NHS
Bath and North East Somerset,
Swindon and Wiltshire
Clinical Commissioning Group

Bath and North East Somerset, Swindon, and Wiltshire (BSW) Learning Disability Mortality Review (LeDeR)

Annual Report 2020 / 21

Learning Disabilities Mortality Review
(LeDeR) Programme

Executive Summary

BSW Key LeDeR Headlines

The following key BSW LeDeR learning and action points have been shared to prioritise and progress into 2021-22, supported by a new BSW LeDeR database enabling enhanced data analysis and utilising national intelligence:

- LeDeR reviews within BSW show the highest reported cause of death as aspiration pneumonia/pneumonia/respiratory causes (mirroring the national picture)
- Acknowledging the improvements made/planned by the Learning Disability (LD) BSW Annual Health Checks project, the system must continue to address annual health checks compliance gaps (with inconsistent quality of outcomes such as a robust health action plan for the person/their carer)
- Further progressions of Learning disability (LD) hospital/care passport availability, quality, due to inconsistent use across BSW
- Improving LD diagnosis accuracy (GP records particularly); identifying and meeting needs (threshold access to specialist services)
- Monitoring of Mental Capacity Assessment/adherence
- Routine health screening attendance gaps (Public Health led breast/bowel/cervical)
- Epilepsy management (linked to aspiration pneumonia/ED attendances)
- A dedicated audit review of Do Not Attempt Resuscitation (DNAR), following the CQC publication Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic: Interim report (cqc.org.uk), aligned to quality and patient safety monitoring and overseen by BSW Learning Disability and Autism (LDA) Board. The BSW LeDeR action plan will be targeted at supporting quality improvement and audit within acute trusts, supported by specialist nurses and quality teams
- The need to recruit substantive BSW wide reviewers as a part of the new 2021 LeDeR national policy implementation, currently planned from June 2021.

LeDeR Background and History

The Learning Disability Mortality Review (LeDeR) programme (a joint health and social care project, involving healthcare providers across the health economy, Local Authority and CCG's) was 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.

The national LeDeR programme rolled out a review process for the deaths of all people with learning disabilities aged 4 years and upwards.

The LeDeR (national and local) programme aims are to:

- identify what works well to support people with learning disabilities (LD) to live long and healthy lives,
- identify (inequality) factors which may have contributed to deaths of people with learning disabilities so that changes can be made to reduce the impact of these factors,
- develop and deliver action planning; to make the necessary changes to health and social care services for people with learning disabilities.

National LeDeR Report Mandate

The 2020/21 NHS Operational Planning Contract Guidance states under 3.3:

‘’an annual report will be submitted to the appropriate board/committee for all statutory partners demonstrating action taken and outcomes from LeDeR reviews”.

2020-21-NHS-Operational-Planning-Contracting-Guidance.pdf (england.nhs.uk)

BSW CCG are working to provide translation of this report into Easy Read.

NHS E Long Term Plan/Patient Safety Strategy Links:

The NHS will:

- *Adopt and promote key safety measurement principles and use culture metrics to better measure how safe it is.*
- *Use new digital technologies to support learning.*
- *Introduce the Patient Safety Incident Response Framework to improve investigation into incidents.*
- *Implement a new and independent Medical Examiner system to scrutinise deaths; directly aligned to LeDeR.*
- *Improve the response to new and emerging risks.*
- *Share insight from litigation to prevent harm.*

BSW 2020 LeDeR Report Timespan

The previous 2019 BSW LeDeR report covered the period from December 2018 to December 2019.

For this year, in line with updated NHSEI guidance, this report is aligned to the 20/21 financial year period, however, does also include data from January 2020 for accuracy and completeness.

LeDeR Commissioning

The Bristol University contract, commissioned to supply the LEDER Platform, closes on 30 April 2021 (as commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England). The newly commissioned South, Central and West Commissioning Support Unit (SCW) LeDeR platform will go live on 1 June 2021. The accompanying (public) website that Bristol hold will also go live from 1 June and both are under development at time of writing. There will therefore be a two month pause and potential new review backlog generated as a result of changes to the LeDeR platform.

BSW LeDeR Governance Oversight

A BSW wide quarterly LeDeR Steering Group was established December 2017 with the dedicated remit to ensure that learning and recommendations are rolled out and embedded from the local BSW LeDeR reviews. Learning and actions from the reviews are tracked and monitored through the LeDeR steering group. The BSW steering group has in 2020 undergone a further governance review in order to better understand current challenges, enhance governance processes (including health and care system resource and capacity) and seek improved opportunities for learning into action across BSW.

Additionally, the learning from LeDeR has been shared on the 17th of March 2021 at the BSW Quality Surveillance Group (GSG) meeting, within a learning disability and Autism Spectrum Disorder (ASD) Deep Dive Presentation. There is a firm commitment from across the BSW health and care system to progress priority actions and gain further assurance during 2021/22.

BSW LeDeR Leadership

The BSW Deputy Director of Nursing and Quality continues in leading the oversight of the BSW LeDeR programme.

BSW Resource Capacity Update

The LeDeR Local Area Coordinator (LAC) role manages the allocation, timeframes for submission, approval and reporting on all LeDeR reviews (in BSW per locality in addition to their current substantive roles). The two previous locality LAC gaps as reported in 2019 were resolved in 2020, and the planned BSW reviewer resource mapping exercise was also completed. The requirement for a further LAC is being reviewed for the BSW ICS, however this will need to be considered alongside planned national changes due in 2021.

BSW Governing Body Report

A BSW LeDeR video was requested and created by two BSW LAC's and shared with the BSW Governing Body on 15th October 2020. This explained the LeDeR programme and give a brief summary of BSW headlines and progress. The link to the video is: https://youtu.be/9MpI-kNRwII

BSW 2020 LeDeR Recovery Plan

As in all sectors, the Covid-19 pandemic has impacted available reviewer and LAC capacity within BSW during 2020. However, BSW did still meet the required Key Line of Enquiry (KLOE); to clear a large backlog of reviews (older reviews that required completion within 6 months of notification) and met the recovery plan by the creative use of NHS England dedicated LeDeR funding, and also resources from The North of England Commissioning Support (NECS) Unit team (commissioned by NHS England) in supporting the completion of delayed reviews.

BSW Access to 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 may be important for local reviewers to access the deceased person's health or care records.

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/.

The BSW Local Area Contacts (LACs) have over the past months experienced considerable time delays for completing reviews due to gaining access to records. Within the BaNES Locality the LAC has had access to a system called Liquid Logic which has proved beneficial, and it is recognised that there needs to be a wider BSW proposal to allow access to various systems to ensure information can flow. The option for BSW reviewers to have SMART card access to improve access to GP records is under consideration, noting the governance requirements to approve this.

2021-22 National LeDeR Policy and Process Amendments

NHS England has announced proposed changes to the national LeDeR programme. A regionally supervised Integrated Care System (ICS) footprint approach has been proposed. Each ICS will be required to have a dedicated LeDeR team, assumed by using existing funding, and each review is proposed to have an initial review and then onward appropriate follow up review as required.

The headline policy changes have been shared in March 2021 which includes:

- A required dedicated Integrated Care System LeDeR delivery team
- A new national LeDeR (2021) policy, so a BSW ICS governance/policy review is therefore now required
- Will now include 18+yrs Autism Spectrum Disorder (ASD) deaths so an increase in the review workload is expected. As a result, a BSW estimated data analysis is underway to estimate the percentage increase to support resource planning
- Rebranded as 'Learning from the Lives and Deaths' (LD and ASD)
- New LeDeR specific job roles announced/required
- Substantive reviewers to work within a dedicated/managed team is required.
- Local Area Contact (LAC) role is to change to work for the ICS, independent from the review team
- New senior reviewer leading the team of reviewers; with dedicated administration required

Policy Delivery timescales:

- **1st June 2021** - The new review process will need to be implemented by ICSs in line with the changes to the web-based platform which will go-live on 1st June 2021. ICSs will need to agree with their regional teams how they will assure quality during the transition phase

- **30th September 2021** - ICSs should have a clear plan in place for the new quality assurance structures and processes and how it will implement the workforce model if not already in place

- **Later in 2021** – notifications and reviews for autistic adults will begin and further guidance will be published

- **1st April 2022** – ICS quality assurance structures and processes to be operational

- **1st April 2022 -** all changes within the LeDeR policy must be implemented by integrated care systems including reviewers working in supervised teams with administrative support

https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

BSW Learning into Action Priorities

Following the completion of the backlog of reviews, the BSW LeDeR action learning workshop was rescheduled and delivered on 29th April 2021 (postponed from January due to system capacity in the Covid pandemic). Feedback is currently under collection to progress.

The learning has also been shared in March 2021 via a dedicated presentation to the BSW Learning Disability and Autism (LDA) Programme Board, Quality Surveillance Group and also additionally via a second BSW LeDeR Newsletter to ensure that learning and key information was shared internally and externally across BSW (see Appendix B).

This report has been written (as nationally required) but also to summarise learning from the BSW LeDeR Steering Group and other local committees to move forwards at pace.

BSW LeDeR Team Feedback

BSW reviewers and Steering Group members have contributed to Appendix C to capture their unique feedback.

LeDeR Programme Historic Timeline:

2015	1st June – establishment of LeDeR programme in response to significant ongoing concerns about the likelihood of premature deaths of people with learning disabilities. The LeDeR acronym stands for Learning Disabilities Death Review and LeDeR is pronounced as 'leader'. Team based at the University of Bristol responsible for developing and rolling out a review process for deaths of people with learning disabilities that takes a holistic perspective of their health and social care needs and how these needs were met.
2016	Pilot sites established and trial review process. NHS England National Operational Steering Group established. Each NHS region appointed an NHS England Regional Coordinator to guide the roll out of the LeDeR programme across their geographical region. First annual report published October 2016, describing the 'set up' activities for the programme.
2017	April – introduction of the national Learning from Deaths framework in England which states that deaths of people with learning disabilities should be reviewed using LeDeR methodology. LeDeR Steering Groups established to cover all Clinical Commissioning Groups (CCGs) (apart from Bristol, North Somerset and South Gloucestershire which was restructuring at the time).
2018	Second annual report published May 2018. Handover of quality assurance of completed reviews from University of Bristol to NHS England. Train the trainer model, and e-learning introduced for training reviewers and local area contacts. Handover of this from University of Bristol to NHS England. Links and interface between LeDeR and other mortality review programmes and initiatives (e.g. reviews of deaths in acute hospitals; child death review process; medical examiners) to avoid duplication.
2019	Third annual report published May 2018. Publication of Action from Learning report by NHS England. NHS Long Term Plan supports the continuation of the LeDeR programme. LeDeR (NECS) project started to ensure more timely completion of reviews.
2020	Department of Health and Social Care publish response to third LeDeR annual report.

