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

NHS
Bristol, North Somerset and South Gloucestershire
Integrated Care Board

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

1 April 2024 to 31 March 2025

Contents

1. Executive Foreword

This report presents an overview of the “Learning from Lives and Deaths – People with a learning disability and autistic People (LeDeR)” service improvement programme for the Bristol, North Somerset, and South Gloucestershire Integrated Care Board (ICB).

Initiated by NHS England, the LeDeR programme aims to enhance the health and wellbeing of people with learning disabilities and autistic people. This national initiative provides a structured framework to review the care of people who have died, ensuring that valuable insights are gained from their care experiences and causes of death.

Within Bristol, North Somerset, and South Gloucestershire, we are committed to continuously improve health and care experiences for people with learning disabilities and autistic people. The LeDeR review process enables us to gain a deeper understanding of an individual’s care journey, alongside the circumstances surrounding their death. This insight informs our ongoing quality improvement efforts, driving us towards our goal of helping people live longer, healthier lives.

This is the sixth annual report published by the Bristol, North Somerset, and South Gloucestershire ICB. It covers LeDeR reviews conducted between 1 April 2024 and 31 March 2025. Some reviews pertain to individuals who passed away in earlier years but were reviewed during this reporting period.

Previously, maintaining timely review completion was a challenge due to limited reviewer capacity, resulting in a backlog of incomplete reviews. To address this, we undertook a procurement process to establish a sustainable reviewer workforce. Since establishing this team, our review performance has steadily improved month on month. Earlier annual reports can be accessed on the ICB LeDeR webpage. The primary purpose of this report is to share key themes and trends identified through LeDeR reviews and to highlight learning and actions taken to enhance services for people with learning disabilities and/or autistic people.

In 2024/25, our focus remained firmly on improving performance, now that this has resolved in 2025/26 the focus will be driving service improvements. System partners are fully engaged with the LeDeR programme, demonstrating a strong commitment to addressing health inequalities and improving outcomes for this population. Data, including thematic insights from LeDeR reviews, is regularly shared with our Mortality Group and Strategic Prevention Oversight Group, ensuring robust oversight is in alignment with broader health inequalities initiatives.

Our improvement programme continues to benefit from investment and collaboration with system partners as well as voluntary and community sector colleagues. While we are proud of the progress achieved through a culture of continuous improvement, we acknowledge there remains significant work ahead.

Key achievements this year include:

- A strengthened primary care focus on raising awareness of the Learning Disability Annual Health Check (AHC) and Health Action Plan (HAP).

- Collaboration between primary care and the ICB Safeguarding Team to implement a ‘Was Not Brought’ policy.
- Joint initiatives involving the ICB, Local Authorities, and Avon Fire and Rescue Service to increase awareness of hoarding.
- Supporting the voluntary and community sector to deploy health navigators, aiming to better understand and reduce barriers to accessing the primary care learning disability register and annual health checks—particularly for citizens from global majority backgrounds.
- Developing a new Health Passport that is now widely used across BNSSG.

This report highlights the outstanding efforts of all partners involved and reflects their dedication to improving the lives of people with learning disabilities and autistic individuals. We extend our sincere gratitude to everyone contributing to this vital work and serving this remarkable community.

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.
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 reducing health inequalities and preventing premature deaths within this population.
ReSPECT	These forms are designed to record a person’s preferences for emergency care and treatment, particularly when they are unable to express their

Term	Definition
Recommended Summary Plan for Emergency Care and Treatment.	wishes themselves. This form replaces the Do not attempt cardiopulmonary resuscitation form.
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.
MUST Malnutrition Universal Screening Tool	A five-step screening tool to identify adults, who are malnourished, at risk of malnutrition or obese. It also includes management guidelines which can be used to develop a care plan.

3. LeDeR programme governance and oversight

The LeDeR governance structure continues to deliver robust governance to support this work programme ensuring 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.

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 Contact. These 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 has delegated chairing responsibilities to the Deputy Chief Nurse for 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 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 are set for the system reflect lessons learned from LeDeR.

3.2 Integrated Care System Co-Improvement Group

The aim of the recently formed Integrated Care System (ICS) Co-Improvement 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 and is chaired by a representative of Bristol City Council.

The LeDeR Governance Group identifies specific areas of focus to the ICS Co-Improvement 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 have reviewed the themes and trends following LeDeR reviews and have been supporting improvements to increase the uptake of the pneumococcal vaccine for our learning disability and autistic population. Progress from this group will be discussed in Section 6.1.1.

3.3 Quality Insight and Oversight Group

The Quality Insight and Oversight Group oversees all completed 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.

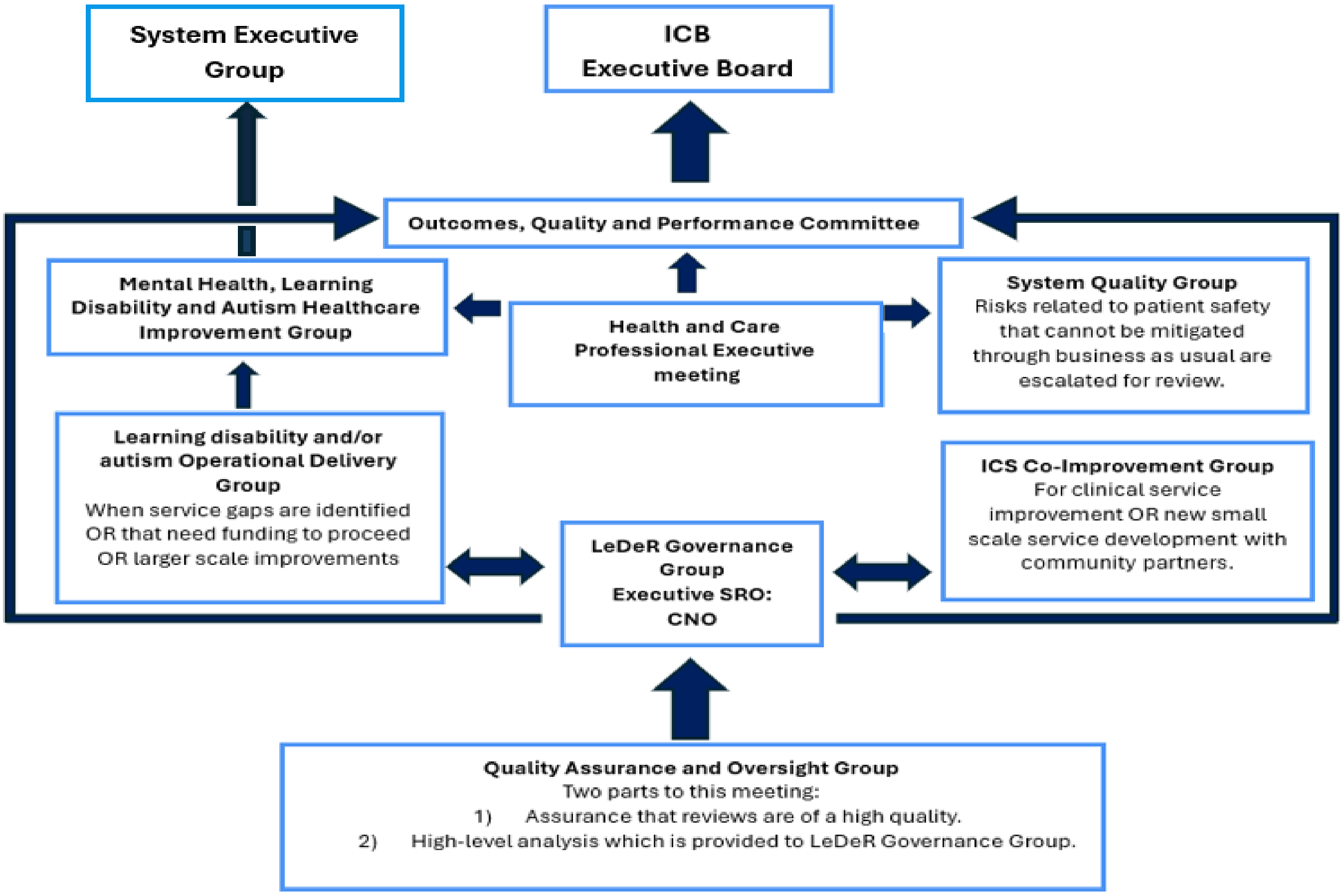
3.4 The LeDeR Team

The Local Area Contact (LAC) oversees the allocation of cases to trained LeDeR reviewers. In 2024 we pursued a procurement process to secure reviewer capacity, and we are now using an agency to fulfil this contract. The LAC meets with the Senior Reviewer and agency Contract Manager regularly to monitor progress and completion of reviews. The LAC completes quality assurance of all completed LeDeR reviews. The LAC prepares papers for the LeDeR Governance Group and Quality Insight and Oversight Group. LeDeR updates are provided to the ICBs Learning Disability and/or Autism Operational Delivery Group and the Outcomes, Quality and Performance Committee. The LAC also sits on the ICS Co-Improvement Group and feeds this group data from LeDeR reviews.

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. The new agency commenced work with the ICB in October 2024 and has addressed the backlog of reviews as well as meeting current demand. The new agency includes a Senior Reviewer who supports reviewers to complete reviews of a high quality as well as providing pastoral support when required. The Senior Reviewer attends the Quality Insight and Oversight

Group understanding what the local area priorities are and themes following completed reviews as well as discussing further improvement opportunities.



4. LeDeR Programme Performance

Since embedding a new reviewer agency, performance has dramatically improved. Deaths of children and young people under the age of 18 who have a learning disability and/or autism 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 third 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 2024 to 31 March 2025	86
Total notifications not yet assigned to a reviewer	0
Total number of reviews currently in progress	33
Number of reviews currently on HOLD	4
Completed and closed reviews in 2024/25	86*

Figure 1.0 *51 reviews that have been completed and closed are pre-April 2024 reviews.

Of the 86 deaths that we were notified of, 83 people had a learning disability and three were autistic people.

The number of deaths notified onto the LeDeR platform continues to increase annually. There is no clear evidence supporting causation; however, we are assuming it is because awareness of the LeDeR programme continues to grow, and thus more professionals are notifying onto the platform. The role of the Medical Examiner (ME) became a statutory requirement in September 2024, ensuring all non-coronial deaths are reviewed, including all deaths of individuals with a learning disability and/or autism. Medical Examiners reviewing all deaths adds an extra layer of oversight, potentially increasing notifications by prompting further discussions.

