Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group

BNSSG CCG Governing Body Meeting

Date: Tuesday 2nd July 2019
Time: 1.30pm
Location: Clevedon Hall, Elton Road, Clevedon, North Somerset, BS21 7RQ

Agenda number: 7.1

Report title: Learning Disabilities Mortality Review (LeDeR) activity data

Report Author: Bridget James, Associate Director of Quality
Report Sponsor: Janet Baptiste-Grant, Director of Nursing & Quality

1. Purpose

The purpose of this paper is to highlight the current position regarding the number of reviews undertaken in BNSSG into the deaths of people with learning disabilities aged 4 years and over. The data includes status of reviews, demographics and outcome data. The paper also presents the position in terms of the number of trained reviewers in BNSSG.

This data is a standing agenda item discussed at the BNSSG LeDeR Steering Group and is submitted to the Quality Committee for assurance.

This data is cumulative from when LeDeR was first introduced in BNSSG in January 2018 to 12th June 2019.

2. Recommendations

The Governing Body is asked to:-

Note the current position regarding the reviews of people with learning disabilities reported to the LeDeR programme within BNSSG.

3. Executive Summary

The Learning Disabilities Mortality Review (LeDeR) Programme is a national programme established in 2015. The purpose of the programme is to:

- Review all deaths of people with learning disabilities aged 4 years and over

- Understand why people with a learning disability die at a younger age than the general population.
- Ensure learning is identified and improvements are made.

The LeDeR Programme is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities (LD) in England. The deaths of people with learning disabilities are reported to the LeDeR programme and subject to an initial review undertaken by a local LeDeR reviewer. These reviews are allocated by the Local Area Contact for either a CCG or STP area. Allocation is dependent on the age of the individual, if any other statutory investigations are underway and availability of the local reviewers.

BNSSG CCG has received seventy-eight (78) notifications to date. Twenty-two percent (22%) of cases have been reviewed and closed. Forty-seven percent (47%) have been allocated to a reviewer and thirty-one percent (31%) are awaiting allocation to a reviewer.

There are eleven (11) LeDeR reviewers actively reviewing cases across BNSSG. The proposed number of reviewers required for BNSSG is twenty two (22).

This current position is a standing agenda item on the BNSSG LeDeR Steering Group where actions have been discussed to improve both the allocation of cases and identifying future reviewers.

4. Financial resource implications

There are no financial implications with this paper.

5. Legal implications

There are no specific legal implications in this paper.

6. Risk implications

The risks associated with this paper relate to a lack of trained active reviewers in BNSSG, the timely allocations of the cases and the prompt review and identification of any learning to support the care and treatment of people with learning disabilities. Actions on how to address these risks were discussed at the LeDeR Steering Group in March 2019 as outlined above.

At the request of the LeDeR Steering Group the Interim Director of Nursing has written to all health providers to request their sign up to supporting the recruitment of staff to become LeDeR reviewers. A commitment for all organisations to commit to protected and allocated time for the staff acting as reviewers has been requested.

Risk rating on the directorate risk register is (Probability x Severity) 4 x 3 = 12.

7. Implications for health inequalities

It is acknowledge that individuals with a learning disability have shorter life expectancies. The purpose of the LeDeR programme is to help identify learning from deaths to decrease early mortality in this group of individuals

8. Implications for equalities (Black and Other Minority Ethnic/Disability/Age Issues)

There are no specific equality implications in this paper.

9. Implications for Public Involvement

There is intention to have involvement from service user representatives in the Steering Group.

Agenda item: 7.1

Report title: LeDeR Activity update – July 2019

1. Background

The Learning Disabilities Mortality Review (LeDeR) Programme was first established in 2015. The purpose of the national programme is to:

- Review all deaths of people with learning disabilities (LD) aged 4 years and over
- Understand why people with a learning disability die at a younger age than the general population.
- Ensure learning is identified and improvements are made.

All LD deaths are subject to an initial review. These reviews focus on the individuals last year of life and include a pen portrait, medical and social review. However following the review if the case meets a set criterion it will then be the subject of a full multi-agency review (MAR) undertaken by an independent panel. This incorporates a sequence of events or processes, drawing on the perceptions of a range of individuals and a range of sources including systems, policies or processes. The resulting report does not make findings of fact but summarises the available information and makes general comments.

Following the role out of the pilot programme the LeDeR Programme was fully implemented by December 2017 across England. All Clinical Commissioning Groups established LeDeR Steering Groups, apart from BNSSG. This was delayed due to the merger of the three CCGs.

