Healthier Together
Improving health and care in Bristol, North Somerset and South Gloucestershire

NHS
Bristol, North Somerset and South Gloucestershire
Integrated Care Board

LeDeR Annual Report: Learning from deaths of people with a learning disability and/or autistic people

1 April 2023 to 31 March 2024

Together we are BNSSG

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1. Executive Foreword

This report provides an overview of the "Learning from lives and deaths – people with a learning disability and autistic people (LeDeR)" service improvement programme for Bristol, North Somerset and South Gloucestershire Integrated Care Board (ICB).

The programme was initiated by NHS England to improve the health and wellbeing of people with a learning disability and for the second year has been extended to include autistic people. This national programme provides a framework for reviewing the care of people who have died and ensuring that learning from their care and their causes of death is understood.

In Bristol, North Somerset and South Gloucestershire we are determined to drive a constant improvement in experiences of health and care for people with a learning disability and autistic people. We will use the LeDeR process to enable us to gain a deeper understanding of a person's care and the cause and circumstances of their death. In turn, this understanding drives our programme of quality improvement to enable people to live longer and healthier lives.

This is the fifth annual report that Bristol, North Somerset and South Gloucestershire ICB has published and includes LeDeR reviews that were undertaken between 1 April 2023 and 31 March 2024. Some of the people in those reviews will have died in the previous year, but their reviews will have been undertaken during the period of this report.

Maintaining performance has been a key issue, leading to a backlog of reviews, contributed by LeDeR portal data outages and insufficient reviewer capacity. We are pursuing the procurement process to achieve a sustainable reviewer workforce and we are determined to improve performance in 2024/25. Previous annual reports are available on the ICB LeDeR webpage. The purpose of this report is to share themes and trends from LeDeR reviews and to report on learning and actions taken to enhance services provided for people with a learning disability and/or autistic people.

During 2023/24, we reviewed our LeDeR governance structure to ensure a strong system approach to challenging health inequalities for our learning disability and autistic population. System partners are fully engaged with the LeDeR programme and there is dedicated commitment to challenge health inequalities and improve health outcomes for people with a learning disability and/or autistic people. Data, including themes and trends following LeDeR reviews, is now shared with our Mortality Group and Strategic Prevention Oversight Group to ensure strong oversight alongside our wider health inequalities work programmes.

We continue to invest in our improvement programme, which is co-produced by system partners and supported by colleagues from our voluntary and community sector and Experts by Experience. We have ambitious plans and, through a culture of continuous improvement, we are proud of our achievements across the partnership, whilst recognising that we a lot more work to do.

Some of our key achievements this year include our acute trusts driving education about constipation and our community provider committing to the new role of the Learning

Disability Screening Practitioner. Primary care focus has been on raising awareness of the learning disability annual health check (AHC) and health action plan (HAP). We have also collaborated with the voluntary and community sector, with a focus on better understanding and reducing the barriers to accessing the primary care learning disability register and annual health checks for our citizens from an ethnic minority background. This collaborative project has highlighted the need for a system approach to achieve equal access to healthcare. Inequalities in housing provision, living in poverty and poor education, impacts access to healthcare. There is a focus on co-production to guarantee we commit to eliminating healthcare inequalities.

This report has allowed partners to showcase their outstanding efforts and demonstrates their dedication to enhancing the lives of our learning disability and autistic population. We extend our gratitude to everyone involved for their continuous dedication and hard work in serving this remarkable group of individuals.

2. Glossary of terms

Term	Definition
ICB Bristol, North Somerset and South Gloucestershire Integrated Care Board	NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board is responsible for the day-to-day running of the NHS for our local area.
LAC Local Area Contact	Programme manager for LeDeR and facilitates the completion of reviews and drives service improvements across the health and social care system.
ED Emergency department	A specialised department within a hospital that provides immediate and urgent care for patients suffering from severe injuries, acute illnesses, mental health crisis, or medical emergencies. Typically, operating 24/7.
CDOP Child Death Overview Panel	A child death review meeting is held to review all the information to understand why the child died. They review and identify any learning points from services involved with the child leading up to their death.
Experts by Experience	A person who possesses deep understanding and insights into a particular subject or issue due to their first-hand lived experience, rather than formal academic or professional training.
LDALS Learning disability and autism liaison service	A specialist team who enables access to healthcare within the acute trusts for anyone with diagnosed learning disabilities or autism over 16 years old.
LeDeR Learning from lives and deaths – People with a learning disability and autistic people	A UK initiative aimed at improving the health and care of people with learning disabilities or autism. It conducts reviews of deaths of individuals with learning disabilities to identify any modifiable factors and make recommendations for improvements in healthcare provision and support services, with the goal of

Term	Definition
	reducing health inequalities and preventing premature deaths within this population.
DNA CPR Do not attempt cardiopulmonary resuscitation	If a person has a cardiac arrest or dies suddenly, there will be guidance on what action should or shouldn't be taken by a healthcare professional, including not performing CPR on the person.
IMCA Independent mental capacity advocate	A person who is an advocate appointed to act on a person's behalf if they lack capacity to make certain decisions.
MCA Mental Capacity Assessment	Legal framework which is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment.
AHC Annual Health Check	A health check for people with a learning disability who are over 14 years old. They are carried out at a GP surgery and review a person's physical and mental health.
HAP Health Action Plan	A health action plan tells you what you need to do to keep healthy and what services or support are needed to maintain a healthy life.
ALDHS Adult Learning Disability Health Service	Part of Sirona care & health, the ALDHS provides learning disability health services within the community and the Learning Disability and Autism Liaison Service within the acute trusts.

3. LeDeR programme governance and oversight

It is essential to have robust governance in place, supporting this work programme to ensure we take a consistent approach to our reviews, work with great care and sensitivity with affected families, loved ones and carers, and gain all possible learning to improve the lives of our citizens going forward. In support of this, we have reviewed our LeDeR Governance Structure this year to ensure it is robust and reflects our working arrangements in the Integrated Care System (ICS).

The Executive Lead responsible for the LeDeR programme continues to be the ICB's Chief Nursing Officer, supported by a Deputy Chief Nurse and the Local Area Co-ordinator. These revised arrangements align the programme more strongly with the wider system patient safety work programmes.

The overall aims of the programme are:

- To support improvements in the quality of health and social care service delivery for autistic people and people with learning disabilities.
- To help reduce premature mortality and address health inequalities for autistic people and people with learning disabilities.

3.1 LeDeR Governance Group

Bristol, North Somerset and South Gloucestershire ICB's Chief Nursing Officer chairs our LeDeR Governance Group which meets bi-monthly. Representatives attend the Governance Group from all Bristol, North Somerset and South Gloucestershire health providers, the three local authorities who commission adult social care, GPs, Independent Care Provider representatives, safeguarding colleagues, and the NHS England regional LeDeR lead. The principal objective of the LeDeR Governance Groups adheres to the four pillars of an Integrated Care Board (ICB):

- Improving outcomes in population health and healthcare.
- Tackling inequalities in outcomes, experience and access.
- Enhancing productivity and value for money.
- Helping the NHS to support broader social and economic development.

This group takes strategic oversight of the reviews of deaths of people with a learning disability and/or autistic people, driving transformation to improve care in services. Health and care partners support in addressing health inequalities, including outcomes, experience, and access. Assurance updates are reported to the ICB Outcomes Quality and Performance Committee via quarterly governance reports, with onward reporting through to the ICB Board. Key areas of escalation are also shared with the Mental Health and Learning Disability Health and Care Improvement Group and associated Operational Delivery Group, where learning from the LeDeR programme will support strategic decision making and ensure priorities set for the system reflect lessons learned from LeDeR.

3.2 Learning Disability and Autism Co-Production Group

The aim of the newly formed Learning Disability and Autism Co-Production Group is to drive small scale quality improvement initiatives. The group comprises of representatives from Bristol, North Somerset and South Gloucestershire health and care providers.

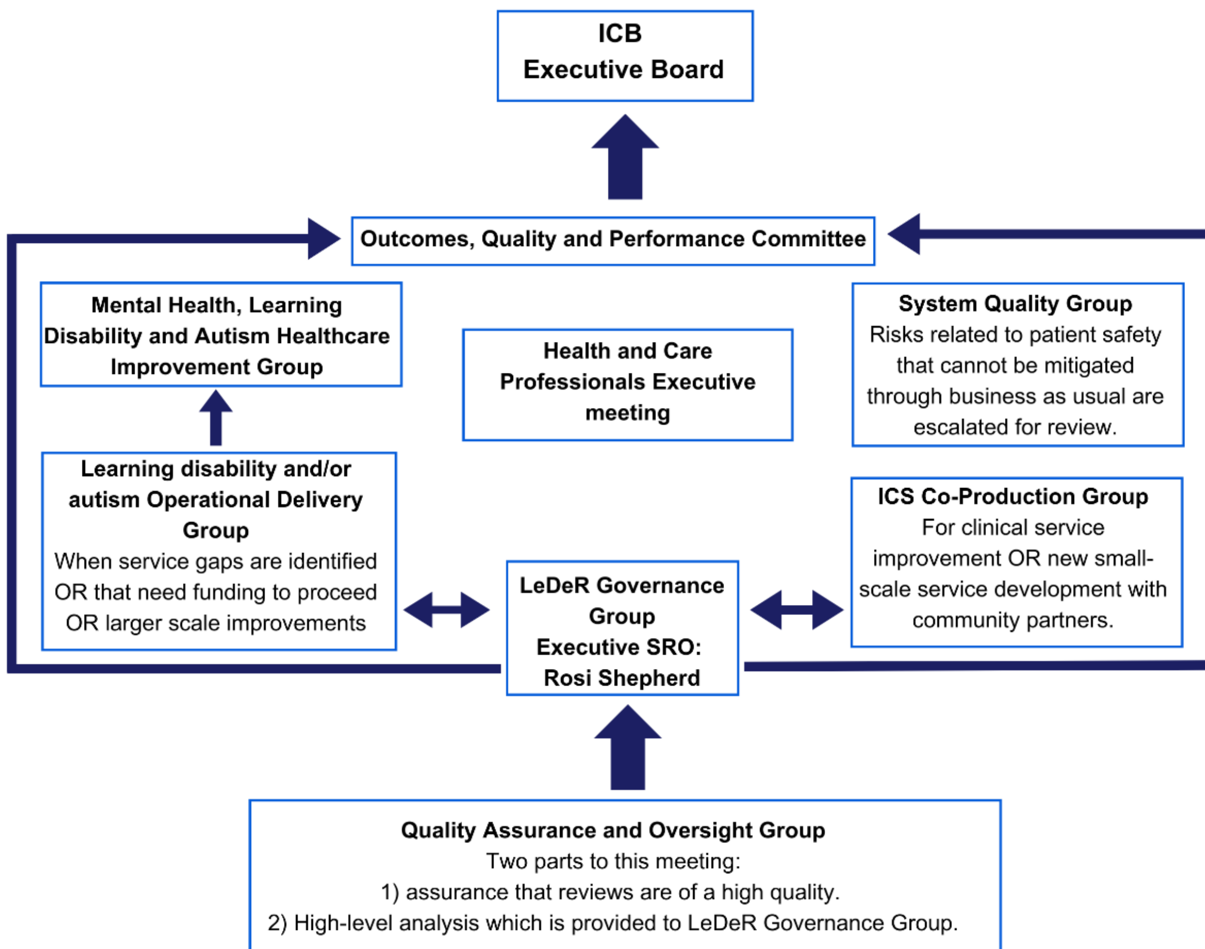
The LeDeR Governance Group identifies specific areas of focus to the Learning Disability and Autism Co-Production group, which is accountable to the Governance Group. If larger pieces of improvement work are required, the LeDeR Governance Group allocate, ensuring the right capacity and skills are available to deliver in a timely way.

During this year we will align this group with the co-production group being led by Bristol City Council, further embedding the learning from LeDeR into the wider work of the system, to improve outcomes for our population in a fully co-produced way.

3.3 Quality Insight and Oversight Group

Bristol, North Somerset and South Gloucestershire ICB continued to strengthen our LeDeR reviews quality assurance process in 2023/24, which resulted in revision to the Terms of Reference for the Quality Insight and Oversight Group, which now oversees all review reports. Meeting monthly, the panel not only provides oversight of the quality of reviews, but also produces an analysis of learning themes. Emerging new themes are reported into the LeDeR Governance Group, where appropriate next steps are agreed.

Membership of the Quality Insight and Oversight Group includes the Local Area Contact (LAC), Clinical Learning Disability and/or autism GP Lead, Safeguarding representatives, Local Authority representatives and all Bristol, North Somerset and South Gloucestershire health provider representatives.



