

Annual report Islington CCG Learning Disability Mortality Reviews (LeDeR)

1st April 2018 – 30th March 2019

Report compiled on behalf of the Islington LeDeR steering group by

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Acknowledgments:

The author would like to extend their thanks to all of the reviewers who have contributed to the LeDeR reviews in Islington, it should be noted that undertaking these reviews has usually been in addition to their day to day work. The LeDeR reviews reflect a great deal of analysis and detective work on behalf of the reviewers, they have each brought to life the circumstances leading up to the death, as well as providing a portrait of the lives of the people they have reviewed.

In addition special thanks has to be given to the Islington Learning Disability Partnership Board Health and well-being Subgroup who have maintained an active interest in the work of the LeDeR programme and have provided additional scrutiny and comments of this annual report

1.0 Introduction

This is the first annual report presented by Islington Clinical Commissioning Group (ICCG) as required by the 'NHS Long Term Plan January 2019'¹.

The LeDeR programme reports on deaths of people with a learning disability aged 4 years and over, the definition used is that of 'Valuing people' (2001)² and includes the presence of:

“a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development”

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It was implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017.

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death.

The LeDeR programme commenced in Islington in October 2016 reviewing all deaths of individuals with a learning disability aged 4 yrs upwards, its aim to positively influence practice and policy by:

- Identifying potentially avoidable contributory factors related to deaths of people with learning disabilities
- Identifying variation and best practice in preventing premature mortality of people with learning disabilities
- Developing action plans to make any necessary changes to health and social care service delivery for people with learning disabilities

The LeDeR programme is administered and managed from Bristol University on behalf of NHS England. Within Islington the Local Area Co-ordinator is David Pennington on behalf of the CCG.

Key processes to deliver Mortality reviews of people with learning disabilities have been established, Islington has a local LeDeR steering group chaired by the Islington LAC. As well as being part of the wider North Central London Steering group (see appendix 1).

¹ <https://www.longtermplan.nhs.uk/>

² Dept of Health (2001) valuing people: a new strategy for Learning Disabilities for the 21st Century

2.0 LeDeR National report

In May 2018 the University of Bristol produced the third annual report of the Learning disabilities Mortality review Programme. The report contains information and recommendations and the intended actions shared by the reviewers. There are 12 key recommendations from the report listed in table 1.

Table 1:

Key recommendations from the national report:

1	Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme
2	NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.
3	There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, health and social care so that 'learning disability' has a common understanding across each of the sectors and between children's and adults' services.
4	Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action
5	The Department of Health and Social Care and NHS England to support national mortality review programmes to work with 'Ask, Listen, Do' and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death.
6	The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia.
7	Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.
8	Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability Code of Practice in relation to identifying and sharing information about people

	with learning disabilities approaching transition, transition planning and care coordination must be addressed.
9	The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children's to adults' health services.
10	The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death.
11	Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording 'learning disabilities' as the rationale for DNACPR orders or where it is described as the cause of death.
12	The Care Quality Commission to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution.

3.0 Comparison between Islington and the National data

3.1 Number of deaths, and gender notified

The LeDeR annual report for 2018³ was published by the University of Bristol in May 2018 indicates that from 1st July 2016 to 31st December 2018, 4302 deaths were notified to the programme. In 2018 this was approximately 85% of the estimated number of deaths of people with learning disabilities in England each year

The national data is sourced from all services based in England, within Islington between 2016 and March 2019 we have had sixteen notifications of deaths and of these eight completed by the end of March 2019 (see table 2).

Table 2:

Year	Number of deaths notified	Completed	Female	Male
2016	2	2	0	2
2017	2	1	2	0
2018	8	5	5	3
2019	4	0	1	3
total	16	8	8	8

³ LEDER annual report 2018 published May 2019 bristol.ac.uk/sps/leder

* It should be noted that the 2 additional reviews were undertaken in 2016 before the commencement of the national programme. These have been included in all of the data.

For the purposes of this report where possible information has been extracted from the initial notification (e.g. gender and age at death). For this reason as the reports has not been submitted and verified by the reviewer the findings should be treated as indicative.

3.2 Age at death

The National report notes that the median age at death was 59 years, for males it was 60 years, for females it was 59 years. In the general population of England the median age of death (for people of all ages including 0-4 years) was 83 years for males and 86 for females.

Within Islington the gender ratio of those that died was 50/50. The median age of death was 57, for men the median was 67 years whilst for women it was 47 years. The youngest recorded death was 9 years, whilst the oldest was 86.

