Barnet Clinical Commissioning Group

Annual Report
Barnet CCG
Learning Disability Mortality Reviews (LeDeR)
1st April 2018- 30th March 2019

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Introduction

This is the first annual report presented by Barnet Clinical Commissioning Group (BCCG) as required through the 'The NHS Long Term Plan - January 2019'.

Health inequalities between different population groups have been well documented, including the inequalities faced by people with learning disabilities. Today, people with learning disabilities die, on average, 15-20 years earlier than people in the general population.

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 concerns on the deaths of people and the introduction of the national Learning from Deaths framework in England in 2017.

Under the LeDeR review process 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, proceed to a multi-agency review of the death.

Key processes to deliver mortality reviews of people with learning disabilities have been established. Our local steering group was established early in 2018 with the Head of Joint Commissioning (CCG) and Health Team Leader (Integrated community LD service) jointly chairing and taking the Strategic lead. The CCG has developed a robust quality assurance process through a Quality Assurance Group to ensure that reviewers are supported and that high quality proportionate reviews are completed and that the lessons learned are put into action in Barnet and across North Central London.

The most significant challenge to the delivery of the programme has been the rate at which mortality reviews are being completed. Barnet is not alone in this regard and the NCL steering group is supporting an action plan to address this. The main reasons for the delays have been:

- Deaths being notified before capacity was in place locally to review
- Limited resources available to undertake reviews and the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review (churn of reviewers)
- reviewers having sufficient time away from their other duties to be able to complete a mortality review

Deaths notified in Barnet CCG to the LeDeR programme

Table 1 below shows deaths reported by year up to 30/03/19, the numbers of reviews completed, numbers still with a reviewer and reviews awaiting allocation.

Table 1

Year	Number of deaths notified	Completed reviews	Reviews allocated	Awaiting allocation
1/04/16 - 30/3/17	1	0	1	0
1/4/17 – 30/3/18	11	5	6	0
1/4/18 – 30/3/19	16	3	11	2

Table 2 shows sources of notifications of deaths to LeDeR in 18/19

Table 2

Barnet Learning Disability Service	63%
Acute Liaison Nurses RFH	21%
Other hospital / health provider	11%
Care & Support provider	5%

Barnet CCG context against National LeDeR findings 2018/19

Table 3	National LeDer data	Barnet LeDer data
Age of death for people with learning disabilities	Men - 59 years Women - 56 years Average - 58 years	Men - 64 years Women - 58 years Average - 61 years 20 people (71%) were over the national average age of 58 years. 9 people (25%) were 70 + years - significantly above the national average[1].

[1] Further analysis will be undertaken in future years to compare this data with Barnet population trends.

Tables 4 and 5 below shows further detail of recorded causes of death in 18/19 and place of death.

Table 4	National LeDer data	Barnet LeDer data
Place of Death	Hospital - 64% Home - 30% Hospice- 2%	Hospital - 44% Home - 38% Hospice – 6% Residential / Nursing – 6% Home of relative / friend – 6%

