

Learning Disabilities Mortality Review (LeDeR) Annual Report

January 2020 to March 2021

**Learning from deaths of people with a
learning disability**



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Introduction

The LeDeR Programme (Learning from Deaths Review of people with a learning disability) is led by the University of Bristol and follows on from the Confidential Enquiry into the premature deaths of people with Learning Disability (CIPOLD) 2013. The findings of that report demonstrated that on average someone with a learning disability lives 20 years less than the general population.

This is the second annual report on the deaths of people with learning disabilities who lived in the Bristol, North Somerset and South Gloucestershire (BNSSG) area. The purpose of the report is to share our findings from LeDeR reviews and to report on the identified learning and the action we have taken to improve practice.

Last year's LeDeR annual reports by Clinical Commissioning Groups were reporting on a calendar year. For this year NHS England and Improvement (NHSE/I) changed reporting to a financial year. However this would lose an important 3 months of data at the beginning of 2020 and result in key issues, themes and learning being unreported, including LeDeR Covid-19 deaths, most of which in BNSSG occurred in March 2020. Our annual report covers the period January 2020 to March 2021, showing 15 months of data and reporting.

Through the BNSSG LeDeR Steering Group, we have been proud to host vibrant meetings where people with lived experience and system partners have fully engaged with the topics discussed and everyone has been passionately committed to listening and learning from these reviews, making real changes across the health and social care system. We continue to challenge health inequality and strive to improve health outcomes for people with learning disabilities with the aim to prevent people from dying prematurely.

October 2020 saw the publication of the Independent Review for Oliver McGowan. This has been a humbling experience. The CCG is deeply sorry for the mistakes it made during Oliver's original LeDeR review four years ago and recognises that the systems and governance that were in place at that time were not good enough. The reports have provided significant learning for the CCG as well as for our system partners along with a set of recommendations that we have accepted unreservedly and are implementing in full. The learning from these review reports is informing systematic improvements to our services to improve the quality and safety of care experienced by people living in our community who have a learning disability and/or autism.

We have worked hard to improve access to healthcare and address health inequality for people with a learning disability with our system partners. There has been a great willingness this year to work together amongst our providers, developing new tools to support practitioners, best practice resources to develop skills and awareness, with strengthened LeDeR processes. Our purpose is to create a strong culture of person-centred care, with vigilant and proactive support for people with a learning disability.

We have achieved good progress through this reporting period and have a strong commitment to continue to improve but we are not complacent, we have much more to do to ensure we provide the best quality and care for all those we serve with learning disabilities.

Alison Moon
Chair of the BNSSG LeDeR
Steering Group

Rosi Shepherd
Executive Director of Nursing

Chapter 1 - Structure for LeDeR

Background

The Learning Disabilities Mortality Review Programme (LeDeR) was established in 2016. LeDeR is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people with learning disability over the age of 4 years are subject to a Learning Disability Mortality Review.

The main purpose of the LeDeR review is to:

- Identify any potentially avoidable factors that may have contributed to the person's death,
- Identify learning and plans of action that individually or in combination, guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

All Clinical Commissioning Groups/STP areas were required to establish a LeDeR Steering Group during 2017/18. This was slightly delayed in BNSSG due to the merger of the three CCGs, it was quickly established in the autumn of 2018 and has now been in operation for two and a half years.

Overview of the national LeDeR process

The national LeDeR Programme, run by the University of Bristol established a process where all deaths of a person with a learning disability who was over the age of 4 years are subject to an initial review. These reviews focus on the individual's last year of life and include a pen portrait describing who the person was, their likes and personality, followed by a review of any medical and social care the person received. Importantly, the review includes making contact with a member of the family or staff carer, their involvement in writing a pen portrait is key. The LeDeR guidance states that these are not investigations, but reviews, with the focus on identifying learning and not apportioning blame.



The final element of the LeDeR review process is to complete a scoring grid on the level of care provided. This is based on the outcome of the reviewer's assessment of the individual's care. The scoring is from 1 (excellent) to 6 (fell short of expected practice), results from this year are detailed on page 20 of the report.

The reviewer is required to identify best practice and areas where improvements could be made. Where significant concerns have been highlighted then the reviewer may recommend a Multi-Agency Review (MAR) is completed. This part of the LeDeR process

requires all the health and social care staff who were involved in the person's care to come together to discuss the case and agree on recommendations to take forward for improving care. If the person has family they are also invited to attend or contribute, and again this is key to providing the background to the individual and ensuring that any concerns or questions that the family may have are addressed.

Following either the initial review or a MAR the case is reviewed by the Local Area Contact (LAC) for the LeDeR programme. This is to ensure all matters have been covered and learning has been identified. The LAC then completes a Quality Assurance checklist and the case is closed. An anonymised version of the case is generated and shared with all relevant organisations, if the family has given permission.

Local BNSSG LeDeR structure and governance

Steering Group

The Executive Lead responsible for the programme is the Executive Director of Nursing and Quality. In February 2019 we held our first BNSSG Steering Group, it has met monthly since this date including throughout the lockdown periods. Representatives attend the Steering Group from all BNSSG health providers, the three BNSSG local authorities which provide adult social care, the Care Quality Commission, GPs, local housing provider of homes to people with learning disabilities and NHS England regional LeDeR leads.

Our LeDeR Steering Group is chaired by the Independent Registered Nurse of the Governing Body and the group takes strategic level oversight of the reviews of deaths of people with learning disabilities and drives transformation to improve care. The role of the LeDeR Steering Group is to:

- Guide the implementation of the programme of local reviews of deaths of people with learning disabilities
- Receive regular updates from the Local Area Contact (LAC) about the local reviews of deaths of people with learning disabilities
- Monitor action plans resulting from local reviews of deaths
- Take appropriate action as a result of information obtained from local reviews of deaths
- To support the identification of and sharing of best practice in the review process
- Provide assurance to the Quality Committee and Governing Body
- For committee members to provide shared governance for LeDeR and reporting back to their own organisations
- Working with NHSE/I and proactively hearing people's voices

Assurance updates are reported to the CCG Quality Committee via the group's minutes of meetings and regular governance reports. The Quality Committee provides assurance and detailed update reports on LeDeR to the Governing Body.



To support the LeDeR process within BNSSG we have a LeDeR Framework Policy providing clear guidance on the process and governance to support the learning from reviewing these cases. The policy is available on the CCG's website.

Clinical Case Review Panel

To strengthen the national LeDeR quality assurance process, we introduced a local additional stage of a Clinical Case Review Panel. It is important to us that we have assurance of the consistency of the grading and the quality of individual reviews. The panel was established in July 2019 and membership includes the Local Area Contact, Clinical Lead GP for Mental Health and Learning Disabilities, CCG safeguarding representative, local authority representatives, social workers and the LeDeR administrator.

The panel reviews all completed cases to ensure all questions have been fully answered, with learning and any best practice identified, and appropriate recommendations formulated prior to closing the case on the LeDeR platform. The panel also identify themes from each review to guide areas for further action.

The LeDeR Team

The Local Area Contact (LAC) is the manager of the BNSSG process ensuring it meets targets and delivers the programme day to day. The LAC oversees the allocation of cases to trained LeDeR reviewers, monitors the progress and completion of reviews and provides quality assurance in the closure process of each case. The LAC prepares content, agenda and papers for the LeDeR Steering Group, Quality Committee and Governing Body.

A LeDeR administrator supports the LeDeR reviewers with case allocations, tracing records from GP's, providers both health and social care, following up queries and generally supporting reviewers with each case. The administrator undertakes preparation of papers and minutes for Case Review Panel, Multi Agency Reviews, Peer Support Group and LeDeR Steering Group.

LeDeR Reviewers

The LeDeR process is supported by a team of trained reviewers from healthcare organisations across BNSSG. The majority of our LeDeR reviewers are volunteers who undertake reviews in addition to their usual role, many of them are clinical professionals working in hospitals or in the community so they often have limited time to dedicate to complete reviews. We are grateful for their time and commitment to contribute to improving health care for people with learning disabilities. Special mention must be given to Sirona whose energy, passion and commitment went above and beyond supporting our programme this year by supplying the majority of our reviewers. We also have two paid independent reviewers who are available to undertake more complex reviews and provide support to the other reviewers.

Buddy Reviewer system for first LeDeR Review

To support reviewers with their first few reviews we set up a 'Buddy System'. Buddies are reviewers with experience of completing several LeDeR reviews and have a wealth of knowledge on the process. The buddies act as a point of contact for advice on where to start, how to approach providers and families and how to ensure their review is of good quality. Buddies provide a safe confidential space to discuss issues and support best practice.

Peer Support Meetings

In addition to the Buddy System, we established Peer Support Meetings to offer additional support to our LeDeR reviewers. Meetings are held on a bi-monthly basis and are less formal than the Steering Group and Clinical Case Review Panel. The aim of the meeting is to support reviewers with their open cases and these are the reviewer's opportunity to tell the LAC of any issues or blocks they may be facing and share their experiences and ideas with other local reviewers.

These meetings also give the LAC an opportunity to update reviewers on information from the Steering Group, Regional meetings and other LeDeR relevant events since the last meeting. Reviewers are also able to update themselves on any emerging themes or their individual needs, such as training and support.

These meetings although not compulsory do benefit many reviewers, through having a safe space to raise any concerns or speaking to other reviewers as to how they might approach a situation. We held 6 online meetings over the period of this report due to the pandemic. On line meetings have enabled more reviewers to attend.

LeDeR Service User Forum

We established a LeDeR Servicer User Forum in partnership with North Somerset People First, comprising of members with learning disabilities. We were only able to meet twice before lockdown. However we have continued to look for creative ways for service user voices to contribute to the Steering Group; through service user led reports about how they were coping with Covid-19 and any emerging issues, presentations about service user audits and service user projects related to LeDeR themes such as constipation.



Chapter Two – Programme Performance

The previous LeDeR annual report by Clinical Commissioning Groups was reporting on a calendar year as specified by NHSE/I. For this year the parameters required by NHSE are to a financial year. However this would lose an important 3 months of data at the beginning of 2020 and result in key issues, themes and learning being unreported, including LeDeR Covid-19 deaths, many of which in BNSSG occurred in March 2020. This annual report covers the period January 2020 to April 2021, showing 15 months of data and reporting.

Deaths notified to the LeDeR programme

Since the programme began in 2017 there have been 200* deaths reported to the BNSSG LeDeR platform covering the period July 2017 to end of March 2021. For the reporting period of this annual report 100 reviews were completed from January 2020 to the end of March 2021. 16 of these reviews were reported in 2019 but completed in 2020.

The LeDeR platform is in transition, moving from the University of Bristol to NHSE/I.

We have not had access to cases on the platform since 1st March and cannot allocate cases to reviewers until the new platform goes live in June 2021. We are aware there are 4 cases reported onto the platform for March 2021, but we cannot view the detail of these. (*NHSE closed access to the platform between 1st March to 31st May 2021 due to transfer of data to a new platform)

NHSE/I required all open cases on the old platform to be completed and closed on the platform no later than 30th April 2021. BNSSG completed all cases by the required deadline.

There were six cases referred for a Multi-Agency Review (MAR) this year.

The table below provides a summary of the status of all cases as at 31st March 2021.

Table 1: Summary of deaths notified in 2020/21

Total notifications Jan 2020 to March 2021	84*
Total notifications not yet assigned to a reviewer (March 2021)	4*
Total number of reviews currently in progress	0
Number of multi-agency reviews (MARS) undertaken in 2020/21	6
Completed reviews in 2020/21	100



NHSE/I key performance indicators for LeDeR activity require reviews to be allocated to a reviewer within 3 months of notification, for reviews to be completed within 6 months of notification and the quality assurance of reviews by the LAC within 2 weeks of completion.

