Bristol, North Somerset and South Gloucestershire
Clinical Commissioning Group

# Learning Disabilities Mortality Review (LeDeR) Annual Report

## 1st April 2021 to 31st March 2022

## Learning from deaths of people with a learning disability

# CONTENTS

# Executive Foreword

The LeDeR Programme (Learning from Deaths Review of people with a learning disability) is led by NHS England and follows on from the work undertaken by the University of Bristol 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. However people with learning disabilities in the Bristol, North Somerset and South Gloucestershire (BNSSG) population live 8 years longer than the learning disability national average, however we still have more to do to narrow that gap.

We are ever mindful of the lessons identified from Oliver McGowan's LeDeR review and this continues to drive improvements across our system. We acknowledge Mr and Mrs McGowan for all the work they continue to do – they have raised the profile of learning disabilities and autism nationally and this has given a huge focus that supports all our developmental work.

This is the third annual report on the deaths of people with learning disabilities who lived in the BNSSG area. The purpose of the report is to share our findings from LeDeR reviews, to report on the identified learning and the action we are taking to improve practice and address health inequalities for people with learning disabilities.

Through the BNSSG LeDeR Governance Group, we have been proud to host vibrant meetings where people with lived experience and system partners have fully engaged with the topics and themes discussed identified in our LeDeR reviews. Everyone has been passionately committed to listening and learning and 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 of preventing people from dying prematurely and improving quality of life.

We have been especially proud of the work undertaken by our GP colleagues in primary care this year, who have ensured people with learning disabilities have an Annual Health Check. This is key to ensure people's long-term health conditions are well managed and GP's agree health goals with their patients. The majority of our GP's met or exceeded the minimum 75% of completed annual health check for the patients with a learning disability on their register. 18% of practices completed100% of their Annual Health Checks

We have worked hard to improve access to healthcare and address health issues for people with a learning disability with all 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 a lot through this year 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 care people with learning disabilities living in our communities.

**Alison Moon**
**Chair of the BNSSG LeDeR Governance Group**

**Rosi Shepherd**
**Executive Director of Nursing and Quality**

# Section 1 – Our structure for LeDeR

## Background

The Learning Disabilities Mortality Review Programme (LeDeR) was established in 2016. It 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 areas were required to establish a LeDeR Steering Group during 2017/18. The local LeDeR process and governance is a key responsibility for the new Integrated Care Systems(ICS)

## Overview of the national LeDeR process

The national LeDeR Programme, run by NHS England introduced a new national policy in April 2021 to build on the programme developed by the University of Bristol. The 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 to ensure any queries or concerns they have are answered in the review and their involvement in writing pen portraits is key. The LeDeR guidance states that these are not investigations, but reviews, with the focus on identifying learning and not apportioning blame.


The reviewer looks to identify best practice by reviewing the person's health and social care records and where identified, areas where improvements could be made. There is either an initial review or a new focussed review - introduced into the process with the new policy. All reviews concerning someone from a black or minority ethnic background automatically becomes a focussed review. In January 2022 NHSE introduced LeDeR reviews for people with autism.

# Our Local BNSSG LeDeR structure

## LeDeR Governance Group

The Executive Lead responsible for the programme is the CCG Director of Nursing and Quality. The LeDeR Governance group has met monthly since February 2019 including throughout the lockdown periods last year. Representatives attend the Governance Group from all BNSSG health providers, the three local authorities which provide adult social care, the Care Quality Commission, GPs, local housing providers of services to people with learning disabilities and NHS England regional LeDeR leads.


Our LeDeR Governance Group is chaired by the Independent Registered Nurse of the Governing Body. 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 Clinical Commissioning Groups Quality Committee via the group's minutes of meetings and quarterly 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 Quality Assurance Review Panel

To strengthen the BNSSG LeDeR quality assurance process, we introduced a local additional stage of a Clinical Quality Assurance Review Panel. It is important to us that we have assurance of the content and the quality of individual reviews. The panel was established in July 2019 and membership includes the Local Area Contact, Clinical Lead GP for Learning Disabilities, GP Safeguarding Clinical Lead, 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 best practice identified, with appropriate recommendations formulated prior to closing the case on the LeDeR platform. The panel also identify themes from each review to guide topics for further action.

## The LeDeR Team

The Local Area Contact (LAC) is the manager of the BNSSG LeDeR 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 promotes quality assurance in the closure process of each case. The LAC prepares content, agenda and papers for the LeDeR Governance Group, Quality Committee and Governing Body.

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

## LeDeR Reviewers

The LeDeR process is supported by a team of trained reviewers from healthcare organisations across BNSSG, from acute hospital Trusts and Community Learning Disability Teams (CLDTs). 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 sometimes have limited time to dedicate to complete reviews. This year many have returned to their main clinical role as services have stepped up face to face work with clients. We are grateful for their time and commitment to contribute to improving health care for people with learning disabilities. We also have two paid independent reviewers who are available to undertake more complex reviews and provide support to the other reviewers.

Over the last year we trained a total of 28 reviewers on the new platform, 12 of these reviewers have been active on cases this year. We have two dedicated independent reviewers who are paid for the cases they complete. They have retired from the NHS but have extensive years of experience at a very senior level, both having been former Directors. We must also acknowledge the services of the North East Commissioning Unit and agency reviewers who have supported us with reviews over the last year in the transition period from the University of Bristol to NHS England.

## 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 for new reviewers.

## Peer Support Meetings

In addition to the Buddy System, we established Peer Support Meetings to offer additional support to our LeDeR reviewers. Meetings are quarterly and the aim is to support reviewers with their open cases. This is the reviewer's additional 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 Governance Group, Regional meetings and other LeDeR relevant events. 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 three 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.

In 80 out of 100 LeDeR reviews last year people had constipation. We funded North Somerset People First to co-produce a project and training on constipation

## Learning Disability and Autism Health Providers Network

New this year to our local structure is the establishment of a Health Providers Network. It has representation from all the health providers in secondary, primary and community care who work with adults with learning disabilities and/or autistic people. We wanted to move actions identified from LeDeR from the governance group to provider organisations.

The Learning Disability and Autism Health Providers Network is an action-oriented group, which takes learning from national and local key themes and trends from LeDeR to ensure the associated quality improvement takes place, and that there is consistency in practice and care for patients with learning disabilities, across NHS providers in BNSSG. The networks overall aims are:

- To agree a programme of joint service improvement initiatives as a result of the health themes coming from LeDeR.
- To act on outcomes from local reviews, identify areas of good practice for development work in preventing premature mortality, and areas where improvements in practice could be made and act on those.
- To ensure that the work programme actively captures and shares local and national learning; aligned to Learning from Lives and Deaths initiatives.
- To take the health learning from national and local key themes and trends, and ensure the associated service improvement takes place.
- To develop health innovations and share best practice between providers to ensure continued quality improvement across services.
- To respond to any resulting LeDeR Focussed Review action plans or recommendations developed as a result of the reviews and take appropriate action as a network to address service shortcomings and identify improvement.

The network has agreed a three-year joint work plan to address issues identified in reviews such as;

- Undertake a 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.
- Hospitals should identify people with learning disabilities who have repeat admissions for constipation related issues and flag this to GPs in discharge letters.
- Ensure DNACPR is audited to ensure order decisions are appropriately made with assessments for mental capacity and best interests assessments fully completed.
- Reasonable adjustments and risk assessments must be in place for everyone with dysphagia appropriate to their living environment - to ensure they are effectively supervised with drinking and swallowing at mealtimes/snack time to avoid choking
- Respiratory specialists need to be involved in improving access and treatment for people with learning disabilities with respiratory conditions to prevent people from dying prematurely
- Reasonable adjustments to be made for people with learning disabilities and for autistic people for appointments, health tests & investigations in primary and secondary care

# Section Two – Programme Performance

## Deaths notified to the LeDeR programme

Since the programme began in 2017 there have been 263 deaths reported to the BNSSG LeDeR platform covering the period 1st July 2017 to 31st March 2022.

In April to June 2021 the LeDeR platform, moved from the University of Bristol to NHS England. NHSE/I required all open cases on the old platform to be completed and closed on the platform no later than 30th April 2021 to prepare for the transition to the new platform. BNSSG completed all cases by the required deadline.

With NHSE now managing the LeDeR platform and introducing a new national LeDeR policy there have been a number of changes. The new operation platform for managing reviews went live in July 2021. Review forms were redesigned with 'Initial' and 'Focussed' reviews which replaced the MAR process. All reviewers had to re-train before they could access the platform and be allocated reviews. There were some teething problems as there are with any software changes but these have largely been resolved through regular dialogue with the regional and national team.


The table below provides a summary of the status of all cases as at 31st March 2022.

### Table 1: Summary of deaths notified in 2021/22

| | |
|---|---|
| **Total notifications 1st April 2021 to 31st March 2022** | 63 |
| Total notifications not yet assigned to a reviewer (to March 2022) | 0 |
| Total number of reviews currently in progress | 7 |
| **Completed and closed reviews in 2021/22** | 56 |

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 initial submitted reviews by the LAC within 2 weeks of completion before taking to panel.

