

## Report to Governing Body - October 2020

**Title:** Quarters 1 and 2 - April-September, LeDeR progress report

**Purpose of paper:** To report on the progress of LeDeR reviews completed and outline themes and issues identified in the reviews. To update Governing Body on progress with the implementation of key performance indicators.

| For Approval/<br>Decision | For Review | Receive for<br>assurance | Receive for<br>information |
|---------------------------|------------|--------------------------|----------------------------|
|                           |            | ✓                        | ✓                          |

### For Discussion

#### Executive Summary:

**All cases from 2019 are completed and closed on the platform. 2020 Cases reported to 30<sup>th</sup> June have all been allocated for case completion by 1<sup>st</sup> December 2020.**

There is a national directive to ensure that all cases notified prior to 30<sup>th</sup> June 2020 are completed by 31<sup>st</sup> December 2020. We currently have 50 open cases that were reported prior to 31<sup>st</sup> June 2020. The breakdown of progress on these cases is as follows:

|   |    |
|---|----|
| Allocated to reviewers – case in progress | 41 |
| Pending MAR                               | 2  |
| With LAC for closure                      | 4  |
| Unallocated                               | 0  |
| CDOP                                      | 3  |

Between 1<sup>st</sup> March and 30<sup>th</sup> Sept 44 cases were submitted for LAC review, all of these were reviewed within 2 weeks

16 cases have been reported since 1<sup>st</sup> July 2020. We are currently allocating cases from April 2020. 2 of these have been allocated to reviewers, 14 are unallocated but not due for completion until 2021.

**There are currently 28 trained reviewers, with 22 active reviewers currently with cases**

**Reviewers** – After two recruitment campaigns in March and September we now have 28 trained reviewers recruited, with 22 active. There is no shortage of reviewers and no backlog from 2019. We have recommended reduction of the risk for completing the reviews in the required timescale to 12, but continue close monitoring should there be a need to escalate for any reduction in LeDeR reviewers or capacity.

**People with learning disabilities across BNSSG generally live 6 to 8 years longer than the learning disability national average**

**Demographics data** – median age of death compared to general population is 66. Ethnicity data shows 94% of notifications in Q1/Q2 20/21 were recorded as White/British. Indications that correct ethnicity code is not being completed in provider records and there is under reporting from BAME communities. Work is underway to look at reasons for this and we have invited BAME leaders to join the LeDeR Steering Group.



**Findings of reviews shows the majority of service users received satisfactory care**

**Finding of reviews** – Grading of care shows LeDeR reviewers overall assessment of the care received on completed reviews identified were satisfactory (61%). People receiving good care was 28%. Those receiving care that fell short of what is expected was 11% Where the Case Review Panel has concerns about quality of care they may downgrade in consultation with reviewer.

|                | Reviews | Closed | Open | Total | % BNSSG Completed  | South West % Completed | England % Completed |
|----------------|---------|--------|------|-------|--------------------|------------------------|---------------------|
| Qtr 1 2020/21  | 70      | 70     | 140  | 50%   | 51%                | 52%                    |                     |
| Qtr 2 2020 /21 | 89      | 67     | 156  | 57%   | Data not available | Data not available     |                     |

**Pneumonia is the most frequently recorded cause of death**

**Cause themes** – pneumonia was the cause of death in 8 cases, heart failure (5 cases) with sepsis (3 cases) and cancer (3 cases) the next most common causes. The number of people with Learning Disability who died in hospital continues to be significantly higher (75%) than those who died at home (19%).

**Completion of Annual Health Checks for people with learning disabilities has been severely impacted by Covid.**

**Slide 3 AHC figures** – GP’s had a 19/20 achievement of 56%. NHSE are expecting 67% by the end of 20/21 Q4. To date performance at the end of Q2 20/21 is:

- Using the 14+ denominator Q2 performance was:  $335/4500 = 7.44\%$

We expect to see incremental improvements in this over Q3 and Q4 with the launch of AHC Action Plan resources to support practices to deliver, launched on TeamNet/Remedy last week, with a new GP LD Forum and training webinars to support delivery of the annual health check. However it is unlikely that we can recover our position to meet the 67% target by end of Q4

**LeDeR Service user Forum has not met due to Covid but service users continue to tell us about their experience**

**LeDeR Service User Forum** – Met twice before lockdown. The group have continued to tell us about their experiences – during lockdown their experiences of Covid, how they are managing in isolation, wearing masks, experiences of Annual Health Checks and in October someone with autism has advised on access recommendations at Southmead.