Table 3:

Age	number	Percentage
4-9	1	6%
10 - 19	0	-
20 - 29	0	-
30 - 39	2	12%
40 – 49	0	-
50 – 59	5	31%
60 - 69	4	25%
70 - 79	3	19%
80 - 89	1	6%

The age at death is 10 years higher for men and 12 years lower for women than the national average. The small number of deaths (16) within Islington mean it is difficult to make any assumptions about these numbers, however the LeDeR steering group will remain vigilant in relation to the age at death.

3.3 Place of Death

Nationally the proportion of people with learning disabilities dying in hospital was 62%; in the general population it is 46%. In the LeDeR 2016/2017 annual report they reported the proportion of deaths in hospital of people with learning disabilities to be 64%. Within Islington the place of death

is similar to the general population with only around 44% of death in Hospital, most people die in their usual place of residence (either their own home, supported living or residential home)

“The End of Life Care Plan was followed. YY wish to stay at XX Lodge nursing home and not be admitted to hospital was respected.”

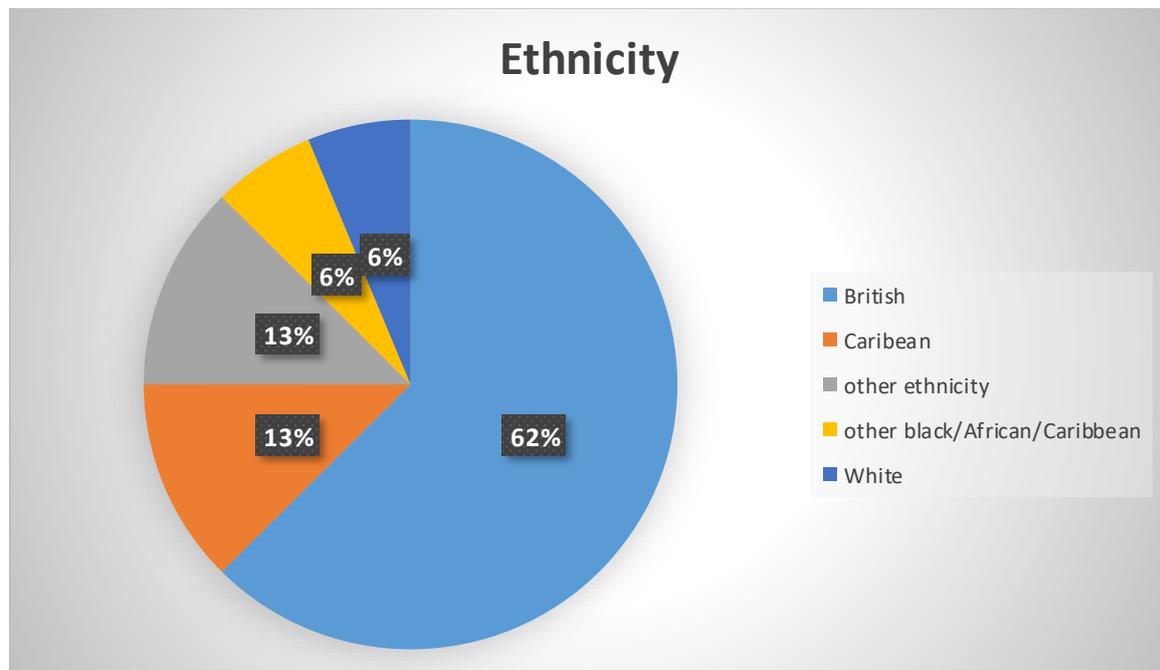
Table: Islington Place of death

Place of Death	Proportion
Hospital	7 44%
Usual place of residence	8 50%
Other	1 6%

3.4 Ethnicity

The proportion of people from Black and Minority Ethnic Groups (BAME) was lower at 10% than that from the population in England as a whole 14%. In Islington 32% of residents are in Black and Minority Ethnic (BAME) groups and 20% of residents “Other White” in 2018⁴. The ethnicity of those within the LeDeR framework broadly reflects the population of Islington.

