 years) with a formal diagnosis of autism.

NEL continues to record sparse numbers of autism only adults. One notification was reported this year, but this had not been reviewed as at the time of authoring this report.

This year's performance was 92%, completion of reviews within 6 months of receipt of notification date. This means completed cases are not always aligned to the reporting period.

A backlog of 33 adults reviews were carried over from the previous financial year to this year. 91 new adults' notifications were received while 68 reviews were completed as at end of March 2024. 47 adults' notifications will be carried forward to 2024-25 financial year. This is the highest backlog of reviews to be carried forward since 2017.

A detailed analysis of 80 completed reviews (68 adults' and 12 child's deaths) will inform this report. It recognises the importance of prior data as a factor in influencing learning, hence this report will use percentages (as proportions of) for comparison linking this year's findings and those of previous years, drawing any key themes and trends, and key learning points.

This year's findings show that average age at death for women was 63 years while for men was 61 years of age. This is significantly lower than the average age of death in the general population which is 82 for men and 86 for women.

Key highlights of this year's report:

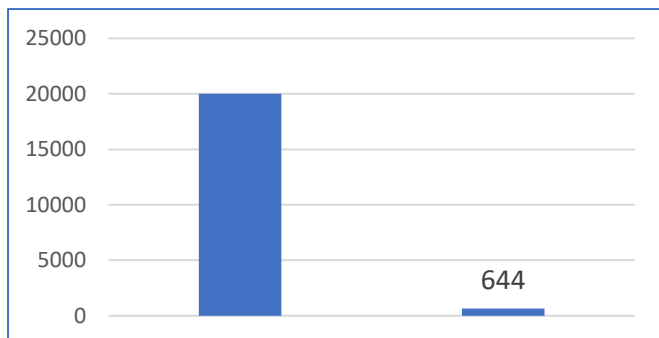
- Common causes of death were respiratory and heart disease related problems
- Improved proportion of people who are receiving good or excellent care
- Evidence of provision of bespoke reasonable adjustments making real difference in improving service users' experience
- More face-to-face annual health assessments
- Safeguarding referrals or alerts not investigated fully
- Continued low uptake of cancer screening programmes.

Actions and recommendations

- To maintain focus on LeDeR programme priorities and the delivery of its requirements
- To work with NEL partners, care providers, families and service users in co-production of what works well to improve quality of care for learning and autistic people across NEL footprint.

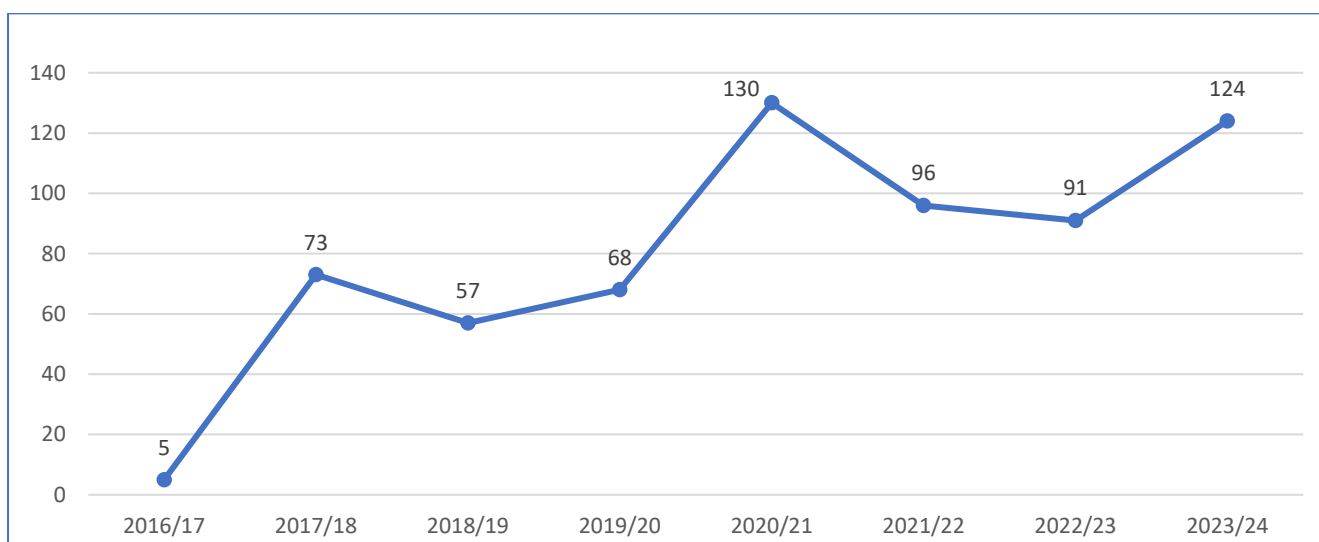
## NATIONAL AND LOCAL DATA

Over the last seven years, the LeDeR Programme has recorded a steady increase in the number of notifications reported via the LeDeR System.



Approximately 20,000 notifications have been reported nationally, 644 of these were North East London and under 3,000 were London notifications.

## NEL trajectory 2016-2024



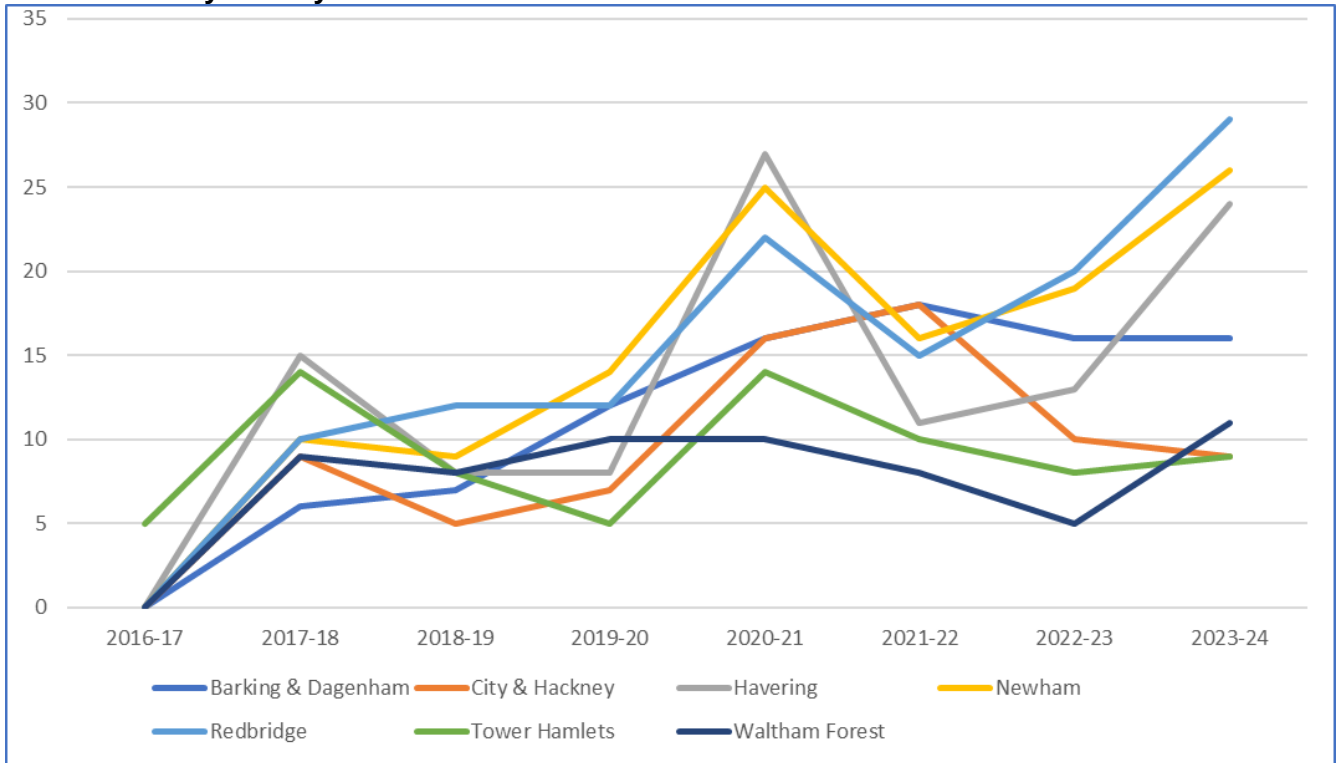
In 2023-24, NEL recorded almost the same number of deaths as seen during Covid-19 pandemic, 2020-21. Improved awareness of LeDeR programme amongst care providers may have played a role in this. More teams are now reporting LeDeR deaths compared to previous years.

While acute learning disability teams and community learning disability services continue to report most of the cases, approximate 26% of this year's notifications were reported by care managers, The London Ambulance Service as well as social care teams. Only one notification was reported by a GP.

Improved awareness is needed for GPs, all health and social care professionals and community voluntary groups to ensure they know how to report a death of a person who was known to have had a learning disability and autism or both. This will help to ensure the LeDeR programme does not miss notifications especially for those from minority ethnic backgrounds and those known to have autistic only diagnosis who may not be known to mainstream learning disability services.

Health and social care professionals, carers, families and friends, can notify a death of someone known to have had a learning disability or autism or both via this link: <https://leder.nhs.uk/report>

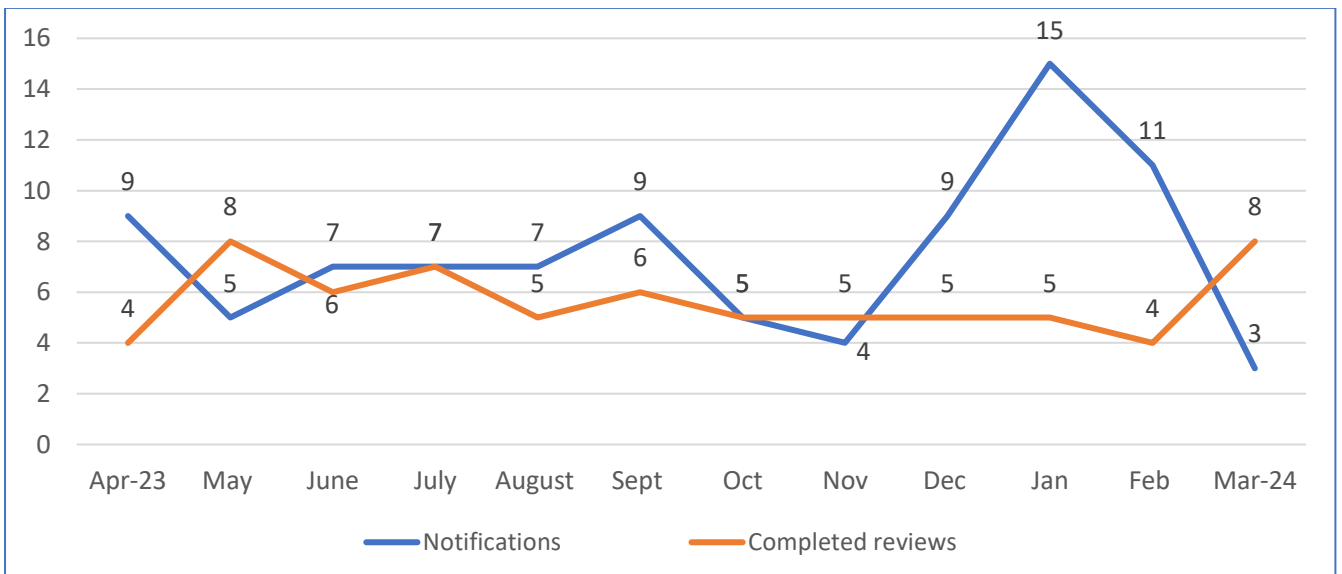
**NEL outlook by locality**



The above graph shows distribution of notifications by locality. It is evident that NEL has recorded a steady increase in the number of notifications since 2016.

