



North Central London
Health and Care
Integrated Care System

NCL Annual Report Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) programme

April 2022- March 2023



LeDeR programme background



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LeDeR Programme Workforce

- The LeDeR programme was managed by the NCL Learning Disability and Autism Programme Team until the end of March 2024. From April 2024, management of the programme will transfer to the Complex Care Learning Disabilities team.
- Positive Support Group (PSG) were commissioned to deliver NCL's reviews in 2022-23. Their focus was also to reduce the backlog of LeDeR reviews.

Outstanding 22/23 LeDeR Reviews

- NCL has 23 incomplete LeDeR reviews from the 2022/23 financial year.
- The LeDeR review team experienced delays in completing these reviews due to a national data breach issue, NHSE platform difficulties and changes in workforce. 2 of these reviews are on hold whilst other statutory process are completed and the remaining 21 are in the process of being completed.
- This report has been concluded without the data from these 23 outstanding reviews. The data from these reviews will be included in the next LeDeR report.

LeDeR Review Backlog

- There are 5 outstanding reviews from the years prior to 2022/23.
- These cases have been allocated to PSG as a priority and are in progress.

Summary 2022/23 LeDeR data

NCL ICS received a total of **65 LeDeR reviews** from April 2022 – March 2023



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Review status	Focused Reviews	Initial Reviews	Total Reviews
On hold	0	2	2
Pending allocation	0	0	0
In review (allocated)	4	9	13
Requiring quality assurance	4	4	8
Completed	19	23	42
Total	27	38	65

Borough	No. of LeDeR notifications
Barnet	16
Camden	9
Enfield	14
Haringey	13
Islington	13
NCL ICS Total	65

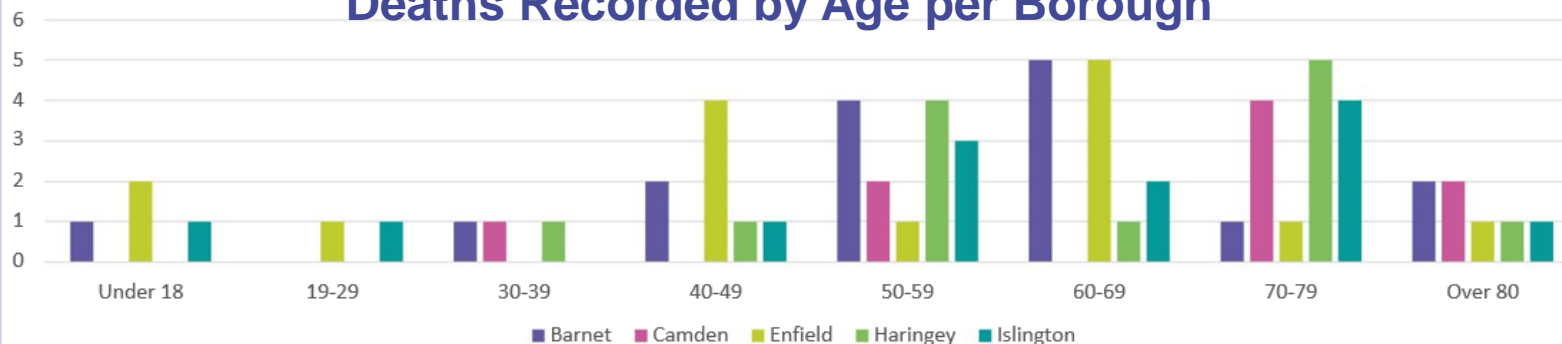
- All 65 LeDeR reviews were for adults with a primary diagnosis of a Learning Disability.
- There were no reviews for autistic adults without a learning disability. It is likely that there is underreporting for this cohort within NCL.
- This is an increase on the 40 reviews received in 2021/2022, but a decrease on the 74 notifications in 2020/21. It is unclear whether the growth in 22/23 is due to increased reporting or an overall increased number of deaths for this cohort.
- The 2022/2023 figure does not include the notifications of 4 child deaths. These were closed on the LeDeR dashboard and managed by the Child Death Overview Panel.