3.4 The LeDeR Team

In August 2023, a substantive new Local Area Contact (LAC) was identified, who continues to manage our LeDeR process. The LAC oversees the allocation of cases to trained LeDeR reviewers and meets with the reviewers regularly to monitor progress and completion of the review. The LAC completes quality assurance of all completed LeDeR reviews. The LAC prepares papers for the LeDeR Governance Group and the Quality Insight and Oversight Group and provides LeDeR updates to our Learning Disability and/or Autism Operational Delivery Group and the Outcomes, Quality and Performance Committee.

Dedicated administration continues to source records from GPs and health and social care providers, as well as liaising with the coroner if the deceased is being reviewed under the coronial process. In addition, they provide general administration support to LAC.

The LeDeR process is supported by a team of trained reviewers. Some of these reviewers already have substantive posts in Bristol, North Somerset and South Gloucestershire community learning disability teams. These colleagues have been able to undertake reviews when there has been capacity to do so. The new LAC undertook a piece of work to measure demand and capacity and identified that this was not a sustainable model going forward. Following a successful business case, LAC is now leading on procuring a more robust service offer, which will address the backlog of reviews as well as meet future demand.

It is essential that strong supervision and support is in place for our reviewers to support the delivery of high-quality reviews, so the LAC has developed a peer support model for all reviewers, where an experienced reviewer provides peer supervision to reviewers monthly. This will ensure reviewers are well supported and they are guided through the review process by an experienced colleague. Additionally, the LAC and LeDeR Administrator meet with all reviewers monthly to ensure the reviewers have all the appropriate notes to complete the review and provide an opportunity to debrief if the reviewer has had a challenging or upsetting review. Within this forum it is an opportunity for the LAC to share updates from the national team, overarching themes, and updates on quality improvement initiatives following learning from LeDeR reviews. In this space colleagues can discuss any areas of the LeDeR process where reviewers feel less confident. From these discussions, further improvement opportunities are discovered and actioned.

4. LeDeR Programme Performance

In July 2023, changes to national policy mean that ICBs are no longer required to report the deaths of children and young people under the age of 18 to the LeDeR platform. These deaths will continue to be reviewed under the Child Death Overview Panel (CDOP). The outcomes of these reviews will be reported to the Strategic Prevention Oversight Group, allowing for triangulation of data and identification of themes. For the second year, the deaths of autistic people continue to be included in the LeDeR programme.

4.1 Bristol, North Somerset and South Gloucestershire data

Total notifications 1 April 2023 to 31 March 2024	75
Total notifications not yet assigned to a reviewer	27
Total number of reviews currently in progress	28
Number of reviews currently on HOLD	3
Completed and closed reviews in 2023/24	43*

*26 reviews that have been completed and closed are pre-April 2023 reviews.

Of the 75 deaths that we were notified of, 71 people had a learning disability and four were autistic people.

The national LeDeR portal underwent an upgrade and notifications were delayed during the period of June 2022 to February 2023. This resulted in ICBs not receiving all notifications during this period, creating a backlog of reviews that needed to be undertaken and delays in allocation and completion of reviews. Delays in ICBs being informed of LeDeR notifications has continued throughout 2023/24. Because of this, three of the reviews included in the table above are for people who died in 2022. The LeDeR portal has also suffered an outage caused by an external dependency and user access issues compounding delays in notification and allocation of reviews. There has also been a process error by the national team which resulted in some reviews not being identified. This has been corrected and, of this group, three were Bristol, North Somerset and South Gloucestershire citizens and their reviews are included in our 2023/24 data.

4.2 Completed Reviews

Completed reviews and Key Performance Indicators	**2023/24**
Number of Notifications	75
Number of Closed Completed Cases	43
Allocation of reviews within 3 months of notification	6.6%
Completion of reviews within 6 months of notification	6.6%
Quality Assurance check of reviews by LAC within 2 weeks of completion.	97.7%

Of the 43 completed reviews, 88% have been completed and closed within the last six months of the financial year, with 60% of completed reviews being notified in 2022/23. Resolving the backlog of reviews from 2022/23 has been prioritised. Focus has been on completing 2022/23 reviews to try and reduce the impact on families waiting for the LeDeR process, as we do not want to prolong or intrude on the grief of loved ones.

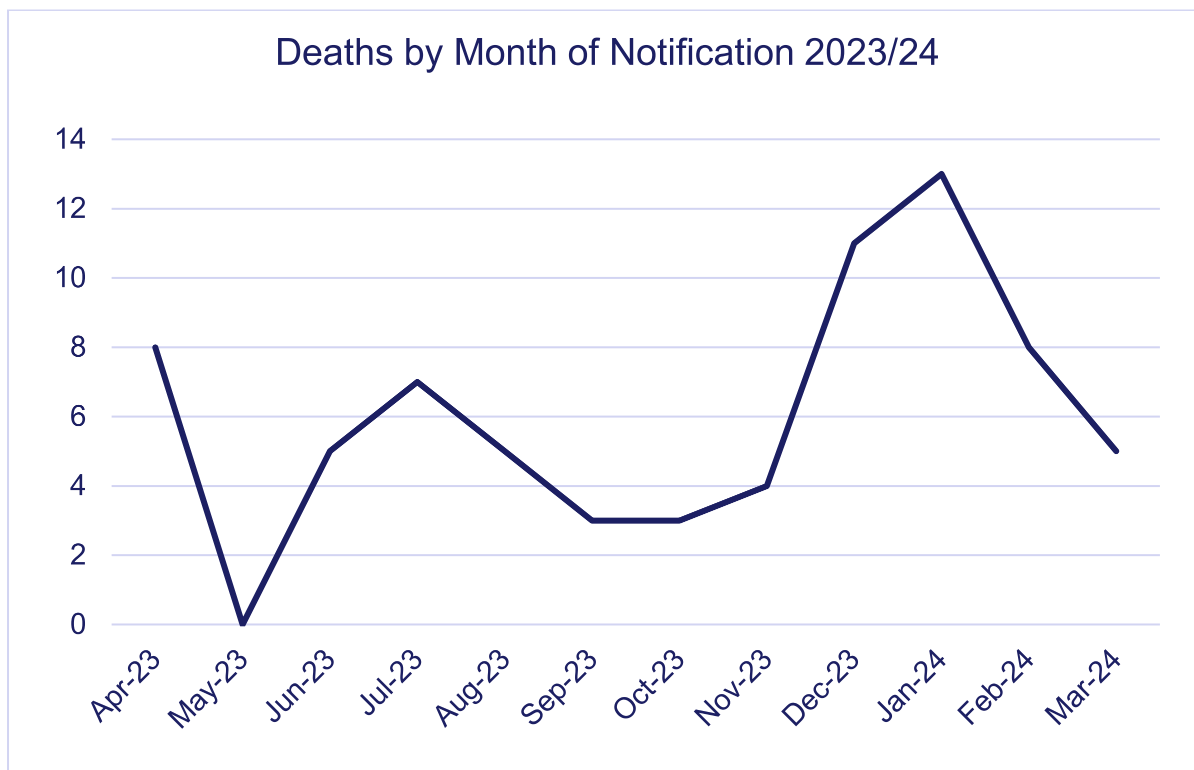


Figure 1: Deaths by month of notification 2023/24

The number of notifications occurring in July 2023 appear to be greater than expected. The national LeDeR report (2022) suggests there were more excess deaths over heatwave periods. Public Health colleagues have reviewed this data and suggest this increase may be due to better reporting of deaths, as well as the impact of the heatwave. In response to national excess death data, Bristol, North Somerset and South Gloucestershire ICB, in collaboration with Sirona care & health, has created an easy read heat exposure leaflet. Further information can be found in section 7.4.

- One focused autism review has been completed and a further four allocated, awaiting completion.
- A combination of the backlog, subsequent changes in the LeDeR portal described above, and our LeDeR capacity, has contributed to the accrual of a backlog of 35 reviews by July 2023. This is being addressed by the procurement of additional capacity from a commissioning support unit as an interim measure, whilst procurement for the longer-term service provision is undertaken.

4.3 Changes in process to improve oversight and performance

Our LeDeR team have reviewed every aspect of the LeDeR process, identifying improvements along the pathway, such as a revised letter to GPs, which is now much clearer about what is required to support a high-quality review. This has resulted in an immediate improvement in the process, reducing waste and shortening the time in which this is undertaken. This is in line with a Getting it Right First-Time approach.

The LeDeR Local Area Contact (LAC) has worked with our current reviewers to streamline our LeDeR review process. There are monthly meetings to understand the barriers to

completing a review within timescales and to reset expectations. This is not an exhaustive list, but includes:

- Triaging LeDeR reviews to understand complexity before allocation.
- A step-by-step process of how to complete a review.
- A reviewer script for family members, so they understand the expectations of what a LeDeR review is and how a reviewer can signpost to the relevant organisation if the family have questions.
- A list of what notes should be prioritised when completing a review.
- Compiling an action/recommendations template.
- Monthly peer support meetings with reviewers to discuss any issues/debrief.

Our reviewers are determined and passionate to improve outcomes and quality of life to those who have a learning disability and/or autistic people. We thank them for their ongoing support of this programme in service of improving the outcomes for our citizens.

4.3 LeDeR reviews: thematic analysis (April 2023 to March 2024)

- Good multi-disciplinary team working between different health and social care services.
- Good examples of supporting someone with a learning disability in old age.
- GPs who have regular communication with the person and care home e.g. weekly ward rounds.
- Awareness of the needs of people with mild learning disabilities who do not meet criteria for specialist teams.
- Late diagnosis of cancer.
- Use of communication aids.
- Classification of care; discharging back into the community. Hospital colleagues may not be enquiring as to whether community providers can support the person if they have an increased level of needs.
- Hospital staff at times not providing individualised care.
- Autism support – reflects the finding of the Emergency Department (ED) Audit with Experts by Experience. Ongoing need to develop understanding of the needs of autistic people, the traits that may present and how to best support. Ongoing need to increase the provision of support in the community for autistic people, including enabling access to mainstream services.

Areas of service improvements are being prioritised based on the themes and data that are identified through the LeDeR reviews, aligning with the Patient Safety Incident Response Framework (PSIRF) methodology. These themes will support the development of specific quality improvement, such as those described in section 7 of this report. We will also work closely with the co-production group at Bristol City Council to ensure that our quality improvement is undertaken in a fully co-produced way.

5. About the people who died

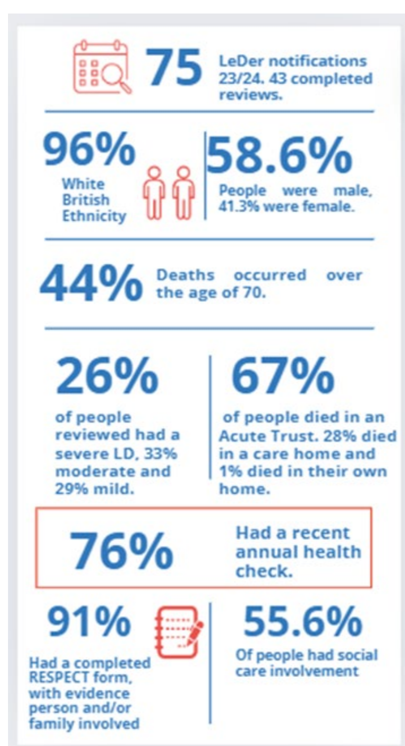
5.1 Demographic data

In 2023/24, we received three LeDeR notifications where the person was from an ethnic minority background and had a learning disability and/or was autistic, these numbers are too small to draw significant conclusions from the data. However, the LeDeR data is being reviewed under the health inequalities work programme, as well as our mortality group, to ensure a variety of professional expertise has oversight of the LeDeR data set.

Bristol, North Somerset and South Gloucestershire ICB has also been working collaboratively with Bristol-based organisation, Autism Independence, to support people from an ethnic minority background to access annual health checks and raise awareness of the primary care learning disability register. The project findings suggest providing equal access to healthcare requires a system-based approach. Competing priorities can inhibit someone’s ability to prioritise their health, such as lack of stable housing provision, meaning deprioritising of attending to their health concerns. The project also suggests the benefit of cultural competence training for healthcare workers.

This would contribute to reducing the barriers to accessing healthcare, such as providing easy read leaflets for everyone and ensuring health related information is provided in a person’s first language. Please see section 7.3 for further details.

Sirona care & health are also working with ethnic minority groups. Section 8.1 highlights Sirona care & health’s drive to understand the challenges faced by local communities to access health services, which will in turn inform quality improvement initiatives to improve access.



Bristol, North Somerset and South Gloucestershire LeDeR data 2023/24

75 LeDer notifications in 2023/24. 43 completed reviews.

96% White British Ethnicity

58.6% of people were male, 45% were female.

44% of deaths occurred over the age of 70.

26% of people reviewed had a severe learning disability (LD). 33% moderate and 29% mild.

67% of people dies in an Acute Trust. 28% died in care homes and 1% died in their own home.