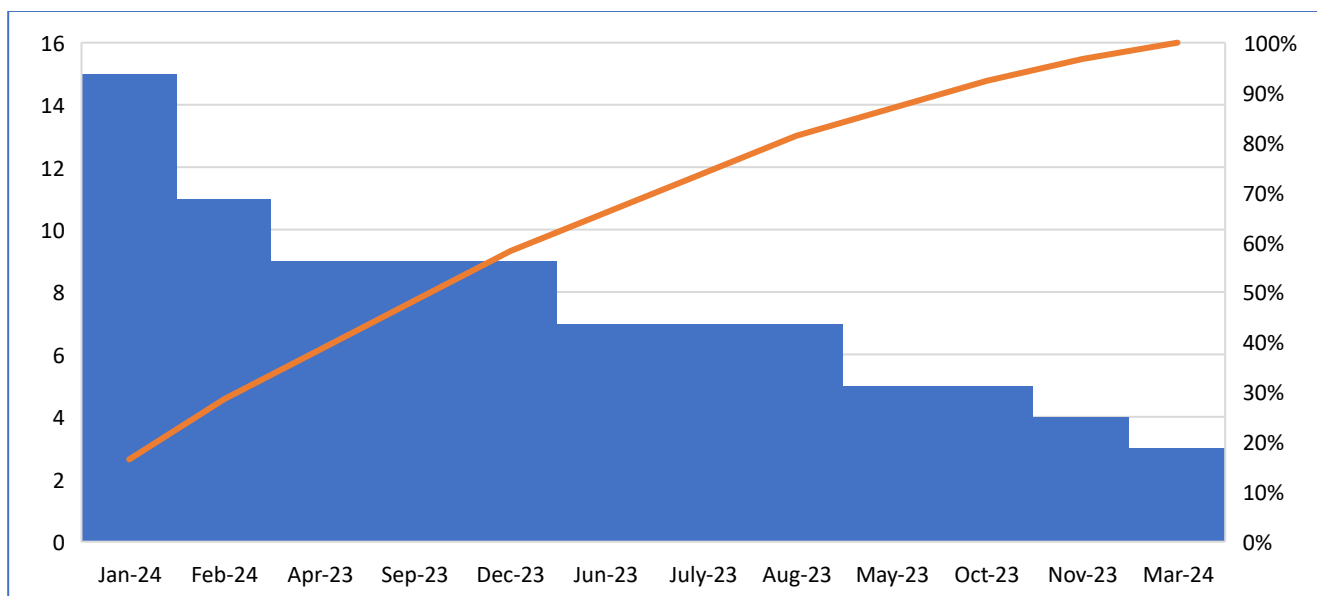
A drop in the numbers received was noted in City & Hackney during the last two years compared to three- four years between 2020 and 2022. Redbridge data show a steady increase over the years, this year being significantly higher compared to previous years. Barking & Dagenham numbers have remained relatively the same over the last four year.

**Progress report 2023-24- notifications received vs completed reviews**



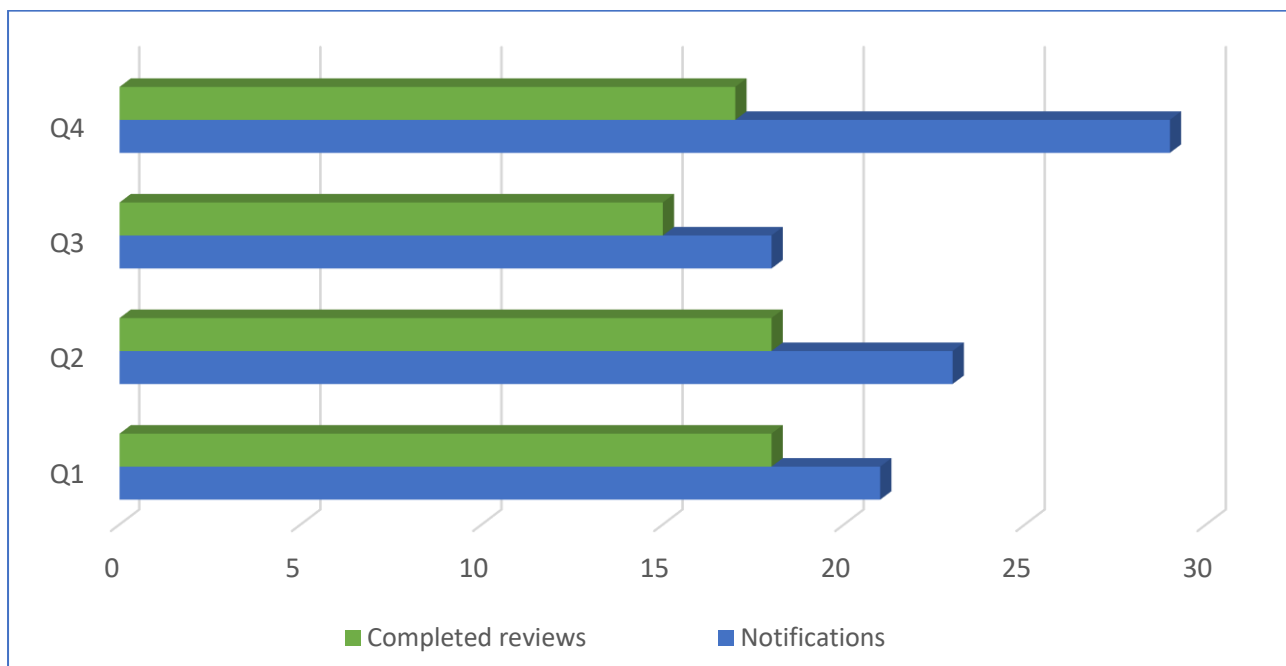
Completion of reviews has been stable through out the year with an average of 5 reviews completed every month; March 2024 recorded the highest number of completed reviews. The highest number of new notifications were recorded between December 2023 and February 2024.

The below graph shows distribution of data on descending order of the frequency with an accumulative line on a secondary axis as a percentage of the total notifications received



More notifications were received than completed with January 2024 recording the highest number of deaths, 15, while April 2023 and March 2024 were the lowest.

### Distribution by quarters

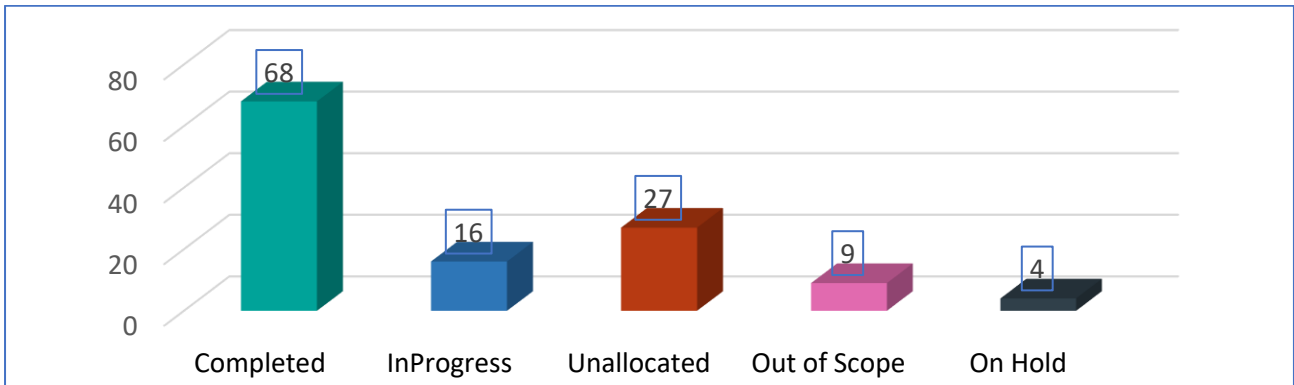


Quarter 4 recorded the highest number of notifications, 29 deaths, the highest since the pandemic, while quarter 3 had the least deaths.



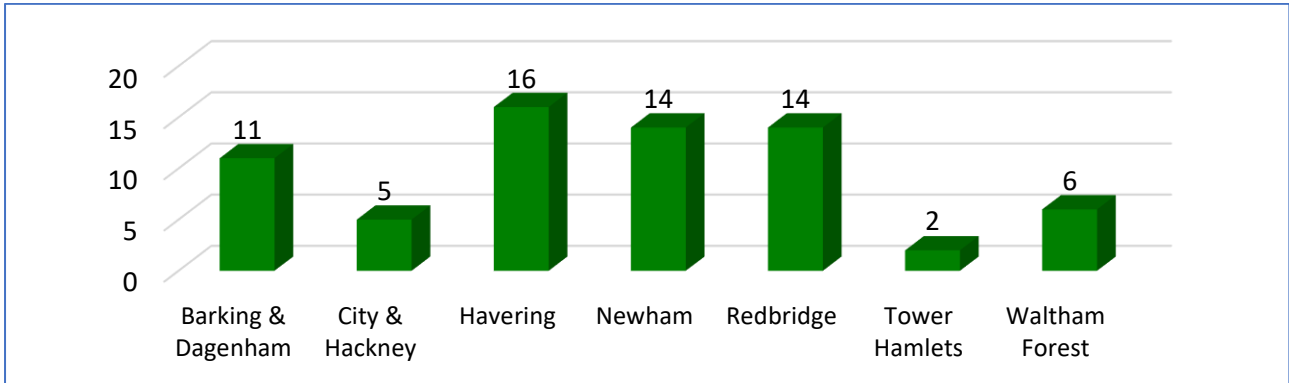
## NEL PERFORMANCE: COMPLETION STATUS

### Review status as at end of March 2024



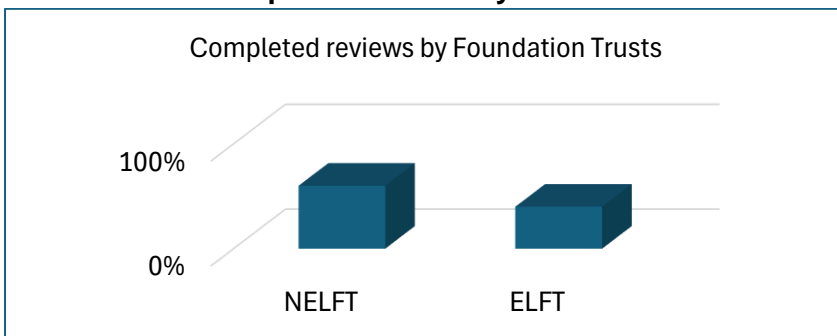
From the above figure, 68 adults’ reviews were completed, 12 in progress, 4 on hold and 18 were awaiting to be allocated.

### Breakdown of completed reviews by locality.



Allocation of reviews is done chronologically by date of notification. Havering completed the highest number of reviews, followed by Newham and Redbridge localities. Tower Hamlets had the least notifications.

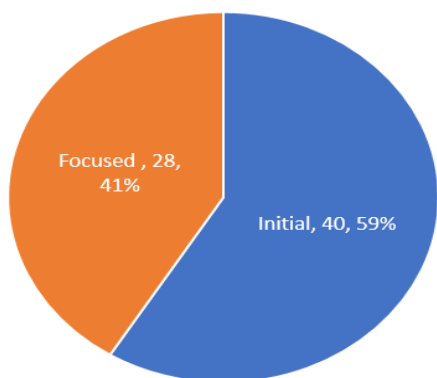
### Breakdown of completed reviews by Foundation Trust.



41 of the completed reviews belonged to NEFT locality while 27 were ELFT. Barking & Dagenham, Havering, and Redbridge (BHR) had majority of the completed reviews.

### Types of Reviews

Current LeDeR reviewing process consist of two types of reviews: Initial and focused. All reported reviews receive an initial review. Initial reviews determine which reviews would be progressed on to a full review if they are not already listed for a focused review.



- 59% were reviewed and closed as initial reviews.
- 41% (28) were progressed to focused reviews. 16 were assigned as focused, people of minority ethnic background and Jewish community.
- 12 initial reviews were progressed to focused due to gaps in care. None of the focused review was because of family request.
- \*NEL completed 2% more focused reviews this year compared to last year, up from 39%-41%.

People from minority ethnic background, Romany Gypsy, Irish traveller and Jewish communities were automatically allocated as focused, in accordance with the LeDeR policy criteria. In most of these reviews, the quality of care was graded as satisfactory 4 or good.

Twelve reviews were progressed onto a focused due to identified gaps in care provision. Most of these were graded as poor and satisfactory 3. All except two, where known to have had mild learning disabilities and or mental health problems.

## NEL PERFORMANCE RATING

As at the end of March 2024, NEL recorded **92%** overall completion of all reviews reported within six months of the receipt of the notification. 4 (8%) reviews which were not completed were on hold due to open statutory investigation, either a coroner's inquest or Serious Incident investigation (SI).

The forty-seven reviews carried forward to this financial year are due to be completed during the first half of this current financial year.

The next parts of this report will focus on the completed reviews and consists of two main parts:

- Section 1- this will concentrate on the analysis of the above 68 adults' reviews and
- Section 2- will focus on child's deaths, looking at the 12 closed LeDeR-CDOP reviews.

## SECTION ONE

### ANALYSIS OF COMPLETED REVIEWS - ADULTS ONLY

#### DEMOGRAPHICS

##### Age groups (adults)

Age groups	2021/22	2022/23	2023/24
19-25	10	8	2
26-35	8	4	3
26-45	2	3	6
46-55	7	6	15
56-65	7	9	11
66-75	8	11	15
76-85	11	15	12
over 86	2	4	4

The above evidence show increase on the numbers of people aged over 65 years old and reduction in the number of young people aged 19 to 45 years old. this is an indication that more people with a learning disability were living longer than was the case 3 years ago. The number of people aged over 86 remained the same as last year but higher than in 2022.