4.2 Completed Reviews

Completed reviews and Key Performance Indicators	**2023/24**	**2024/25**
Number of Notifications	75	86
Number of Closed Completed Cases	43	86
Allocation of reviews within 3 months of notification (excluding on HOLD reviews)	6.6%	62%
Completion of reviews within 6 months of notification	6.6%	32%
Quality Assurance check of reviews by LAC within 2 weeks of completion.	97.7%	88.4%

Figure 1.1

Of the 86 completed reviews, 59% of reviews were notified pre-April 2024. Resolving the backlog of reviews had been a priority of the ICBs and we have successfully achieved this in 2024/25. **Fig 1.1** demonstrates the improvements in performance over the last two years. This is due to the ICBs commitment to people with learning disabilities and/or autistic people, their families and loved ones as well as the ICB's dedication to the LeDeR programme. To note, reviewers have prioritised the backlog of reviews, ensuring families' grief is not prolonged by the LeDeR programme. Consequently, key performance indicators have been affected due to this prioritisation. The ICB has increased confidence that performance will improve further into 2025/26 now that additional capacity has been procured. An ICB partner organisation, Sirona care & health, continued to support the LeDeR programme through 2024/25 and in January 2025 used their own funds to support eliminating the backlog of reviews.

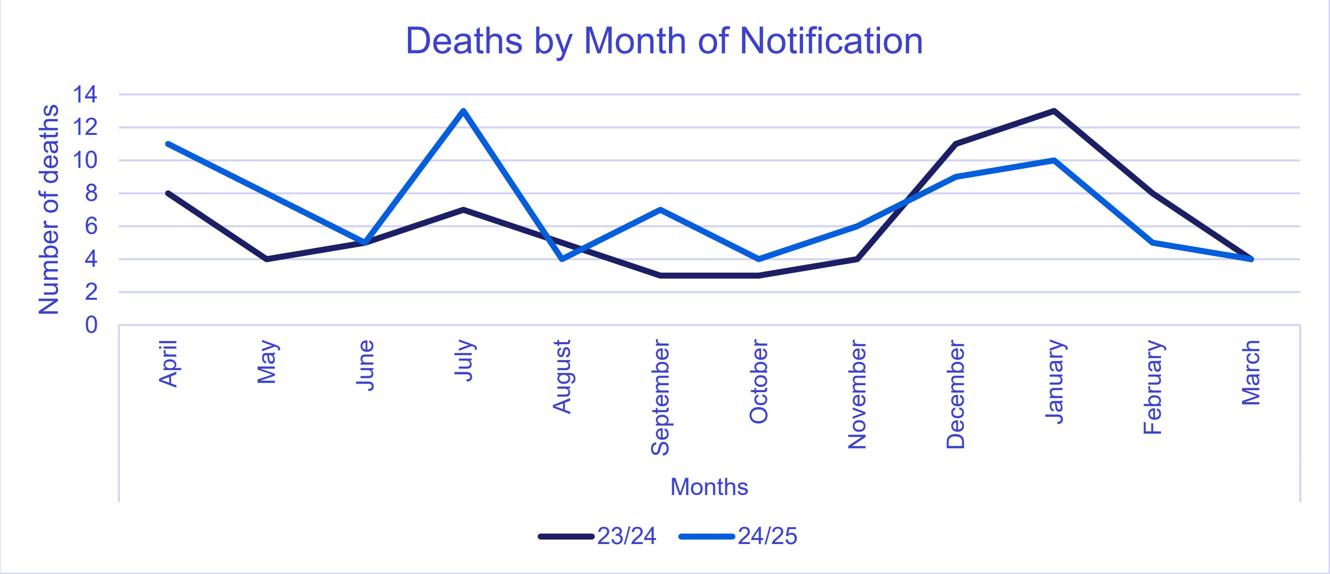


Figure 1.2: Deaths by month of notification 2023/24, 2024/25

There have been three spikes in the number of notifications; April 2024, May 2024 and January 2025. The last published national LeDeR report was in 2022, this is because the national team have been focussing on publishing the NHS 10 Year Health Plan. 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, created an easy read heat exposure leaflet. To accompany this leaflet a short video has also been made[1].

The causes of death for months with additional notifications have been reviewed, and 42% of these deaths were contributed to pneumonia, aspiration pneumonia or a chest infection. The pneumococcal and influenza vaccine are two key inoculations that can reduce the harm from these respiratory infections. Vaccine uptake is a local priority for reviewers to

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[1] Staying safe when it is hot

include when completing LeDeR reviews. From the completed reviews Covid and influenza vaccines are regularly administered to people who have a learning disability, however, up until January 2025, national guidance for the pneumococcal vaccine did not include people who have a learning disability (only if the individual is also at increased risk of aspiration). We are keen to work with system partners to replicate the success of Covid and influenza vaccines with the pneumococcal vaccine now that it is available to persons with a learning disability. The ICB, along with system partners, has a key focus on how we can support more people to access and receive the pneumococcal vaccine. This programme of work has been delegated to the ICS Co-Improvement Group and more information can be found in Section 6.1.1.

4.3 Improving oversight and performance

In 2023/24 the LeDeR team reviewed every aspect of the LeDeR process, identifying improvements along the pathway, for example revising the letter sent to GPs, making it clearer about what is required to support a high-quality review. Consequently, we have seen improvements in the timeliness of appropriate paperwork provided by system partners. This year we have endorsed this process, making adjustments so that we are responsive to the needs of the people we serve. An example is working with the Medical Examiner so that they can inform families of the LeDeR programme earlier and what it entails before reviewers make contact. This has meant families are already aware of the LeDeR programme and are prepared for a reviewer to contact them.

The Senior Reviewer of the agency attends the LeDeR and Oversight Panel and this means that they hear feedback immediately and have a better understanding of our local priorities. This leads to a better service to the families involved, better professional relationships with our partners but also an improved quality of review.

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.

4.4 LeDeR reviews: thematic analysis (April 2024 to March 2025)

A thematic analysis of the reviews completed between April 2024 and March 2025 using Braun and Clarke's (2013) methodology demonstrated the following themes with sub-themes:

Theme	Sub-Theme
1) Barriers to engaging with support	Fear of procedures Anxiety Self-neglect Unwise decision making when have capacity Strong will to make own decisions Fear of professionals Hoarding

2) Support systems	Parental/Carer advocates Carer's assessments Transition between paediatrics and adult services Package of care Carer support
3) Integrated Care	Care plans Multi-disciplinary team working Mental Capacity Act (MCA) /Deprivation of Liberties/Best Interest Independent Mental Capacity Advocate (IMCA) Health passport Discharges from secondary to primary care Primary Care Secondary care Community care provision Communication between professional teams Learning disability teams
4) Safe, continuous care	Missed appointments Continuity of care Capacity concerns Care home support Local Authority care reviews Safeguarding input

Areas of service improvements are prioritised based on the themes and data that are identified through the LeDeR reviews, aligning with the Patient Safety Incident Response Framework (PSIRF) methodology. Themes following LeDeR reviews will support the development of specific quality improvement, such as those described in section 7 of this report.

4.4.1 Barriers to engaging with support

The families and carers who supported LeDeR provided examples of how the deceased interacted with health and social care services, providing personal experiences of challenges some faced. Findings from the reviews suggest some people mistrusted healthcare providers and therefore were reluctant to follow advice from professionals. Other people refused to attend appointments and disengaged with healthcare services. Some had a fear over certain interventions, for example some were needle phobic leading to not accepting vaccines. Whereas others had sustained and frequent poor experiences with healthcare organisations leading to anxiety and fear of attending healthcare providers. Reasonable adjustments, use of easy read materials, the use of health passports and an increase of healthcare staff attending Oliver McGowan Mandatory Training will all support improving experiences for people who have a learning disability and/or autistic people. Conversely many families praised the care and support their loved ones received with many relatives sharing they could not fault the care that was provided.

Findings also indicated that some individuals with a learning disability or autism, who had capacity to make their own decisions, occasionally made choices that were viewed by others as unwise. Examples include self-discharging against medical advice, not waiting to be seen or walking out of healthcare appointments. North Bristol Trust (NBT) is engaging with people who do not comply with pressure relieving treatment to see whether compliance can be improved. Learnings from these engagement sessions will be shared with the LeDeR team to see if we can improve compliance within other healthcare settings and other medical interventions. Many reviews suggested carers used a behaviour plan which supported people when they displayed challenging behaviours, by using techniques to reduce anxieties.

Hoarding is an emerging theme following reviews. The NHS definition[2] of hoarding is “where someone acquires an excessive number of items and stores them in a chaotic manner, usually resulting in unmanageable amounts of clutter. The items can be of little or no monetary value.” Hoarding is a condition and is often associated with self-neglect. Hoarding is a fire risk and can make providing health and social care more challenging if care is provided in the person’s home. Primary care colleagues have been working with the Fire and Rescue Service to improve advice provided to GPs. More information can be found in Section 7.1.

4.1.2 Support Systems

From the completed reviews it was very clear the importance of family and carers to people who have a learning disability and/or autistic people. Family members were often a keen advocate for their loved one and would often participate in best interest decision making and multi-disciplinary team meetings. However, there were examples of where next of kin were not informed of care planning arrangements. Examples were provided including a family not becoming aware of a safeguarding referral, and information not being shared with family when they held lasting power of attorney for health and welfare.

Some of the deceased had lived, in care facilities for most of their lives. They had a good quality of life and there were multiple examples of how carers had supported the person and their family. Examples included, carers regularly attended outpatient appointments with people who had learning disabilities as well as supporting them during hospital admissions. Carers often stayed with the person throughout their hospital stay. Some people could not communicate their needs verbally, so would need carers to anticipate their needs; this happened successfully and frequently. An example of carers surpassing expectations is arranging provision for a bed for a family member after they noticed they were sleeping on the floor. There were also examples of young adults receiving transition planning such as receiving respite stays in a local hospice as part of their move from paediatric to adult services. These additions not only supported the person but also eased concerns for their loved ones.

Many people had a health passport that was completed and updated in the community and taken into hospital during an admission. This information was invaluable and empowered health care staff to better support the person. A new health passport has been created to be used across all health and social care settings; more information can be found in Section 8.5.

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[2] Hoarding disorder - NHS

There are examples where people with a learning disability and/or autistic people did not receive a package of care. Some of these lived at home with parents or siblings and provides an insight into the minimal health and social care some families receive or wish to receive or are made aware of whilst caring for a person who has a learning disability and/or autism.

4.1.3 Integrated Care

Evidence was provided in reviews of the different care plans used to support people, these included National Early Warning Score (NEWS2), a tool developed to detect and respond to clinical deterioration, RESTORE2 a tool to detect soft signs of early deterioration, bowel charts, speech and language, diabetic and epilepsy charts. All these care plans monitor changes in people’s condition enabling appropriate intervention when needed. The epilepsy charts included emergency treatment plans enabling the person to receive timely care whilst in the community. However, there were occasions when, for instance, the person suffered from constipation, but health care staff did not always initiate a bowel chart so monitoring of bowel movements was not always recorded. The impact of this being likely delays in treatment.

Multi-disciplinary team working was apparent in many reviews. This joined up working ensured the person received holistic, timely care. Team working was present both in the community and secondary care settings. The person’s GP was integral to coordinating care. There were many examples of the GP acting on Carer’s concerns promptly.

The Acute Learning Disability Team were regularly involved with people who required a hospital admission. This team supported the person and their families and carers making recommendations such as reasonable adjustments, as well as ensuring mental capacity assessment discussions happened prior to treatment decisions. On a small number of occasions, there was a delay in the Acute Learning Disability Team being made aware of the person’s hospital attendance. This did not impact the treatment that the person received but may have made their admission more comfortable.