76% of people had a recent annual health check.

91% of people had completed a RESPECT form, with evidence of person and/or family involved.

55.6% of people had social care involvement.

Bristol, North Somerset and South Gloucestershire ICB continues to receive more notifications of deaths of men than women, which is consistent with national data reporting. The National LeDeR report (2022) reports that 55% of people with a learning disability who died were male.

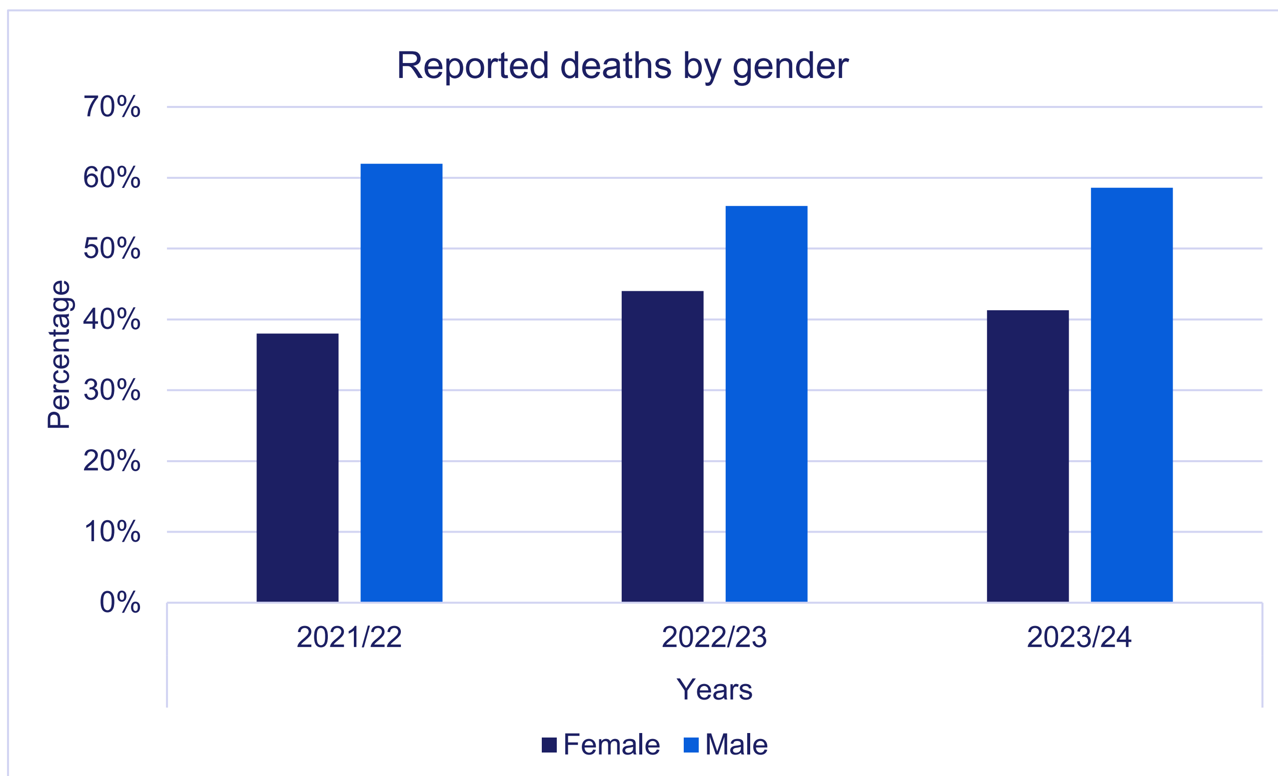


Figure 2: Reported deaths by gender

5.2 Median age of death

There has been no change in the overall median age trend over time in Bristol, North Somerset and South Gloucestershire for people who have a learning disability.

Nationally, the median age for death in 2022 was 62.9 years. This is an increase from 2018, where the median age at death was 61.8 years. The median age of death for women is 68 years and for men it is 67 years.

Figure 3 and Figure 4 demonstrate data from the Health and Care of People with Learning Disabilities Experimental Statistics 2022 to 2023, which shows Bristol, North Somerset and South Gloucestershire having an older population on the learning disability register compared to England.

Percentage of patients with a learning disability by age and sex

Figure 3: Percentage of patients with a learning disability by age and sex in England (2022/23)

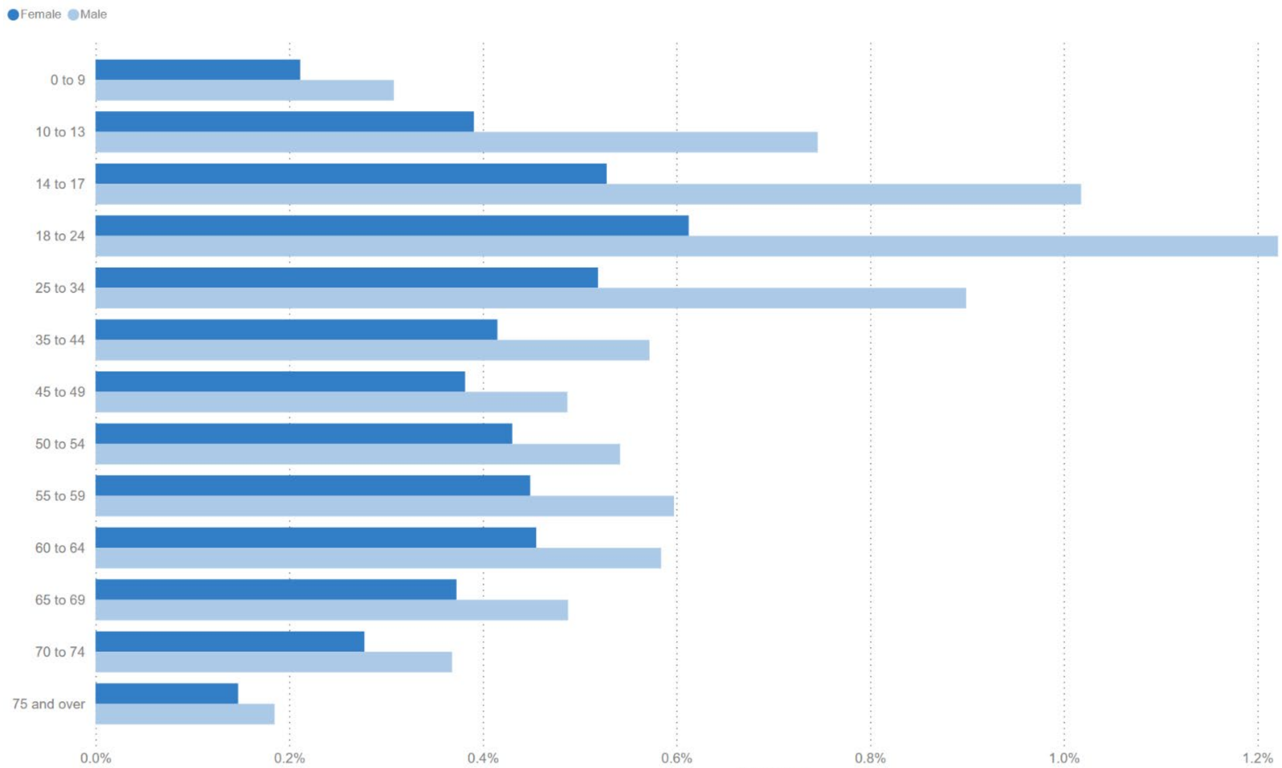
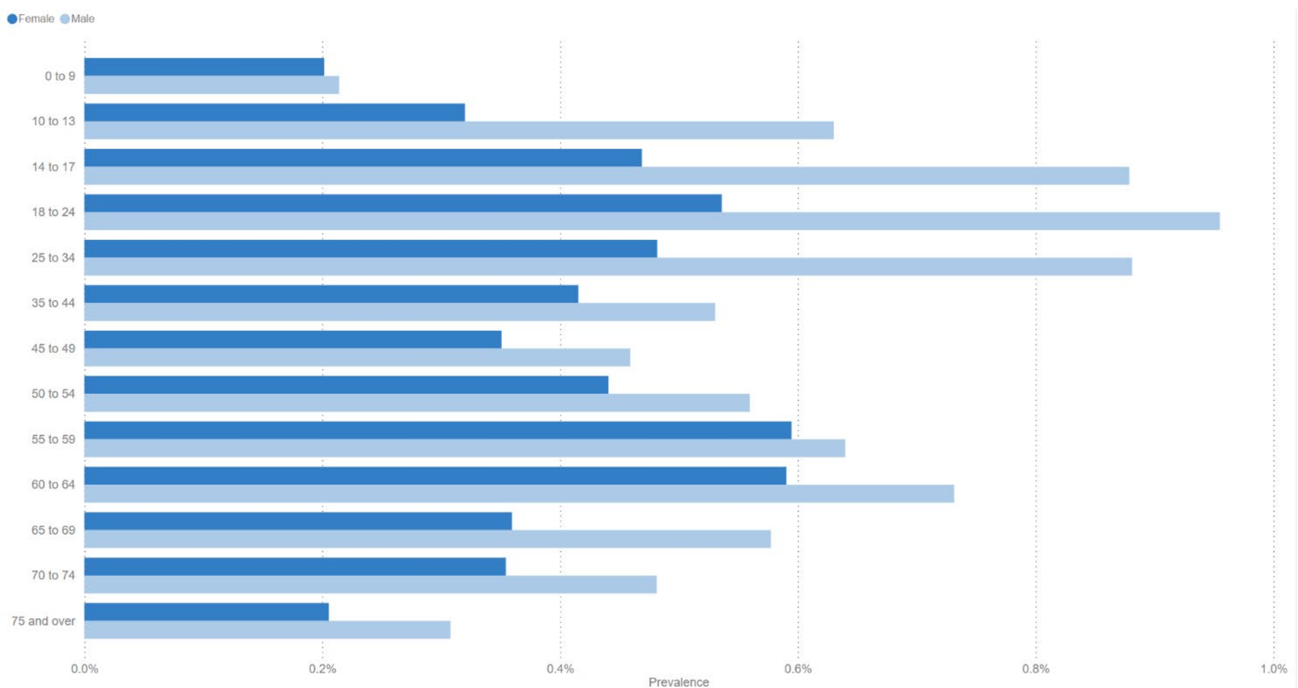


Figure 4: Percentage of patients with a learning disability by age and sex in Bristol, North Somerset and South Gloucestershire (2022/23)



People registered on Bristol, North Somerset and South Gloucestershire GPs learning disability register

We are pleased to be able to report that there has been a 13% increase in the number of people on the learning disability register since 2019. This increase will mean that a greater number of people will be able to access support through their annual health check, as well as being a contributory factor to an increase in reported deaths.

Figure 5: Learning disability: QOF prevalence (all ages)

Recent trend: Increasing

Period	NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board - QUY					England
		Count	Value	95% Lower CI	95% Upper CI	
2014/15	●	4,076	0.4%	0.4%	0.4%	0.4%
2015/16		-	-	-	-	0.5%
2016/17	●	4,547	0.5%*	0.4%	0.5%	0.5%
2017/18	●	4,598	0.5%	0.4%	0.5%	0.5%
2018/19	●	4,814	0.5%	0.5%	0.5%	0.5%
2019/20	●	4,904	0.5%	0.5%	0.5%	0.5%
2020/21	●	5,120	0.5%	0.5%	0.5%	0.5%
2021/22	●	5,397	0.5%	0.5%	0.5%	0.5%
2022/23	●	5,524	0.5%	0.5%	0.5%	0.6%

Source: Quality and Outcomes Framework (QOF), NHS England

5.3 Level of learning disability

The data shown in section 5.1 indicates that 26% of people who died had a severe learning disability, 33% had a moderate learning disability and 29% had a mild learning disability. We will continue to develop our understanding of this data, in partnership with our Directors of Public Health, to ensure that any insight it gives us supports our wider programmes of work to support people with a learning disability linking those insights through to our Health and Care Improvement groups supporting system transformation in service of reducing health inequalities.

A theme for us to address with system partners during 2024/25 will be the learning that some people who have a mild learning disability can struggle to get their needs met effectively by health and social care.