##### Civil partnership (adults aged 18 years and over)

Information collected shows a slight increase on the proportion of people recorded as having had civil partnerships. They were all known to have had mild learning disabilities.

	2021/22	2022/23	2023/24
Civil partnership/relationships	13%	6 (11%)	8 (12%)
Single	87%	45 (84%)	54 (79%)
Prefer not to say/ unknown	-	3 (5%)	6 (9%)

##### Ethnicity

According to Office of the National statistics 2022, more than half (53%) of NEL's population is of Black, Asian or Mixed ethnicity compared with 11% across England. All NEL boroughs except City and Hackney (combined) and Havering have predominately non-white populations. NEL's places (postcodes) vary greatly in their diversity.

Reviews completed showed that 76% of the person who died were white, while 24% were other ethnic minority backgrounds. This is different to last year's data which showed that 69% of people who died were white compared to this year's 76%.

Ethnicity	2022-23	2023-24
White	69%	76%
Black African/ Caribbean	8%	7%
Bangladeshi	6%	3%
Indian	6%	3%
Pakistani	3%	3%
Other Asian	5%	3%
Other ethnic groups & prefer not to say	Less than 5%	5%

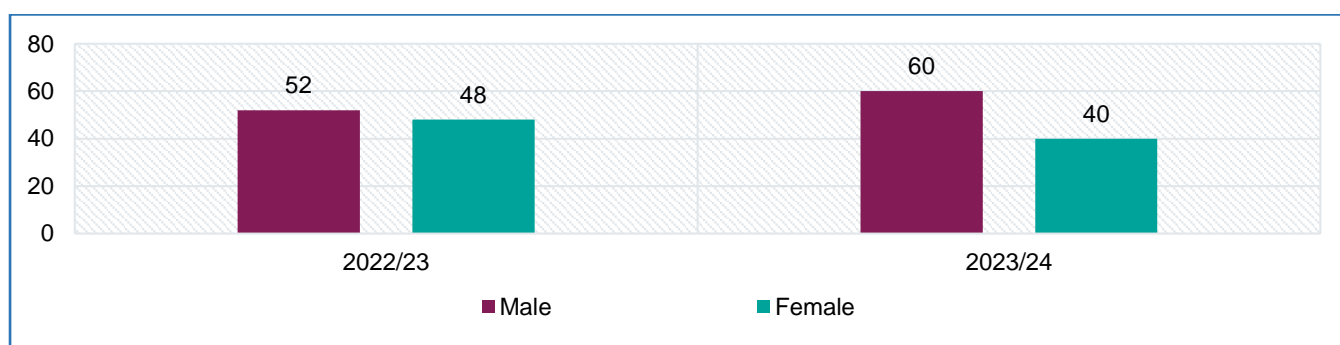
## Types of care funding

There are two common types of care funding that a person may be eligible for- Local Authority funding and NHS healthcare funding or a mix of the two. An assessment of an individual's health and social care needs is undertaken to determine the support that best meets their health and wellbeing needs in a holistic manner. A care plan is then developed detailing the person's needs, how it will be given as well as who should provide it.

73% of people reviewed received local authority funded care, 9% received NHS Continuing Healthcare (CHC), 15% had joint package between health and social care, while 3% were part self-funded and local authority funded.

## Gender

60% of the completed reviews were males and 40% females. The average age was 62, same as last year. The youngest of the adults being 19 and oldest 87 years old, with a median of 63 years.



## Living arrangements

Living arrangements as at the time of death	2022/23	2023/24
Family/ own home	29%	13%
Rented/ shared flats	32%	9%
Residential/ Nursing care homes	29%	66%
Supported Living	10%	10%
Hospice	29%	2%

The proportion of the people living in their own homes decreased from 29% to 13% and an increase in the proportion of people living in residential and nursing care settings, from 29% last year to 66%. There was evidence of improved awareness of LeDeR programme and reporting of deaths in residential care settings, approximate 26% of this year's notifications were reported by care managers. There was no information to indicate that the type of accommodation or where one lived contributed to the person's cause of death.

## Learning disability and autism

Information gathered indicate that 69% of all the people reviewed had a single diagnosis of a learning disability while 31% had both a learning disability and autism diagnosis. Those known to have mild learning disability and autism were more likely to have mental health problems than those known to have a learning disability only diagnosis.

Disability category	Numbers	Percentage
Learning disability	47	69%
Learning disability and autism (dual diagnosis)	21	31%
Autism (without a learning disability)	0	0

## Levels of severity of a learning disability

All people with a learning disability are clinically grouped into four categories: mild, moderate, severe and profound/ multiple. The above data shows a reduction in the proportion of people with profound and multiple learning disability in 2023-24 compared to last year, 2022-23.

Category	2022-23	2023-24
Mild	26%	25%
Moderate	33%	38%
Severe	29%	34%
Profound/multiple	8%	3%
Not recorded	2%	0%

## Place of death

Hospital settings continue to top the list of places of death. 59% of people died in hospital settings, 8% a decrease from 67% last year. 9% more people died in their own homes or usual place of residence this year. Evidence shows that most people with a learning disability are taken to hospital when critically unwell and more likely to die from the hospital. Reviewers suggested more education and training to support families and carers to ensure people dies in their preferred places especially those on end-of-life pathway.

Place of death (all ages)	2021-22	2022-23	2023-24
Hospital	56%	67%	59%
Usual place of residence (own home/ family home/ paid accommodation)	32%	29%	38%
Hospice	8%	3%	3%
Other	4%	< 1%	0%

Out of the 38% (26) who died in their homes/usual place of residence, more than half, (14) were expected deaths, 15% (10) died in their preferred place surrounded by friend and family. Some care providers did more than it is expected of them to ensure that the person's preferred place of death was achieved.

## Out-of-Area Placements for people with learning disabilities and autism

75% were placed locally within their boroughs and 25% were placed in the nearing boroughs, within NEL area, dependent on the available accommodation placements and individual needs. Redbridge recorded the highest number of out of borough placements mainly from Waltham Forest, Barking & Dagenham and Havering. A few placements into NEL area were recorded from Essex, Haringey, Southend, and Dorset.

Poor handover from placing Local Authority teams was recorded as a common issue causing delayed access to the Community learning disability services. These patients had to be registered with a local new GP to refer them to access local community learning disability services resulting in gaps in the person's care.

With social care element retained by the placing authority, records show absence of or delayed annual reviews to ensure unmet needs were picked and the package of care was reflective of the individual's needs. Reviewers' recommendation was for the need to review outside of borough placement processes to ensure that the receiving teams have all the information required about the person to ensure smooth transfers and continuity of care.

**Religion:** This is the first time NEL LeDeR team has collected data on religion. 62% of the people were recorded as Christians, 10% Muslim (Islam), 9% Jewish, 3% Hindu while other groups (Sikhism, Buddhism, Judaism and no religion or not recorded) accounted for 19%.

## LONG-TERM HEALTH CONDITIONS

Pre-existing health conditions also known as long-term conditions are medical problems or injury that a person has had treatment for, for some time. The most common recorded long-term conditions from people who died were as shown below.

Health Conditions at the time of death	Percentage (%) 2020 - 21 (290)	Percentage (%) 2021-22 (19)	Percentage (%) 2022-23 (25)	2023-24 (68)
Cancers	38 (13%)	4 (21%)	11 (44%)	28(40%)
Cardiac (heart related) conditions	48(16%)	8 (42%)	10 (40%)	30 (44%)
Constipation (prescribed laxatives)	168 (58%)	12 (65%)	13 (52%)	46 (67%)
Dementia/ Alzheimer's	24 (8%)	3 (16%)	6 (24%)	14 (21%)
Dental problems	158 (54%)	8 (42%)	2 (8%)	22 (32%)
Diabetes (Type 1 & Type 11)	164 (54%)	11 (58%)	12 (48%)	15 (22%)
Dysphagia, (swallowing problems)	152 (52%)	6 (32%)	6 (24%)	18 (26%)
Epilepsy/seizures	168 (58%)	13 (68%)	10 (40%)	14 (21%)
Falls (risk of falls)	175 (60%)	17 (89%)	14 (56%)	32 (47%)
High blood pressure (hypertension)	150 (52%)	13 (68%)	15 (60%)	38 (56%)
Hyperthyroidism & Hypothyroidism	72(25%)	3 (16%)	2 (8%)	21 (30%)
Impaired mobility	181 (62%)	18 (95%)	17 (68%)	42 (62%)
Incontinence	108 (37%)	8 (42%)	16 (64%)	36 (53%)
Iron, Vitamin D and B12 deficiency	142 (49%)	6 (32%)	11(11%)	31 (45%)
Mental health needs	99 (34%)	10 (52%)	9 (36%)	7 (10%)
Obesity	102 (35%)	14 (75%)	14 (56%)	44(65%)
Renal/ chronic kidney disease	64(22%)	8 (42%)	8 (32%)	16 (23%)
Respiratory conditions/problems	174 (60%)	15 (75%)	14 (56%)	46 (67%)
Sensory impairment e.g. hearing or visual problems or both	55 (19%)	7 (36%)	4 (16%)	6 (8%)
Swallowing problem (risk of aspiration)	No data	No data	5 (20%)	8 (12%)

Many people with a learning disability have considerable and often multiple, physical and mental health conditions. They are at increased risk of developing chronic conditions from both genetic and lifestyle factors.

This year's long-term conditions data above show no significant variation from previous years and the national data. Heart-related, respiratory problems, gastro-intestinal conditions, including constipation, and obesity were amongst the most prevalent conditions. Dysphagia and vitamin deficiencies were also noted as common.

Rare syndromes or conditions such as cushing syndrome, Eisenmenger's complex, Fragile X syndrome, Niemann-pick disease, pica disorder and Hodgkin's lymphoma were recorded. These syndromes were known as life limiting and had a direct impact on the person's life expectancy. All people known to have these syndromes died before the age of 40 years. Average age at time of death was 35years, which is significantly lower that the recorded average of all deaths this year, which is 62 years.

### Poor communications and mobility

Almost all the people who died had mobility issues, risk of falls and most of them were supported in almost all their activities of daily living at the time of their death. Communications was poor, some non-verbal and required people to speak slowly and or use simple language, easy read materials and pictorials to aid understanding. Provision of information in a format suited to the person was noted as key in enabling access to services as well as facilitating good quality care and treatment.

## RECORDED CAUSES OF DEATH

A medical certificate of cause of death (MCCD) is a legal record of the fact of death. This provides families with an explanation of how and why the person died. It is important this record is accurate.

Statistical information on deaths is important for monitoring the health of the population, designing, and evaluating public health interventions, recognising priorities for medical research and health services, planning health services, and assessing the effectiveness of those services.

Certification of death can be done by the doctor who was caring for the person or by a GP who had seen the person in the last a few days prior to the person's death. If no one is available, the death must be referred to the coroner to investigate and certify the cause.

Common top 10 causes of death gathered from completed reviews were:

- Cardiac related problems
- Respiratory problem
- Aspiration pneumonia
- Cancers (colon, breast, prostate, lung, gall bladder)
- Multiorgan failure (unspecified)
- Sepsis
- Epilepsy
- Diabetes
- Dementia
- Renal problems (full list available in appendices).

Less common recorded causes of death documented this year were smoking, choking, suicide, anorexia, and fatty liver. Also noted were congenital syndromes and rare syndromes such as Cushing Syndrome, Prader Willi syndrome and Fragile x syndrome.

Some doctors were found to verify death virtually and, in some instances, recording causes of death that do not fully reflect the cause of death or identify a disease or pathological process which could cause death or contribute to the cause of death such as a learning disability, being deaf and blind, long-term oxygen, being housebound or having mental health issues. Recording learning disability as a cause of death was also found to be happening in acute settings.

The LeDeR team has provided feedback to the relevant teams through the local medical examiners to ensure training of clinical staff responsible for completing Medical Certificates of Cause of Death.

Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales has also been shared with GPs who were known to have verified deaths virtually. This guidance replaces the guidance provided during the Coronavirus pandemic and doctors are encouraged to familiarise themselves with these updated procedures relating to the documentation and issuing certificates of cause of death.