Table 2: Completed reviews and KPI's

Completed reviews and Key Performance Indicators	2018	2019	Jan-20 to Mar-21
Number of Notifications	42	66	84*
Number of Closed Cases	4	47	100*
Total number of MARS completed	2	3	6
Allocation of reviewers within 3 months of notification	19%	26%	52.4%*
Completion of reviews within 6 months of notification	2.4%	7%	19.9%*
Quality Assurance of reviews by LAC within 2 weeks of completion.	21.4%	86.4%	100%

**All 84 cases reported in 20/21 were closed by 30th April, so although closed within 6 months of notification they will be included in figures for 2022*

LeDeR Reviewers

Over the last year we have trained a total of 31 reviewers, 28 of these reviewers have been active on cases this year. We have two dedicated independent reviewers who are paid for the cases they complete. The dedicated reviewers have retired from the NHS but have extensive years of experience at a very senior level, both having been former Directors. The senior reviewers are allocated our more complex cases and also lead the Multi Agency Review meetings where these are identified.

The majority of our reviewers are volunteers who undertake reviews in addition to their day job, the majority are nurses, allied health professionals or social workers from Community Learning Disability Teams (CLDT). At the end of 2019 we had 9 active reviewers so recruiting and training 31 reviewers has been a great success. We have the largest number of active trained reviewers in the South West Region.

We are especially proud of, and grateful to, all our reviewers who are dedicated to completing high quality reviews. Not only have they engaged fully with the review process but have personally reflected on the reviews to embrace learning for their own practice.

Actions taken to address Key Performance Indicator's

We developed a recruitment pack to encourage more people to become reviewers. This helped people to understand the role and provide guidance to managers on releasing staff to undertake this work. Working from home during lockdown has increased the opportunities for clinical teams to support this work and this has had an impact of increasing the numbers of reviewers, which allowed us to allocate cases more quickly.

We have also implemented weekly follow-up with reviewers to ask how their cases are progressing, checking if they need any support from us to access notes or querying if there is anything that is delaying them from completing the review.

The panel has met monthly throughout the pandemic and weekly during December 2020 and March 2021 to prioritise the completion of reviews to meet deadlines set by NHSE for closure of all cases on the old platform by 30th April.

LeDeR reviews - notified to 30th April 2021	ALL NOTIFICATIONS OF DEATHS OF PEOPLE AGED 18+ (EXCLUDING REVIEWS 'ON HOLD')							NOTIFICATIONS RECEIVED OVER 6 MTHS AGO					REVIEWS 'ON HOLD'	Child deaths		
	Total	Unallocated	In progress	Completed	Unallocated	In progress	Completed	Reviews with CCGs for completion			Total reviews still outstanding	People aged 18+	Total notified to date:	Completed	%	
								Outstanding	Completed	Completed						Waiting for other investigation
Region, steering group & CCG	No.	No.	No.	No.	%	%	%	No.	No.	%	No.	%	No.	No.	%	
England total	11417	919	212	10286	8%	2%	90%	119	5524	98%	125	2%	68	835	587	70%
SOUTH WEST	1116	68	11	1037	6%	1%	93%	6	677	99%	8	1%	6	67	39	58%
BANES, Wiltshire & Swindon	138	10	0	128	7%	0%	93%	0	71	100%	0	0%	0	13	8	62%
BANES, SWINDON & WILTSHIRE CCG	138	10	0	128	7%	0%	93%	0	71	100%	0	0%	0	13	8	62%
BNSSG	178	9	0	169	5%	0%	95%	0	133	100%	0	0%	1	10	9	90%
NHS BNSSG CCG	178	9	0	169	5%	0%	95%	0	133	100%	0	0%	1	10	9	90%
Cornwall and Isles of Scilly	101	12	8	81	12%	8%	80%	4	55	93%	6	8%	3	9	5	56%
NHS KERNOW CCG	101	12	8	81	12%	8%	80%	4	55	93%	6	8%	3	9	5	56%
Devon	202	23	3	176	11%	1%	87%	2	103	98%	2	2%	1	17	8	47%
NHS DEVON CCG	202	23	3	176	11%	1%	87%	2	103	98%	2	2%	1	17	8	47%
Dorset	171	3	0	168	2%	0%	98%	0	88	100%	0	0%	1	7	3	43%
NHS DORSET CCG	171	3	0	168	2%	0%	98%	0	88	100%	0	0%	1	7	3	43%
Gloucestershire	193	3	0	190	2%	0%	98%	0	135	100%	0	0%	0	7	6	86%
NHS GLOUCESTERSHIRE CCG	193	3	0	190	2%	0%	98%	0	135	100%	0	0%	0	7	6	86%
Somerset	133	8	0	125	6%	0%	94%	0	92	100%	0	0%	0	4	0	0%
NHS SOMERSET CCG	133	8	0	125	6%	0%	94%	0	92	100%	0	0%	0	4	0	0%

Multi Agency Reviews (MARS)

During 2020/21 six MARS were held. Each case involved the person's GP and a range of other professionals such as community nurses, CLDT members, social workers, care home managers, hospital consultants and residential key workers. The MAR meeting is not an investigation but an opportunity to reflect on the reviewer's findings and concerns to identify learning and make changes to practice.

Two of the MARS involved next of kin, ordinarily these are face to face meetings where we can properly brief and support family members. We delayed these two MARS due to Covid-19 hoping that they could be held face to face, however the lengthy lockdown prevented that and we held the MAR meetings on line.

We held small preparatory sessions with next of kin, supporting them to think about what they wanted to say and providing reassurance that they could stop the meeting at any time. Reviewing the cases proved to be very emotional and distressing, family members

were still grieving. We found the on-line format very limiting, not being able to have a pot of tea, hold a hand, offer tissues and take a breath. In the end we agreed to hold the MARs without the person and fed back on discussions outside of the MAR meeting.

Minutes and an action plan are agreed with all the participants who attended the MAR. A sample summary of the recommendations from these cases is presented below. Completion is monitored by the Clinical Case Review Panel and reported to the Steering Group.

Summary of example MAR actions
<ul style="list-style-type: none"> • If someone with a learning disability has abdominal pain and a change in behaviour the GP and care staff should consider constipation and take appropriate action
<ul style="list-style-type: none"> • When someone is diagnosed with a life limiting condition/prognosis, there should be early involvement of the hospice service for advice and guidance to support the person to plan what they want to happen
<ul style="list-style-type: none"> • CHC and discharge teams should update discharge protocols to include arrangements for support and information for families to find a care home. This should include making contact with their counterparts in other areas when discharge is out of county
<ul style="list-style-type: none"> • Care homes to implement use of fluid balance charts for patients whose fluid intake needs close monitoring to ensure they are not dehydrating
<ul style="list-style-type: none"> • ICU to involve family at an early stage of decision-making to reduce confusion. The context and fluidity of a DNACPR should be explained so that everybody understands why it is in place and the point at which it will be implemented.
<ul style="list-style-type: none"> • When non-clinical staff have concerns about a patient they know very well, they should feel able to raise this with senior/clinical staff without their opinion being dismissed or ignored. This helps when there are clinical bank staff on shift that do not know that patient very well. To be addressed in handovers & briefings to Agency Staff.
<ul style="list-style-type: none"> • Staff to be trained on how to check dosage of medications that come in different forms and dosages. Ensure all staff are trained on how to administer different dispensations. Staff must have confidence to ask senior colleagues if they are not familiar with a certain variation or a drug and do not have experience of administering it in that form.
<ul style="list-style-type: none"> • Care Home staff to be trained in RESTORE2 and the use of Pulse Oximeters
<ul style="list-style-type: none"> • Training/awareness raising for community staff on when to refer to End of Life and Palliative care services for guidance and advice
<ul style="list-style-type: none"> • Training in recognition of 'soft signs' - people with LD often do not present with usual symptoms that are evidence of illness such as a chest infection but will show soft signs that they are unwell (behaviour/mood changes, lethargic, not eating).
<ul style="list-style-type: none"> • People with LD who are placed an emergency placement that is not able to meet their needs must have regular follow up and close monitoring until a suitable placement is found.
<ul style="list-style-type: none"> • Frequent placement moves can impact on ability of health professionals to keep track specialist treatments/referrals and ensure continuity of care. Best Interests meetings were not held to consider when a placement move was being planned by the family.

Chapter 3 - About the people who died

Pen Portraits

All of the reviews include a pen portrait of the person who died. For every case we quality assure at Case Review Panel we always start with reading aloud the pen portrait. This gives us a real sense of the person; their likes and dislikes, their favourite things, what they liked to do, their friends and family, what kind of character and personality they had.

We have learned of amazing people; with a great sense of humour, people who liked sports and the outdoors, loved cowboy films and Elvis impersonators, enjoyed concerts and music from Abba and heavy metal to Vivaldi, someone who played the bagpipes, people who were the life and soul of the party to people who preferred their own company. We heard about people who took care of their appearance, loved jewellery and painting their nails, members of amateur dramatics and pantos, special Olympians, cheeky chappies, who were all so well loved by family and their carers. We have also found out about a few people who had very sad lives; some who had spent time in institutional care and who were horribly abused which had an impact on them for the rest of their lives.

These portraits help us connect to the person and remind us to consider whether the care and treatment they received would have been good enough if it was our relative, our sister, our son, our grandma.

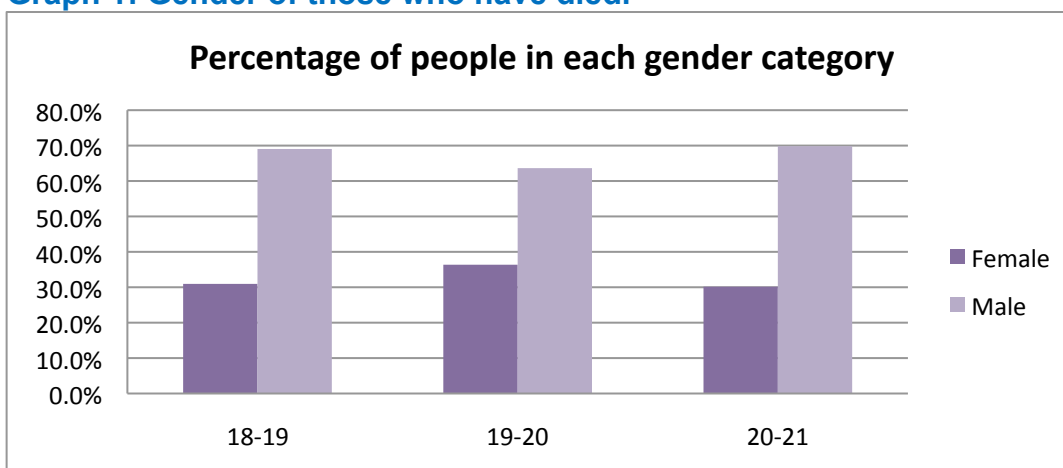
Demographic data

The following graphs provide the demographic information of those that died.

Graph 1 shows the gender of those who died. 70% of deaths reported were male and 30% were female. We do not have comparisons with regional and national data as it is not yet available.

Nationally the population of people with learning disabilities is younger and more dominantly male than the general population so it is important to make allowance for these characteristics in evaluating the number of deaths. There is a prevalence for more men to be diagnosed as having a learning disability as many syndromes are XY linked conditions.

Graph 1: Gender of those who have died.