2. Current Position for BNSSG

2.1 LeDeR Steering Group

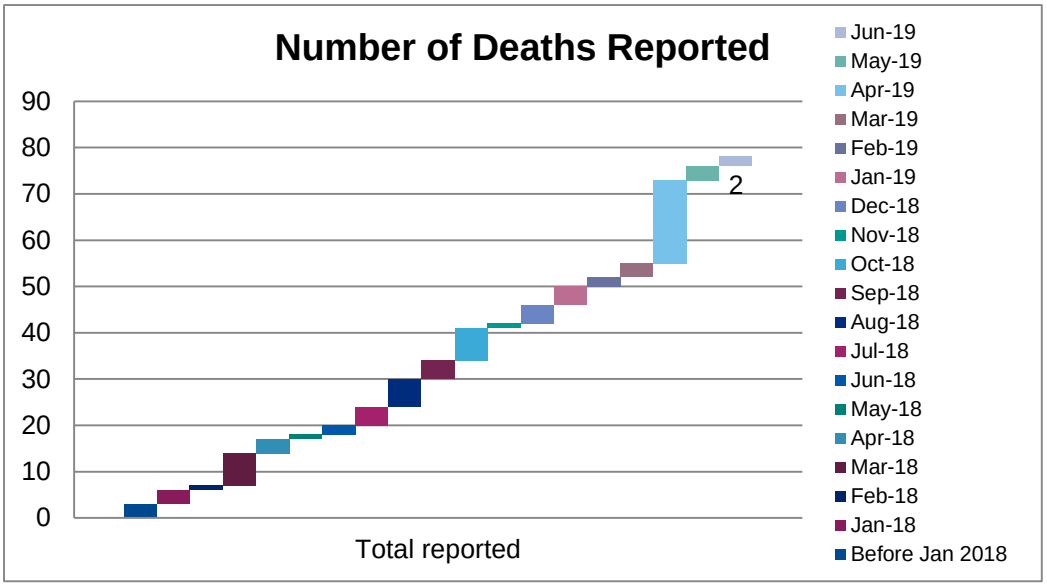
A LeDeR Steering Group was established in February 2019 and monthly meetings have been held since then. The governance for the group has been established and focus is now on reviewing the data and individual cases to identify themes and trends for learning and improvement. The membership for the group is from BNSSG STP Health and Social Care organisations and also includes the NHSE Regional LeDeR lead. Standing agenda items include national and regional updates on the LeDeR programme and to support this, the CCG is also represented at the SW regional LeDeR group.

The CCG has two Local Area Contacts (LACs). Their role is to ensure all cases are reviewed. The LAC is notified from the LeDeR platform of any new cases in the BNSSG area. The LAC is responsible for allocating these cases to a trained reviewer that is active on the platform.

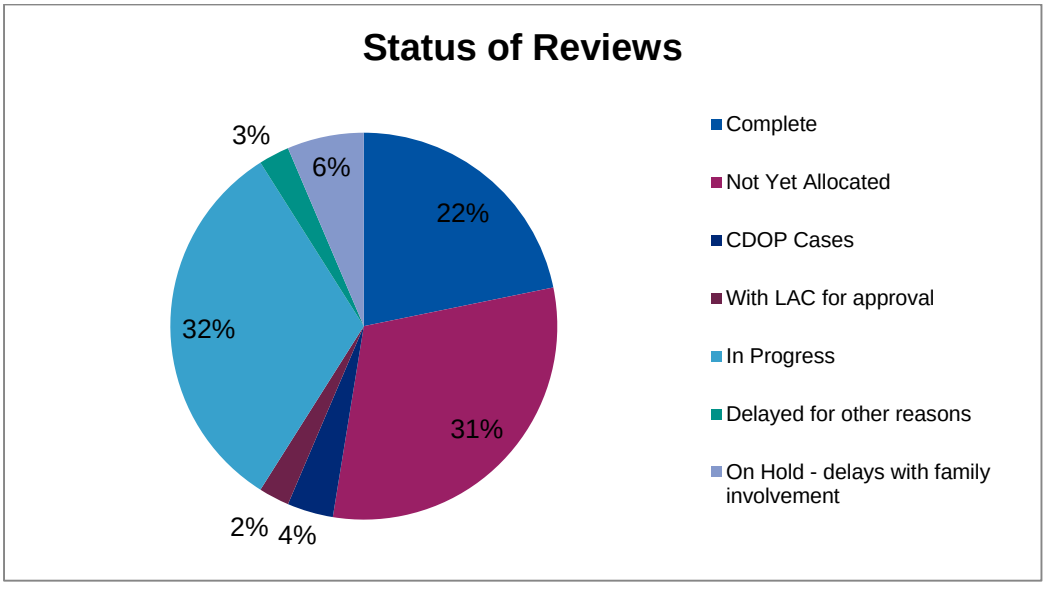
The following data was discussed at the June 2019 LeDeR Steering Group. Graphs/tables and pie charts depicting the all data relating to BNSSG LeDeR activity is presented at appendix 1.

2.2 LeDeR Cases

Number of cases: As at the 12th June, Bristol, North Somerset and South Gloucestershire had received a total of 78 LeDeR referrals since January 2018. The graph below shows the monthly reporting rates since this was recorded within BNSSG. It is noted that following a reminder to all stakeholders on how to report the death of a person with Learning Disabilities a spike is seen in the number reported in April 2019.



Status of cases: The following pie chart shows the status of all 78 cases.



