NHS
Camden
Clinical Commissioning Group

Learning Disability Mortality Review (LeDeR) Annual Report 2018/19

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1. Introduction

The purpose of this report is to provide NHS Camden Clinical Commissioning Group (CCG hereafter) with the local Learning Disability Mortality Review (LeDeR) programme annual report. The LeDeR programme[1] is delivered by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England (NHSE). The overall aim of the programme is to drive improvement in the quality of health and social care services delivery and to help reduce premature mortality and health inequalities.

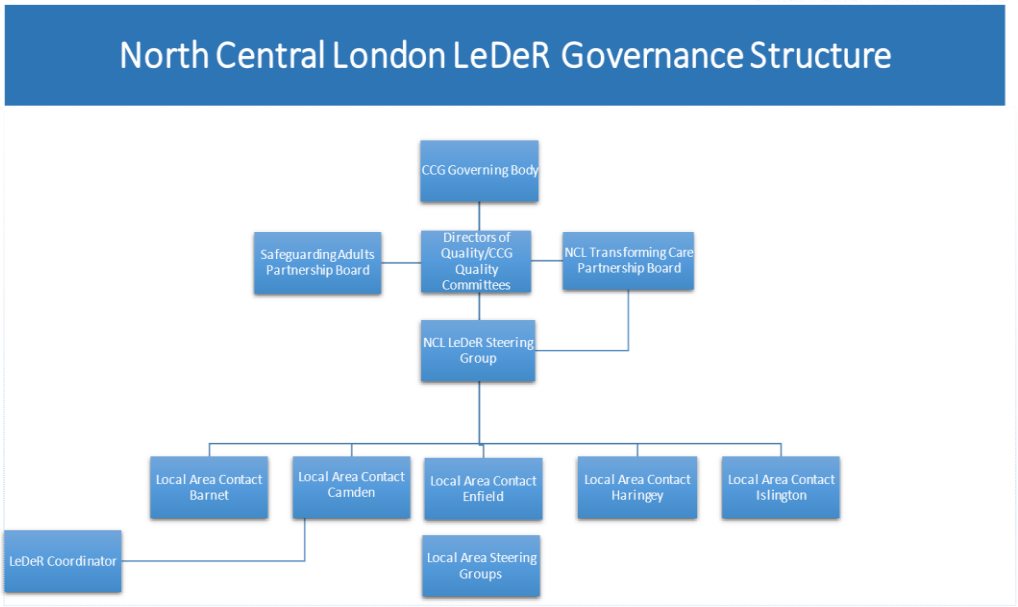
The Confidential Inquiry in to Premature Deaths of People with a Learning Disability[2] (CIPOLD) reported the median age at death for males was 65 years. Men with learning disabilities died on average 13 years earlier than men in the general population. Median age at death for women was 63 years showing that women with learning disabilities died on average 20 years earlier than women in the general population. As a result, all deaths of people with learning disabilities aged 4 years and over must be reviewed using the LeDeR framework, regardless of whether the death was expected or not, the cause of death or the place of death. The reviews aim to positively influence practice and policy by:

- Identifying the 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.

2. Governance

Camden LeDeR has been in place since December 2016 and is coordinated by the CCG Designated Nurse for Safeguarding Adults who also line manages the North Central London (NCL) LeDeR Coordinator. Camden LeDeR reports in to the Quality and Safety Committee and also the Camden Safeguarding Adults Partnership Board. The Assistant Director of Special Projects for Islington CCG is the North Central London lead reporting in to NHSE.

[1] http://www.bristol.ac.uk/sps/leder/
[2] http://www.bris.ac.uk/cipold/



CCG LeDeR leads across NCL meet quarterly to look at emerging themes and opportunities for improvements. Camden CCG is updated, via the Quality and Safety Committee in relation to any identified risks and the progress of improvements. As the action plan develops, the LeDeR steering group will progress development of formal links to existing learning disability groups to ensure the findings are discussed with experts by experience to influence the actions required.