Introduction and Context

1.1 The Learning Disabilities Mortality Review (LeDeR) programme is currently funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). It is the first national programme of its kind in the world.

1.2 Its overall aims are:

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

Those covered by the LeDeR programme

The LeDeR programme reports on deaths of people with learning disabilities[5] aged 4 years and over[6]. The definition of 'learning disabilities' is that of 'Valuing People' (2001)[7] and includes the presence of:

'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.'

1.3 The programme was established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD). http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

1.4 CIPOLD reported that for every person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so. More recently, analysis of data from the Primary Care Research Database suggested that the all-cause standardised mortality ratio for people with learning disabilities was 3.18, and that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.

1.5 The LeDeR programme contributes to improvements in the quality of health and social care for people with learning disabilities in England by supporting local areas over) using a standardised review process. This enables them to identify good practice and what has worked well, as well as where improvements to the provision of care could be made. Recurrent themes and significant issues are identified and addressed at local, regional, and national level (LeDeR website extracts) and annual reports are published nationally.

1.6 The Department of Health and Social Care previously published a government response to LeDeR aligned to the recommendations NHS Long Term Plan:

Easy read: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/easy-read-long-term-plan-v2.pd

1.7 What is LeDeR in Easy Read?

The Learning Disabilities Death Review Programme, known as LeDeR, is funded by NHS England.

It is trying to improve the care and medical treatment and to help reduce early deaths of people with learning disabilities.

The LeDeR programme team at the University of Bristol helps trained people review the deaths of people with learning disabilities.

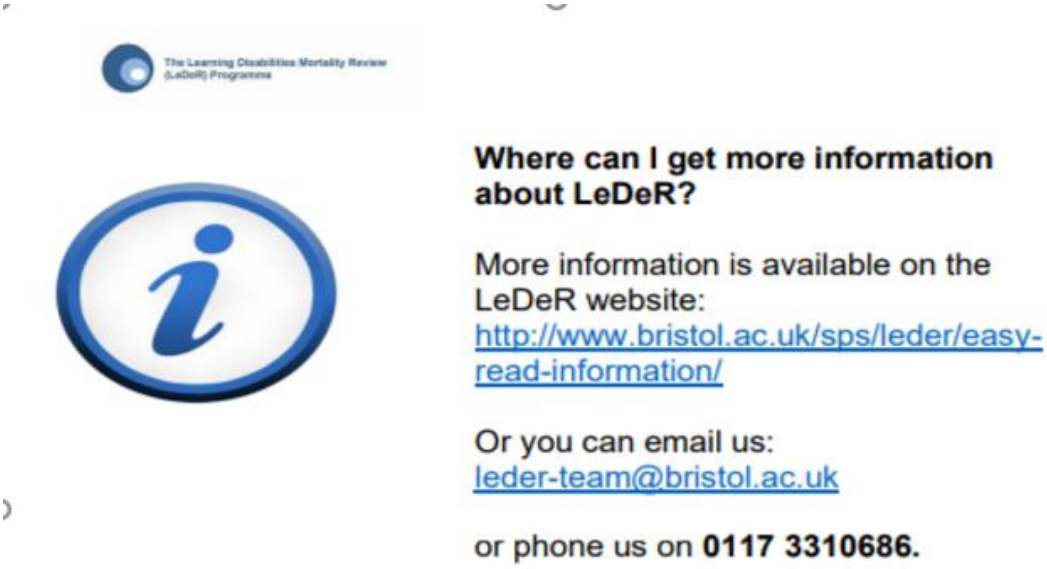
The important things the programme is doing:

1. The LeDeR programme is trying to make a difference to the lives of people with learning disabilities.

2. The programme needs to hear from people with learning disabilities and their families.

3. When working with other investigations and reviews, we promise to work together.

4. The programme is trying to make sure that reviews of deaths lead to better care for people with learning disabilities.



1.8 **LeDeR National Roles and Responsibilities:**

The University of Bristol
The universities' role is currently to complete the following (although handover is planned by the 1 June 2021):

- Record all reported deaths of people, aged 4 and over, who have learning disabilities (as mandated by the LeDeR policy).
- Provide technical support for local NHS and care staff in England, who carry out reviews into each death.
- Ensure all the confidential data about deaths and reviews is stored securely on the university's computer servers.
- Analyse, report on, and make recommendations about all completed reviews.

1.9 **NHS England (NHS E)**
NHS E funds and manages the LeDeR programme, with the aim to improve the quality of health and social care.

1.10 **The Healthcare Quality Improvement Partnership (HQIP)**
HQIP manages the current contract between the University of Bristol and NHS E.

1.11 **Clinical Commissioning Groups (CCG's)**
The LeDeR website summarises that CCG's 'work in every area of England to make sure that LeDeR reviews are carried out in a timely way. CCGs also monitor the quality of reviews, and embed the learning and actions required.

1.12 **North of England Commissioning Support Unit (NECS)**
NECS have been commissioned by NHS England to carry out some of the delayed LeDeR reviews (notified before 1 January 2019) on behalf of CCG's and have supported BSW by completing some high-quality backlog reviews.

1.13 **LeDeR Steering Groups**

The LeDeR Steering Groups are based in each designated area of England and are responsible for developing plans and making sure that learning from local reviews improves care and treatment both locally and nationally. BSW has a dedicated Steering Group, with previously approved Terms of Reference that are currently under review to reflect local plans and further action into learning aspirations (see 1.13).

1.14 **BSW LeDeR Steering Group (SG) Structure**

A BSW LeDeR Steering Group was first set up in 2017 and a wide range of health and social care colleagues were invited across BSW.

There have been challenges in 2020 with full provider membership for some meetings due to the Covid pandemic health and social care impact, however the planned BSW LeDeR governance policy and process has been reviewed, amended, and approved.

The steering group instigated a Quality Assurance Group in 2020 to oversee the quality of reviews and approve submission.

The main focus continues to be local learning into action (as more reviews have been completed), also aligned to the national learning. There is a dedicated LeDeR action plan which is being updated and progressed for 21/22. The CCG also awaits the national LeDeR handover and associated system, and process changes due in 2021.

1.15 **LeDeR National Annual Report**

The 2020 fourth national LeDeR annual report was published by Bristol University in 2020 and the links are:

Easy Read Report: LeDeR_2019_annual_report_FINAL2.pdf (bristol.ac.uk)
Full Report:LeDeR_2019_annual_report_FINAL2.pdf (bristol.ac.uk)

"The care given at the hospital involved multiple specialities, but it was not coordinated in an effective way." (reviewer).

"Social care package does not seem to have changed to meet his changing needs." (reviewer).

1.16 To avoid duplication the national report is signposted and referenced, whilst also highlighting below the 10 key national recommendations as follows, with a national caveat that:

''The recommendations were developed prior to the COVID-19 pandemic. We acknowledge that due to the pandemic, they may not be able to be acted on immediately''.

Summary of recommendations[3]

Recommendation 1. A continued focus on the deaths of all adults and children from BAME groups is required.

Recommendation 2. For the Department of Health and Social Care (DHSC) to work with the Chief Coroner to identify the proportion of deaths of people with learning disabilities (and possibly other protected characteristics) referred to a coroner in England and Wales.

Recommendation 3. (Repeated from the House of Lords Select Committee on the Mental Capacity Act 2005).The standards against which the Care Quality Commission inspects should explicitly incorporate compliance with the Mental Capacity Act as a core requirement that must be met by all health and social care providers.

Recommendation 4. Consider the recommendations from the 'Best practice in care coordination for people with a learning disability and long term conditions'[4] (March 2019) report and:

- Establish and agree a programme of work to implement the recommendations.
- Liaise with NIHR regarding the importance of commissioning a programme of work that develops, pilots and evaluates different models of care coordination for adults and children with learning disabilities.

Recommendation 5. Adapt (and then adopt) the National Early Warning Score 2 regionally, such as the Restore2™ in Wessex[5], to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by:

- Involving people with learning disabilities, their families and professional organisations.
- Disseminating for use across acute, primary and community settings.

Recommendation 6. Consider developing, piloting and introducing:

- Specialist physicians for people with learning disabilities who would work within the specialist multi-disciplinary teams.
- A Diploma in Learning Disabilities Medicine
- Making 'learning disabilities' a physician speciality of the Royal College of Physicians.

Recommendation 7. Consider the need for timely, NICE evidence-based guidance that is inclusive of prevention, diagnosis and management of aspiration pneumonia. The outcome of such considerations should be shared with DHSC and NHSE.

Recommendation 8. Right Care to provide a toolkit to support systems to improve outcomes for adults and children at risk of aspiration pneumonia.

Recommendation 9. Safety of people with epilepsy to be prioritised. The forthcoming revision of the NICE Guideline 'Epilepsies in children, young people and adults' to include guidance on the safety of people with epilepsy, and safety measures to be verified in Care Quality Commission inspections.

Recommendation 10. For a national clinical audit of adults and children admitted to hospital for a condition related to chronic constipation. The National Clinical Audit and Patient Outcomes Programme is one way this could happen.

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[3]The recommendations were developed prior to the COVID-19 pandemic. We acknowledge that due to the pandemic, they may not be able to be acted on immediately.
[4]https://ipc.brookes.ac.uk/publications/pdf/Care_coordination_for_people_with_LD_%26_long_term_conditions.pdf
[5] https://westhampshireccg.nhs.uk/restore2/

1.17 **The national report identified some best practice:**

Table 24: Best practice most frequently identified in completed reviews in 2019

Best practice most frequently identified	Care met/exceeded best practice	Findings of multi-agency review	Deaths from pneumonia	Deaths from sepsis	Deaths from epilepsy	Deaths from DVT/PE	Deaths from diabetes	Deaths from asthma	Deaths from influenza	Deaths from BAME groups	Deaths of children	Deaths aged 18-24 years	Deaths aged 75+ years
Good quality multi-disciplinary working		✓		✓		✓	✓	✓	✓		✓	✓	✓
Holistic person-centred care	✓	✓				✓	✓					✓	✓
Regular proactive reviews of health condition, needs and risk assessments	✓	✓	✓		✓			✓					
Well-coordinated care	✓	✓	✓								✓		✓
Good communication with families		✓		✓								✓	
Good quality end-of-life care		✓		✓							✓		
Reasonable adjustments to care		✓					✓						
Full and accurate record keeping		✓						✓					

The main areas in which best practice was most frequently mentioned were:

- Person-centred care.
- Multi-agency working.
- Advocacy.
- The use of reasonable adjustments

"The care plan which details how to support Thomas is exceptional. From just this plan, you are able to understand who he was, the care and support he needed, how to understand him, keep him well, comfortable and pain free. It includes photographs and detailed instructions on a number of things including how to position him at different times, to sleep, to relax for example." (reviewer).