Under the Equality Act 2010, organisations have a legal duty to make changes in their approach or provision to ensure services are accessible to people with disabilities as they are for everyone else which is called reasonable adjustments. Mencap[3] define reasonable adjustments as changes that organisations or individuals providing services must make to prevent someone's disability from putting them at a disadvantage compared to non-disabled people. In the reviews, multiple examples were provided whereby the person received reasonable adjustments. Examples included provision for double appointments, showing videos to help the person engage with activities of daily living, open visiting hours for family, medications adjusted to support the person’s ability to self-administer and comply with the person’s own preferences. However, there were instances whereby health care staff were not aware of the person’s reasonable adjustment request even though it was documented on the organisation’s IT system.

Adherence to the Mental Capacity Act was inconsistent. Whilst many Mental Capacity Assessments were completed liaising with appropriate people and documented correctly.

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[3] About reasonable adjustments | Mencap | Easy Read

On other occasions, advocates for the person were absent, with poor documentation of assessment. If the person does not have appropriate next of kin support, Independent Mental Capacity Advocates (IMCA) can be sourced. Review findings suggest the responsibility of the appropriate professional to instigate the Mental Capacity Assessment was unclear and IMCA were not always used. On one occasion a Mental Capacity Assessment for a Deprivation of Liberties was incorrectly completed as no patient identifiers were included. The use of an IMCA was raised in reviews specifically the support they provided when dealing with complex decisions. Learning Disability Teams were another source of support who often raised the need of Mental Capacity Assessments with healthcare professionals. The ICB's Learning Disability and Autism Clinical Lead provides quarterly webinars to Primary Care which includes the Mental Capacity Act, raising awareness of this vital element. The Oliver McGowan Mandatory Training, which has and continues to be successfully attended by provider organisations, also covers the use of the Mental Capacity Act.

There were several instances where discharge from secondary care was suboptimal, or individuals experienced difficulties accessing community care post-discharge. For example, care home staff often found it challenging to seek timely advice from local agencies on how to support individuals being discharged back into the community. Care homes also reported difficulties in engaging with community services to obtain appropriate equipment or support.

In some cases, individuals with mild learning disabilities struggled to access mainstream healthcare services. One example involved a palliative patient discharged home, whose family faced significant challenges providing adequate care due to limited support from community networks. A family shared that they had to "battle to receive annual funding for equipment," while a care home described the "red tape" and barriers in securing essential equipment through community support.

Secondary care teams also highlighted delays in identifying suitable care providers and arranging funding, which in turn delayed safe discharge planning. Care homes and GPs similarly reported difficulties accessing community services on behalf of patients. In one case, the lack of urgent podiatry appointments led a GP to escalate the issue to the vascular team at the acute hospital.

Recognising, accessing and treating pain was a frequent finding. Some people who have a learning disability and/or autistic people are non-verbal. Pain assessments were not always made accessible to people who did not communicate verbally. Pain assessments were not completed regularly, and sufficient pain relief was not always prescribed. One care home shared the person was "discharged with insufficient pain relief following their fall". University Hospitals Bristol and Weston (UHBW) complete pain audits to better understand assessment, documentation and treatment for pain; more information can be found in Section 8.3.

Many of the people who were reviewed attended ophthalmology and dentist appointments, with many of these appointments provided in the person's usual place of residence. Routine ophthalmology and dentistry appointments are imperative to prevent concerns from escalating. It is widely considered that good dental hygiene can reduce early onset of dementia as well as some cardiac diseases. Nationally, accessing NHS dental care is very challenging including for people with learning disabilities and autistic people.

4.1.4 Safe, Continuous Care

Autistic people and people who have a learning disability on occasion ‘missed’ appointments. Missed appointments occur for multiple reasons including digital exclusion. A small number of reviews shared that GPs had sent text messages out to the person either inviting them to appointments or offering vaccines/screening. In these cases, the people concerned were unable to read and these messages went unread. It is important to ensure GP surgeries are aware how best to contact patients who require reasonable adjustments. In a small number of reviews care homes did not promptly reply to primary, community or secondary care appointments. In two reviews this led to the District Nurse team rejecting a referral due to no communication from the care home. Care homes on occasion did not respond to Annual Health Check (AHC) appointments as well as invitations to vaccinations and screening appointments. Health professionals did not always follow up with the patient or carer why the appointment was missed or why there had been no response to health screening/vaccine programmes. In response to this emerging theme the ICB’s Learning Disability and Autism GP Clinical Lead collaborated with safeguarding colleagues to produce a ‘Was Not Brought’ policy which was shared with primary care. Further information can be found in section 7.3.4.

Continuity of care was important to the people reviewed. Measures were taken by health and social care staff to maintain continuity, for example having the same GP treat the person. This included regular care home reviews by the same primary care provider, which is an established practice in Bristol, North somerset and South Gloucestershire. Families and care providers have shared excellent feedback about regular GP contact. Care home staff who are familiar to the person being present at appointments or during hospital admissions. Hospital staff listened to carers when the person was admitted into hospital. One example shared “a side room was provided so that carers could support him better and sensory lighting could be used”. Without continuity of familiar people, anxieties could increase, and the person could display challenging behaviours. The Community Adult Learning Disability Health Service (ALDHS) are another great support to the person with a learning disability but also for their families and carers. An example is when the person was provided palliative care, the ALDHS arranged significant support to family members.

Social workers keenly supported the person in the community. There were many examples whereby social workers supported the person to maintain independence, including providing deputyship for finances. Social care were responsive to the person’s changing needs. A provided example: the person required additional care which the current care provision was unable to provide, therefore the social worker, visited multiple suitable care homes until the person found one they liked. Social workers regularly reviewed the person’s social care package, and a family member shared “the care commissioned by the Local Authority was supportive”. Health and social care teams were prompt to complete a safeguarding referral if they had concerns about the person and any actions following these embedded promptly.

4.1.5 Palliative Care

Some individuals had received palliative care. End-of-life discussions took place with the person, and efforts were made to honour their wishes, for example, where a person expressed a desire to die in their usual place of residence, measures were taken to ensure this happened. It was important that healthcare professionals recognised when someone was approaching the end of their life, so that appropriate palliative measures could be implemented to ensure comfort.

Healthcare professionals consistently involved both the individual and their family in end-of-life planning, ensuring care reflected what mattered most to the person. Inpatient palliative care teams were engaged to support this process, initiating palliative care pathways and prescribing anticipatory medications. These teams also facilitated referrals for Continuing Healthcare (CHC) funding to enable palliative care to be delivered in the community when appropriate.

GPs played a key role in supporting both the individual and care home staff, referring to local hospices, prescribing anticipatory medications, or involving district nurses or palliative care teams. District nurses provided regular visits to patients receiving palliative care, offering symptom management and ongoing support for the person, their family and carers.

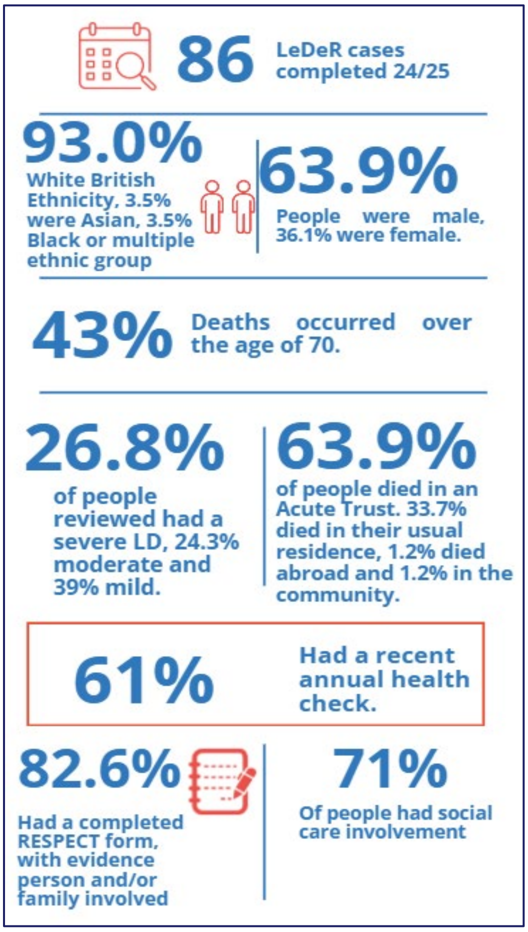
However, on a small number of occasions, care home staff reported feeling under-prepared to support individuals at the end of their life. Some staff shared that they were "chasing the hospice for support" and had expected "greater community support."

5. About the people who died

5.1 Demographic data

In 2024/25, the ICB received six LeDeR notifications where the person was from a global majority background and had a learning disability and/or was autistic, these numbers are too small to draw significant conclusions from the data. Even though this is a small number this is an increase from three global majority deaths in 2023/24. However, the LeDeR data is being reviewed under the health inequalities work programme, as well as the mortality group, to ensure a variety of professional expertise has oversight of the LeDeR data set.

Development of the work completed in 2023/24. Autism Independence, in collaboration with Bristol, North Somerset and South Gloucestershire ICB, have continued to support people from a global majority to access primary care and utilising health navigators. Please see section 7.3.4 for further details.



86 LeDeR cases completed 24/25

93.0% White British Ethnicity, 3.5% were Asian, 3.5% Black or multiple ethnic group

63.9% People were male, 36.1% were female.

43% Deaths occurred over the age of 70.

26.8% of people reviewed had a severe LD, 24.3% moderate and 39% mild.

63.9% of people died in an Acute Trust. 33.7% died in their usual residence, 1.2% died abroad and 1.2% in the community.

61% Had a recent annual health check.

82.6% Had a completed RESPECT form, with evidence person and/or family involved

71% Of people had social care involvement

Figure 1.3: BNSSG LeDeR summary data

Bristol, North Somerset and South Gloucestershire LeDeR data 2024/25

86 LeDeR notifications were received in 2024/25 and 86 LeDeR reviews were completed – an increase from last year which was 75 LeDeR notifications in 2023/24 with 43 completed reviews.

93% White British Ethnicity – down from 96% last year

63.9% of people were male, 36.1% were female (56.6% and 45% last year)

43% of deaths occurred over the age of 70 compared to 44% last year.

26.8% of people reviewed had a severe learning disability. 24.3% moderate and 39% mild. Last year we saw 26% of people reviewed had a severe learning disability. 33% moderate and 29% mild.

63.9% of people died in an acute trust a reduction from 67% last year. 33.7% died in their usual place of residence representing an increase from 28% last year and, 1.2% died abroad and 1.2% died in the community. 61% of people had a recent annual health check. 82.6% of people had completed a RESPECT form, with evidence of a person and/or family involved. 71% of people had social care involvement, a significant increase form 55.6% last year.