**Wider themes identified by reviews are management of catheters, constipation & epilepsy and moves at End of Life**

**Areas for improvement** – poor management indwelling catheters are components regularly identified in reviews leading to admissions for sepsis. Constipation continues to be a topic where advice and plans for diet, water intake and exercise are lacking. People with epilepsy are not referred to specialists. When people are on End of Life pathways they can be moved several times inappropriately in the last year of their life – instead of being given support to die at home with friends and staff who know them

**Action learning from LeDeR reviews is used to drive improvement with providers through Steering Groups and the LD Cell**

Learning themes identified by the LeDeR Case Review panel are reported to the LeDeR Steering Group, to provider Steering Groups and the LD Cell. Presentations of findings have also been made to the Academic Health Science Network, Local Authority Partnership Boards and lessons from MARs in the GP Bulletin



## Action Required

The Governing Body is asked to note contents of this report and support the work programme outlined. The Steering Group is asked to recommend the data & learning points for publication.

The Governing Body is asked to approve the recommendation that completion of Annual Health Checks for people with learning disabilities is added to the Area Risk Registers

|  |   |
|--|---|
| <b>Financial resource implications</b>                                 | BNSSG CCG has been able to support compliance in the completion of LeDeR reviews with funding from NHS England to employ two dedicated LeDeR reviewers. The delivery of the LeDeR programme requires continued funding beyond March 2021  |
| <b>Legal implications</b>  | No legal implications associated with this paper  |
| <b>Risk implications</b>   | Without organisational/whole system sign up & engagement there is a risk to the ability of the CCG to meet the KPI requirement of allocating and sustaining completion of reviews within 6 months. This will affect the ability of the wider system across BNSSG STP to take and embed learning from LeDeR reviews    |
| <b>Equality &amp; Diversity Impact – reducing health inequalities.</b> | Learning from themes is reported to the BNSSG LeDeR steering group and enables recommendations/ actions to reduce health inequalities for people with learning disability to be implemented across BNSSG. LeDeR programme focus is on improving equality and diversity outcomes for people with learning disabilities |
| <b>Engagement with patients and/or public:</b>                         | A LeDeR Service User Forum is in place, stood down during Covid but service users voices are reported monthly to the LeDeR Steering Group   |
| <b>Authors</b>   | <b>Lesley Le-Pine – Quality Lead and LeDeR Programme</b>  |
| <b>Sponsoring Director</b>   | <b>Rosi Shepherd – Director of Nursing and Quality</b>  |

