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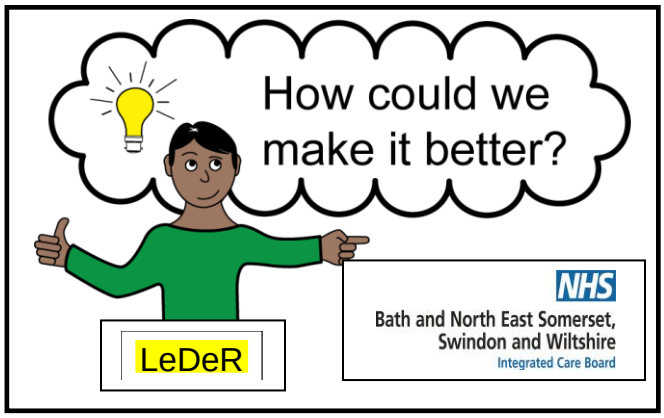

Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR) Annual Report

1st April 2023 to 31st March 2024

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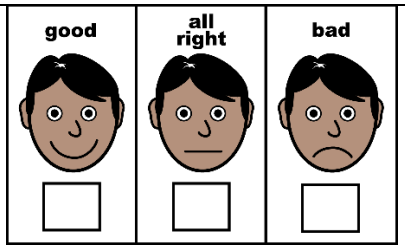
Executive Summary: BSW LeDeR Report

LeDeR remains a non-mandated service improvement programme which aims to learn from the deaths of adults with a learning disability and/or autistic adults to improve care, reduce health inequalities, and prevent premature mortality for people with a learning disability and autistic people.

This report includes **Easy Read** wherever practicable, to ensure accessibility and inclusion for people with a learning disability.

	**LeDeR informs local service improvement using learning from LeDeR reviews, highlighting good quality care and areas requiring improvement.**
	**LeDeR makes local service improvements based on themes emerging from reviews at a regional and national level.**
	**LeDeR influences national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.**

The following learning action report builds on learning from previous BSW LeDeR annual reports over the last few years and:

- now has the national policy and BSW LeDeR information for reference in the appendix section
- is written to share headlines from the national policy and summarise analysis of the 2023-24 BSW LeDeR reviews, acknowledging that BSW reviews have been on hold since February 2024 due to the depletion of historical LeDeR funding and advise that an options appraisal is under review to seek funding to restart reviews
- shares the collaborative and joint BSW Learning Disability and Neurodiverse (LDAN) Programme LeDeR learning actions taken
- identifies the key LDAN/LeDeR system action priorities required in 2024-2025.
- awaits a national update for anticipated changes to the LeDeR programme

Following BSW collaborative working/approval by the BSW LeDeR Quality Assurance Group, the BSW LDAN Steering Group members, this report will be presented BSW Executives and the Quality Assurance and Outcomes Committee for approval for publication on the ICB website, as required by NHS England.

(Easy Read pictures are included with consent from ‘Easy on the I’ and Easy Health.Org)

1. What is LeDeR?

1.2 The Learning from lives and deaths-People with learning disability and autistic people (LeDeR) programme is funded by NHS England. It is the first national programme of its kind in the world and commenced due to health inequalities:

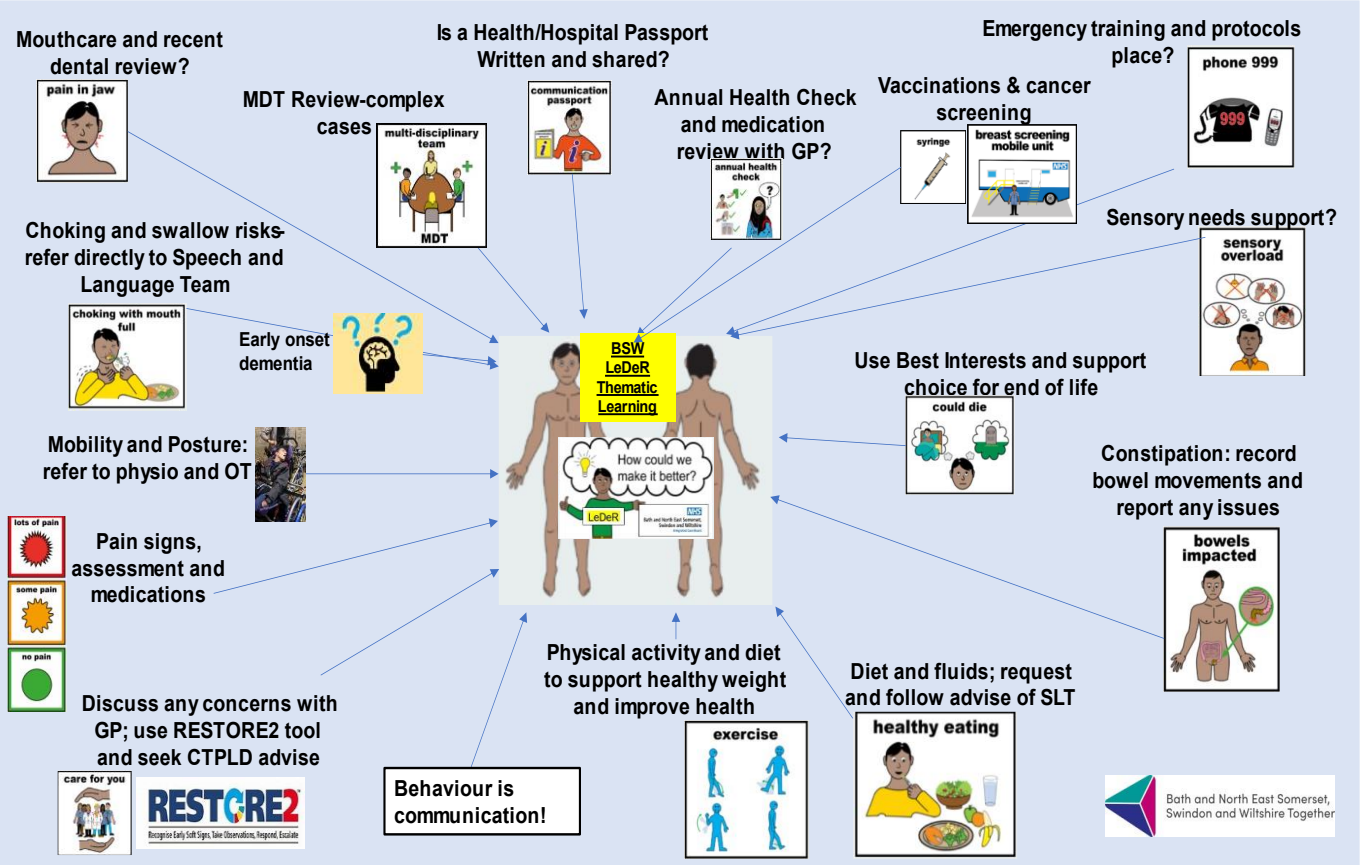
1.3 The national LeDeR team have been reviewing the current policy and an update is anticipated that will make changes to current policy and processes.

BSW LeDeR information can be found in the appendices.

LeDeR National Policy Link:
https://www.england.nhs.uk/wp-content/uploads/2021/03/LeDeR-Policy-2021-Easy-Read.pdf

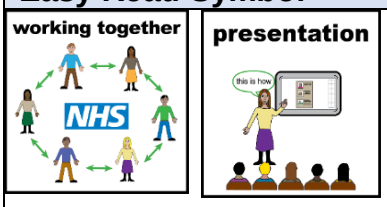
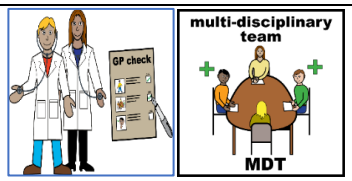
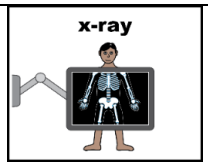
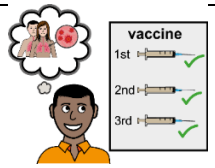
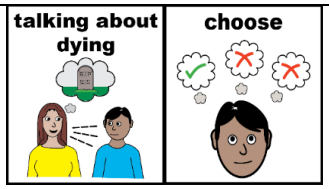
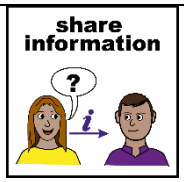
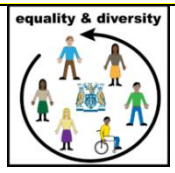
1.4 BSW Thematic LeDeR Learning Over Time

1.5 The following Easy Read poster contains thematic BSW learning from completed LeDeR reviews over the last few years. It is continually updated and shared across health and social care in BSW, to ensure that action is taken.