3. Local Performance

The Camden LeDeR steering group is chaired by the CCG Designated Nurse for Safeguarding Adults and has membership from across health and social care safeguarding adults and learning disability professionals. Membership has now extended to colleagues from integrated commissioning. The purpose of the steering group is to coordinate the reviews to ensure that they are of sufficient quality and that learning is disseminated in to practice and service development.

Funding for one year to appoint a LeDeR Coordinator across North Central London (NCL) was provided from NHSE. However, there is no permanent additional resource to deliver the LeDeR programme, meaning staff who become reviewers must complete reviews in addition to their existing workloads. Since December 2016, Camden have been notified of 13 deaths for review, 11 have been completed, one is in progress, and one is awaiting the outcome of a Safeguarding Adults Review. It should be noted that LeDeR is not a statutory review process and must await the outcomes of any statutory reviews such as Safeguarding Adults Reviews or Child Death Overview Panel reviews to conclude before a LeDeR can be submitted. As a consequence, the quarterly performance data submitted to NHSE may occasionally show delays in completion of reviews which are outside of the LeDeR programme control. Nevertheless, NHSE have highlighted Camden as being a high performing site for completion of reviews.

There are no plans to discontinue the LeDeR programme. The NHS Long Term Plan sets out a commitment to accelerate the LeDeR initiative to identify common themes and learning points and provide targeted support to local areas.[3]

[3] https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf

4. Learning and Improvement

Figure 1: Place of Death

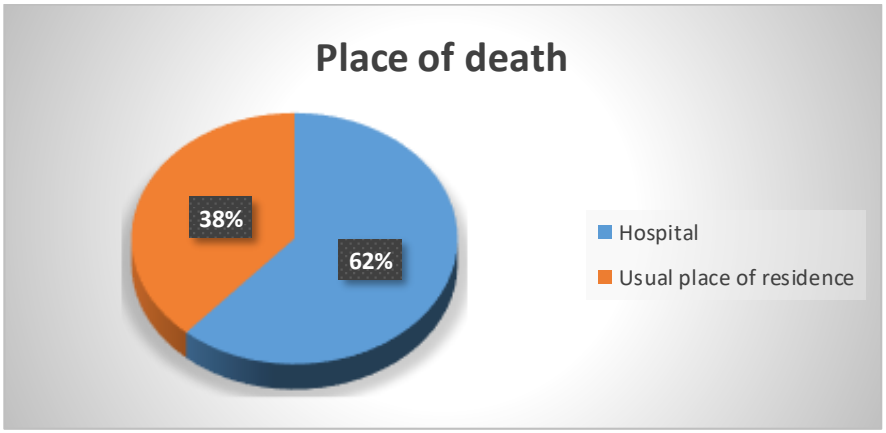


Figure 1 shows 62% of those people reviewed died in hospital. While some conditions do result in an emergency admission to hospital and also death if medical intervention is not successful, it is recommended that end of life care for people with a learning disability could be improved. Such improvements could increase the numbers of people who are able to have end of life care in their home setting. The Community Learning Disability Service have been working closely with supported living staff, hospital and community health care staff to make improvements in care and support for people to be safely managed at home. This is an area for monitoring on the LeDeR action plan. There is also considerable work required and also in progress to identify deteriorating conditions to avoid emergency admission and premature death which are detailed in Figure 2 below.

