NHS
Halton
Clinical Commissioning Group

NHS
Warrington
Clinical Commissioning Group

LeDeR Annual Report
2020-2021

The Learning Disabilities Mortality Review
(LeDeR) Programme

Document Version Control

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LeDeR Annual Report 2020-2021

1. Introduction

The Learning Disability Mortality Review (LeDeR) programme is part of a national focus upon improving the lives and care of people with Learning Disabilities. It has derived as an outcome from a series of national reports that describe that whilst care in many instances has improved over the last decade, many aspects have not. There are still marked health inequalities for people with learning disabilities, compared to that of the general population. To put this into context the life expectancy for people with learning disabilities today can be equated to what the rest of the public could have expected in 1940. Today, people with learning disabilities die, on average, 15-20 years sooner than other people in the general population. These health inequalities are not inevitable, and progress can be achieved by preventative and/ or timely access healthcare.

Reviewing the circumstances surrounding the deaths of people with a learning disability provides a real opportunity to learn from the past to help prevent avoidable deaths and improve future care for others.

Since 2019 NHS Halton Clinical Commissioning Group (HCCG) and NHS Warrington Clinical Commissioning Group (WCCG) agreed to take a combined approach to delivery of the LeDeR programme through the establishment of a LeDeR panel, shared Local Area Contact, and agreed governance frameworks to capture local learning.

This annual report focuses on Halton and Warrington in respect of activity and findings relating to Learning Disability Mortality Review (LeDeR) for 2020-21. The report has been produced by HCCG and WCCG as required by the 'The NHS Long Term Plan January 2019'. The report provides:

- An overview of the LeDeR review activity undertaken for Halton and Warrington.
- An overview of the work that has been undertaken locally to engage with the national programme and implement positive actions for any learning identified.

2. National LeDeR Programme

The Learning Disabilities Mortality Review (LeDeR) programme is a national initiative to review the deaths of people with Learning Disabilities. The programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives.

The LeDeR Programme supports reviews of deaths of people with learning disabilities aged 4 years and over; and the Programme supports reviews of all deaths, irrespective of the cause of death or place of death.

The programme is currently led by the University of Bristol, on behalf of NHS England/Improvement (NHSE/I). The programme is a joint health and social care project, involving healthcare providers across the health economy, Local Authorities and Clinical Commissioning Groups'.

The aim of the programme is to drive improvement in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities in this population, through mortality case review.

This work forms part of the wider Transforming Care agenda and NHSE/I's commitment to address health inequalities experienced by people with learning disabilities.

From April 2021 the LeDeR programme input from the University of Bristol will cease and the programme will sit under the sole leadership of NHSE/I. To support this, change a national LeDeR policy has been implemented - the implications of this for 2021-2022 are detailed in section 12.0.

3. National Progress

The LeDeR National Annual Report 2020-2021 has not been published at the time of writing the HCCG/WCCG Annual Report. Therefore, it is not possible to include any national comparison data within this report and this will be reviewed for learning at a later date.

National learning in respect of Covid has been shared from the University of Bristol LeDeR programme and this is detailed in sections 7.2- 7.3.

4. Local Progress

In 2019 in response to capacity demands, competing priorities upon reviewers and to enable sustainability of approach HCCG and WCCG agreed to jointly pilot a panel multi-agency approach to completion of the LeDeR reviews. This moved away from the previous method of allocating one review to one reviewer.

Systems were developed and implemented to support the panel and dedicated administration support identified.

All cases are triaged and HCCG and WCCG support identification and collection of the information needed ahead of the panel.

The panel consists of an independent chair, and multi-agency representatives with a broad range of knowledge and skills in relation to learning disability who meet regularly to review the circumstances surrounding a notified death to identify local learning.

Appendix 1 to this report provides a flowchart of the process from initial notification to completion of the review, including pathways to learning and the supporting governance arrangements.

5. Local Activity

Locally across Halton and Warrington in the reporting period of April 2020 to the end of March 2021 there have been 36 new deaths notified to LeDeR for local review. In total within the reporting period 62 deaths have been reviewed or quality assured through the HCCG/WCCG LeDeR panel as this reporting period also captured the cohort of backlog reviews (refer to 5.2) and 2 reviews from 2019-21 which were delayed due to statutory processes. 4 reviews were removed from LeDeR as they were found to be out of scope as the individuals did not have a learning disability.

There are 10 reviews that whilst notified within 2020-2021 remain ongoing and will be reported for learning in the 2021- 2022 report.