5.4 Impact of covid on people

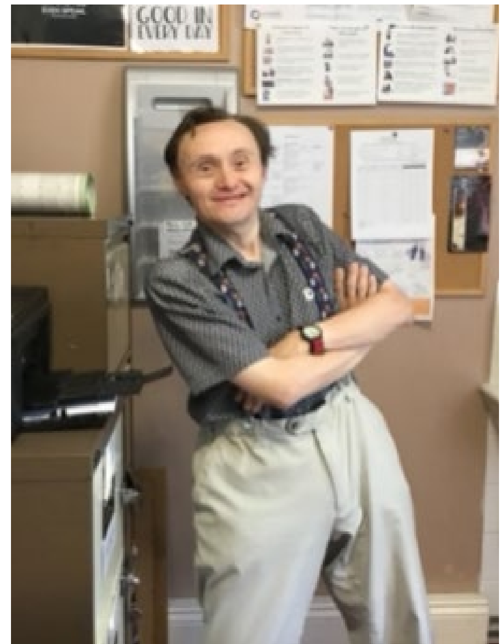
The longer-term impact of the Covid-19 pandemic still features in many LeDeR reviews. People continue to feel the learned behaviours of the isolation experienced due to the pandemic. The use of face masks prohibited people's ability to lipread, so even when restrictions lifted some barriers to communication remained. Day centres closing during the pandemic also affected people who became more isolated. The change in consistent daily activities lead to anxiety to accessing the community when restrictions lifted.

This vulnerable cohort of people continue to experience the detrimental side effects of social isolation of which the pandemic created. Emotional wellbeing support from the Adult Learning Disability Health Service is still required due to the ongoing impact of this isolation.

5.5 Involving next of kin

Families, carers and loved ones are invited to take part in the LeDeR reviews that we conduct. In one third of completed LeDeR reviews, the next of kin kindly shared their insight into the life of the person that died, including their experiences of health and social care. Many family members were complimentary about the care provided, especially in care homes where the person had lived. On some occasions, carers who were well known to the person who died also contributed to the LeDeR process. There have been numerous examples of how care home staff have gone above and beyond to support the people they care for and their loved ones.

5.6 Alan's Story



We are so grateful to Alan's sister for providing his story, which we have been able to share and shows the importance of involving families in our reviews. Alan's sister has asked that we refer to him by his given name in the report and not use a pseudonym.

Alan lived with his Mum until she died suddenly in 2017. Alan's Mum did not drive, so Alan could be quite isolated. In Alan's 20s, his Mum agreed to outreach support 2 to 3 times a week, so that Alan could be taken out on day trips.

Alan's Mum's health deteriorated, and Alan helped increasingly at home and used some of his outreach time to do a little extra food shopping. Alan really enjoyed shopping and was happy and proud to help out.

After his Mum died, Alan experienced a significant episode of poor health and an extended period in hospital. He then moved to live in supported accommodation. During this time, Alan, who had previously seemed to have very minimal speech which he rarely used, started to speak much more. He started by talking to hospital staff and then his speech further developed when he moved into his new accommodation. The staff supported him in talking and his sister, with whom he had frequent contact, was both amazed and delighted.

Although Alan's speech was still limited, he made good use of it and continued to expand his vocabulary and use of short phrases. He was able to hold simple conversations over the phone. Alan proved that being in your late forties is no barrier to learning to talk!

Alan lived in a little annex and had a sense of independence and growing confidence, his personality shone. He made choices for himself and had a great sense of style. He also had a great sense of humour and a sense of fun. Alan's sister would treat him to items that he had not had previously, such as an iPad. He turned out to be both very good and very interested in technology.

Alan thrived in his new life. His sister would take him out and about for coffee, or to a garden centre, or to go clothes shopping. She remembers being a little daunted when he requested an orange shirt, but they successfully located one and the shade they found turned out to suit him. It became a firm favourite, together with his Christmas braces, which he wore all year.

Alan loved being in the garden, TV, dancing, magic, playing his harmonica and using his iPad. He loved interacting with his favourite staff. Alan became known in the local area and would take a daily short walk independently to the local café to pick up his lunch. He became friends with the people who worked there. His mobility was limited by his health, and he had never been anywhere by himself when he lived with his Mum. He loved his daily walk, and it represented an enormous achievement for him both physically and in terms of his independence and confidence.

Alan's health gradually got worse over the last two years of his life, with frequent admissions to hospital. The Care Provider found a rehabilitation bed for Alan. At the end of the six-week rehabilitation period, Alan was asked if he would like to stay. He chose to stay, saying "I love it". Alan had made friends with the other residents and Sophie, the little dog. Alan had never had a dog at home previously and loved Sophie, he would tell staff all about her when he was in hospital. Although his world continued to contract due to ill health, he made the best of life and made new friends during his hospital stays.

Alan's sister says "When my mother died, I just wanted Alan to have a happy and fulfilling life. I was amazed and humbled by what he went on to achieve. I would like to thank all the people who supported him."

Thank you to Alan's sister, who kindly gave permission for Bristol, North Somerset and South Gloucestershire ICB to share Alan's photos and life story.

6. Cause of death

6.1 High level summary

It has been noted from our LeDeR data this year, that we have seen an increase in reported deaths of people who had a learning disability and/or autistic people during 2023/24. We will continue oversight of this through our Strategic Oversight Prevention Group, where we can review with our Directors of Public Health. We do not believe this to be a significant increase and it is likely due to improved reporting and the increased number of people now on our GP registers.

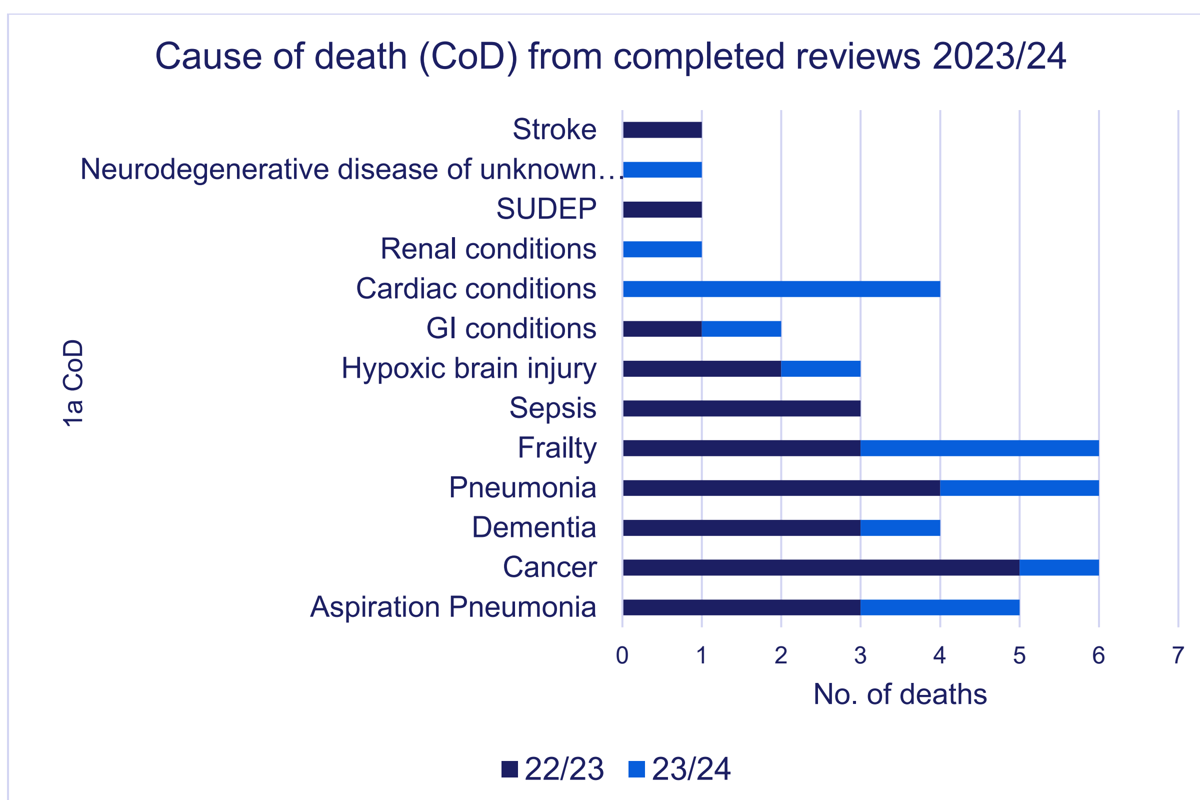


Figure 6:Cause of death (CoD) from completed reviews 2023/24

Our completed reviews show us that the three most common causes of death were cancer, frailty, and pneumonia. Of the people who died from cancer, three people had pancreatic cancer, one lung, one lymphoma and one bowel cancer.

We have observed a difference in the causes of death between 2022/23 and 2023/24. In 2022/23, cancer was the most common cause of death followed by pneumonia, sepsis, frailty, dementia, and aspiration pneumonia. In 2023/24, cardiac conditions were the most common cause of death followed by frailty, pneumonia, and aspiration pneumonia. All apart from one of the people who died from frailty and dementia were over the age of 75 years, correlating with the greater life expectancy of our population and indicating that people who have a learning disability are dying from older age ailments.

We are pleased to be able to report that there were no death certificates where a learning disability was included as a 1a cause of death and we are grateful to the Medical Examiner's office for supporting this change with our clinical teams. In 25% of our reviews, the death certificate included the learning disability as a contributory factor. Our clinical lead for learning disability and autism has reviewed these and deemed them appropriate in relation to the individual circumstances of the people whose deaths were being reviewed. Ongoing collaboration with the Medical Examiners will support continued appropriate guidance regarding not using learning disability as a 1a cause of death.

We use the same definition for avoidable deaths in this report as the LeDeR national report (2022) by applying the OECD/Eurostat lists of preventable and treatable causes of death for people who are less than 75 years old. In essence, avoidable deaths are deaths where, if certain possible and reasonable steps were taken, then the death may not have happened in the way that it did, and it therefore can be classed as having been avoidable. This does not necessarily mean that there were failings of care, but that the person died from a cause of death that, if reasonable circumstances were different, they would likely not have died from.

Key data in the NHS England LeDeR action from learning report 2022/23 found that "42% of deaths were deemed "avoidable" for people with a learning disability. This is a reduction from 2021 data, which found 50% of adult deaths were avoidable. This compares to 22% for the general population." Bristol, North Somerset and South Gloucestershire LeDeR data suggests 39% of deaths had a preventable or treatable cause of death. Deaths caused by epilepsy, pneumonia, aspiration pneumonia, sepsis and some types of cancer are all deemed preventable and/or treatable deaths.

To address preventable or treatable causes of death, a range of initiatives have been imbedded across the Bristol, North Somerset and South Gloucestershire health and care system. Section 7.1 discusses the Learning Disability Screening Practitioner at Sirona care & health. The aim for this practitioner is to increase cancer screening uptake in the learning disability population. The practitioner works with the learning disability population to understand the barriers to accessing screening and provides training on self-examination.

There remains a high prevalence of pneumonia related deaths. People with a learning disability and/or autism are not categorised as high risk under current guidance to receive the pneumococcal vaccine. Section 8.1 discusses the ambition of Sirona care & health to increase uptake of the pneumococcal vaccine in the learning disability population. Bristol, North Somerset and South Gloucestershire ICB plans to work with One Care, the GP federations that represents and supports General Practice, to increase the offer of this vaccine.

The LeDeR Annual Report (2022) suggested suicide prevalence was high for autistic people. Section 8.5 provides assurance that the Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) Suicide Prevention Strategy is ongoing and includes autism awareness.

These initiatives are just a few examples of the commitment Bristol, North Somerset and South Gloucestershire ICS has in reducing preventable or treatable deaths for our learning disability and autistic communities.

6.2 Comorbidities

Every person with a completed review had at least two comorbidities, one person had eleven comorbidities, as shown in Table 1. Many people had cardiac conditions, such as hypertension and cardiovascular disease, and respiratory conditions, including asthma and chronic obstructive pulmonary disease (COPD). There was a high incidence of people suffering from constipation and many people had mental health conditions such as psychosis, anxiety, and depression. Diabetes and kidney disease were also prevalent comorbidities.