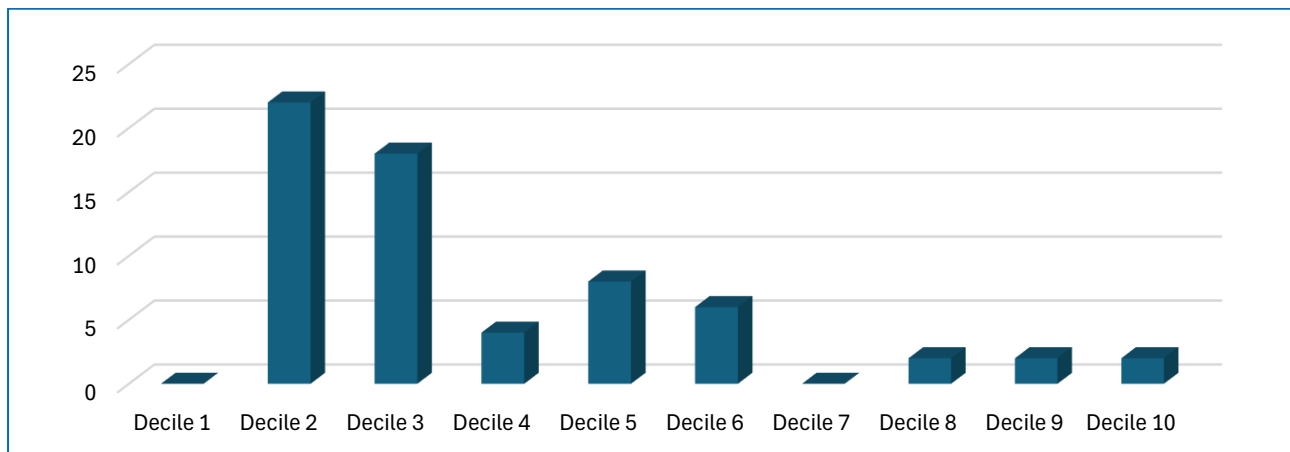
### Expected and unexpected deaths

65% (44) of all deaths were expected, whether they died from hospital, hospice or their usual place of residence. Deteriorated over the last twelve months was unmistakable and the care provider and family were informed of this outcome. 14 of them were successfully assessed and placed on end-of-life care pathway or were on palliative care pathway at the time they died.

Feedback from families and carers of those who were on end of life or palliative care pathways was positive, they felt well informed and supported during this sorrowful time. In two reviews the persons died before the palliative care could be implemented. The reviewer felt an earlier assessment could have provided a comfortable and dignified death.

35% (21 people) died unexpectedly; these were suddenly deaths or within a brief period of deterioration. 80% (17 of them) were referred to the coroner to verify cause of death whilst 4 were verified by a GP or attending doctors. Six (6) of the coroner's referrals progressed onto coroners' inquests. Conclusions from coroners' inquests were shared with the relevant care providers to ensure learning is taken forward to improve local practice.

### Levels of deprivation



Research evidence show that people living in the most deprived areas are two times more likely to die prematurely compared to those living in the least deprived areas. Using residential postcode, the Office of National statistics, [English indices of deprivation 2019 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/publications/english-indices-of-deprivation-2019), has been able to calculate a deprivation index based on 7 main domains (income, employment, education, health (physical and mental health) and crime). Each area is then placed in one of 10 deciles (groups with 1 being the poorest and 10 being the most affluent areas). This report found a clear association between the risk of premature deaths in adults and early child death and the level of deprivation (for all categories of death except cancer).

Using the same methodology, NEL data showed that over 71% of the people lived in the most deprived parts of Newham, Barking & Dagenham, City and Hackney and Waltham Forest. 21% lived in the marginal areas (decile 5-7) while 9% (decile 8-10) lived in affluent parts of Havering and Redbridge area. People who lived in decile 8-10 lived longer than those in decile 2-4.

### National mortality rate from avoidable deaths.

According to Kinston University London who process LeDeR data show that there was a drop in the number of cases that were deemed 'avoidable deaths' from 50% to 42% as at December 2022. New data for 2023 calendar year will be released later after August 2024.



## GRADING OF CARE

All completed reviews are evaluated to understand how good or poor the quality of care provided was. Six categories were used, grade 6 being the best or excellent care and 1 one, being the poorest care.

Grade	Description of care provided.	2022-23 (25)	2023-24 (68)
6	Excellent care	12%	3%
5	Good care (it met expected good practice)	36%	52%
4	Satisfactory care	24%	26%
3	Care fell short of expected good practice but did not contribute to the cause of death.	16%	9%
2	Care fell short of expected good practice, this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	8%	9%
1	Care fell far short of expected good practice and this contributed to the cause of death.	4%	1%

Reviewed cases indicate that more people continue to receive good quality of care, year on year. 81% received care that met expected practice in most areas (grades 4, 5 and 6), an increase of 8% from 2022/23 year. 9% received poor care and this may have impacted on the person's wellbeing but did not contribute to their cause of death. 1.5% (1 person) the care provision fell below expected standard and this contributed to the person's death.

Those who received poor care, five were males and two females, and their deaths were unexpected. They all died from preventable or treatable health problems such as pneumonia, sepsis, pulmonary embolism (PE), multiorgan failure as result of large bowel ischemia (due to constipation) and infection (unspecified). Six were known to have had a mild learning disability diagnosis; two were known to mental health services with a formal diagnosis of schizophrenia, depression, personality disorder and behaviours that challenge.

Safeguarding referrals were raised on all poor care reviews, four progressed into a section 42 and learning has been identified and areas of learning taken forward by the relevant care providers.

The six people who received grade 3 care (9%); 3 were expected deaths and 3 unexpected deaths. Unexpected causes of deaths included death from multiple injuries (suicide related), sepsis and bronchopneumonia. One person was known to mental health teams.

Reviews graded as good and excellent (5 and 6) the persons' deaths were expected. They were all on end of life or palliative care pathway. They were either continuing health care (CHC) funded or joint health and social care funded. They had either moderate or severe or profound/ multiple learning disabilities, and notable complex health needs. Multidisciplinary meetings (care coordination) and effective communication were evident from records.

### Key conclusions about quality of care provided:

- people known to have mild learning disabilities and mental health problems are more likely to receive poor care, likely to die of treatable or preventable causes compared to those with severe and profound learning disability without mental health problems
- severe to profound/ multiple learning disabilities individuals were more likely to receive good to excellent care and more likely to have advanced care planning in good time.
- Men were more likely to receive poor care compared to females.
- No evidence to indicate people of minority ethnic backgrounds were disproportionately impacted because of their ethnicity.

## CARE PROVIDED TO PEOPLE WITH A LEARNING DISABILITY

The term 'people with a learning disability' has been used to refer to persons known to have had a single diagnosis of a learning disability and those with both a learning disability and autism. No one in the data used was known to have had a formal autism only diagnosis.

### Annual Health Checks (AHCs)

Annual health checks (AHC) also known as annual health assessments (AHA) is a reasonable adjustment that is aimed to effectively detect unmet health needs in people with a learning disability.

These checks are needed because:

- primary care services tend to be reactive, responding to problems raised by patients
- people with learning disabilities may be unaware of the medical implications of symptoms they experience, have difficulty communicating their symptoms or may be less likely to report them to medical staff
- carers may not always attribute clinical symptoms to physical or mental illness

The National guideline on challenging behaviour and learning disabilities, recommends that people with a learning disability, aged 14 years and over, should be offered an annual health. These checks provide a way to detect, treat and prevent new and unmet health conditions in a timely manner.

All 68 persons were entitled to annual health assessments. 85% (58) had regular annual health checks while 15% (10), reviewers found no record of annual health checks. This was a significant increase from 68% recorded last year and reflective of the overall NEL ICB performance of 84%. This is above the national set target of 75%.

Of all those who had annual health assessments, 57% (33 persons) of records read that the person had had a health action plan completed or reviewed. A few, six (6) copies of completed health assessment template (Cardiff format) were made available to reviewers. It was evident from these copies the persons had comprehensive and good quality health assessments as required of the national guidelines. This was excellent practice and feedback was provided to these GPs.

### Annual health assessments and Health Action Plans

Year	Eligible for AHC (numbers)	% AHC completed within 12-18 months	% HAP updated/ created	Declined AHCs
2022-23	56	68%	25%	3%
2023-24	68	85%	57%	2%

A small number (2%) of people were noted to have declined annual health assessment, which left reviewers bewildered if these carers or families knew the importance of annual health assessments in detecting early signs of ill health or deterioration and for actions to be taken in good time.

### Mode of delivery of annual health assessments

Year	Had AHA	Face to face	Telephone/ virtual	No record
2022-23	38	10 (26%)	14 (37%)	14 (37%)
2023-24	58	32 (55%)	15 (25%)	18 (31%)

Further analysis of completed health assessment records showed that a considerable proportion of people had face-to-face assessments, this rose from 26% last year to 55% this year as shown above.

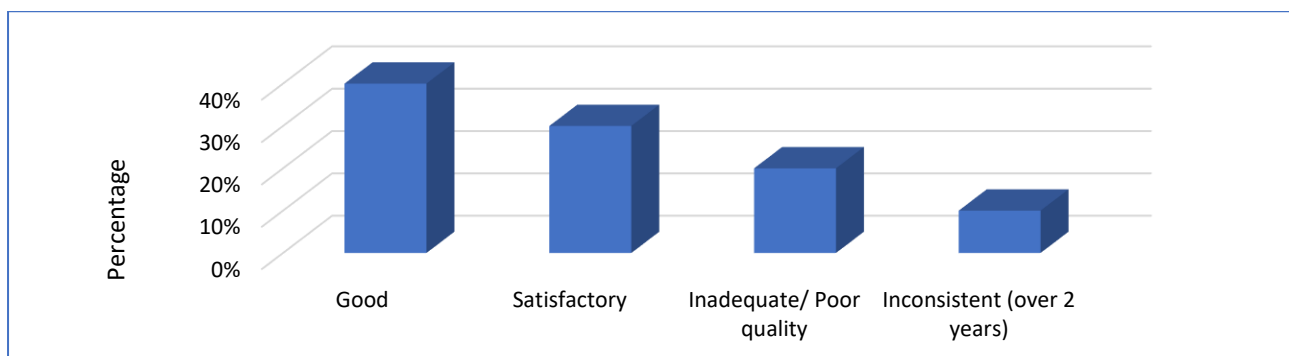
## WHAT A GOOD ANNUAL HEALTH ASSESSMENT SHOULD LOOK LIKE

A quality annual health assessment should cover the following areas:

- A detailed review of the persons pre-existing health conditions and medicines especially those on repeat prescriptions
- Physical examinations and observation - looking out for unidentified problems or new symptoms.
- Lifestyle factors such as diet, physical activity levels, sleep patterns, mental wellbeing, alcohol intake and tobacco use.
- Body composition measurements, for example weight, Body Mass Index (BMI) and waist circumference, blood pressure and resting heart rate.
- A blood and urine tests are recommended, and this should be requested in plenty of time for the results to be available at the assessment.
- A talk about staying well and any help that one may need.
- At the end of the consultation session, health action plan should be developed or updated to reflect any key messages the person should take away and next follow up dates.

Guided by the above criteria, all 58 annual health assessments were evaluated and grouped into four categories as shown on the graph below.

### Quality of annual health assessments



40% were assessed as good, 30 % satisfactory and 20% as inadequate or poor. There were noticeable inconsistencies in the way these assessments were completed across GP practices but also within the same record. Adopting one standard way of completing annual health assessments, using the agreed templates, would not only help deliver good-quality annual health assessment but also support audit process.

Structured medicines reviews are highly recommendation as key part of annual health check. Medicine reviews are aimed to ensure the individual is not overmedicated and that they are taking the right medicines and at the right dosage or amount. Over 80% of all records reviewed reported 'medicine reviews were completed' however, a few records had details to indicate what medicines were reviewed. In some reviews there was evidence of overmedication- 'a one-off prescription' becoming a repeat prescription on the person's medical record.

Continual use of antibiotics without a review could lead into Antimicrobial Resistance (AMR). AMR occurs when bacteria, viruses, fungi and parasites no longer responds to antimicrobial medicines. One person was found to have been on repeat prescriptions of Amoxicillin to treat recurrent chest infections resulting in an increased risk of side effects and antimicrobial resistance.

### Key findings about annual health assessments

Some GPs carried out considerably basic checks or conversations (such as blood pressure); no observations and physical examinations, no weight taken or vital signs, no blood or urine tests prior to

the appointments and missed appointments were not being followed up. Virtual/ telephone assessments were common.

Dental referrals were being made but no follow ups or support to ensure this happens. In one case, the person had loose teeth, had problems eating but declined to see a dentist. There was no evidence recorded to show anything was being done to support this person. Absence of regular screening for diabetic people and most GPs were addressing carers and not the person.

Some records indicated a declined examinations or that the patient was not cooperating and no details to indicate what steps the GPs took to engage with these patients. No mental capacity assessments were completed to ascertain if the person understood what was happening and the risks of not participating in these assessments nor any support sought from community learning disability teams.