1.6 BSW 2023-24 LDAN LeDeR Actions

1.7 BSW LeDeR has jointly and collaboratively worked with the BSW LDAN Programme during the year, and key collective headline learning achievements and improvement activity in 2023-24 includes:

Easy Read Symbol	Action	BSW Rational
	**Working together and telling people about BSW LeDeR learning in lot of meetings**	Continue advising health and social care of LeDeR learning actions required
	**Started a project group to help more people have an annual health check at the doctors**	Increase annual health checks to meet the 75% target and avoid deteriorations/deaths
	**Helping people to have tests (diagnostics) in all three acute hospitals**	Improving planning and reasonable adjustments to complete outpatient diagnostic tests for early diagnosis
	**Worked to increase vaccinations for people with a learning disability**	Reduce avoidable/preventable deaths from Covid, flu and respiratory illnesses
	**Looked at forms called ReSPECT to improve decisions when people with a learning disability are unwell or dying**	LD ReSPECT audit in the three BSW acute hospitals to identify learning actions (as per South West LeDeR audit)
	**Sharing information with people to help them stay well as an action from last year's report**	Sharing LeDeR action learning from last year's report-health promotion & prevention
	**BSW are part of a national passports working group**	Working towards a national standardised Hospital Passport template for consistency and quality
	**Helping people make reasonable adjustments**	Reducing inequalities and meeting needs, sharing the new Digital Flag information

1.8 BSW LeDeR Governance Group Members: LeDeR Actions

BSW LeDeR Governance Group members are from BSW health and care providers and are integral change agents to make the quality improvements required from LeDeR learning. Members have been invited to share their LeDeR action feedback and here is a summary:

Title/Provider	LeDeR Feedback
Associate Director, The Great Western Hospital, Swindon.	The Trust has well established LeDeR review governance and learning processes which enables the Trust to respond effectively to any learning coming through this process. The process compliments that of Structured judgement reviews and the work of the Medical Examiner's Office. A review is conducted of every death of a person coded as having a Learning Disability and/or Autism (LDA) using LeDeR methodology. Learning is reported quarterly through internal governance routes and actions are taken forward and monitored via the Trust LDA Forum and the Trust Patient Quality -Sub Committee. For 2023 – 2024 local learning in the main has mirrored the national picture and aspiration pneumonia continues to be the top reported cause of death. Death attributed to cancer has also increased which again links to regional learning regarding access to cancer screening. There has also been learning regarding the Mental Capacity Assessment aspect of ReSPECT form completion and the need to improve pathway access for diagnostic procedures. Further learning has been regarding safe discharge processes. The Trust is committed to put LeDeR process learning into action and have forwarded several projects this year in support of this. Highlights are as follows: • Development of an out-patient diagnostics pathway • The development of a co-designed 'reasonable adjustment' pathway (to overarch other pathways) in the new Emergency Department • Focus on identification of vulnerability within out-patient systems with a view to developing prioritisation processes in support of the equal access agenda • A project has commenced looking at enhancing Trust pre op and surgical pathways for children with additional needs • Paediatric environment project – provision of a low stimulus room for children with behaviours that challenge will complete in 2024.

	• Introduction of Oliver McGowan mandated LDA training into the Trust • Human Rights/Mental Capacity Act (MCA) Training has been introduced into the Trust in 2023 for International Nurse cohort and an MCA Masterclass has been developed for Trust staff which runs bi-monthly • Preventing deconditioning (including in-patient positioning to reduce the risk of aspiration pneumonia). This project is being led by the Associate Director of the Allied Health Care Professional workforce at the Trust and will progress in 2024. • The Trust Speech and Language Therapy (SaLT) team going to be leading on a 'communication' project looking at the use of communication aids on basewards at the Trust • The Trust is part of a BSW working group looking at the development of an electronic MCA form to compliment the electronic 'ReSPECT' form • The Trust is exploring opportunities to support regarding access to cancer screening service • The Trust has developed a multi-agency discharge hub which is supporting high levels of relevant information sharing to ensure safe discharge to onward destinations • Monitoring of the reasonable adjustments built into the newly opened emergency department
LD Liaison Nurse, The Royal United Hospital, Bath.	• The RUH have agreement to recruit a Lead Nurse for Learning Disability and Autism. • The Learning Disability and Autism team have developed an inpatient and outpatient tracker, enabling the trust to identify flagged individuals and to ensure that we have a process for meeting and supporting patient journey. • Learning Disability & Autism Champions Network: We have a network of over 100 Learning Disability and Autism Champions across the Trust. They are a link between the Learning Disability and Autism Team and ED and wards across the Trust. They advise and support across their respective areas in respect of reasonable adjustments and meeting the needs (including communication needs) of people with a learning disability and autistic people. We hold quarterly huddles to share ideas and learning to improve patient experience when accessing the hospital. Topics covered so far include mental capacity and dysphagia.

	• Bespoke MCA training has been delivered across the Trust. • The team started an Advance Care Planning and end of life project which is still in progress. • The Oliver McGowan Mandatory Training commenced in the trust in June 2023. We have achieved real success in promoting the training and our statistics are promising. • Student Nursing Associate apprenticeship started in October 2023 specialising in Learning Disabilities and Autism. • Easy read leaflets launched in January 2024. These include a variety of areas, such as hospital stay, outpatients, Learning disability team to name but a few. There are several in a draft stage to add to the available resources. • Supporting Adults with a Learning Disability and Autistic People Policy launched in February 2024. • Developed Respect Audit tool for oversight of quality, following the BSW LeDeR ReSPECT audit learning. • We have also developed a bespoke training package for new HCSW and our preceptorship programme, surrounding learning disabilities and autism that has a key focus on health inequalities and key areas practitioners need to focus on areas of concern such as Aspiration Pneumonia, Constipation, Epilepsy and Sepsis.
AWP Learning Disability Consultant Nurse	• Current audit happening within mainstream in-patient areas to scope how AWP are identifying people with a Learning Disability and/or Autism and clinically recording onto the patient records on the Rio system. Alongside this is scoping the hospital passports completed for those identified. The outcome will support the improvements required around the importance of recording and the availability of reasonable adjustments, support identified learning regarding reasonable adjustments, physical health and importance of hospital passports and AHC • Reducing Restrictive Practice and Positive Behavioural Support (PBS) – trust wide piece of work to review the trust wide training, now includes learning around learning disability, autism and PBS – policies have been updated to reflect this and in line with the RRP strategy for the Trust. • Easy Read ‘Use of Force leaflet’ available

	• Suicide prevention – on-going trust wide work in line with the Suicide Prevention Strategy and inclusive of autism and suicide prevalence. • LD CPD facilitators in post to support with the delivery of training and learning for our workforce, to include Physical Health, LeDeR, Reasonable adjustments, communication and Mental Health – this is progressive. • LeDeR processes aligning with the Patient Safety Incidence Response Framework (PSIRF) delivery for the trust • AWP have 14 Trainee RNLD's who we are supporting through the ASPIRE / MSC route of NMC registration – this will enable an increase in AWP workforce to continue and enhance the workforce availability to support people with a Learning Disability/ Neurodiversity needs across the trust.
ICB Clinical Lead, LDAN Commissioning Hub	• The LDAN Commissioning Hub continue to focus on improving the care and treatment of people with a learning disability and autism and learning from their lives and deaths • Developing communication materials and engaged with stakeholders and experts by experience to increase the uptake of Annual Health Checks • We continue to undertake Care, (Education) and Treatment reviews for our inpatients and those living in the community who remain at risk of hospital admission to a mental health hospital. These reviews help us to identify that support that people might need to stay healthy and well and reduce the need for people to remain in hospital • BSW are the lead commissioner for a brand-new specialist hospital for people with a learning disability and autism who have mental health needs, this is due to open in Autumn 20205. • BSW promotes Health Passports to ensure that reasonable adjustments are shared with those who need to know about a person • BSW ICB are developing a website to support people with a learning disability and autism to identify sources of support with their health [previous BSW LeDeR action] • A Practice Forum has been established for system partners, clinicians, commissioners, and others to discuss patients care and treatment and work together to identify the best pathway for them including the use of universal services and

	identifying how reasonable adjustments can be made • Community services for people with a learning disability, autism and neurodivergence are currently being re-procured by the ICB, known as Integrated Community Based Care, this transformation will have a positive impact on the care that patients receive and ensure that community-based care across BSW is joined up • The ICB through the BSW Academy continues to support the roll out of the Tier 1 and Tier 2 Oliver McGowan Mandatory Training to system partners .
HCRG Head of Complex Health Needs Service & Clinical Specialist Speech and Language Therapist Learning Disabilities and Autism	Action Plan for 2024-25 • Look for primary care guidance on how the GP DES programme will be delivered for 2024-25 and adapt practice accordingly. • Update GP (QOF) registers for 2024-25 include transitions patients and Down Syndrome (as per Dementia pathway good practice) • Continue to support and educate GP practices on identifying patients with Learning Disabilities. • Continue to support the AHC programme as required. • To continue to try and get better access to health information between HCRG and primary care. Update smart cards and continue to try to access system one. • To carry out an audit on the quality of health checks across BANES including the use of health action plans • To look at some screening samples and what adjustments may be required to increase the uptake following a targeted support intervention such as bowel screening workshops or a visit to a breast screening unit.