Demographics – Age



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Deaths Recorded by Age per Borough



- The average life expectancy for a person from the general population in the UK is between 78.6 to 82.6 years (dependent on gender)¹ however, the national average age of death for people with a learning disability is 62.9 years.² This demonstrates that people with learning disabilities are still dying significantly younger than the general population.
- In NCL the average age at death for people with learning disabilities has increased from 59 years in 2020-2021 to 60 years in 2022-23, which demonstrates a slight improvement in reductions of premature deaths for this cohort.
- Enfield has the lowest average age of death for people with learning disabilities out of the five boroughs. The reason for this is unclear and will be investigated by the incoming LeDeR Coordinator.
- In NCL, Black, Asian and Minority Ethnic (BAME) people with learning disabilities are dying at a significantly younger average age than those of White – British and White – Other ethnicities. This reflects NCL's overall population health findings which show that BAME communities experience poorer health outcomes and greater health inequalities.³

Borough	Average age at death (years)
Barnet	57.8
Camden	68.2
Enfield	52.2
Haringey	62.5
Islington	59.9
NCL ICS	60.1

Ethnicity	Average age at death (years)
Any other ethnic group	30
Asian or Asian British	35
Black, Black African, Black Caribbean or Black British	40
White - British	68
White - Other	66

1) Office for National Statistics (ONS), released 11 January 2024, ONS website, statistical bulletin, National life tables – life expectancy in the UK: 2020 to 2022

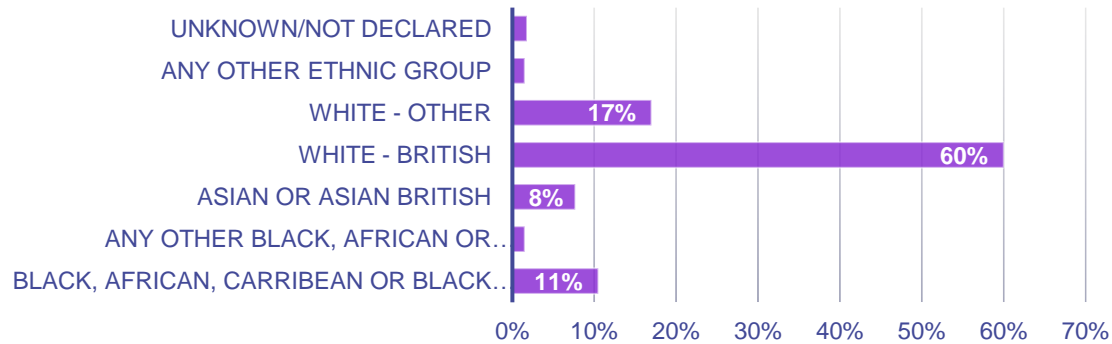
2) Kings College London, LeDeR Report 2022 (published November 2023)
3) North Central London Population Health and Integrated Care Strategy, 6 April 2023

Demographics – Ethnicity and Gender

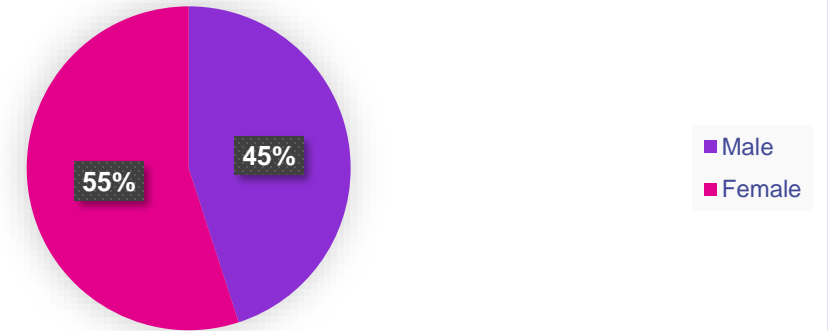


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Deaths Reported by Ethnicity



Deaths by Gender



- The data on deaths reported by ethnicity is consistent with 2020-2021 and 2022-23 reporting, with white British residents continuing to be the largest ethnic group for which LeDeR notifications are received.
- NCL is a very diverse region, and the five constituent boroughs have Black, Asian and Minority Ethnic (BAME) populations ranging from between 30%-44% of their total populations.⁴ Given this, BAME deaths are likely underrepresented in the LeDeR data. This may be due to under-reporting of LeDeR deaths or missed diagnoses within NCL BAME communities.
- BAME deaths will continue to be automatically eligible for focused reviews, given that BAME residents with learning disabilities are dying at a younger age than white NCL residents. The focus on BAME deaths will support the LeDeR team to understand the specific challenges facing this cohort.