### Table 2: Completed reviews and KPI's

| Completed reviews and Key Performance Indicators | 2018 | 2019 | Jan-20 to Mar-21* | Apr - 21 to Mar - 22 |
|---|---|---|---|---|
| Number of Notifications | 42 | 66 | 84* | 63 |
| Number of Closed Completed Cases | 4 | 47 | 100* | 56 |
| Total number of MARS completed | 2 | 3 | 6 | N/A |
| Allocation of reviewers within 3 months of notification | 19% | 26% | 52.4% | 70% |
| Completion of reviews within 6 months of notification | 2.4% | 7% | 19.9% | 35% |
| QA check of reviews by LAC within 2 weeks of completion. | 21.4% | 86.4% | 100% | 100% |

**This was a 15 month period due to NHSE changes from calendar year to financial year and included a backlog of cases from the previous year*

**Actions taken to address Key Performance Indicator's**

We have continued to improve on KPI performance with an 18% improvement in allocating cases and a 16% improvement I completion of cases. This is in part due to the new initial reviews having shorter forms with lots of tick boxes. We find the new review forms lack depth and we introduced a checklist for our reviewers to ensure key information is included. Working from home during lockdown increased the opportunities for clinical teams to support this work. However as lockdown has eased, clinical teams have had to prioritise face-to-face work with clients which has reduced the capacity of our reviewers.

We have a 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 Quality Assurance Review Panel met quarterly as cases were not completed during the transition. The Panel has met monthly again in quarter 4 as case completions are back on track.

## LeDeR Reviewers

Over the last year we trained a total of 28 reviewers on the new platform, 12 of these reviewers have been active on cases this year. We have two dedicated independent reviewers who are paid for the cases they complete. They have retired from the NHS but have extensive years of experience at a very senior level, both having been former Directors.

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). 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 new review process but have personally reflected on the reviews to embrace learning for their own practice.

In the transition to the new LeDeR platform there was a three-month delay in being able to access new notified cases. NHSE commissioned North East Commissioning (NEC) to review cases for CCG's. This continued until December 2021. We are grateful to the NEC for their reviewers completing LeDeR reviews.

| **Summary of best practice examples** |
|---|
| • Well co-ordinated End of Life Care and consistency of support for a dignified death |
| • Very good MDT meeting to discuss DNA CPR with family as patient had advanced Alzheimer's |
| • Excellent co-ordination of care and carers tailoring opportunities such as playing piano and taking him to recitals of classical music |
| • Advocating on the person's behalf with ambulance staff, insisting person was taken to hospital. |
| • Many examples of the Learning Disability and Autism Liaison Team making timely assessments and supporting people in hospital which significantly improved their care |
| • A sensitive and compassionate approach in hospital – withdrawal of treatment was delayed until all family members could be present at the bedside |
| • MDT meeting held prior to discharge to consider Mum's ability to care for son as she had just recovered Covid and son was immuno-compromised |
| • Several examples of well timed advanced care planning involving the person, their family or an IMCA |
| • Effective follow up from GP and primary care team when discharged from hospital |
| • Lots of examples of collaborative working and involvement of family members |
| • Excellent co-ordination of care between primary and secondary care with innovative reasons adjustments |
| • Taking person's wishes into account in End of Life care allowing the person to die in their own home with friends and family, supported by palliative care |
| • Reasonable adjustments were made so mum could stay in hospital with her son as he died. |
| • Use of supported living environments being a positive alternative to care homes for people who prefer a family environment |

| Summary of improvement recommendations – individual reviews |
| --- |
| • Breaking bad news about a terminal cancer diagnosis needs to be done after a careful assessment of the persons understanding with appropriate supports and resources in place |
| • Checking learning disabled patients for pressure area injuries during prolonged hospital stays |
| • Ensure sepsis guidelines are followed in hospital to identify sepsis in the learning disability population which may be overlooked due to diagnostic overshadowing |
| • With staff turnover, new carers need training and support to understand someone's personal history and get to know them so they can provide the best possible support |
| • Regular monitoring of weight gain or sudden weight loss and taking action when the person has a low or high BMI with dietary protocols to support staff |
| • Training for surgeons on mental capacity and the patient's right to choose NOT to have life saving surgery and make 'unwise decisions' |
| • Lack of placement review by local authority when person(s) was placed in unsuitable accommodation |
| • Ensure ambulance staff are aware of the different presentation of Covid in people with learning disabilities |
| • Training/awareness raising for community staff on when to refer to End of Life and Palliative care services for guidance and advice |
| • Delays to putting DOLs in place whilst people were in hospital |
| • Develop an eating and drinking pathway for dysphagia that includes adaptations to textured diets, tools and resources and keeping food tasty/edible |
| • Carers assessments to be completed for those living with a family member |
| • Hospitals to ensure death notifications are sent to GP's |
| • Patients with Williams Syndrome to be considered for abdominal CT scans to assess for bowel obstruction when they present with diarrhoea and 'coffee ground' vomit |
| • Video calls to be routinely arranged with family members who cannot visit hospital. |
| • Professionals must explain clearly the pros and cons why something is needed to parents/family members in a person's best interests – for example a change of PEG tube to a newer version |

# Section 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 check at Quality Assurance 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 great outdoors, going for walks with the family dog. Keen gardeners and those who loved to grow their own veg. We had one lady who so loved gardening she had her own wheelbarrow. When she became ill and couldn't leave her bed, staff brought the wheelbarrow into her bedroom filled with plants and flowers.

Everyone loved holidays, especially by the sea or going abroad. We heard about people who loved cowboy films and Disney fans, enjoyed concerts, musicals and music from Abba and to classical concerts, people who were the life and soul of the party to people who preferred their own company. We learnt about people who took care of their appearance, loved jewellery and painting their nails, members of amateur dramatics and pantomimes. All the people 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.

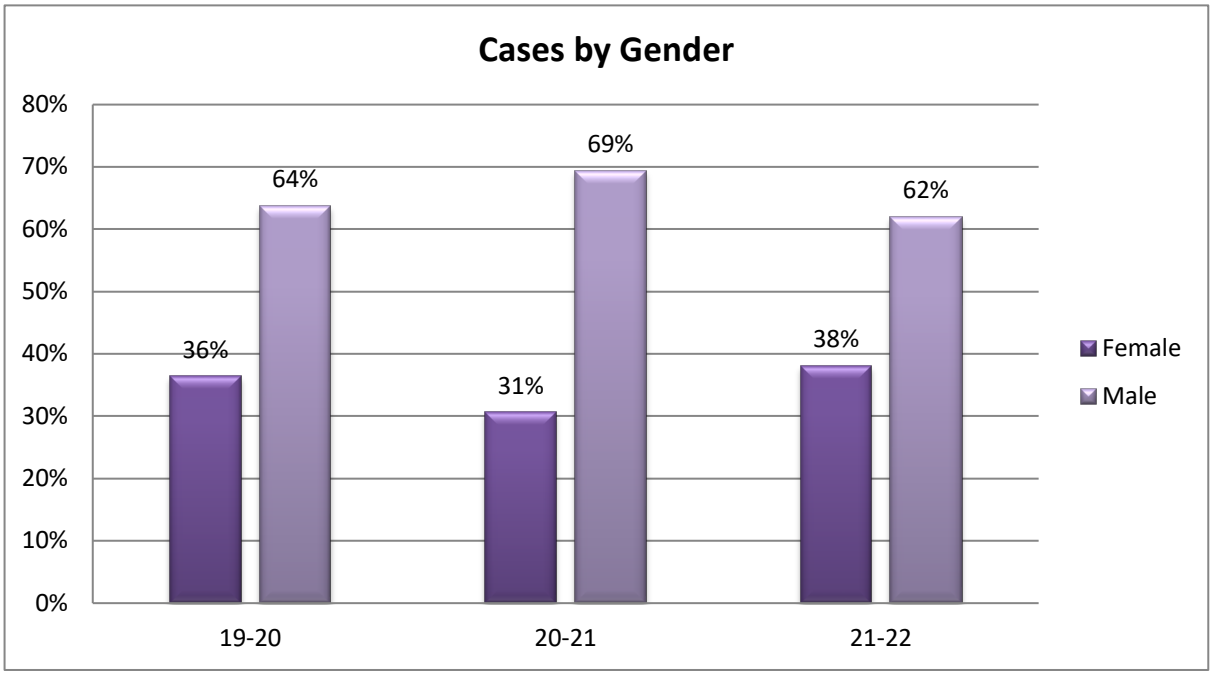
These portraits help us connect to the person and remind us to consider whether the care and treatment they received would have been good enough if it was our relative, our sister, our son, our grandma.