Graph 2: Median Age of death

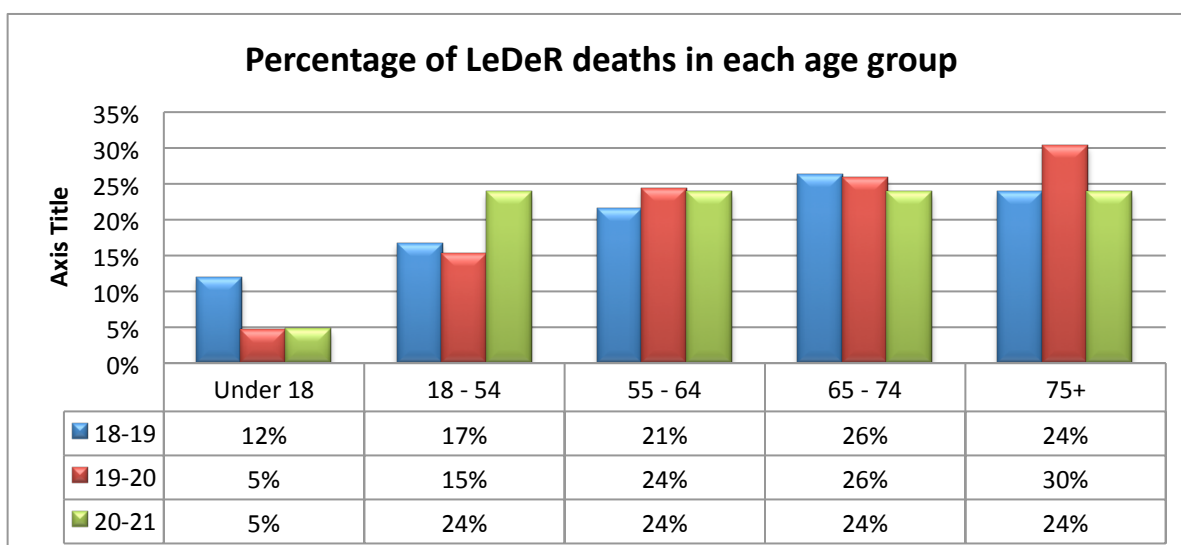
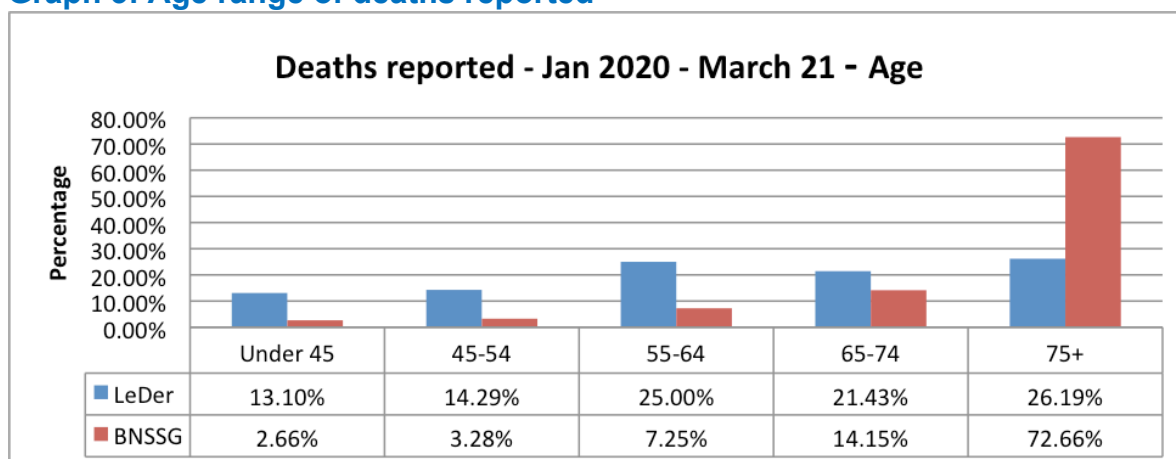
Median Age of Death	BNSSG LeDeR		BNSSG general population	
	Male	Female	Male	Female
Jan 20 – Mar 21	71	66	81	86

	BNSSG LeDeR		BNSSG LeDeR Overall	South West LeDeR	National LeDeR
	Female	Male			
2020/21	66	71	68	62	60

Reviewing the comparative data men with a learning disability live slightly longer than women with learning disability but die 10 years younger than the general BNSSG population. However people with learning disabilities in the BNSSG population live 8 years longer than the learning disability national average.

The majority of learning disability deaths (26%) were in the over 75 age group, the same as the BNSSG population. However the spread of deaths throughout all age groups is much higher than the general population. We have seen more people living into their 80's and 90's this year but these have been those with few co-morbidities and leading fit and active lifestyles.

Graph 3: Age range of deaths reported



Ethnicity

Graphs 4 and 5 below show the ethnicity of deaths reported to the LeDeR platform. There continues to be a low number of learning disability deaths reported from Black and other minority ethnic (BoME) communities. This does not compare with the racial profile for BNSSG and we believe there may be under reporting of deaths from these communities.

People with learning disabilities and/or autism experience health inequalities and those in BoME communities are further disadvantaged and under represented as users of learning disability health services. We want to find out what the barriers are for individuals and families to access health services for adults with learning disabilities.

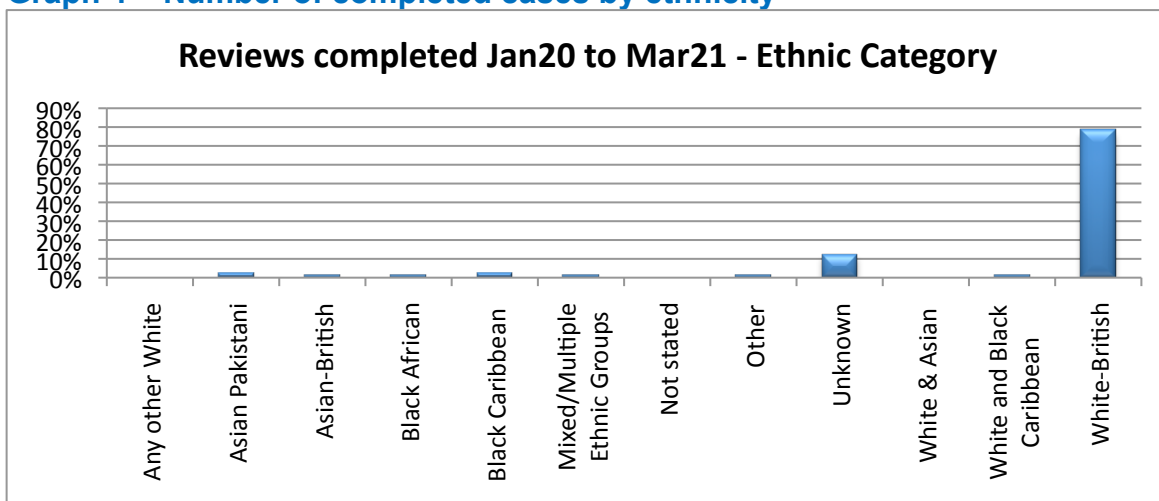
To address this we have funded new work with Autism Independence, who are leading a project to reach out to families from Black, Asian and other ethnic communities who have an adult with learning disabilities and/or autism. The purpose will be to find out people's stories and experiences of services supporting a person with learning disabilities in the family.



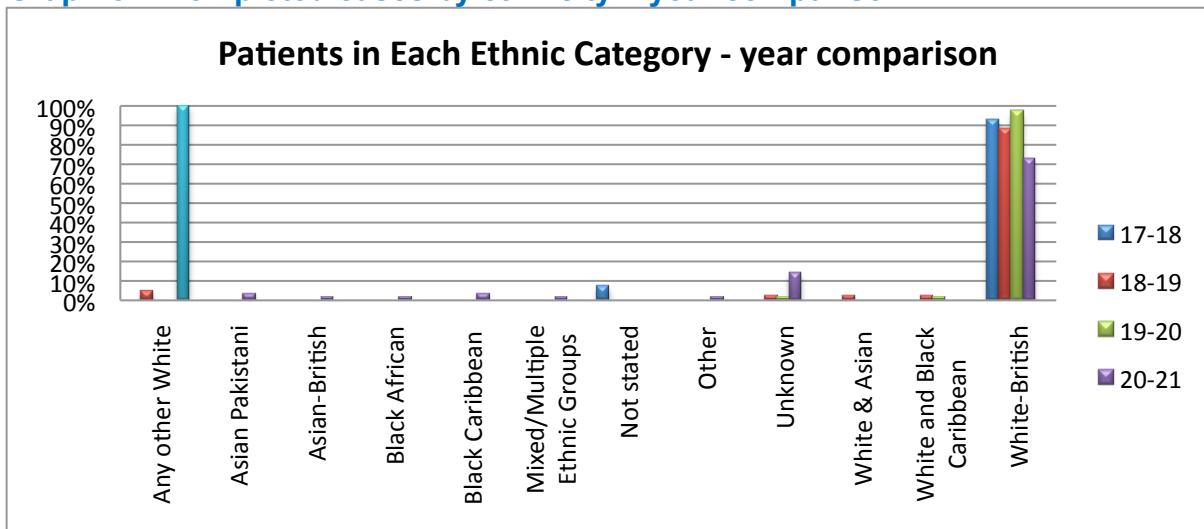
This work will support the Healthier Together vision for people with learning disabilities and autism from all communities to access high quality, fully integrated care that meets their expectations of services. It will contribute to a plan to coproduce improvements in how we support people better. This project will start those conversations to understand the challenges and commission in a way that meets the needs of our population.

We want to hear stories of peoples' past and current experience – listening will be the first step. Initially, work will start with a BNSSG focus and then the project findings and recommendations will help us plan how we have similar conversations across the South West region.

Graph 4 – Number of completed cases by ethnicity



Graph 5 – Completed cases by ethnicity – year comparison

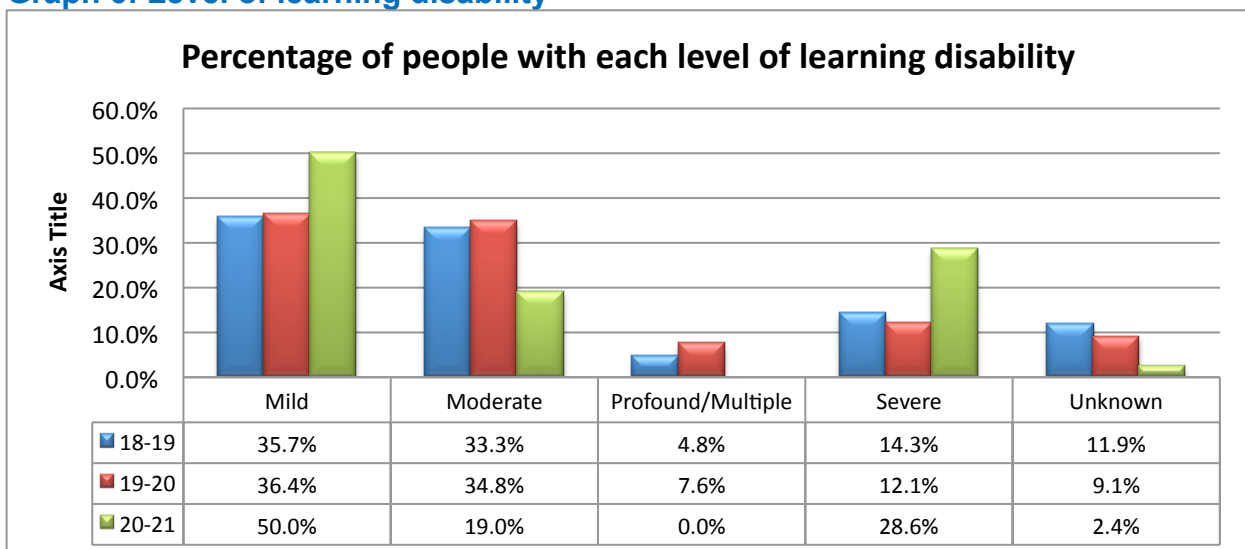


Level of Learning Disability

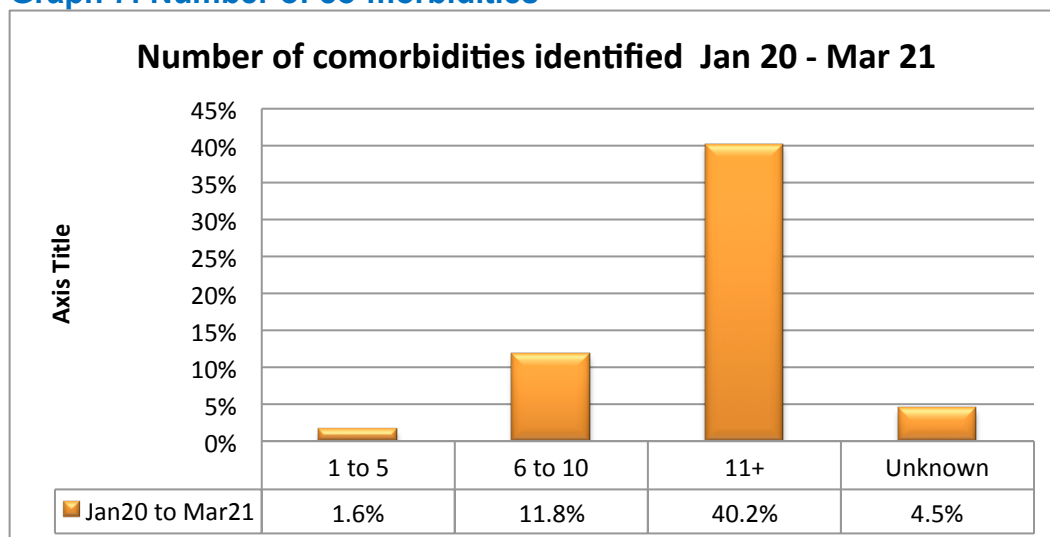
The level of learning disability in reviews is determined by what is recorded on the GP learning disability register, GP notes or documented by another professional. These are generally taken from SNOMED codes but are not necessarily accurate as it is open to individual interpretation if not diagnosed by a specialist. People may be diagnosed at birth or soon after – for example Down’s Syndrome. Someone with Down’s Syndrome may have a profound disability or another individual with Down’s Syndrome is able to read, write, drive a car and go to university. So the level of learning disability is only an indicator.

