NHS
Bedfordshire
Clinical Commissioning Group

Agenda Item: 15.0

Governing Body *held in public*	***Report*** Date of Meeting:

Report Title	Learning Disability mortality review (LeDeR) annual report briefing and local response.	
Report Author	**Presented By**	**Responsible Director**
Anna Taylor	Anne Murray	Anne Murray **Signature:**
Purpose for presenting report	This report outlines the national and local position in relation to the LeDeR review programme, including key points from the latest published national annual report from May 2019.	
Action Required:	For discussion /To give assurance /For information only	
Approval Route:	*[List Groups/Committees that have reviewed this document and date received]*	
Further Assurance:	LeDeR is regularly reported through the LeDeR steering group and also through ICQC	

Which Strategic Objectives does this report provide evidence for?	**Please Tick ✓**
We will commission high quality, safe and sustainable models of care that deliver effective clinical outcomes and patient experience using evidence based decisions and best practice	√
We will ensure that there is a financially sustainable and affordable healthcare system in Bedfordshire.	
We will lead, engage and operate as an effective place based and STP wide system partner to achieve greater integration of care delivery.	√
We will support local people and stakeholders to have an influence on services we commission to ensure our decisions are informed and shaped by local views and insights.	√
We will operate and manage our Governing Body to the highest standards of accountability and transparency.	

Implications/Assessments	**Yes**	**No**	**N/A**
Have any financial implications been signed off by the Chief Finance Officer?			√
Have any quality implications been signed off by the Director of Nursing & Quality?	√		
Have any privacy implications been signed off by the Head of Information Governance?			√
Have any conflicts of interest implications been signed off by the Corporate Office?			√
Have any public engagement implications been signed off by the Head of Communications & Engagement?			√
Has an Equality Impact Assessment been carried out?			√

Key Risks	The LeDeR programme targets will not be achieved for BCCG
Executive Summary	The University of Bristol published their third annual report of the Learning Disabilities Mortality Review (LeDeR) programme on 21st May 2019. The LeDeR annual report demonstrates the inequality in expected mortality for those with learning disabilities compared to the general population has continued to increase. The report includes recommendations for action at a national level and national funding has been announced.

Introduction

The University of Bristol's third LeDeR annual report presents information about the deaths of people with learning disabilities aged 4 years and over notified to the programme from 1 July 2016 – 31 December 2018.

With a backdrop of the NHS Long Term Plan's commitment to reducing the premature mortality of people with a learning disability, the findings of the LeDeR annual report are clearly relevant.

Background

The National Learning Disabilities Mortality Review (LeDeR) programme commenced in June 2015 with implementation of the LeDeR process in Bedfordshire from the 1st October 2017. The review process was established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD). The LeDeR programme was commissioned to improve the standard and quality of care for people with a learning disability. It was commissioned by NHS England, initially for a three year period and is managed by the Healthcare Quality Improvement Partnership (HQIP), with the programme being delivered by the University of Bristol.

The 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.

The previous national annual report published in 2018 highlighted that people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

Further multi-agency reviews (MAR) of some of the more complex cases may be necessary subsequent to the initial review process of all notifications. Priority Themed review of any deaths related to 4-25 year olds and anyone from the BME community with Learning disabilities had been directed by the Programme team's processes, but this direction was withdrawn in early December 2018.

At the completion of the review, an action planning process identifies any service improvements that may be indicated. This action plan is reviewed and monitored by the six weekly Steering Group Chaired by BCCG's Clinical Lead for Learning Disabilities and disseminated through the CBC and BBC Safeguarding Adults Review Sub Group.

Discussion

The latest published report cites deaths reviewed where there were concerns about the quality of care, and identified an increasing disparity in life expectancy for people with learning disabilities compared to those from the general population. On average, the age of death is 23 years younger for men with a learning disability and 27 years younger for women. It was acknowledged that comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified from the age of 4 years, while general population data also includes information about children aged 0-3 years.
In addition, it was also recognised that more people who died at a younger age had profound and multiple learning disabilities, and some of these would have complex medical conditions or genetic conditions that may make an earlier death likely.

Key findings of the annual report included;

- The proportion of people with learning disabilities dying in hospital is higher (62%) than in the general population (46%).
- Almost a half (48%) of deaths reviewed in 2018 received care that the reviewer felt met or exceeded good practice, slightly more than the 44% in the 2017 report.
- The proportion of deaths notified from people from Black, Asian and Minority Ethnic (BAME) groups was lower (10%), than that from the population in England as a whole (14%). However, children and young people from BAME groups were overrepresented in deaths of people with learning disabilities.