## 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 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

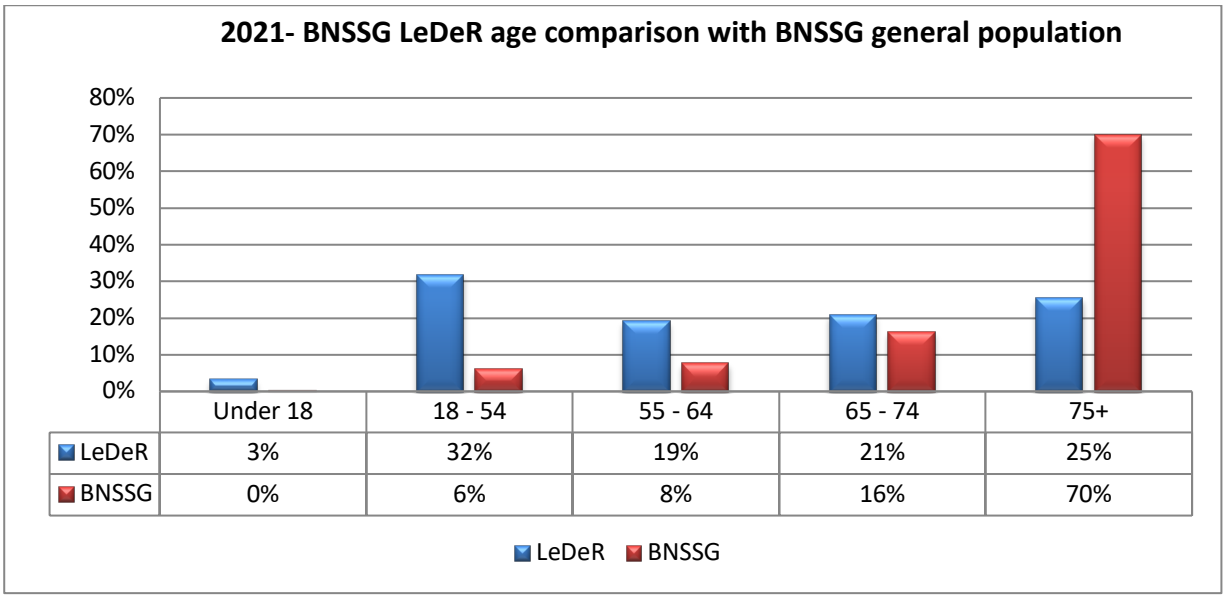
| Median Age of Death | BNSSG LeDeR | | BNSSG general population | |
|---|---|---|---|---|
| | Male | Female | Male | Female |
| April 2021 – Mar 2022 | 71 | 67 | 79 | 85 |

| | BNSSG LeDeR | | BNSSG LeDeR Overall | South West LeDeR | National LeDeR |
|---|---|---|---|---|---|
| | Female | Male | | | |
| 2021/22 | 67 | 71 | 68 | 62 | 60 |

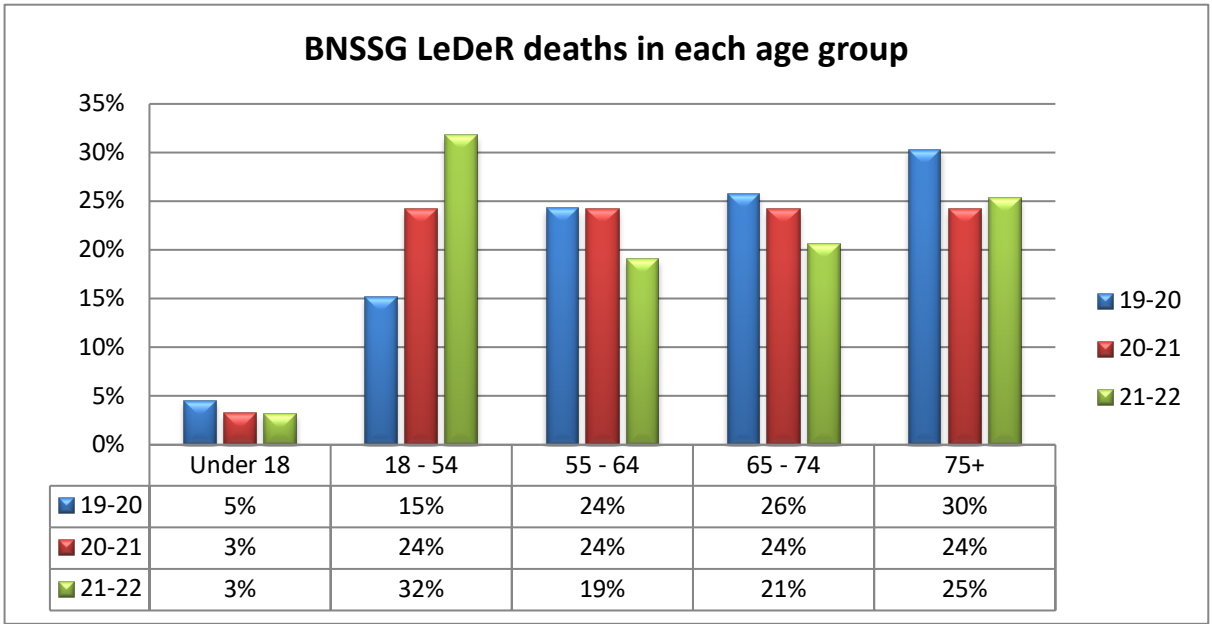
Reviewing the comparative data men with a learning disability live slightly longer than women with a learning disability but die 10 years younger than the general BNSSG population. However people with learning disabilities in the BNSSG population live 8 years longer than the learning disability national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

The majority of learning disability deaths (25.4%) were in the over 75 age group, the same as the BNSSG population. However the spread of deaths throughout all age groups for people with learning disabilities 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 fewer co-morbidities and leading fit and active lifestyles.

## Graph 3: Age range of deaths reported




| | Under 18 | 18 - 54 | 55 - 64 | 65 - 74 | 75+ |
|---|---|---|---|---|---|
| LeDeR | 3% | 32% | 19% | 21% | 25% |
| BNSSG | 0% | 6% | 8% | 16% | 70% |




| | Under 18 | 18 - 54 | 55 - 64 | 65 - 74 | 75+ |
|---|---|---|---|---|---|
| 19-20 | 5% | 15% | 24% | 26% | 30% |
| 20-21 | 3% | 24% | 24% | 24% | 24% |
| 21-22 | 3% | 32% | 19% | 21% | 25% |

## Ethnicity

Graphs 4 and 5 below show the ethnicity of deaths reported to the LeDeR platform. Although we have had a few more deaths reported from Black and other minority ethnic communities this year, there continues to be a low number of learning disability deaths reported from these communities. This does not compare with the demographic profile for BNSSG and we believe there may still be under reporting of deaths from these communities.

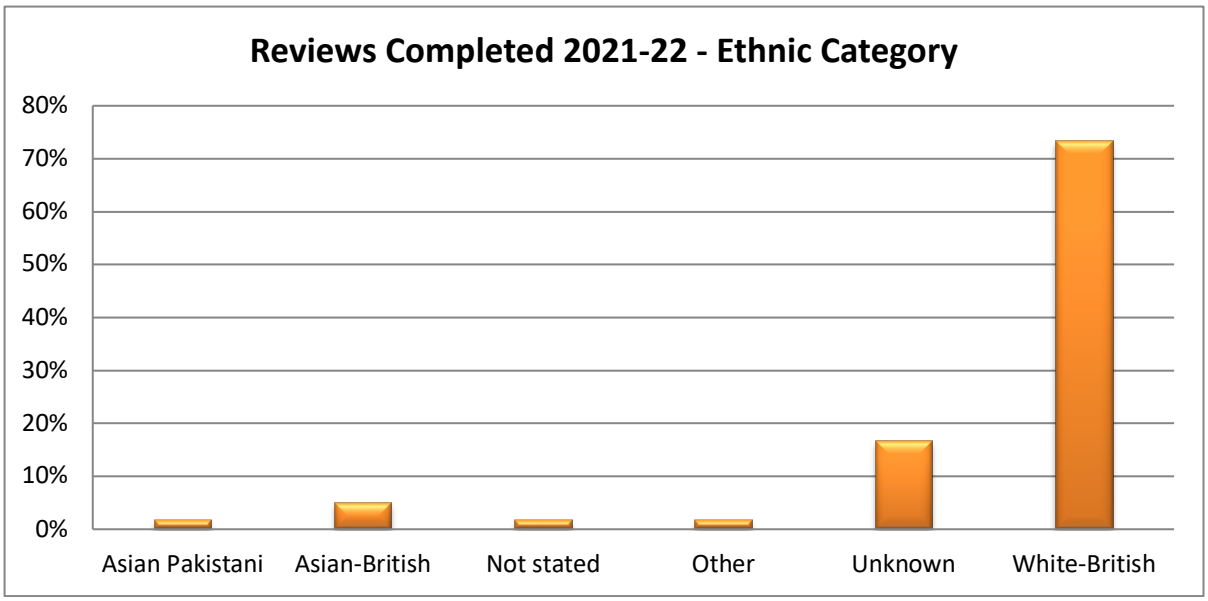
People with learning disabilities and/or autism experience health inequalities and those in ethnic minority communities are further disadvantaged and under-represented as users of learning disability health services.

We wanted to find out what the barriers are for individuals and families to access health services for adults with learning disabilities and autism. To address this we funded new work with Autism Independence, who undertook 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 was to find out people's stories and experiences of services supporting a person with learning disabilities in the family.