- A greater proportion of LeDeR notifications for female residents were received than for males in 2022-23.
- This follows the pattern seen in NCL in 2021/22 but differs from the national LeDeR findings where 55% of deaths were males.⁵
- Based on data from the 2021 census, the higher number of female LeDeR reviews could be partially because all five boroughs have slightly larger female populations.

4) Information gathered from each NCL Local Authority's Joint Strategic Needs Assessment (JSNA)

5) Kings College London, LeDeR Report 2022

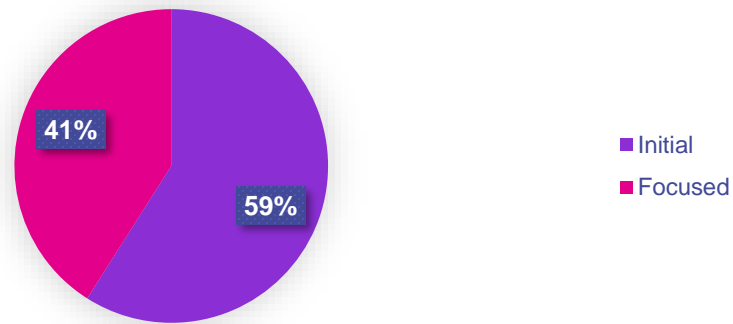
Initial vs. focused reviews

41% of NCL reviews were **focused** compared to 23% of national reviews in 22-23



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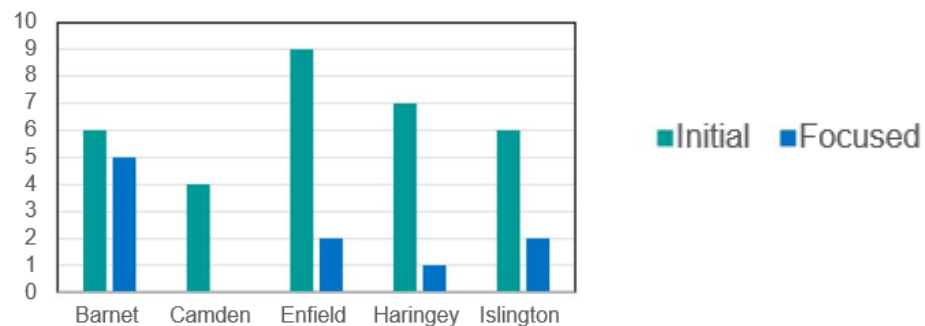
Initial Vs Focused Reviews



NCL criteria for focused reviews:

1. Black, Asian or Minority Ethnic background (BAME) deaths
2. Where the reviewer identifies that there is scope for learning from the case
3. Concerns about the quality of care
4. Autistic adults without a learning disability
5. Respiratory deaths
6. Cancer-related deaths

Initial Vs Focused Reviews by Borough



- 41% of NCL reviews were focused due to 38% of deceased clients being from BAME backgrounds and 32% of deaths relating to respiratory issues.
- Barnet has the highest number of focused reviews, as there were 4 respiratory related deaths and 1 cancer related death in the borough.

Primary causes of death

Diseases of the **respiratory system** were the most common cause of death in NCL



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Cause of death	NCL 2021-22	NCL 2022-23	National Figures 2022 ⁶
Diseases of circulatory system	15%	26%	16%
Diseases of the respiratory system	55%	34%	20.3%
Covid-19	18%	Covid deaths were included in the respiratory category	5.7%
Neoplasms (Cancer)	6%	8%	14.5%
Diseases of the nervous system	0%	6%	13.6%
Congenital malformations and chromosomal abnormalities	0%	0%	13.3%
Diseases of the digestive system	0%	6%	7%
Mental and behavioural conditions (includes dementia and delirium)	0%	3%	3.7%
Diseases of the genitourinary system (i.e. kidney failure)	3%	0%	2.5%
Endocrine nutritional and metabolic diseases (i.e. Diabetes)	3%	0%	2.1%
Sepsis	6%	8%	Not a separate national category
Other causes of death	0%	9%	7%
Total	100%	100%	100%

- **Respiratory related deaths** remain the highest causes of death in NCL.
- NCL's figures are higher than the national figures. **NCL's respiratory working group** is developing a plan to reduce respiratory related deaths.
- **Cardiac and circulatory system** concerns have significantly increased and are higher than the average national figures. The incoming LeDeR co-ordinator will work closely with clinicians to understand the causes of this.