Figure 2: Causes of Death

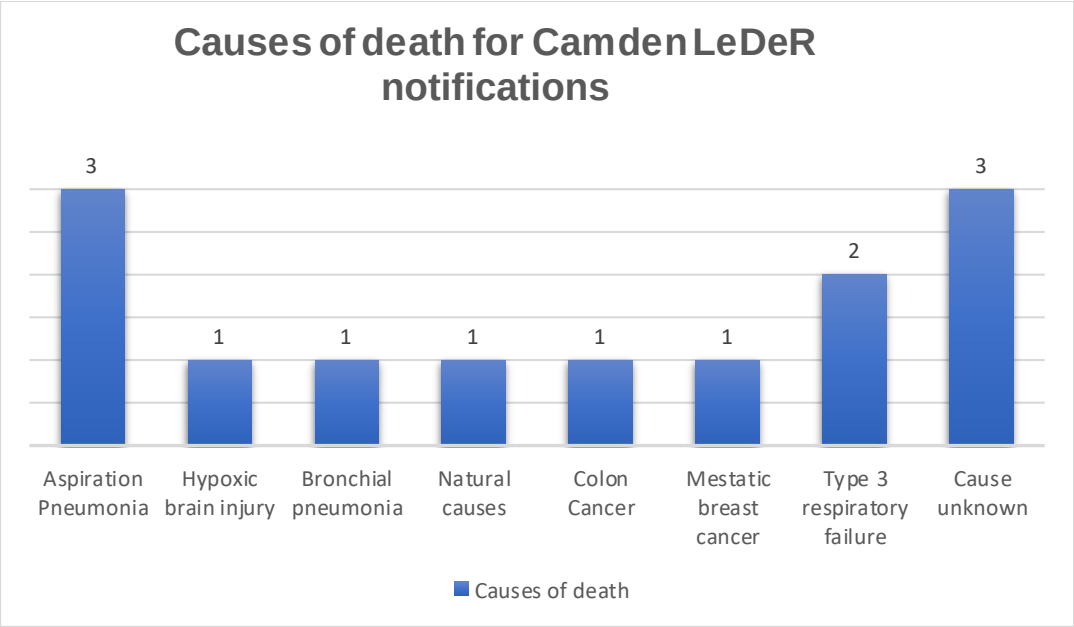
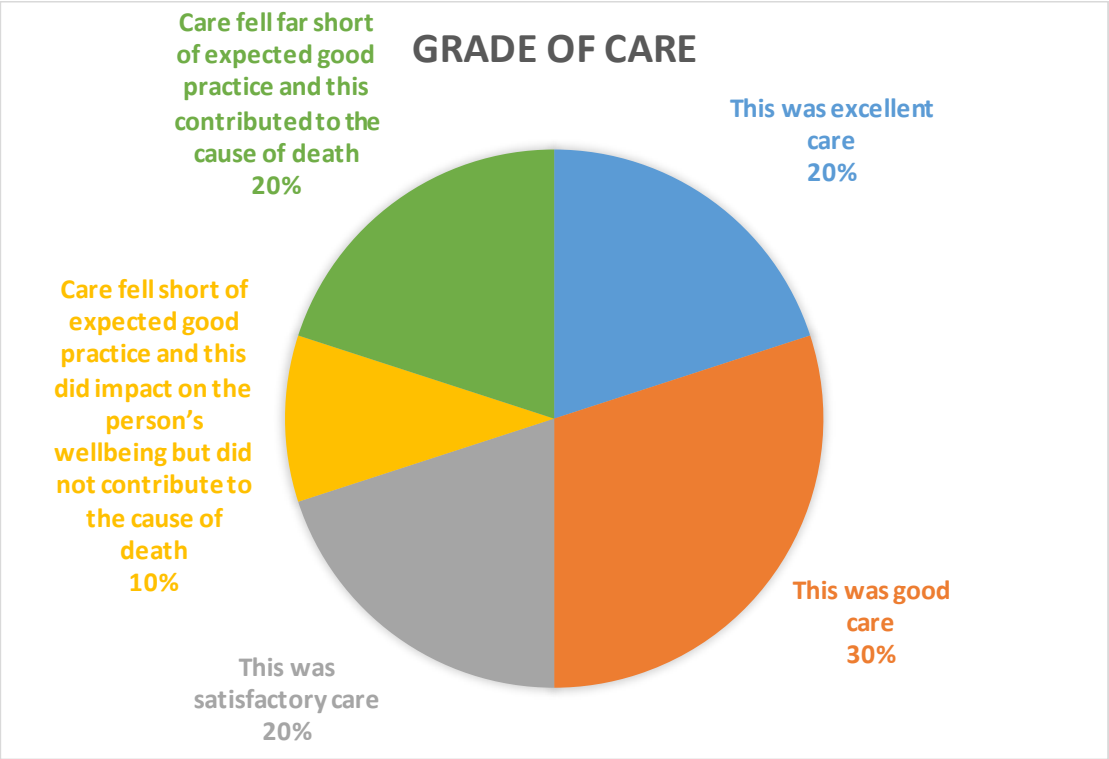