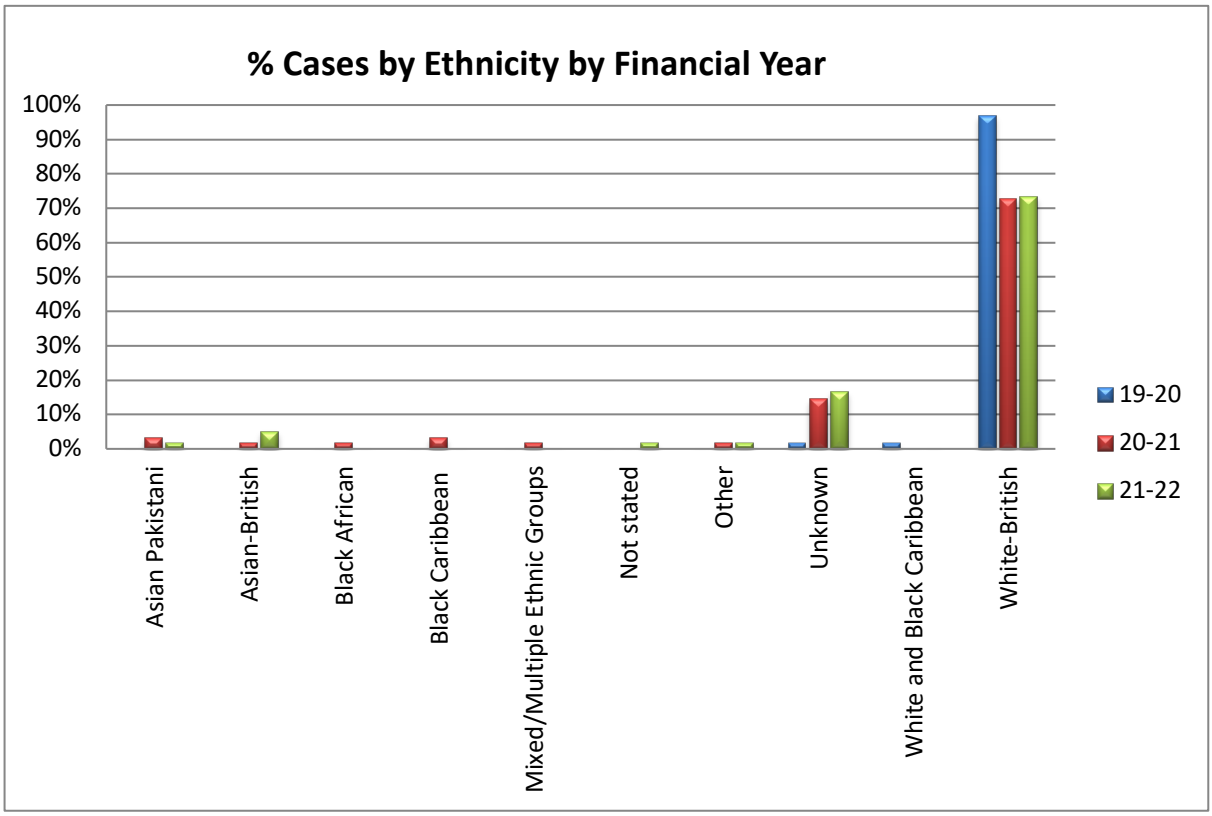
This project work is completed and the project report is being finalised. This work will identify issues and make recommendations to support the Healthier Together vision for people with learning disabilities and autism from all communities to access high quality, fully integrated care that meets their expectations of services. It will contribute to a plan to co-produce 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 everyone in our population.

We wanted to hear stories of peoples' past and current experience – listening was the first step. Initially, work has had a BNSSG focus. Then project findings and recommendations will be shared with colleagues in the South West Region. This will help us plan how we have similar conversations to support people from different black and minority communities across the region.

### Graph 4 – Number of completed cases by ethnicity




### Graph 5 – Completed cases by ethnicity – year comparison



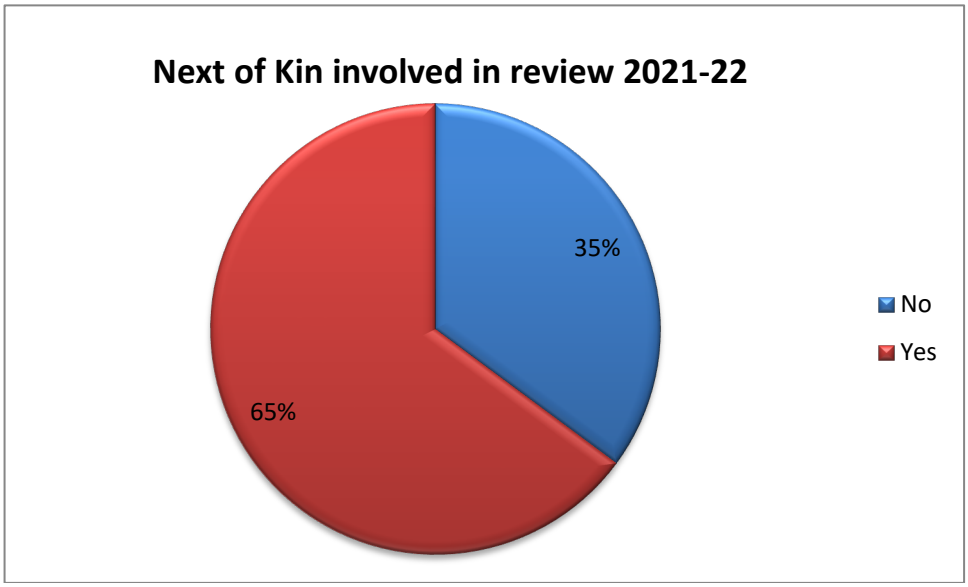

## Child death data

During 2021/22 there were 2 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.

## Involving next of kin in reviews

This year we have collected data on whether next of kin were involved in the review process. 65% of reviews included next of kin. Sometimes parents but more usually due to people's age, a brother, sister, niece or nephew. Where people have previously lived in long stay hospitals family connections were often lost. Care providers have made special efforts over the years to re-connect people to family sometimes successfully, sometimes not.

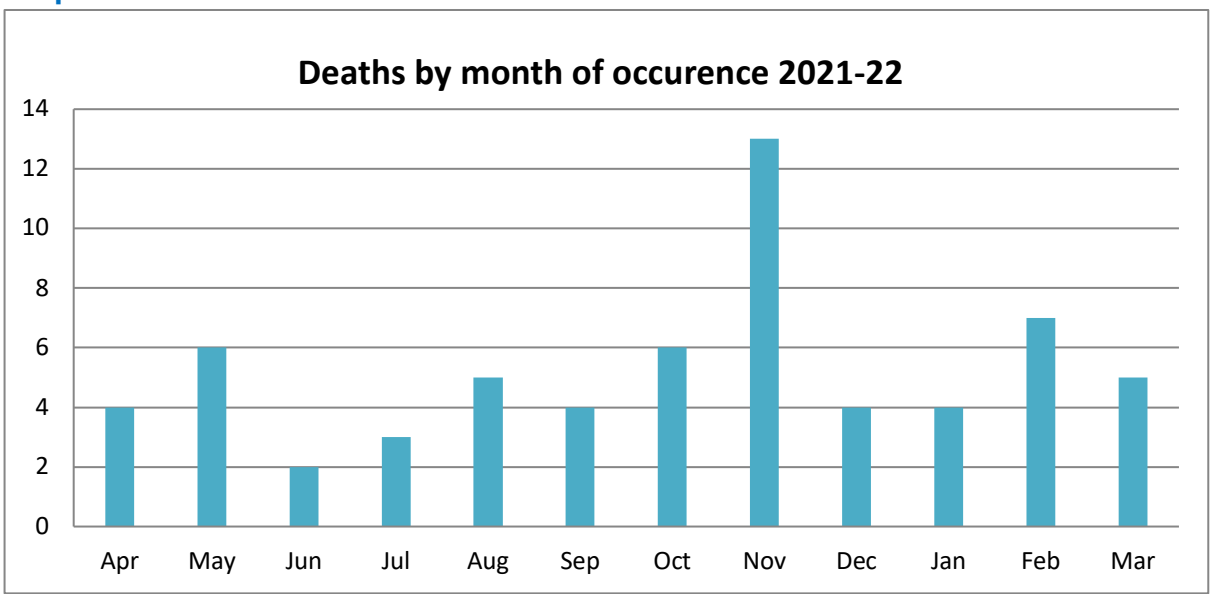
We have also found in reviews where there was no next of kin, that care staff who knew the person really well was involved in the review. Some care staff have known their residents for twenty, thirty years or more and have very close relationships.



# Section 4 – Cause of death

Highest month with 13 deaths was in November 2021, whereas last year, February 2020 was the highest month. Deaths were mostly attributable to pneumonia's. There have been two Covid-19 deaths this year compared to 19 Covid deaths last year.