This leaves a total data cohort of 49 reviews that have been subject to analysis as below to help inform local learning within this annual report.

The table below shows the status of the review activity for the 2020-2021 reporting period.

Table 1

Activity	Halton	Warrington
New reviews notified 2020-2021	17	19
completed	7	14
Ongoing (will report learning in 2021-22)	6	4
Removed no LD	4	1
Backlog reviews completed	14	12
Other activity		2 •X1 CDOP- 2019-20 delayed closure waiting on CDOP review paperwork •X1 review 2019-20 delayed pending SAR decision
Total activity via panel per CCG	31 reviews	31 reviews
Cases used for data analysis and learning	New - 7 Backlog - 14 Other - 0 Total - 21	New - 14 Backlog - 12 0ther - 2 Total - 28
Total panel activity	Combined oversight/management of 62 reviews	

5.2 Backlog reviews

An additional £5 million was invested by NHSE/I in 2019/2020 to address the backlog of un-reviewed cases and increase the pace with which reviews are allocated and completed. The money was invested in developing a dedicated workforce through a Commissioning Support Unit (NECS) to undertake reviews and develop systems and processes to embed mortality reviews and quality improvement activity across the health and social care system.

HCCG and WCCG had a backlog of reviews from pre-December 2018 that met the specification for completion by NECS. These were all transferred and completed by end of December 2020 and are therefore included in the data and learning within this report. However, it is to be noted that the care and services within these reviews' dates from pre 2019/2020, therefore the data and learning is reported as a stand- alone cohort within this report.

All reviews completed as part of the backlog work once complete were discussed at the Halton/Warrington LeDeR panel for quality assurance, sign off and to ensure the capture of local learning.

6. What we have learnt in 2020-2021

6.1 Demographic Data Comparisons

Table 2

Demographic	Reviews 2020-21		Backlog Reviews	
	Halton	Warrington	Halton	Warrington
Gender Male	**71%**	**43%**	**64%**	**25%**
Female	**29%**	**57%**	**36%**	**75%**
Age Under 55	**14%**	**64%**	**31%**	**60%**
55-64	**29%**	**15%**	**31%**	**30%**
65 and over	**57%**	**21%**	**38%**	**10%**
Average age at death	**69**	**53**	**57**	**57**
BAME	**0%**	**14%**	**0%**	**0%**

Observation:

New reviews

- Within the new reviews the data shows a higher percentage of deaths in males for Halton
- The age at death for Warrington is highest in the under 55 category. One death was for a child within this group.

Backlog reviews

- Within the backlog reviews there is a notable higher percentage of female deaths for Warrington
- The age at death for Warrington is highest in the under 55 category.

In 2020/ 2021 reporting it is noted that there have been only 2 notifications of a death for people with learning disabilities from the Black, Asian or Minority Ethnicities (BAME) and both were for Warrington. This correlates to the national picture and is picked up for targeted awareness raising of LeDeR with BAME communities in 2021-2022 and aligns to the national LeDeR Policy priorities (refer to section 12)

6.2 Cause of Deaths

Of the new reviews conducted in 2020/21 the two most common recorded causes of death were:

Table 3- New reviews

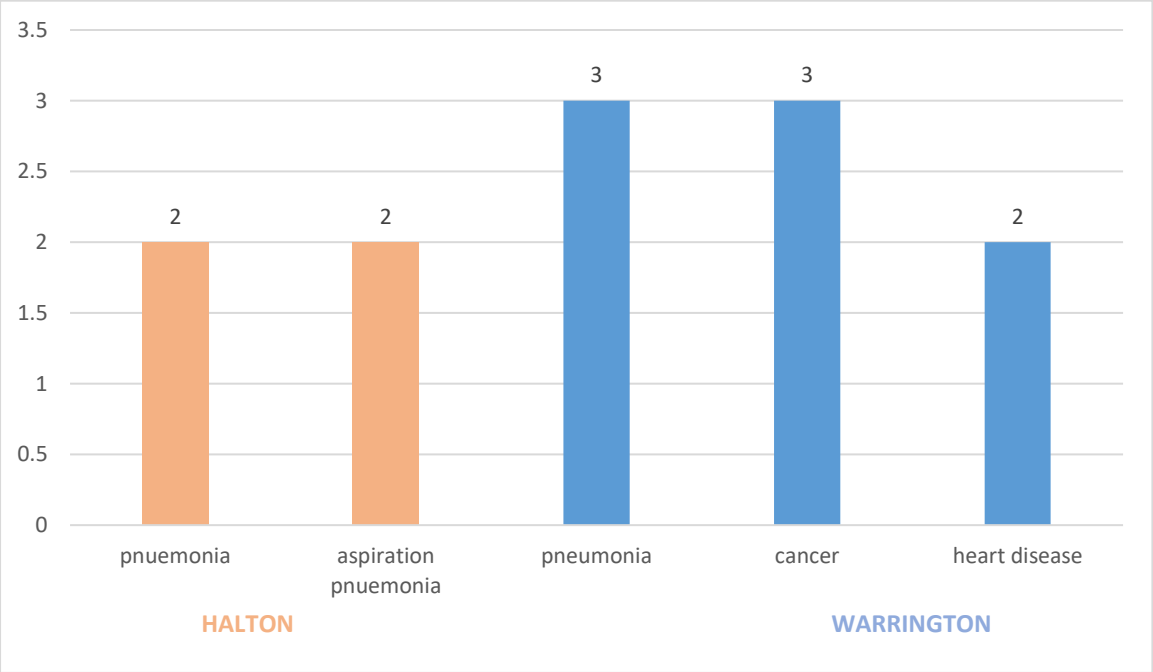


Table 4 – Backlog reviews

Of the backlog reviews the two most common recorded causes of death were:

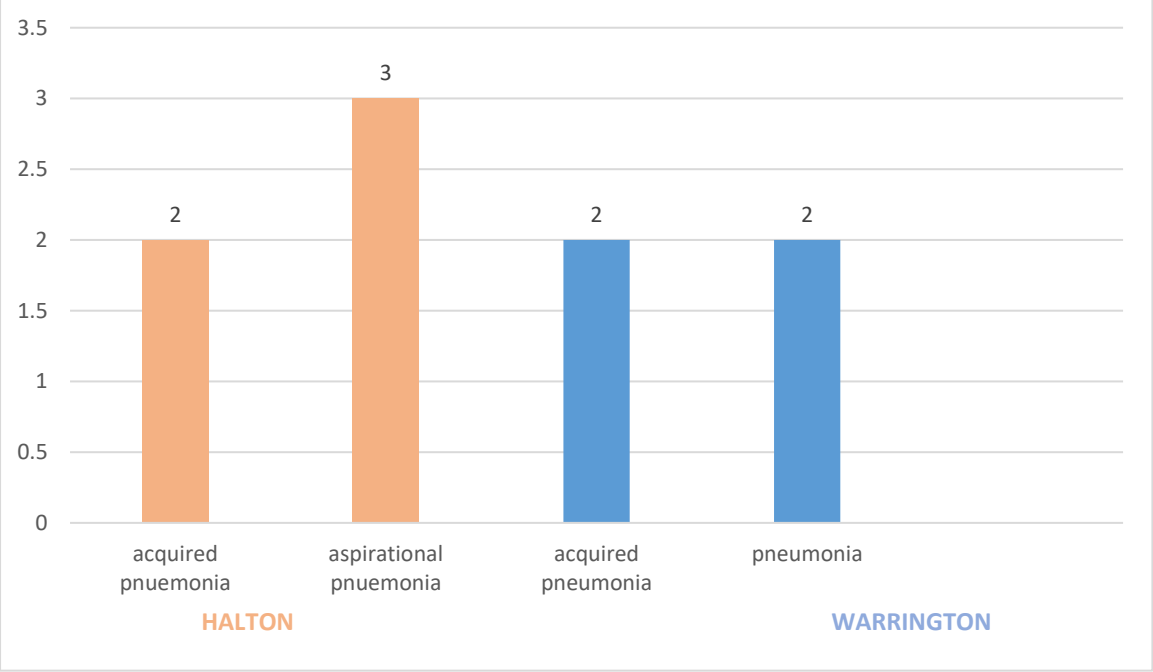


Table 5 -Total recorded causes of death – new reviews

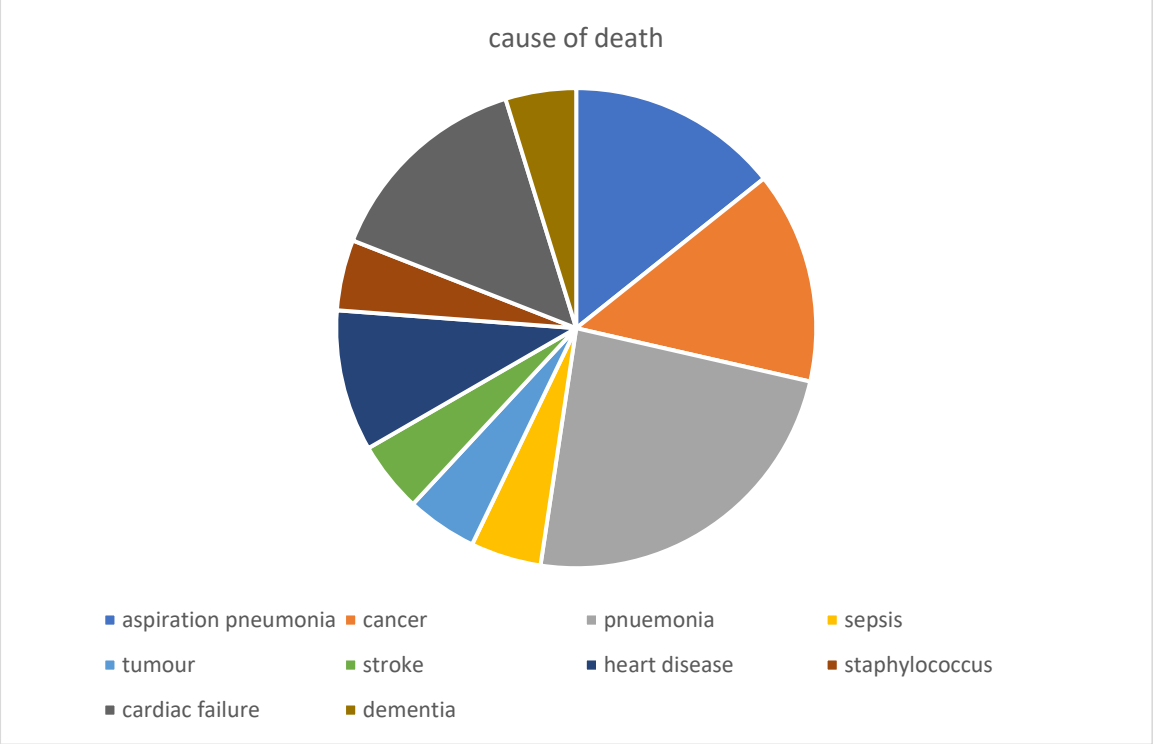
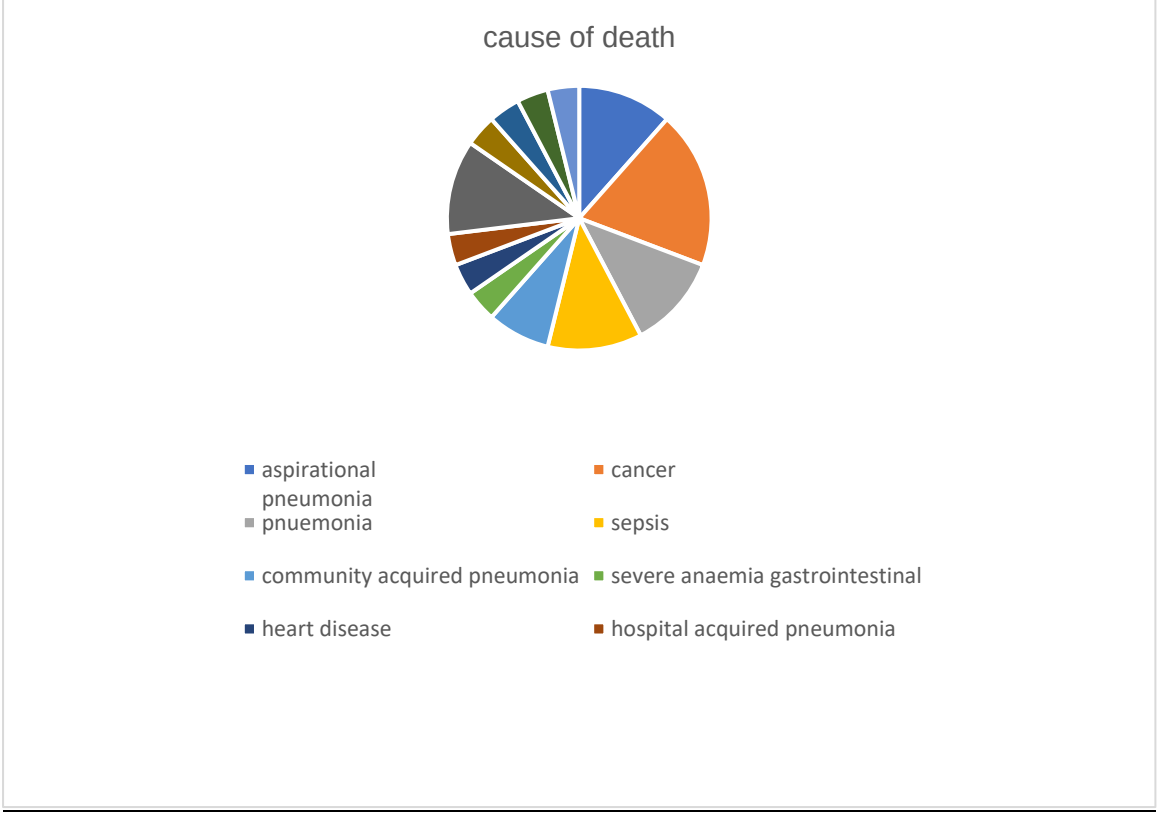