We have seen more deaths of people with severe learning disabilities, this year which is primarily due to Covid-19. This has been particularly apparent with those who had poor physical health and multiple co-morbidities. This is reported in detail in Chapter 5

Graph 6: Level of learning disability



Graph 7: Number of co-morbidities



Every person in the reviews had one or more co-morbidities. The highest number of co-morbidities for one individual was 14. In the older age group some co-morbidities were due to age. There was a high incidence of diabetes, epilepsy, obesity, heart disease and cancer.

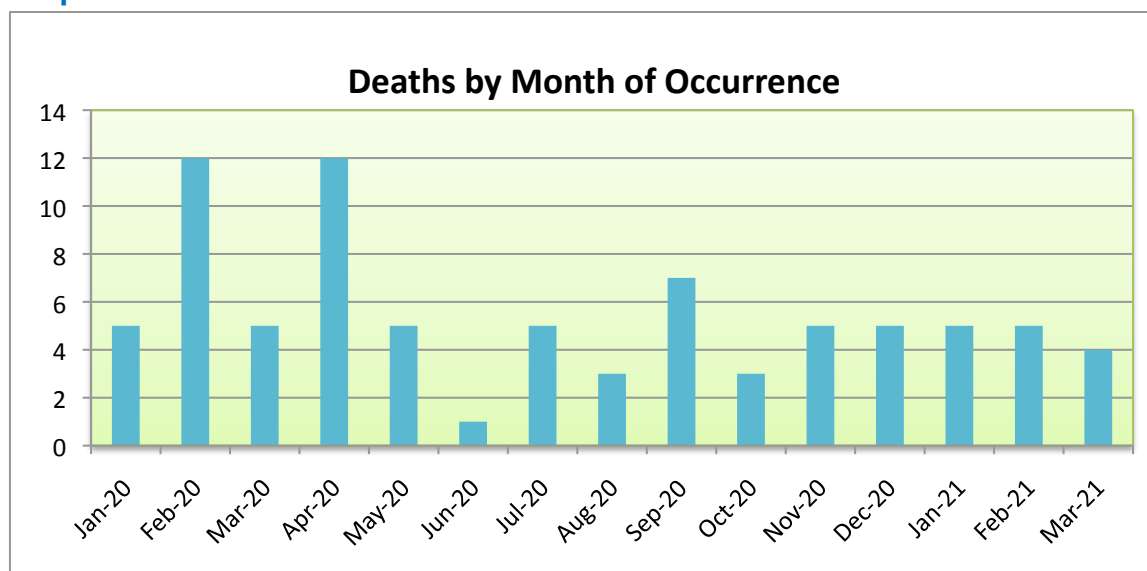
Child death data

During 2020/21 there were 4 cases notified to the LeDeR platform, which related to the death of a child with learning disabilities. All child deaths are reviewed as part of the statutory Child Death Overview Process (CDOP) and therefore separate LeDeR reviews are not undertaken. Due to the small number of cases, demographic data has been withheld to prevent inadvertent identification of the individuals.

Chapter 4 – Cause of death and Quality of Care

Deaths in February 2020 were mostly attributable to pneumonias that compares with a similar level of reported cases last year. The majority of Covid-19 deaths began in March through to April 2020, with a further small spike of Covid-19 deaths in September 2020. We undertook significant work to review and learn from Covid-19 deaths of people with learning disabilities and this is detailed in chapter 5.

Graph 8: Month of death



Cause of death

The reviewer records the cause of death in the review as detailed on the person's death certificate. From the completed reviews, 38% of deaths were related to pneumonia as the primary cause, as shown below. The next most frequently reported cause of death was Covid-19 (17%). These are looked at in detail in chapter 5.

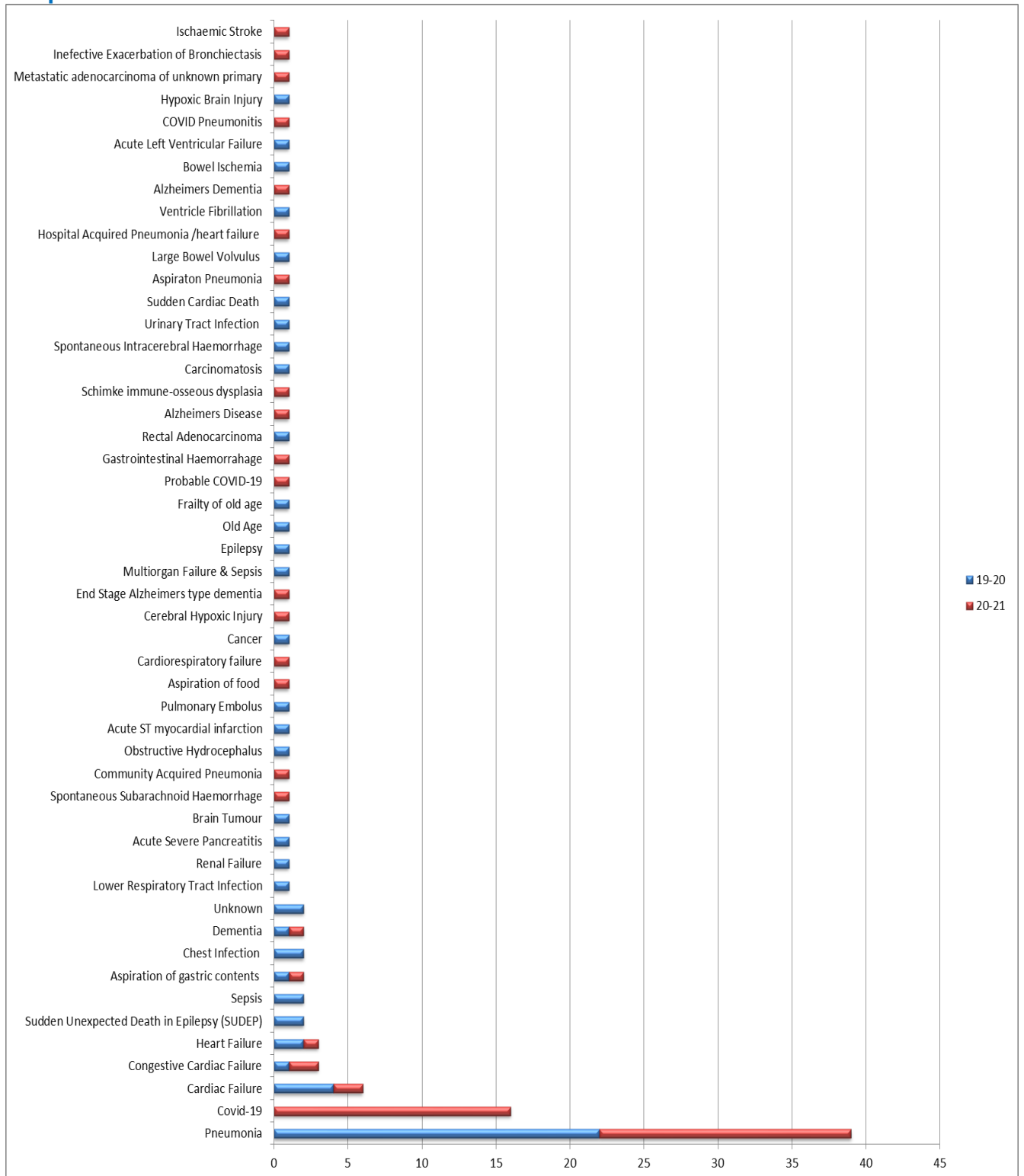
Type of pneumonia	Percentage of the 38%
Generic Pneumonia	47%
Bronchial Pneumonia	13%
Aspiration Pneumonia	40%

Reviews have identified that a small number of death certificates state, for example, 'learning disability' or 'Down's Syndrome' as a secondary cause of death. The LAC has discussed this with the new medical examiners to ensure appropriate guidance is given to clinicians about not using this incorrectly as a cause. We will also raise this issue with providers to address in learning disability awareness training for medical staff.

Graph 9: Main causes of death

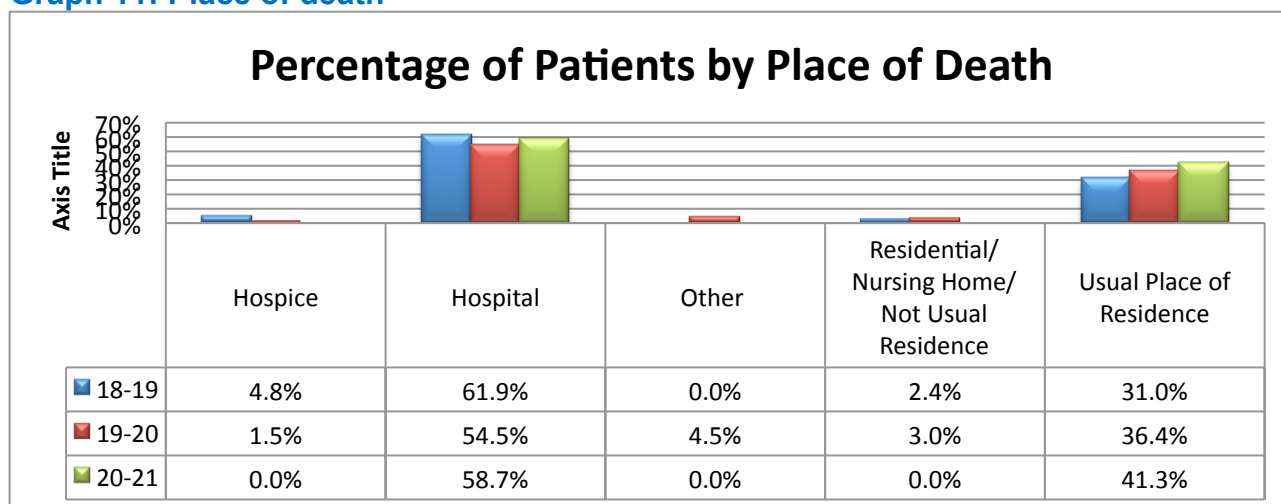
Main Causes of Death - Jan 20 – Mar 21	19-20	20-21
Pneumonia (including Aspiration)	25	24
Covid 19	0	16
Cancer	3	6
Respiratory disease	1	5
Cardiac failure	4	6
Sepsis	3	4
Old Age - frailty	1	4

Graph 10: detailed breakdown of causes



Graph 11 shows the place of death for cases reported in 2020/21. For BNSSG 58% of the deaths occurred in hospital. This is slightly more than last than last year largely due to Covid-19. There has been an increase in the numbers of people supported to die at home. There has been a noticeable effort this year where people were on End of Life care for residential staff to make special arrangements for the person to die at home with friends and family.

Graph 11: Place of death



An individual’s choice for their place of death is taken into account and usually documented through ReSPECT forms which we have seen used much more this year either with care home staff or through support of the learning disability liaison nurses in hospital. Sometimes Mental Capacity Assessments or Best Interests meetings are used. There has been some involvement of specialist bereavement services but no-one from the reported deaths was in hospice care this year.