### Graph 6: Month of death



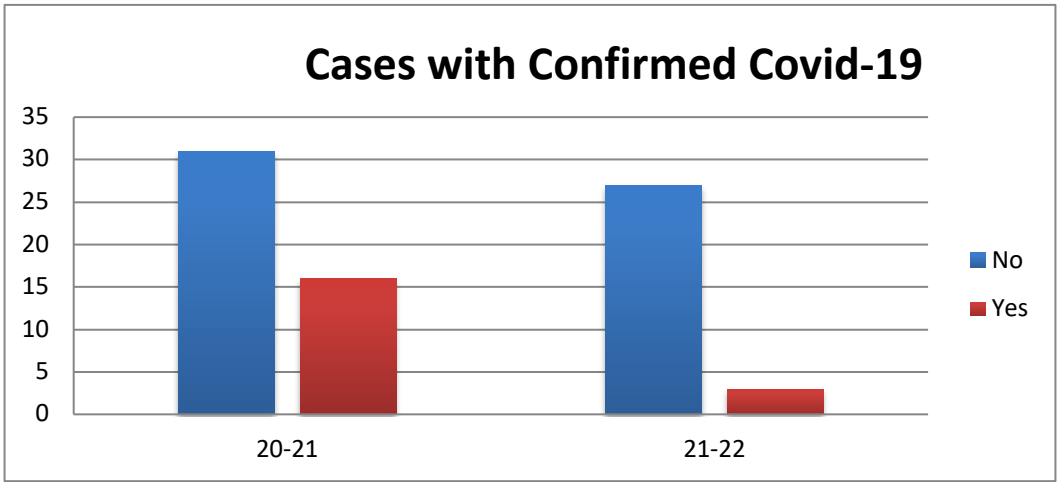

## Cause of death

The reviewer records the cause of death in the review as detailed on the person's death certificate. From the completed reviews, 23% of deaths were related to pneumonia as the primary cause.

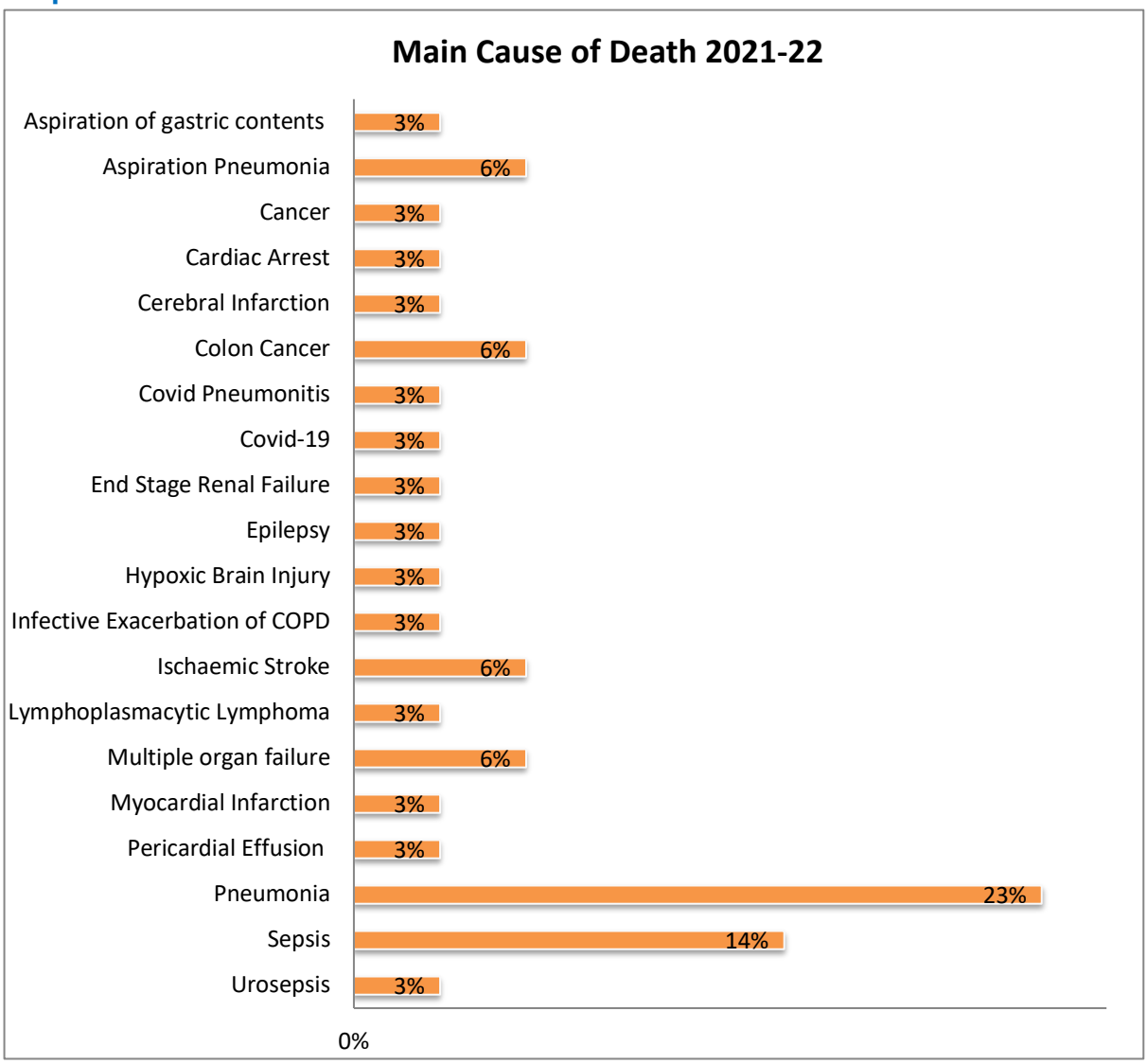
Reviews have identified that a small number of death certificates state, for example, 'learning disability' or 'Down's Syndrome' as a secondary cause of death. This has been discussed with the medical examiners to ensure appropriate guidance is given to clinicians about not using this incorrectly as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

We have seen fewer deaths due to Covid this year, with much lower numbers.

### Graph 7: Covid Deaths

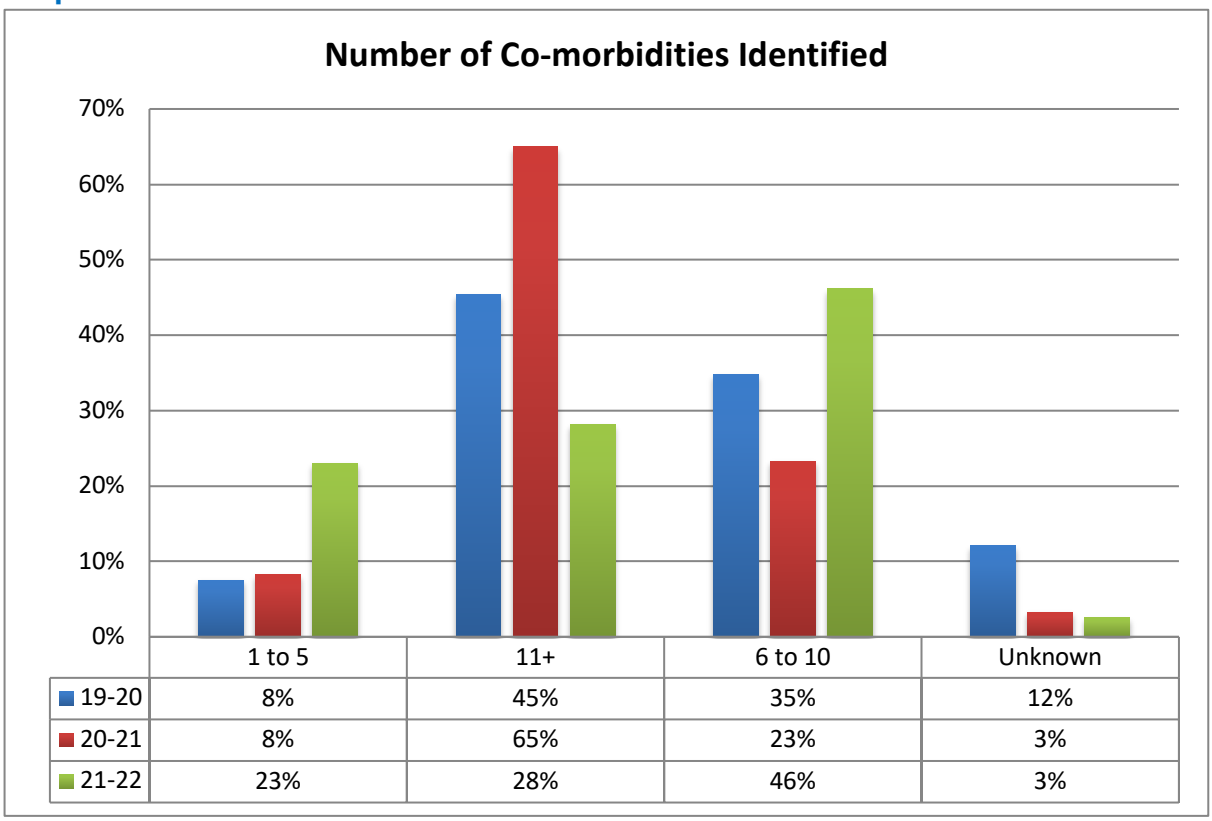


## Graph 8: Main causes of death




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.