Reporting of cases: The table below shows the reporting origin from January 18 to June 19

Organisation	Total Reported		Organisation	Total Reported
UHB	8		NS Council	6
WAHT	2		GP's	3
NBT	19		Social Care Providers	14
AWP	11		Out of Area	2
BCH	9		CDOP	6
NSCP	2		BNSSG CCG	1
Sirona	3			

The total number reported in the table is greater than the total numbers reported due to some cases being dual reported. A robust process is in place to ensure duplicates are identified and not counted as separate cases. From the data it can be seen that North Bristol Trust are the most frequent reporter. It is expected that following the awareness raising of how to report deaths of people with learning disability numbers of cases will increase from other providers. This will be a positive improvement to ensure all cases are notified, but will impact on the additional requirement for more reviewers.

2.3 Demographic data of LeDeR cases

The data shown below relates to 78 deaths of people with Learning disability in the BNSSG area from January 18 to June 2019:

- In BNSSG 64% of the reported deaths related to males, this is higher than the national average of 55%.
- 85% of the individuals were White-British origin of those where ethnicity was stated. Two individuals where ethnicity was identified stated anything other than White-British and 13% did not have this recorded.
- 65% of people died in hospital, this is similar to the South West 59% and National 62%. However, compared with the general population (46%) dying in hospital this is significantly higher.
- The location of the GP practice approximately correlates to the size of the general population (Bristol 53%, North Somerset 23% and South Gloucestershire 24%)
- The youngest individual was aged 8 years old and the eldest 91 years. This means that in BNSSG the median age of death for a service user with a learning disability is 65 years. The graph at Appendix 1 shows the ages by gender and age banding of under 18, 18 – 54 years, 55 – 64 years, 65 – 74 years and 75 and over. The issue of having an upper age limit on reviews has been discussed at national meetings, but it has been felt that learning is as important on those who have lived full life expectancy as from those who have died at an earlier age.

2.4 Outcome of Closed Reviews

Sixteen of the 78 cases have been completed, two of these were Child Death (CDOP) cases, which we do not receive a full review and therefore outcome information is not known. For the Fourteen 14 cases which have received full reviews, the following information has been identified.

- The majority of cases reviewed related to individuals with a mild or moderate Learning Disability.
- The most frequent cause of death identified is aspiration or bronchial pneumonia and cancer. These causes are in line with the national findings.
- Over two thirds identified that the individual had a DNACPR in place. Further analysis of this data is being undertaken to identify appropriateness. This will be detailed in the next report.
- A key issue that has been highlighted nationally is whether the annual health check has been completed. Within the BNSSG data over a third of reviews did not identify whether annual health checks had been completed or not as this was not a standard question and relied on the reviewer. It is noted that the LeDeR review forms have been changed and this is now a standard question.
- All reviews identified good or satisfactory care.

2.5 LeDeR Reviewers

As previously reported the LeDeR programme has identified that across the STP footprint BNSSG will require (as a minimum) 22 reviewers. This number was calculated based on the average number of annual death notifications for the BNSSG area (approx. 66 per annum) and those that are anticipated to meet multi-agency reviews that BNSSG will be required to undertake.

In 2017 LeDeR training days were held and twenty–six (26) people were trained. However, of this number there are now only eleven (11) active reviewers and a further five (5) who have accessed their password from the platform but not undertaken a review.

In March 2019 a dedicated reviewer was recruited on a short term basis and a further individual recruited in April 2019 to complete the backlog of reviews. They have been allocated 10 reviews each. This has been possible through NHSE funding. These two reviewers have established a ‘buddying’ system for new reviewers. However these are short term recruitments for the purpose of clearing the backlog of cases. Active recruitment of local staff is essential to cover the new cases reported each month otherwise the number of pending cases will start to increase again.

The data shows that as at June 2019 we have twenty-four (31%) of cases unallocated to a reviewer. This compares to a national percentage of 38% to be allocated to a reviewer. To support the allocation of cases the LAC and Coordinator undertake weekly reviews to:

- Assess progress
- Send reminders to reviewers requesting updates on progress,

- Where possible allocate cases, and
- Quality assure any completed reviews.

2.6 Leader Reviewer Support

To support the LeDeR reviewers a peer support group was established in March 2019 aimed at providing advice and support to current and potential reviewers. The peer support group is chaired by the BNSSG Local Area Contact and has to date held three meetings with further meeting dates booked every 6 weeks to the end of the year. The peer support group has Terms of Reference with the main purpose of the group being to ensure the reviewers remain engaged with the LeDeR programme and have the opportunity to identify their development and learning needs in completing LeDeR reviews.

In addition, the group will take operational actions from the LeDeR Steering Group and report back best practice as well as identified issues or risks to their ability in completing reviews and meeting the KPI's. The actions already agreed by the group have included peer reviewers attending local learning disability events to raise the profile of the benefits for local services taking learning from the LeDeR reviews and to recruit staff willing to be a reviewer from each provider.

Further funding has also been identified from NHSE to support the recruitment of an administrative role to provide essential chasing of records and to support the reviewers. A LeDeR administration model used by Dorset CCG has been reviewed to be emulated in the BNSSG area. HR recruitment processes are currently underway for this post.

3. CCG actions to support the LeDeR process

BNSSG CCG was late in establishing their LeDeR steering group due to the CCGs of Bristol, North Somerset and South Gloucestershire merging in April 2018. It was agreed during this time that the governance for LeDeR programme was via the Quality Committee. In November 2019, the quality team highlighted the actions needed to support the LeDeR programme across BNSSG. An action plan was drafted and an update on these actions is presented at Appendix II.