A number of concerns about the deaths of people were highlighted including system level issues, staff training, care coordination and communication, do not attempt cardio pulmonary resuscitation (DNACPR) orders, and recognising signs of deterioration.

Key points included;

- The report identified recommendations at a national level that cover availability of data; identification of people with learning disabilities; listening to families; priority programmes of work needed; service and care coordination; transition from childrens' to adults' services; and addressing bias.
- The report also states there is much that can be done at a local level to reflect on the learning coming from the reviews of deaths, and to translate that into actions for improvements.
- Separately NHS England NHS Improvement have published 'LeDeR: Action from learning' which provides an overview of actions taken in response to recommendations from the second annual report and action going forward. This report states that CCGs working with local authority and NHS partners have made significant progress towards completing LeDeR reviews but that there is still a long way to go.
- The national bodies have committed to invest an additional £5 million to address the backlog of unreviewed cases and increase the pace with which the reviews are allocated and completed.
- They have also committed to a national action to tackle the major conditions that cause death amongst people with learning disabilities based on lessons learned from reviews.

- In 2019/20, the University of Bristol aims to report more regularly about themed learning, and the learning into action collaborative will continue to co-ordinate national responses to the information emerging from reviews.

The NHS Long Term Plan makes a commitment to reducing the premature mortality of people with a learning disability and it is as part of this that NHSE/I have committed to provide funding to CCGs to support them to complete outstanding reviews notified up until 31/12/18. For Bedfordshire this equates to 8 reviews.

4302 deaths have been notified to the programme from 1st July 2016 to 31st December 2018. By 31st December 2018, reviews for 25% of these notifications had been completed, with 37% in progress and 38% still awaiting allocation to a reviewer. The programme said this indicated continuing and significant problems with the timeliness with which reviews take place.

The NHSE/I report indicates there will also be investment to secure the long-term future of the LeDeR programme so that the wealth of learning it provides continues to be translated into action.

Current position in BCCG

The table below indicates the current number of LeDeR notifications received across Bedfordshire since the programme 'went live' on 1st October 2017 to date. The number of reviews which form the backlog for which funding is to be allocated i.e. from 1st October 2017 – 31st December 2018 are also shown together with the number of reviews allocated or in progress and completed.

Notifications received to date	**Notifications in progress /allocated**	**Reviews completed**	**Backlog awaiting funding allocation**	**Received after 31.12.18**
29	11	3	9	6

Compared to the national position (detailed above) to 31st December 2018, BCCG have completed 13% of cases with 48% of cases allocated or in progress and 39% of cases unallocated.

2 of the notifications in progress, received in June and July 2018, are deaths related to children requiring completion of the CDOP process before they can be completed for LeDeR. There is a considerable backlog of CDOP cases currently, although these LeDeR cases have been flagged. Recent CDOP guidance looking at the interface between the CDOP and LeDeR processes has identified that panels may find benefit in having additional 'learning disability themed meetings' at which common contributory factors leading to deaths, and frequently made learning points and recommendations, can be reviewed together. Local processes are being adapted to ensure this takes place, and it is hoped that conclusion of the CDOP process will be completed by the end of December.
A further 4 of the notifications in progress have had the initial reviews completed and require further multi agency review which are currently being arranged and will be completed by the end of October.
It is hoped that the remaining 5 cases which are in progress will also be completed by the end of November.

A meeting with Local Area Coordinators (LAC) from across BLMK is scheduled to identify the challenges locally in completing reviews and recruiting reviewers. A workshop is also planned on 16th July 2019 to map out the three CCGs' current LeDeR processes in order to share good practice, identify opportunities to accelerate the pace of reviews, and bring a level of consistency of approach to reviews in BLMK.

At a recent Eastern region LAC meeting, the programme team advised that the backlog of unallocated reviews is to be addressed by CSU but that a case could be made by local areas should they have a strong desire to complete their own reviews.

Bedfordshire CCG continues to organise and host the six weekly BLMK LeDeR Steering group where the learning from reviews is disseminated and 'learning into action' plans will be developed and monitored.

Recommendation

Further clarification is required regarding the funding allocation locally, a planned approach to completing backlogged reviews and whether CSU will be employed to complete these reviews. Joint work planned between BLMK as previously described will inform this decision making.

In the meantime, BCCG continues to proactively plan and manage cases in the event funding is not be available for additional resource.