Reviewers advocate for a close working relationship between GPs and community learning disability teams, families and carers, and those others who already have good relationships with these hard to engage patients. This will help GPs and other health care professionals to improve levels of engagement with these patients.

### Covid-19 and Flu Vaccinations

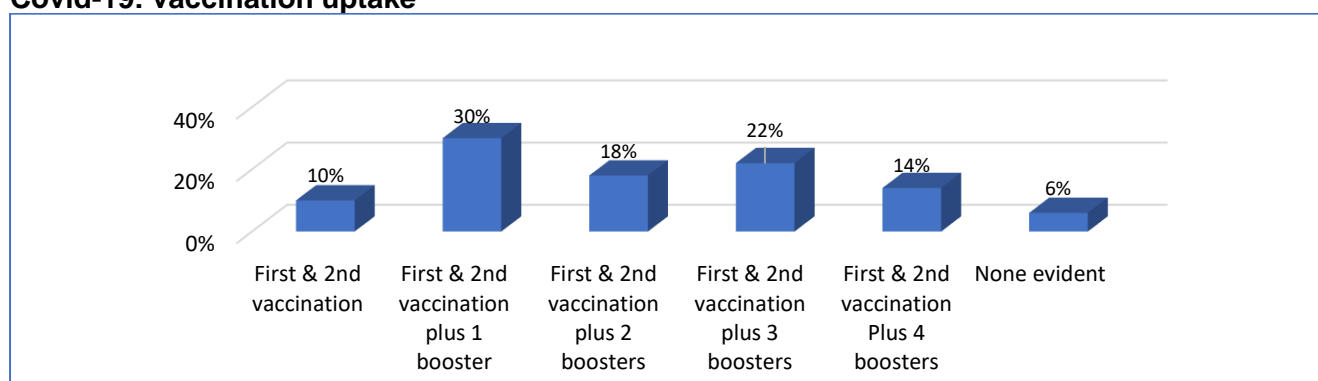
The Covid-19 vaccination is the most important part of protecting everyone who is at increased risk of severe illness from covid-19. These same patients should take a booster dose every 12 months.

Conclusions from reviews indicate that all adults had the first two doses and 2 or more boosters. Four (4) adults declined Covid-19 vaccination. There were no reasons provided and it is not clear a risk assessment, or mental capacity assessment was completed to determine if the person understood the risks of not having a Covid-19 vaccination.

Although, evidence show Covid-19 deaths have significantly declined, the risk of dying from Covid-19 related illness still exist. Findings revealed that of the two people who died from covid-19 related illnesses; one had not had any Covid-19 vaccinations while the second one had the initial two doses and no boosters.

This evidence clearly reinforces, the government's advice that people should top up their protection especially those at increased risk of serious illness from Covid-19. Getting a Covid-19 vaccine helps reduce the risk of getting severe symptoms but also to help one to recover more quickly if one catches Covid-19.

### Covid-19: vaccination uptake



### Flu Vaccination

Annual flu vaccination is recommended for everyone aged 6 months or older. It is important that people with a learning disability and those who support them have flu vaccine to lower the risk of catching flu.

It helps lower the risk of having serious illness from the flu and needing to stay in the hospital or dying from influenza virus infection.

Flu vaccination	2020-21	2021-22	2022-23	2023-24
% uptake	45%	61%	79%	78%

Data collected this year reveals that, 78% of people who died had flu vaccination. This is similar to last year's data. People with complex health needs, as is the case for most people with a learning disability, are high risk of serious illness or death if not vaccinated. The national target is 75%, however, improved uptake to have everyone vaccinated would be good.

### **DNACPR (Do Not Attempt Cardiopulmonary Resuscitation)**

Patients believed not fit for resuscitation, are those that are very unwell, unlikely to get back to the health they had before, and their heart and/or brain may be permanently damaged. DNACPR helps ensure that a patient's death is dignified and peaceful. It is important that resuscitation decisions are discussed with the patient and or with relatives and carers before the need for resuscitation.

63% of the people reviewed had DNACPR orders in place. This is a slight increase in proportion from 61% last year. Most of them were completed correctly and implemented appropriately. Families, next of kin and those involved with the person's care were involved in these decisions.

It was noted that resuscitation was attempted in one case following instructions from 999 call. On arrival, the Ambulance crew, informed staff that the person had a DNACPR order in place. The care provider was not aware of this decision which had been made when the person was in hospital.

Other concerns identified were: DNACPR forms not fully completed and unacceptable reason(s) recorded such as that the person had a learning disability. More awareness is needed to ensure appropriate recording of DNACPR order. Families to be involved and care providers provided with a copy of DNACPR.

### **Mental Capacity Act and Mental Health Assessments**

A learning disability diagnosis means the person has a reduced intellectual ability and or difficulty with a few or more of everyday activities. A learning disability makes it harder for a person to learn, understand or do things, for example household tasks, socialising or managing money – this affects the person for their whole life.

The 5 main principles of the Mental Capacity Act:

- Always assume the person can make the decision until you have proof they are not.
- Try everything possible to support the person to make the decision themselves.
- Do not assume the person does not have capacity to decide just because they decide that you think is unwise or wrong.
- If you decide for someone who cannot make it themselves, the decision must always be in their best interests.
- Any decisions, treatment or care for someone who lacks capacity must always follow the path that is the least restrictive of their basic rights and freedoms.

Mental capacity assessment is needed where a person is unable to make a particular decision at a particular time because their mind or brain is affected by illness or medication or a change in the persons' environment. Lack of capacity may not be a permanent condition; therefore, mental capacity assessment should be time- and decision-specific. Information gathered by reviewers showed that most the people (81%) required MCA assessment from time to time. Three quarters of them (60%) had MCA assessment; half of whom (30%) had DoLs (Deprivation of Liberty safeguards) in place. This is unmistakable evidence of good practice, ensuring people with a learning disability get the support they need.

In reviews where MCAs were indicated but not completed or considered, reviewers felt completing one could have benefited the person. In some cases, the individuals lost their ability to carry out their daily activities while they were assumed to have capacity, most of whom were those known to have mild learning disabilities.

### **Mental health restrictions**

All persons known to have mental health problems have the right to the best available mental health care. Restricted patients are those who are subject to special controls under the Mental Capacity Act, due a recognised mental health problem.

Five (5) of the persons reviewed had one or more of these mental health restrictions during their last 5 years. Common recorded sections were 2, 3, 4, 37/47, 41, 47/4, 136 and Court of Protection. Teams demonstrated good knowledge and implementation of mental capacity act and application of best interests of the person.

Findings also, showed delays in CoP decisions and while this may not have directly contributed to the person's death, this impacted on their health and wellbeing. One person died while waiting for a Court of Protection decision for DoLs to be put in place.

Ten people did not have mental capacity assessments completed or considered; they were all known to have a mild learning disability and had mental health problems. They were deemed to have capacity in most areas however, the overall quality of care they received was graded as poor or satisfactory. Reviewers recognised that their mental health problems may have overshadowed their physical and social needs therefore, they could have benefited from MCA assessments.

### **Use of psychotropic medicines**

Psychotropic drugs are designed to treat behaviours that are challenging in people with learning disabilities who may not have mental illness. These medicines have a wide range of side effects such as weight gain, drowsiness, changes in mood, distortion of perception, constipation and anxiety. Weight gain can bring across other morbidities such as diabetes and cardiac problems.

37% (25) people were known to mental health services for one or more of the following problems- depression, anxiety, bipolar disorder, behaviours that challenge, low moods schizophrenia or psychosis. They were all prescribed psychotropic medication. Excessive use of these medicines can negatively impact the person's quality of life as it can affect their mental and physical wellbeing.

NEL has funded STOMP (stopping overmedication projects for people with a learning disability and autism). The aim is to support people stop or minimise overuse of psychotropic drugs and where possible prescribe or refer to alternative therapies such as positive behavioural support (PBS) services. The outcome is to help people to stay well and have a good quality of life without over medicating them.

### **Recommendations in respect of mental health and application of Mental Capacity Act:**

- professionals to ensure MCA principles are embedded in practice by assisting and advising colleagues from multi-agencies providing care
- more use of independent mental capacity advocacy services (IMCA) as indicated
- more staff awareness of the needs of people with a learning disability and when to request for MCA and DoLs assessments.

### **Non-invasive ventilation- home oxygen**

Bilevel positive airway pressure (BiPAP) and continuous positive airway pressure (CPAP) machines are devices that assist with breathing. Reviewers found, two people had been prescribed BIPAP and CPAP machines. There was evidence that families were being trained to ensure they were competent using home oxygen. Common identified issues were noted as incorrect calibration and masks not being

changed regularly. This raised a question around who ensures maintenance of these machines in the community. These issues have been raised with the respiratory services to ensure arrangements are put in place by prescribing service to ensure regular maintenance and supply of masks.

In one case, the person was not using oxygen regularly, no risk assessments or regular review completed, and it was not clear from records available to the reviewer why the person needed home oxygen. Regular reviews by GPs and respiratory services were recommended to ensure these prescriptions were required.

### **Palliative Care and End of life Care**

DNACPR instructs health care providers not to perform a cardiopulmonary resuscitation (CPR) if a patient's breathing stops or if the patient's heart stops beating. This is not to say active treatment and care stops or that the person is end of life.

Palliative care is usually provided to a person who has a life-limiting (terminal) illness. Palliative care is provided alongside other therapies to treat the persons' health conditions. End of life care is a form of palliative care provided when one is close to the end of life.

61% of people were on palliative care pathways while 14% had been progressed to end-of-life care. Five people who were not on palliative care pathway, had been referred for end of life care, but unfortunately, they died before the care could be commenced. They all died in hospitals, which was not their preferred place. Reviewers emphasised the importance of advanced care planning and support for people with learning disabilities to die in their preferred place.

### **Obesity and weight management**

Public Health guidance 2022, show a higher proportion of people with learning disabilities are obese. Achieving healthier diets and healthier weight is one of the top 10 priorities for protecting and improving public health. Being obese increases the risk of many health problems including heart disease, high blood pressure, strokes, diabetes, some types of cancer and causes mobility difficulties. Weight control is recognised as a challenge because of conditions such as Prader-Willi Syndrome or use of specific medications.

### **Weights (BMI data in kgs/m2)**

	Not weight recorded	Underweight (<18.4)	Normal weight (18.5-24.9)	Overweight (25-29.9)	Obese (>30)
2020/21	36%	7%	25%	14%	35%
2021/22	36%	11%	19%	11%	23%
2022-23	29%	16%	19%	26%	9%
2023-24	12%	16%	19%	22%	31%

NEL data reveals improvement in the proportion of people being weighed, however, the gap between those underweight and those obese is widening. The lowest recorded BMI this year was 13kgs/m2 and the highest was 62.5kgs/m2 compared to 16.01kgs/m2 and 41.6kgs/m2 recorded last year. Also, the proportion of the people recorded as obese (including clinically obese) has risen from 9% last year to 31%. Almost half of those who were categorised as obese, weighed over 40kgs/m2.

There was evidence that GP provided diet, physical exercise information and advice were provided, however, reviewers recognise that the task of helping people with learning disabilities to achieve these set targets involves additional complexities. Therefore, it is vital GPs and care providers to ensure people with learning disabilities have support and reasonable adjustments provided to achieve equitable access to weight management programmes. Dietitian referrals for those underweight were noted.

## **OTHER KEY ASPECTS OF CARE**

### **Acute care and hospital discharges**

Unsafe or failed discharge occurs when a person is sent home when they are not able to adhere to the agreed care plan or before a proper diagnosis is given or when not clinically well enough to manage in the community. A few unsafe discharges were recorded. Below are some of the findings gathered from completed reviews:

- patients were sent home without all the test results being appropriately reviewed and without a proper diagnosis
- before a new care package was in place and in some instances, odd hours as result of delayed transport, without considering care provision at night care
- before equipment's such as pressure relieving mattresses were delivered
- without enough medicines to last them long enough to contact their GPs for more
- discharge meetings and assessments being conducted virtually
- without discharge information to help care providers know of any changes in the person's situation to inform care provision such as new diagnosis or new prescription or key decisions such as DNACPR.

Other acute care areas requiring improvement were around poor communication during handovers and pain management whilst waiting in emergency departments.

In one case, a patient was nil by mouth however, this was not communicated to incoming staff, no message displayed on the patient board or above the patient bay notice, or communication books. In coming staff found food on the patient's table and supported them to eat which led to their death as a result of aspiration. This was recorded as suboptimal care for a deteriorating person and a serious incident was completed ensure learning is taken forward.

All emergency departments have long-waiting times, it is important that staff ensure patients wait-well, they should receive regular and adequate pain relief while they wait. A calm waiting spaces or priority to be given to those who may struggle waiting in noisy and crowded areas is recommended. Effective communication is key in ensuring good quality and safe care.