The attached action plan demonstrates that all actions are on track. Those actions relating to process have been completed. However, the main issue to address is recruiting sufficient numbers of LeDeR reviewers and supporting them to undertake reviews. Further work has been undertaken by the Peer Reviewer Group to look at ways to raise the profile of the role and to support new reviewers with their first few reviews.

In addition, the Interim Director of Nursing has written to the provider Directors of Nursing requesting an update and assurance on their Learning Disability arrangements and their support for the recruitment of their staff to become LeDeR trained reviewers.

The NHS Long Term Plan supports the continuation of the LeDeR programme therefore the CCG has reviewed and updated the Learning Disabilities and Autism schedule within the providers' NHS contract to reflect national changes to these standards and assure provider engagement in the LeDeR process. Compliance will be monitored via the provider's quality sub group meetings.

4. Financial resource implications

There are no financial implications in this paper. Non recurrent funding has been received from NHSE to support the two dedicated reviewers and for the appointment of administrative support.

5. Legal implications

There are no legal implications in this paper

6. Risk implications

The risks associated with this paper relate to a lack of trained active reviewers in BNSSG, the timely allocations of the cases and the prompt review and identification of any learning to support the care and treatment of people with learning disabilities. Actions on how to address these risks were discussed at the LeDeR Steering group in March 2019 as outlined above.

At the request of the LeDeR Steering Group the Interim Director of Nursing has written to all health providers to request their sign up to supporting the recruitment of staff to become LeDeR reviewers. A commitment for all organisations to commit to protected and allocated time for the staff acting as reviewers has been requested.

Risk rating on the directorate risk register is (Probability x Severity) 4 x 3 = 12.

7. Implications for health inequalities

It is acknowledge that individuals with a learning disability have shorter life expectancies. The purpose of the LeDeR programme is to help identify learning from deaths to decrease early mortality in this group of individuals.

8. Implications for equalities (Black and Other Minority Ethnic/Disability/Age Issues)

There are no specific issues in this paper

9. Consultation and Communication including Public Involvement.

Family and carer involvement in each case is essential to the LeDeR process. The Steering Group members plan to have involvement from service user representatives.

10. Recommendations

The Governing Body is asked to:

- Note the current position regarding the review of people with learning disabilities reported to the LeDeR programme and trained reviewers with BNSSG.

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Appendices - None

Glossary of terms and abbreviations

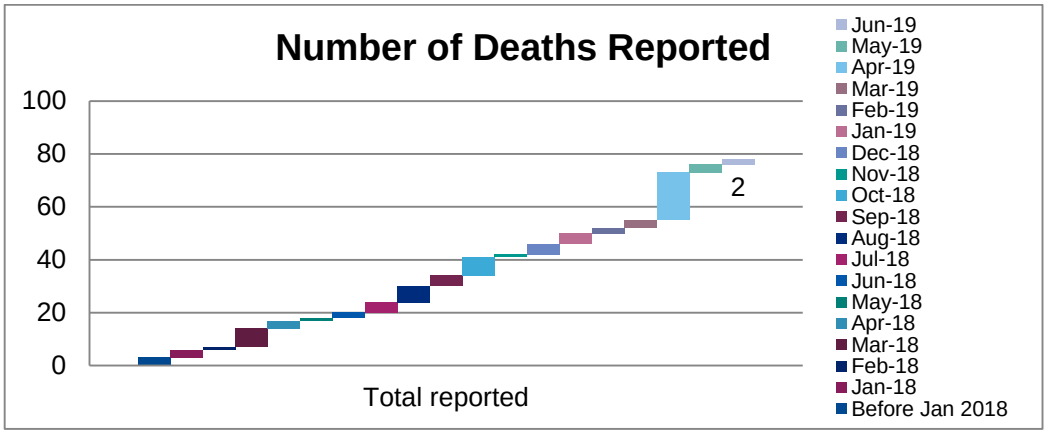
LeDeR	Learning Disabilities Mortality Review Programme is a national programme established in 2015 to review all deaths of people with learning disabilities aged 4 and over.
MAR	Multi-agency review undertaken into a death of a person with learning disabilities by an independent panel. This occurs if certain criteria are identified in the initial review.
LAC	Local Area Contact – a trained individual identified to manage the LeDeR programme within a CCG or STP area.
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation

Appendix I

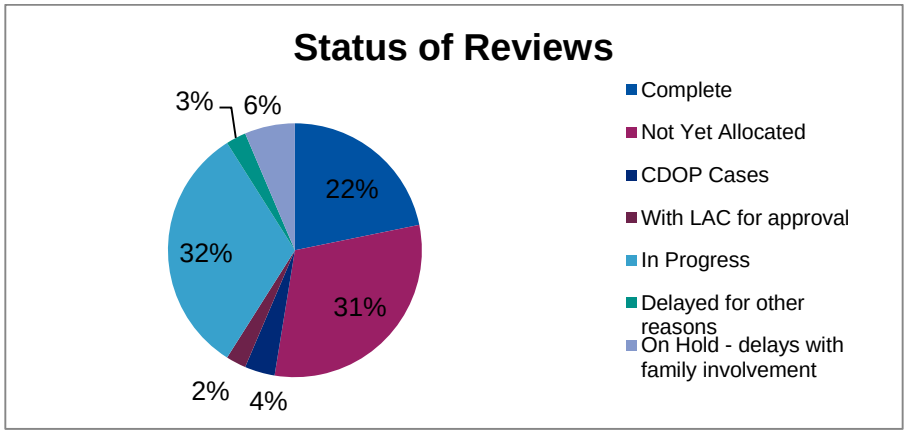
Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group