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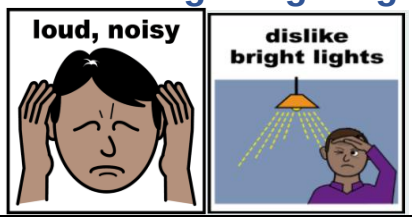
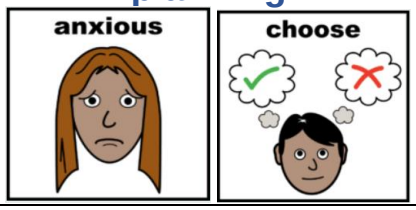
1.9 BSW LeDeR Action-Reasonable Adjustments Easy Read Guidance Shared

Supporting People with a Learning Disability, and/or Autism

BSW LeDeR Learning	Reasonable Adjustment Solution Ideas
Hidden disability 	Flag on records to alert all staff to needs/adjustments required. Offer/promote Sunflower lanyard to enable visual clue to hidden needs Ensure a Health/Hospital Passport is in place, shared, updated, and followed
Noise/Bright Lighting 	Find/dedicate a quiet waiting area to reduce impact of noise Reduce brightness in dedicated waiting area to reduce sensory stimuli
Anxiety/Anger/Procedure planning 	Offer visits to see and understand the appointment area, meet the staff, carer support and social stories Easy Read information, preparation visits, capacity assessment, advocacy support and continuity of staff
Promoting Understanding 	Double appointment times to ensure time to explain and gain understanding. Provide a simple written/printed summary of advice and actions to follow. Easy Read materials to support information sharing and understanding Ensure carer/support person attends too
Non-attendance 	Carer/family support for appointments Text reminders Non-responders follow up process
Medication/health compliance concerns 	Annual Health checks with a health action plan Medication reviews Carer/family support during appointments Consider specialist referrals for support i.e. Community LD team

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[Reasonable Adjustments] Communication Tips

Always ask to read the persons Health/Hospital/Communication Passport to understand how to communicate with the person and:

- use accessible language
- avoid jargon or long words that might be hard to understand; use short sentences and simple language and speak clearly and slowly
- be prepared to use different communication tools
- follow the lead of the person you're communicating with and go at the pace of the person you're communicating with; check you have understood and be creative.
- Give the person time to process your question and to respond.
- Start with an open-ended questions- to avoid those that can be answered with a simple yes or no. If the person does not appear to understand the question, ask it again in a different way or use different words.
- Consider using pictures or draw simple picture to help the person explain their symptoms
- Questions involving time or quantity can be challenging. Try to link this with something that happens in a person's life such as a weekly activity.
- Don't focus just on their spoken language, also observe their body language.
- Carry out any care and support in a place where there are limited distractions. For instance, Silence or put on 'do not disturb' on your phones.

Information adapted from:

https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability

G-Care - Education & Training - Reasonable adjustments for people with a learning disability (glos.nhs.uk))

https://g-care.glos.nhs.uk/education-type/51

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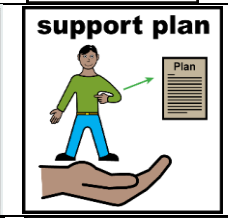
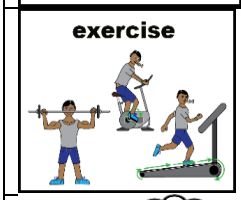
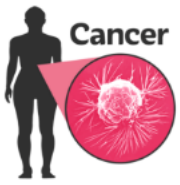
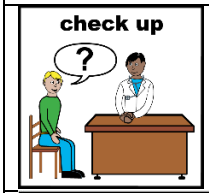
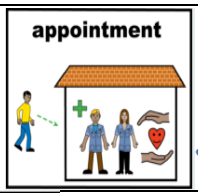
1.10 BSW 2022-23 LeDeR Report Action-Easy Read Service user Information

Following last year's BSW LeDeR report action, an easy read leaflet was developed and shared to help service users, and their carers understand how to stay well. This will continue to be promoted in 2024-25:

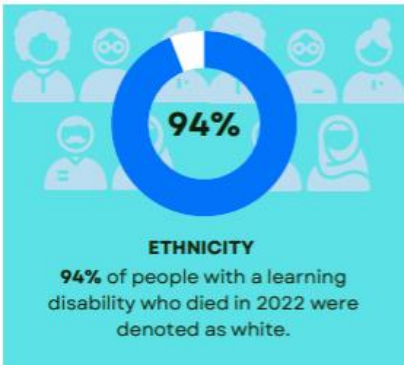
Helping you to stay healthy happy and well

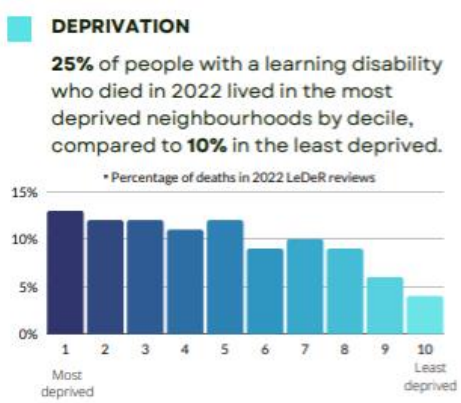
 	**it is important that you keep healthy happy and well**
 	**write and share your health/hospital passport so that staff know what you need and how to help you**
 	**eating healthy food and drinking lots of water helps you to stay well**
 	**exercise helps you to stay happy and well and can be fun!**
 	**there are covid and flu injections and cancer screening and your doctor or nurse can help you to get them**
  	**ask your doctor and dentist for an annual health checks to see how to stay healthy**
 	**there is help you at your doctors surgery reception if you need it**

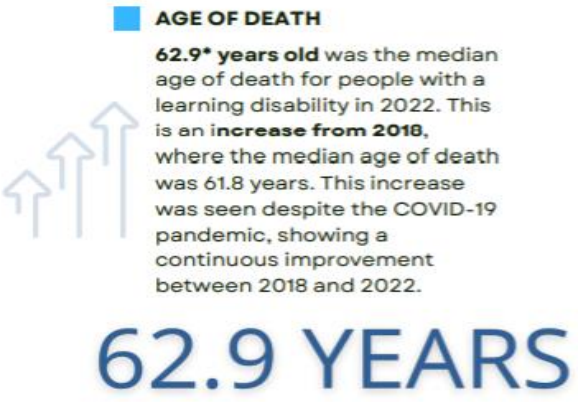
2 The 2022-23 National LeDeR Annual Report-Infographics

2.1 The following information is extracted to demonstrate a high level summary of the last national LeDeR report findings.

2.2 Protected Characteristics and Deprivation:





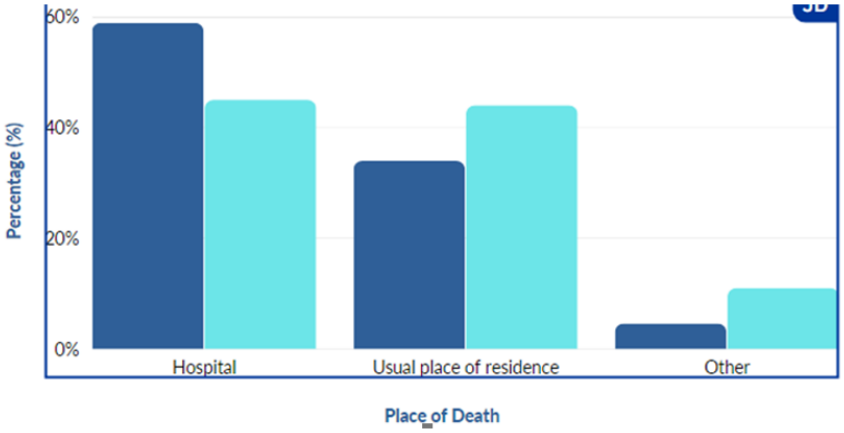


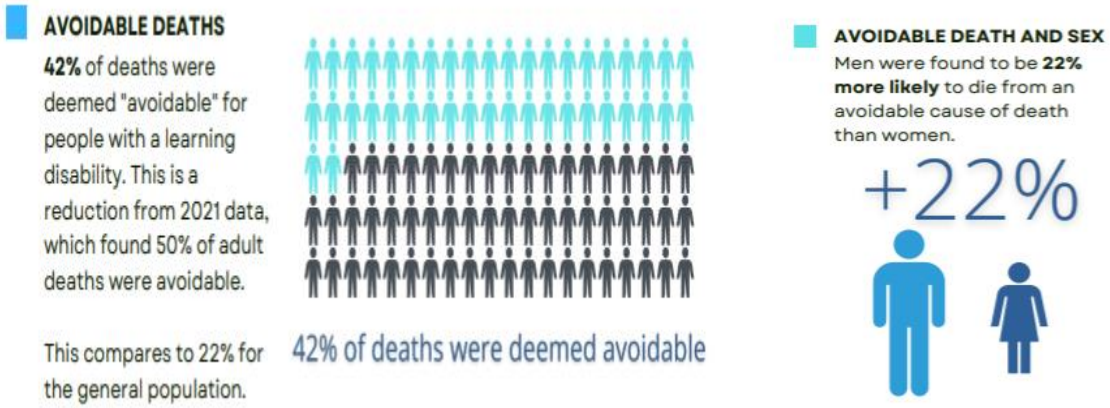
*Calculation based on adult (>18) data only for both 2022

Top 3 underlying causes of death
Respiratory conditions
Cancers
Conditions of the nervous system (including epilepsy)

2.3 Place of Death

57% of national LeDeR deaths occurred in hospital:





2.4 Deaths of Autistic Adults-New in LeDeR

110 deaths of adults with a diagnosis of autism only (and no learning disability) were notified to LeDeR and of these 36 had a completed notification.

Because of the very small numbers no conclusions can be drawn from this data, and it is NOT representative of deaths of autistic people in England in 2022 who died. 29 were male at birth and 7 were female at birth.