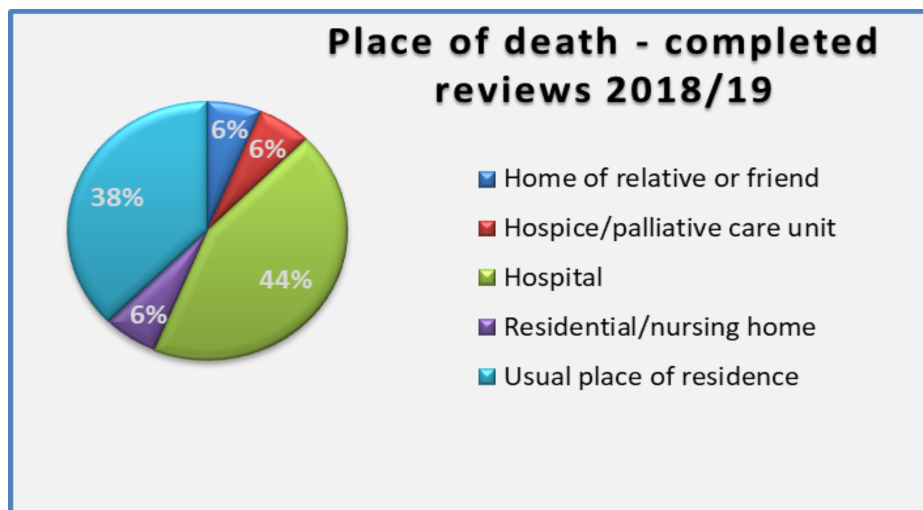
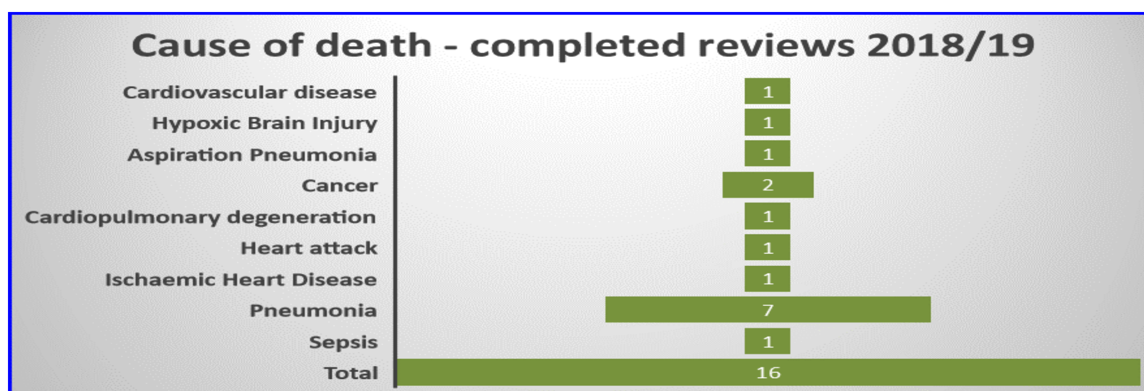


Table 5	National LeDer data	Barnet LeDer data
Main Causes of Death	1) Respiratory - 31% 2) Circulatory - 16% 3) Sepsis - 11% 4) Cancer - 10%	1) Pneumonia (respiratory) - 29% 2) Cancer - 7% 3) Other - 21%[2]



[2] 43% - reviews not yet completed (main causes of death to be confirmed)

Themes, learning points and recommendations from reviews

Adult

- There was a need for better discharge processes and information
- Better access to diagnostic pathways e.g. blood tests
- Earlier recognition of signs and symptoms of ill health
- Need for care co-ordination for those with most complex needs

Child

- Following the death of a child with learning disabilities (aged over 4 years) Child Death Overview Panel (CDOP) investigations are completed and the outcome notified through the LeDeR process. There have been no notifications in Barnet in 2018/19, new CDOP processes have been introduced in 2019 and one notification of a child death has recently been notified.

Good practice examples from completed reviews

- GP health checks identified breast cancer
- End of Life plans - care providers ensuring that wishes of residents fulfilled
- Good examples of support by the learning disability community team nurses towards individuals with complex health care
- Good examples of reasonable adjustments in the dementia pathway – early co-ordination
- Evidence of good communication and work with patients and families in local hospitals
- Reasonable adjustments by North London Hospice
- Care provider advocacy – continuity of care and developing / building relationships

Barnet CCG LeDeR Activity/ Achievements in 2018-2019

BCCG has had an active role alongside our commissioned community learning disability service and has established and embedded our local steering group to oversee the LeDeR programme of work and to ensure our learning is taken into action alongside the NCL Leder Project Co-ordinator. The steering group is well represented by health including the North London Hospice and the Royal Free Hospital Trust and social care through joint commissioning, care quality and the voluntary sector.

For all those who die in the care of NHS providers, a rapid mortality review takes place and forms a part of providers' own internal mortality governance and learning arrangements, thus ensuring any key quality and safety issues relating to clinical practice are reviewed and acted upon in a timely fashion. These rapid reviews are then also available to LeDeR Reviewers to support their work.