Bristol, North Somerset and South Gloucestershire ICB continue to receive more notifications of deaths of men than women, which is consistent with national data reporting. The National LeDeR report (2022) shows that 55% of people with a learning disability who died were male. At the time of writing this annual report the National LeDeR report reviewing data from 2023 is still awaiting to be published. Data analysis will be compared to the most recent published National LeDeR report (2022).

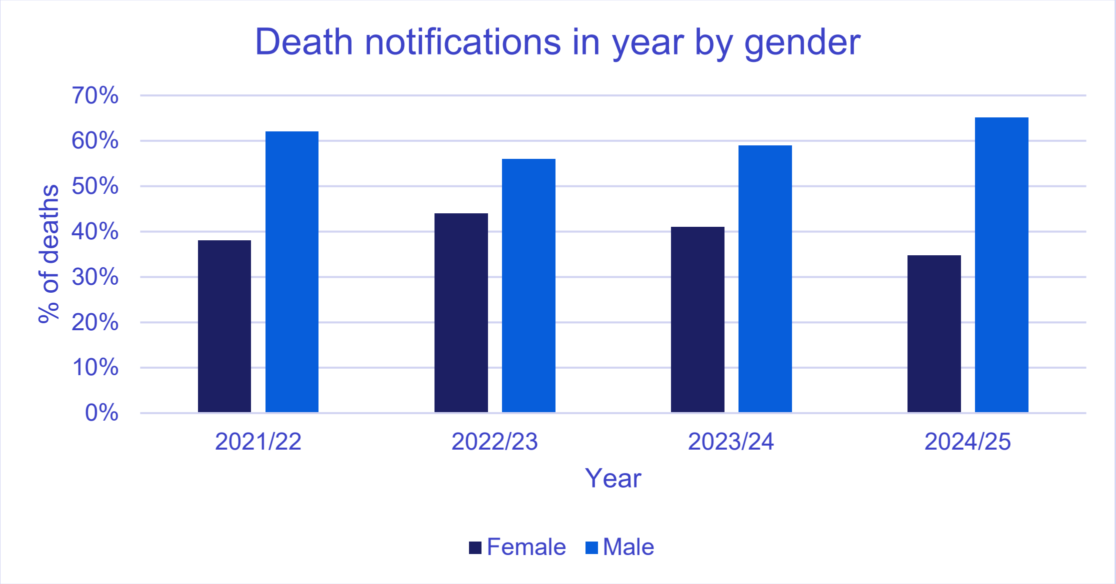


Figure 2: Reported deaths by gender

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 residents living in Bristol, North Somerset and South Gloucestershire is 64.

Figure 3 and Figure 4 demonstrate data from the Health and Care of People with Learning Disabilities, Experimental Statistics 2023 to 2024 - NHS England Digital, which shows Bristol, North Somerset and South Gloucestershire having an older population on the learning disability register compared to the rest of England.

Percentage of patients with a learning disability by age and sex

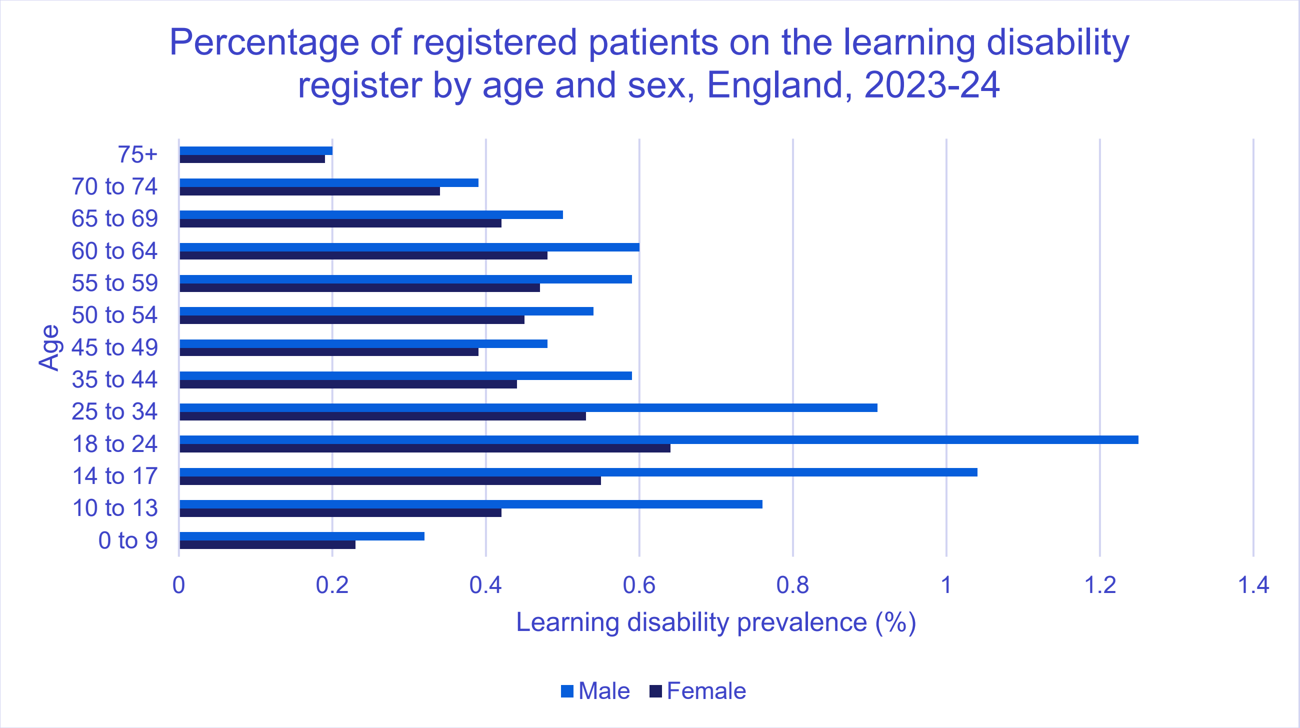


Figure 3: Percentage of patients with a learning disability by age and sex in England (2023/24)

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

Recorded data suggests on 31 March 2025 5,390 people were on their GPs learning disability register. Using Fingertips data we are pleased to report that there has been an 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. To note, NHS England have noted data quality issues on the Fingertips data set, leading to incorrect coding at local level which may have inflated the number of people on the QOF Learning Disability Register in some areas. Due to these concerns, we have used NHS England Digital data.

	31/3/25	**31/3/24**
Total number of people on the GP Learning Disability register	5,390	5,297

Figure 4: Learning disability: QOF prevalence (all ages): [MI] Learning Disabilities Health Check Scheme, England, March 2025 - NHS England Digital

5.3 Level of learning disability

The data shown in section 5.1 indicates that 26.8% of people who died had a severe learning disability, 24.3% had a moderate learning disability and 39% had a mild learning disability. In 2023/24 we discovered some people who have a mild learning disability can struggle to get their needs met effectively by health and social care. Last year a priority for 2024/25 was to understand the learning from deaths of people who have a mild learning disability. A theme from completed reviews of those with a mild disability suggest some people do not meet a threshold to receive a package of care or have capacity to decline care leading to unmet health and social care needs.

The ICB will continue to develop its understanding of this data, in partnership with our Directors of Public Health, to ensure that any insight supports 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.

5.4 Impact of Covid on people

Families continue to share the impact of the Covid-19 pandemic had on their loved one. Consequences of lockdown include people not wanting to leave their home after the pandemic restrictions were lifted. The loss of day centres being closed during the pandemic and the impact this has had on people, including loss of engagement in-group activities and a reduction in motivation to be active. People continue to feel the learned behaviours of the isolation experienced due to the pandemic. The change in consistent daily activities lead to anxiety to accessing the community when restrictions lifted.

Three years after the pandemic ended, 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. Local Authorities also support people struggling with social isolation and are responsible for day centres ensuring low attendance is addressed.

5.5 Involving next of kin

Families, carers and loved ones are invited to take part in the LeDeR reviews that the ICB conduct. In 2024/25 47% of families shared their loved one’s story. This is an increase from one third of families participating with LeDeR in 2023/24. The next of kin are invited to share 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. Many family members were complimentary about the care received from General Practice; one person feedback they felt the GP ‘was her rock.’

5.6 About the people who died

The individuals who passed away led lives filled with diverse interests, talents and meaningful experiences. Each person had a unique story, marked by personal achievements, community involvement and memorable moments. Some people taught themselves to read and write, one person attended Bristol City College, some played musical instruments, whereas others were artistic and joined an art club.

Many music fans' tastes spanned a rich spectrum, including Bengali music, Rock 'n' Roll and Dolly Parton. Many had worked or volunteered within Bristol, North Somerset and South Gloucestershire. One person celebrated their birthday by staying at the prestigious Ritz Hotel in London.

Faith and spirituality played a significant role in the lives of many. Carers made meaningful efforts to support individuals in practising their faith. This included helping them attend religious services, observe rituals, and engage with spiritual communities, ensuring their beliefs were respected and upheld.

A strong sense of community and belonging was evident, many people actively participated in local life, frequenting churches, enjoying coffee outings, watching football matches, shopping trips and attending performances at Bristol Hippodrome.

Public transport was used often and many people found satisfaction and a sense of independence in navigating their local areas via buses and trains. Notably, three individuals made the significant act of stopping smoking.

Many people enjoyed going on holiday and having day trips, these excursions brought joy and left cherished memories.

6. Cause of death

6.1 High level summary

There has been an increase of reported deaths of people who had a learning disability and/or autistic people in 2024/25. The ICB does not believe this to be a significant increase, and it is likely due to improved reporting. There has also been an increase in the number of people on our GP registers. Oversight continues through the Strategic Oversight Prevention Group, where the ICB can review with Directors of Public Health. To note, in 2023/24 43 reviews were completed, in 2024/25 86 reviews completed, providing a wider range of data to examine.