Acute teams should review discharge process to ensure it is safe to send a person home. MDT meetings to be held face to face and to include social care teams, community learning disability teams and the care providers, families, and carers. A detailed discharge report to be share with the care providers and GPs to make sure they are informed of any actions that need to be applied.

### **Communication and pain management in non-verbal patients**

65% of all people reviewed were either non-verbal or had limited communication. Communicating pain is a huge challenge for people with a learning disability and requires curiosity and patience. Paying attention to nonverbal cues such as body language and eye movement, restlessness, facial expressions, rigid limbs and even moaning. Sometimes these nonverbal cues can give even more insight into what a patient needs rather than just what they "tell" you. It is important professionals' look out for nonverbal signs of discomfort, depression and anxiety.

Working closely with carers and family members who know the person well is encouraged. Findings revealed that some GPs were asking patients to bring along family members or carers who can speak on their behalf. This helps the treating doctor to provide more effective care.

### **Carers assessments**

All people providing care to a disabled person or child or caring for the elderly are entitled to a carer's assessment. 13 carers were eligible for carers assessment however, only five (38%) had a carers assessment. Four were offered carers assessments but they declined.



Carers assessments are important, it considers the things that a carer wants or need to achieve outside of caring role and the impact caring has on their ability to carry out those activities and how this affects their health and wellbeing. Carers support helps make life easier for the care giver. Review findings indicate that many carers often declined assessments and waited until 'crisis point' before accepting support. Recommendations were made around regular carers' conversations to ensure they understand the importance of accepting support before they hit 'a crisis point' and may have nowhere to turn for help.

Both health and social care professional should be more curious about family dynamics and caring issues that may be raised, this could, in some cases be an indicator that the family is not coping well. Honest communication is key to ensure families can engage in these conversations.

### **Provision of reasonable adjustments**

Provision of personalised reasonable adjustments ensures that people with learning disabilities, or physical or mental health conditions, are not substantially disadvantaged when accessing services or carrying out day-to-day activities. This could include early or late appointments, longer appointments, somewhere quiet to wait, priority appointments, easy read information, supply of specific equipment, home adaptations.

There was evidence to indicate that over 80% of the people reviewed were provided with reasonable adjustments. One GP went above and beyond, he would provide a late appointment to the person and close down the practice early to see this one patient who did not like waiting in a common reception with other patients.

There were recorded instances of delayed or absence of provision of vital equipment or items such as mobility chairs, pressure relief mattresses, servicing non-invasive ventilation (NIV) machines, provision of information in a format not suited to the person. In some cases, appointment information was being sent by post or text when the person could not read. Services should ensure they know the person well and their preferred mode of communication is documented on their systems. Also, messages should be copied to their next of kin or carers to ensure appointments are not missed.

Equality Act 2010 organisations have a legal duty to make changes in their approach or provision to ensure that services are as accessible to people with disabilities as they are for everybody else.

### **Role of Community learning disability services**

Community learning disability services were established to support, improve and maintain a person's physical and mental health, reducing barriers to them living an independent and fulfilled life. Reviewers recognised that different local teams operated different criterion for accepting peoples access to community learning disability services. Some referrals were declined.

A delay of up to 6 or 8 months to transfer care from one locality to another (out of borough placements) was evident. Sometimes the handover process was not properly done or not done at all, causing further delays.

A review of the out of locality placements is needed to ensure continuity of care and smooth transfers. More awareness is need amongst health and care professionals, especially GPs to understand the role of community learning disability teams.

## NATIONAL CANCER SCREENING PROGRAMMES

LeDeR programme collects data on three main national cancer screening programmes: cervical, bowel and breast cancer screening.

### a) Bowel cancer screening programme

Every two years, all adults aged 54 to 74 years old are invited to take part in bowel screening. A testing kit is posted to the patient's address, and it is expected that the sample would be returned as per instructions provided. The test results are shared with the person GP. This is repeated every 2 years.

The scope is changing, and it is expected that all over 50 years old will be eligible for bowel screening by 2025. This year, bowel screening was offered to all those aged 54- 74 years old.

### a) Bowel screening uptake

Year	Eligible persons	% uptake	No response received	declined
2022-23	24 (aged 60-74yrs)	33%	46%	21%
2023-24	30 (aged 54-74yrs)	40%	47%	13%

30 people (44%) were within this age group, and it is expected they would have received one or two testing kits within the last 5 years of their life. 12 (40%) returned their testing kit. Although NEL recorded improved uptake, this is way below the national average.

The Office of National Statistics 2022-23 show that 72% (up from 70.2% year before), of the general population adequately participated in bowel cancer screening programme.

### b) Cervical screening

Females aged between 25 to 64 years qualify for cervical screening every 3 years. Data collected from completed reviews show that 12 females were within this age and eligible for cervical cancer screening. Only 3 (25%) had screening done within the last 3 year. Cervical screening uptake continues to fall way below the national 80% target, with 68.7% of eligible individuals adequately screened in 2022-23.

Records show, half were spoken to by the GP team but declined. The decisions to decline were made by family members or carers supporting the person. It is unclear if the person was meaningfully involved in this decision and if this was in the person's best interest.

'Gender fluid' or transgender individuals with 'unclear gender identify or gender dysphoria' are less likely to be offered cervical or breast screening despite them being biologically females. GPs should ensure they have the right information on their system for these individuals to benefit from appropriate screening programmes.

### c) Breast screening programme

Breast screening targets mainly women aged between 50 and 75 years old. Women get a mammogram every three years and every two years for those deemed at risk for breast cancer.

17 females were eligible for breast screening; 7 (41%) had breast screening completed and a similar number declined the offer. While NEL records show a slight increase in uptake, from 37.5% to 41%; these figures are notably below national target and average uptake by the general population. In 2022-23 national records show 64.2% uptake against 70% national target.

Male breast cancer is rare, and men are far less likely to examine their own chest and are not able to have mammograms or breast screening. Usual signs include a lump or a mass in the breast or thickened tissue, an unusual discharge of fluid from the nipple, or orange-peel or puckered skin.

For the first time, NEL recorded a death of a male from breast cancer. Carers noticed a hard bony lump over the chest. A GP appointment was arranged for an urgent x-ray which showed nothing of concern. Seven months later, the person complaint of pain below the breastbone, the lump had grown and became painful to touch. An ultrasound was requested, and a diagnosis of breast cancer was confirmed. Due to the person having other complex health issues, a decision was reached that he would not be suitable for chemotherapy. Palliative care was commenced, and he sadly died a few weeks later. Recorded cause of death was 1a) Breast cancer.

Screening men for breast cancer has not been studied to know if it is helpful; mammography and or ultrasound are usually done if a lump is found. More awareness of breast cancer in learning disability men was advised and for those at high risk for breast cancer to be supported to discuss how to manage their risk with their doctor.

#### **d) Testicular and prostate cancer screening programmes**

Analysis of completed reviews showed no record of uptake for testicular screening (aimed at males aged 15-55years) and prostate screening (for males over 50 years). 16 males were eligible for testicular screening and 33 for prostate screening. Records indicate that five people were offered prostate screening, but they declined.

Analysis of causes of deaths showed two people had died from prostate cancer. Both were recorded as 1b) on their death certificates as a disease or condition thought to be the underlying cause of death. Both had no record of having had prostate screening. Prostate screening is non- invasive and requires a blood test- prostate-specific antigen (PSA) blood test. More support is needed especially for those known to have needle phobia.

#### **e) Other age-appropriate screening programmes**

- Abdominal aortic aneurysm (AAA) screening for men over 65 years old; 18 people were eligible and only one (5%) was recorded to have had abdominal aortic aneurysm screening.
- Diabetic eye screening, a test to check for diabetic retinopathy (eye problems caused by diabetes). All people aged 12 or over, diagnosed with diabetes should get a letter every 1 or 2 years asking them to have an eye screening test. Eighteen people (18) were known to have a diabetes; only 4 (22%) accessed regular retinopathy screening.

Improved working relationships between Cancer Alliance teams, community learning disability teams and primary care teams to improve awareness of cancer screening and age-appropriate screening programmes amongst people with a learning disability and autism was recommended.

## SECTION TWO

### NEL LEDER CHILD DEATH OVERVIEW PANEL (CDOP) REPORT 2023-2024

This section of the report summarises analysis of completed LeDeR-CDOP child death reviews between 1 April 2023 and 31 March 2024. NHS NEL ICB has two CDOP (Child Death Overview Panel) teams: Outer London which covers Barking Havering & Redbridge locality (BHR) and Inner London area covering Waltham Forest, Tower Hamlets, Newham and Hackney (WELC).

Since July 2023, child death data is hosted by the National CDOP system. LeDeR-CDOP child death reviews are completed jointly by the CDOP Team, and the LeDeR team. LeDeR programme does not review cases for children known to have autism only diagnosis without a learning disability.

Whilst there is some backlog, the delay in taking complex cases to CDOP is around waiting for other processes to complete such as coroner's inquests and learning reviews. It is important to note reviews are performed up to and over one year after the death, this time can vary depending on the circumstances of the death and the completion of other reviews and investigations taking place into the child's death.

#### New notifications 2023 – 24

CDOP review process analyses all deaths of children who are resident in the North East London (NEL) area, regardless of where they died. This data is drawn from the database of notifications (Form A from the National CDOP data set).

Borough	2022-23	2023-24
Barking and Dagenham	3	1
Havering	2	1
Redbridge	4	3
Waltham Forest	5	2
Newham	3	2
City and Hackney	1	1
Tower Hamlets	3	4
<b>Total</b>	<b>21</b>	<b>14</b>

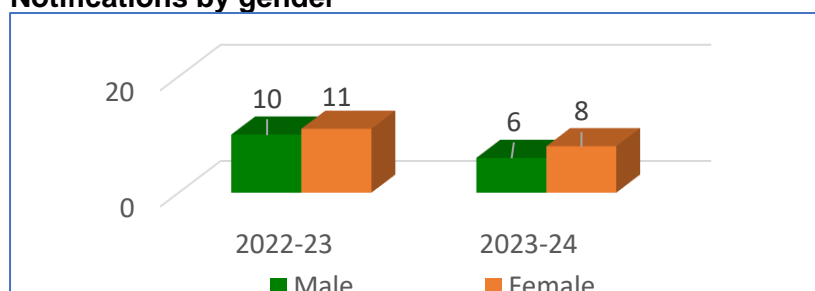
NEL CDOP team were notified of the death of 14 children with a Learning Disability; 33% lower than the previous year, when there were 21 deaths.

From the above data, inner boroughs recorded more notifications than outer borough localities.

#### Completed reviews 2023/24.

12 reviews were completed this year. BHR completed 4 reviews while WELC completed 8. Below is the analysis of the completed reviews.

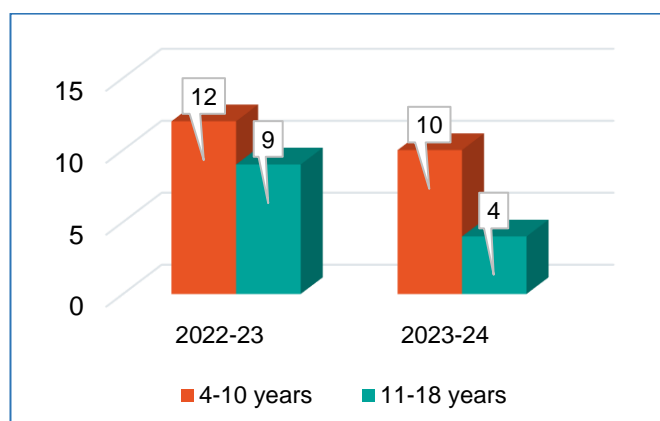
#### Notifications by gender



A higher proportion of females' children died compared to males. In adults' reviews, more males died compared to females.

## Notifications by Age group

Data collected show that a significant number of children died before the age of 11 years old. They were known to have had complex health needs, some had rare genetic/ chromosomal conditions, most of them were known to have had severe to multiple/ profound learning disabilities. Some lived longer than expected of their condition. They were all on a palliative care pathway.



## Ethnicity

Ethnicity	12
White British	2
Asian or Asian British - Pakistani	1
Black or Black British - African	3
Asian or Asian British - Indian	2
Asian or Asian British – Bangladeshi	2
Asian or Asian British	2

83% of the children were of minority ethnic background compared to 76% of adult deaths were white.

A higher proportion of Black African children died compared to other ethnic groups. A similar data was evident in adults' reviews

## Category of child death/ Common causes of death

During the CDOP meeting, panel members categorise a child's death according to nationally defined ten categories that are determined by the Department of Health. Below is NEL position under each category.