"Upon visiting the home, it quickly became apparent that the passion to challenge inequalities in care for people with learning disabilities was an integral culture of the environment." (reviewer).

"There was a reduction in the need for hospital admissions from chest infections or pneumonia over a period of 12 months…due to prompt action to avoid aspiration when he had episodes of vomiting and chest physiotherapy given twice daily." (reviewer).

1.18 **National key issues found:**

Table 25: Summary of key issues most frequently identified in completed reviews in 2019																		
Issues most frequently identified	**Overall care graded as 6**	**Overall care graded as 5**	**Concerns noted about care**	**Delays in the provision of care**	**Problems with org systems/processes**	**Gaps in the provision of care**	**Findings of multi-agency review**	**Deaths from pneumonia**	**Deaths from sepsis**	**Deaths from epilepsy**	**Deaths from DVT/PE**	**Deaths from diabetes**	**Deaths from asthma**	**Deaths from influenza**	**Deaths from BAME groups**	**Deaths of children**	**Deaths aged 18-24 years**	**Deaths aged 75+ years**
Delays in the diagnosis and treatment of illness	✓	✓	✓	✓			✓	✓	✓				✓	✓	✓	✓	✓	
Poor care coordination and communication between agencies	✓	✓			✓	✓	✓	✓	✓		✓				✓	✓	✓	
Omissions in care or the provision of substandard care	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓		✓		
Application of the Mental Capacity Act		✓		✓			✓	✓	✓	✓							✓	
Lack of timely referral to specialists, including learning disability services					✓			✓	✓	✓	✓							
Out-of-date assessments, care plans or policies						✓		✓		✓		✓					✓	
Lack of holistic and proactive care	✓	✓						✓		✓								✓
Training needs of carers					✓			✓		✓		✓		✓				
Delays in escalating concerns									✓	✓	✓	✓						
Poor engagement with families		✓									✓				✓		✓	
Poor hospital discharge arrangements			✓								✓	✓						
Lack of attention to physical health needs	✓								✓		✓							

1.19 **National Learning: Service Improvement Themes:**

- Delays in the diagnosis and treatment of illness.
- Poor care coordination and communication between agencies.
- Omissions in care or the provision of substandard care.
- Poor application of the Mental Capacity Act. •
- Lack of timely referral to specialists, including learning disability services and neurologists.

"...there was an acceptance that mum's wishes be followed rather than adherence the Mental Capacity Act." (reviewer).

"She had just transitioned from children's to adults' services and the parents found this difficult. ...The family felt no one had explained to them the process [of decision-making] or mentioned the Mental Capacity Act." (reviewer).

"DNACPR had to be completed twice as initial DNACPR reason given not to resuscitate was Downs Syndrome which was not appropriate. The learning disability speciality nurse spotted this and requested for it to be changed." (reviewer).

"There was a lack of physiotherapy to assist with postural care in relation to swallowing and exercises." (reviewer).

1.20 Causes of deaths: General Population verses LD/LeDeR.

Table 10: The most frequently reported underlying causes of death, by ICD-10 chapter, in people with learning disabilities by gender, age group, ethnicity and level of learning disabilities

	General population*		People with learning disabilities												
	Male all ages %	Female all ages %	Male age 4+ %	Female age 4+ %	Age 4 -17 %	Age 18-24 %	Age 25-49 %	Age 50-64 %	Age 65+ %	White British	BAME groups	Mild LD	Mod'te LD	Severe LD	Prof/ multip-le LD
Respiratory system	14%	14%	20%	19%	16%	18%	19%	15%	26%	20%	19%	18%	19%	23%	24%
Circulatory system	26%	23%	15%	14%	4%	7%	11%	15%	19%	15%	12%	7%	20%	19%	9%
Congenital and chromosomal	0.2%	0.2%	14%	15%	13%	14%	13%	23%	7%	15%	10%	19%	17%	11%	5%
Neoplasms	30%	26%	13%	15%	5%	5%	13%	17%	15%	15%	11%	22%	14%	8%	6%
Nervous system	6%	7%	14%	12%	27%	33%	21%	11%	7%	12%	21%	7%	10%	16%	30%
Digestive system	5%	5%	7%	7%	4%	7%	7%	7%	7%	7%	7%	8%	6%	7%	9%
Mental behavioural & neuro-developmental	7%	12%	4%	5%	*	*	3%	3%	8%	5%	2%	3%	6%	6%	4%
Endocrine, nutritional and metabolic	2%	2%	3%	3%	12%	5%	4%	2%	2%	2%	7%	3%	2%	2%	3%
External causes	6%	3%	3%	2%	4%	*	3%	3%	2%	2%	3%	3%	2%	3%	3%
Genitourinary	1%	2%	3%	3%	*	*	2%	2%	3%	3%	*	3%	2%	2%	3%
Infections	1%	1%	2%	2%	8%	*	2%	1%	2%	2%	3%	2%	2%	1%	*
All other causes	2%	5%	2%	3%	5%	3%	3%	2%	3%	3%	3%	4%	1%	2%	2%
Total number	**266,305**	**272,334**	**3,444**	**2,539**	**368**	**221**	**894**	**1,958**	**2,159**	**5,034**	**516**	**978**	**1,115**	**888**	**355**

1.21 As per 2019 BSW report people in the general population more frequently died from cancer and diseases of the circulatory system than people with learning disabilities. People with learning disabilities more frequently died from congenital malformations/ chromosomal abnormalities and diseases of the nervous system (e.g. epilepsy) than people in the general population.

1.22 The most commonly reported condition specific underlying causes of LD death vary by gender and age group when compared to the general population:

Table 11: Leading underlying causes of death (with ICD-10 codes) by age group and gender		
Age group	**People with learning disabilities (deaths notified to LeDeR in 2018 and 2019)**	**General population[35] (deaths registered in 2018)**
Males		
5-19	Cerebral palsy (G80)	Suicide and injury/poisoning undetermined intent (X60 – X84)
20-34	Cerebral palsy (G80)	Suicide and injury/poisoning undetermined intent (X60 – X84)
35-49	Bacterial pneumonia (J12 – J18)	Accidental poisoning (X40 – X49)
50-64	Down's syndrome (Q90)	Ischaemic heart diseases (I20 – I25)
65-79	Bacterial pneumonia (J12 – J18)	Ischaemic heart diseases (I20 – I25)
80+	Bacterial pneumonia (J12 – J18)	Dementia & Alzheimer's disease (F01-F03, G30)
All males	*Down's syndrome (Q90)*	*Ischaemic heart diseases (I20 – I25)*
Females		
5-19	Cerebral palsy (G80)	Suicide and injury/poisoning undetermined intent (X60 – X84)
20-34	Epilepsy (G41 – G41)	Suicide and injury/poisoning undetermined intent (X60 – X84)
35-49	Bacterial pneumonia (J12 – J18)	Malignant neoplasm of breast (C50)
50-64	Down's syndrome (Q90)	Malignant neoplasm of breast (C50)
65-79	Bacterial pneumonia (J12 – J18)	Malignant neoplasm of trachea, bronchus and lung (C33–C34)
80+	Bacterial pneumonia (J12 – J18)	Dementia & Alzheimer's disease (F01-F03, G30)
All females	*Bacterial pneumonia (J12 – J18)*	*Dementia & Alzheimer's disease* (F01-F03, G30)

1.23 **National Medical causes of death:**

Mirroring BSW's findings for pneumonias and respiratory diseases

Table 13: The ten conditions most frequently cited in Part I of the MCCD		
	No.	**%**
Bacterial pneumonias (J12 – J18)	1,444	24%
Aspiration pneumonia (J690)	948	16%
Down's syndrome (Q90)	658	11%
Dementia and Alzheimer's disease (F01 – F03, G30)	545	9%
Sepsis (A40 – A41, R65.2)	432	7%
Epilepsy (G40 – G41)	348	6%
Ischaemic heart disease (I20 – I25)	325	5%
Cerebral palsy (G80)	294	5%
Acute lower respiratory infections (J20 – J22)	265	4%
Heart failure (I50)	196	3%

NHS England National Learning into Action

1.24 NHSE updates are shared via the South West LeDeR Operational and Learning into Action Groups, and a national update is awaited in terms of the key recommendations as per the national LeDeR Report, noting the pandemic caveat.

2 December 2019-20 BSW LeDeR Deaths Data Analysis

2.2 BSW Population Health

2.3 The latest BSW Population Health update shows:

- People with a learning disability (LD) have higher rates of primary care contacts and secondary care activity compared to people without LD.
- People with learning disability in BSW have an average of ~3 long term conditions compared to less than 2 for the rest of the population.
- People aged 16-25 with Autism have the highest average of elective admissions compared to those with other Mental Health (MH) diagnosis or no MH diagnosis.
- People aged 65+ with Autism have the highest average of A&E attendances, emergency admissions, unique prescription types, and total cost compared to those with other MH diagnosis or no MH diagnosis.
- People aged 65+ with a learning disability have the highest average elective admissions compared to those with other MH diagnosis or no MH diagnosis.
- There is variation in the number of people with a learning disability or Autism Spectrum Disorder (ASD) (all age) across PCNs.
- The 3 Primary Care Networks (PCN's) with the highest number of people with a recorded ASD and/or a development disorder are Sarum South, Wyvern and Three Valleys.