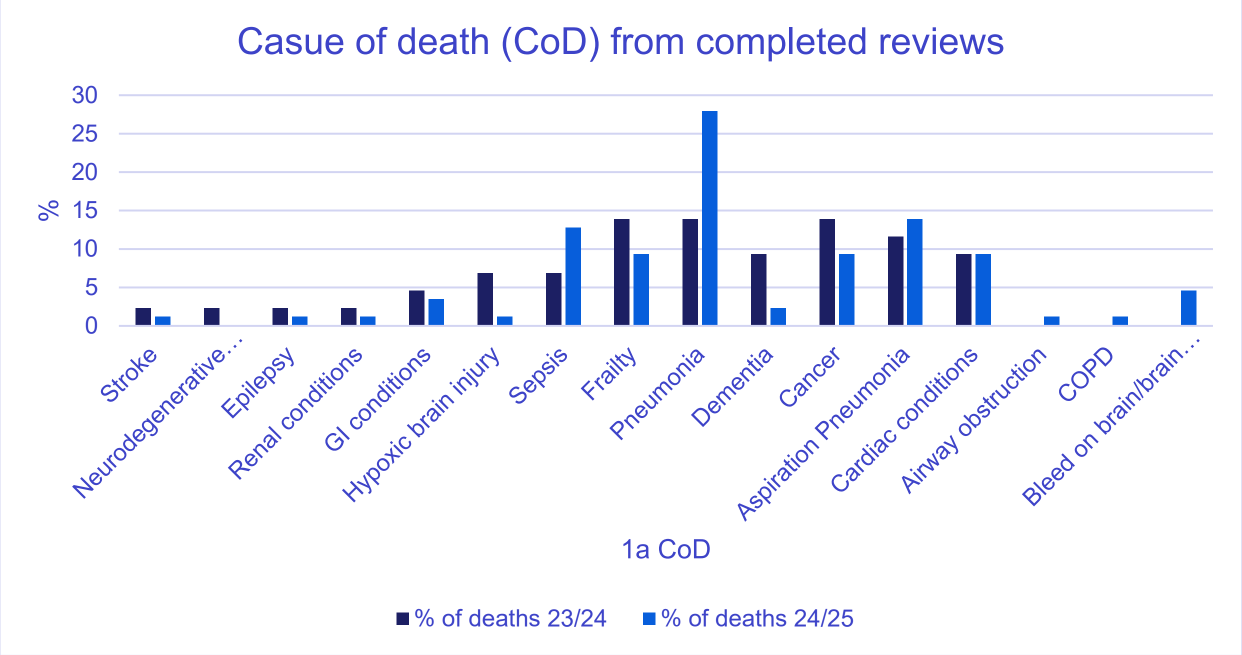


Figure 5: Cause of death (CoD) from completed reviews

From completed reviews, the three most common causes of death were pneumonia, aspiration pneumonia and sepsis. Compared to the three most common causes of death in 2023/24 being, cancer, frailty, and pneumonia. As the numbers of deaths are small it is expected for variation in causes of death year-on-year.

The oldest person reviewed was 94 years old. 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 the population and indicating that people who have a learning disability are dying from older age ailments. In 2023/24, the ICB observed an increase of deaths relating to cardiac conditions, in 2024/25 there has been a similar trend. National mortality[4] data suggests an increasing mortality rate from cardiovascular disease in Bristol, North Somerset and South Gloucestershire, this aligns with the national picture.

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[4] Mortality Profile - Data | Fingertips | Department of Health and Social Care

The ICB is pleased to be able to report that there were no death certificates where a learning disability was included as the immediate cause of death and grateful to the Medical Examiner's office for supporting this change with clinical teams. In 16% of the reviews, the death certificate included the learning disability or autism as a contributory factor. Autism stated as a contributory factor is a new theme with 3.5% of completed reviews stating this. To note, only one autistic person's death had autism as a contributory factor on their death certificate, the other people had a learning disability and autism. In comparison in 2023/24, 25% of reviews the death certificate included learning disability as a contributory factor. The ICB's Clinical Lead for Learning Disability and Autism has reviewed these and deemed them appropriate in relation to the individual circumstances of the people who died. Ongoing collaboration with the Medical Examiners will support continued appropriate guidance regarding not using learning disability or autism as a 1a cause of death.

The ICB uses 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 51% of deaths had a treatable cause of death. Deaths caused by epilepsy, pneumonia, aspiration pneumonia, sepsis and some types of cancer are all deemed treatable deaths.

To address treatable causes of death, a range of initiatives have been embedded across the Bristol, North Somerset and South Gloucestershire health and care system, which can be found in section 7. Including in section 7.2 which discusses insights from the Learning Disability Screening Practitioner at Sirona care & health. The aim for this practitioner is to increase cancer screening uptake in people who have a learning disability. The practitioner works with people who have a learning disability to understand the barriers to accessing screening and provides training on self-examination.

There remains a high prevalence of pneumonia and sepsis related deaths. The pneumococcal vaccine helps protect against some types of bacterial infections that cause serious illnesses like sepsis and pneumonia. In January 2025, guidance on the inclusion criteria to receive the pneumococcal vaccine incorporated chronic neurological conditions such as Parkinson's, motor neurone disease or a learning disability (if the person is at risk of aspiration pneumonia). Section 6.3.1 discusses the key system programme to increase uptake of the pneumococcal vaccine for people who have a learning disability. Bristol, North Somerset and South Gloucestershire ICB is working collaboratively with all system partners to increase the offer of this vaccine including improving knowledge and 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 local learning disability and autistic communities.

6.1.1 ICS Co-Improvement Group – Pneumococcal vaccine

The ICS Co-Improvement Group have been working to improve awareness and eventually uptake of the pneumococcal vaccine. Figure 5 demonstrates from the completed reviews the majority of deaths were caused by pneumonia, aspiration pneumonia or sepsis. Respiratory disease continues to be one of the biggest causes of death for people who have a learning disability. Up to 8.4% of all respiratory deaths were caused by aspiration pneumonia (LeDeR 2022) and as previously stated respiratory related deaths are often avoidable or preventable.

As part of the ICS Co-Improvement Group; Bristol City Council sent a survey to their care management teams to gain views and knowledge on the pneumococcal vaccine. Survey responses suggested a lack of awareness of the pneumococcal vaccine and the benefits of this vaccine to people who live with a learning disability. Responses received regarding the challenges to people receiving the vaccine included a lack of accessible information available, lack of publicity and a lack of trust in the vaccine. In response the GP Clinical Lead for Learning Disabilities and Autism has raised awareness of the pneumococcal vaccine at a Primary Care Event and provided easy read leaflets on the ICB's Remedy page. REMEDY is Bristol, North Somerset and South Gloucestershire's referral pathway and joint formulary platform. An expert by experience incorporated in the ICS Co-Improvement Group has advised the group on information that would help service users to make an informed decision about whether to receive the vaccine. This advice is being incorporated into further workplans and raising awareness of the pneumococcal vaccine is a priority for 2025/26.

6.2 Comorbidities

Every person with a completed review had at least two comorbidities, one person had nine comorbidities, as shown in Figure 6. Many people had cardiac conditions, such as hypertension and cardiovascular disease, and/or respiratory conditions, including asthma and chronic obstructive pulmonary disease (COPD). Adherence to screening and medication control can be difficult for all population groups. People do not take their medication for a range of reasons including a poor understanding of the medical condition as well as the side-effects of the medication. 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.

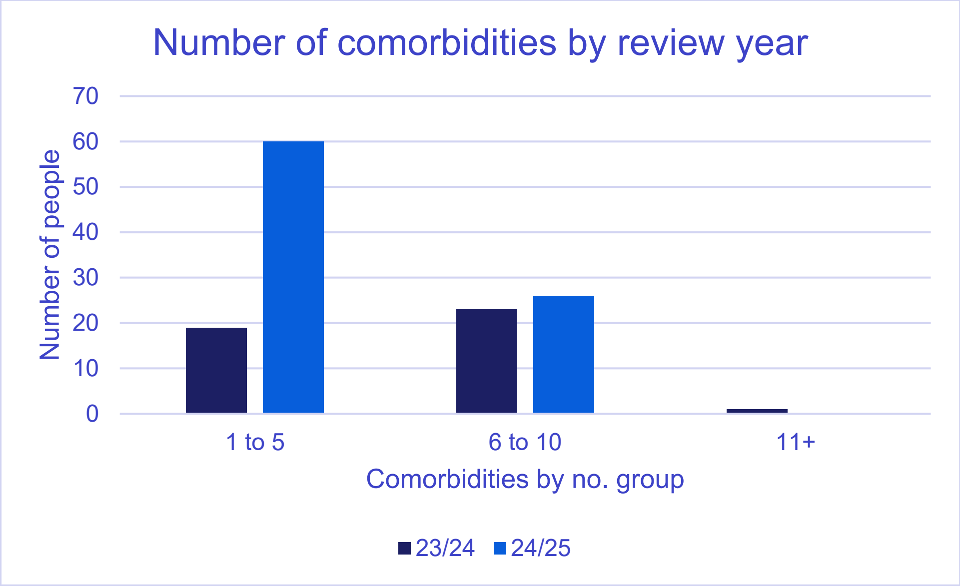

Figure 6: Number of comorbidities by review year

People suffering from constipation is a consistent theme. North Bristol Trust (NBT) in collaboration with People First hold an annual "Poo Matters" event to raise awareness of the importance of managing constipation and its related complications for patients with a learning disability and/or autistic people while in NBT's care, further information can be found in section 8.4. Brandon Trust, a local care provider, is also progressing work to raise awareness of constipation. Brandon Trust is collaborating with the CIDER research team, on a bid to help them research constipation with the ambition each person under their care will be given an individualised bowel plan.

6.3 Place of death

In 2024/25, 64% of people notified to the LeDeR platform died in a hospital setting this is a decrease of 2% compared to 2023/24. The national LeDeR report (2022) suggested 59% of deaths occurred in hospital. The 'other' place of death refers to the person dying abroad or in the community. Figure 7 shows the trends relating to the place of death over the last two years. Further data validation is required to understand the trend toward dying in hospital. To note, there has been an increase in the numbers of deaths occurring in the person's usual place of residence, many of these deaths occurred whilst the person resided in their care home.

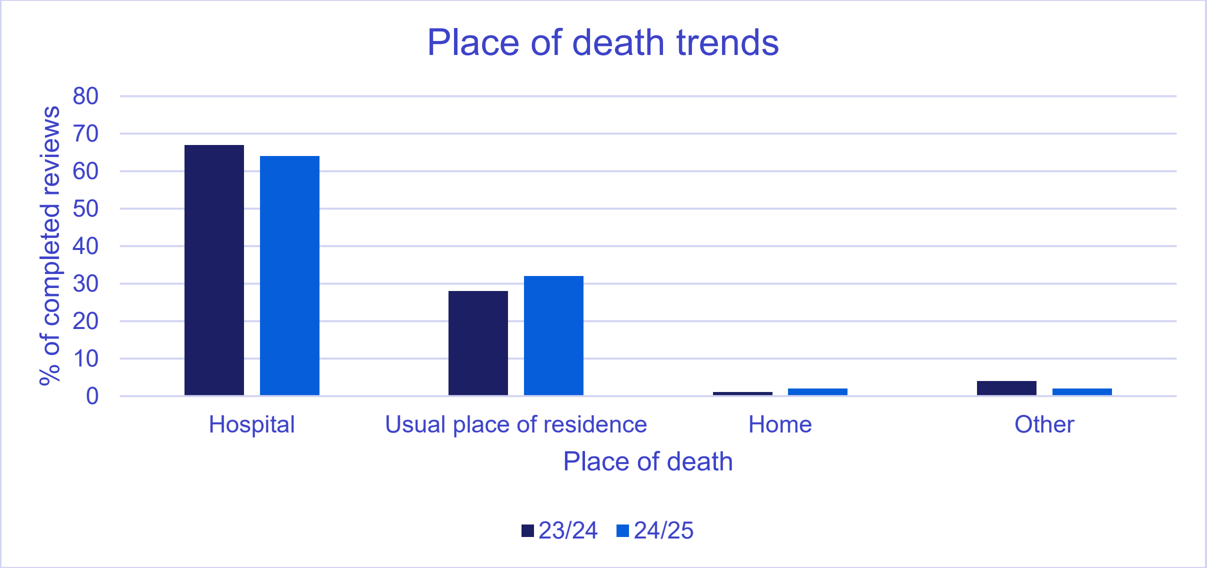

Figure 7: Place of death trends

Acute trusts complete a mortality review for every person who has a learning disability and dies in their care. Acute Trusts interrogate their mortality data, to ensure learning is obtained and improvements are made. Initial feedback suggests that people attend hospitals when they are extremely poorly, leading to minimal opportunity to provide treatment. Maintaining good health in the community is paramount and partners are using innovative ways to support people to stay well. Sirona care & health for example have piloted using Point of Care Testing (POCT) instead of using venepuncture to obtain blood samples. This is beneficial for people who are non-complaint with venous blood taking and are presenting as unwell. Feedback has been positive with some people accessing POCT who have previously declined venous testing. Please refer to section 8.5 for further details.