To ensure robust oversight of quality and governance processes LeDeR reviews are considered by our Quality Assurance Group (QAG) and LeDer action plan and themes are reported to the CCG internal Quality and Oversight Operational Group. Bristol University (LeDeR system host) no longer quality assures any of the LeDeR Reviews captured in the programme database.

GP clinical lead

In 2019 Barnet CCG appointed a local GP clinical lead to support and champion learning disabilities, specifically the LeDeR processes, attending meetings of the steering group, quality assurance group and multi-agency reviews. With the support of the CCG board the post is bringing essential perspectives from primary care to our quality assurance process and to support implementation of our action plan.

North Central London (NCL) LeDeR Steering group

The NCL group shares learning, actions and best practice and service improvements are agreed based on national and local themes arising. BCCG consistently receives all notifications of deaths of those with a learning disability from the national system and coordinates the reviews. To address the challenge of the backlog of reviews / limited resources to complete reviews the CCG has an ongoing campaign to recruit and support training of reviewers to deliver more capacity to complete reviews; this includes third sector partners.

Work of the NCL LeDeR Coordinator

The role of the co-ordinator has had a significant impact on progress and consistency – work local to Barnet includes:

- Attending Have Your Say Group at Barnet Mencap alongside Health team leader to gain feedback on Thumbs up communications and start the conversation flashcards
- Attended EOLP event for 'Start the conversation' at North London Hospice - this is one of Barnet's LeDeR workstreams
- Attended MARs, helped form agenda and post follow-up admin including minutes
- Quality assurance meetings
- Supported LD GP clinical on LeDeR work

- Worked with Nurse Development Lead to attract practice nurses to become reviewers

In addition, the co-coordinator has a vital role in supporting reviewers to access information, identify blocks and barriers and to ensure that local area contacts have good information and data to deliver their role.

Local Action Plan

Reviewing activity is a key priority and we have developed a local action plan to ensure that the learning from the reviews is acted on. We have identified four key themes for our plan and have summarised activity to date under these themes.

1. Early Warning Signs (of ill health)

- A number of our reviews showed potential early warning signs of deteriorating health being missed. Mostly this is due to difficulties of people with severe learning disabilities communicating when they are unwell. It was identified that further support needs to be put in place to up-skill care providers/support workers to identify early warning signs and empower them to raise these concerns appropriately
- Several models of recognising and recording signs of health were reviewed by the Steering group and final decision was focused on the STOP and WATCH campaign, originally launched by the Cumbria LD Service
- 2019/20 will see the roll out of the STOP and WATCH Campaign with training and sharing of a simple visual tool to raise awareness of signs of deteriorating health that is aimed at support workers

2. Discharge from Hospital - Hospital Discharges

- The Local Acute Liaison Nurse has been part of developing an easy read hospital discharge summary
- A draft discharge checklist prompt sheet has been developed and is being shared for feedback from local care providers

3. Diagnostic pathways

- A joint quality improvement project has been developed between Barnet and Haringey learning disability services to identify barriers to people with learning disabilities getting blood tests. The project has focused on 20 people needing blood tests, examining the barriers they have faced and mapping out what the best care pathway might be. This is likely to be formally launched in 2020

4. End of Life Planning

- Recognition of ‘good deaths’ when end of life plans are in place

- Joint planning meeting with North London Hospice
- Agreed on four target groups- people with learning disability, parents of people with learning disabilities, paid care staff and mainstream health services

Engagement

A priority for the local steering group has been ensuring effective and meaningful engagement with people with learning disabilities and their families and carers. The Chief Executive of Barnet Mencap is a member of our steering group and we have also undertaken the following engagement:

- Members of the steering group have attended the local service user engagement 'Have your say' group on a number of occasions. The group helped design the end of life pack, gave feedback on the LeDeR process and helped design the Thumbs Up Award
- We have visited the Parents Action Group to feedback on the outcomes of the findings from our first year of reviews and to get feedback on our plans

We would like to sincerely thank all those that have taken part in events and meetings in particular the Parent Carers Group, Mencap Have Your Say Group and those that attended and contributed so much to the Dying Matters event.