		No of								
Locality	PCN	Population	MH	SMI	Personality Disorders	Eating Disorder	Depression	Autism Spectrum Disorder	Developmental Disorder	Dementia
BANES	BATH INDEPENDENTS PCN	24864	3587	403	113	33	3204	29	61	151
	HEART OF BATH PCN	25156	4392	410	160	18	3894	32	107	259
	KEYNSHAM PCN	24317	4261	322	109	14	3778	28	92	319
	MINERVA HEALTH GROUP PCN	34633	5926	692	209	30	5196	63	201	308
	THREE VALLEYS HEALTH PCN	62609	11792	882	266	40	10728	111	376	456
	UNITY MEDICAL GROUP PCN	29304	2656	310	114	23	2315	18	38	107
SWINDON	BRUNEL HEALTH GROUP PCN1	35661	5501	532	128	9	4901	63	110	248
	BRUNEL HEALTH GROUP PCN2	25161	2819	336	90	10	2558	38	110	34
	BRUNEL HEALTH GROUP PCN3	42048	7112	576	165	17	6512	76	187	208
	BRUNEL HEALTH GROUP PCN4	28665	5162	532	167	11	4658	72	128	198
	GREAT WESTERN HEALTH CARE PCN	28751	5358	525	164	16	4857	86	186	113
	WYVERN HEALTH PARTNERSHIP PCN	49697	9386	1147	203	30	8283	114	344	396
	WHALEBRIDGE PRACTICE	11814	1314	110	28	3	1194	29	30	31
WILTSHIRE	BRADFORD ON AVON & MELKSHAM PCN	45014	7896	655	182	32	7010	91	193	452
	CALNE PCN	31622	4614	490	140	14	4049	62	97	208
	CHIPPENHAM, CORSHAM & BOX PCN	56003	9036	738	267	26	7855	101	340	569
	DEVIZES PCN	29675	5644	978	171	18	4888	55	175	219
	EAST KENNET PCN	31979	5272	445	111	20	4732	35	155	303
	NORTH WILTS BORDER PCN	49406	6718	596	164	25	5936	79	145	424
	SALISBURY PLAIN PCN	17181	3023	269	74	8	2748	36	66	110
	SARUM NORTH PCN	29385	5046	526	148	15	4498	51	140	238
	SARUM SOUTH PCN	70998	12572	1139	404	49	11073	116	388	796
	SARUM WEST PCN	29032	4423	366	94	9	3881	41	99	322
	TROWBRIDGE PCN	47779	8867	1017	299	19	7988	91	287	321
	WESTBURY & WARMINSTER PCN	38613	7402	766	191	18	6689	73	153	424
Grand Total		899367	149779	14762	4161	507	133425	1590	4208	7214

2.4 BSW Notifications per locality (LeDeR is death notification dependant)

A total of 63 notifications were received in the period of 1 December 2019 – 31 March 2021. Notifications of death are broken down per locality. Swindon received 23 notifications during the period stated. Wiltshire received 27 notifications and BaNES received 14 notifications (table 1).

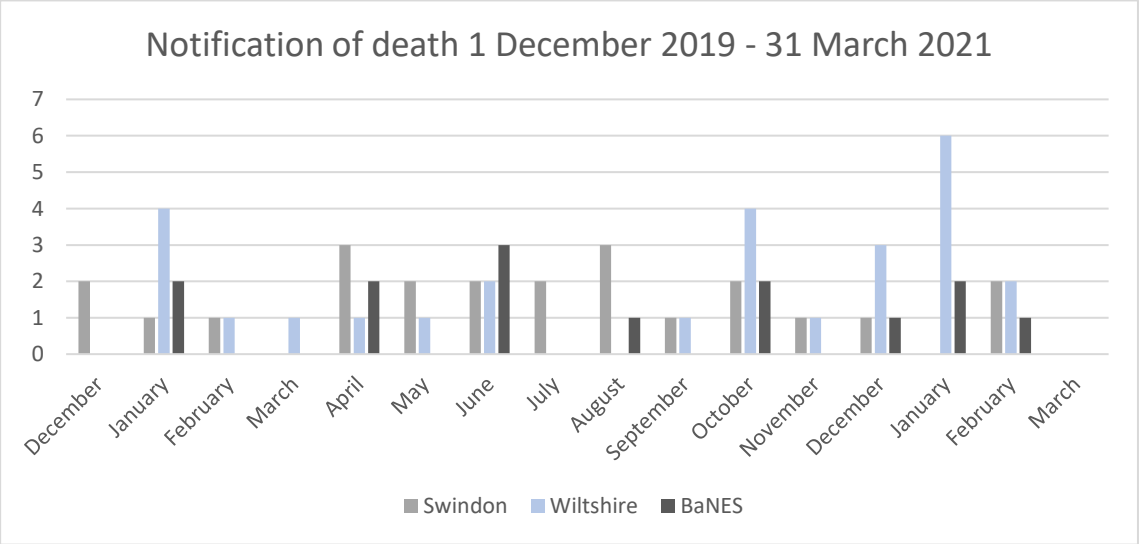


Table 1

2.5 BSW Completed reviews

The data in table 2 shows a November to December 2020 cluster due to focused efforts to complete reviews. Future reviews will be completed across the whole year.

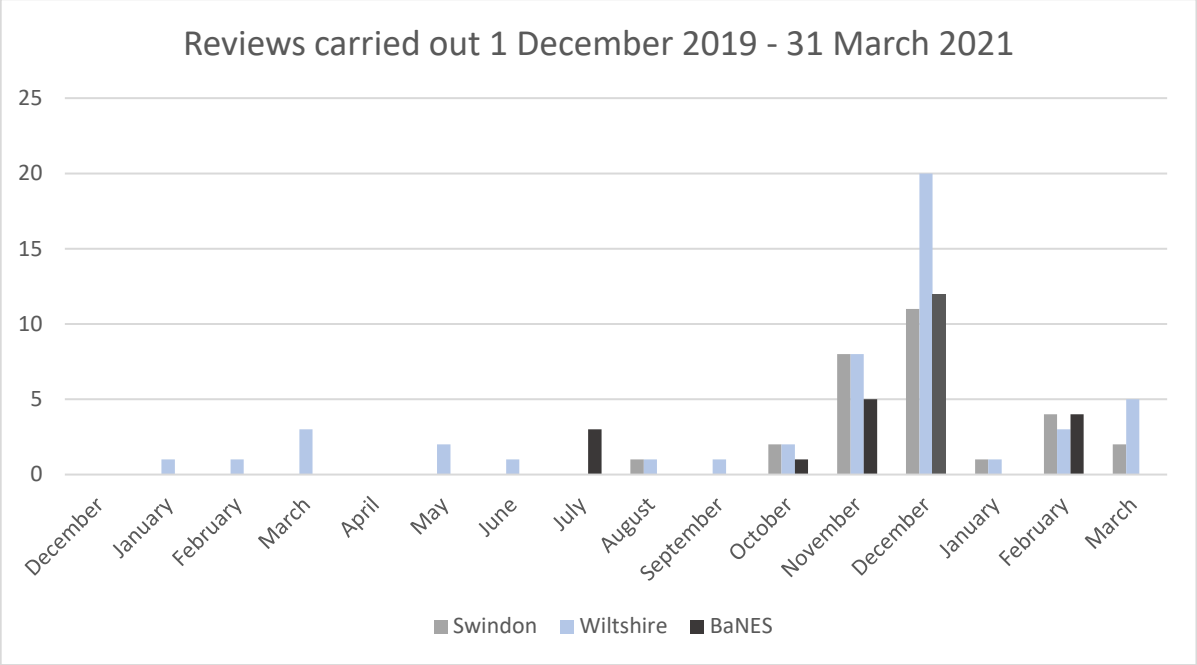
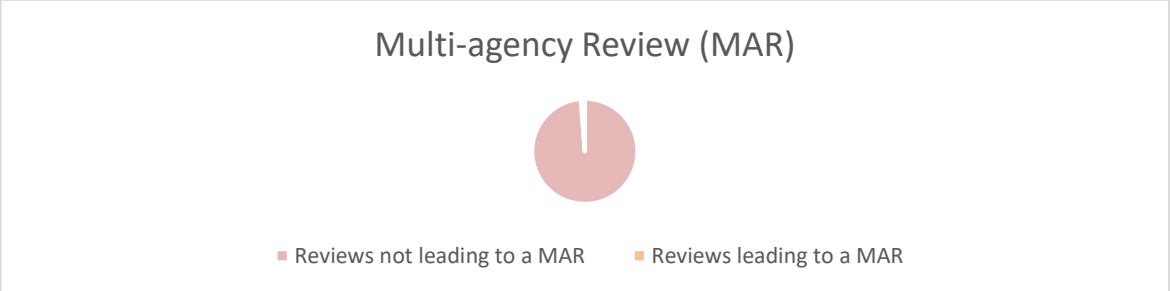


Table 2

A total of 103 LeDeR reviews were carried out during the period of 1 December 2019 – 31 March 2021. This number included reviews that had been received prior to this period and were completed as part of the NHSE Key Line of Investigation (KLOE) which stipulated that all reviews over the 6 month review period had to be completed by 31 December 2020. Reviews completed are broken down by locality. 49 reviews were completed in the Wiltshire locality, 29 reviews were completed in the Swindon locality and 25 reviews were completed in the BaNES locality.

2.6 **LeDeR Multi Agency Reviews (MAR's) and Other Statutory Oversight**

MARS are instigated when concerns are raised which require multi-agency review. Out of the 80 reviews completed, 1 case required escalating to the Muli Agency Review (MAR) process. Any concerns have, for assurance, been followed up through other processes such as safeguarduarding adults reviews and serious incident monitoring (avoiding duplication and ensuring investigation and learning).



2.7 **Performance against national target**

2.8 Table 3 captures the backlog of reviews completed in 2020, and assurance processes are now in place to meet the requirement to complete reviews within 6 months of notification.

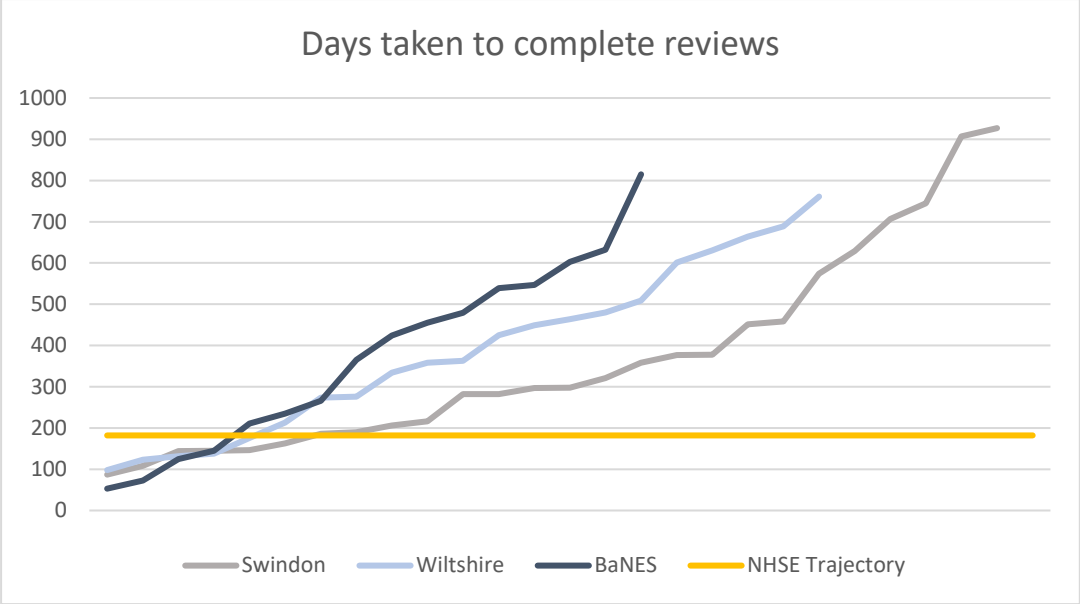


Table 3

2.9 Demographic Data: Location of deaths

Table 4 illustrates that the majority of deaths occur in hospital. As expressed in the BSW LeDeR Governing Body video there is opportunity to review end of life planning for people with a learning disability, to capture choice and individual preferences.