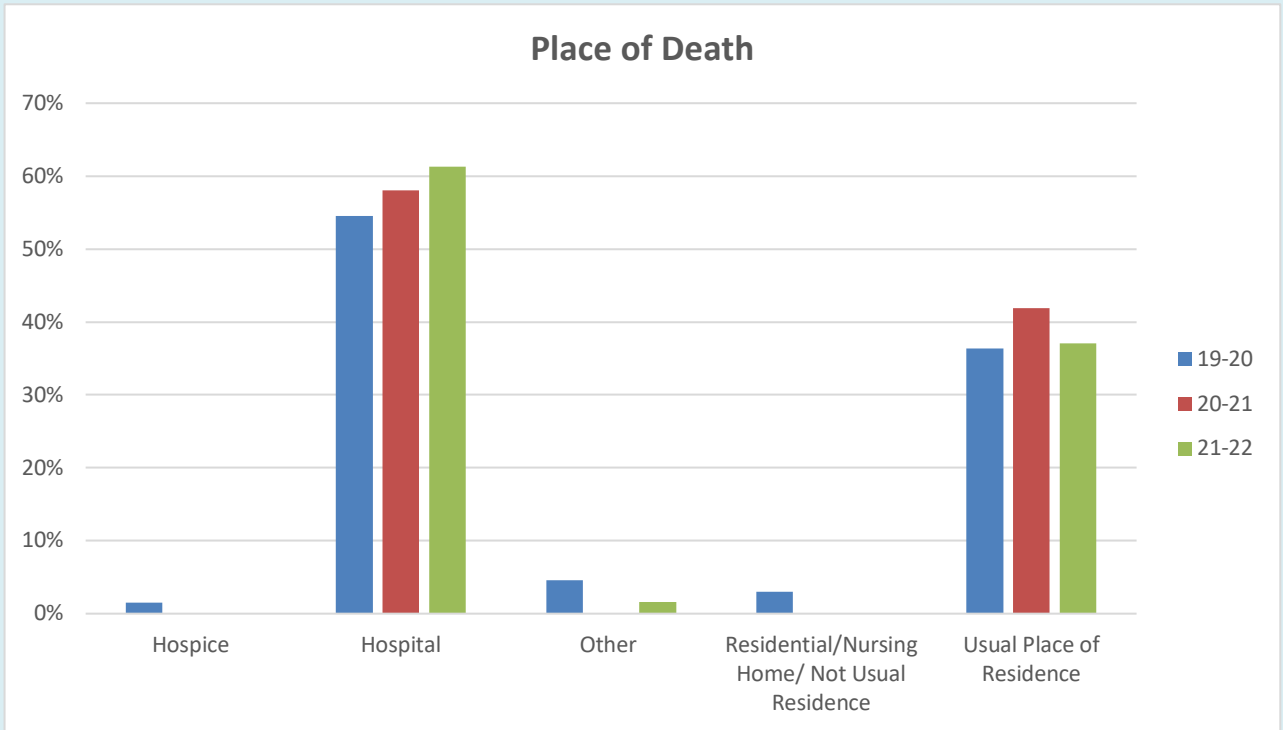
## Graph 9 - Number of co-morbidities




| | 1 to 5 | 11+ | 6 to 10 | Unknown |
|---|---|---|---|---|
| 19-20 | 8% | 45% | 35% | 12% |
| 20-21 | 8% | 65% | 23% | 3% |
| 21-22 | 23% | 28% | 46% | 3% |

Graph 10 shows the place of death for cases reported in 2021/22. For BNSSG 61% of deaths occurred in hospital. There has been a decrease in the numbers of people supported to die at home but a noticeable effort this year where people were on End of Life care and residential staff had to make special arrangements for the person to die at home with friends and family with some very positive practice.

## Graph 10: Place of death



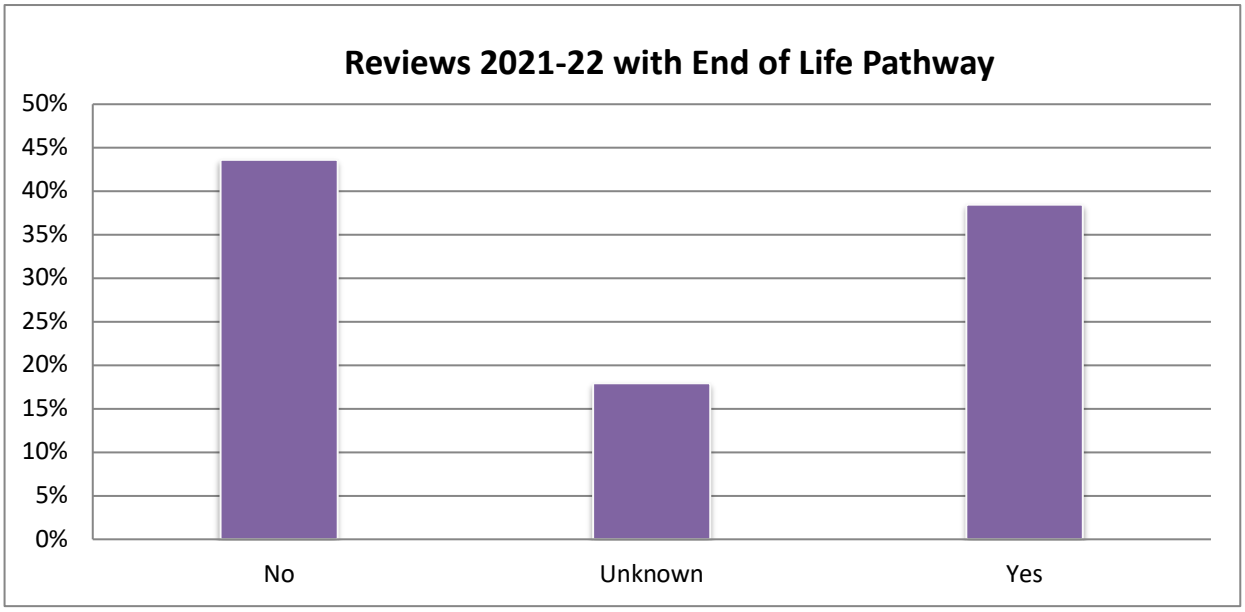
An individual's choice for their place of death is taken into account and usually documented through ReSPECT forms which we have seen used much more this year either with care home staff or through support of the learning disability liaison nurses in hospital. Sometimes Mental Capacity Assessments or Best Interests meetings are used. There has been some involvement of specialist bereavement services and staff in hospices supporting End of Life care.

## End of Life

Within the reviews we look 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 38% of the reviews. Our ambition is to work with primary care, providers and hospice services to increase End of Life planning to be addressed in more 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 involving animals and family pets. One man who loved horses wanted a horse drawn hearse at his funeral.