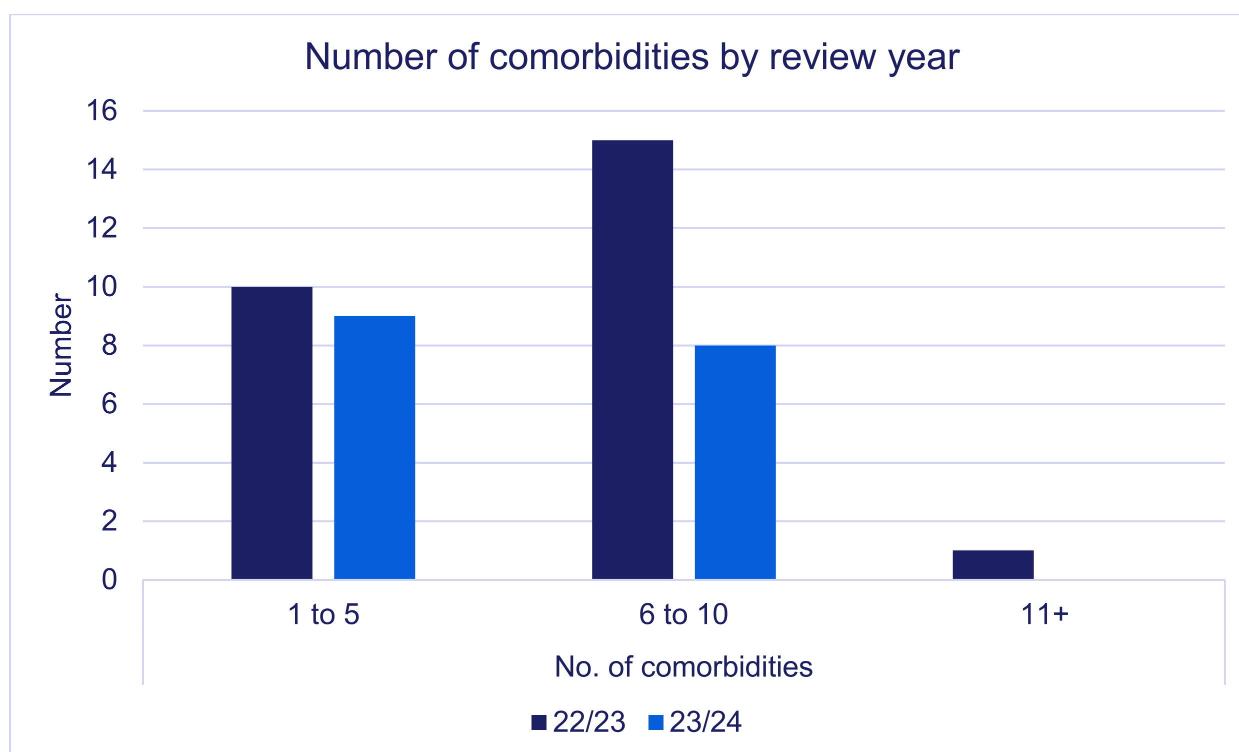


Table 1: Number of comorbidities by review year

People suffering from constipation is a consistent theme. Sirona care & health and both acute trusts using Patient First have all driven constipation awareness initiatives. Section 8 provides further detail, but Sirona is collaborating with care providers to improve constipation awareness. University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) has focused on improving documentation of fluid and stool charts. Lastly, Patient First and North Bristol NHS Trust (NBT) have collaborated to provide constipation awareness sessions focussing on how to maintain good bowel health.

6.3 Place of death

In 2023/24, 66% of people notified to the LeDeR platform died in a hospital setting. The national LeDeR report (2023) suggested 59% of deaths occurred in hospital. The 'other' place of death refers to the person dying abroad. Table 2 shows the trends relating to the

place of death since 2021.Further data validation is required to understand the trend toward dying in hospital.

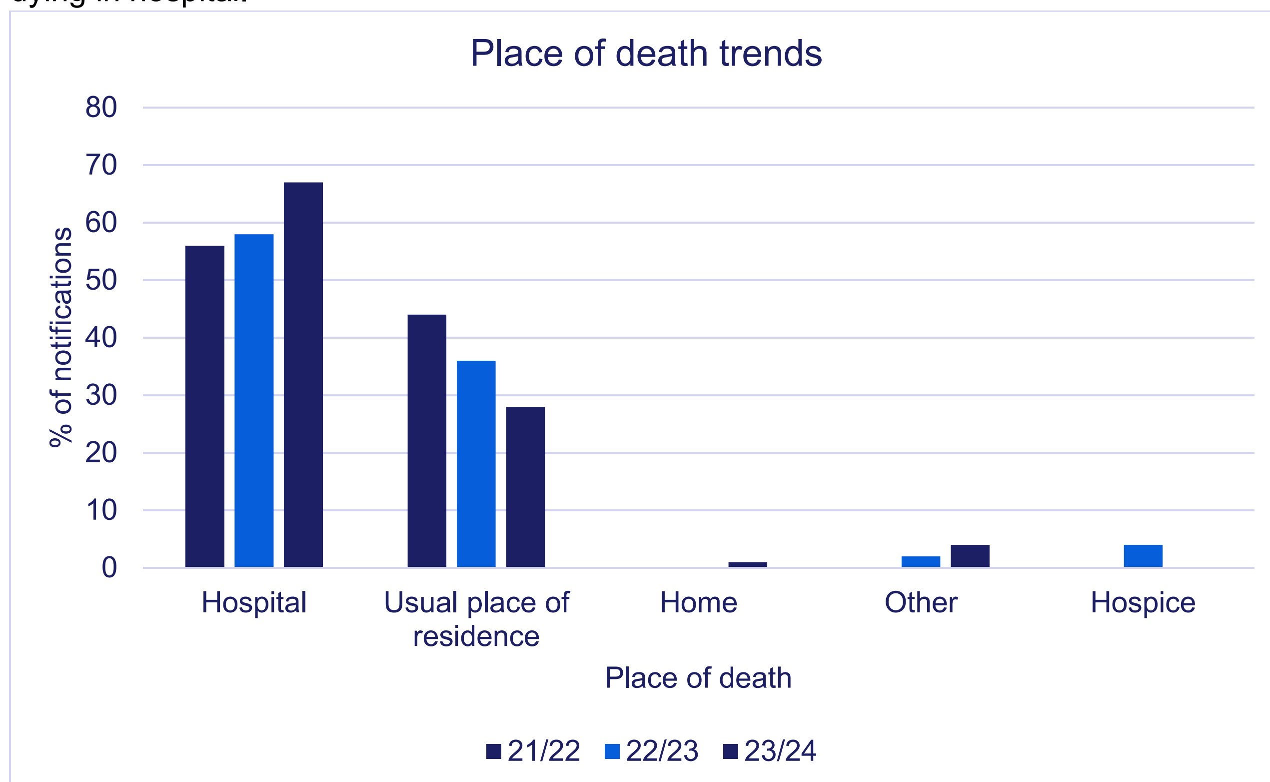


Table 2: Place of death trends

Our acute trusts complete a mortality review for every person who has a learning disability and dies in their care. Initial feedback suggest that people attend hospitals when they are extremely poorly, leading to minimal opportunity to provide treatment. There is a need to support people to remain well in the community. Section 8.1 provides narrative on a Point of Care Testing (POCT) project driven by Sirona care & health. The aim is to provide finger prick blood testing to demonstrate if someone has infection markers. This is beneficial for people who are non-compliant with venous blood tests and are presenting as unwell.

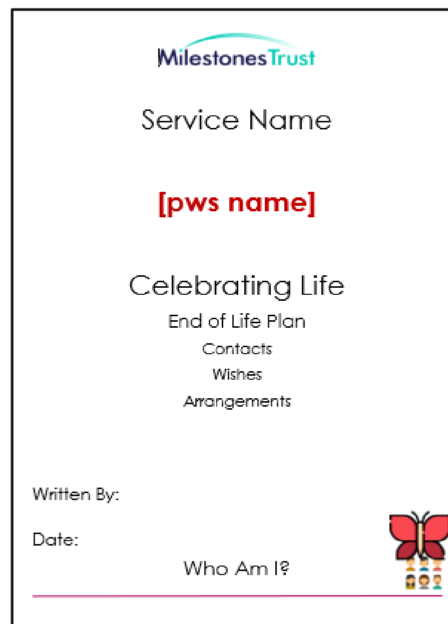
Another initiative to support people in the community is to ensure Care Homes support people to access annual health checks. The clinical lead for learning disability and autism has developed and shared a resource pack for our care homes, which provides information on reasonable adjustments, health action plans and what to expect at an annual health check, please refer to section 7.2.4 for further information.

The LeDeR reviews have praised the continued efforts made by carers and the wider multi-disciplinary team to ensure the person dies at home if this is their wish. There have also been examples of funding being provided proactively and quickly to ensure carers have the appropriate tools to support the person at their usual place of residence.

Many reviews supported the use of the 'Celebrating Life' document created by Milestones Trust. This document covers all areas, from final day wishes, to funeral arrangements and practical advice on who to contact in the event of the person dying. This document allows the person to take control and ensure their voice and wishes are heard.

There have been examples where timely end of life discussions have taken place with the person before their death in the presence of their next of kin. If the person did not have capacity, best interest decisions have been made with the involvement of the next of kin to provide supportive or palliative care.

There have been examples where people have planned their own funerals and care home staff have supported any special requests. Care home staff have also provided support to other residents due to the loss of a well known and loved resident.



6.4 Do Not Attempt to Resuscitate - cardio-pulmonary resuscitation (DNA CPR)

Figure 7 suggests 91% of people whose deaths were reviewed had a Do Not Attempt to Resuscitate - cardio-pulmonary resuscitation (DNA CPR) form in place at time of their death, with the data in Figure 8 demonstrating the percentage of people who had a DNA CPR form completed and followed correctly. Of this 91% of reviews that had a DNA CPR, 77% had a DNA CPR in place prior to their last episode of care. Indicating that doctors, either their GP or hospital team, had initiated this process prior to their last episode of care.