Category of Child Death	2023-24
1. Deliberately inflicted injury, abuse, or neglect	0
2. Suicide or deliberate self-inflicted harm	0
3. Trauma and other external factors, including medical/surgical complications/error	0
4. Malignancy	1
5. Acute medical or surgical condition	1
6. Chronic medical condition	2
7. Chromosomal, genetic or congenital anomaly	5
8. Perinatal / neonatal event	0
9. Infection	2
10. Sudden unexpected, unexplained death	1

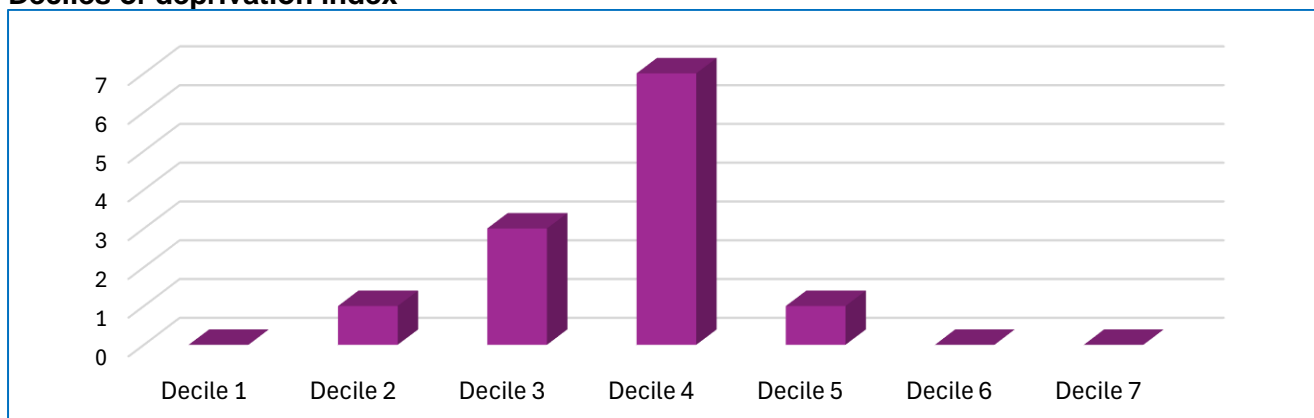
Analysis of certificates of death information indicated that the top six recorded common causes of death in children were: respiratory related problems; Chromosomal, genetic or congenital anomaly; hypoxic ischemic injury; aspiration pneumonia; infection of unknown origin and septic shock. All these deaths were expected except for one. Although the child was on a palliative care pathway, there were no signs to indicate end of life.

## Child Mortality and Social Deprivation

The English [indices of deprivation \(2019\)](#) found a clear association between the risk of early child death and the level of deprivation. Analysis of LeDeR-CDOP reviews completed in 2023-24, indicated that

11(92%) lived in the 4 most deprived areas (decile 1-4). Only 8% (1 child) lived in the marginal areas, decile 5; none in decile 6-10.

### Deciles of deprivation index



### Modifiable Factors

CDOP conducts an independent multi-agency analysis of the reports from the Child Death Review (CDR) meeting consisting of partners and senior professionals with no named responsibility for the care of the child during their life. These meetings help identify any modifiable factors.

Modifiable factors are defined as ‘those aspects of care’ which may have contributed to the death of the child, and which might, by means of a locally or nationally achievable intervention, be modified (changed or improved) to reduce the risk of future deaths

CDR members are tasked with taking the learning from these cases and sharing it widely within their organisations in order that multi-agency partners are aware of the risk factors when supporting and advising parents and carers.

There were no modifiable factors recorded except in 1 review this year; the parents did not recognise the severity of their child’s illness in time. The learning was around parents to be aware of any changes in their child’s behaviours or moods and to seek assistance or advice of unsure.

### Themes from CDOP Reviews

Three common themes were identified in children’s deaths; these were communication, assessment and management of pain and mental capacity act application particularly in non-verbal children.

#### Communication

Most children who died were nonverbal. Communicating with children with learning disabilities often requires use of clear and simple language, visual aids, repetition, and requires a lot of patience. CDR process recognises that it is a skill to gauge their understanding level and to adjust one’s communication style and format accordingly. Suggestions were made around professionals using concrete examples, gestures, and allowing extra time for the child to process information.

Offering encouragement, praise, and positive reinforcement were recorded as key in boosting their confidence and engagement in communication. Working very closely with parents/ carers who know the child very well as they can help interpret their facial expressions and body language.

## **Assessing Pain**

Assessment and management of pain for non-verbal children was identified as an issue specific to understanding how unwell the child was. Assessing pain in children with learning disabilities requires a tailored approach that considers their unique communication abilities and comprehension level. This might involve using visual aids, simple language, or pain scales with pictorial representations. Observing changes in behaviour, facial expressions, or body language can provide valuable clues about their pain experience. Working in partnership with caregivers or support staff who know the individual well can enhance the accuracy of the assessment.

## **Mental Capacity in children and young people**

The principles of Mental Capacity Act 2005 apply to anyone over the age of 16 years old. The aim is to protect vulnerable people around decision-making. Having a learning disability does not necessarily mean that a person lacks mental capacity. Mental capacity refers to a person's ability to make decisions and understand the consequences of those decisions.

Assessment of mental capacity involves evaluating whether a person can understand, retain, weigh, and communicate information relevant to a specific decision. Young people with learning disabilities may have varying levels of mental capacity, and it is crucial to assess each person individually.

Two of the children were aged 16 years and over and mental capacity assessments were not recorded. They were assumed to have no capacity and their families and carers were involved in making all the decisions. It is not clear what areas they may have had capacity on and if they understood what was happening with their care.

Recommendations were made around using appropriate assessments and involving professionals such as psychologists, psychiatrists, or social workers to support and determine the person's mental capacity to make decisions. In cases where the person was deemed to lack capacity, a 'best interest decision' meeting should be recorded.

The focus should always be on empowering individuals to make decisions to the best of their ability while providing appropriate support and safeguards when needed. Using independent mental capacity advocacy services was recommended to work with families and carers.

## SECTION 3

### FOCUSED REVIEWS: SUMMARY OF EMERGING THEMES

Detailed analysis of all 28 completed focused reviews was carried out to identify main themes and trends. Over 140 areas of positive practice and over 80 areas needing improvement were evident. These findings were grouped into ten categories as per the LeDeR guidance.

#### Themes and trends from completed focused reviews



The results shown in the table above gives affirmation that there is lots of good reliable professional practice in care provision and appropriate and timely implementation of care pathways.

There were equally more areas of learning and improvement identified from these same categories. See more details on page 28.

#### Recognising a deteriorating person

A timely response to a deteriorating person is key to improving patient safety and outcomes. Detecting, understanding, and interpreting abnormal vital signs and other observations, and escalating care appropriately is a complex process that requires good knowledge and understanding of the person.

Early warning signs include observed changes in the person's normal behaviour, such as sleep, eating, drinking and mood. Other common presenting complaints are headache, nausea/vomiting, dizziness, loss of concentration, disorientation, irritability, memory loss.

Suggestions were made around care staff to speak to someone senior if the person they are caring for seems different to usual self; keep a clear record of observations (score chart) and seek medical advice if these changes persist. Reviewers shared that expansion of significant 7 training to all the NEL localities would be greatly beneficial. Feedback from this training revealed that more carers felt more confident in identifying a deteriorating person and were able to escalate appropriately. This training is currently being offered to Barking & Dagenham, Havering and Redbridge areas.



## **Safeguarding**

Conclusion of completed reviews demonstrate good understanding of safeguarding adults' processes.

Safeguarding concerns were raised where there was reasonable cause to suspect that vulnerable adults were at risk of or experiencing abuse and neglect/ self-neglect. There were missed opportunities for raising safeguarding referrals particularly around self-neglect. Some referrals were not investigated fully, either because they lacked risk information to take them forwards or the person died before this could be concluded and closed. Reviewers' opinions were that referrals should not be closed because the person died. All safeguarding referrals should be thoroughly reviewed, and any learning taken forward to improve local practice.

On specialist areas of practice, such as where there were issues relating to pressure ulcers, specialist advice or decision-making protocols (such as national guidance on pressure areas), these should be followed and fully complied with.

## **Transition**

Between the ages of 16 and 18, it is expected that a young person will start a "transition" to adult services. This should involve **all** the services involved with the child such as health and social care, mental health, education, financial benefits for the young person and their family, work and housing.

Transitioning to adult services is a significant change especially for those known to have significant mental health problems; such cases need to be handled carefully and sensitively to ensure this change does not act as a catalyst for increased poor mental health. This can be even more challenging for people who are 'gender fluid' or undergoing gender identity process.

In one review, the reviewer identified that transition to an adult placement may have worsened the person's mental health. Although the person had a care coordinator, there was little evidence to indicate multi-agency working. No record to indicate that the person was viewed holistically in relation to their learning disability and the impact this may have had on their mental health and understanding of transitioning to adult services. Close working relationships between the specialist learning disability team, GP, mental health team and the care provider may have helped this young person whose care was graded as below the expected standard in some areas.

The reviewer noted that despite numerous hospital admissions relating to mental health problems, C(E)TRs were not in place or considered. The reviewer's opinion was that this young person may have benefited from C(E)TR reviews. A smooth and successful transition should be a gradual process rather than a single event and tailored to suit the person's needs.

## **Coroners' cases**

This year's data show that NEL recorded a higher number of coroners referrals compared to previous years. Areas of learning were identified in some reviews: in one review, the coroners report did not evidence investigation or examination of a head wound during the post-mortem. In another review, the coroner 's report states that death was due to "natural causes and was not caused by the action or inaction of any third party." The family was unhappy with this conclusion, they believed the death was because of neglect.

Cause of death was recorded as a 'learning disability' in two other reviews. These finding were feedback to the coroners office.

## SUMMARY FINDINGS AND RECOMMENDATIONS

### Professional practice and provision of care

#### **Annual Health Assessments and health action plans**

- Thorough annual health assessments leading to early diagnosis and treatment for new conditions and more health action plans. Professionals' curiosity on unusual complaints/symptoms/signs of deterioration.
- More face-to-face appointments, home visits and provision of suitable appointment times
- More referrals to retinopathy screening for people known to have diabetes
- Effective structured medicines reviews to stop or minimise unnecessary repeats or overmedication.
- More discussions about healthy weights and support to be made available to access available weight management services
- GPs to involve community learning disability teams more for support especially with those hard to reach and missing appointments
- More dental checks, referrals to specialist services especially those with dental phobias.
- GPs to ensure patient/ next of kin contacts details are updated regularly not to miss appointments/ important messages

#### **STOMP/ Structural Medicines Review (SMRs)**

- More liaison with STOMP teams to support regular medicine reviews to stop/ minimise overmedications especially enemas, antipsychotics and antidepressant medications
- Regular risk assessments to be completed on individuals at risk of self-harm from medications overdose
- GPs to carry out thorough reviews on patients' conditions and medications especially when registering new patients.

#### **Pressure ulcers/ skin damage**

- Consistency in the use of risk assessment tools to help prevent the development and management of pressure ulcers
- Standardised pressure ulcer tools to be used across acute and residential/ nursing care homes
- Carers to be made aware of the importance of good nutrition, hydration as well as frequently checking pressure reducing or relieving equipment

#### **Non-Invasive ventilation/ home oxygen**

- Regular review and risk assessment on patients using home oxygen
- Clear guidance on effective use of CPAP & BiPAP machine and masks
- Regular maintenance of these machines to ensure they are calibrated correctly and working efficiently
- Carers/ families to be well trained, including refresher training, to ensure they can operate these machines properly- efficiently and safely

### Diagnosis and treatment

- Diagnosis overshadowing/ delayed diagnosis- more professional curiosity on changes in the person behaviours or new symptoms leading to referrals to specialist services,
- monitoring/ follow ups of referrals to ensure timely diagnosis and treatment
- Appropriate risk assessments on falls, dysphagia patients,
- Behaviour support plans support by MCA assessments

### Referrals/ appointments

- Timely referrals and follow-ups for missed appointments
- Ensure updated patient contact details on clinical systems to ensure patient receive information about their appointments
- Provide appointments times suited to the person; provide quiet space if they have to wait longer than expected
- Carers to be supported to access services with ease by providing them with the required information

### Discharges from the hospital

- Safe discharges to be a priority and reviewed across acute teams
- People with learning disability to have senior review prior to discharge.
- All test results to be reviewed before being discharged.
- Good communication and handover to community teams or care providers
- Information about new diagnosis and new medicines to be communicated to GPs and care givers.
- Ensure care packages/ equipment are in place before sending someone home.
- Elderly and vulnerable people living in their own homes not to be discharged at late hours without carers
- Review of funding process and its impact on discharges

### Mental Capacity Assessments

- All persons known to have a formal learning disability require regular MCA assessment on those areas they need support with or as deemed appropriate.
- Mental capacity assessment to be applied where the person declines care to ensure they understand the risks associated with their decisions.
- More use of Independent Mental Capacity Advocacy services (IMCA) especially where no family is involved.
- C(E)TR to be made available to eligible individuals.
- Best interest to be applied where the person lacks capacity in decision making

## Understanding the needs of people with a learning disability & autism

### Education and Training

- Improved communication between professional and care givers
- More awareness and information sharing with families/ carers.
- Support implementation of Oliver McGowan mandatory training.
- Training on specific conditions especially some of the rare conditions/ syndromes
- Closer working relationships with Community Learning disability teams

### Meaningful Information provision

- Information to be provided in suitable format to the end user e.g. Use of easy read or pictorials. No text messages to patients who cannot read.
- Clinical interpretation and translation services to be made available; minimise use of family and friends for accuracy
- 

### Communication with carers and families

- Good communication amongst professionals/ sharing information
- Meaning engagement with the patients, carers, and families regarding all aspects of care provided.
- Family/ carers to be made awareness of support available to them
- Professionals to actively listen to carers and families.
- More use of updated hospital passports/ Urgent care plans
- Professionals to address the person and only talk to carers, where appropriate

### Recognising deteriorating person

- More training on care staff on recognising deterioration and clear escalation pathways
- Easy to use tools and scoring system to help carers pick up any changes and action to be taken in good time to commence the necessary diagnosis and treatment
- Good record keeping- legible, accessible, to those who may need this information, and should have enough details.