Assessment of the quality of care

One aim of undertaking LeDeR reviews is to share best practice when care has gone well to support people with learning disabilities live full and enriching lives. Reviews also identify learning from when things haven’t gone as well for an individual and to use this information to support improvements in the health and social care for others. It is important to us that the assurance for the consistency of the grading and the quality of each review is discussed at the Clinical Case Review Panel.

On completion of a case the reviewer is required to make an assessment of the level of care provided on a range from 1 (excellent) to 6 (Care fell far short of expectations). This assessment is then quality assured by the Case Review Panel through discussion. This can result in going back to the reviewer for more discussion, asking the reviewer for detail on a specific point or may result in a change to the grading in agreement with the reviewer.

The following table shows the level of care provided for completed reviews in 2020/21. From the reviews 8 out of 10 people with a learning disability in BNSSG received care that is satisfactory or good. There were no cases where it was identified that the care received contributed to the death of the individual. Whilst there was a lot of very good care identified in reviews, there were no cases where the care provided, across a range of providers in the last year of the person’s life were felt to be outstanding. This emphasises the importance of gaining assurance on the robustness of the process. Findings and themes identified in reviews are discussed at provider learning disabilities groups.

Table12: Grading of care

Care Score	Percentage	Total & Ratio
1 - This was excellent care and met current best practice.	0.0%	61/84 8:10
2 - This was good care	40.98%	
3 - This was satisfactory care	42.62%	
4 - Care fell short of expected good practice & this did impact on the person's wellbeing but did not contribute to cause of death.	14.75%	10/61 6:6
5 - Care fell short of current best practice in one or more significant areas, although not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.	1.64%	
6 - Care fell far short of expected good practice and this contributed to the cause of death.	0.00%	

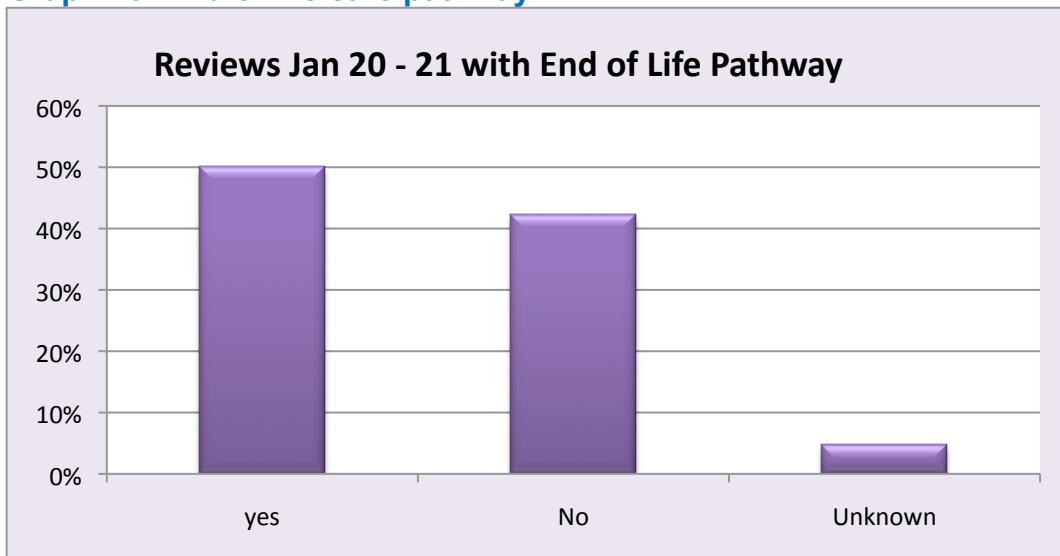
End of Life

Within the review there is a requirement to identify if End of Life care planning was in place for those where death was expected. The following graph shows that this was the case for 50% of the reviews, an increase of 12% from last year. Our ambition is to work with primary care, providers and hospice services to increase End of Life planning to be addressed in 65% of reviews

There has been more evidence of End of Life discussions taking place with the person themselves this year and involving family members in those discussions. We have had some lovely examples of people planning their own funerals, with songs, poems, special requests and one man who loved horses having ridden much of his life, having a horse drawn hearse at his funeral.

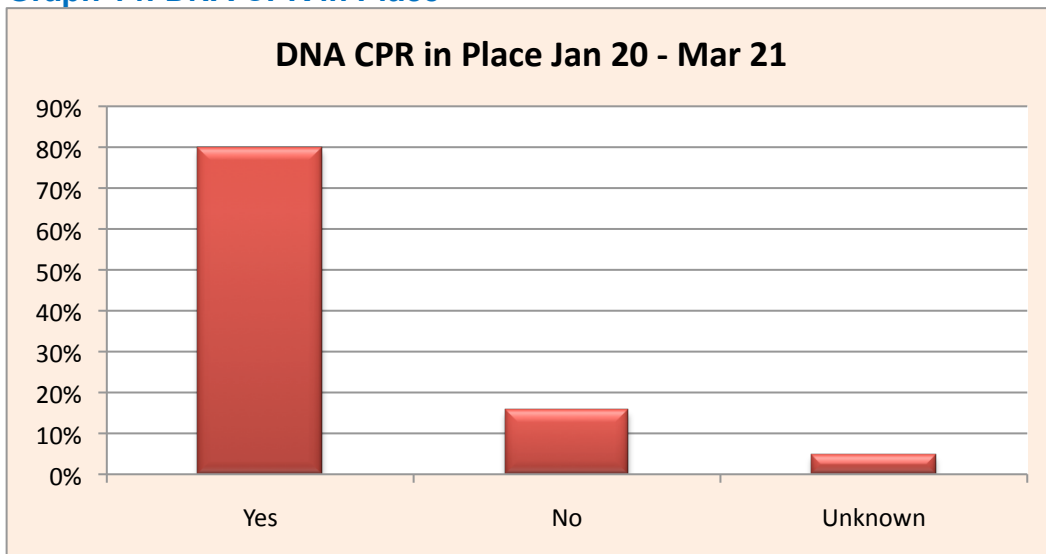


Graph 13: End of life care pathway

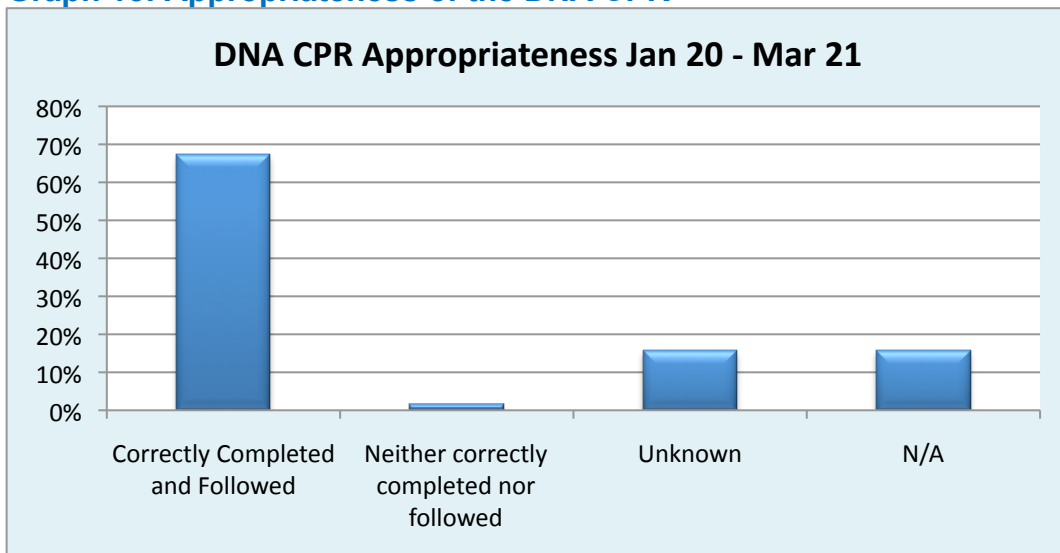


In addition, the reviews look to see if a 'Do Not Attempt Cardio-Pulmonary Resuscitation' order was in place or not. The following graph shows that for 80% of the reviews this was the case, an 8% increase on last year.

Graph 14: DNA CPR in Place



Graph 15: Appropriateness of the DNA CPR



Of the reviews where a DNA CPR order was in place the reviewers noted that 67% were appropriate, correctly completed and followed. For 15% of cases paperwork was not available to the reviewers to assess the completion. The reviewer assesses appropriateness and looks for Mental Capacity Assessments, Best Interest meetings and involvement of next of kin or an Independent Mental Capacity Assessor (IMCA).

Annual Health Checks

Last year evidence of completion of Annual Health Checks (AHC) for people with learning disabilities was generally quite low, particularly finding the documentation to review the discussion and any health goals. We understand the importance of the AHC in keeping people with learning disabilities in optimum health, therefore we undertook specific work to address this over the year and look at how we could better support GP's and practice staff to complete AHC's.

A small AHC task and finish group developed a toolkit of AHC resources to support GPs & practices, validated by Community Learning Disability Teams. These were made available by setting up an AHC portal with 30 recommended resources hosted on GP platforms – Teamnet/Remedy, including easy read invite letters

We identified lead Learning Disability GP's in every practice to establish a contact list and established a BNSSG Learning Disability lead GP Forum. We then developed and delivered a multi-agency training webinar for GP's on AHC's – 90 minutes training and discussion attended by 66 GP's. Further webinars were held on Covid vaccination, consent and reasonable adjustments.

The group also worked with Healthwatch, service users and carers to develop an easy read 'Get Ready' Checklist to prepare people with learning disabilities for their annual health check. GP feedback has been that these have improved the quality of AHC's, helped to focus the discussion on important issues and save appointment time.

We have been pleased to see much better compliance with completing the AHC evidenced in reviews with good documentation available. GP practices in BNSSG met the 67% completion target.

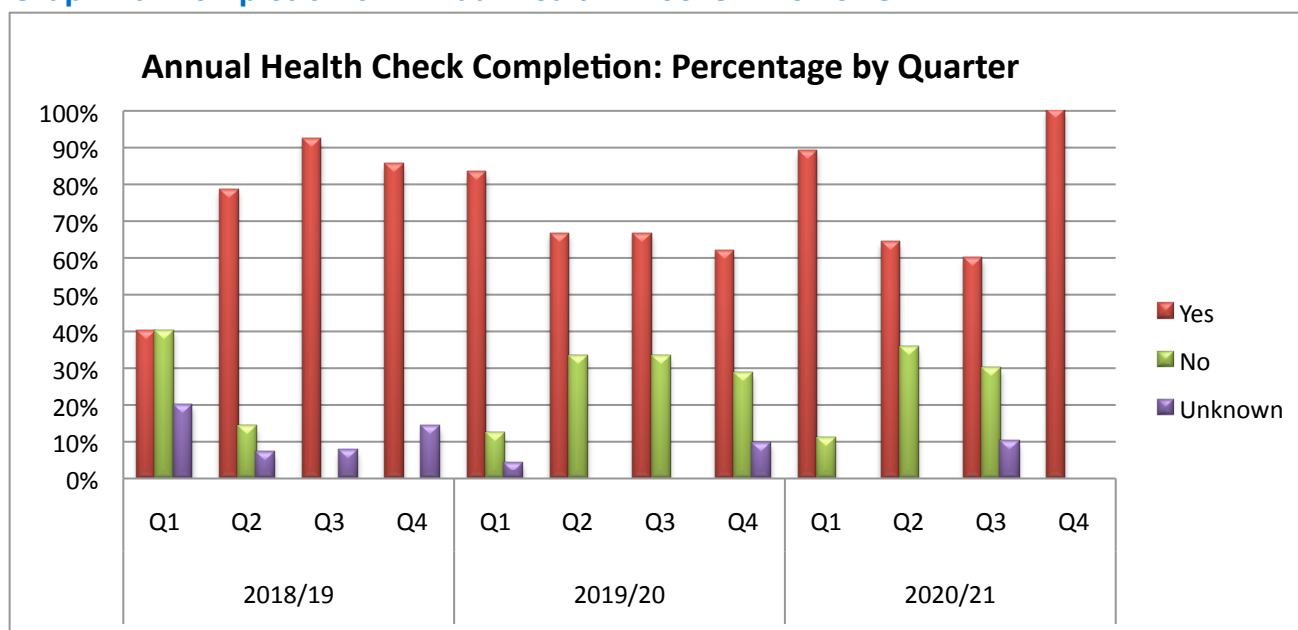


Our GP's have impressively continued to complete AHC's, the majority of which were face to face using personal protective equipment, in a year of Covid lockdown and prioritised the health of people with learning disabilities addressing many of the health inequalities usually faced by this client group.