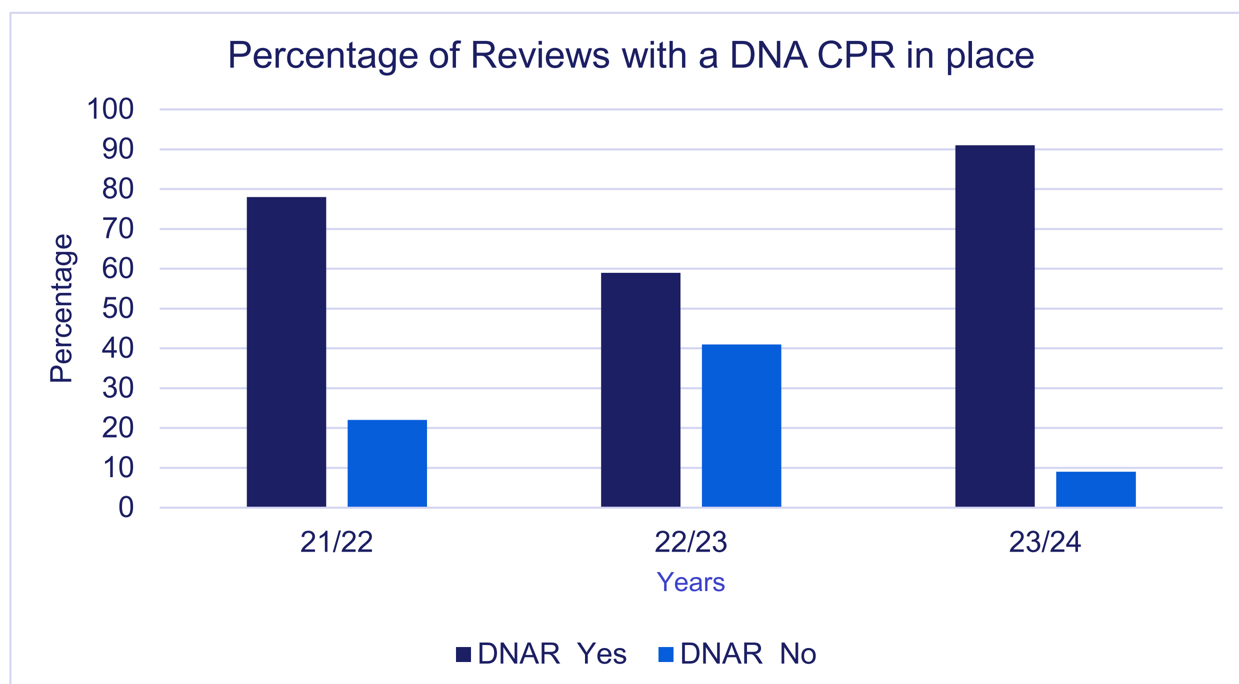


Figure 7: Percentage of Reviews with a DNA CPR in place

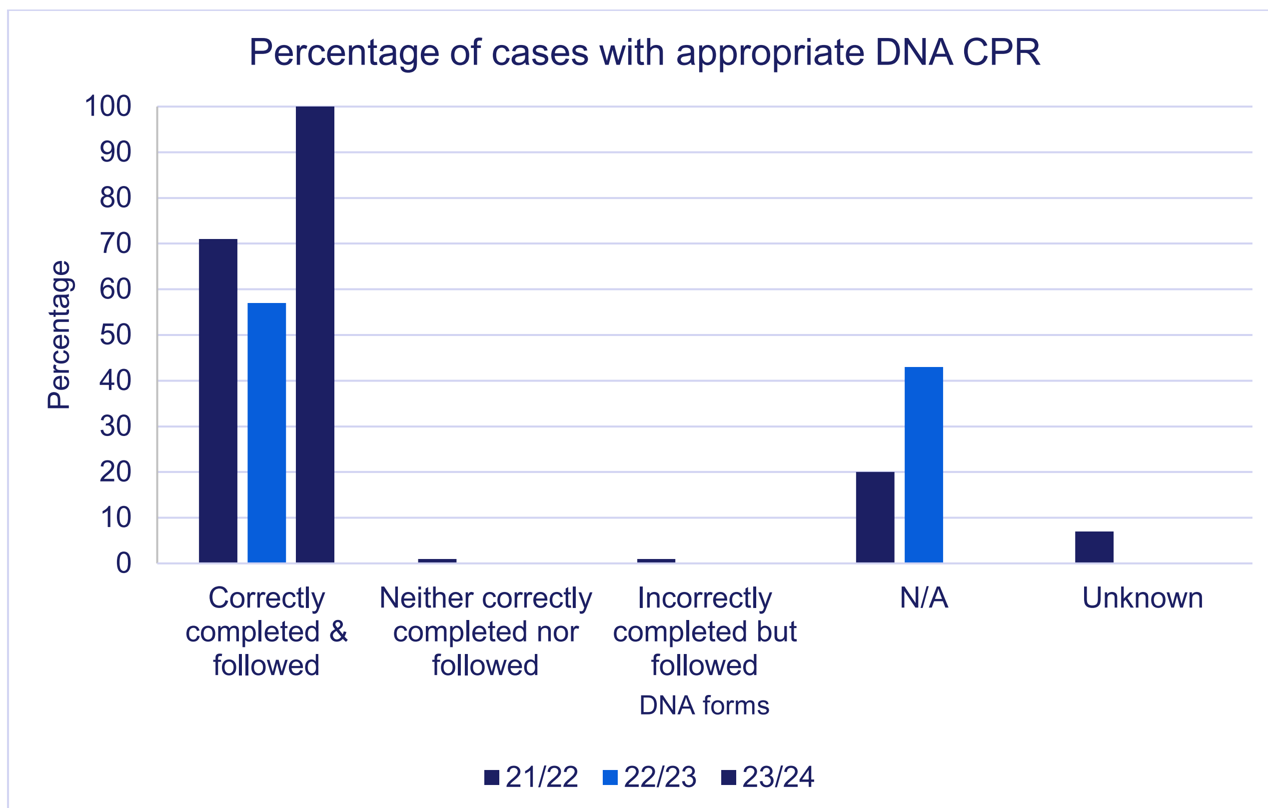


Figure 8: Percentage of cases with appropriate DNA CPR

Our acute trust colleagues undertook a DNA CPR audit for people with a learning disability, this was reported in our LeDeR report 2022/23. Actions completed by the trusts following this audit were:

- Audit findings were shared with the learning disabilities and autism team.
- Review whether poor practice was trust wide.
- Review whether non-discussed DNA CPR forms were discussed with next of kin or Independent Mental Capacity Advocates (IMCA).
- A re-audit was conducted once actions were completed.

The re-audit of fifty people occurred in 2023, 76% of people were for cardiopulmonary resuscitation (CPR) and a ceiling of care was identified in 82% of patients. Three patients had their learning disability considered as a rationale behind a DNA CPR decision, however a learning disability was not recorded as a sole reason for DNA CPR on any forms, this in comparison to 22.2% in the original audit.

The re-audit demonstrated that the majority of DNA CPR decisions were discussed with the person, however, at times this decision was discussed with the next of kin, and for a small proportion, an Independent Mental Capacity advocate (IMCA) was consulted. If the person lacked capacity, evidence of completing a mental capacity assessment (MCA) was not always clearly documented in line with the trust's documentation.

7. Learning from reviews

7.1 Cancer screening

Cancer remains a disproportionate cause of death for our citizens who have a learning disability, and we know that early diagnosis gives people much better outcomes. The Kings College London national LeDeR Annual Report 2021 found areas of concern in primary and community care around a lack of preventative healthcare (screening programmes and vaccinations) and difficulties accessing appointments. Cancer screening rates are lower for our learning disability population in comparison to the general population – see Table 3.

Cancer screening	People with a learning disability uptake	General uptake
Breast	44.3%	63.6%
Cervical	37.7%	69.1%
Bowel	49.6%	71.9%

Table 3: Uptake rates for cancer screening

A learning disability screening practitioner has been appointed to work with people across the Bristol, North Somerset and South Gloucestershire footprint and sits within the Adult Learning Disability Health Service (ALDHS). One of the key aims for this role is to increase uptake of cervical, breast and bowel screening, as well as Abdominal Aortic Aneurysm (AAA) screening and Diabetic Retinopathy for people with a learning disability.

The practitioner has been engaging with people with a learning disability to gain their views on the main barriers to screening, to feed this back to health services and improve pathways and guidance. Training in self-examination, red flags for cancer, and cancer screening will be offered to people with a learning disability across Bristol, North Somerset and South Gloucestershire in 2024 to inform, empower and promote choice in the screening programmes. The training is based on current best practice guidance and will make use of anatomical models as a hands-on training resource to ensure the sessions are interactive, engaging, and educational.

Regular webinars are now offered to care providers and carer networks across Bristol, North Somerset and South Gloucestershire. The aim is to upskill support staff and unpaid carers in spotting the signs of cancer, reporting changes and supporting people with learning disabilities with the National Screening Programmes. Support teams will then be equipped with the knowledge and tools to support their service users with the tests.

The screening practitioner is liaising with primary care and the screening programmes to create a network of key contacts to offer support, strategies, and recommendations to increase screening uptake. Regular meetings are held to discuss support and improvements for the patient group. The ALDHS is developing a pathway for a Health Navigator to offer support to people with a learning disability who has not responded to breast and cervical screening - this is currently being piloted for a small number of Primary Care Networks.

Primary care events are attended by the learning disability screening practitioner. Engagement activities are provided to increase the visibility of the team and encourage discussion about supporting people with a learning disability. Collaboratively with Bristol, North Somerset and South Gloucestershire ICB, the screening practitioner hosted and delivered a webinar for primary care staff on 'supporting people with learning disabilities with screening' in February 2024.

Training is offered to health professionals by 'care navigators' to promote use of reasonable adjustments and personalised health care. Training sessions were completed for aortic aneurysm screening in early 2024. Care navigators will:

- Provide direct support to people whereby their learning disability is their main barrier, deliver education on how to overcome barriers by utilising reasonable adjustments.
- Liaise with the GP to ensure that mental capacity and Best Interests decision making are appropriately documented where decisions are made not to take part in screening.
- Inform all health services where the person has capacity and is declining to take part in screening (data cleansing).
- Refer to the wider Adult Learning Disability Health Service (ALDHS) for learning disability specific support - hospital learning disability liaison, community learning disability nursing teams etc.
- Signpost back to GP if reasonable adjustments need to be considered where mental health or other health conditions are the primary presenting barrier to accessing screening.
- Liaise with the breast screening programme and the practitioners in cervical screening to offer a similar service.
- The learning disability screening practitioner offers remote support to service users, carers or professionals via the Sirona care & health ADHLS Advice and Guidance phone line or email.

7.2 Annual health checks

Earlier in the report, it was highlighted that in Bristol, North Somerset and South Gloucestershire, people with a learning disability are living to an older age compared to the national average, but there is a decline in this older population accessing annual health checks (AHC). The following section describes the initiatives to ensure our older citizens continue to access annual health checks and the support that this can provide them with.

There were 5,297 people registered on their GP learning disability register as of 31 March 2024. At the end of March 2024, 3,851 people, equating to 72.4%, had received their annual health check in 2023/24. However, these figures require further validation as there has been a coding issue identified, which may impact data up until March 2024. This is a national issue resulting in some illnesses being coded incorrectly, which may be resulting in the over reporting of patients into the GP learning disability register.

7.2.1 Deliverables

Percentage of patients receiving a Learning Disability AHC and HAP

We understand the importance of annual health checks (AHC) and the part they play in enabling access to healthcare. We believe if all people who have a learning disability have a high quality AHC, it will improve access to preventative services, detect problems earlier and reduce premature mortality.

Figure 9 indicates a decrease in AHC and health action plans (HAP) for our population comparing 2021/22 to 2022/23, especially in older age groups.

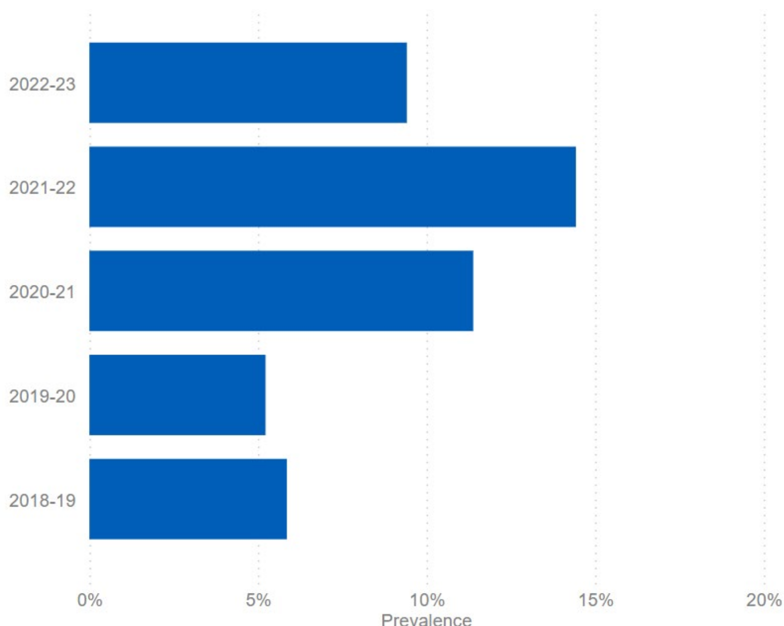


Figure 9: Percentage of patients who have received an annual learning disability check (aged 14 years or over) and have been provided with a health action plan, as of 31 March.

Percentage of patients receiving an AHC and HAP by age in 2021/22

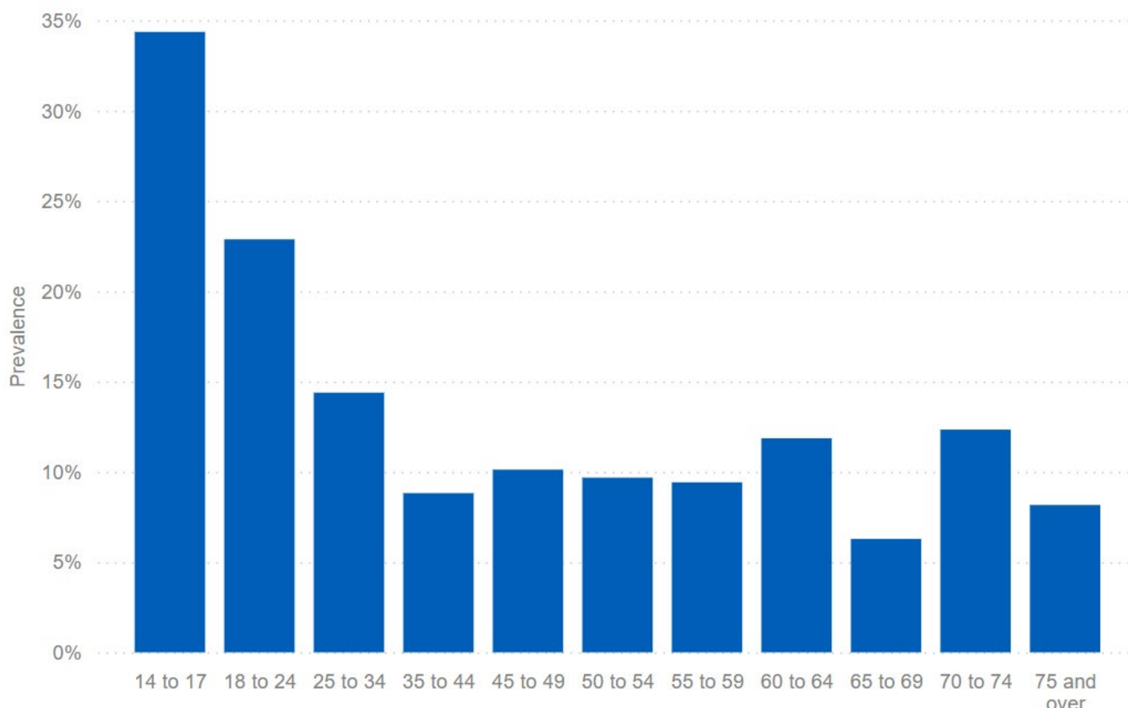


Figure 10; Percentage of patients who have received an annual learning disability health check (aged 14 years or over) and have been provided with a health action plan, 2021/22.