Objectives and plans for 2019-2020

The NHS Operational Planning and Contracting Guidance 2019/20 (10-year plan) now includes four deliverables in relation to the LeDeR programme. Barnet CCG aligns to these as follows:

- CCGs are to be a member of Learning from Deaths report (LeDeR) steering group and have a named person with lead responsibility
    - See appendix 1 attached for our local governance and reporting arrangements
- There is a plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.
    - **NCL and Barnet CCG** prioritise and track all new notifications and ain to achieve this. Subject to family and carer views

- CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews
    - The CCG contributes learning from reviews to NCL and the London Steering Groups where themes are collated. Completed and anonymised reviews

are shared in our steering group and key issues and progress reported to a sub group (case review) of the adult safeguarding board The NCL co-ordinator role ensures that consistency and key themes are identified and actioned across the STP

- An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews

Although this is our first annual report Barnet CCG has already provided information reports through its internal governance arrangements. This annual report will also be shared in the same way and across partner agencies.

Work streams 2019/20

The following priority action areas for 2019/20 have been identified from completed reviews:

- Annual Health Checks – linking LeDeR findings to training and support for practices
- Cancer screening – work programme with Public Health and primary care within BCCG
- Respiratory – services for people with profound physical and learning disabilities
- Start the conversation plan – end of life planning
- Care Coordination – review of community service specification
- In 2019/20 we will develop closer links to the safeguarding adults board

In addition to the actions above the Barnet Steering group have agreed the following local priorities:

- Improve links to ASB
- Focus on flagging and identification
- The CCG will continue to work with local providers across both Health and Social Care services and the voluntary sector to continue improving the general physical health of people who have a learning disability
- The CCG will continue the local implementation of our local 'Stop and Watch' campaign[3] (see Appendix 3)

The GP lead for learning disability at the CCG and members of the primary care team will ensure that the learning from LEDER is disseminated to GP practices including through refreshed DES training and outreach to practices. This is supported by the Thumbs Up awards and My Health Matters campaigns.

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[3] With thanks to North Cumbria CCG

The CCG will support a refreshed communication campaign to focus on the prevention of early death in those with a learning disability and include:

- Increasing annual health checks
- Flu immunisation campaign
- Cancer screening
- Constipation
- Diabetes