Last year the Clinical Lead for Learning Disability and Autism developed and shared a resource pack for our care homes, which provided information on reasonable adjustments, health action plans and what to expect at an annual health check. This year the Clinical Lead has developed a ‘Was Not Brought’ policy empowering primary care to have professional curiosity if a person misses an appointment. More information can be found in section 7.3.4.

A consistent theme following completed LeDeR reviews are 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. Please refer to section 4.4.5 which highlights the palliative care support people were provided with at the end of their life, including the various community teams who supported the person and their family.

6.4 Recommend Summary Plan for Emergency Care and Treatment – ReSPECT

ReSPECT forms are what is historically known as Do Not Attempt to Resuscitate – cardio-pulmonary resuscitation (DNA CPR) forms. ReSPECT forms are designed to record a person's preferences for emergency care and treatment, particularly when they are unable to express their wishes themselves. Figure 8 suggests 90% of people whose death were reviewed had a ReSPECT form in place at time of their death, with the data in Figure 9 demonstrating the percentage of people who had a ReSPECT form completed and followed correctly. Of the percentage of reviews, where the person had a ReSPECT form, 90% of forms were correctly completed and followed acknowledging that the person or their family members were involved in decision making. ReSPECT forms can be completed by the GP or hospital teams and community-initiated ReSPECT forms can be taken into hospital if a person presents.

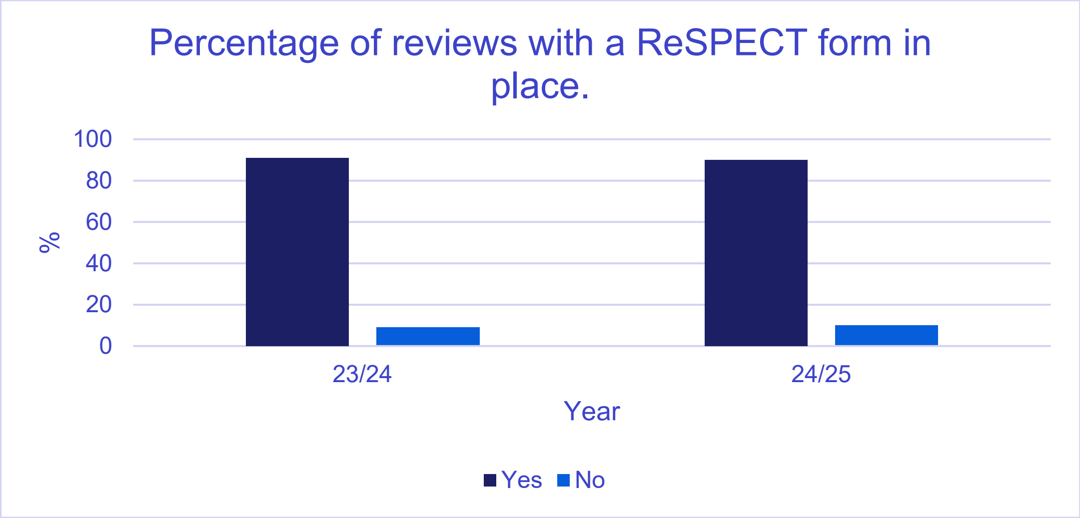

Figure 8: Percentage of Reviews with a DNA CPR in place

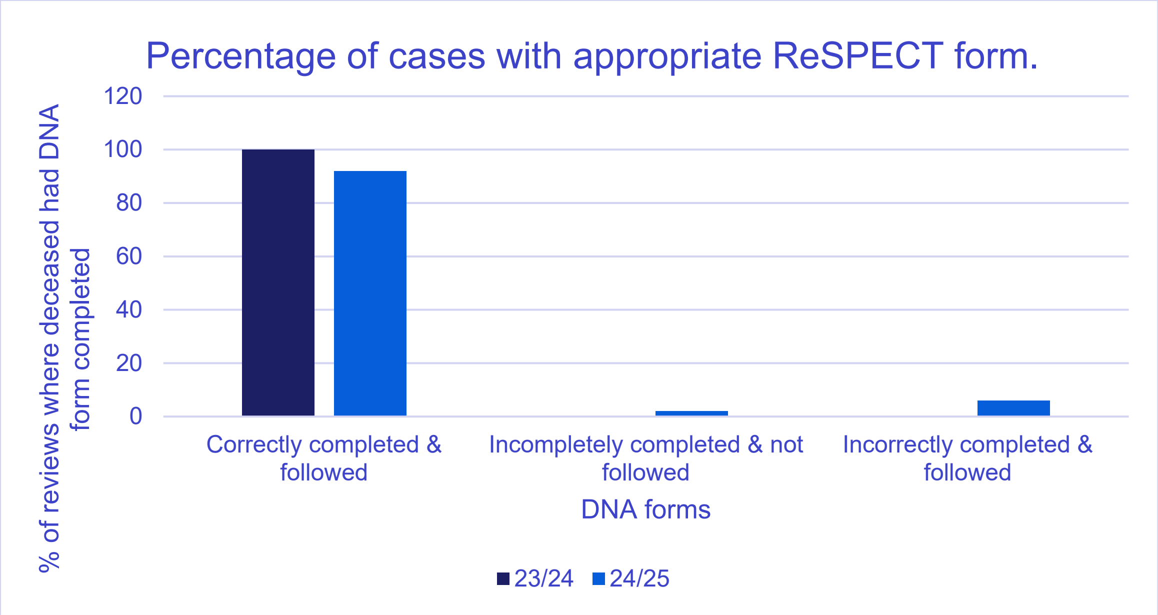

Figure 9: Percentage of cases with appropriate DNA CPR

ReSPECT forms was a topic of interest following the thematic analysis of the completed LeDeR reviews, as described in Section 4.4. There are two key points of interest concerning ReSPECT forms:

1) Was the ReSPECT form completed correctly?
2) Was the ReSPECT form followed correctly?

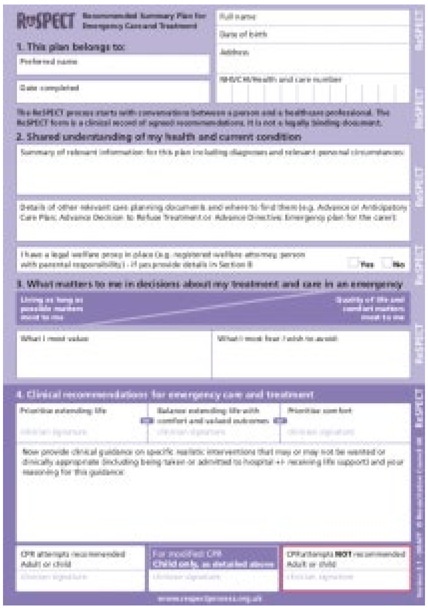

Figure 9 illustrates the findings that the majority of ReSPECT forms were completed and followed correctly. Elements contributing to a completed ReSPECT form included whether discussions surrounding DNA CPR were with the person, incorporating MCA practices and, if the person did not have capacity, whether an IMCA was involved. Often family members supported the person with these decisions, and these discussions were undertaken sensitively. On a small number of reviews this process was not optimal with one person sharing “the doctor lacked empathy when discussing ReSPECT”. There were many examples whereby the person asked not to attend hospital settings and for care to be provided in the community, this was documented on the form and many ReSPECT forms were updated regularly responding to a person’s changes in health.

Occasionally ReSPECT discussions did not involve family members or an IMCA, and information in the ReSPECT form was incomplete, this could lead to the person’s wishes about their care in an emergency not being met.

Most ReSPECT forms were completed correctly and examples whereby health professionals followed the documented advice. For example, paramedics not transporting a person from the community into hospital because this was against their wishes, instead liaising with the person’s GP to initiate optimal community support. ReSPECT forms on occasion were not followed, this included cardio-pulmonary resuscitation commencing even though the person had documented DNA CPR, and the person being admitted into hospital even though it was stated care should be provided in the community. It is discussed in section 4.4 that some care homes did not feel prepared to provide end of life care, and thus there is an opportunity to improve education and skillset in this area.

7. Learning from reviews

7.1 Hoarding

In section 4.4.1 it was discussed an emerging theme from completed reviews was hoarding. Increased knowledge around hoarding and executive functioning in relation to mental capacity means that people who would not have been considered for safeguarding in the past may now be seen as in need of safeguarding. Capacity to consent to safeguarding referrals to the local authorities needs to consider this change in knowledge around functional capacity, self-neglect and the impact hoarding may have on capacity to consent. The ICB collaborated with Avon Fire and Rescue to share the risks and mitigations of hoarding with primary care colleagues. Information that was shared included top tips for hoarding that can be discussed with the person that the professional is concerned about. An easy read leaflet has been provided to primary care and has been added to BNSSG REMEDY page.

7.2 Cancer screening

Cancer remains a disproportionate cause of death for citizens who have a learning disability and 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 the local learning disability population in comparison to the general population.

A Learning Disability Screening Practitioner was recruited in October 2023 and sits within the Adult Learning Disability Health Service (ALDHS) in Sirona care & health. Their role is to increase the uptake of breast, bowel, cervical, Abdominal Aortic Aneurysm (AAA) and diabetic eye screenings for people with a learning disability in Bristol, North Somerset and South Gloucestershire.

The Learning Disability Screening Practitioner provides education sessions to people with a learning disability in the area. These sessions include the importance of breast and testicular examination, signs and symptoms of cancer and what to expect from the national screening programmes. In 2024/25, 154 people with a learning disability attended these sessions, plus 76 carers supporting them. The training sessions use a variety of different training materials to ensure its accessible, including anatomical models, videos, pictures, physical demonstrations and easy read.

In 2024/25, 47 people attended a webinar aimed at care providers and carers, hosted by the Learning Disability Screening Practitioner, to learn about support available to people with a learning disability to attend their screening appointments. The aim is to upskill staff and improve knowledge of screening programmes to ensure that people with a learning disability are well supported to attend. Ten support workers from various care providers across Bristol, North Somerset and South Gloucestershire attended separate face to face training sessions.