BNSSG LeDeR Activity at 12.06.19

Activity Data



A total of 78 deaths in BNSSG have been reported to the LeDeR programme. There was a spike in reporting in April following a reminder of how to report being sent to all stakeholders.



27 deaths are currently pending allocation of a reviewer and 36 are allocated and in the process of being reviewed.

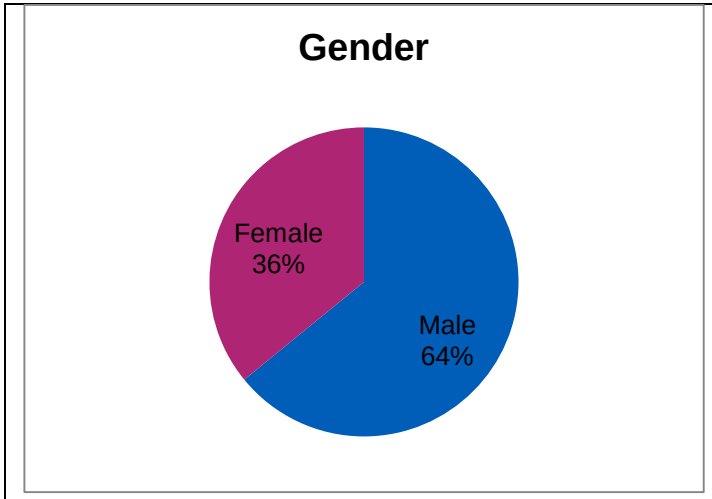
Organisation	Total Active Reviewers	Active Reviews	Completed Reviews
BNSSG CCG	3	3	2
UHB	2	2	0
WAHT	1	0	1
BCH	2	1	1
NSCP	1	1	1
Dedicated	2	29	10
Total	**11**	**36**	**15**

The majority of cases are being reviewed by two Dedicated reviewers. There are currently no active reviewers from NBT, Sirona, the Local Authorities or AWP.

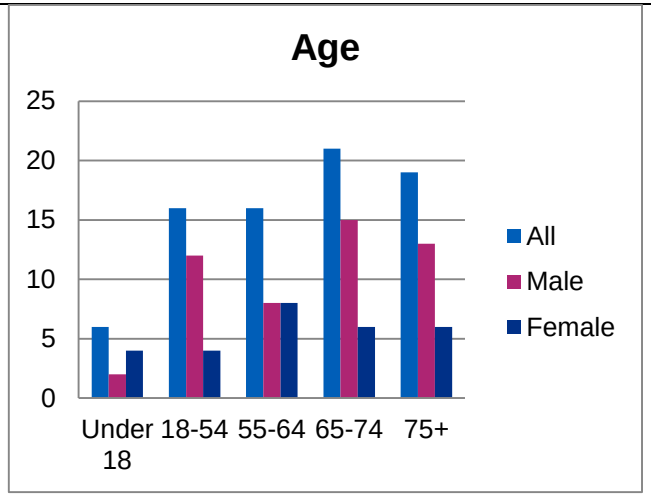
Organisation	Total Reported		Organisation	Total Reported
UHB	8		NS Council	6
WAHT	2		GP's	3
NBT	19		Social Care Providers	14
AWP	11		Out of Area	2
BCH	9		CDOP	6
NSCP	2		BNSSG CCG	1
Sirona	3			

The number reported in this chart is higher than the total numbers reported due to some cases being dual reported. The most frequent reporter of deaths is NBT.