Percentage of patients receiving an AHC and HAP by age in 2022/23

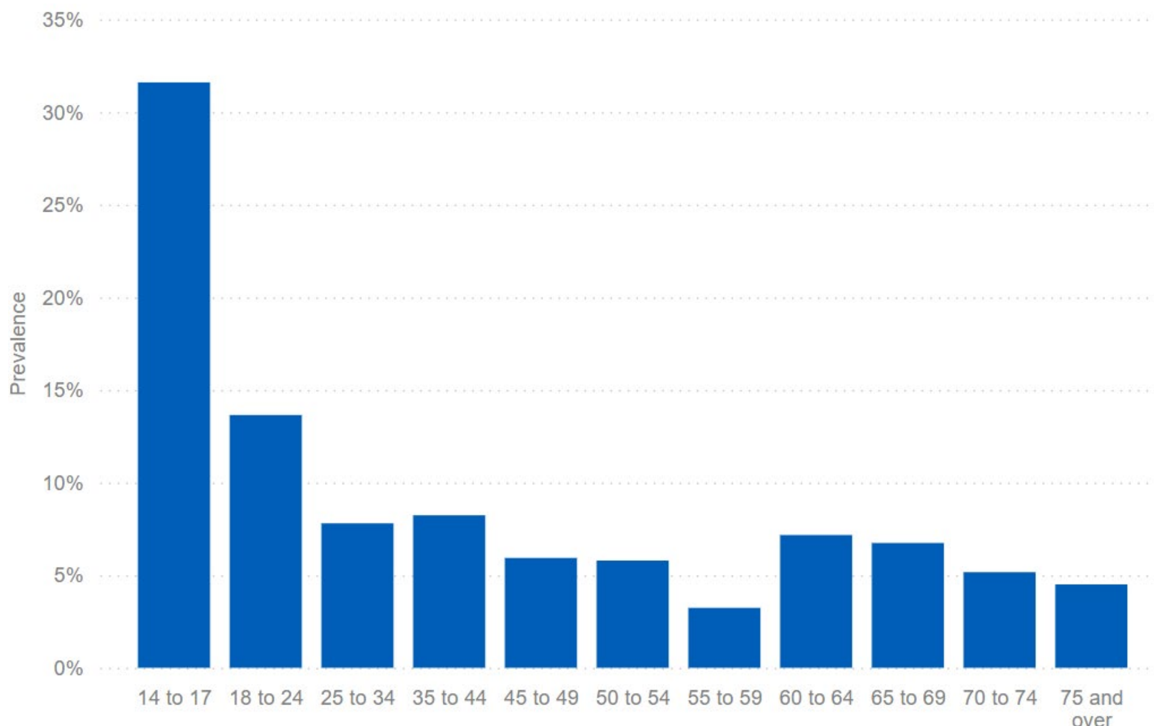


Figure 11: Percentage of patients who have received an annual learning disability health check (aged 14 years or over) and have been provided with a health action plan, 2021/22.

The data in Figure 12 demonstrates 73% of the people who had been subject to a completed LeDeR review received an AHC within their final 12 months, with 37% also having a HAP. The King's College London national LeDeR Annual Report 2022 suggested 72% of the population had received an AHC.

To note: these figures are dependent on the reviewer completing the AHC questions in the review. When GP notes are reviewed the consultation notes will state when the AHC is completed and what tests were involved, however the HAP is stored in a separate area which is not always received when requesting GP notes. Therefore, this data must be treated with caution and the percentage of HAP may increase.

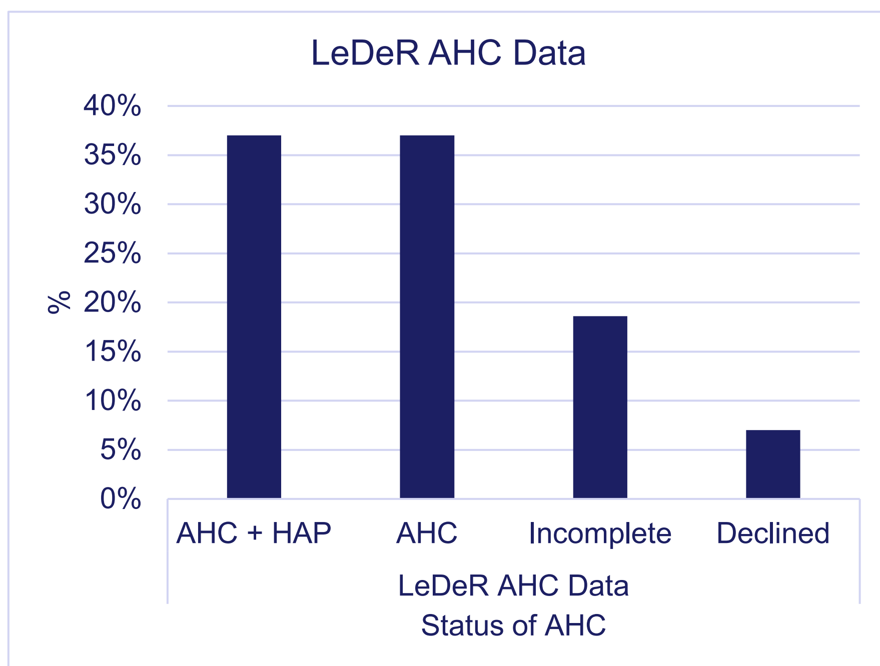


Figure 12: LeDeR AHC Data

The LeDeR AHC data demonstrates the majority of people reviewed under the LeDeR programme received an AHC within the last 12 months of their life. Incomplete reviews include people who were already receiving palliative care or had a prolonged hospital admission.

7.2.2 Training to Primary Care

Our Learning Disability and Autism General Practice Lead continues to provide quarterly training sessions on AHC to GPs. This is to raise the profile of AHC, HAP and the care and support of people with a learning disability and/or autistic people. Teaching has been provided to the system Frailty Network as well as nurses new to General Practice. Targeted screening training has been provided to the GP forum, including AHC and HAP best practice.

Learning disability annual health checks (AHC) are completed in a primary care setting. The Adult Learning Disability Health Service (ALDHS), in conjunction with the Lead Learning Disability General Practitioner, has developed a training webinar package which covers what an AHC is and how to deliver one, including reasonable adjustments, pre-check support and post check follow up (health action plans).

The first primary care AHC webinar was delivered to 60+ primary care practitioners and is scheduled to be repeated annually each November, to coincide with primary care patterns of completion, which tend to be in Q4.

7.2.3 Annual Health Check (AHC) toolkit

To complement the annual primary care webinar series, the ALDHS is working in conjunction with our partners in the South West and has established a ‘call to action’ working group from NHS England’s South West regional team. This will develop a new annual health check (AHC) toolkit for primary care following the removal of the Royal College of GP’s (RCGP) AHC toolkit.

This will provide a comprehensive guide on how to complete an AHC, increasing the consistency of AHC’s completed within Bristol, North Somerset and South Gloucestershire. It will also have interactive links to resources and for onward referrals.

REMEDY is Bristol, North Somerset and South Gloucestershire’s referral pathway and joint formulary platform. The learning disability and autism REMEDY pages are updated regularly, including sections on top 10 tips for transition, a ‘how to guide’ for AHC and health action plans (HAP), epilepsy reviews, syndrome specific checks, pain scales, easy read appointment cards and more.

7.2.4 AHC ongoing projects

Patients missing appointments policy

A theme from our LeDeR reviews suggests people who have a learning disability do not consistently attend healthcare appointments. There are a variety of reasons behind nil attendance, however, we want to raise the profile and challenge ourselves as health professionals to explore reasons behind nil attendance. The LeDeR team are liaising with Bristol, North Somerset and South Gloucestershire ICB safeguarding team to see if we can

create a system-wide missed appointment approach for primary care. The learning disability and/or autism clinical lead is attending the ICB safeguarding conference in June 2024.

Resource pack for care and residential homes
A resource pack for carers within nursing and residential care homes and supported living environments, aims to support them to ensure the people they care for are accessing annual health checks and are on the learning disability register. Information in the pack includes:

- What are annual health checks for people with learning disability?
- Reasonable adjustments
- What happens at the annual health check?
- How to prepare for the annual health check
- Health action plan
- Learning disability register
- Supporting people to live healthy lives.

All information in the pack includes easy read leaflets as well as video clips.

Quarterly Learning disability newsletter for primary care
The quarterly Learning Disability Newsletter for primary care covers hot topics and shares information about annual health checks, health action plans and other relevant information.

7.3 Increasing access for our ethnic minority population

Bristol, North Somerset and South Gloucestershire ICB is collaborating with Autism Independence, a Bristol based organisation, to raise awareness of learning disability register and annual health checks (AHC) within ethnic minority groups. This project took place between January and April 2024.

This project reviewed two areas of concern:

- Raising awareness of annual health checks and the learning disability register.
- Supporting families to access their GP to ensure the person is added to the learning disability register and books/attends an AHC

7.3.1 Raising awareness

Colleagues at Autism Independence created easy read digital posters in five different languages: Arabic, English, Polish, Somali, and Urdu. These easy read posters have been sent to all GPs within Bristol, North Somerset and South Gloucestershre and can be displayed in GPs reception area digital screens as well as paper form.

An easy read health check leaflet has been produced again in the five different languages.

The Accessing Annual Health Checks video has also been created to explain what an annual health check (AHC) is, with advice on what to expect. This video is aimed at people who are from an ethnic minority background and includes a case study of a person who has been supported by Autism Independence to attend their GP and received an annual health check.

Colleagues at Autism Independence visited schools, Hindu temples, Community Centres/Events, Mosques, and shopping malls to ensure the learning disability AHC message was heard at multiple forums.

7.3.1 Supporting families

Colleagues at Autism Independence provided practical support to families, carers, and individuals to navigate the health system. This also supports the person who has a learning disability to get on their GPs learning disability register, as well as support to attend an annual health check (AHC).

Qualitative data gained from the project suggests there are many barriers to people accessing AHC. There is a lack of knowledge from families with individuals not always understanding the importance of the AHC, thinking it is just another GP appointment.

Some people are already on the learning disability register and accessing AHC, once they are in the system in many cases the process works well. However, this is not always the case, the feedback suggests some families do not always receive a written health action plan, and on occasion, once the AHC is completed, the actions are not followed up. Some people who were already on the learning disability register found they received no contact from the GP once they had moved house and therefore changed GP. Moving house can happen frequently due to housing issues.

On occasion, AHC GP reminders were not written in an accessible language, so the individual did not know to attend an appointment. Although individuals may speak English when it is not their first language, this does not avoid communication barriers, including from the written information used. This has been seen in the text messages used by some GP practices to communicate with their patients, this technology can be a barrier and so messages go unread.

Some families are subject to crowded housing conditions and for these families there are competing priorities to meet basic needs, such as housing, food, and education, which may be prioritised over an AHC. Some carers who have childcare commitments alongside supporting a person with a learning disability may struggle to achieve attendance at health and care appointments. Some GP facilities are not ergonomically adjusted to accommodate both a child and person with a learning disability in a comfortable, desensitising

environment. Some carers or families struggle to accept the diagnosis of learning disability, which creates a stigma in some communities. This can also have an impact on carers and families mental health.

7.3.2 Considerations following this project

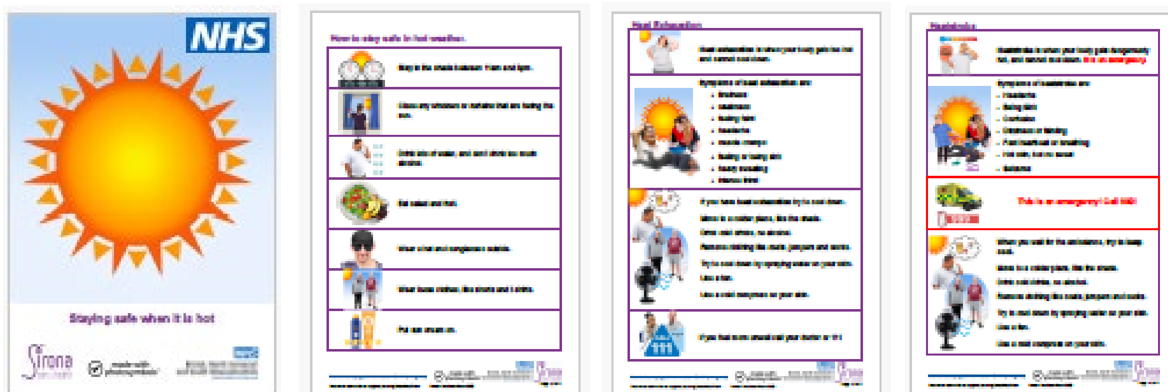
Considerations following this project to increase access for our ethnic minority population include:

- Culturally equip healthcare professionals to make accessing annual health checks easier.
- Ensure GP receptionists access Oliver McGowan Mandatory Training
- GPs to ensure all communication is provided in an easy read format, ensuring the context is relatable to a person from an ethnic minority background.
- Add a reasonable adjustments flag if someone has a learning disability or has communication issues.
- Ensure annual health checks (AHC) are easy for people to access. A suggestion is for GPs or Practice Nurses to provide AHC in community settings. The current process is not culturally equipped to support all young people with a learning disability.
- Improve AHC and health action plan (HAP) awareness in families. Awareness must start earlier than just before the young person turns 14 years old. Professionals from health, education and social care all need to be involved in providing a consistent message.
- Raise awareness with families that a person has a legal right to request reasonable adjustments.
- Healthcare settings must create a safe space for people and parents of young people with additional needs.
- The healthcare workforce must be culturally competent; this concerns the language used and a greater understanding of the stigmas faced by communities and barriers to using technology (e.g. text messages may not be used or read.)
- Secure phase two of this project would entail creating a health campaign in schools, colleges, and health services.
- Healthcare workers must have a better understanding to distinct between a learning disability, autism, learning difficulty, ADHD etc. This project found professionals at times conflate them. There is a need for all professionals to provide accurate information to families and carers to empower them to navigate the health system appropriately.
- Ensure patient groups include people who have a learning disability and are from an ethnic minority background.
- Ensure the Autism Independence Annual Health Check posters are displayed in all GP waiting areas.
- Healthcare information must consistently be available in other languages. Feedback from the public has said there has been a lack of translated information leaflets.

