1. INTRODUCTION

This is Haringey's first Learning and Disabilities Mortality Review (LeDeR) annual report. The report provides an update on the work undertaken by the LeDeR steering group since the programme started in May 2017.

2. BACKGROUND

The Learning Disabilities Mortality Review (LeDeR) Programme was established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD). CIPOLD reported that for every one person in the general population who dies from a cause of death amenable to good quality care, three people with learning disabilities (LD) would do so. Whilst the majority of illnesses that led to the deaths of people with LD were promptly recognised and reported to health professionals, for more than a quarter there was a significant difficulty or delay in diagnosis, further investigation or specialist referral and for a further quarter there were problems with their treatment.

The LeDeR programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The programme commenced in June 2015 with a number of pilot sites identified, it was extended nationally in April 2017 with the expectation that all deaths of people with a learning disability would receive an initial review of the circumstances surrounding their deaths, and whether failures of care were indicated.

The overall aim of the LeDeR Programme is to drive service improvement in the quality of health and social care service delivery for people with LD and to help reduce premature mortality and health inequalities in this population. It supports local areas to review deaths of people with LD in England and to use the lessons learned to effect improvements to service provision. It also contributes to national and international evidence about mortality in people with LD.

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. Themes and learning identified in reviews would also be available as a growing body of qualitative data gathered by the University of Bristol, which hosts the LeDeR programme.

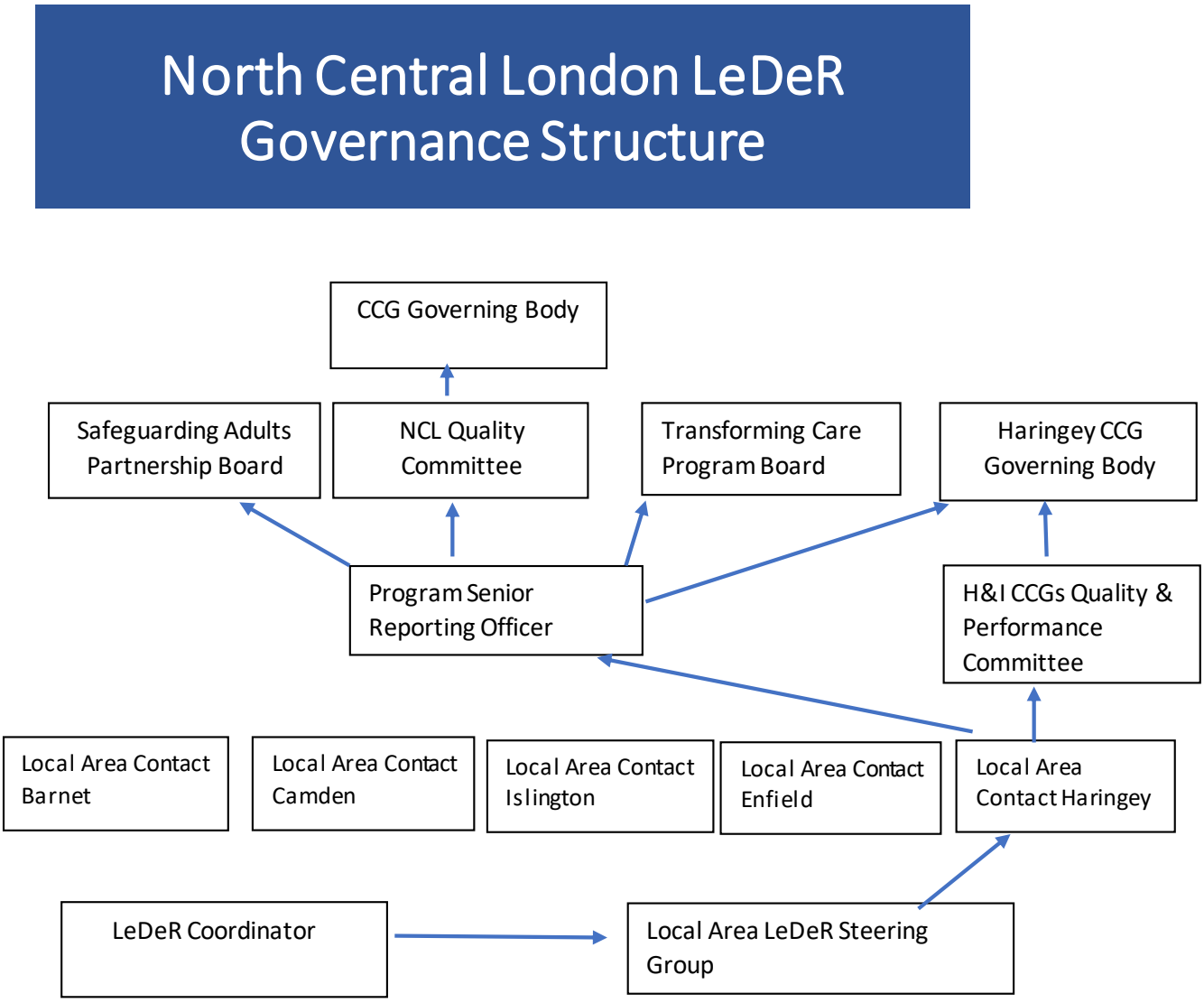
The LeDeR Programme has adopted the definition of learning disabilities that is used in the Learning Disabilities White Paper 'Valuing People' (2001), which states that a person with learning disability has the following:

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

3. GOVERNANCE ARRANGEMENTS

NHS England holds responsibility for delivery of the LeDeR programme.

Each STP in London has an STP wide LeDeR steering group to support the local steering groups. North Central London (NCL) has a LeDeR steering group that reports into NHSE London LeDeR programme. The steering group escalates issues identified by the local steering groups to NHS England and the LeDeR programme, it also resolves issues and challenges from local reviewers. Another key role for the NCL steering group is to negotiate usage of money from NHSE allocated at STP level to support LeDeR.



3.1 Local Governance Arrangements

Locally, the Director of Nursing and Quality for Haringey and Islington CCGs is the strategic lead for LeDeR, and currently the Head of Quality Improvement Haringey CCCG is the Local Area Contact for LeDeR (LAC) who chairs the steering group with co-chairing carried out by the CCG quality team (Head of Quality Improvement or Assistant Director of Quality).

3.2 Local Steering Group

Haringey has a well-established a local steering group that meets on a quarterly basis. There is strong partnership working in Haringey to drive the LeDeR agenda forward, there is representation from Local Authority, North Middlesex University Hospital NHS Trust and Whittington Health NHS Trust and CCG representatives. The steering group is aligned to the North Central London and the London Region steering groups.

The LAC and Haringey CCG's Designated Professional Safeguarding Adults quality check all completed LeDeR reviews against a set of standards provided by the programme.

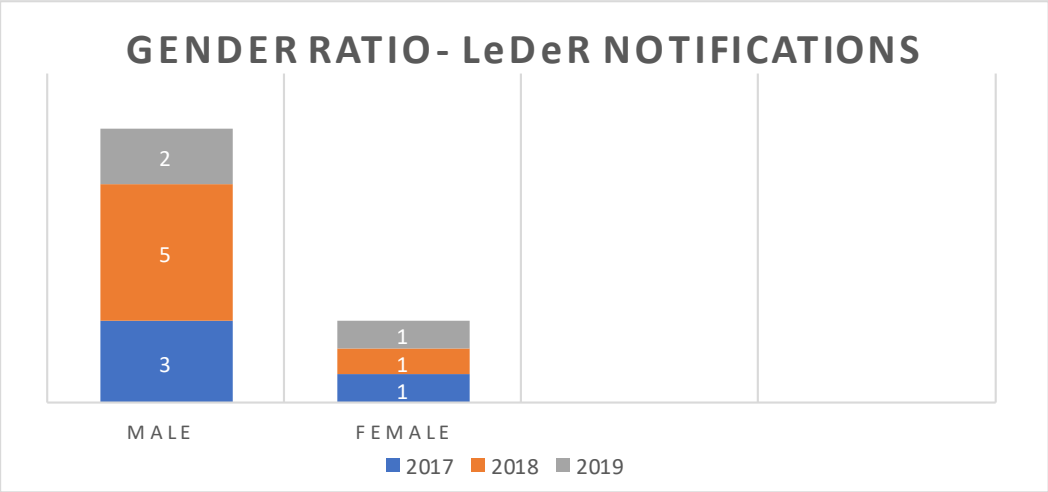
The Local Area Contact (LAC) is responsible for:

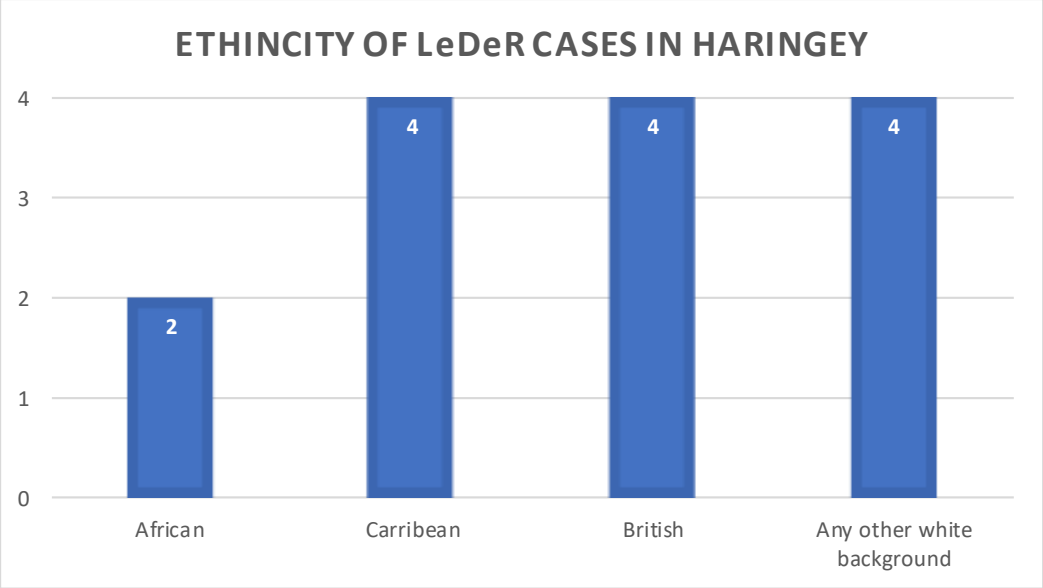
- Monitoring and oversight of all cases and escalation of risks to NEL group and local agencies.
- Quality Assurance review of reports
- Resolving issues and challenges from reviewers
- Allocation of cases and review of progress

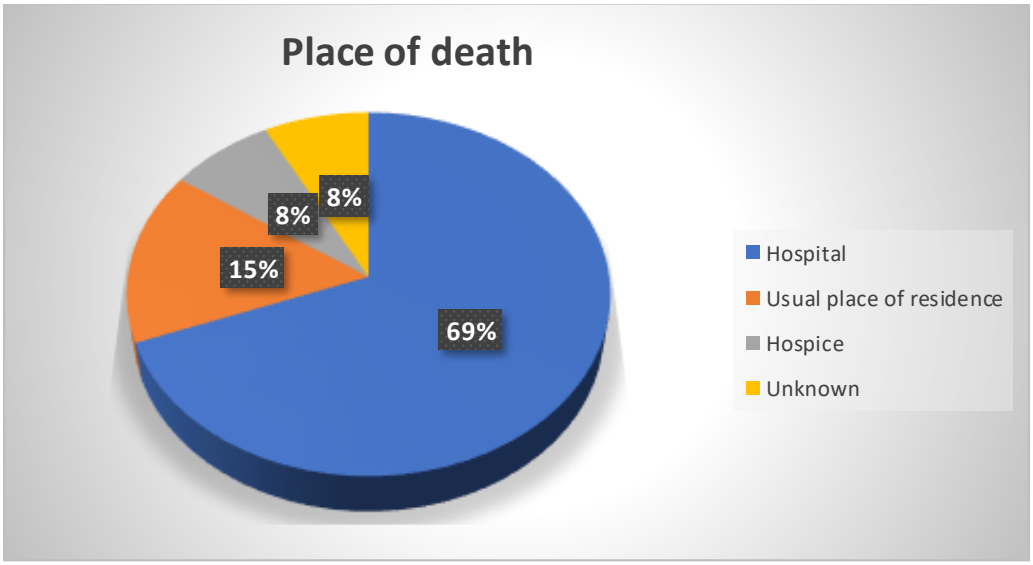
4. LOCAL CONTEXT

Since February 2017, Haringey has received 13 LeDeR case notifications, of the 13 cases, 12 were adult cases with one child notification. None of the cases met the criteria for a multi-agency review.

4.1 Demographical data







Haringey has had more male deaths compared to female; however our sample is too small to draw any meaningful conclusion from the data.

69% of deaths in Haringey were in hospital and the national figure is 62% whilst the proportion for people in the general health population is 46%.