### Care Coordination

- More MDTs especially those with complex health needs
- Accurate recording of diagnosis/ records
- Move home visits, shift from telephone consultations for people with a learning disability,

## Age-appropriate screening programmes and vaccination

### Improve uptake of Cancer screening programmes

- Working closely with Cancer Alliance teams to improve awareness and uptake of all national cancer screening programmes including breast screening in men
- Clear monitoring system for patients on remission/ follow-up appointments
- Improved communication between GPs, care providers and specialist services.

### Flu jab and Covid19 vaccinations

- Desensitisation for people known to have needle phobia, to start at early ages.
- Provide information in a format suited to the end user.
- More carers/ family education about the importance of vaccinations in protecting the person from serious illness.

## Obesity and weight management

### Obesity and weight management

- More support for people with a learning disability and autism around diet, health eating and physical exercise set targets to achieve health weights.
- More accessible public health initiatives with support for people requiring extra assistance
- Effective monitoring of weights and weight management programmes/referrals
- Improved communication between clinical teams and care providers' participation in the development and implementation of weight management plans.

## DNACPR & End of life

### Do not Attempt Cardiopulmonary Resuscitation (DNACPR)

- Improved awareness about End-of-life care; ensure good understanding of what this means to the families and carers; DNACPR does not mean end of life or ceiling of care
- Advanced care planning with the person and deliver their wishes
- Involve families/ carers and care providers in DNACPR decision making process
- Appropriate clinical reasons to be documented on DNACPR form; a learning disability is not a reason for DNACPR

## Social care assessments and package of care

### **Care Assessments.**

- Regular social care reviews to reflect the person needs.
- Professional curiosity on people declining care and/or carers assessments.
- Carers support and information provision leading to more carers assessments.
- IMCA/ MCA referrals and assessments as indicated.
- Timely implementation of care packages especially for those coming out of from hospitals.
- More engagement with care providers and information sharing detailed handovers especially out of borough placements.

### **Safeguarding**

- Appropriate safeguarding referrals to avoid possible missed opportunities around self-neglect.
- Thorough review of referral and improvements in practice
- Appropriate DoLs and court of protection referrals as indicated.
- Regular DoLs reviews/ updates to ensure they reflect the persons needs at the time.

## **NATIONAL AND LOCAL INITIATIVES AND PROJECTS**

LeDeR programme is a service improvement tool. The purpose is to support services create an environment in which change, and improvement can flourish. It is about leading differently and in a way that fosters a culture of continuous learning from past occurrences, patient and family experiences. It is also about providing care staff with the means, skills and support that will enable them to take ownership of improving quality of care.

Across North East London, great progress has been made to improve access and standards of care for people with a learning disability and autism or both.

Nationally and locally, there are initiatives or projects which have been put in place addressing varied issues aimed at achieving better health outcomes for people with a learning disability and autism.

### **National initiatives**

LeDeR reviews have consistently identified common avoidable deaths amongst people with a learning disabilities and increased risk of having two or more long-term conditions. As part of 'action from learning' a number of national initiatives have been developed around dysphagia and aspiration pneumonia, cancer screening, Epilepsy, Respiratory problems, Sepsis, constipations, diabetes, seasonal flu as well as early warning signs in recognising deterioration. The team has produced information materials accessible to both care providers and service users.

National records show, overall cancer screening uptake is lower than national target and significantly lower for people with a learning disability and autism. Cancer Alliance campaigns seek to normalise people going to see their doctor sooner, if they notice anything unusual to them for a 'peace of mind' check. Discovering a cancer early, when it isn't too large and hasn't spread, improves the chances of successful treatment.

In the same way as the national LeDeR initiatives, information has been produced in different languages and formats to increase cancer awareness across all communities and to give people the confidence to spot early signs of cancer-- finding cancer early helps save lives.

Health and Social Care Act requires that all health and social care organisations to ensure their staff are training in learning disability and autism appropriate to their roles. Learning disability and autism training aims to provide the health and care workforce with the right skills and knowledge to improve and promote awareness of the needs of people with a learning disability and autistic adults; enable staff provide safe, compassionate and informed care. The Oliver McGowan Mandatory training is a recommended training, and it is being rolled out in England.

### **Local initiatives**

A lot has been happening across North East London footprint. Some of these activities include:

- Co-production of national initiatives and replicating this locally such as promoting uptake of national cancer screening programmes and education on breast cancer in men.
- Recruitment of learning disability practitioners, working with GPs to improve the quality of annual health assessments and health action plans and to provide dietetic support for those not covered under mainstream services
- STOMP projects to ensure regular and structured medicines reviews especially psychotropic medications
- Public Health weight management initiatives tailored for people with learning disabilities
- Continued campaign on provision of personalised reasonable adjustments to improve access to services hence equity in health and social care outcomes
- Support the implementation of Oliver McGowan Mandatory Training

## CONCLUSION

Health inequalities are unjust differences in the health status between groups, populations or individuals and are preventable. People with a learning disability and autism are more likely to experience health inequalities compared to those without a learning disability and or autism. They are more likely to have complex health and social care needs, and this can lead to challenges in terms of identifying new or unknown health issues and escalating them in good time.

Most common barriers to participation experienced by people with a learning disability and autism are poor communication, accessibility to services, absence or lack of relevant assistive technology, low knowledge and awareness of their needs, and perceptions regarding learning disability and autism.

The LeDeR programme continues its commitment to support local teams to understand why people with a learning disability and autism are dying early from avoidable causes and what they can do to improve services based on what local reviews show.

The NEL ICB LeDeR Governance group is committed to working with both local health and social care providers and partners to develop local action plans across NEL localities aimed to embed a culture of continuous learning and improve the health and care outcomes for people with a learning disability and autism.

Suggested actions to be taken forward from this year's report:

- To maintain focus on LeDeR programme priorities as per LeDeR policy
- To promote co-production of National initiatives addressing premature deaths and health inequalities facing people with a learning disability and autism
- Continue providing feedback from completed reviews to all our care providers to embed a culture of continuous learning and service improvement
- To support the implementation of Oliver McGowan Training programme
- To ensure that the voices of people with lived experience and others from minority ethnic groups are heard and their views are incorporated in NEL LeDeR Governance process.

Together, we can enable people with a learning disability and autism engage fully in life hence better health outcomes and reduced health inequalities.



## REFERENCES

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[Service Improvement Tools - LeDeR - Learning from lives and deaths – People with a learning disability and autistic people - FutureNHS Collaboration Platform](https://www.futurenhs.org/collaboration-platform/service-improvement-tools-leder-learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people)

## CONTACTS AND FURTHER INFORMATION

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## Appendix 1: Full list of long-term conditions data 2023-34

Long-term Conditions	Person(s)
Epilepsy	21
Gastro-intestinal (GI) conditions including constipation, hernias	19
Respiratory problems: Asthma, Chronic Obstructive Pulmonary disease (COPD)	18
Hypothyroidism/ hyperthyroidism	15
Cardiac issues (aortic stenosis, Heart Failure, ischaemic Heart Disease, Valvular Heart Disease, Femoral Artery Occlusion congenital heart defect, pacemaker insitu, Atrial fibrillation).	15
Diabetes Mellitus (Type 1&2)	15
Hypertension	15
Mental health conditions ((including serious mental illness (SMI) anxiety, depression, Paranoid Schizophrenia/Schizoffective Disorder, challenging behaviours)	14
Acute Kidney Injury (acute &chronic), Renal problems	12
Dysphagia	12
Vitamin deficiencies (D, Iron, folate, B12 B6)	11
High Cholesterol	10
Poor mobility	10
Sensory impairment (registered fully or partially blind and/ or deaf, Glaucoma, congenital cataract, conjunctivitis, myopia, )	8
Cerebral palsy	7
Dementia (Vascular dementia	7
Arthritis/ Gout	6
Incontinence, Urinary catheter insitu and recurrent UTI's	6
Skin conditions (Eczema, rash, psoriasis	6
Cancers (colon/ bowel, gastro-intestinal, breast, prostate, skin cancer, transitional cell carcinoma, leukaemia)	5
Downs syndrome	5
Fractures	3
Frailty (mild, moderate or severe frailty)	3
Lower Limb ischaemia (a severe blockage of the arteries in the lower extremities)	3
Allergies	2
Autism	2
Hydrocephalus	2
Hypernatremia (high sodium concentration in the blood)	2
Osteoporosis	2
Parkinson's disease	2
Cushing syndrome	1
Eisenmenger's complex	1
Fragile X syndrome	1
Hepatitis B	1
Kienbock's disease	1
Niemann-Pick Disease	1
Pica Disorder	1
Prader Willi syndrome	1
Severe Anorexia	1
Hodgkin's Lymphoma,	1
Unique neurological and rare conditions (Hodgkin's Lymphoma,	1

**Appendix 2: MCCD recorded causes of deaths and the various categories 2023-24**

Causes of death	1a)	1b)	1c)	2	Occurrences
Cardiac related problems (Ischemic heart attack, cardiac failure, cardiac arrest, heart diseases, Acute Cardiac Arrhythmia, Cachexia. )	12	5	x	7	24
Respiratory related problems (Bronchopneumonia, pneumonia, covid pneumonia, community acquired pneumonia, bilateral pneumonia, asthma, COPD, Acute tracheobronchitis, Fungal Pneumonia, chest infection)	12	5	x	5	22
Aspiration pneumonia/ dysphagia	12	3	x		15
Learning disabilities	x	x	2	10	12
Sepsis (including. urosepsis & septic shock)	9	1	x	1	11
Hypertension	4	5	x	2	11
Cancers (colon, breast, prostate, lung, gall bladder)	8	1	x	1	10
Multiorgan failure (unspecified)	6	x	x	2	8
Dementia	0	4	x	3	7
Old age/ frailty	2	x	x	4	6
Downs syndrome	x	x	6	0	6
Diabetes	x	1	x	5	6
Chest infection	4	x	x	1	5
Chronic kidney disease	3	x	1	1	5
Cerebral palsy	0	1	1	3	4
Obesity/Fatty liver	0	1		2	3
Epilepsy	x	x	1	2	3
Hernia	x	x	1	1	3
Schizophrenia	x	x	1	2	3
Lung fibrosis	2	x	x	0	2
Intracerebral haemorrhage	2	x	x	0	2
Pulmonary Thromboembolism	2	x	x	0	2
Covid19	2	x	x	0	2
Hypoxia/ choking	1	x	1	x	2
Parkinsons	x	x	1	1	2
Undiagnosed congenital syndrome	x	x	1	1	2
Hydrocephalus/ Microcephalus with spastic quadriplegia	x	x	x	2	2
Cachexia/ Anorexia	1	x	x	0	1
Acute megaloblastic anaemia	x	x	1	0	1
Fragile X syndrome	x	x	1	0	1
Cushing syndrome	x	x	1	0	1
Blind & deaf	x	x	x	1	1
Bedbound	x	x	x	1	1
Long-term oxygen	x	x	x	1	1
Bowel obstruction	x	x	x	1	1
Multiple injuries due to suicide	1	x	x	x	1