Annual Health Check (AHC) data



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Completed Annual Health Check in the 12 months prior to individual's death	Percentage of NCL reviews	Percentage of national reviews 2022
Yes	43%	47%
No	38%	18%
Unknown	19%	36%

- Annual Health Checks (AHCs) can lead to the identification of undiagnosed problems and are central to reducing avoidable deaths in the LD population.
- **19%** of residents who had an annual health check in the past 12 months in NCL, had a **completed health action plan**. Whilst there are no national statistics to compare this percentage to, the national LeDeR report highlights **nationwide concerns that not all annual health checks result in the development of health action plans** (where necessary) or clinically indicated actions being undertaken. There is a risk that if AHCs do not convert into actionable plans, there is very little benefit for patients.
- **28%** of residents who had an AHC completed within 12 months of their death, **declined routine screening**. It will be explored whether further **reasonable adjustments** are required to increase the uptake of screening.

Review findings – Quality of care and support



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Examples of **positive practise** from 2022/23 reviews include:

- Cases where supported living providers and care homes continued to provide people with **emotional support and companionship in acute settings**
- Reviews which highlighted that **voluntary sector** organisations (such as Barnet Mencap) helped people, who may have otherwise been isolated, to live a **meaningful and fulfilled life**
- Cases where NCL **Day Services** (such as Community Link) played a significant role in providing people with **friendship, community and purpose**.
- Instances where **communication books and hospital passports** had been carefully developed to ensure a smooth transition for people moving to **hospices for end-of-life care**
- **Partnership working** between integrated LD teams and ward staff
- Support and reasonable adjustments from **LD Liaison nurses**

Areas of **concern** from 2022/23 reviews include:

- **Lack of reasonable adjustments** made to support people to attend GP and specialist follow-up appointments. For example, limited supply of easy read information and sending of texts that people may not have read
- The need for all adults with a learning disability to have had an **Annual Health Check** completed within the last 12 months. Compliance with this is below 50%.
- The quality of support offered on wards when LD liaison nurses are not on duty
- The high number of deaths due to **respiratory conditions**
- The high and increased proportion of deaths were due to **circulatory conditions** compared to 2021/22
- **BAME residents dying at a significantly younger** than residents from other ethnicities
- Approximately **23% of LeDeR deaths were due to avoidable causes**, highlighting a need to improve care pathways to improve the prevention and management of early deaths

LeDeR Action Plan



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Theme	Action	Completed by
Deaths related to the circulatory system	<ul style="list-style-type: none"> Complete a deep-dive into all focused reviews related to the circulatory system to understand key themes and preventative measures required to reduce avoidable deaths 	December 2024
Respiratory related deaths	<ul style="list-style-type: none"> Deliver improvements within the respiratory care pathway for LD residents through the NCL respiratory working group 	Ongoing
Cancer related deaths	<ul style="list-style-type: none"> Share data on all cancer related deaths (focused reviews) with the Camden and Islington Health Facilitator for Cancer Screening in the Community integrated learning disability service, to support an increased uptake in cancer screening 	July 2024
No reviews recorded for autistic residents without a learning disability	<ul style="list-style-type: none"> Develop and disseminate clear communications to NCL hospitals and health and social care providers to ensure they are aware that they must report the deaths of autistic residents without a learning disability 	December 2024
Deaths of BAME residents	<ul style="list-style-type: none"> Complete a deep-dive into all focused reviews for BAME residents to identify the causes for deaths at younger ages and to identify preventative measures required to reduce avoidable deaths 	December 2024
Increasing AHCs	<ul style="list-style-type: none"> Work with the NCL Annual Health Check Working Group to increase AHC completion Develop clear communications for all agencies in the LD sector to promote Annual Health Checks 	Ongoing
Ensuring reasonable adjustments are widely offered	<ul style="list-style-type: none"> Collaborate with the primary care team, and acute settings to ensure reasonable adjustments are available for all clients with a learning disabilities 	Ongoing
Incomplete reviews	<ul style="list-style-type: none"> Continue the work with PSG to complete the review backlog Ensure the learning and key themes from historic reviews are shared with NCL stakeholders 	December 2024
Delivering NCL-wide change and learning from LeDeR reviews	<ul style="list-style-type: none"> Establish an NCL-wide LeDeR meeting where common themes are raised as well as cross-border issues Ensure experts by experience can contribute to all borough steering groups and the development of action plans 	October 2024



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