Further plans to support AHC's

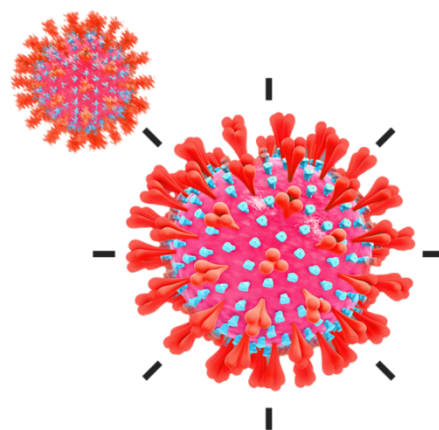
- From the success of the pilot rollout the LD champions programme to all GP practices across BNSSG supported by CLDT staff
- Develop further training sessions for practice nurses & other staff involved in AHC
- Learning disability AHC's are now included in the Phase 3 primary care prioritisation work Ensuring Health Action Plans are produced as a result of the AHC
- Targeted support for practices who have low AHC compliance
- Engage GP LD Leads and PCN Clinical Directors to support delivery - Work with PCN's to set up locality LD forums
- 'buddy' practices with high compliance with those who are struggling
- Regular prompts & support calls to practices about progress with annual health checks.
- Provide pertinent information on reasonable adjustments, coronavirus issues, vaccine, MCA, Best Interests and consent etc
- Linking AHC to various quality improvement projects e.g. STOMP and improving uptake of cancer screening (particularly bowel cancer)
- GP's advise too many AHC templates on EMIS – BNSSG will develop one agreed AHC template and put on EMIS
- Develop AHC audit tool with LD GPs – auditing 5 completed AHC per practice

Graph 16: Completion of Annual Health Checks in reviews



When **Robin** registered as a new patient at the surgery, Robin's GP met him for an initial consultation. Less than 2 weeks later carried out an Annual Health Check. This was completed comprehensively with a high level of detail, with clear outcomes and goals in a Health Action Plan. The GP surgery demonstrated an in-depth knowledge of Robin's health, took the time to liaise with family members to ensure holistic understanding of presentation, and well documented considerations for future treatment. They also visited his care home every week, so any ongoing or minor issues that may not usually warrant an appointment could be addressed with ease and allow early identification of concerns.

Chapter Five – Covid-19 Deaths



From March 2020 to the end of March 2021 in BNSSG we had 16 confirmed Covid-19 deaths of people with learning disabilities - 9 in hospital, 7 in the community, with an age range of 54 to 87. The majority of Covid-19 deaths were in March and April 2020.

Rapid Reviews

In the first wave of Covid-19 we wanted to ensure we could identify any lessons as quickly as possible and share these with learning disability providers. All hospital deaths had a Rapid Review completed using an NHSE template to identify any local learning ready for the second wave. We also commissioned Sirona, provider of out CLDT services to undertake rapid reviews for people with learning disabilities who died in the community.

Findings from both hospital and community reviews were presented to the BNSSG LeDeR Steering Group in September 2020 and shared with a wide range of providers in hospitals, care homes, primary care and Community Learning Disability Teams in order to learn lessons for any second wave.

The Rapid Review findings were;

Findings/recommendations for Residential Care

- People did not present with usual symptoms
- Went off food, sleepy & lethargic
- Review of building layout to prepare for isolation
- Staff training needed in RESTORE2
- Use of pulse oximeters – know persons baseline
- Review use of agency staff in outbreak
- End of Life – grief support for staff and residents

Findings/recommendations for Primary Care

- People did not present with usual symptoms
- Varying experience of GP support
- Diagnostic overshadowing
- DNACPR usage
- Out of Hours and weekend management
- Proactive support for LD patients

Findings/recommendations for Hospital Care

- LD Liaison nurses provided good support
- Access for home staff to visit on ward
- Share information with home staff & next of kin
- Discharge checklist
- Improve care planning and handover between shifts

Findings/recommendations for CLDT's

- Diagnostic overshadowing
- Improve support to GP practices
- Work more closely with care homes
- Set up CLDT advice line providing clinical advice
- Roll out LD champions in GP practices
- LD Support for hospices

As our LeDeR Service User Forum could not meet during lockdown we asked people to send us 'Coronavirus Service User Impact' reports to tell us about their experiences, anything they were worried about and anything they wanted to escalate to us to raise concerns. The main worry people had was isolation, particularly those who lived alone as

services completely closed. They were dependent on voluntary organisation such as People First who supported individuals with food parcels, socially distanced walks and easy read information about keeping safe during Covid-19.

There were emerging reports nationally in the summer of 2020 that DNACPR was being blanket applied to people with learning disabilities, particularly in London and Birmingham. We wanted to be sure this was not the case in BNSSG and reviewers were asked to check very carefully if any DNACPR documentation was in place and ensure it was properly applied and consented through an MCA assessment or Best Interests meeting with the individual, their next of kin or an IMCA.

There was no evidence from either of our local reviews that 'Do not resuscitate orders' were applied inappropriately to people with learning disabilities in any of our hospitals in BNSSG.

We also commissioned an in-depth report of all 16 Covid-19 deaths from completed full reviews. Findings were presented to our LeDeR Steering Group In February 2021.

In-depth review of 16 Covid-19 deaths

The report identified there may be under reporting of deaths, as LeDeR is not mandatory. 14 of the 16 deaths reviewed occurred between March and May 2020. During this time there were difficulties with personal protective equipment (PPE) as well as a lack of guidance from the government regarding its usage. This could provide some rationale as to why there were so few deaths reported beyond May to January 2021, as guidance was clearer and PPE readily available. However, as previously identified, the learning disability population is six times more likely to die from COVID-19. Therefore, the report saw these as the minimum numbers of people who died from COVID-19 across BNSSG. Below is a summary of the Covid-19 specific findings;

Complying with hands, space, face

Most of the people who died would not have been able to follow the government guidance themselves and required significant support to do so. People with learning disabilities are sometimes unable to follow guidance such as wearing masks, keeping two meters distance including when they enter high-risk environments.

7 of the people reviewed had a diagnosis of a dementia, 11 people had behaviours that were challenging for services. This further impacted on the difficulties in following issued infection prevention control guidance. One person was noted to persistently follow staff around, and would regularly go into other resident's bedrooms, this was of particular concern when they contracted COVID-19. Some of the restrictions caused great distress to residents

DNACPR



Isolation plans in homes:

Across a number of care settings there was evidence of difficulty in isolating residents due to the design and layout of the buildings. The functionality of the settings was such that they were designed to be sociable places with shared living spaces and open plan areas. Where this was not the case, outbreaks were easier to control. One home was able to completely section off half of the home once an outbreak occurred; in the outbreak side every resident contracted COVID-19, in the second side of the home there were no cases of COVID-19.

Commissioned Care:

Two people living in a residential service also required nursing care. Nursing needs were provided by district nursing rather than the in-house staff. This could have been a likely source of infection as these were the only residents in the homes to receive District Nursing care and to contract COVID-19.



‘Nursing Home’ status

Where a home employed nurses, their clinical competence allowed provision of medical care to ensure all residents were supported when the outbreak occurred. The nursing team were able to complete regular, accurate observations and utilise the National Early Warning Score (NEWS)2 system to early identify deterioration. Once identified deterioration was communicated to GP’s effectively, utilising evidence-based decision making during remote consultations, to ensure people received rapid treatment.

As part of the review it was identified that some of the residential care homes were described on Care Quality Commission (CQC) websites as providing “Accommodation for people who require nursing or personal care, learning disabilities”. The staff within these residential homes were not able to support those who required nursing care. This was misleading and led to assumptions by primary care and others that qualified nursing care was available when it was not, which led to delays and miscommunication when residents became unwell.

RESTORE2 (Recognise Early Soft Signs, Take Observations, Respond, Escalate)

Care providers acknowledged in the review that they were not trained in monitoring physical health or providing end of life care, both of which were expected during the pandemic. As a result, care staff relied heavily on GP’s and Out Of Hours (OOHs) support, often calling on a daily basis and as health further deteriorated this would increase to multiple calls a day.

There was no evidence of any of the residential services using RESTORE2 for monitoring any deterioration. This led to untrained staff, without the tools or knowledge required to monitor residents with COVID-19. More than one home took digital readings of oxygen saturation levels and blood pressure, but not manual observations such as respiratory rate

to enable a full hand over to the GP or Out of Hours. One GP noted "they were unable to give any detail of why they are unwell". Other homes that did have the ability to take a full set of observation did not have a set of baseline readings, which made clinical decision making more difficult.

There was further evidence that staff's inability to recognise signs of deterioration and act appropriately when needed. In one case, staff contacted the GP surgery rather than emergency services when someone was showing clear signs of a stroke. Another person had fallen and was unable to move from the floor due to pain. The care team called the GP instead of an ambulance prolonging the time taken for the person to receive the care they needed.

Patrick became unwell and his care home staff contacted the GP surgery by phone. They said he was 'breathing quicker' but they were not encouraged to count the breaths to enable a clear picture of deterioration. When the GP visited 2 hours later his respiratory rate was 32, which is very high. If the GP had known the respiration rate this may have enabled them to do a visit sooner, or advise to contact emergency services instead.

End of Life (EoL) Care:

Across residential services staff were willing and able to care for people at the end of their life. They were passionate about the people they supported, wanting to ensure that they were able to continue to support them throughout their life, including at the end of their life. Most homes had no training in providing end of life care even though they were supporting older adults, some of whom had experienced a decline in health and the care staff did not have time to access additional training, especially during the pandemic.

In homes where there were multiple deaths, staff said that they needed time and support to deal with bereavement and the trauma of the effects of caring for others during the pandemic, but nothing was available through work. Bereavement support was also required to support residents with their grief and loss of losing a friend and housemate to Covid. One service sourced bereavement support through St Peters Hospice, which staff were given dedicated time to access.

Oxygen Masks

People with learning disabilities in the review found it difficult to tolerate wearing oxygen mask when admitted to hospital. All were assessed as requiring oxygen but were unable to tolerate the masks or nasal cannula. As a result they did not have oxygen treatment and it is possible that this may have contributed to death. There was no evidence of proactive support to enable tolerance of this through reasonable adjustments or desensitisation.

Action from the report

The report makes recommendations for social care, acute services, primary care and community services. The LeDeR Steering Group has asked for the report to be disseminated and for learning briefs to be developed for each sector. The Covid-19 report's findings will also be presented to the Learning Disability and Autism Programme Board to ensure actions are picked up in the work programme.

Chapter Six – Learning from reviews

Learning from local reviews - Clinical Case Review Panel identified themes

From an overview of completed local reviews during 2020/21, the Clinical Case Review Panel has identified a number of recurring themes. These focus on areas where improvements can be made to improve the health and social care for people with learning disabilities. There is usually more than one theme per review.

Table 6: Recurring themes

Learning theme	Number of LeDeR reviews where identified
Annual Health Checks - Health Action Plans	61
Constipation	73
Catheter Care	49
Epilepsy	27
Reasonable adjustments	17
Mental Capacity Assessments, Best interest meetings	47
Record keeping and communication	26
Cancer screening	31

The Clinical Case Review Panel noted many areas of good practice including:

- Regular staff continuing to visit the person whilst they were in hospital.
- GPs undertaking home visits and ward visits to support people staying at home.
- Best interest decision-making meetings involving family.
- Multi-disciplinary meetings in hospital to review full care of the person, including physical health, cognitive and behavioural needs.
- Primary care undertaking more comprehensive patient reviews involving CLDT's and residential staff

Examples of best practice;

- People with learning disabilities in hospital having a clear easy read hospital passport that is fully completed by residential staff
- Innovative reasonable adjustments that increase access & reduce health inequality
- Having a designated person responsible for coordinating the person's healthcare
- Supporting residents to die in their own home, surrounded by people who know them with the required level of support
- Continuing Health Care providing top up packages for people in residential homes to support changing healthcare needs as people age, ensuring people are not moved unnecessarily from their homes of 25+ years in the last year of their life.