Grouped Underlying Cause of Death for Autistic Adults without a learning disability	Totals
Respiratory Conditions	8
Suicide, Misadventure, or Accidental Death [**11**]	11
Cardio-Vascular and Stroke	<5
Cancer	<5
Other [**12**]	8

Underlying cause of death for autistic adults with a learning disability (grouped ICD-10 codes)	Totals in the data
Respiratory conditions	**66**
Cardiovascular conditions	**27**
Cancer	**22**
COVID-19	**17**
Stroke, Cerebral Haemorrhage or Embolism	**8**

10 of the 36 reviews for autistic adults were rated as receiving overall care quality at grade 3 or below (i.e. generally indicative of poor care). Concerns included:

- A lack of high-quality training, awareness, or understanding of the specific needs of autistic people.
- A lack of adequate support services being provided, specifically tailored towards the needs of the person, or a lack of providing support to access services.
- Overlooking the potential impact of a relationship status change for autistic adults.
- A lack of crisis escalation plans, or a lack of an awareness of the increased risk of suicide in autistic adults.
- A lack of communication between different professionals and agencies providing support.
- Overshadowing of the impact of autism by other co-occurring mental health conditions

2.5 Easy Read Report : https://leder.nhs.uk/images/resources/action-from-learning-report-22-23/NHS-LeDeR-2022-2023-V12.pdf

2.6 Full Report: https://www.kcl.ac.uk/research/leder

3 2023-24 BSW LeDeR Deaths: Local Analysis of BSW Data

3.1 This part of the report is created using only local BSW LeDeR quantitative data and qualitative intelligence for BSW adult LeDeR reported deaths up (until BSW reviews were put on hold in February 2024).

Note-Child deaths are not in scope for LeDeR, child deaths are reviewed, and lessons are learnt by local Child Death Overview Panel processes (CDOP).
For further CDOP information please follow the link:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf

3.2 LeDeR Notifications Caveat

3.3 LeDeR remains notification of death dependant, to enable a LeDeR review to take place. As the programme remains non-mandated, the number of LeDeR death reviews in BSW are not validated or referenced with the total number of LD now ASD deaths. Additionally, the accuracy of demographic information and LD/ASD diagnosis is a noted action requiring improvement locally in BSW and nationally. BSW have been increasing the LeDeR programme campaign communication; to improve notification numbers. BSW have updated and shared a reviewer quality checklist which is improving the completion of all demographic information when available.

3.4 There have been minimal autism notifications in BSW and in the South West despite promotion of the policy change last year to include autism, with notification for BSW autism reviews only being sadly out of scope on review commencement.

3.5 BSW Quality of Information and Information Sharing Delays

3.6 Delays in receiving requested health and social care records sharing has delayed the completion of some reviews, affecting BSW compliance in year. Delays in Structured Judgement Reviews were also a theme in 22-23 and progress has been noted in 2023-24, but some delays did occur. Escalation has occurred in each case.

3.7 BSW Data Presentation

The following data relates to learning disability deaths only by notifications and reviews during the reporting period. Where there are low numbers of less than 5 in some areas data is presented as a percentage or excluded to protect confidentiality.

3.8 BSW LeDeR Notifications

3.9 A total of 53 BSW LDA LeDeR death notifications were received in the reporting period 01/04/23-31/03/24 compared to 56 last reporting year (noting caveat that notifications are not mandated and that the numbers are relatively small compared to the rest of the population). No autism only deaths were in scope for a review.

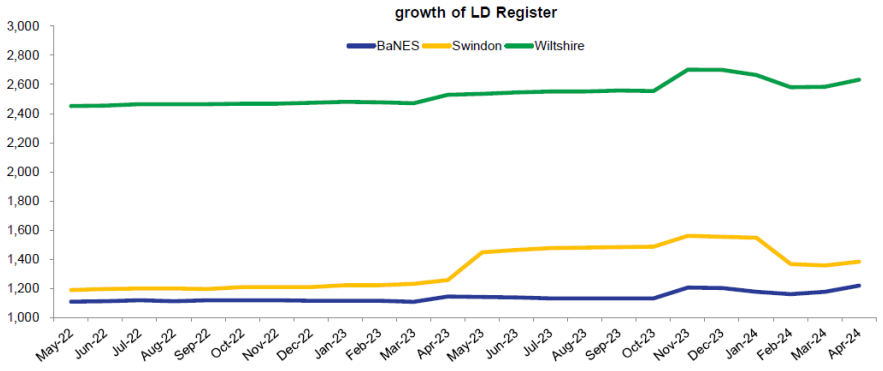
3.10 The lenth of time from death to LeDeR notification varied during the year. Some deaths were notified retrospectively following indentification and not all were in scope.

3.11 BSW LD Population Data

3.12 LD data is extracted from the GP LD Registers:

Locality	LD Register 2022-23	LD Register 2023-24
BaNES	1,108	1,177
Swindon	1,233	1, 359
Wiltshire	2,472	2,584

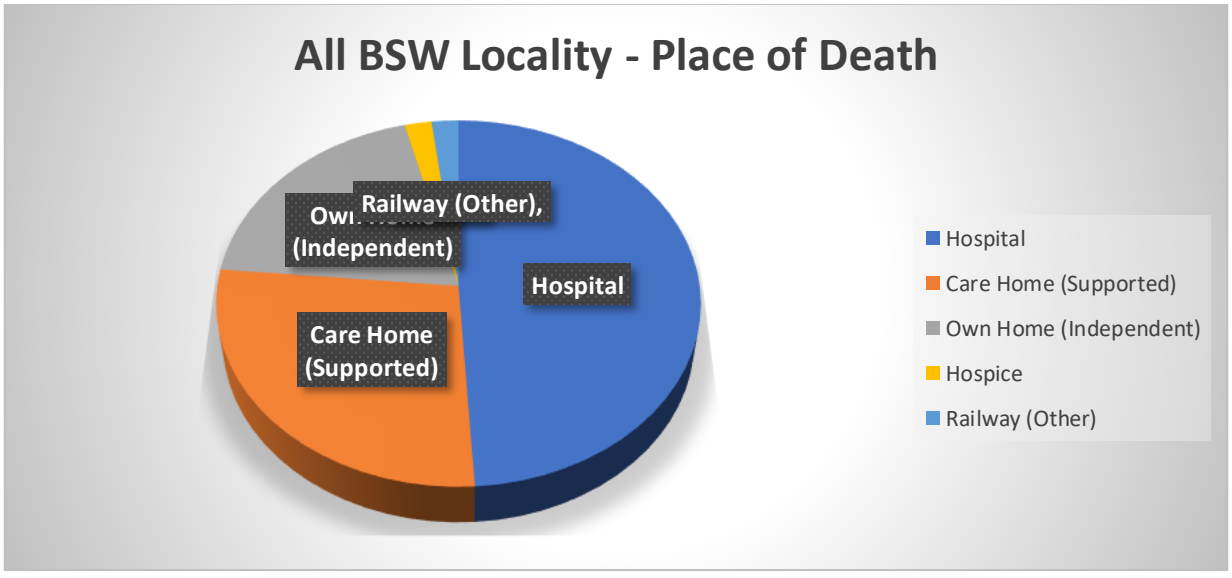
3.13 The number of people recorded on the BSW GP LD registers which has increased by 307 people when compared to last year's GP LD register data:



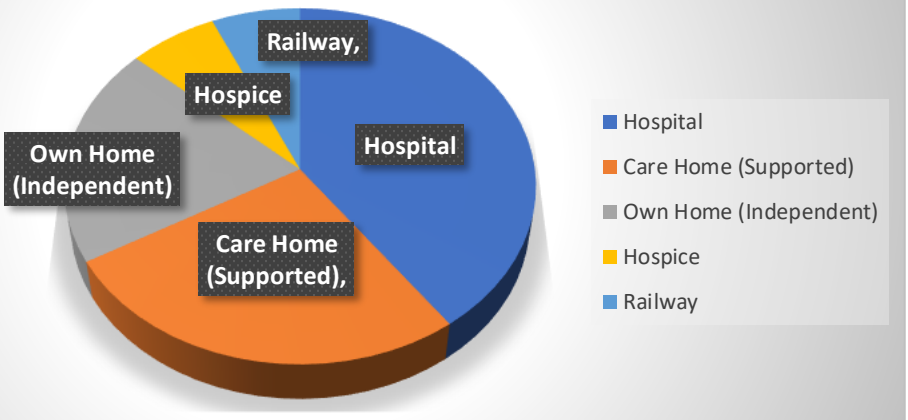
3.14 BSW LeDeR Place of Death

3.15 The deaths in each locality are those that occurred between the 1st of April 2023 to the 31st of March 2024.

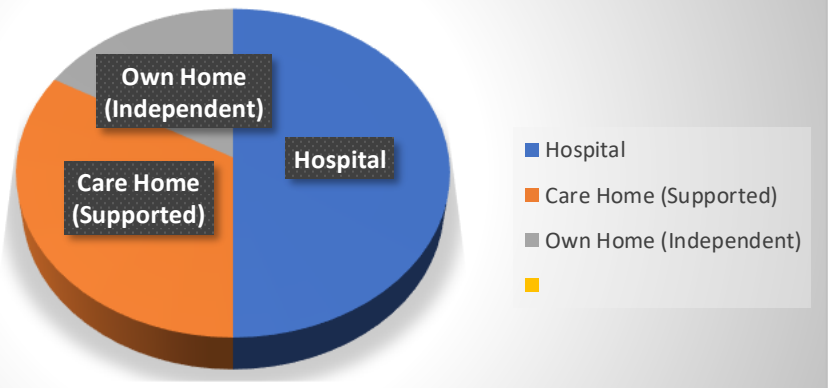
3.16 The following graphs shows that most people died in hospital (in BSW, Bristol or other out of area hospitals) as per previous reports:



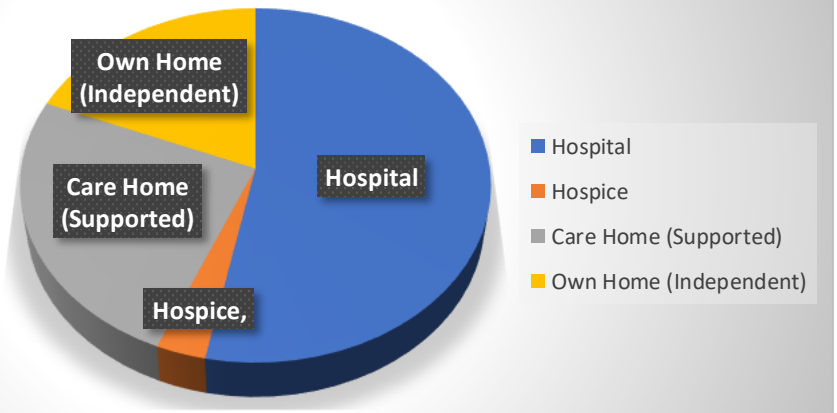
Banes Locality - Place of Death



Swindon Locality - Place of Deaths

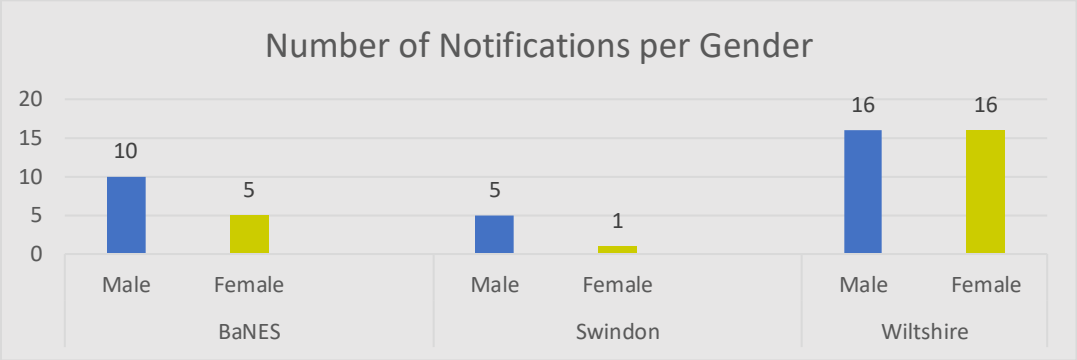


Wiltshire Locality-Place and Numbers of Deaths



3.17 Gender

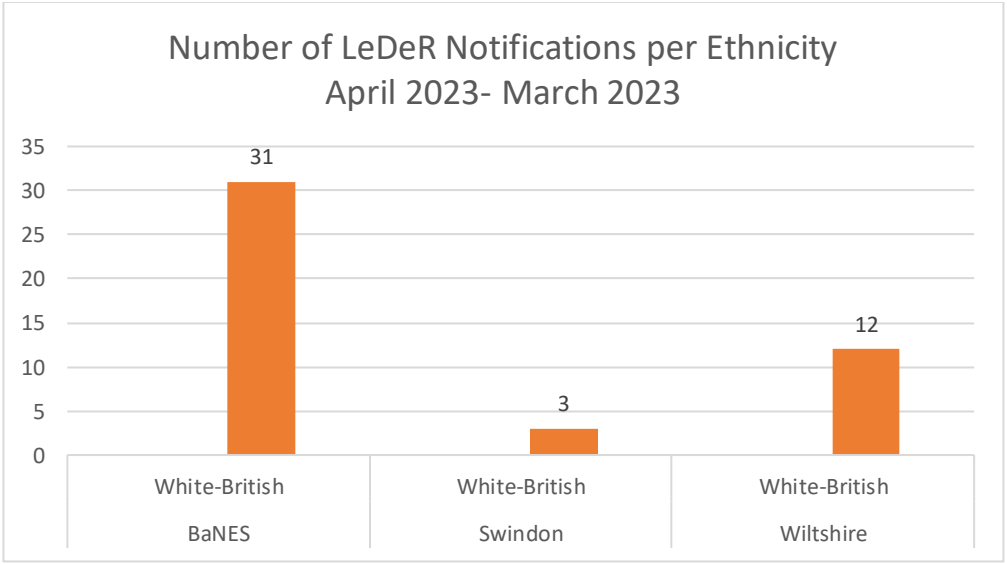
The following graph shows the gender breakdown per locality:



There has been more male than female deaths reported in BaNES and Swindon during this year, which also aligns to the fact that there are more men on the BSW GP registers, so reflective of the current learning disability GP register data.

3.18 Ethnicity

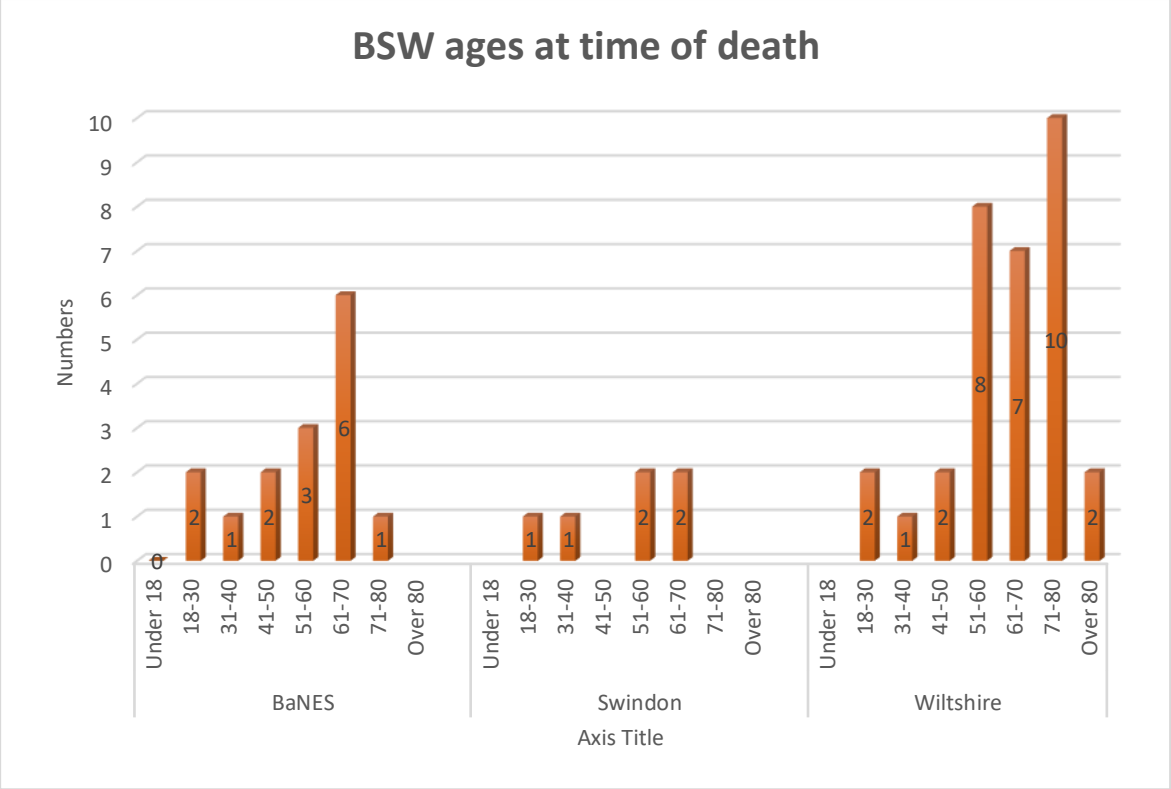
The information for ethnicity is taken directly from BSW LeDeR notifications which continue to demonstrate a lack of minority ethnic notifications:



- The remaining notifications did not include ethnicity demographics
- Note-Ethnicity is not a mandated when notifications are made

3.19 Age at Death by Locality

The ages at death in BSW LeDeR deaths during the year, showing locality variation with most deaths occurring in those over 51+ years:

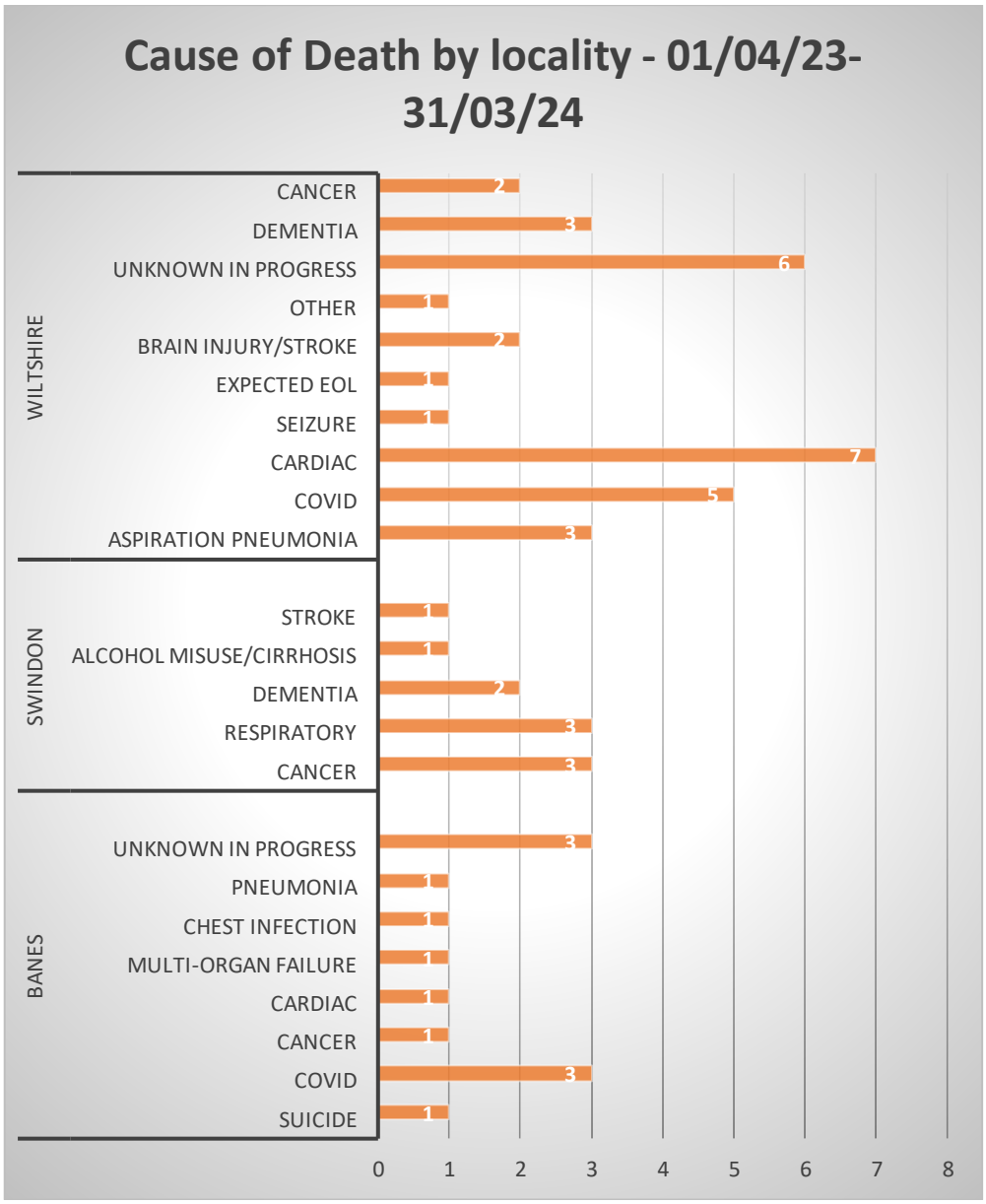


3.20 Causes of BSW LeDeR (LD only) Deaths in 2023-24

BSW LeDeR cause of death data is either shared in the LeDeR notification or later received during a review. Due to a variety of causes, data representation requires qualitative and quantitative information to draw a rounded conclusion.

Key BSW themes (noting small numbers and that some reviews remain on hold so cause of death is awaited) are as follows which reassuringly align to BSW plans already in place :

- Cardiac
- Covid
- Aspiration pneumonia and respiratory illnesses
- Cancer
- Dementia



3.21 BSW Reviews-Qualitative Stories

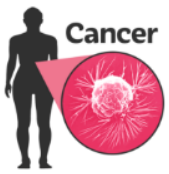
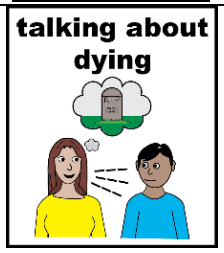
Individual LeDeR review details are not shared in this report due to confidentiality. Thematic learning is noted by the team and is represented in this reports learning actions.

3.22 Local Data Shared

The above data/this report has been shared with the BSW LDAN Steering Group and Board members, for future system learning action.

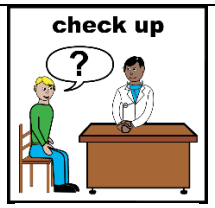
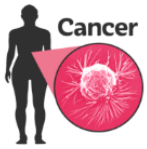
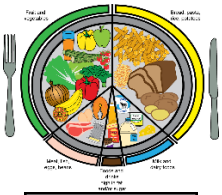
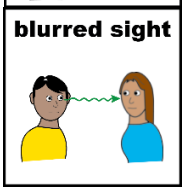
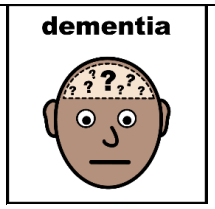
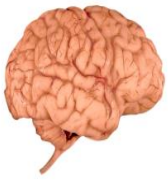
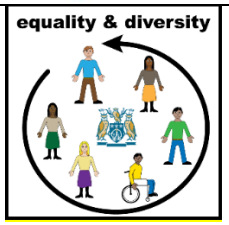
4 Annual Report Learning: 2024-2025 LDAN & LeDeR Priority Actions

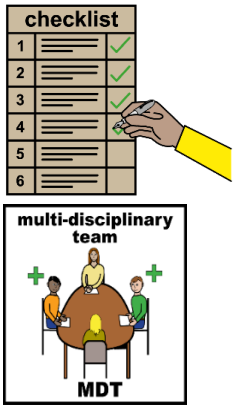
4.1 The following Easy Read summarises the LeDeR and LDAN Programme actions planned in 2024-25 with rational for each high level priority:

Easy Read Symbol	Action	BSW Rational
	**More people to receive annual health checks**	Manage existing conditions and identify new health concerns to prevent avoidable deaths Ensure Health Action Plan is in place too
	**More people to have cancer screening**	Identify and treat cancer early to improve outcomes and avoidable deaths
	**Improve community care and support to help people stay at/or closer to home**	BSW Integrated Community Based Care procurement delivery. Keep people safe and well at home. Continue plans for the new build LDAN Mental health inpatient unit
	**Increase information on a BSW ICB website for service users and staff**	To maximise use of commissioned services and signpost early intervention and prevention offers in line with the BSW needs led approach to support.
	**Ensure hospital passports and the Digital Flag are used**	Ensure that people's needs are known and met by the use of health passports and Digital Flags on all records
	**Check that people are involved in decisions (ReSPECT audit actions)**	Ensure that people and their carers are involved in decisions about end of life planning; to reduce deaths in hospital and ensure cardiopulmonary resuscitation decisions are made with people. BSW completed an audit in year in all three acute trusts and actions will continue to be monitored by each trust following the learning.

4.2 BSW 2022-23 LeDeR Annual Report Actions: Ongoing Assurance:

Easy Read Symbol	Action	Context
	**Continue sharing the South West Dysphagia 'Knowledge and Skills' document with all BSW providers of care (as dysphagia training is not mandatory to ensure staff know what to do)**	BSW LeDeR causes of deaths thematically noted aspiration pneumonia. Oral hygiene needs managing to reduce oral bacterial load and risk of aspiration. The SW LeDeR group produced a guide to upskill care staff as dysphagia training is not mandatory.
	**Helping social care providers to recognise and report earlier when people are unwell using:** RESTORE2 Recognise Early Soft Signs, Take Observations, Respond, Escalat	Identifying ill health, preventing deterioration and therefore avoiding admissions
	**Continue sharing the BSW information leaflet on how to help people (and their family/carers) to stay 'healthy, happy and well' including:** • **Annual Health Checks and action plans** • **Vaccinations** • **Cancer screening and prevention** • **Dental, hearing and eye checks**	Prevention in an Easy Read document for service users.

     	• **Healthy diets and exercise** • **Hobbies and enjoyable activities** 	
 	**Information sharing to carers and families to recognise, report and seek diagnosis/support for people with early signs of dementia**	Early recognition, dementia support and end of life planning and recognition
	**Work with minority ethnic community groups to identify and remove barriers to diagnosis, specialist care and support**	Increase minority ethnic LD or autism diagnosis, improving access to support and ensuring associated LeDeR death notifications

	**BSW in-house reviewers**	BSW still require a substantive team of reviewers to align with the national 2021 LeDeR policy. BSW ICB previously used ring fenced national LeDeR funding to source quality assured agency reviewers and this funding stream has been used up. An updated options appraisal paper has been drafted for executive review and system progression; to secure dedicated system reviewers whilst noting the finite finances that all ICB's are required to deliver to- which may affect access to dedicated resource for a non-mandated programme.
	**Look at how to increase the involvement of families in reviews (who often do not respond to LeDeR requests)**	Increase information to engage families to participate in reviews.
	**ICB Contract Quality Schedules**	To ensure LeDeR learning: reasonable adjustments & digital flag, hospital passports and Oliver McGowan training are implemented

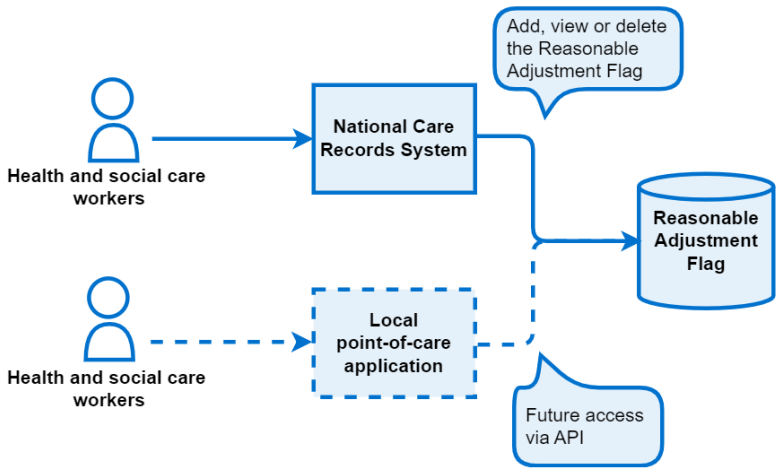
5 New National Reasonable Adjustments Digital Flag is Imminent

Based on the Equality Act (accessible services for people with disabilities) and The NHS Long term Plan, NHS Digital have built and successfully trialled a flag within the NHS; to enable health and care professionals to record, share and view details of reasonable adjustments needs, to further support meeting the Accessible Information Standard and most importantly people's needs-directly from LeDeR learning. The flag will provide:

- basic context about a patient
- key reasonable adjustments and the details related to this
- further information to aid health and care workers

Flag benefits:

- The Flag is immediately visible (to reception staff, as permitted by local role-based access controls) when the patient is referred or presents for care, often when no other information is available.
- It will ensure that details of impairments and other key information (such as communication requirements) are shared consistently across the NHS – with patient consent.
- Supports carers to feel less stressed by informing them of adjustments to services.
- It can help to reduce stress both for the patient and those treating or supporting them.
- Specialist teams will be able to set the Flag – driving up the number of patients recorded on registers, who are identified for and can benefit from adjustments. This will help screening services to adapt services to ensure patients receive screening.
- It satisfies legal obligations under the Equality Act 2010 and NHS contracts and as defined in the NHS Long Term Plan.