Table 6 -Total recorded causes of death – backlog reviews



Observation:
There is a range of causes of death noted. Pneumonia and Aspiration Pneumonia remain amongst the highest which is consistent from 2019-2020 and aligns with the backlog reviews.
There were 3 confirmed Covid deaths in the reporting period- these have not been added to the table as the reviews are not completed and will form part of the 2021-22 data set. Detail as known is reported in section 7.0.

6.3 Place of death

Table 7

Place of death	Reviews 2021		Backlog reviews	
	Halton	**Warrington**	**Halton**	**Warrington**
Hospital	57%	50%	79%	67%
Own home (inc. nursing home)	43%	50%	21%	33%

Observation:

The backlog data for both Halton and Warrington shows a higher percentage of people dying in hospital. When this is compared to the 2020-21 data an improved picture is noted in people dying in their own home.

6.4 Do not attempt cardio- pulmonary resuscitation decisions (DNACPR)

Table 8

Reviews 2020-21		Backlog Reviews	
Halton	**Warrington**	**Halton**	**Warrington**
71%	50%	71%	100%

Observation:

- The reviews did not indicate any areas of concern in relation to the DNACPR decisions in place, all were found on the evidence available to have been appropriate. The panel did not find any instances were a DNACPR should have been in place and was missing.
- There was noted in a small number of reviews a lack of understanding re DNACPR's, the decision-making process and accountability for the decision, by families and carers.

This could be an area for consideration by medical/clinical staff going forward.

6.5 Annual Health Checks

Table 9

	Reviews 2020- 2021		Backlog Reviews	
	Halton	**Warrington**	**Halton**	**Warrington**
AHC completed	**100%**	**93%**	**71%**	**67%**

Observation:

- Comparison of the backlog data to the 2020-21 data shows a much-improved picture relating to the completion of an Annual Health Check for people with a learning disability in the reviews within LeDeR.
- Whilst the rates of completed Annual Health Checks (AHC) within the LeDeR reviews for 2020-21 was positive there was variance in the reported uptake of screening, and it was difficult to assess the impact of an AHC on managing an individual's healthcare needs. The quality of AHC's and the outcomes need to be the focus of local audit for 2021-2022.

6.6 Grading of care

The chart below shows the grade and criteria for measuring care used in LeDeR reviews and the score achieved during 2020-21.

Table 10

Grade of Care	Description	Reviews 2020-21		Backlog Reviews	
		Halton	Warrington	Halton	Warrington
1	This was excellent care (it exceeded current good practice).	0%	7%	7%	0%
2	This was good care (it met current good practice in all areas).	86%	64%	43%	42%
3	This was satisfactory care (it fell short of current good practice in minor areas, and no significant learning would result from a fuller review of the death).	14%	22%	50%	33%
4	Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning would result from a fuller review of the death	0%	7%	0%	25%
5	Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death	0%	0%	0%	0%
6	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person	0%	0%	0%	0%

Observation

Comparison of the data from the backlog reviews and the 2020-21 reviews shows an improving picture in relation to the grading of reviews for both Halton and Warrington