Furthermore, an Assistant Practitioner in the ALDHS has been contacting and supporting people on the learning disability register who have not responded to screening appointment invitations. In 2024/25, 169 people with a learning disability who were eligible for breast screening were contacted:

- 63 people declined support.
- 26 people were uncontactable.
- 30 people were unable to tolerate breast screening (due to high levels of fear/anxiety). Health promotion was given, but further support was declined.
- 28 appointments were offered (7 were not brought, 4 attended but were not screened).
- 17 people were screened, of which 2 required further investigation for suspected breast cancer.
- 5 still pending outcomes.

These people were non-responders, which means that without this intervention, they likely would not have attended a breast screening.

This work is now embedded in practice, and the ALDHS Assistant Practitioner is now supporting people who are on the routine call for breast screening.

The team have started to extend the support to people with a learning disability attending for bowel and cervical screening.

The Learning Disability Screening Practitioner attended seven community engagement events to promote screening for people with a learning disability, including the South Asian Community Health Day and the Chinese Community Health Day. As well as raising awareness of screening and self-examination, the events facilitated many meaningful networking opportunities, leading to numerous activities and workstreams.

Cervical Screening will be the next project for the Learning Disability Screening Practitioner, in response to the high number of non-responders to cervical screening for people with a learning disability. The team are asking people with a cervix and have a learning disability what enablers and barriers there are in attending cervical screenings, collating an accurate picture of why people are and are not attending. This will shape future plans of how to enable people to attend and is in line with NHS England ambition of eliminating cervical cancer by 2040. The Learning Disability Screening Practitioner will also work alongside the

South West NHS England Vaccination and Immunisation Team and the South West Learning Disability and Autism Programme to develop a project to improve access to cervical screening for people with a learning disability.

7.3 Annual health checks

National experimental statistics for health and care of people with learning disabilities interactive tool[5] demonstrates in Bristol, North Somerset and South Gloucestershire there were 5,390 people registered on their GP learning disability register as of 31 March 2025. At the end of March 2025, 4,217 people, equating to 78.24%, had received their annual health check in 2024/25, with 76.01% of people receiving a completed health action plan (HAP). In comparison nationally 79.88% of people had a completed health check and 77.80% had a completed HAP.

7.3.1 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, improve quality of life and reduce premature mortality.

Percentage of patients receiving an AHC and HAP by age in 2024/25

The data in Figure 10 demonstrates 81% of people for whom a LeDeR review had been completed had received an AHC within their final 12 months, this is an increase from 73% in 2023/24. 69% of those also had a health action plan. The King’s College London national LeDeR Annual Report 2022 suggested 72% of the population had received an AHC.

These figures are dependent on the reviewer completing the AHC questions in the review. When GP notes are reviewed the consultation documentation 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. Reasons for incomplete AHC include the person not receiving a check in the previous 12 months before they died or healthcare staff considered the person too frail to receive an AHC. In one person’s healthcare records there was no evidence that they were invited to or received an invitation for an AHC. Another person had received multiple input from healthcare in the last 12 months, and another person had recently moved from Wales. Apart from one, all the people who had not received a recent AHC were over the age of 60. This aligns with 2022/23 national age related AHC data which suggested, the older people become, the uptake for AHC reduces.

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[5] [MI] Learning Disabilities Health Check Scheme, England, March 2025 - NHS England Digital

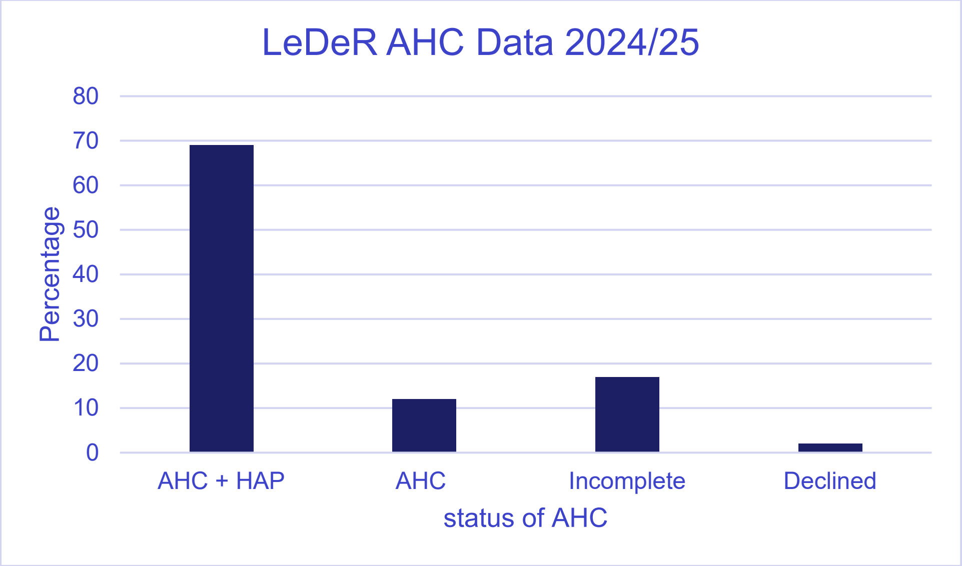

Figure 20: LeDeR AHC Data

7.3.2 Training to Primary Care

The Learning Disability and Autism Clinical Lead continues to provide quarterly training sessions on AHC to GPs. In 2024/25, colleagues from Sirona care & health Adult Learning Disability Health Service (ALDHS) supported the Clinical Lead providing information on the Reasonable Adjustment Flag and AHC pre-health check questionnaire. This is to raise the profile of AHC, HAP and reasonable adjustments to enable better support of people with a learning disability and/or autistic people. The ICB collaborated with Healthwatch to create an up-to-date check list[6] for patients and carers to engage with prior to the AHC. This will help to collect information, encourage patients and carers to think about concerns and helps focus the AHC.

Sirona care & health's ALDHS staff, with colleagues from People First, ran a project looking at the accessibility to GP surgeries with the aim to share good practice about supporting people with a learning disability to access primary care and making recommendations for improvements. This looked at physical access to buildings, how the surgery communicates and implements reasonable adjustments as well as discussing their approach to AHC. Good practice and recommendations are shared using the quarterly Primary Care webinar.

7.3.3 Annual Health Check (AHC) toolkit

Last year the ICB reported the ALDHS was working in conjunction with partners in the South West in response to a 'call to action' from NHS England to develop a new annual health check (AHC) toolkit for primary care following the removal of the Royal College of GP's (RCGP) AHC toolkit. The new AHC toolkit has been launched this year and supports clinicians with a step-by-step approach to learning disability AHC and HAP from invitation to follow up. It includes sections on Transition, epilepsy, Stopping the Over-Medication of People (STOMP) with learning disabilities and autistic people and syndrome specific checks. It includes links for clinicians, patients and supporters. This was developed by the ICB, Sirona care & health, Healthier Together and Cornwall Partnership. To support

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[6] Healthwatch BNSSG_LD Annual Health Check_Checklist_Oct 2021

implementation the ICB Clinical Lead provides an annual ‘back to basics’ webinar for all primary care staff new to annual health checks introducing the new South West annual health check toolkit[7]. In addition, support is offered to individual GP practices for staff training, improving the quality of AHC and HAP. The training offer includes regular learning disability teaching as part of the “new to primary care” nurse programme for the Avon Local Medical Committee.

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, new resources include easy read appointment card templates, The Victoria and Stuart[8] project an end-of-life care planning toolkit form, pain scales and body maps.

7.3.4 AHC ongoing projects

Patients missing appointments policy
People with a learning disability often rely on others to access healthcare and often face barriers when attempting to access primary care. Following a theme from 2023/24 LeDeR reviews which suggested people who have a learning disability do not consistently attend healthcare appointments a ‘Was Not Brought’ policy was launched in Primary Care in collaboration with the Clinical Lead and the ICBs safeguarding team. The ‘Was Not Brought’ policy is now live for both adults and children and includes a risk assessment tool. The policy prompts GP IT systems to code missed appointments as ‘Was not Brought’ instead of ‘Did not Attend’ focussing on what this means for the person and the consequences of non-attendance using professional curiosity.

Reasonable adjustment flag

The project followed the NHSE requirement for all primary care providers to develop a reasonable adjustment flag for patients with learning disabilities and/or autistic people. Primary care use an IT programme called EMIS which is used to record medical notes. A protocol was developed for EMIS which prompts the user to add reasonable adjustments at every patient contact and alerts the user to review existing reasonable adjustment alerts. This has been launched to all GP practices within Bristol, North Somerset and South Gloucestershire. Reasonable adjustments can be used for other vulnerable patient groups for example people with dementia or suffer severe mental health needs.

7.4 Autism Independence and Health Navigators

Last year the ICB’s work with a voluntary sector organisation called Autism Independence to increase access for people from a global majority background to access AHC’s was shared. Following last year’s AHC project raising awareness of AHC for people who have a learning disability from global majority background, funding was provided to Autism Independence for two years to employ three health navigators and a project coordinator to continue this work. Subsequently three health navigators have been recruited; they speak Polish, Punjabi, Urdu and Somali. The health navigators provide targeted language specific support for people where English is not their first language and support them to navigate

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[7] Learning Disability Annual Health Check Toolkit
[8] End Of Life Care Planning | The Victoria And Stuart Project

the health system. Interventions can be brief where someone attends a workshop or coffee morning and they feel confident to go to the GP themselves to set up appointments, to more intensive support where an appointment is booked and health navigators attend appointments with the family or the individual. The service provided will depend on the level of need and the language support which is required.

Autism Independence is an established culturally intelligent service meaning it already has strong links to the Somali community. Autism Independence are now seeing a steady increase in the number of families they are working with from other communities. Looking at their data, and where people have chosen to share their ethnicity, they can see Pakistani, British Pakistani, Bangladeshi, Iranian families and British families are attending their workshops and coming to them for support.

A current priority for Autism Independence is a continued focus to improve engagement with the Polish community. Autism Independence know from the ‘We Deserve Better’ report that reaching out to religious leaders in communities can help raise awareness of important health advice. The Polish speaking health navigator has contacted a Catholic priest who is active in the Polish community in Bristol and their focus will be on building that relationship. This approach will be replicated with other religious establishments across Bristol, North Somerset and South Gloucestershire.

Autism Independence will continue to attend health events across the city and coffee mornings at schools. The latter will be a combination of secondary schools and primary schools. One of their main priorities is to support people over the age of 14 to have their AHC, but it is also vital that information about the learning disability register is shared much earlier, so there is a focus on primary schools advising parents to get their child on the learning disability register and explaining the benefits of this.

Autism Independence have presented the work they do to support people to have their AHC at GP surgeries. Autism Independence have also attended the Primary Care Network Community Forum meeting with plans to attend more of these in the future.