A case study is available: https://digital.nhs.uk/services/reasonable-adjustment-flag/reasonable-adjustment-flag-case-study

The digital flag will be rolled out during 2024, noting national delays from the panned launch in January 2024. The BSW Digital Transformation Group are sighted and overseeing IT systems interoperability.

Information:https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

The ‘go live’ date is awaited at time of writing.

Appendices

Appendix A: LeDeR Background, Policy and BSW Governance

LeDeR Background and History

LeDeR was first established in 2015 as a response to the recommendations from the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013). CIPOLD reported that people with learning disabilities are three times more likely to die from causes of death that could have been avoided with good quality healthcare (following previous Mencap reports called Death by Indifference, which exposed institutional discrimination).

CIPOLD Report Link: https@//www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

1.5 The Department of Health and Social Care previously published a government response to LeDeR aligned to the recommendations in the NHS Long Term Plan as documented in the executive summary.

1.6 The Oliver McGowan campaign was championed by Oliver's mother following learning from his tragic LeDeR review. National training is being rolled out in 2023 as a result of the learning and BSW have progressed this at pace:
Oliver McGowan | Oliver's Campaign |

South West LDA Programme-Health Inequalities and Improvement Group

BSW are also active members of the South West (SW) LDA Programme-Health Inequalities and Improvement Group, which was established to focus on the known health inequalities across the SW and nationally.

Key priorities agreed at the start include:

- Triangulation of findings and ambitions around health equality across NHSE; quarterly meetings in place with a focus on understanding and pushing forward the agenda for improving health (regional network of leaders and managers involved in health equality including safeguarding and broader health equalities).
- Link with Southwest (SW) LD and autism health equality programme
- Link with the SW GP Network as a mechanism to raise awareness of LD and autism in Primary Care
- Focused work to be conducted by the southwest equalities programme to understand the Mental Capacity Act and DNACPR, pneumonia and all associated issues, cardiac conditions, and cancer/screening.
- To ensure that lived experience people are at the centre of the health and equality program

- Increase Annual health checks for people with an LD (designed to review the health of people on a practice LD register) ensuring that coding's are correct within GP practices.
- Constipation project for adults with a learning disability and autism; plans to pull together a constipation pathway, review individualized bowel care plans and work toward a SW awareness campaign.
- Flu and COVID vaccination programmes
- Health and Wellbeing Network with the regional adjustment digital flag

LeDeR National Roles and Responsibilities: LeDeR 2021 Policy

NHS England (NHSE): National and South West

NHSE funds, manages, and monitors compliance within the (non-mandated) LeDeR programme. The NHSE South West LeDeR team now share quarterly LeDeR compliance data which is also shared with the SRO.

There is a South West LeDeR operational group of which the LeDeR LAC's are members and contribute to operational discussions.

LeDeR National IT Platform

The Bristol University contract commissioned previously to supply the national LEDER Platform and system ended on 31 May 2021 (and was initially commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England).

NHS commissioned the South, Centre, and West Commissioning Support Unit (SCW) to deliver the LeDeR platform, which went live on 1 June 2021, and has remained under continual development since. The platform has generated ongoing system operability issues since its launch, and these continuing concerns have been raised at the South West LeDeR (Local Area Contact) Operational Meetings.

LeDeR Legal Basis To Access Health and Care Records

A key part of the Learning Disability Mortality Review (LeDeR) programme is to support local areas to review the deaths of people with learning disabilities. As part of this process, it is important for local reviewers to access the deceased person's health or care records, and this is nationally agreed for LeDeR. The LeDeR web platform states that section 251 of the NHS Act 2006 is the legal basis for LeDeR information sharing: https://leder.nhs.uk/your-personal-information

Health records relating to deceased people do not carry a common law duty of confidentiality, but it is Department of Health and General Medical Council (GMC) policy that records relating to deceased people should be treated with the same level of confidentiality as those relating to living people. However, whilst confidentiality is an important duty, it is not absolute.

Professionals can disclose personal information if:

- The patient consents. This is not applicable in the LeDeR programme as the person who is the subject of the review will have died without giving consent.

- It is required by law. This is not applicable in the LeDeR programme as there is no legal mandate for confidential patient-identifiable information to be shared for use by the programme.

- It is allowed by law. Some legislation falls short of creating a duty to share confidential information; instead, it makes it possible for organisations to share confidential information. Such confidential information sharing must be necessary and proportionate to the purpose. Section 251 of the NHS Act 2006 provides the Secretary of State for Health with the authority to make regulations that set aside legal obligations of confidentiality to allow the disclosure of confidential patient information in situations where it is not possible to use anonymised information and where seeking consent is not practical. Further information about Section 251 can be found by following the link: http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/.

Noting the ongoing delays in the sharing patient and client records requests, the ambition remains for future BSW reviewers to have SMART card/IT access to improve access to GP and system records. This will be progressed if and when a BSW dedicated and substantive reviewer team is in place.

Integrated Care System Ownership

The 2021 LeDeR policy makes it clear that the governance oversight within the ICS rests with an agreed executive lead, and that ICS's must ensure that LeDeR is an integral part of ICS governance and quality reporting arrangements:

> *'Local governance arrangements should feed into local quality surveillance groups and, for local authorities, health, and wellbeing boards, to ensure the people who can affect the necessary improvements understand the issues that need to be addressed. Collaborations between partners across health, care services, public health and the community and voluntary sector will be key to help to address health inequalities, improve outcomes and deliver joined up, efficient services for people with a learning disability and autistic people'*

And:

> *Local authorities are expected to contribute to and be part of ICSs and have a role to play in reducing health inequalities and premature mortality of people with a learning disability and autistic people. Local governance arrangements must promote meaningful co-production with people with lived experience.'*

The BSW LeDeR SRO and LAC will ensure that LeDeR is embedded in all ICB and Integrated Care Partnership (ICP) strategy and associated implementation plan during and beyond the next financial year.

BSW LeDeR Programme Governance Arrangements

The BSW LeDeR Governance and Assurance Group (previously called a Steering Group in the old national policy) is tasked with the remit to ensure that learning and recommendations are rolled out and embedded from the learning of local BSW and national LeDeR reviews. Members of the group include expert representation from the BSW acute hospitals, mental health and local authorities, as well as Healthwatch to represent the public.

Assurance and approval of all LeDeR progress and annual reports continues via the BSW Quality and Outcomes Assurance Committee (QOAC) and BSW LDA Programme Board.

LeDeR reports into the BSW Learning Disability and Autism Programme Board with LeDeR aligned directly to the workstream pillars:

BSW LeDeR Panel: Quality of Reviews

A previous BSW LeDeR governance and quality improvement review instigated a Quality Assurance (QA) Panel for the members to have oversight assurance of all reviews and to challenge any gaps in information or concerns, which is documented through the confidential BSW QA Panel notes. Members are experts from BSW providers who challenge and approve reviews collectively.

The BSW Quality Assurance (QA) Panel receive case learning summaries under the Panel review process to ensure robust case learning is shared (and improvements are recognised as required by members to share the learning in each locality). The panel also focus on the lives and wellbeing of people to seek learning and action required.

A BSW checklist was developed and shared with reviewers; to improve the quality and detail of reviews post the national 2021 policy implementation (which saw the LeDeR review template cut significantly with an identified potential risk of key information being missed). The BSW Local Area Contact (LAC) amended this checklist during 2022-23 in response to a few quality concerns. The updated checklist was shared with all reviewers and is now required to accompany all completed reviews for assurance that BSW expectations are met.

There is an NHSE expectation to convert more (initial) LeDeR reviews into (in-depth) focused reviews. The South West LAC's group have discussed that local quality checklists (seeking more assurance beyond the initial review constraints) may have inadvertently affected the focused review numbers.

A live QA Panel action tracker is in place to monitor action delivery.

BSW LeDeR Executive Leadership

The BSW ICB Chief Nurse is the Executive Lead for LeDeR. The Deputy Chief Nurse continues in leading the oversight and delivery of the BSW LeDeR programme.