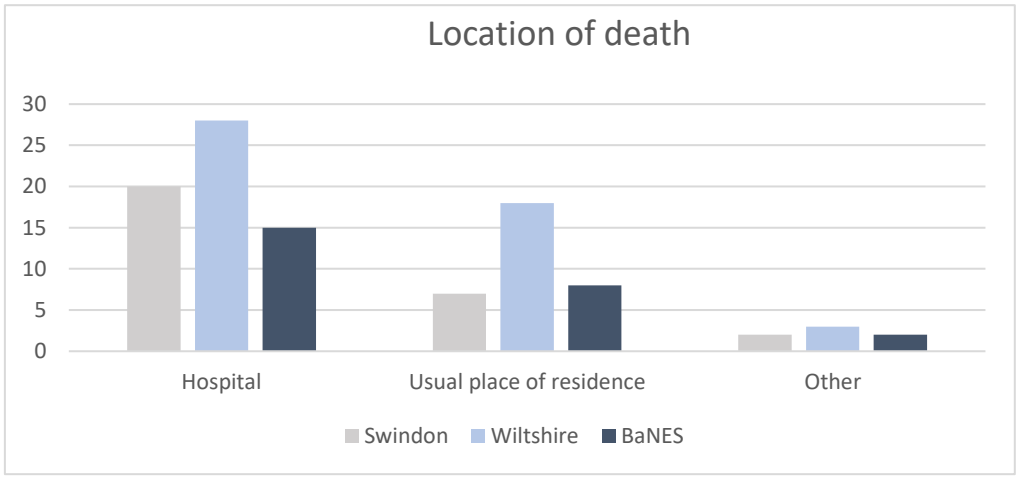


Table 4

2.10 Age ranges

BSW data does indicate positive care in terms of avoiding younger deaths (as per LeDeR methodology), with the median age range between 51 and 80 (table 5).

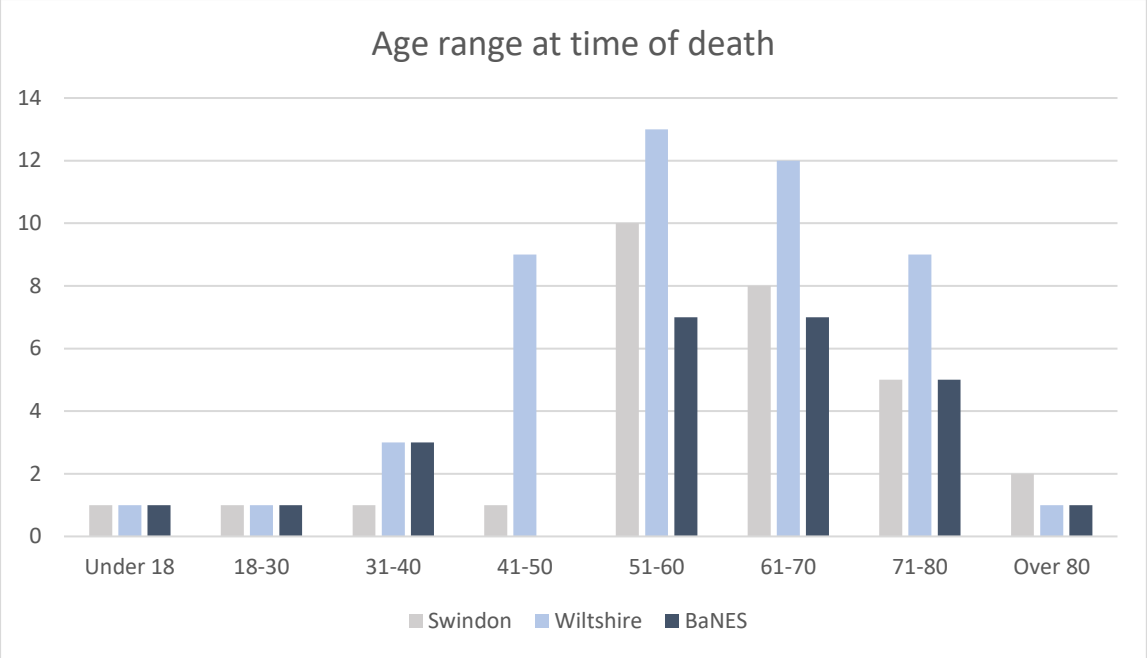
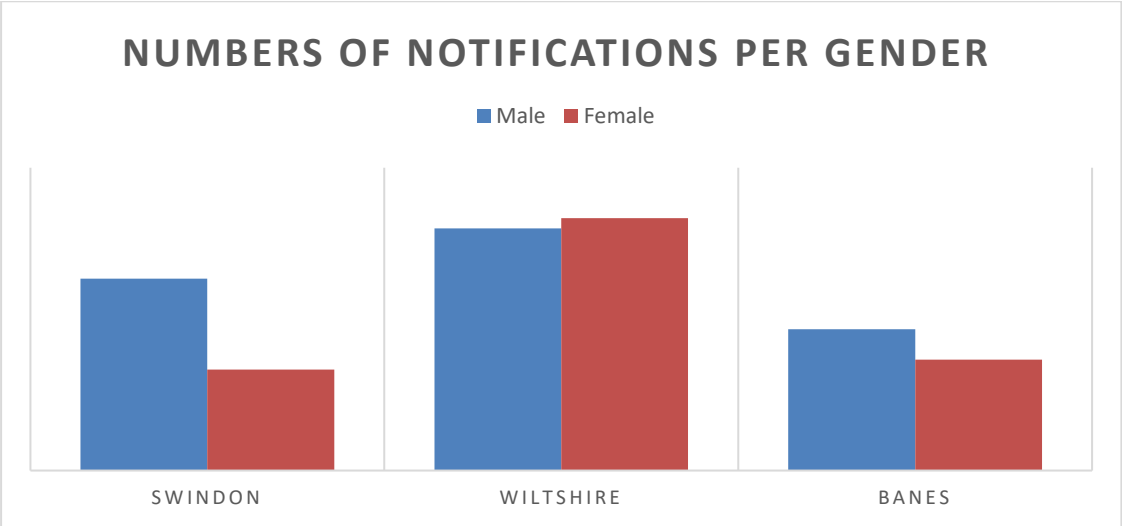


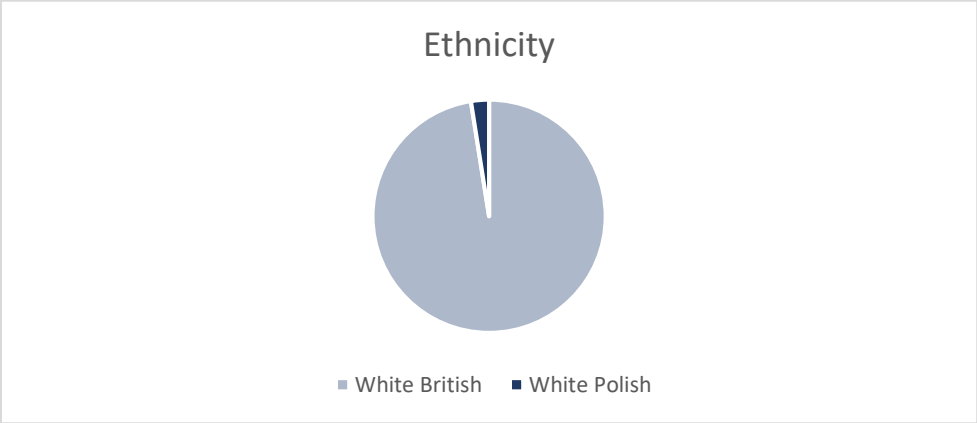
Table 5

2.11 Gender

There is a fairly even distribution for gender across BSW reviews.



2.11 **Ethnicity**



2.12 Mirroring the low national reporting LeDeR picture, BaME reporting in BSW has historically been low and is dependent on demographic data accuracy. A BSW lead has been identified to further review this gap in the coming year.

2.13 A BSW targeted BaME GP system analytical review was undertaken in September 2020 via SystmOne, (excluding the 5 Practices across the BSW which are using EMIS as unable to extract their LD patient data):

- looking at all those patients currently registered at a BSW GP Practice with a learning disability (LD)
- using the same definition of LD as reported in QOF:

	LD Count	List Size*	Prevalence
BaNES	1,145	205,949	0.56%
Swindon	1,130	232,520	0.49%
Wiltshire	2,324	482,642	0.48%
BSW	4,599	921,111	0.50%

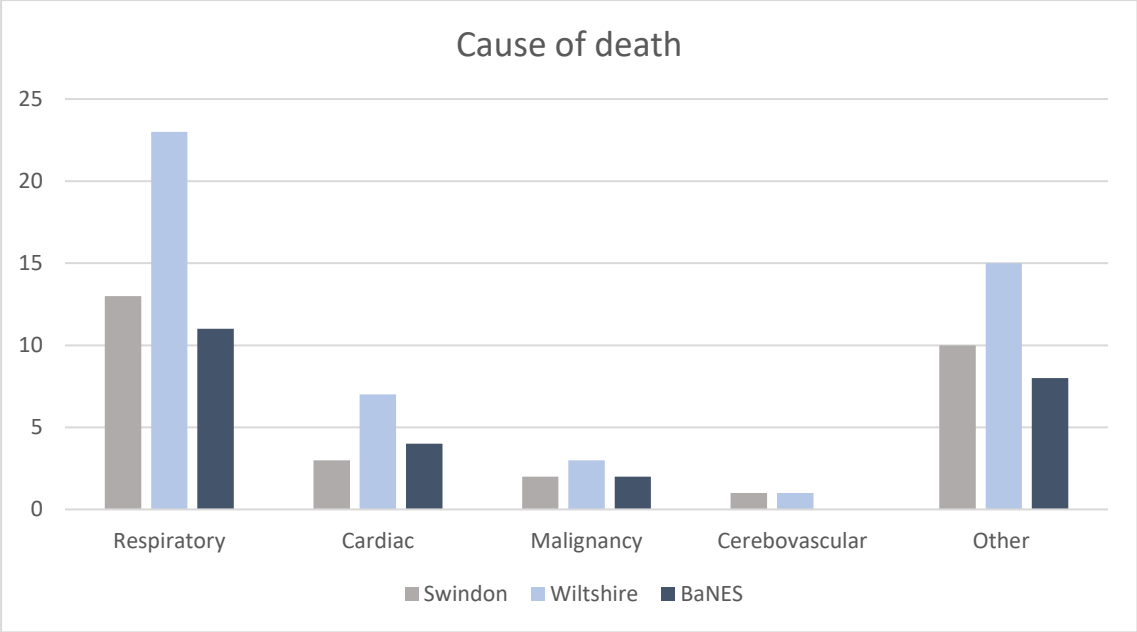
*List size excludes EMIS practices.