5. PEFORMANCE

The table below shows Haringey's performance in completing reviews.

Table:

Year	Number of deaths notified	Reviews allocated	Reviews completed	Reviews completed in 6 months timescale
01/02/17-30/03/18	4	4	4	0
01/04/18-31/03/19	8	8	0	0
01/04/19-31/06/19	1	1	0	0

Haringey like most areas has faced challenges in completing the mortality reviews within the stipulated 6 month timeframe. This is due to varying reasons:

- Lack of reviewers in the system and difficulty recruiting reviewers especially from outside learning disability services
- Trained reviewers capacity and high turnover of trained reviewers
- Lack of administrative support for LeDeR - since January 2019 there was no administrative support for LeDeR. There is now an NCL LeDeR Coordinator in post
- Delays in receiving/accessing health records from care providers
- Delays in starting a review due to statutory reviews being undertaken e.g. delays due to; inquests, serious incident process, child death overview process.

6. EMERGING THEMES IN HARINGEY

Of the four completed cases, emerging themes from the completed case are similar to themes identified at a national level such as the lack of implementing the Mental Capacity Act. Lessons learnt includes:

- Questions over capacity should be clearly documented in the notes particularly when closing a case.
- Use of the hospital passport
- Recognition of early warning signs of ill health
- Soon after admission of a patient with LD into hospital, the relevant community LD team should be involved.
- There should be a Multi-disciplinary (MDT) approach to managing a patient's risk due to complex physical and mental health – this should be clearly documented
- Multi-agency discharge planning meeting/teleconference should be compulsory.
- People with Learning Disabilities (PWLD) have access to Annual Health Checks (AHC) and health screening programmes - this is also part of Haringey CCG's Equality Objectives plan for 2017 – 2019 and the Primary Care Quality Objective 2019/2020.

7. HARINGEY LeDeR ACTIVITY ACHIEVEMENTS

Haringey were highlighted in the National NHS England report on Action into Learning for two action initiatives:

1. In Barnet and Haringey, the community learning disability team are working with district nursing, phlebotomy, primary care and acute hospitals on a quality improvement project to improve access to blood tests for people with a learning disability and ensure that they can access the service in a timely manner
2. Haringey Learning Disabilities Partnership developing a complex physical health pathway to reduce the risk of hospital admissions, help to maintain and improve health and improve quality of life for adults with learning disabilities - both initiatives will be reported back to steering group on progress

8. HARINGEY CCG'S STRATEGIC OBJECTIVES FOR 2019/2020

The NHS Operational Planning and Contracting Guidance 2019/20 includes four deliverables in relation to the LeDeR programme, Haringey CCG has already begun to put measures in place to ensure they are met, as outlined below:

- CCGs are to be a member of Learning from Deaths report (LeDeR) steering group and have a named person with lead responsibility.
  Haringey CCG is already engaged in the steering group and the Director of Nursing and Quality is the Named Person with Lead responsibility.

- There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area

- CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.

- An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.
  This is the first annual report produced for LeDeR, the report will be shared with the Quality and Performance Committee within the CCG as well as with partner agencies.

9. HARINGEY LeDeR LOCAL STEERING GROUP PRIORITIES FOR 2019/2020

- Improve and strengthen the local process to enable reviews assigned and completed within timescale.
- Development of a stronger governance process around LeDeR action plans, ownership of progress, and escalation of risk associated with these.
- Develop service user and families/carers involvement in the LeDeR programme in Haringey
- Develop a mechanism for disseminating learning from LeDeR to GP Practices in Haringey
- To raise awareness of the LeDeR programme within Primary Care and to develop LeDeR champions in each of the Haringey GP surgeries
- To hold a feedback event of the LeDeR work in for all stakeholders
- Strengthen the quality assurance governance process
- Share idea and work collaboratively with other CCGs across NCL by developing an overarching NLC LeDeR action plan pulling together common themes ensuring capacity is maximised and to avoid duplication of effort
- Recruit more reviewers and offer training and supervision to reviewers

10. CONCLUSION

Haringey CCG continues to be committed to delivering the LeDeR programme. The past year has been exceedingly challenging due to the lack of resources such as the availability of trained reviewers, time for reviewers to undertake the reviews due to competing work priorities. Through the LeDeR steering group, there has been a more coordinated and collaborative approach to improving annual health checks for people with learning disability between the Assistant Director of Primacy Care and the Learning Disabilities Commissioners.