Bath and North East Somerset, Swindon and Wiltshire Partnership
Working together for your health and care

NHS
Bath and North East Somerset, Swindon and Wiltshire
Integrated Care Board

Appendix B

BSW LeDeR Inequality Priorities and The Public Sector Equality Duty

The Public Sector Duty

The Duty came into force in April 2011 which requires public sector bodies to have due regard to the need to achieve the objectives set out in the Equality Act 2010 to:

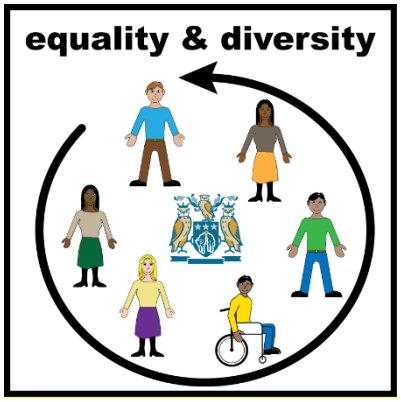
(a) eliminate discrimination, harassment, victimisation, and any other conduct that is prohibited by or under the Equality Act 2010.

(b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it.

(c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

To ensure transparency, and to assist in the performance of this duty, the Equality Act 2010 (Specific Duties) Regulations 2011 require public authorities, named to publish:

- Equality objectives, at least every four years (from 6th April 2012)
- Information to demonstrate compliance with the public sector equality duty (from 31st January 2012)



The BSW LeDeR Local Area Coordinator (LAC) is a member of the BSW Inequalities Group and reports about the LeDeR annual report to the group to share inequalities learning and action required.

National Priorities and LeDeR Triangulation

NHS Long Term Plan 2019

The Long Term Plan (LTP) was developed to '*make the NHS fit for the future, and to get the most value for patients.'*

Chapter two of the NHSE Long Term Plan looks at health inequalities and sets out the ambition that people with a learning disability and autistic people *'get better support.'*

Page 52 of the plan specifically focuses on learning disability and autism:

- *'Action will be taken to tackle the causes of morbidity and preventable*
- *deaths in people with a learning disability and for autistic people.*
- *The whole NHS will improve its understanding of the needs of people with learning disabilities and autism and work together to improve their health and wellbeing.*
- *Reduce waiting times for specialist services.*
- *Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives.*
- *Increased investment in intensive, crisis and forensic community support*
- *We will focus on improving the quality of inpatient care across the NHS and independent sector.'*

Easy Read Long Term Plan Link: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/easy-read-long-term-plan-v2.pdf

NHSE 2024-25 Operational Planning Guidance

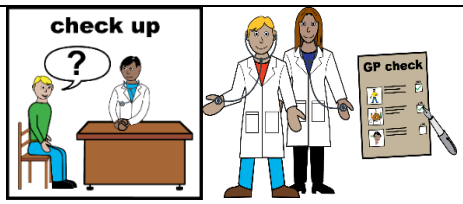
The 2024/25 NHS Priorities and Operational Planning Guidance notes mental health progress in reducing mental health inpatient admissions for people with a learning disability, along with a rise in the numbers of autistic people in mental health settings which requires focus, and the key system actions required are:

- *reduce admissions of autistic people into mental health inpatient care and increase discharges into community settings so that the overall number of autistic people in hospital is lower*
- *continue to discharge people with a learning disability with the longest lengths of stay into community settings and continue to make progress on reducing the number of people with a learning disability in hospital*
- *ensure that each learning disability annual health check is accompanied by a health action plan*
- *develop integrated, workforce plans for the learning disability and autism workforce to support delivery of the objectives set out in this guidance (using the 2022/23 workforce baseline exercise to inform plans)*
- *ensure training for staff includes training in learning disability and autism, appropriate to their role, in accordance with the requirements of the Oliver McGowan Code of*

Practice,8 and support delivery and uptake of wider learning disability and autism workforce initiatives such as the National Autism Trainer Programme

- *improve autism diagnostic assessment pathways through implementation of the national framework*
- *continue to improve the accuracy and increase the size of GP learning disability registers*
- *support delivery and use of the reasonable adjustment digital flag to reduce the health inequalities of people with a learning disability and autistic people*

The Planning Guidance has two key related objectives:

	**Annual Health Check and Plan** ***1.*** *Ensure 75% of people aged over 14 on GP learning disability registers receive an annual health check and health action plan by 31st of March 2025*
	**Avoiding and reducing specialist hospital admissions** ***2.*** *Reduce reliance on mental health inpatient care for people with a learning disability and autistic people, to the target of no more than 30 adults or 12–15 under 18s for every 1 million population*

Link: https://www.england.nhs.uk/wp-content/uploads/2024/03/2024-25-priorities-and-operational-planning-guidance-v1.1.pdf

Appendix C

Reasonable Adjustments

Under the Equality Act 2010 umbrella, anticipatory 'reasonable adjustments' are required by public sector organisations to ensure that services are accessible to disabled people under the Accessible Information Standard: https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

Over the last few years, the LeDeR programme has recognised a need to improve the recognition and meeting of the needs of people with a learning disability such as:

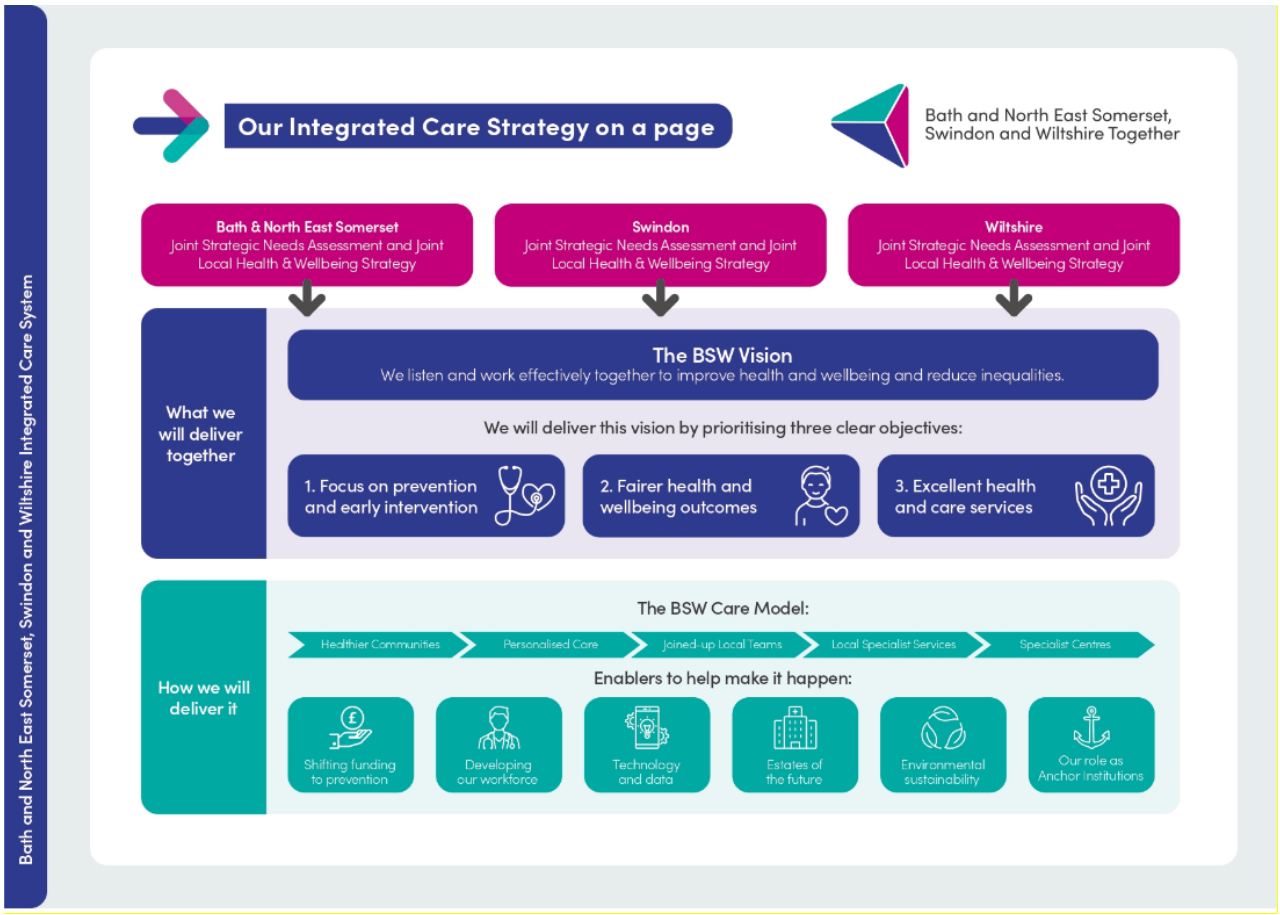
- reading or writing
- explaining symptoms or a sequence of events
- understanding new information or taking information in quickly
- remembering basic information such as date of birth, address, health problems and appointments
- managing money
- understanding and telling time
- understanding how to prevent ill health and managing any health needs.

This report therefore also includes Easy Read in key areas to support inclusion.

ICB Strategy

BSW LeDeR and System Inequality Progress: Integrated Care Partnership (ICP)

The BSW LeDeR programme works to ensure that the LeDeR actions are aligned and progressed as a system through the new BSW strategy vision delivery and targeted pillars of work as agreed via LDAN Programme Board.



A link to the full Strategy is: [Integrated-Care-Strategy-v4.pdf (bswtogether.org.uk)]