Special thanks to Ifrah Omar and Sharmin Haque who supported multiple families in accessing their GP, and supported families through the AHC process. Also, Nura Aabe and Vanessa Scott for their dedication to supporting people with a learning disability who are also from an ethnic minority background.

7.4 Heat Exposure

Following the [King's College London national LeDeR Annual Report 2022](), which suggested there were a higher number of excess deaths due to heatwaves, Bristol, North Somerset and South Gloucestershire ICB, in collaboration with Sirona care & health, our community provider, have produced an easy read 'heat wave' information leaflet. This has been reviewed with colleagues from People First and an easy read video will also be produced ready for the summer months. This video will be shared with health and social care settings to ensure individuals remain safe during hot weather.



7.5 Reasonable adjustments flag

Recent guidance has stipulated that health and care settings implement the reasonable adjustment standard. This is in two phases - the first phase is to ensure that a reasonable adjustment flag is incorporated in the organisation's IT system. The second phase is for the organisation's current IT system to integrate with NHS England Spine digital flag.

Bristol, North Somerset and South Gloucestershire ICB, in collaboration with Sirona care & health Adult Learning Disability Health Service (ALDHS), has taken the opportunity to raise awareness of reasonable adjustments in an easy read format which can be used by all healthcare settings.

Reasonable adjustments are a key part of ensuring that people with a learning disability and/or autistic people can access healthcare provision. This includes accessing primary care's annual health checks (AHC). To aid primary care understanding of what reasonable adjustments are and how they can be completed, a communication package is being developed by the ALDHS with support from the learning disability and/or autism clinical lead.

Key communications for reasonable adjustments are aimed at staff, patients and carers:

- Staff – guidance to be held in staff areas, behind desks, staff rooms etc. This includes practical examples of reasonable adjustments that can be easily implemented in care to aide people with a learning disability and/or autistic people.
- Patients and carers - guidance on reasonable adjustments to be displayed on practice waiting room screens.

The communication pack will be shared via all communication channels and launched at upcoming webinars.

8. ICS LeDeR Progress

8.1. Sirona care & health ALDHS

Accessible catheter passport

Local LeDeR learning identified a theme around urinary tract infections for people with learning disabilities who have catheters. This was also supported by learning from local clinicians who had identified issues surrounding catheter care.

With the aim of reducing urinary tract infections, the Adult Learning Disability Health Service (ALDHS) have co-produced a catheter passport with Sirona care & health Integrated Network Teams, Experts by Experience and colleagues from urological services in neighbouring trusts. This passport will be used by the Integrated Network Teams, including community nursing. It is in an easy-to-read format for use by people with a learning disability, to support their understanding of what a catheter is, how to care for it and when care is required. It will also be a way of documenting episodes of catheter care.

Why is this important?

- Improved independence with catheter care.
- Improved understanding of catheter care.
- Reduced risk of physical health complications through miss management of the persons catheter.
- Faster access to care should issues arise through appropriate, easy to read sign posting.

Horizon Planning

Theme	What	Why
Improving patient experience of primary care	Secret shopper - GP access – primary care support.	To gather direct feedback from service users on the challenges they face in accessing primary care services across Bristol, North Somerset and South Gloucestershire. On asking People First they identified "One GP" as the most significant barrier to accessing health care.
	Service user voice video	To communicate service user feedback to health care professionals aiding the delivery of training.
Improving the representation of seldom heard ethnic minority groups.	Access and support to health services for people from ethnic minority backgrounds	LeDeR and local review of data highlighted that access to learning disability specific support is low for people from an ethnic minority background. 4% of LeDeR reviews are represented by people with ethnic minority backgrounds. To scope the challenges faced by the local communities of Bristol, North Somerset and South Gloucestershire in accessing health services, to inform quality improvement initiatives to aid access.
Addressing specific clinical needs highlighted from LeDeR	Constipation: improving knowledge within care providers	Constipation remains an ongoing issue for people with a learning disability. Improving awareness within the social care system will enable earlier identification and support through non-medical interventions.
	Pneumonia: increasing pneumococcal vaccine uptake	Pneumonia remains the largest cause of death in the learning disability population. As well as other measures, increasing the uptake of the pneumococcal vaccine will aid the reduction of severe health complications to respiratory illness.
	Sepsis: improving early identification of infection and avoiding overshadowing	Point of Care Testing (POCT) – The ALDHS is at the initial stages of a new project to allow for finger prick (capillary) blood testing for infection markers. This will allow for bloods to be checked when a patient is non-compliant with venous blood tests and is presenting as unwell, source unknown. This will improve the clinical picture to aid decision making and potentially earlier identification of an underlying infection otherwise unknown.
	Heatwaves: reducing the increase of deaths reported during heatwaves	As highlighted in the King's College London national LeDeR report – the ALDHS plans to work with our system partners to identify how we can better support our local learning disability population to keep safe in extreme weather events.
End of life Care	Improve the end-of-life experience of people with a learning disability	Learning from Sirona Structure Judgement Reviews (SJR) indicates that people with a learning disability do not have the same access to end-of-life care planning as the general population, and respect forms are not as proactively completed.

8.2. University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) - Constipation

Constipation was identified as an issue in 80% of LeDeR reviews in Bristol, North Somerset and South Gloucestershire in 2023/24, as reported in our LeDeR annual report 2022/23. It was agreed at the Learning Disability Provider Network that an audit of people with a learning disability and/or autistic people would be undertaken across the acute trusts, looking specifically at the incidences of constipation, whether people were repeatedly admitted for constipation or if constipation featured at death.

A tool was developed, and a retrospective audit was undertaken at UHBW. The tool focused on people admitted for at least 3-5 days.

The findings did not support that constipation was a problem identified at admission, during admission, or at death in the random selection of patients who were identified as having a learning disability and/or autistic patients.

Why is this important?

It was important for staff to recognise that constipation can be challenging to manage when caring for people with a learning disability and/or autistic people, and it can be a significant risk to them. The Trust wished to identify key areas in:

- Gaps of knowledge or skills in reducing the risk of constipation
- Managing constipation
- Sharing information with GPs regarding ongoing management of constipation

Not all autistic people or those with a learning disability can communicate that they are constipated, uncomfortable or have abdominal pain. It is important for staff to be able to anticipate this potential problem and act, accordingly, thus reducing the risk of constipation and its associated complications.

Horizon planning

The constipation audit identified that documentation of fluid and stool charts could be improved. The aim is for the divisions within UHBW, following a focus on improved documentation, to undertake a further audit during 2024. This will demonstrate if the recording of fluid charts and stool charts has improved.

8.3 People First - Flushed with Success

'Feeling Excited and Confident after Achieving Something' – this is how People First feel about their progress and the title relates to constipation, although in a more discreet way.

Often viewed as a simple function, good bowel health can be affected by many factors. People with a learning disability and/or autistic people often face additional barriers and challenges. Constipation

remains highly prevalent, impacting people both physically and mentally.

For some, it can affect relationships, placements, and lead to significant health crises – all of which can have cost implications for services. The topic of constipation requires a different perspective to ensure equity and to prevent diagnostic overshadowing for people with a learning disability and/or autistic people.

Patient First have presented Constipation awareness sessions to:

- the social care team
- the Sirona care & health bladder and bowel service
- managers from a large learning disability provider
- CAFFI health

Social groups in South Gloucestershire were visited, engaging with 31 people with a learning disability who shared their thoughts on poo. Despite initial reservations from some, by the end of the session everyone was discussing their bowel movements.

Throughout the project, there has been interest expressed and requests for advice, including from representatives of NHS Wales, NHS England, Cornwall Partnership NHS Foundation Trust and two large learning disability care providers operating in the Bristol, North Somerset and South Gloucestershire area. Requests for easy read information on subjects related to bladder and/or bowel issues highlights the need for development, as well as creating a national platform for sharing. Patient First have offered awareness sessions, workshops, and carer training.

Horizon planning

Further development of bowel and bladder resources, toolkits and accessible information. This will include the development of individual bowel care plans and promoting the use of these with care providers.

Evaluation forms evidence the added value to addressing constipation for people with learning disabilities and are relevant and transferable to other ‘at risk’ groups. By linking with other areas, we hope to share best practice.

Locally, Patient First would like to work collaboratively with schools and colleges to increase awareness at an earlier age, to prevent reinforcement of barriers that emerge over time by promoting a more healthy, balanced approach to conversations.

8.4 North Bristol NHS Trust (NBT)

North Bristol NHS Trust (NBT), in collaboration with Patient First, hosted a 'Poo Matters Week' as constipation management was one of the highlighted themes in structured judgement reviews and the LeDeR report.

Why does this matter?

This is a key theme in LeDeR reviews, and NBT wanted to raise awareness of bowel charts, food and fluid monitoring and its importance to staff. NBT co-produced a constipation training week with People First and this was a huge success.

8.5 Avon and Wiltshire Mental Health Partnership NHS Trust (AWP)

Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) are conducting an audit to identify any autistic patients and/or patients with a learning disability documented in their electronic patient record. This will enable the Trust to identify if those inpatients have a completed hospital passport and have had reasonable adjustments included in their care plan. Once this has been completed, the Trust will be able to undertake follow up training with their clinical teams about the importance of recording reasonable adjustments and the need for hospital passports.

The Trust has now ensured that their Reducing Restrictive Interventions training includes learning about working with autistic people and/or people with a learning disability, including the use of positive behavioural support. Policies have been updated to reflect this and are in line with the Reducing Restrictive Practice and Positive Behavioural Support Trust-wide strategy.

AWP's Suicide Prevention Strategy is ongoing and includes autism awareness. The LeDeR process is being reviewed to ensure it is aligned with Patient Safety Incident Response Framework (PSIRF) delivery within AWP.

Learning Disability Continuing Professional Development facilitators are in post to support the delivery of training and learning for the AWP workforce. This includes, physical health, LeDeR, reasonable adjustments, communication, and mental health.

Fifteen trainee learning disability nurses are being supported through further education routes, enabling an increase in workforce supporting people with learning disabilities and people who are neurodivergent across AWP.

9. Summary

All system partners in Bristol, North Somerset and South Gloucestershire Integrated Care System (ICS) are committed to drive constant improvement in the experiences of autistic

people and people with a learning disability and improve both their health outcomes and their experience of health and care services.

This is our fifth LeDeR annual report, it demonstrates our growing depth of understanding of the needs of our population and our continued commitment to improvement. We are proud to present this report, showcasing our ongoing improvement activity, as well as our ongoing commitment to ensuring robust governance to deliver high quality reviews. Through that process, we continue to take the learning from our LeDeR reviews and work in partnership to deliver quality improvement, co-produced with Experts by Experience and supported by many key voluntary and community sector organisations.

Having successfully transitioned the LeDeR work programme over to a new team within the ICB and aligning it with our wider patient safety and system governance, we have identified some key areas of focus for 2024/25. These include ensuring that we have sustainable arrangements in place for LeDeR reviewer capacity, to complete the reviews in a timely way, as well as developing our data platform.

We will continue our quality improvement through co-production with Experts by Experience and system partners, strengthening our links with the co-production team hosted by Bristol City Council and our Directors of Public Health through our Strategic Prevention Oversight Group. This will ensure that the themes and trends identified through the LeDeR programme are viewed alongside the rest of our mortality data. We will also share themes and trends with the Mental Health and Learning Disability Health and Care Improvement Group, ensuring our learning from LeDeR influences wider strategic decision making.

As a system, we remain committed to this service improvement programme and ensuring that we address health inequalities experienced by people who have a learning disability and/or autistic people. This report has provided an opportunity for partners to share their excellent work and illustrates how committed they are to improving the lives of people with a learning disability and autistic people who live in our community.

We would like to thank everyone involved for the ongoing commitment and hard work to this amazing group of people that we serve.