	BaME LD Count	% LD BaME
BaNES	39	3.4%
Swindon	82	7.3%
Wiltshire	45	1.9%

There is a large proportion of (LD) patients in SystmOne which **do not** have an ethnicity recorded, so the data was incomplete at that point. Work is required to continue to improve GP patient demographic data.

2.14 **Causes of BSW LD Deaths**

BSW data illustrates respiratory disease as the highest cause of deaths in 2020 (as per number of notifications in this reporting timeframe), but Covid 19 is also a noted factor. Further review is planned, alongside awaited national learning https://www.england.nhs.uk/wp-content/uploads/2020/07/Action-from-learning-report-2020-1.pdf

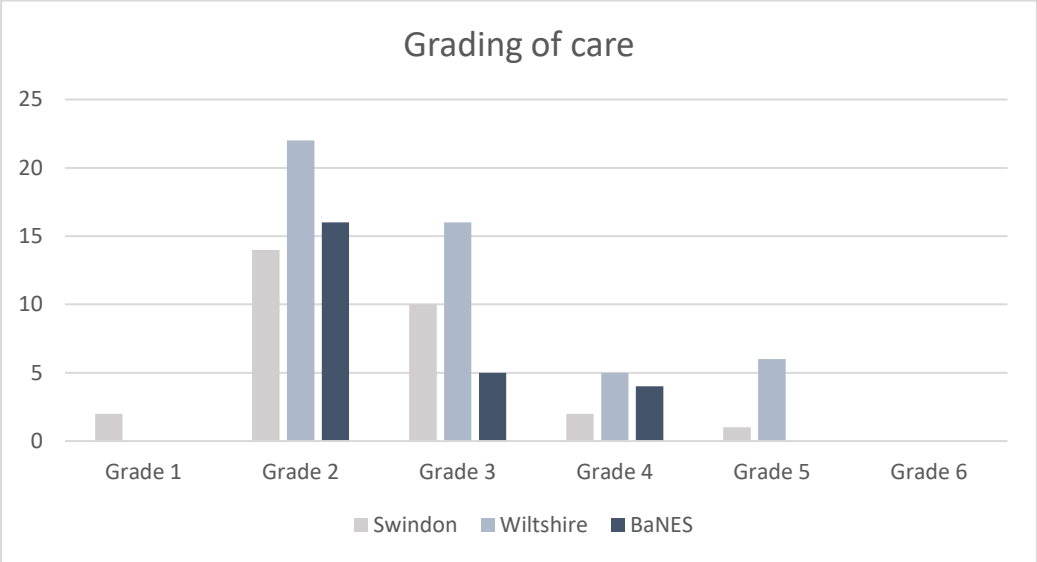


2.15 **BSW LeDeR Quality of Care Grading (see key on next page)**

Reviewers are required to grade care received as set out in the LeDeR framework (see grading of care pg25). All reviews were discussed at BSW quality assurance panel to ensure essential criteria was being met and quality of reviews consistent.

Reviews in grade 5 have been followed up, one by a multi-agency referral (MAR) and the others by safeguarding or serious incident processes as required.

The triangulation of LeDeR, safeguarding and quality data is being strengthened and will continue to be driven through the LeDeR steering group and Quality Performance and Assurance Committee (QPAC) throughout 2021/22.



LeDeR Grading Key:

1 = This was excellent care (it exceeded good practice)

2 = This was good care (it met expected good practice)

3 = This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing)

4 = Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death

5 = Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death

6 = Care fell far short of expected good practice and this contributed to the cause of death

3 The Deaths of Children in BSW with a Learning Disability

Since June 2019, LeDeR has separated the reporting of review progress for child deaths from those of adults. Rather than being subject to a full LeDeR review, child deaths are reviewed, and lessons are learnt by local Child Death Overview Panel processes (CDOP) with input from a LeDeR reviewer or LAC when invited. LeDeR LACs are sent and upload the completed CDOP review form only, with no other LeDeR process required. This report therefore refers only to adult deaths.

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

4 BSW Learning and Action Plans:

4.1 Recommendations made by reviewers.

The LeDeR review template requires reviewers to also submit proposed recommendations following their review; to identify learning and action needed. BSW LAC's (and the Quality Assurance Panel members) interpret and follow up specific actions such as safeguarding or serious incidents. Thematic learning is captured within the BSW Learning into Action tracker.

4.2 The key LeDeR 2021-22 learning action priorities (aligned to the thematic learning) are:

- Continued progression with the improvement to the access and the quality of GP annual health checks (monitored and reported by the BSW Learning Disability and Autism Programme Board and Primary Care Commissioning Committee)
- To review the impact of respiratory disease and BSW care pathways for those with LD
- A planned review of BSW Hospital/Health Passports
- Focus on the reliability of GP diagnosis and LD coding; to meet the health and care needs of individuals, plus accuracy of patient recorded demographics.

4.3 Individual case actions are followed up as required and some have instigated safeguarding referrals and also serious incident oversight as previously noted.

4.4 **What has been done/planned to address learning from local reviews?**

Thematic:

- With reviews now completed, BSW have shared the thematic actions to prioritise and progress. The learning has been collated and shared (see report details). As per 4.2 the key priorities will be progressed via the LeDeR workshop and Steering Group.

Collaborative:

- Some reviews link to other BSW processes, so collaborative system learning needs to develop further i.e. serious incidents and safeguarding. Other areas include vaccination uptake to align with disease prevention and BSW has progressed well particularly for the new Covid vaccination:

Vaccinations

Flu Vaccinations - 20/21

- During 2020/21 BSW successfully provided flu vaccinations to 76.6% (347) of people recorded in the at risk group of people with a severe learning disability. This is above the SW average of 70.9%.

Covid Vaccination Uptake

- The table below shows the number of covid vaccination first doses that have been given across BSW to people with an LD as at 09/03/2021, broken down by locality.

Locality	Cohort - patients on the LD register aged 16+	Cohort minus exclusions	Patients still to do 1st dose (eligible)	1st dose given		% uptake 1st dose
BaNES	924	901	244	658		73%
Swindon	997	980	284	695		71%
Wiltshire	2201	2138	467	1671		78%
Grand Total	4122	4019	995	3024		75%

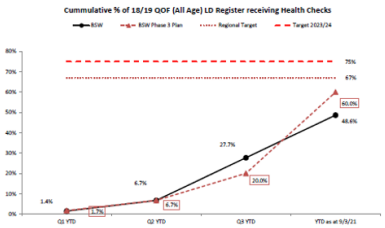
4.5 Quality Improvement (QI):

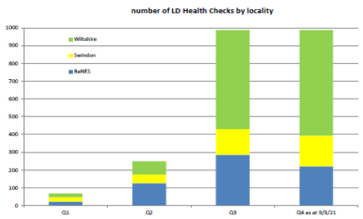
- A BSW led QI 'Super Team' pilot is underway to improve uptake and quality of Annual Health Checks. Commencing in Wiltshire with a nominated GP Practice. Evaluation is to be undertaken independently by Bristol University. This is a key action under LeDeR and noted progress continues.

NHS Long Term Plan commits to improve uptake of existing annual health checks in primary care for people aged over 14 years with a learning disability so that at least 75% of those eligible received a health check each year by 2023/24. To achieve this target, BSW needs to achieve a regional target of 67% compliance in 2020/21.

BSW CCG has received 'a call to action' from NHSE/I as the BSW area is currently the worst performing in the South-West area.

A quality improvement approach is being used to develop tests of change ideas to improve performance and outcomes for people with a learning disability in the BSW population. Improvement demonstrated with BSW CCG now reporting 48.6%.





4.6 Autism Spectrum Disorder (ASD) Adult Waiting List Quality Improvement Pilot

This GP Clinical Lead role pilot is running for three months initially, using quality improvement (QI) methodology where the GP will arrange appointments with people on the wait list. The objective is to support the development of resources, sign posting and assess risk level. It is anticipated to demonstrate that those who receive an appointment felt supported, heard and that there is a robust plan put in place

should people feel they are heading towards a crisis. Further work planned under the BSW Learning Disability and Autism (LDA) Board includes:

- Third Sector pre-post diagnostic autism diagnostic support offers, in development at locality level, to commence in Q1 via NHS E non-recurrent funding allocation.
- Children and Young People ASD SWAT team to focus on sharing best practice and informing future equitable model of care.
- Investment request submitted for Swindon locality regarding Autism Diagnostic Practitioners
- Co-production of BSW ASD models
- Await national framework; link to NHS E forums to raise our systems challenges and champion the need.

4.7 **Learning Disability Collaborative**

BSW is supported by the West of England Academic Health Science Network (WEAHSN) & NHSE/I, who are developing quick guide videos for Primary Care teams alongside delivering regular webinars to people, families, social care staff & NHS staff to improve access to care and support.

4.8 **What has been done/planned to address learning from local Covid reviews?**

4.9 BSW LeDeR has not seen a dramatic Covid impact reported to date. Learning from the national LeDeR report has been shared and the need to improve the identification of the softer signs of deterioration are noted.

4.10 As a part of the national recommendations BSW are reviewing the implementation advantages of RESTORE2 mini file (hampshiresouthamptonandisleofwightccg.nhs.uk) verses NEWS2 in care homes, to support earlier identification of deterioration, again aligned to the WEAHSN programme. Pulse oximetry equipment has also been obtained to further progress remote monitoring for people.