### Graph 11: End of Life care pathway

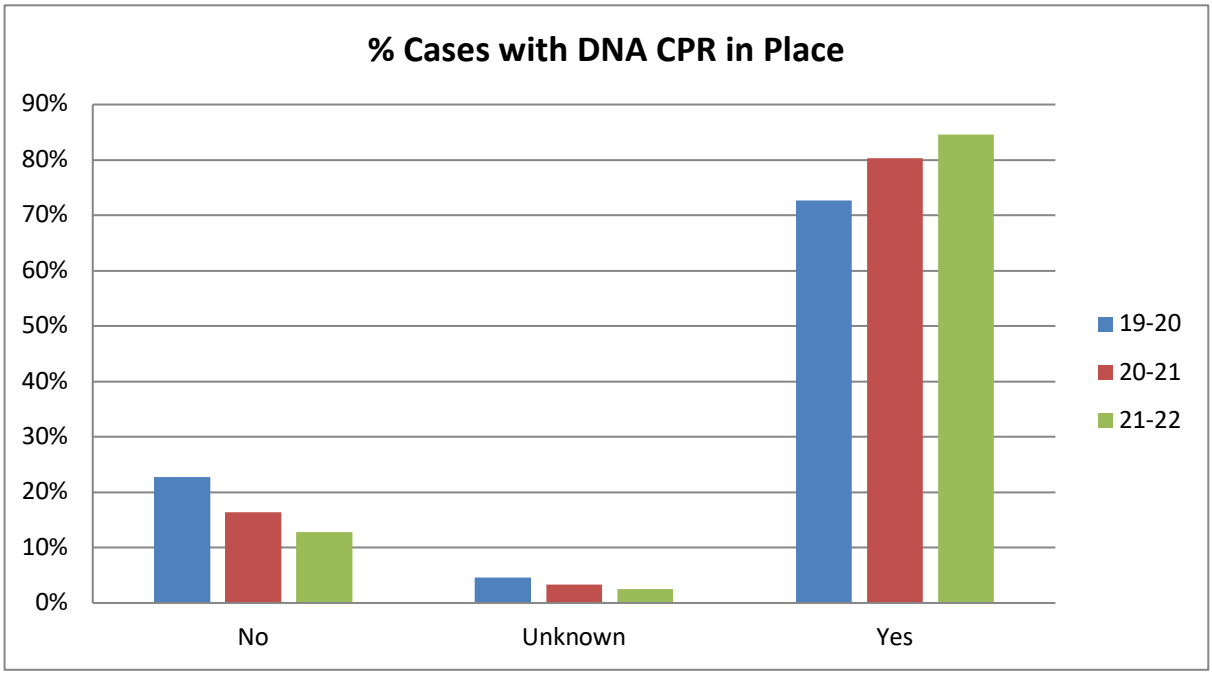


## Support for End of Life Care:

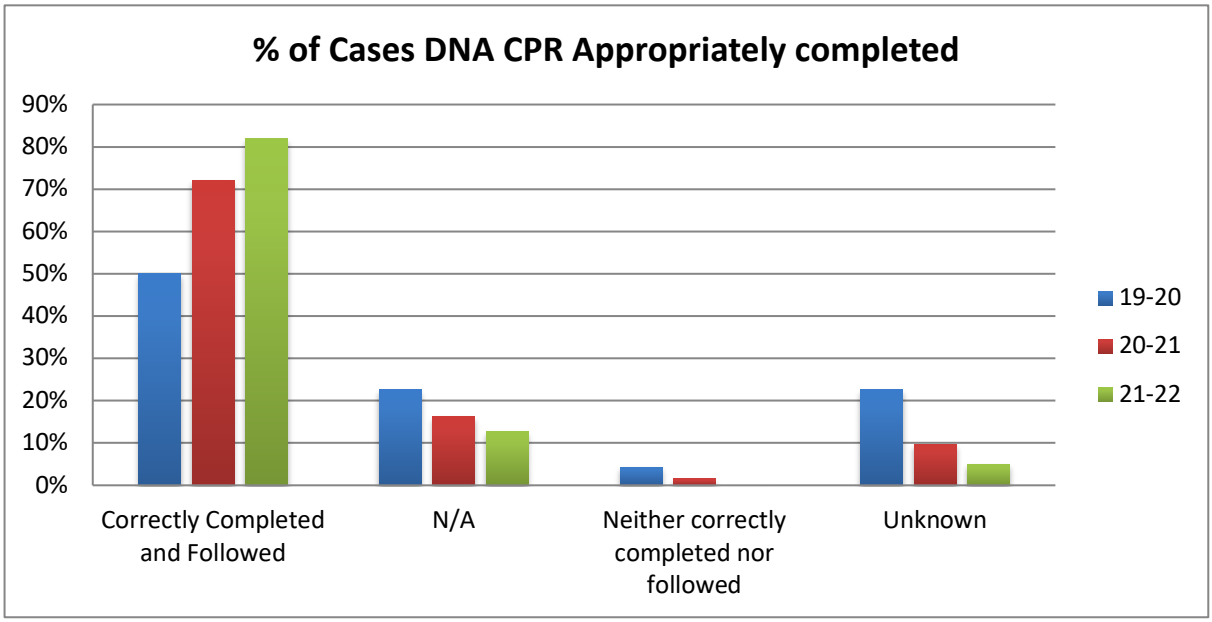
Across residential and support services staff are very willing and able to care for people at the end of their life. They were passionate about the people they supported, wanting to ensure that they were able to continue to support them throughout their life, including at the end. Most homes had no training 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. Several services sourced bereavement support through St Peters Hospice, which staff were given dedicated time to access.

In addition reviews look to see if a 'Do Not Attempt Cardio-Pulmonary Resuscitation' order was in place or not. The following graph shows that for 85% of the reviews this was the case, an 5% increase on last year. There has also been an increase in the paperwork being correctly completed

### 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 82% were appropriate, correctly completed and followed and increase of 10% on last year. For 5% 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

In previous years evidence of completion of Annual Health Checks (AHC) for people with learning disabilities in completed mortality reviews was generally low, particularly finding the documentation to review the Annual Health Check discussion and any agreed health action plan goals. We have worked closely with GP practices to improve completion rates over the last two years. 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.

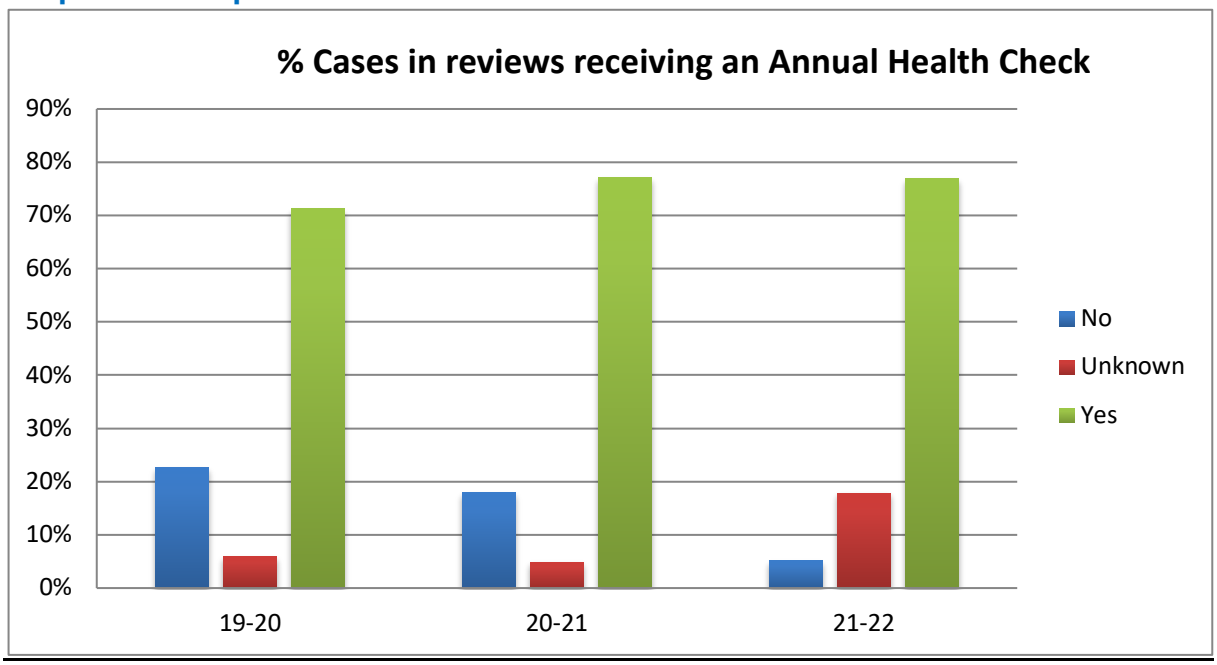
In 2020/21 we established a lead Learning Disability GP's contact list in every practice to establish a BNSSG Learning Disability lead GP Forum. We then developed a series of webinars for GP's and practice nurses on AHC's. Further quarterly webinars were held this year on cancer screening, constipation, obesity and autism. These are well attended by practice staff, (40+ staff) and recorded for those who cannot attend.

We continued to develop a toolkit of AHC resources to support GPs & practices, validated by Community Learning Disability Teams on the AHC portals hosted on GP platforms – Teamnet/Remedy, including easy read resources on a range of topics.

We have been especially proud of the work undertaken by our GP colleagues in primary care this year, who have ensured people with learning disabilities have an Annual Health Check. This is key to ensure people's long-term health conditions are well managed and GP's agree health goals with their patients. The majority of our GP's met or exceeded the minimum 75% of completed annual health check for the patients with a learning disability on their register. 18% of practices completed 100% of their Annual Health Checks

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.

### Graph 15: Completion of Annual Health Check evidence in reviews




Further plans to support AHC's

- Develop further webinar sessions for practice nurses & other staff involved in AHC
- A learning disability newsletter with regular briefings on key issues
- Ensuring Health Action Plans are produced as a result of the AHC
- Targeted support for practices who have low AHC compliance
- 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
- Commissioned people with learning disabilities to develop an easy read Health Action Plan template
- Commissioned actors with learning disabilities to produce videos about Annual Health Checks to reach people who live independently or at home with family

When **David** registered as a new patient at the surgery, David'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 David's health, took the time to liaise with care staff to ensure holistic understanding of the health conditions David had and the help he needed to address the health goals in his Health Action Plan. There were regular visits to the care home, so any ongoing or minor issues that did not usually warrant an appointment could be addressed with ease and allow early identification of concerns with support staff.

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 North Somerset People First who supported individuals with food parcels, socially distanced walks and easy read information about keeping safe from Covid-19 during the last year. North Somerset People First provided tremendous support to people with learning disabilities and have recently celebrated being established for 30 years.

# Section Five – Learning from reviews

## Learning from local reviews - Quality Assurance Review Panel identified themes

From an overview of completed local reviews during 2021/22, the Quality Assurance 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 |
|---|---|
| AHC – no information on Health Action Plans | 40 |
| Constipation | 48 |
| Obesity | 33 |
| Aspiration pneumonia | 29 |
| Catheter Care | 10 |
| Reasonable adjustments | 33 |
| Mental Capacity Assessments, Best interest meetings | 38 |
| Cancer screening | 22 |

**The Quality Assurance 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.

# Actions 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 Heath 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.

In reviews this year Health Action Plans were sometimes 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.

## Improving uptake of Annual Health Checks

There are a considerable number of people in supported living or with families who miss out on AHC. We are working with the Brandon Theatre Group – actors with learning disabilities who will produce scenario videos about the Annual Health Check and Health Action Plans. This will promote AHC/HAP and empower to people to have better understanding of an annual health check, why they are important for keeping healthy and help people to ask their GP about their personal health goals.

## Health Action Plans

53% of AHC do not result in a Health Action Plan - the health goals the GP agrees with their patient. This diminishes the likelihood of health improvement in the patient. Currently there is huge variation in the types and styles of Health Action Plans used by GP's. Some are a simple letter of 2-3 pages, others are 25 page complex documents. Brandon Engagement Group – is a forum of people learning disabilities. We are working with the group to develop a template that captures the required elements of a HAP, consult with GP's on a developed draft before finalising an easy read template

## Constipation

From the reviews completed this year 80% people reviewed continued to have an issue with constipation, some very severely, with impacted bowels that resulted in sepsis. This year we also saw a 30% increase in the number of people who were obese with a BMI over 30.