What action are we taking to address themes identified?

Annual Health Check – Health Action Plans

Every person with learning disability on a GP register should be invited for an Annual Health Check (AHC) by their GP, supported where required by community providers. Following the AHC, each person should be given a Health Action Plan (HAP) by their GP. This is a summary of the discussions and the health goals agreed for the person to work on with their carers or support staff. We have outlined on page 21/22 the work undertaken to support GP's with AHCs. In reviews this year Health Action Plans were mentioned but it was hard to find copies of them in notes reviews or on EMIS. That may be because the HAP has been given to the person following their check-up. Anecdotal evidence is that the goals agreed are verbally discussed but not provided in writing.

As part of developing a single electronic template for the Annual Health Check on EMIS we are looking at building a tool to extract the health goals agreed into an easy read template to give the person at the end of their annual check. This electronic version may be limited by the inclusion of photos, but we will develop an easy read Health Action Plan and discuss with our learning disability lead GP's how best to implement.

Constipation

From the reviews completed this year 73/100 people had an issue with constipation, some very severely, with impacted bowels that resulted in sepsis.

We commissioned a co-produced project with North Somerset People First called "Poo Matters", led by a senior learning disability nurse from Sirona Care and Health. The group explored issues about constipation and found out peoples' experience. Group members said they didn't know what constipation was and would be too embarrassed to talk about poo with their GP. One person thought it was normal to only poo once every three weeks.

The group identified a range of resources to support discussions such as detailed models of the Bristol Stool Chart, an anatomical apron with Velcro parts showing how your insides work, a model flushing loo and a poo board game. The group developed recipes to test and a 'sweetcorn challenge' to help learn how quickly your bowels moved. Recipes including Constipation Cookies, celeriac mash, apples stuffed with dates and Weetabix cake. The project worked remotely though lockdown through the use of Zoom sessions for discussions and remote cookery sessions. Members of the group presented their work to the LeDeR Steering Group in February 2021

Our plan is to roll out the project across BNSSG. We are developing a resource pack which will include details on how to access the models, easy read resources, easy read recipe cards which include ratings for how they taste and how easy the recipe is to make.

Bob said he didn't know he was constipated until he was involved in the project. He thought a stool was something you sat on. He has enjoyed taking part and can now talk to anyone about poo. He feels much better in himself, is not in pain and discomfort every day and said it has really helped reduce his anxiety and general mental health. Bob has enjoyed testing the recipes and finding out foods he likes to keep him regular. Bob says he is a new man!

Catheter Care

One of the frequent themes from LeDeR reviews is poor management of catheters for people with LD often leading to sepsis and people being admitted to hospital. We set up a task and finish group with the BNSSG Continence Service, providers and the University of the West of England. Our current plan of work is;

- identify good resources about catheters - leaflets/models ideally easy read for people with learning disabilities
- develop an easy read catheter passport
- NBT/LD liaison team to set up notifications to the Continence Service when someone is discharged with a catheter
- develop a catheter pathway for people with LD
- look to develop catheter champions across BNSSG
- Working with Photosymbols to create bespoke catheter symbols for us, working with Catheter Service and learning-disabled models
- develop special interest teams in CLDT
- develop training for carers/residential staff about catheter care.

Reasonable adjustments

Reasonable adjustments (RA) may require innovation & thinking 'outside the box' to support people to access services. This is best done with family or support staff that knows the person really well. We are involved in a national pilot to develop an electronic RA flag on the health record of the person with a learning disability. This will enable the recording of any individualised adjustments to ensure the person has all they support they need when visiting their GP or a hospital setting. We are working with providers and NHS Digital to ensure this can be shared across our different patient record systems are compatible.

The Learning Disability Liaison Nurses in our acute hospitals have developed reasonable adjustment checklists and yellow resource boxes in every clinical area so they are readily available to support a person with learning disabilities and/or autism with adaptations. The Liaison Nurses have worked closely with primary care to adapt medi rooms (clinical treatment rooms) to make it less frightening whilst people are having procedures such as having bloods taken & other urgent medical tests. These include the use of calming lights, music and other distraction techniques. This work will link with the RA flag project.



Epilepsy

People with learning disabilities who have epilepsy should be reviewed by a Consultant Neurologist and/or a specialist epilepsy nurse for poor seizure control or a medication reduction if the person has been seizure free for several years. Reviews have noted a number of Sudden Unexpected Deaths in Epilepsy (SUDEP) where carers and residential staff have not had specialist advice to support people with seizures, especially at night. There has been good practice by GP's reviewing medications and withdrawing these when people have been seizure free for years. However in all cases the fits returned very quickly.

We are working on developing a specialist epilepsy pathway for people with learning disabilities in primary care. We are also looking to develop a specialist equipment resource list and guidance for carers/residential staff to reduce risks, for example trip hazards caused by laying cushions or mattresses on the floor at night.

Mental Capacity Assessments, Best interest meetings

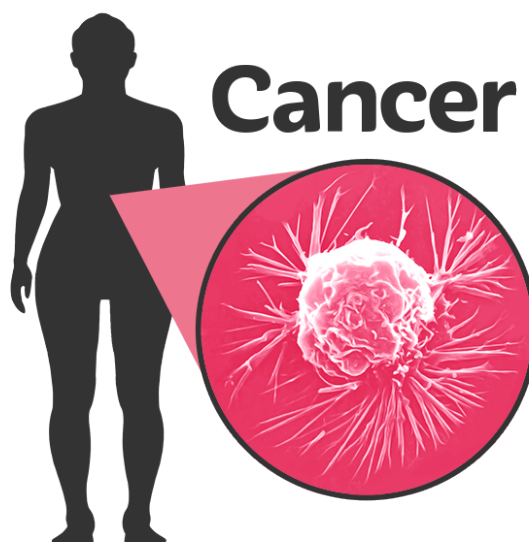
The reviews this year identified many Mental Capacity Assessments and Best Interest decisions mentioned in GP notes however there was little evidence of decisions being documented or recorded properly and not necessarily undertaken as they should be in primary care for important decisions involving people with learning disabilities. The process was sometimes confused and there was not enough involvement of Independent Mental Capacity Assessors (IMCA's) when there was no next of kin. This is particularly for things like vaccinations, DNACPR, ReSPECT forms and End of Life Care.

To address this we are 'pinching with pride' forms developed by one of our providers, North Bristol Trust to document MCA/BI decisions. We have adapted these for use in primary care and have distributed these to GP practices, included as resources on Remedy and Teamnet and promoted in the GP Bulletin.

We have asked BNSSG safeguarding to review the training plan for GP's on MCA/BI decisions to address this. We are planning a lunchtime refresher session with input from the team. We have some great examples and lived experience stories from our safeguarding GP, a parent and the local authority social workers working with people who have learning disabilities which are ideal scenarios for update training alongside the new forms.

Cancer Screening

Reviewers check that people with learning disabilities have been invited and supported to attend screening appointments. National programmes are for Bowel, Breast and Cervical screening. The evidence in reviews is mixed - some people are supported very well to attend screening appointments. However there are documented in many GP notes, where a decision has been made



that the person 'will not tolerate screening'. This is often assumed without any consideration of reasonable adjustments nor as part of a Best Interests meeting.

From NHS Digital breast screening data for there is a 15% difference between women with learning disabilities attending a screening appointment compared to women in the general population in England. 34% of eligible women with learning disabilities attend cervical screening compared to 75% of women without learning disabilities. Colorectal screening is closer to the uptake for the general population but the test is less invasive.

To address this we are working with Cancer Research UK and MacMillan GP's and have developed a webinar for BNSSG GP's on Cancer Screening for people with learning disabilities to be held in June 2021. This will include Professor Pauline Heslop as keynote speaker on the importance of screening, the Learning Disability Liaison Nurses talking about reasonable adjustments for breast screening and colonoscopy, service users from Brandon Trust and their residential staff talking about their experience of screening and how they are supported to attend appointments. We are collating a range of easy read resources and leaflets on cancer for Remedy and Teamnet. Cancer Research UK will also be offering training to BNSSG practices on cancer screening.

Areas where we have more work to do

Aspiration Pneumonia - We have not addressed how we might improve treatment of aspiration pneumonias and need to undertake work to explore this with our system partners. Working with respiratory experts we want to find out if there is more that could be done to reduce this as our highest cause of death.

Record Keeping and communication – This continues to be an issue in the many reviews and documents. Staff from all of our providers need support and training to recognise the importance of timely, accurate and reliable notes in all patient records. Whilst many providers have worked hard to introduce new forms there continue to be gaps in documenting key decision making processes.

Sharing Learning Themes

The LeDeR Steering Group will provide regular information on the learning themes and recommendations identified from LeDeR reviews to the Learning Disability and Autism Programme Board to inform their programme of work. Some of the agreed priorities identified for health will be progressed as part of the Learning Disability Health Providers Network.



Chapter Seven – Oliver McGowan Independent Review

The Independent Review into Oliver McGowan’s LeDeR Process was published in October 2020 along with the second Multi-Agency Review (MAR) into his care. The report was commissioned by NHS England following unresolved concerns expressed by Oliver’s family.

The CCG is deeply sorry for the mistakes it made during Oliver’s original LeDeR review, (as in the action plan in appendix 1) and recognises that the systems and governance that were in place at that time were not good enough. As identified in the review the CCG did not have previous experience of undertaking LeDeR reviews at that point and in hindsight should have recognised that Oliver’s case needed referral to a higher-level independent review from the outset.

Both reports provided significant learning for the CCG as well as our system partners along with a set of recommendations that we accept unreservedly and will implement in full. The learning from these reviews informs systematic improvements for services to improve the quality and safety of care experienced by people living in our community who have a learning disability and/or autism.

In the three years since Oliver’s first LeDeR review was completed we have significantly improved our LeDeR processes and governance. Executive oversight is strengthened, operation of the LeDeR process is robustly managed and support for reviewers is significant. Our learning and LeDeR journey brings us to a very different place from that first review.

The MAR action plan has been discussed at the BNSSG LeDeR Steering Group and Governing Body. Executive leads from across the system have contributed to the review of activity that has been completed in regard to our commitment to fully implement all of the recommendations. These have also considered alongside the broader ambition of ensuring that key areas of learning are embedded into system transformation work to ensure the consistent delivery of high quality and accessible services for people who have a learning disability or who are autistic across BNSSG.

BNSSG is on the Project Board for the Oliver McGowan pilot training project in Gloucestershire and so far we have 50 places allocated for our providers on the Tier 2 training to be launched in June 2021.

The reports and action plans have been discussed by the BNSSG Governing Body and system partners and were discussed in November 2020 and January and March 2021. Full details in Board Papers on the BNSSG website. <https://bnssgccg.nhs.uk/events/>

A copy of the completed action plan for the LeDeR Process is attached as appendix 1.



Chapter Eight - Conclusion and recommendations

8.1 Conclusion

This is the second Learning Disability Mortality Review (LeDeR) annual report for Bristol, North Somerset and South Gloucestershire CCG. The report provides the detail of how the LeDeR process has been implemented, demonstrating how our governance arrangements support a robust approach to learning from the deaths of people with learning disabilities.

There are national changes planned for the LeDeR programme as we develop into an Integrated Care system (ICS). Although the changes are significant we are passionately committed to keep learning as a result of LeDeR reviews to continue to drive an innovative work programme that makes changes to improve services and address health inequalities experienced by people with learning disabilities.

The ICS model will need to have the flexibility and structural model to have an adequate resource of reviewers to be able to allocate and complete reviews within the given timeframes and this will be strong focus for us in 2020/21.