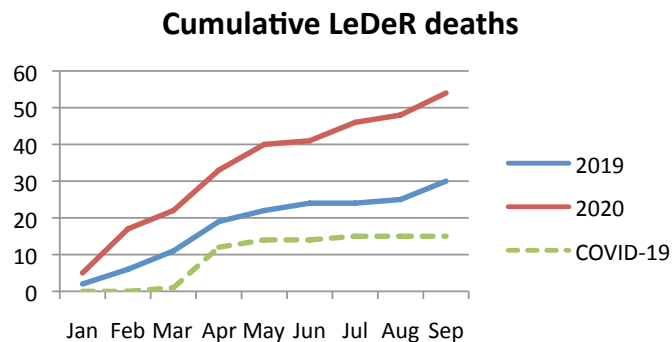


## Nursing & Quality Exception Report – Learning Disability Mortality Reviews (LeDeR)

|   |   |   |
|---|---|---|
| <p><b>Lesley Le-Pine</b></p> <p><u>Current position</u></p> <ul style="list-style-type: none"> <li>156 deaths in BNSSG have been reported to the LeDeR programme.</li> <li>Oldest cases to be reviewed start in April 2020</li> <li>Number of deaths reported - 72% increase in reports compared to same period last year due to COVID</li> <li>NHS England require all deaths notified to June 30th 2020 to be completed by December 2020 .</li> <li>Paper to outlining trajectory and risks presented to Sept LeDeR Steering Group</li> </ul> | <p><b>Report for : Quality Committee</b></p> <p><u>Actions</u></p> <ul style="list-style-type: none"> <li>Weekly review of LeDeR case tracker to monitor and chase reviewers progress to keep up pace of completion</li> <li>Currently 50 open cases reported to 30th June 2020 - progress on these cases is:                     <ul style="list-style-type: none"> <li>3 CDOP</li> <li>37 Review commenced</li> <li>4 Pending MAR</li> <li>2 With Panel for closure</li> <li>4 Unallocated</li> </ul> </li> </ul> | <p><b>Reporting Period: Month 6</b></p> <p><u>Risks/assurance gaps</u></p> <ul style="list-style-type: none"> <li>Reviewers unable to complete cases in the required timescale.</li> <li>Restoration or services may lead to delays completing LeDeR reviews</li> </ul> |
|---|---|---|

### Month 6 position – 30 September 2020

|   |    |
|---|----|
| Open cases @ 30 September                   | 66 |
| Allocated reviews                           | 40 |
| Cases waiting allocation to reviewer        | 18 |
| Backlog cases with NEC                      | 0  |
| Child Death Overview Panel                  | 3  |
| Multi Agency Reviews (delayed due to COVID) | 4  |
| Completed, panel review & closed            | 89 |



### COVID-19 deaths reported to 31<sup>st</sup> Aug

|   |           |                   |
|---|-----------|-------------------|
| MARCH                                   | 1         | Age 72            |
| APRIL                                   | 12        | Age range 54 - 87 |
| MAY                                     | 2         | Age 60 & 73       |
| JULY                                    | 1         | Age 67            |
| JUN/AUG/SEPT                            | 0         |                   |
| <b>Place of death</b>                   |           |                   |
| Home                                    | 6         |                   |
| Hospital                                | 10        |                   |
| <b>TOTAL COVID</b>                      | <b>16</b> |                   |
| <b>NON COVID deaths since 1st March</b> | <b>23</b> |                   |

**Key successes**

- BNSSG completed the highest number of reviews in SW region at 57%
- NHSE are providing further funding 2020/21 to support programme
- BNSSG has largest number of trained reviewers in the SW region
- BNSSG awarded one of 8 NHSE national exemplar sites for learning disabilities Annual Health Checks
- BNSSG asked to advise 3 other CCG's on LeDeR best practice

**System actions**

- System working group developing comprehensive single overview plan.
- Learning Disability Contract schedule to be signed off with providers
- LD annual health checks by GP's reviewed. Improvements required in uptake and quality
- Assurance requested from UHBW that all LD Covid deaths have been reported
- Quality audit of annual health checks planned for 2021

**CCG specific actions**

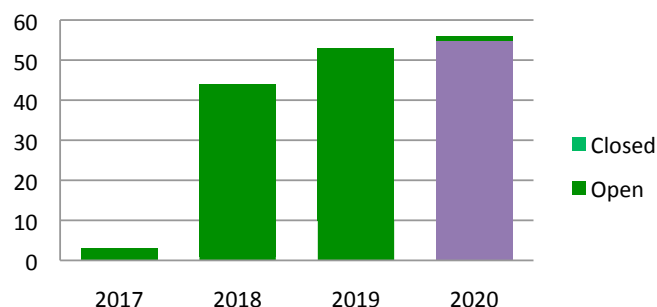
- CCG maintaining a pool of trained reviewers to enable timely allocation
- Cases allocated immediately on training completion & buddied with more experienced reviewers for support with case
- All LD GP's leads in BNSSG contacted re support for Annual Health Checks
- Implementation plan for AHC in progress – resources go live by end of October
- New Forum being established in December with training and support for learning disability Lead GP's (post in every practice)