Figure 2 shows a significant proportion of deaths are associated with respiratory problems, this is in-keeping with the national LeDeR findings which show 31% of deaths as being attributable to respiratory conditions in 2017. As a result, the CCG and CLDS (Camden Learning Disability Service) have worked to promote flu vaccine uptake in GP Practices and CLDS led task and finish work to produce materials for individuals and their carers on

prevention of pneumonia and when to seek medical assessment. There are also a number of deaths where the cause has not been available to the reviewer, which is an area for further exploration and improvement.

Figure 3: Conclusion of Reviews



It is encouraging that 70% of reviews in Camden concluded, using the NHSE quality markers, that care was satisfactory, good or excellent. However, for 30% of individuals reviewed, their overall care fell short of good and unfortunately, in some cases, contributed to their death. A significant contributory factor to failings is the poor understanding and application of the Mental Capacity Act 2005, which has also been a consistent finding in reviews nationally. 2 of the 13 deaths reviewed raised concerns which met the threshold for a statutory Safeguarding Adults Review, one of which has been published for Adult W and one for Adult V V which has not yet concluded.

Actions taken in relation to reviews to date have included:

- Advice and support materials developed for individuals and carers developed by a task and finish group led by CLDS for constipation and pneumonia.
- GP safeguarding adults meetings and training featured recommendations from LeDeR including embedding the mental capacity templates in the electronic records, coding patients with learning disabilities and their carers, uploading the learning disability constipation pathway to the GP internet.
- A focus on meeting the needs of vulnerable people was a key design principle in the Adult Elective Orthopaedic Services Review and has been incorporated in to the proposed models.
- CLDS working with supported living services to upskill carers around identifying and responding to deteriorating signs and symptoms

- A successful drive to increase annual health checks in Camden for people with learning disabilities
- Mental Capacity Act (MCA) masterclass for GP's held and a template for recording MCA assessments and best interests decisions promoted in the electronic GP record
- 'Jargon buster' guide developed by Royal Free Hospital
- Guided tours of hospital and discussion about hospital experiences arranged by UCLH to reduce anxiety

5. Priorities for 2019/20

CCG LeDeR priorities for 2019-20

CCG Strategic Aim	Safeguarding Priorities
Improve the quality and safety of commissioned services	To support and monitor commissioned services compliance with the Learning Disability Improvement Standards
Improve health outcomes, address inequalities and achieve parity of esteem	To share LeDeR learning across all commissioned services and monitor improvements using the safeguarding adults assurance tool to support innovation across North Central London
Involve member practices and commissioning partners in key commissioning decisions	To continue to work with both the Named GP for Learning Disabilities and Safeguarding Adults to ensure LeDeR learning is disseminated to practices and in to provider service improvements
Work jointly with the people and patients of Camden to shape the services we commission	To deliver the LeDeR programme to capture the experiences of people with learning disabilities and their families and disseminate to inform commissioning work.
Maintain financial stability and ensure sustainability through robust planning and commissioning of value-for-money services	To work with CCGs across NCL and partner agencies on to deliver the LeDeR programme and initiatives to ensure resources are improving outcomes for people with learning disabilities