8. ICS LeDeR Improvements

8.1 Brandon Trust

Brandon Trust is a charity and a care home provider for people who have learning disabilities and/or autistic people. Brandon Trust started a new grief café called the Listening Lounge to help people understand death and dying. The Listening Lounge provides a safe and inclusive space where topics related to death, such as illnesses and grief can be explored in a way that meets the specific needs of the people they support. The Listening Lounge has been co-produced with Experts by Experience to ensure it is inclusive and accessible. People with a learning disability and/or autistic people experience grief and loss but often people can suppress their emotions, leading to feeling there is no one to talk to and can lead to behaviours which may become a concern. The Listening Lounge supports people with a loss of someone using activities such as, painting, baking, making a memory box or gardening amongst many other activities. Brandon Trust is also collaborating with the CIDER research team working on a bid to help research constipation. The aim is for each person in their care will be given an individualised bowel plan. This has been trialled in a hospital with good results, and the research team are now ready to try this in a community setting.

8.2 Milestones Trust

Milestones Trust is another care home provider for people who have learning disabilities and/or autistic people. Milestones Trust support a variety of people with varying needs from complex nursing to complex behaviour to supported living with comorbid mental health needs.

Milestones Trust received a grant related to dysphagia for modified diet training and skills. This was used to support people at risk of dysphagia to ensure safer mealtimes and adequate diets to meet nutrition needs. A Malnutrition Universal Screening Tool (MUST) is being used to measure and ensure nutritional wellbeing There have not been any concerns around people’s nutritional input since upskilling and increased training has been provided.

Milestones Trust Learning Department, Clinical Nurse Advisor and Nurse Practitioners utilised knowledge, best practice and lived experiences of people with mental health conditions to develop internal training to be delivered to all teams. This has also been delivered to teams whose main commissioning is supporting people with learning disabilities, autism or both, but also comorbid mental health conditions.

Milestone Trust continues to provide holistic end-of-life care. A barrier remains surrounding nurse competency of syringe pumps and Milestones are working with the Social Care Nursing Advisory Council members and local teams to formulate a solution to this barrier to provide holistic end of life care for people at home.

Their End-of-life Policy has been reformulated to be more accessible to teams in actively planning and having discussions. Experts by Experience have reviewed the policy in line with their new involvement policy and this has aided the reformatting of the document they use to support people with learning disabilities and/or autistic people to be involved in advance planning.

Over the last 12 months, Milestones Trust have also been working with primary care to delegate venepuncture for people who, at times, struggle with this procedure to their internal nursing team. This enables familiar faces to provide this service to people with Learning Disabilities and/or Autistic people and over time has led to less restrictive practices. An additional benefit to maintain nursing competencies.

Looking ahead to the next twelve months nurses will be trained in chest auscultation assessment. The aim is to improve confidence in assessing chest sounds and liaising with professionals confidently to aid diagnosis and treatment. The potential of this is early identification of chest complaints and will aid earlier communication with GPs with potential benefits of preventing unnecessary hospital admissions.

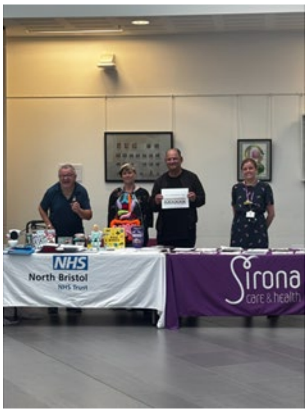
8.3. University Hospitals Bristol and Weston NHS Foundation Trust (UHBW)

A selection of autistic patients and those with a learning disability were audited to gain insight into how well UHBW staff manage their pain on admission and during their admission. This audit theme came from UHBW’s analysis of 2024 mortality reviews. Section 4.1.3 described autistic people or those with a learning disability do not always have a voice, UHBW wanted to evidence that all patients have access to good pain control. Overall, the audit results were favourable. Further audit on use of the Abbey Pain Tool will be undertaken specifically at the Weston General Hospital site during 2025, giving assurance that all autistic patients and those with a learning disability will receive timely pain control when they are unable to voice their concerns.

UHBW will have a changing place facility at Weston General Hospital for physically disabled people who need to use the toilet with a hoist provided. This need was identified through the Weston General Hospital service user hospital group. Autistic patients with a learning disability or both will benefit greatly from this resource, allowing those with a complex physical disability to use the toilet in a dignified manner with specialist equipment to support patients, visitors and carers. Work will commence in early 2025 on this facility and clear signage will be developed to support inclusivity.

UHBW has found that some autistic people or those with a learning disability wait longer for an outpatient appointment. All people should have equitable access to UHBW services, using reasonable adjustments to engage with autistic people or those with a learning disability is key to reduce missed appointments and improve screening opportunities. A proposal for the post of Equality Access Improvement for Learning Disabilities and/or Autism Spectrum Conditions has been submitted to UHBW's charity for consideration. This will enable the post holder to deep dive and explore the reasons behind missed appointments etc.

8.4 North Bristol NHS Trust (NBT)



Constipation remains one of the themes in LeDeR reviews both nationally and locally across the regions for patients with learning disabilities and/or autistic people. The Trust takes this seriously and continues to work on educating staff across the Divisions to ensure there is continuous monitoring of this. The Trust hold an annual "Poo Matters" event to raise awareness of the importance of managing constipation and its related complications for patients with a learning disability and/or autistic people while in NBT's care. The Trust has collaborated with the Poo Matters Museum who run a tour to support raising awareness among staff. This campaign and awareness will support gastro and bowel cancer awareness over the coming year.

Autism Alert Card

Instructions
1. Fold and stick both sides together
2. Cut out and fold your card
3. Fill in the spaces
4. Carry it in your purse or wallet

Emergency contact details
Name: ....
Number: ....
Email: ....
Please contact this person

I am autistic
Please see inside for important information.
National Autistic Society

Thank you for ordering your Autism Alert Card.

Many members of the public don't understand autism and how things they take for granted might cause difficulties for people on the spectrum. This card is a great way for you to let them know you are autistic and that you may need some extra time or help in certain situations.

NBT worked in collaboration with the Bristol Autism Spectrum Service to explore the process of developing their Autism training for NBT staff. This focusses on how to support patients who are accessing healthcare with reasonable adjustments. The plan is to launch this in 2025 alongside the use of Autism Cards and a reasonable adjustment checklist for patients to hand to staff when they arrive in the hospital. The Autism Alert card was a recommendation from the ED audit report by people with lived experience of autism and it is great to see this has been followed through by the team.

Another key focus for NBT is people transitioning from paediatric services to adult. The Trust recognises the importance of working with other service providers including education providers and some of the private sector partners to support a seamless transition for patients to improve health outcomes and experience. In the last financial year, the learning disability and autism liaison team have attended 2 transition coffee mornings at local schools. This was an opportunity to introduce the service and support with understanding the transition into adult health care. NBT received feedback that patients and families would appreciate contact to start sooner (age 14+) to start preparing. NBT have worked on transition packs which can be sent to local schools and services to give to patients and their families. The pack will include a leaflet for both UHBW and NBT teams, a health passport and contact details. This work will continue over the coming year.

8.5 Sirona care & health

Sirona care & health, along with People First, have developed a new Health Passport that is now widely used across Bristol, North Somerset and South Gloucestershire. This is available in easy read and plain English formats. This is now called a 'Health Passport' rather than 'Hospital Passport' as the documents were known before. The rationale for this was to promote that the documents can be used across all health and social care settings. Prior to this there was no consistent documentation of health/hospital passports across Bristol, North Somerset and South Gloucestershire for people attending hospital. The feedback for the Health Passports has been positive, with people reporting they feel more confident in appointments when they have them, and that they use the passports for various appointments, such as in hospitals, GP surgeries, opticians and at pharmacies.

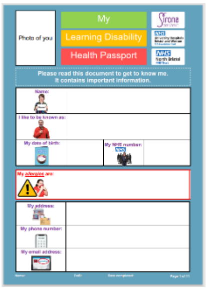
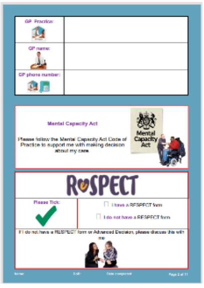


Photo of you
My
Learning Disability
Health Passport

Please read this document to get to know me.
It contains important information.

Name:
I like to be known as:
My date of birth:
My NHS number:
My allergies are:
My address:
My phone number:
My email address:



GP Practice:
GP name:
GP phone number:

Mental Capacity Act

Please follow the Mental Capacity Act Code of Practice to support me with making decision about my care.

RESPECT

Please Tick:
☐ I have a RESPECT form
☐ I do not have a RESPECT form

If I do not have a RESPECT form or Advanced Decision, please discuss this with me

Some people with a learning disability struggle to access venous blood tests. Point Of Care Testing (POCT) offers finger prick testing instead which is less invasive. Last year the ALDHS completed a pilot project exploring how POCT could be beneficial for those who struggle with venous blood testing. Three health events with ALDHS and Accure Health took place at People First. This pilot project was run to identify how POCT could help earlier identification of diabetes and high cholesterol in those who avoid traditional blood tests. The feedback on the pilot project was very positive, with some accessing POCT who decline venous testing.

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

A priority for AWP has been incorporating a digital reasonable adjustment flag as well as staff training, so they are aware and confident in using and implementing the flag. A Mental Health Learning Disability and Autism Improvement Group reviews key aspects of the reasonable adjustment flag implementation such as the Reasonable Adjustment Service user policy; workforce training and reviewing clinical systems.

Using a 'train the trainer' model AWP will be delivering Positive Behavioural Support training to clinical and non-clinical staff. This will improve quality outcomes and reduce restrictive practice to support engagement.

9. Summary

All partners across the Bristol, North Somerset and South Gloucestershire Integrated Care System (ICS) remain fully committed to driving continuous improvement in the experiences of autistic people and people with a learning disability. There is a shared focus to improve both health outcomes and individuals’ experiences of health and care services.

This is the sixth LeDeR Annual Report, which reflects deepening understanding of the needs of the local population and sustained commitment to improvement. The ICS is proud to present this report, which highlights both the ongoing quality improvement work and the ICS’s commitment to maintaining strong governance that ensures high-quality reviews.

Through this work, the ICB continues to draw valuable insights from LeDeR reviews and apply those lessons in collaboration with system partners. This approach is supported by Experts by Experience and with collaboration with a wide range of voluntary and community sector organisations.

A key priority in 2024/25 was establishing a sustainable model for LeDeR reviewer capacity. This has now been achieved. As a result, performance has significantly improved, and reviews are being completed more promptly, respecting loved ones’ grief periods and allowing earlier learning to inform action.

The quality improvement journey through the ICS Co-Improvement Group, working alongside Experts by Experience and system partners will be maintained. The ICB will continue to share progress on the LeDeR programme with Directors of Public Health through the Strategic Prevention Oversight Group, ensuring that emerging themes and trends are considered alongside wider mortality data. In addition, the ICB will continue to share learning with the Mental Health and Learning Disability Health and Care Improvement Group to ensure LeDeR insights inform broader strategic decision-making.

As a system, the ICS remains strongly committed to this vital improvement programme and to tackling the health inequalities faced by people with a learning disability and autistic people. This report is an opportunity to showcase the excellent work taking place across the system and demonstrates the dedication of all partners to improving the lives of people in our community.

The ICB would like to extend our heartfelt thanks to everyone involved for their continued dedication and hard work in support of this important group of people we serve.