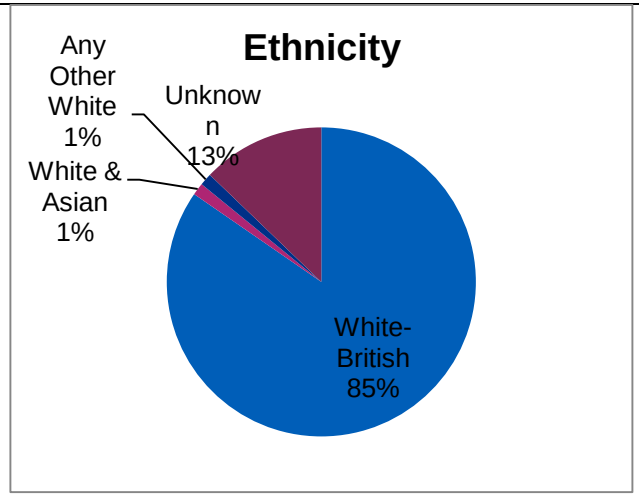
Demographics



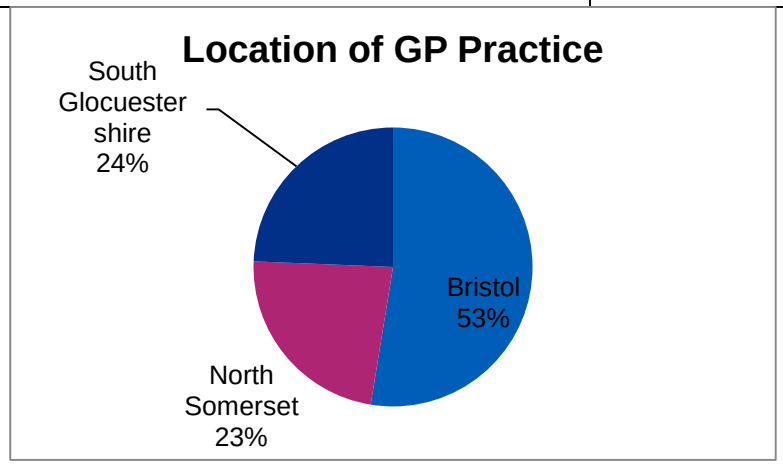
In BNSSG 64% of the reported deaths related to males, this is higher than the national average of 55%.



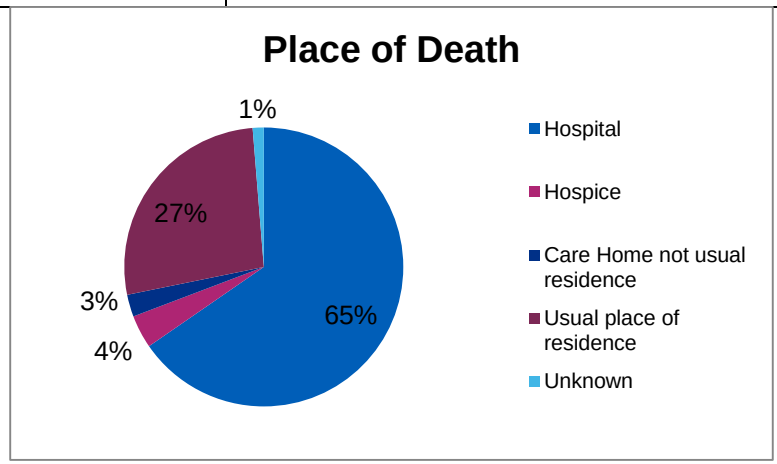
The median age of death of a personal with LD in BNSSG is 65 years; this is four years above the South West and National median.



Only 2 individuals whose ethnicity was known were identified as anything other than White-British.



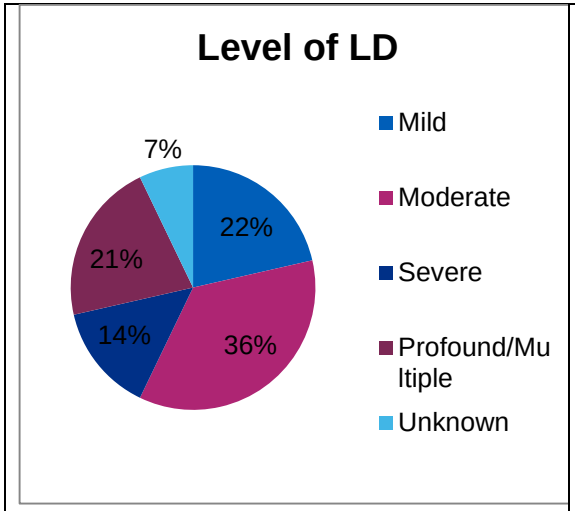
The location of the GP practice approximately correlates to the size of the general population.



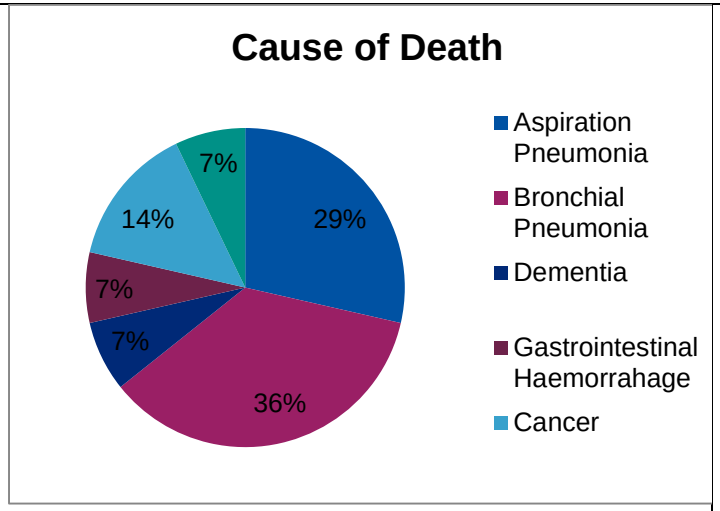
65% of people died in hospital, this is similar to the South West 59% and National 62%.