4.11 **What has been done/planned to address learning from the national report i.e. LD acute hospital nurses?**

4.12 BSW system, with support from LD Specialist Nurses, remains fully committed to LeDeR aims and are supporting learning across BSW. Currently, 2 of the 3 acute providers employ LD specialist nurses with a plan for a third in the near future. The nurses were able to discuss organisational support plans for people with a Learning Disability within the BSW Quality Surveillance Group. More detailed analysis across the 3 acute hospitals is now needed in order to share themes, trends and innovative working. This is a focus of the workshop on 29 April 2021 to revisit:

- the current BSW acute hospital LD Specialist Nurse provision for assurance/action
- the equity and access for support to all people with a learning disability

- system learning to improve care and treatment.
- sharing of the focused review of any reported incidents and complaints, including opportunities to make adjustments to the complaints process for people with a learning disability to further enhance learning and align staff education and training.
- sharing of learning in relation to outcomes from safeguarding referrals
- Quality improvement initiatives aimed at improving outcomes and experience for people with a learning disability.
- Consistent progression of the Learning Disability 'passport'
- To support the rollout of the 'softer signs' toolkit, designed to identify deterioration in an adult with Learning Disabilities who is unable to tolerate physical observations. Trialled in some Trusts nationally, the 'soft signs' toolkit allows observations to be documented, and any deterioration in a patient's condition to be noted and acted on appropriately. Clinically led, the roll out within one Trust (using a quality improvement methodology) will support patient safety and practitioners involved in delivering care. Sharing of outcomes will be presented to the BSW LeDeR steering group.

5 Local priorities for delivery in 2021/22 and the evidence base that supports them.

5.1 All age LD/ASD was agreed as one of the strategic priority programmes for BSW CCG. "Our plan for health and care 2020-2024" outlines the following CCG plan for learning disabilities and autism:

- Reviewing capacity within the system to respond to demand and support people with LD to live independently.
- Developing an integrated health and care pathway which covers the lifespan of a person with LD (working with the Academic Health Science Network), ensuring a better transition between children and adult services to avoid people getting 'lost in the system".
- Developing an integrated health and care pathway for people diagnosed with an autistic spectrum disorder and reducing waiting times for assessment
- Training health and care professionals to support people with a LD and encourage more people into LD nursing
- Increasing availability of social prescribing and community-led support
- Working with local authorities to provide adequate local housing
- Improving people's choice, control and independence.

5.2 A multiagency Programme Board has been developed with membership across our system. Feedback from LeDeR reviews is a standing agenda item. The Programme Board agreed four key priority workstreams, which have been continuing during the Covid period to co-create the transformation of our services with partners, people, families, carers and supporters:

5.3 BSW have submitted a 3-year LD/ASD Road Map to NHS E as required in March 2021 and BSW LeDeR has fed into the plan. The plan is in continued development

with key system partners to develop and define the work programme for the next 3 years.

'They were real people who were loved and cared for; if somebody just reads clinical case notes they've got no real sense of who that person was and what was important to them in their lives' (family member)

'When my daughter died, there wasn't a review process in place at all. But I think had it been there... it would have given us the confidence that the learning that we had from that experience could be captured and could prevent other people having relatives die in similar circumstances' (family member)

5.4 Oliver McGowan Case and BSW Learning into Action Plan

5.5 Oliver McGowan lived with cerebral palsy, epilepsy, autism and learning disabilities and died aged 18, on 11 November 2016. This was found to be due to a combination of pneumonia and hypoxic brain injury in Southmead Hospital, Bristol. The brain injury was caused by seizures and Neuroleptic Malignant Syndrome (NMS), an adverse effect of antipsychotic medication, Olanzapine.

5.6 An independent Learning Disability Mortality Review (LeDeR) found that Oliver's death was 'potentially avoidable'. The review made a number of recommendations:

- Staff who are new Lead Reviewers or are new Local Area Contacts should work with someone who has experience. This is known as a 'buddy'.
- Reviewers and Local Area Contacts need to have the time to do their job and also have some admin support.
- There must be a good clear process for LeDeR in each area.
- The LAC and the lead reviewer should say how much support is needed at the start of the LeDeR process. The process is a team task not just one person.
- There needs to be a senior lead person for the LeDeR process in each CCG area who report actions to the board.
- The senior leads for LeDeR need to make sure that the process is finished in good time and in the right way. They will also get involved if there are problems such as getting all the information.
- When the Reviewer and the LAC do not have much experience of a MAR, they will get support from a 'buddy' who does.
- There should regular support for the reviewers and it should be documented.

- There needs to be proper support for reviewers and good systems so that recommendations are done in good time and lessons are learnt across the country.
- Each CCG must look at their own systems and processes and learn from Oliver's re-review.

5.7 BSW CCG had already reviewed the learning points within a dedicated action plan, that has since been shared with the LDA Programme Board for comment and progression, NHSE and the South West LeDeR Operational meeting members as requested. This plan requires national action feedback to further progress.

6 Evaluating Impact

6.1 **What have BSW put in place to monitor and review action plans/service improvements?**

6.2 BSW has developed an action plan and generated the top themes as shared from reviews. This plan will now be refined and shared to ensure mobility of progress. The plan is written to be clear and specific to actions, ownership, and timeframes.

6.3 Specific actions have lead committees identified for progress monitoring and challenge such as the LDA Programme Board.

6.4 The annual health checks are a noted example of the progress of LeDeR work.

6.5 BSW Annual LeDeR reports are written to capture progress and risks.

6.6 **How will BSW evidence that service improvements are making a difference to people with LD and their families?**

6.7 The lead committee and members for the coproduction with service users, their carers and/or families is the BSW LDA Programme Board. LeDeR does directly align to the LDA Board Road Map plans and will dovetail progress in unison with the members.

6.8 All CCG intelligence will continue to be monitored to triangulate experience and feedback.

7 BSW 2019 LeDeR Report Reflection

7.1 Key recommendations from the previous report were in two parts as below and all were achieved for assurance.

Part one relates to BSW LeDeR processes and capacity and part 2 to BSW actions*:*

Part One:

1. To set a SMART trajectory of recovery plan, to ensure that all reviews occur within 6 months of notification as per LeDeR timeframes by July 2020.

2. *BSW LAC and reviewer capacity scoping exercise by 13 March 2020*
3. *Strengthen social, primary care and educational engagement with LeDeR, to ensure robust reviews occur and to capture system learning and actions.*
4. *Review the Steering Group Terms of Reference, membership, and previous action planning to further embed learning into action as the key focus now that more reviews have been completed.*

Part Two:

1. *Share national learning and instigate local action planning to reflect the learning i.e. a review of Do Not Attempt Cardio-Pulmonary Resuscitation for people with a learning disability (CQC recent 2021 report now published too)*
2. *Review BSW annual health check compliance as a key measure of primary care support in the prevention and early detection of disease and ill health*
3. *Share this report to disseminate the learning and actions and ensure that they are followed up in a BSW system responsibility as follows:*

- *The BSW LeDeR Steering Group*
- *Quality and Performance Assurance Committee*
- *The BSW LD/ASD Programme Board*
- *Locality LD and Autism Committees*
- *Health and Social Care joint committees*
- *BSW Quality Surveillance Group*

8 Conclusion and Next Steps

8.1 BSW system has made good progress in 2020, in terms of completing the backlog of LeDeR reviews; creating a new and dynamic BSW LeDeR database; supporting new reviewers, progressing annual health check improvements and generating a 2020 learning action plan.

8.2 Governance and quality assurance processes have been strengthened via the LeDeR Steering Group and Quality Assurance Group terms of reference. The Steering Group has supported raising the profile of LeDeR and the important outcomes the programme is aiming to achieve. Feedback and presentations have been provided to the Learning Disability and Autism (LDA) Programme Board; Safeguarding Partnership Boards; CCG Quality Performance and Assurance Committee, BSW Quality Surveillance Group and BSW CCG Governing Body.

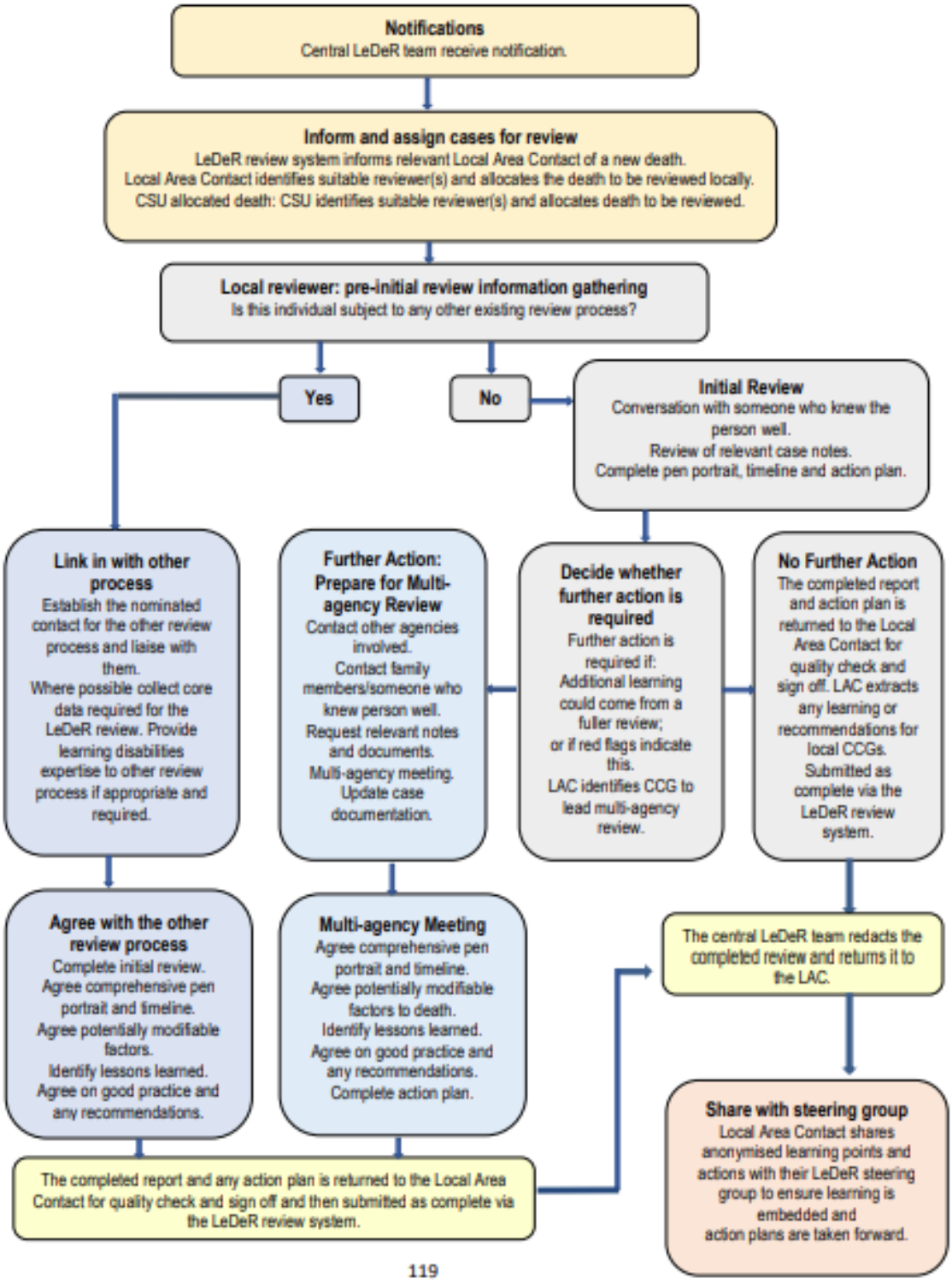
8.3 The quality improvement workshop in April 2021 is an opportunity to further engage with key stakeholders across health and social care, including experts by experience, to share learning from both BSW and national reviews and embed a priority system action plan that can achieve further improved outcomes for the population of BSW. The outcomes will be embedded within the LeDeR Steering Group and the LDA Board for progression.