We want to strengthen our partnership with North Somerset People First and develop support to establish other self-advocacy groups across BNSSG. Their expertise and guidance will help us develop and establish the voice of people with learning disabilities across BNSSG and their experiences will drive our work.

8.2 Recommendations

The report identifies areas where further work is required in 2021/22. This includes:

- Undertake further work to make improvements in all the key areas we have addressed this year; Annual Health Checks, Health Action Plans, constipation, catheter care, reasonable adjustments, epilepsy, Mental Capacity Assessments & Best Interests
- Undertake work to explore how we could address aspiration pneumonias and work with respiratory specialists to see if there are ways to reduce this as our highest cause of death.
- Work with system partners on training to improve documentation and record keeping.
- Working with our system partners to embed sustained learning and improvement of care for people with learning disabilities. Ensuring learning identified from reviews informs day to day practice across our providers in health and social care.
- Undertake a system review to ensure End of Life Pathways are appropriately used and fully involve people with learning disabilities and their families, including the use of accessible information and ReSPECT plans.

- Ensure DNACPR is audited across our hospitals to ensure order decisions are appropriately made with safeguarding assessments for Mental Capacity and Best Interests assessments fully completed.
- Greater inclusion of people with learning disabilities in our work, their attendance and contribution at the steering group and co-production of workshop events and training programmes.
- Hosting and contributing to more specifically themed learning events during 2021/22 developing lessons and best practice from LeDeR work, including working with the West of England Academic Health Science Network Learning Disabilities Collaborative, to share learning and best practice.
- Continue to work with system partners to develop shared best practice, audits and innovations through the BNSSG Learning Disability Health Providers Network.
- Continue to promote and share action learning with the aim of ensuring all people with a learning disability and or/autism experience good or excellent care

These actions will be addressed through the new Learning Disability and Autism Health Providers Network and reported to the LeDeR Steering Group and the Learning Disability & Autism Programme Board.



LeDeR Annual Report 2020/21

Appendix 1 - Independent Review - Oliver McGowan – LeDeR Process Recommendations

	Recommendation	BNSSG - Current Position	Planned
1	Reporting a person's death to the LeDeR programme should be mandatory, with the responsibility placed on clinical commissioning groups (CCGs) to ensure this happens in their locality.	<p>Action for the Department of Health.</p> <p>However BNSSG local promotion of LeDeR shows reporting of deaths on our platform increases year on year. This is reported monthly to LeDeR Steering Group and the CCG Governing Body</p>	Any further recommendations from the Department of Health will be fully implemented
2	Clear guidance should be produced to enable CCGs to effectively 'triage' individual deaths, to ensure that the most appropriate governance methodology is used to review them (based on circumstances and complexity).	<p>Action for the National LeDeR Team</p> <p>We agree and BNSSG will develop a local protocol for the triage, escalation and commissioning of independent reviews in line with the Serious Incident Framework to ensure the most appropriate level of investigation and governance is identified.</p>	Any further recommendations from the National LeDeR programme Team will be fully implemented
3	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.	All LeDeR reviewers in BNSSG are buddied with a more experienced reviewer. This has been in place since March 2020	BNSSG Complete
4	There should be clear guidance on the roles of buddy and second reviewers.	<p>Action for the National LeDeR Team</p> <p>BNSSG has a clear guidance pack for reviewers and buddies. We also have in place a bi-monthly Peer Support Group for reviewers to come along and share issues and concerns about the cases they are working on.</p>	BNSSG Complete
5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.	BNSSG employs a LeDeR administrator to support LeDeR reviewers with all notes pulling, appointments, information required. Line managers of LeDeR reviewers are required to sign a release form to confirm that the person has capacity in their workload to undertake LeDeR reviews.	BNSSG Complete
6	There must be a transparent process for LeDeR in each locality, with robust governance and appropriate	BNSSG has an established a monthly Clinical Case Review Panel. The Panel has a minimum membership of a GP, Nurse, Social Worker and	BNSSG Complete

6	<p>There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.</p>	<p>BNSSG has an established a monthly Clinical Case Review Panel. The Panel has a minimum membership of a GP, Nurse, Social Worker and other health professionals. Each completed initial review is quality assured by the panel. LeDeR reviews are governed by the LeDeR Steering Group which meets monthly and Case Review Panel minutes are included in Steering Group papers every months. LeDeR progress is also reported monthly to Quality Committee & Governing Body through the QPR</p>	<p>BNSSG Complete</p>
7	<p>Governance of LeDeR should be appropriately embedded into emerging new structures, such as sustainability and transformation partnerships (STPs) and integrated care systems (ICSs), from the onset.</p>	<p>Action for NHS England</p> <p>In BNSSG LeDeR is an integral part of transformation Partnership Boards for Learning Disabilities. The Director of Nursing is system leader for LD and we are developing a clear system plan and an integrated approach. This was presented to the Governing Body in August 2020</p>	<p>Part of NHSE ongoing work plan.</p>
8	<p>Additional guidance should be produced that supports and advises LeDeR reviewers and LACs in situations where there are local disputes regarding the process or outcome of a LeDeR. This must include an independent escalation procedure to be used where there is a difficulty or impasse that cannot be resolved locally.</p>	<p>Action for the National LeDeR Team</p> <p>The BNSSG Clinical Case Review Panel quality assures & validates the care score given by the reviewer. Where the Panel does not agree with the care score or recommendations, further discussion is held with the reviewer to confirm any evidence used for the assessment. This would include escalation to the LeDeR Steering Group and the LD Director if required</p>	<p>Any further recommendations from the National LeDeR programme Team will be fully implemented</p> <p>BNSSG Complete</p>
9	<p>The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like.</p> <p>Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).</p>	<p>After completing BNSSG LeDeR training reviewers are sent a welcome pack with comprehensive information. This includes guidance for reviews, the buddy process, Peer Support Group, timescale for completion, Case Review Panel process.</p> <p>All reviewers are automatically invited to Peer Support and the Case Review Panel signs off the final review. It is never left to one individual.</p>	<p>BNSSG Complete</p>
10	<p>Each CCG must identify an executive lead to be</p>	<p>BNSSG appointed the Director of Nursing as Executive lead for the</p>	<p>BNSSG Complete</p>

11	<p>Experienced reviewers should be used when circumstances are intricate or challenging. The national LeDeR team should hold a national database of such reviewers to aid this process.</p>	<p>Action for the National LeDeR Team</p> <p>In BNSSG our database of reviewers identifies our more experienced reviewers. We also have local dedicated reviewers who are former NHS Executives. Several of our experienced reviewers have been former Directors of Nursing. We have also used NEC who have a database of experienced reviewers</p>	<p>Any further recommendations from the National LeDeR programme Team will be fully implemented</p>
			BNSSG Complete
12	<p>The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.</p>	<p>LeDeR data on case progress is reported monthly to the LeDeR Steering Group, Quality Committee and Governing Body. The Executive lead intervenes when required with executives in other agencies.</p>	BNSSG Complete
13	<p>When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.</p>	<p>BNSSG has a clear MAR policy which is available on the website and the MAR process is strictly adhered to. Reviewers always involve buddies where required and if necessary they will be co-contributors in the MAR, to up-skill and develop the less experienced reviewer. The LAC also meets with the reviewer, providing guidance and supervision</p>	BNSSG Complete
14	<p>One of the requirements for a MAR is determined by an initial scoring system of 1–6, with a score of 6 indicating that 'care fell short of current best practice in one or more significant areas resulting in the potential for or actual adverse impact on the person'. Currently, this scoring is not carried forward into the main report.</p> <p>It is recommended that there is a review of this scoring process and that the initial score is retained as a record in the main report.</p>	<p>Action for the National LeDeR Team</p> <p>We agree the scoring should be carried into the main report</p> <p>In BNSSG the Clinical Case Review Panel quality assures and validates the care score given by the reviewer. The Panel will also discuss with the reviewer if they believe the assessment of care requires a higher grading to denote poor care. We have held MARs on a score of 4.</p>	<p>Any further recommendations from the National LeDeR programme Team will be fully implemented</p>
15	<p>In regard to the MAR meeting it is recommended that there is action taken to:</p> <ul style="list-style-type: none"> ensure that families are central to the process, are offered full sight of all documents, & are invited to attend all or part of the meeting as they 	<p>Action for the National LeDeR Team & CCGs</p> <p>In BNSSG family members are central to the review and are the first person the reviewer contacts. All documents and meetings include family if they wish.</p>	BNSSG Complete

15	<p>In regard to the MAR meeting it is recommended that there is action taken to:</p> <ul style="list-style-type: none"> ensure that families are central to the process, are offered full sight of all documents, & are invited to attend all or part of the meeting as they wish review the purpose of the MAR with specific reference to the function of Question 8 (now Question 9 in version R05) should this question be retained, provide clear guidance for MAR participants; also, to think through whether this question should be asked in confidence if it is a particularly difficult situation provide specific guidance & training for MAR chairs delivered by the national LeDeR team & families to include key topics such as the Mental Health Act, Mental Capacity Act and best interest decision making 	<p>Action for the National LeDeR Team & CCGs</p> <p>In BNSSG family members are central to the review and are the first person the reviewer contacts. All documents and meetings include family if they wish.</p>	BNSSG Complete
		<p>In BNSSG the MAR chair is experienced and trained in chairing multi agency meetings. The Clinical Case Review Panel includes safeguarding experts who advise the MAR chair.</p>	Any further recommendations from the National LeDeR programme Team will be fully implemented
			BNSSG Complete
16	<p>There should be a review of the LeDeR methodology against similar processes, such as child death reviews, in order to garner the learning and include any improvements as appropriate.</p>	<p>Action for the National LeDeR Team</p>	Any further recommendations from the National LeDeR programme Team will be fully implemented
17	<p>A system process chart should be developed to enable reviewers to ensure they are undertaking the review correctly. This should include standard templates and a self-assessment tool that reviewers can use, to ensure consistency across the country.</p>	<p>Action for the National LeDeR Team</p> <p>In BNSSG we have a local system process chart and a guidance pack for reviewers. The Clinical Case Review Panel assure quality and consistency in local reviews</p>	Any further recommendations from the National LeDeR programme Team will be fully implemented
18	<p>There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.</p>	<p>BNSSG reviewers have the Peer Support Group and direct access to the LAC for advice and guidance. Our reviewers are employed by different agencies in the system and line managers are asked to</p>	BNSSG Complete

19	The LeDeR guidance must make explicit (to all parties) that it is completely acceptable for LeDeR reviews, where appropriate, to arrive at differing conclusions to other reviews or inquests. This is on condition that they have the evidence to support this determination and that the LeDeR itself was subject to correct governance processes.	<p>Action for the National LeDeR Team</p> <p>The BNSSG LeDeR Policy Framework and MAR policy was amended to reflect it is acceptable to arrive at differing conclusions, on condition that the evidence is available to support this decision and correct LeDeR governance processes have been followed. Updated policy documents and welcome/support pack for reviewers were presented to December LeDeR Steering Group 2020</p>	BNSSG Complete
20	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	BNSSG has buddying and peer support as well as regular access to the LAC – support structures for reviewers were strengthened with new welcome/support pack. LeDeR recommendations are robust, actioned in a timely manner and incorporated into system action plans and contracts with providers. BNSSG is an active participant in the regional LEDER operational group that also shares lesson. All recommendations are included in the Annual Report that is published and reported nationally.	BNSSG Complete
21	Each CCG must formally undertake and document and review its own systems and processes against the learning and recommendations arising from Oliver’s re-review.	BNSSG have developed this action plan in response to the learning and recommendations outlined in Oliver’s independent review. We have implemented all of the recommendations and the governance process for completion of this action plan was reported to BNSSG LeDeR Steering and the Governing Body in December 2020	BNSSG Complete
	This review and accompanying action plan must be submitted to, and monitored by the local integrated care system (ICS), giving feedback to the national LeDeR team on progress. The panel wishes for a senior, single point of contact from NHS England to ensure all actions are taken and progress monitored.	<p>Action for NHS England.</p> <p>NHS England South West regional representatives sit on the BNSSG LeDeR Steering Group that meets monthly and they are active members. The action plan for this review will be reported to the local ICS.</p>	