Outcome of Closed Reviews

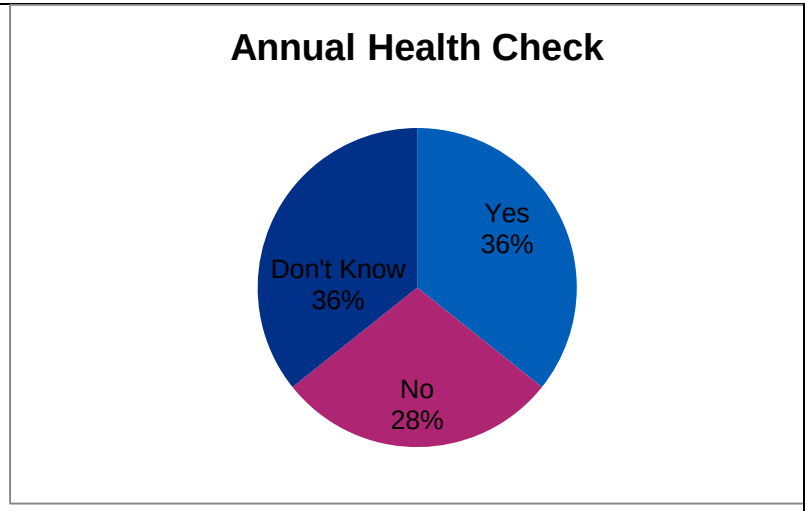
Seventeen cases have been completed, two of these were CDOP cases, which we do not receive a full review and therefore outcome information is not known. The 15 cases which have received full reviews have identified the following information.



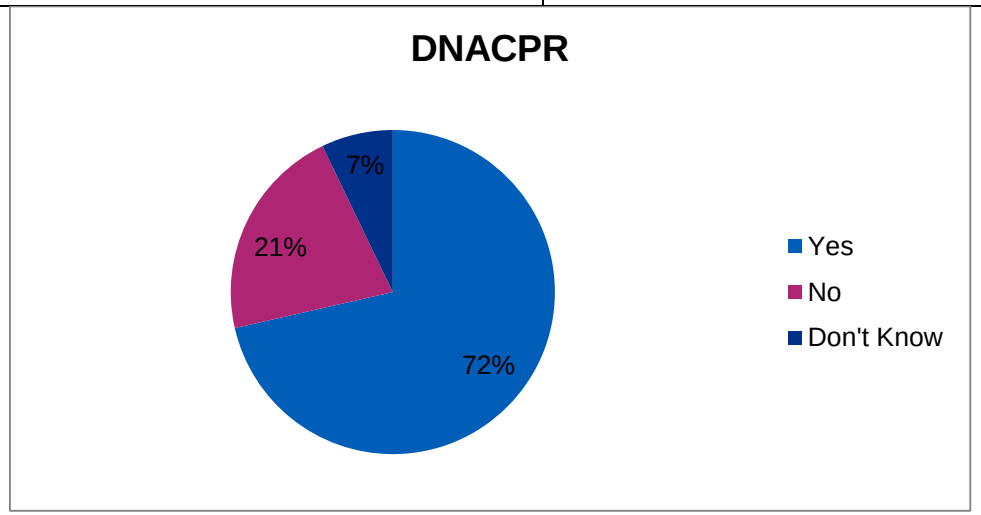
The majority of cases reviewed related to individuals with a mild or moderate Learning Disability.



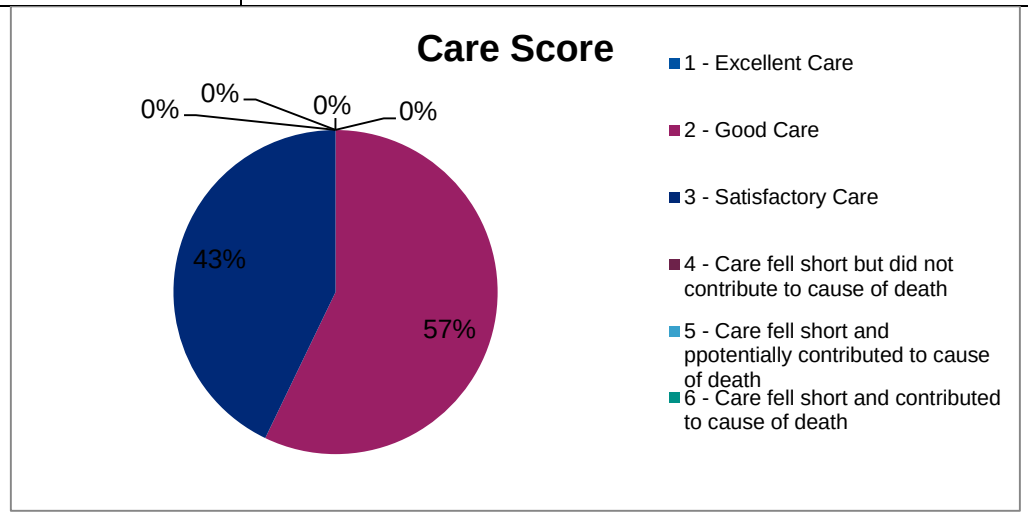
The most frequent cause of death identified is Aspiration or Bronchial Pneumonia.