**Assurance**

- Completed reviews are quality assured by the LAC within two weeks.
- Clinical Case Review panel quality assures consistency of reviews
- Internal Audit Report March 2020 rated LeDeR system as reasonable assurance
- Annual Report submitted to the Quality Committee and Governing Body demonstrating action taken and learning outcomes from LeDeR reviews.
- Local rapid reviews of Covid deaths identified no anomalies compared to national review and captured useful local learning

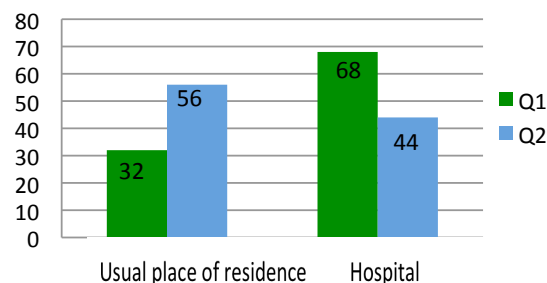
## Supporting Analysis – LeDeR

### Status of Reviews by Year of Notification



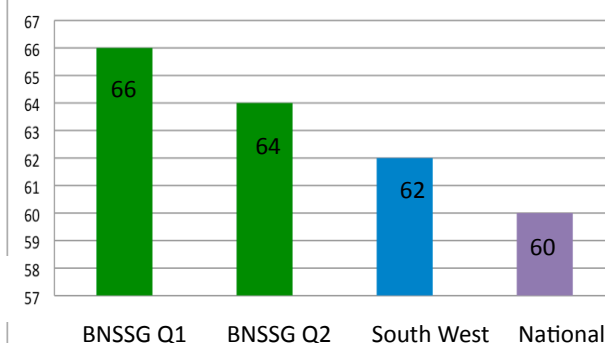
All backlog cases from from 2019 are now completed and closed on the platform. Of the 4 Multi-Agency Reviews (MAR) two are completed, one is booked and one waiting to be arranged with family members once Covid restrictions are lifted. Review Panels are held every two weeks.

### Place where person died



The number of people with a learning disability who died in hospital continues to be higher than those who died at home. The STP plan to improve health inequalities is aimed at decreasing early death and support more choice in place of death

### Median age of death for people with learning disabilities

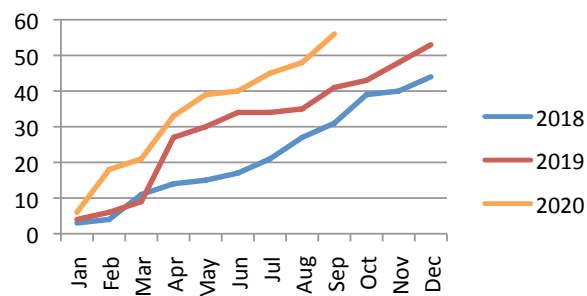


The average age of cases reviewed is 66. Compared to the UK life expectancy of 79.3 for (2018 data). Typically people with learning disabilities are dying up to 12 years earlier than the population average. People in BNSSG appear to live 6 years longer than the LD national average

| Activity Data as at 30 <sup>th</sup> Sept 2020 for ALL notified cases | Number of cases | % of Cases |
|---|-----------------|------------|
| Completed   | 89              | 57%        |
| With LAC for approval   | 2               | 1%         |
| Unallocated   | 18              | 12%        |
| MAR process   | 4               | 3%         |
| With Reviewers  | 40              | 26%        |
| CDOP Cases  | 3               | 2%         |

This table shows rolling activity for all cases, including those reported after 30th June which are not due for reviews to be completed until 2021. BNSSG now has the highest completion rate in the South West and the highest number of cases reported compared to other CCG's.