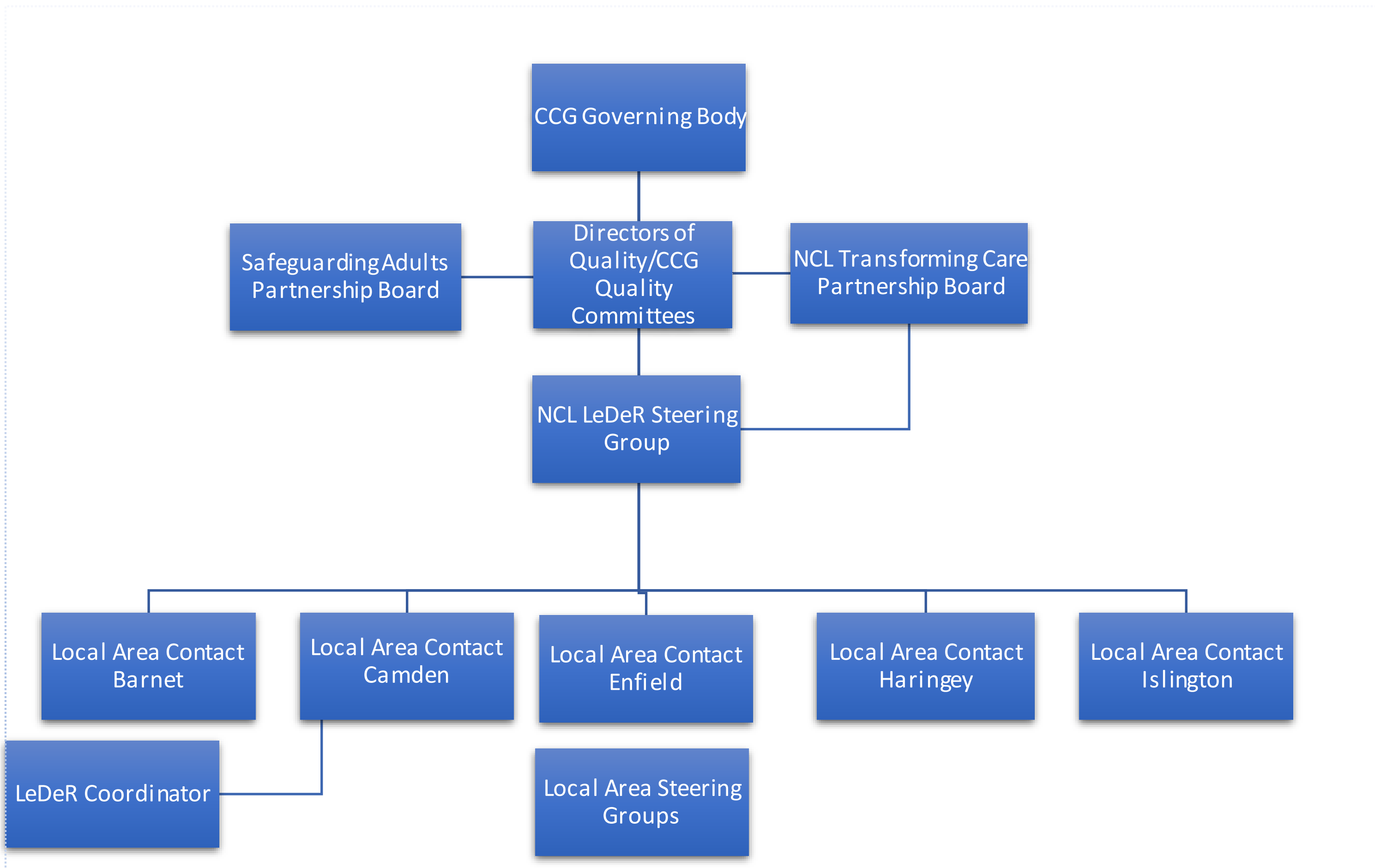
Conclusion

Barnet CCG continues to be committed to delivering the LeDeR programme. The past year has been challenging due to lack of resources and capacity including availability of trained reviewers and the time for reviewers to undertake reviews due to competing work priorities. However, we have laid foundations and have focused on what was achievable. Robust governance systems have been embedded to ensure the quality assurance process and share learning from the reviews across the system.

To support future delivery and recover the position additional reviewers have been trained and plans are being made to extend our 'classroom based - on line training' and 'peer support'. As pressure on time and resources increases it is inevitable that there will continue to be a waiting list of cases to be reviewed.

To conclude the first annual report, we wish to sincerely thanks and acknowledge all our reviewers who have completed reviews with commitment and dedication and who are helping us to improve the health outcomes of people with learning disabilities in Barnet

Appendix 1



Appendix 2

Thumbs Up Awards

Today the learning disabilities team presented its first Thumbs Up award to the Longrove GP practice in Barnet. The event saw the Surgery staff, patients and the learning disability staff come together to celebrate the good work the Longrove Surgery do with people with learning disabilities.

The Thumbs Up award is a new initiative by the learning disability team. It is a recognition award of good practice for GPs and will help service users make decisions about who to go to for healthcare. To receive an award, the Surgery must achieve 6 standards of care that ensure people with learning disabilities fair access to healthcare. These include having accessible information, attending GP training and promoting the My Health Matters folder to their patients. The service users reported that they always feel well supported at Longrove and were glad that their hard work was being recognised. The Thumbs Up award will be promoted across the borough and GP practices invited to apply for the award.