Just over a third of reviews did not identify whether annual health checks had been completed or not. It is noted that the review forms have been changed and this is now a standard question.



Over two thirds of reviews completed identified that the individual had a DNACPR in place.



All completed cases to date have a care score of Good or Excellent care.

Appendix II

Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group

70 YEARS OF THE NHS 1948 - 2018

BNSSG CCG LeDeR Action Plan – update June 2019

Recommendation	Date identified	Actions	Person responsible	Date Reviewed	Outcome/ Comments
BNSSG CCG to establish a LeDeR Steering Group with member representation from all health and social care providers across BNSSG	November 2018	• Draft terms of reference • Invite key leads from provider organisations, three local authorities, primary care, LD support groups, CQC. • Agree agenda and TORs	Jenny Thompson, Bridget James	**Dec 2018** **February 2019** **June 2019**	Draft terms of reference approved by Quality Committee in December 2018. First meeting held with good attendance from health and social care Monthly meeting held since February 2019. Agendas and TORs agreed Action complete
BNSSG CCG to ensure adequate leadership for the LeDeR programme to support its full implementation across the health community	November 2018	• Identify key individuals to the following roles: - Senior lead - Local Area Contact - LeDeR coordinator	Bridget James	**December 2018** **February 2019** **June 2019**	Key individuals identified and trained. Key individuals in place since February 2019 Action complete

Recommendation	Date identified	Actions	Person responsible	Date Reviewed	Outcome/ Comments
BNSSG CCG to ensure there are adequate numbers of trained LeDeR reviewers across the health community	December 2018	• Review current LeDeR reviewers list. • Identify possible new reviewers	Jenny Thompson	**January 2019** **February 2019** **June 2019**	List reviewed. Only 15 trained reviewers are currently active from the 29 trained. Recruited a temporary LeDeR reviewer to focus on LeDeR reviews only Recruited a second temporary reviewer to complete review backlogs. 5 more reviewers recruited via the peer reviewer support group with plan in place to increase pool of reviewers from across BNSSG
To support LeDeR reviewers re-establish the peer support group	February 2019	LAC to contact all active reviewers to invite to a peer support group.	Jenny Thompson	**March 2019** **June 2019**	First peer reviewer support group held Monthly peer reviewer support groups held since February 2019. Peer reviewer group TORs signed off. Group renamed to Peer reviewers focus group to reflect the group's remit as a working group. Action complete

Recommendation	Date identified	Actions	Person responsible	Date Reviewed	Outcome/ Comments
Allocation of cases	February 2019	Cases to be allocated to reviewers	Jenny Thompson/Kat Tucker	**June 2019**	10 cases allocated to one fixed term reviewer. and 15 cases to second fixed term reviewer in March and April 2019. One case each allocated to two reviewers May 2019. 5 reviewers competing training May/June 2019. Requirement to more reviewers on risk register
Embedding learning and actions from LeDeR reviews	February 2019	Learning from completed LeDeR reviews to be shared and embedded into practice across all organisations in BNSSG	LeDeR Steering group/LAC	**June 2019**	Cases discussed at LeDeR Steering group in March and April 2019. Learning shared. LeDeR panel established May 2019 to agree specific learning to take to each steering group meeting.
Contractual arrangements/ sharing agreement across the organisations	February 2019	Develop information sharing agreement	Jenny Thompson/ Bridget James	**June 2019**	DIAP form submitted to IG group May 2019. Recommendation from IG group to complete information sharing paper. This paper completed in draft and sent to IG lead. Awaiting feedback
Engagement from provider organisations – sign up	February 2019	All organisations across BNSSG to sign up to full engagement with the LeDeR programme	Jan Baptiste-Grant	**June 2019**	Provider representatives attending LeDeR steering group and adhering to TORs. Letter sent by DON BNSSG CCG requesting full

Recommendation	Date identified	Actions	Person responsible	Date Reviewed	Outcome/ Comments
					engagement from all organisation leads
Implement the NHS Learning disability standards	February 2019	All organisations to implement the NHS learning disability standards published in June 2018	Organisation Leads	**June 2019**	UHB and NBT have LD steering groups in place with LD standards on agenda. LD schedule detailing LD standards shared with all providers contracted by BNSSG CCG. Assurances regarding a providers LD arrangements added to quality subgroup agendas
Provider level assurance	February 2019	All organisations to provide assurance to CCG and NHS England on LD services including: • Plans to support the transitions in care for PwLD/Autism from children's to adult care, including shared documentation • Training: In relation to ○ LD ○ MCA ○ Consent and Best Interests training especially in ED's	Organisation Leads/Directors of Nursing	**June 2019**	All providers completed NHS improvement LD self-assessment December 2018 and to complete action plans. Assurances regarding a providers LD arrangements added to quality subgroup agendas. Request for assurance from Directors of Nursing on the specific elements in this action sent in June 2019. Director of Nursing level discussions planned for July 2019.

Recommendation	Date identified	Actions	Person responsible	Date Reviewed	Outcome/ Comments
		• Interventions for people with challenging behaviours • Implementation of the Hospital Passport • Multi-disciplinary approach to care planning for complex case management for PwLD/Autism • Reasonable adjustments			