### Cumulative number of deaths reported



A total of 156 deaths in BNSSG have been reported to the LeDeR programme since it began in 2018. This year has seen an increase in number of deaths reported, not just due to Covid but a better awareness or LeDeR amongst all providers. Eight deaths were reported in September 2020.

| Grading of care for closed cases  | Q2 April – June 2020 | Q3 July – Sept 2020 |
|---|----------------------|---------------------|
| 1 = excellent care  | 0                    | 0                   |
| 2 = good care   | 2 (75%)              | 5 (28%)             |
| 3 = satisfactory  | 0                    | 11 (61%)            |
| 4 = care fell short of current best practice in one or more significant areas             | 1 (25%)              | 2 (11%)             |
| 5 = Care fell short of current best practice and some learning could result from MAR      | 1                    | 2                   |
| 6 = care fell short of best practice resulting in potential for, or actual adverse impact | 0                    | 0                   |

Case Review Panel process is now more robust with a minimum of a GP, nurse, & social worker. Each case is scrutinised in depth and any concerns or queries, including grade is discussed with reviewer who has access to more information. Where Panel have concerns about quality of care they may downgrade in consultation with reviewer.

## Learning Disabilities – Annual Health Checks

|              | Patients on register aged 14 and over | LD and Health check done<br><i>Patient Count</i> | HC done action plan agreed<br>Patient Count | HC done action plan declined<br>Patient Count | Learning disability health check not done nor declined in 2020/21<br><i>Patient Count</i> | Moderate or Severe Learning disability<br><i>Patient Count</i> | % Receiving health check | % With action plan | % Not receiving health check |
|--------------|---------------------------------------|--|---|---|---|--|--------------------------|--------------------|------------------------------|
| 2019/20      |                                       |  |   |   |   |  |                          |                    |                              |
| Q1           | 4235                                  | 411  | 256   | 2   | 3858  | 253  | 10%                      | 6%                 | 90%                          |
| Q2           | 4336                                  | 503  | 256   | 0   | 3858  | 253  | 12%                      | 6%                 | 88%                          |
| Q3           | 4363                                  | 665  | 775   | 9   | 2802  | 252  | 15%                      | 18%                | 85%                          |
| Q4           | 4446                                  | 932  | 406   | 17  | 1871  | 252  | 21%                      | 9%                 | 79%                          |
| <b>Total</b> | <b>4446</b>                           | <b>2511</b>                                      | <b>1693</b>                                 | <b>28</b>                                     | <b>1871</b>   | <b>252</b>   | <b>56%</b>               | <b>38%</b>         | <b>44%</b>                   |
| 2020/21      |                                       |  |   |   |   |  |                          |                    |                              |
| Q1           | 4458                                  | 107  | 56  | 0   | 4349  | 248  | 2%                       | 1%                 | 98%                          |
| Q2           | 4500                                  | 335  | 174   | 2   | 4160  | 249  | 7%                       | 4%                 | 93%                          |
| Q3           |                                       |  |   |   |   |  |                          |                    |                              |
| Q4           |                                       |  |   |   |   |  |                          |                    |                              |
| <b>Total</b> | <b>4500</b>                           | <b>442</b>                                       | <b>230</b>                                  | <b>2</b>                                      | <b>4160</b>   | <b>249</b>   | <b>10%</b>               | <b>5%</b>          | <b>90%</b>                   |

Practices that opted out are  
 BRIDGE VIEW MEDICAL  
 THE MERRYWOOD PRACTICE  
 BIRCHWOOD MEDICAL PRACTICE

Covid has had a severe impact on GP practices capacity to undertake health checks for people with learning disabilities in the first two quarters of this year.

GP's had a 19/20 achievement of 56%. NHSE are expecting 67% by the end of 20/21 Q4. To date performance at the end of Q2 20/21 is:  
 Using the 14+ denominator Q2 performance was:  
 $335/4500 = 7.44\%$

We expect to see incremental improvements in this over Q3 and Q4. Actions are underway to launch of AHC Action Plan resources to support practices to deliver, launched on TeamNet and Remedy this week, with a new GP LD Forum established with the first meeting arranged in December to meet 3-4 times per year. Training webinars for GP's and practice nurses to support delivery of the annual health check.

Area teams and PCN's need to support the delivery of Annual Health Checks for people with learning disabilities.

**However it is unlikely BNSSG practices can recover the position to meet the 67% target. This needs to be added to Area risk registers.**