8.4 The CCG will continue to work with the NHSEI South West team to review and advise the BSW system of the imminent proposed national LeDeR policy changes and future plans.

8.5 Further BaME population work will be undertaken by the nominated lead.

Appendix A

The LeDeR Review Process



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Appendix B - BSW Newsletters / Information

Learning Disabilities Mortality Review (LeDeR) Programme

NHS
Bath and North East Somerset, Swindon and Wiltshire
Clinical Commissioning Group

Welcome to the BSW LeDeR Newsletter (No 2 January 2021)

This is our second Bath and North East Somerset, Swindon and Wiltshire (BSW) newsletter regarding the programme called LeDeR (please follow this link: http://www.bristol.ac.uk/sps/leder/) which is the first national programme of its kind aimed at making improvements to the lives of people with a learning disability (LD). Previous national enquiries found that people with LD were dying much younger than the general population, and that improvements to health and social care provision are required. NHS England pledged to review every death of a person with LD to identify actions to prevent premature similar deaths and BSW CCG are totally committed to the LeDeR improvement programme.

BSW CCG LeDeR Oversight:

The LeDeR BSW programme covers BaNES, Swindon, and Wiltshire collectively.

The CCG has a dedicated LeDeR Steering Group which is chaired by The Deputy Director of Nursing and Quality, Sharren Pells. The Steering Group regularly meet to ensure BSW progress and improve learning.

BSW CCG LeDeR Reviews Progress

The CCG had a backlog of reviews that required completion by the end of December 2020, and this has now been achieved. The total number of completed BSW reviews completed is now 115.

BSW LeDeR: Learning from Reviews

The key themes of learning from local reviews are:

- The largest number (of national and) local deaths are reported as caused by pneumonia (swelling of the lung tissue), aspiration pneumonia (caused by breathing in fluids or a substance) and respiratory related diseases (such as lung cancer, asthma, or chronic obstructive pulmonary disease).
- The need to improve the use of Hospital Passports; to ensure reasonable adjustments are made to meet individual needs during hospital admissions.
- Improve support for people admitted to hospital by those who know them.
- To improve proactive health prevention such as attendances for routine (cancer) screening (working with Public Health as the lead).
- To improve the number of annual health checks (and the resulting quality of the health action plan)
- Improve the quality of LD diagnosis to ensure that people are able to access the right care and support.
- To improve the uptake of annual flu, pneumococcal and now Covid-19 vaccination
- Opportunity to review the end-of-life planning for people with LD; what is their choice for where and how they will be cared for when the end of their life is near, what services are needed to provide care at home to avoid unnecessary hospital admissions.

BSW LeDeR: Actions- ‘So what are we doing?’

People with learning disabilities died in hospital more than people who do not have learning disabilities.

This was the same as last year.

- Increasing the number of BSW Reviewers to ensure ongoing timely completion of all future reviews.
- A BSW wide action plan is developing; to ensure that the necessary changes are made to improve health and social care support.
- Looking at our population to improve communication and support, such as the Black and Minority Ethnic who are underrepresented in BSW and national LeDeR reviews.

- Gaining Expert by Experience representation at the BSW LeDeR Steering Group; to ensure the voice of service users is present.
- Improving BSW LeDeR feedback reporting across the local health and social care system; who are we telling what we need to do and how?
- Working with statutory process partners to improve communication and learning (such as Serious Incidents and Safeguarding Adult Reviews)

What do you want from the next addition? Please email and tell us:
BSWCCG.Leder@nhs.net

General Information and Resources Links for Staff/Providers:

What is a learning disability?

- *The National Institute of Health and Care Excellence (NICE) states that 'a learning disability is generally defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood'.*
- *The Department of Health in the UK defines a learning disability as 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood'.*

LeDeR National Notification and Previous Reports:

LeDeR Platform Death Notification: call 0300 777 4774 or online:
https://www.bris.ac.uk/sps/leder/notification-system/

LeDeR National 2019 Annual Report: http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL.pdf

LeDeR Easy Read National Report:http://www.bris.ac.uk/media-library/sites/sps/leder/LeDeR%20Easy_read_annual_report_2019%20FINAL.pdf

LeDeR Covid Initial 50 Reviews Report 2020: http://www.bristol.ac.uk/media-library/sites/sps/leder/Summary%20of%20findings%2050%20LeDeR%20reveiws%20of%20deaths%20related%20to%20COVID19.pdf

BSW Info:

LeDeR Local Area Contacts (LAC's):

BSW LeDeR Email: BSWCCG.Leder@nhs.net

BSW 2019 Annual LeDeR Report: https://bswccg.nhs.uk/docs-reports

Mencap Hospital Passport Template Example:

https://www.mencap.org.uk/advice-and-support/health/health-guides

2020-21 Flu Campaign:

- Official flu letter published: https://www.gov.uk/government/publications/national-flu-immunisation-programme-plan - people with a learning disability are specifically mentioned in the appendix of clinically at-risk groups.
- This year's Easy Read supporting document has also been published: https://www.gov.uk/government/publications/flu-leaflet-for-people-with-learning-disability
- Further supporting resources: https://www.england.nhs.uk/increasing-health-and-social-care-worker-flu-vaccinations/
- PHE guidance suggesting the nasal spray can be used as a reasonable adjustment for people with a severe needle phobia: https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities/flu-vaccinations-supporting-people-with-learning-disabilities

Constipation Resources:

Grab guide: Constipation - Let us talk about poo!
https://improvement.nhs.uk/documents/3482/constipation_grab_sheet_1.pdf

Poo matters - https://www.england.nhs.uk/wp-content/uploads/2019/05/constipation-resources-families-carers-stage-31-web.pdf

National Covid-19

Easy Read Face Mask Guide**:**

Easy Read face coverings guidance.pd

National Covid Campaign Resources:

The updated campaign materials on the Campaign Resource Centre replace previous Stay Alert branded materials and include messaging on:

- Stay Home, Protect the NHS, Save Lives – *several graphics attached for ease.*
- Symptoms and Isolation
- Hands, Face, Space and reducing transmission.

Keepsafe, made by Photosymbols, latest Easy Read resources:

- Back in Lockdown
- Covid vaccine - who gets it first? – uses the Joint Committee on Vaccination and Immunisation priority list.
- Keeping safe
- The NHS is open
- If you get ill
- More available via https://www.keepsafe.org.uk/
- Easy Read; Covid Vaccination info: https://www.keepsafe.org.uk/vaccine-questions?fbclid=IwAR3XT2mIKAvQ1LBq0WgqFEtopO_GqEfztyQDKmsOO5j1E0aogUnEwzTJ9FQ

MCA and Covid Vaccinations:

The Mental Capacity Act (2005) (MCA) and deprivation of liberty safeguards (DoLS) during the coronavirus (COVID-19) pandemic: additional guidance (updated 24 December 2020). Includes best interest decisions on the following (and others). See webpages:

- Offering a vaccine to someone who lacks the relevant mental capacity
- Testing someone who lacks the relevant mental capacity without their consent

NHSEI

general film on vaccinations for people with a learning disability and autistic people

Visiting Guidance:

Please see a link to the visiting guidance which has been updated in light of the latest Tier announcements. The expectation is that visits within Mental Health settings should continue to be facilitated based on individual risk assessments and PPE guidance being adhered to.

https://www.england.nhs.uk/coronavirus/publication/visitor-guidance/

Appendix C

BSW LeDeR Team Voices

The BSW LeDeR reviewers were invited to share direct quotes to ensure that their voices are heard:

1) *''Being able to do LEDER is a privilege to have an insight into someone's life and death. Some journeys are amazing and some journeys not so good, but I hope my little bit of work can make a positive difference.*
2) *''LeDeR is underestimated in terms of the resource needed to complete a review, as the learning needs time and attention. I do really enjoy this work; as an opportunity to really understand someone's life, likes, wishes, and needs; what reasonable adjustments actually mean in practice and how to improve the wellbeing, experiences, and lives for people with LD''.*
3) *''There is a need to make sure those who care for them understand what is happening, and to have medical terminology clearly explained, especially when in unfamiliar places or when a distressing event occurs"?*
4) *"Undertaking a review gives you a real sense of the good work that is undertaken by so many but sadly also where fundamental care gaps exist that could be very simply filled by providing the appropriate communication prompts or training".*
5) *'' The LD nurses are an amazing source of information and helped me as a reviewer and where they are involved it is very noticeable. Contacting families via telephone is difficult particularly in COVID with having to have difficult conversation over the phone, often where families have no idea of the LeDeR process.*
6) *'' Support -I have felt supported by the LAC [new reviewer]. I feel that my initial review has taken some time as I have been working through the process. The information can be quite in depth and you must work through it. You also are waiting for responses and arranging meetings which can take weeks to complete…. GP practice not always able to engage or respond to my requests".*
7) *''It has been an interesting and rewarding year facing into new challenges which have given opportunities to learn and grow personally and professionally whilst contributing to the learning disability community through the LEDER reviews''.*
8) *"I find that it is a real privilege to look over a person's life and speak to their families, to understand the person…and to try and understand the events and appraise this in a way that is both factual and in a respectful, compassionate way. Sometime has been spent with local authority partners explaining the purpose and scope of the Leder project and how their contribution is necessary".*

BSW LeDeR Steering Group Member Voices:

1) *'Reviews highlighted a lack of support to access cancer screening and indicated that people had not received the annual health check. There is a*

need to be innovative, to work at the same pace as the person with needs and make great efforts to find creative practical solutions.''

2) *''Steering Group worked really well towards end 2020 to ensure we completed review backlog. It is really important to get the LeDeR workshop progressed so we can ensure that we take actions forward to avoid repeating these experiences.'' [Nb Lessons learnt have since been shared]*

3) *'' What is now really important following the good work to get the reviews completed in line with the target of December '20, is to build on robust plans on how the recommendations from the reviews are turned in to actions and are closely monitored to ensure continuous and sustained improvement for our population''.*