Table:

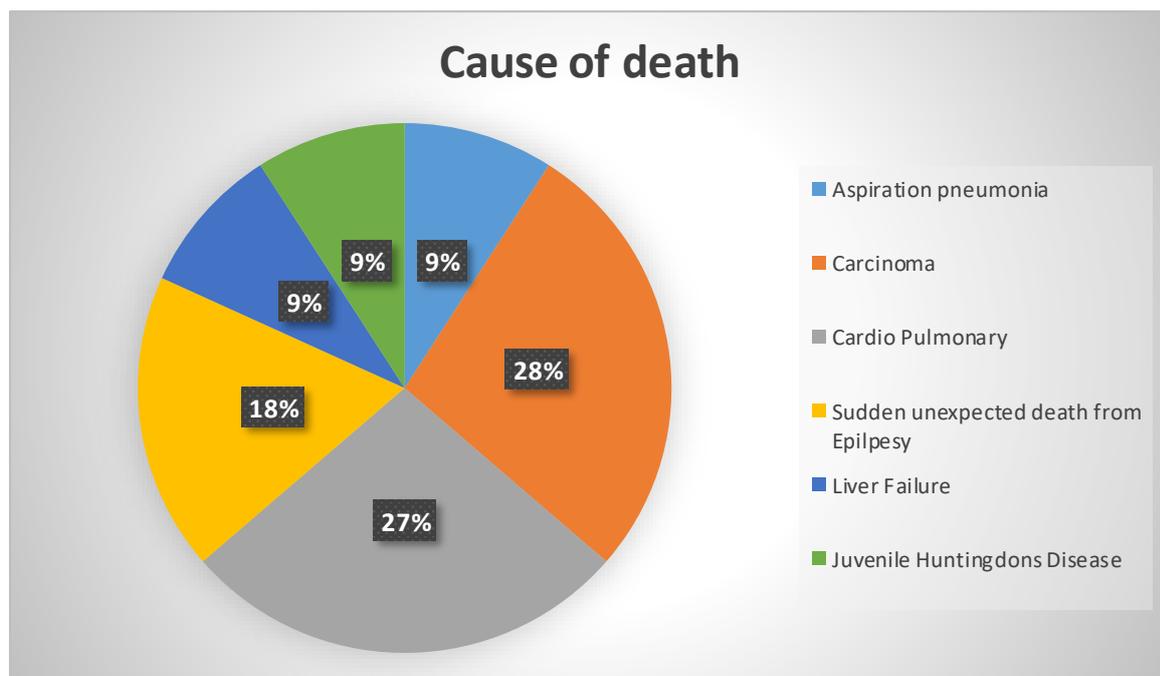


⁴ State of equalities in Islington; Annual Report 2018 LBI

3.5 Causes of Death

Nationally the medical conditions most frequently cited anywhere in Part I of the Medical Certificate of Cause of Death were: pneumonia (25%), aspiration pneumonia (16%), sepsis (7%), dementia (syndrome) (6%), ischaemic heart disease (6%) and epilepsy (5%). Across the general population more frequently die from cancer and diseases of the circulatory system than the people with learning disabilities.

Table : Islington Cause of deaths



4.0 Themes, learning points and recommendations from reviews

“XX had a good level of service and care from Islington Learning Disability partnership including bespoke epilepsy care plans by a very experienced Learning Disability Nurse and by regular contact with a very experienced long-term social worker who knew XX and her family well”

Across several cases there were incidents where the Annual learning Disability health check had not taken place, however it was also clear in some of these cases there was a great deal of input from primary care services.

Reviewers of the Islington deaths found many examples of good and excellent practice, frequently patients were supported by multiple services and individuals who provided person centred care, providing assistance and support in the persons preferred place of death. In all of the reviews a further multi-agency review was not required/indicated

“Mental Capacity Assessments were completed using reasonable adjustments such as Easy Read documentation, taking time to provide extended appointments to ensure ZZ had all information and time to consider and weigh the range of choices available to her and the consequences of her decision making.”

Learning from reviews:

- Service users should be given additional support to take part in annual health checks
- Extra work is required to improve communication regarding health promotion, e.g. screening, requests to attend appointments should be provided in a more accessible format
- Using genealogy services were able to make contact with family that had lost contact many years ago. This could potentially be used to support contact with families where contact has been lost
- End of life planning should be discussed as early as possible, supported by active conversations about death and dying
- Further work is required on assessing capacity and recording best interests decision making

5.0 Conclusion and next steps

Islington continues to be committed to deliver the LeDeR programme. During the past year our reviewers have managed competing priorities to deliver thorough reviews. There are still a number of reviews to be completed, the Islington LeDeR will continue to monitor progress and the actions arising from these reviews.

The Islington LeDeR steering group will continue to lead on implementing local learning locally, and will support more people to train to become reviewers.

Moving forward it is the intention of the NCL LeDeR steering group to host an overall action plan. This will help to identify themes and opportunities across NCL, helping us to maximise the use of resources. Initial themes identified include:

- End of life
- Annual health checks
- Mental Capacity Act
- Shared records

Appendix 1

North Central London LeDeR Governance Structure