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 developed recipes to improve diet and 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 through lockdown using Zoom sessions for discussions and remote cookery.

They also delivered co-produced a constipation pilot training programme for 40 carers. Our plan is to roll out the project and training across BNSSG with a resource pack which will include details on how to access the educational tools, easy read resources, recipe cards and training for carers and families raising awareness about constipation and how to address it.

**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!

## Obesity

A growing number of reported deaths have a BMI over 30. This has increased during lockdown with people eating poorly and taking little exercise. We held a webinar with GP's on Obesity and Constipation including information from dieticians and social prescribing in December attended by 48 GP's.

Our 'Healthy Me' cookery school will address obesity and constipation for people with learning disabilities in partnership with Square Food Foundation and housing and support providers, commencing in March. We want to support people to make connections between what they eat and their health. The learning will be more sustainable by teaching learning disabled people themselves to cook and take an active role in decisions about their meals and snacks. Participants selected will have difficulties with their weight and complete before and after food diaries. It will include on-line homework, 'come dine with me' social element to invite friends & family to dinner, training & recipe kits for managers outlining the importance of healthy, wholesome foods and the link to people's health. We plan to link to gardening projects growing herbs & vegetables. Project evaluation by the University of Bristol. There will also be a conference planned in the autumn and an event with system leaders.

## Aspiration Pneumonia

We are beginning work with Speech and Language Therapists in Sirona to look at how we can raise awareness in primary care and with care homes to reduce the risks of people aspirating. We will develop a pathway and set up an equipment library to support families and residential services to be able to try aids and adaptations to see if they are suitable for their family member/clients to reduce incidence of choking.

## Catheter Care

One of the frequent themes from LeDeR reviews is poor management of catheters for people with learning disabilities often leading to sepsis and people being admitted to hospital. We are working with the Continence Service to;

- identify good resources about catheters - leaflets/models ideally easy read for people with learning disabilities
- develop an easy read catheter passport
- Working with Photosymbols to create bespoke catheter symbols for us, working with Catheter Service and learning-disabled models
- develop training for carers/residential staff about catheter care.

## 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 some 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.

HHS 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.

We held a cancer screening webinar in June attended by 68 GP's covering reasonable adjustments and other supports. We have provided guidance to GP's on 'supporting people with LD who have cancer' developed with providers and Cancer Research UK. We are working with screening colleagues to provide dedicated screening days

# Section 6 - Involving people with learning disabilities and autistic people in our work

## Annual Health Check Videos

Increasing uptake of Annual Health Checks. We are working with Brandon Theatre Group – actors with learning disabilities to produce scenario videos about the Annual Health Check and Health Action Plans. This will promote AHC/HAP with people with learning disabilities and empower people to have better understanding of an annual health checks, why they are important and ask their GP about their health goals.

## Autism Audit of Emergency Departments


We are working with a group of autistic people to audit the emergency pathway experienced by autistic people. We started with an audit tool recommended by NICE – people felt this was out of date, used patronising language and was not developed by autistic people. We re-designed the audit tool and have audited 3 hospital EDs with one more to go in May 2022. These whole day audits include evaluating the department for access, adaptations, accommodating reasonable adjustments and interviewing key staff for their understanding of autism. Recommendations are made to each ED and hospital with further developments such as purchasing reasonable adjustment resources and training. Our next plan is to audit the Children's Hospital Emergency Department with parents and young people with autism.

## Autism Training for ED staff

We have been working with BASSS developing the content of autism training programme across the system for 2022/23. It will ensure autistic people are co-trainers in delivering training and paid accordingly on an experts-by-experience rate. From the ED autism audit work recommendations, the project will also provide co-produced short workshops, tailored for Emergency Department staff across BNSSG. Developed an 'experts by experience' component to the training where autistic people share stories and experiences of using services. Four tailored webinars are planned for September 2022.

## Reasonable adjustments

Through the ED access audits being undertaken by autistic people we have identified recommendations to expand the availability of reasonable adjustment resources for people with learning disabilities and autistic people across all the hospital sites. These will be made available in a wide range of clinical areas to support people's access needs and promote a calming environment for example; ear defenders, soothing lights and smells, 'fidgets',

weighted blankets or lap pads, dark glasses or visors for light sensitivity, augmented alternative communication boards.

## Health Action Plans

53% of AHC do not result in an accessible Health Action Plan - the health goals the GP agrees with their patient. This diminishes the likelihood of health improvement for the patient. Currently there is huge variation in the types and styles of Health Action Plans used by GPs. Some are a simple letter of 2-3 pages, others are 25-page complex documents. We are working with Brandon Engagement Group – a forum of people learning disabilities. The group will develop an easy read template that captures the required elements of a HAP, consult with GPs on a developed draft before finalising a template for use across BNSSG.

## Healthy Me – Obesity

Increase in reported deaths in LeDeR are for people who are clinically obese with a BMI over 30. This was a factor in more than 35% of reviews. We want to support people to make connections between what they eat and their health – working in partnership with Square Food Foundation and housing & support providers. The learning will be more sustainable by teaching learning disabled people themselves to cook and take an active role in decisions about their meals and snacks. Participants selected will have difficulties with their weight and complete before and after food diaries.

Course will commence in May with face-to-face classes in Square Foods training kitchen. Include on-line homework, 'come dine with me' social element to invite friends & family to dinner, training & recipe kits for managers outlining the importance of healthy, wholesome foods and the link to people's health. We plan to link to gardening projects growing herbs & vegetables. Project evaluation by the University of Bristol. There will also be a conference planned and an event with system leaders.

## Poo Matters

As mentioned previously in 100 completed LeDeR reviews last year, 80 people with learning disabilities had constipation as a factor in their death. We have further funded this work to extend the roll out of co-produced pilot training led & presented by people with learning disabilities and Sirona. It includes a pack advising best practice educational materials. The co-produced awareness training will be available for support staff, carers & family members & services across BNSSG.

## Training programme to identify deteriorating health in people with learning disabilities in residential settings.

The basic principle is a series of bite size sessions for support staff – they will be aimed primarily at new and less experienced staff in housing and support providers and will aim to give staff a solid foundation on how to support people with their health in proactive way. This is particularly important as we come out of the pandemic where housing and support providers have recruited many staff new to caring for people with learning disabilities and often have no clinical skills or training. Examples of training are;

- Supporting people with intimate care needs. Supporting with dignity but also using this time to make observations that might alert staff to signs of ill health.

- How to recognise when someone is unwell (soft signs – as a precursor to Restore2 for new staff)
- Health Inequalities – Why people with LD die younger and what we can do to change this
- Health Screening – what screening people should have, how to prepare and attend appointments

## Rebuilding self-advocacy across BNSSG/ICS

Ensuring people with learning disabilities have voice and influence is a key ambition in our system strategy. It requires commitment and funding to build systems for people with learning disabilities to be equal partners in our different work streams. Currently there is little or no involvement of people with learning disabilities in key meetings about learning disabilities. The pan disability model has not been successful in representing or bringing the voices of people with learning disabilities to the table.

By disinvesting in self-advocacy 10 years ago we reduced the ability for People First groups and other linked forums for people with learning disabilities to have a voice and the opportunities to speak up. We are now beginning again, building foundations and self-advocacy skills amongst people with learning disabilities. Having secured 3 year funding we plan to grow and build support for people to speak up for themselves. Elected members and self-advocates with learning disabilities who have 20+ years of experience of speaking up will lead the project, supported by North Somerset People First support workers & BNSSG, working in partnership with Local Authority colleagues, commencing in April 2022.

## Autism Forum

Working in partnership with Bristol City Council and Bristol Autism Spectrum Service (BASS) we are working to develop a BNSSG/ICS wide Autism Forum. The model of the Forum will be flexible to incorporate a range of opportunities for autistic people to have a voice. It will be an on-line meeting with an open invite rather than fixed membership.

Meetings will be themed on issues such as hospital access, support from GP's, transport, police, etc where people with lived experience can share their story or contribute to discussions from their perspective. Autistic people can dial in, camera on or off, contribute via the chat function or send email points in advance. The Autism Forum will be hosted by the Bristol Autism Spectrum Service, with access to the mailing list for 5000 clients with autism, as well as invites to user-led groups such as Diverse, Auti-MS.

# Section Seven - Summary

This is the third 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.

The national changes planned for the LeDeR programme did have an impact on our ability to undertake reviews in the first half of the year as the transition from old to new platform took place. These are largely resolved. As we develop into an Integrated Care system (ICS) we are passionately committed to keep learning as a result of LeDeR reviews and continue to drive an innovative work programme that makes changes to improve services and address health inequalities experienced by people with learning disabilities.

## Action Learning

The LeDeR Governance Group provides regular information on the themes and recommendations identified from LeDeR reviews to the Health Providers Network and 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 work plan that reports to the Programme Board.

Individual improvement recommendations made from single reviews will be shared with the Health Providers Network to assess if they can be appropriately included in the wider work programme.

We have strengthened our partnership with North Somerset People First and commissioned a three-year programme of work to develop support to establish other self-advocacy groups across BNSSG. This 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.