7. 0 Covid 19

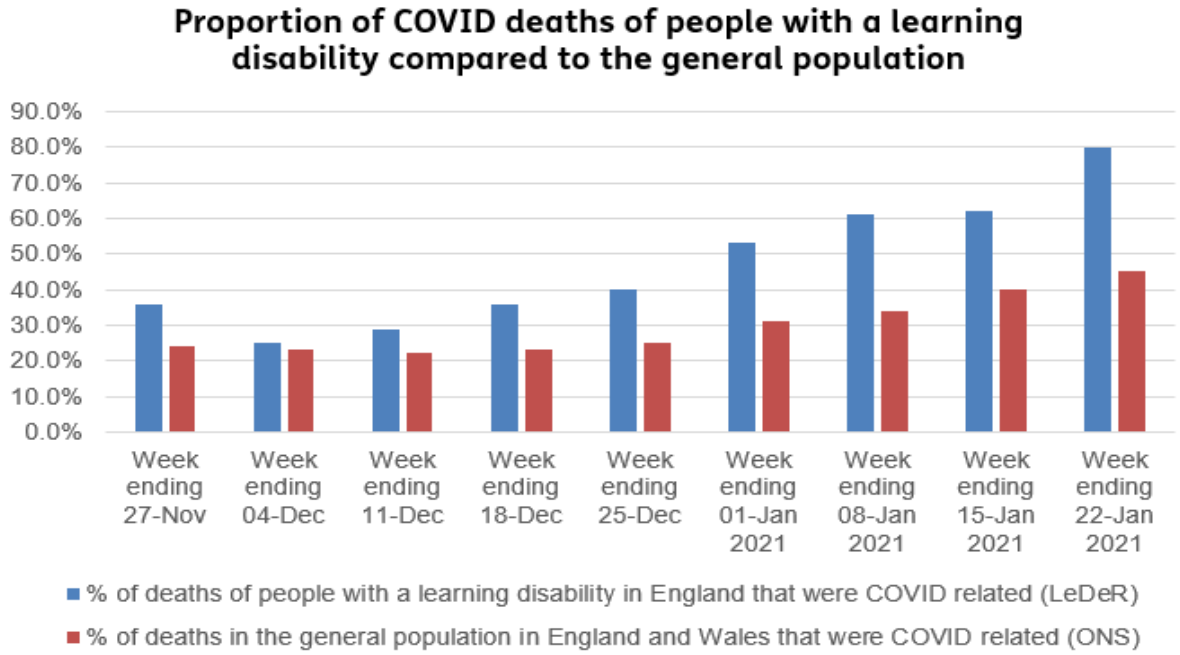
During 2020-21 for Halton and Warrington there were 3 deaths notified to LeDeR with a confirmed Covid diagnosis, and 1 with a suspected diagnosis. All of these have been notified towards the end of the reporting period and the reviews remain in progress.

National data from LeDeR and the Office for National Statistics (ONS) **(**Table11) shows that in every week since the end of November 2020, people with a learning disability have died from COVID disproportionately from the general population. And as the second wave continues to unfold, the disparity between the proportion of COVID deaths has grown dramatically throughout December and January.

This aligns to the local picture for Halton and Warrington. No Covid deaths were reported between April – November 2020 into LeDeR for Halton and Warrington, however from

December 2020 to end of March 2021 we have received the 3 confirmed Covid deaths and 1 suspected Covid death notified into LeDeR.

Table 11



During the first wave of the pandemic (April-June) all deaths notified within LeDeR were subject to a rapid review and Covid related questions to enable a rapid response to any learning identified. This data was shared with NHSE/I to inform an audit for the Northwest.

From the LeDeR reviews undertaken there was notable good practice to support people with a learning disability during the pandemic period to meet their healthcare needs and specially to die in their preferred place of care. Some examples have been shared below:

MDT organised for rapid transfer of a person from nursing home to relatives home for their End of Life care due to restrictions on visiting at the nursing home and the distress this would have caused

Local acute provider supported families and carers to maintain contact with the people with a learning disability whilst in acute care through individualised approach to visiting restrictions

Support wrapped rapidly around an individual to prevent a hospital admission and to enable them to die at home with familiar faces and loved ones. End of Life care provided in line with Covid requirements.

7.1 Learning from the pandemic

Local:

- Within Halton and Warrington services worked collaboratively across the system partnership to manage the health and social care needs of people with a learning disability.
- Learning disability nursing teams and healthcare providers ensured all people with a learning disability and a known risk of respiratory conditions were flagged with acute providers due to an increased risk of admission.
- Hospital passports were updated and shared with acute providers to support any admissions.
- Consultations were maintained via virtual platforms or telephone consultations to ensure healthcare needs were managed in a timely manner.

7.2 National/Regional:

Recommendations were identified by the University of Bristol, Public Health England, and from a Northwest audit of the Rapid Reviews of people with a learning disability, that sadly lost their lives in the first wave of the Covid Pandemic.

The findings from the reports were aligned and were reviewed under the Transforming Care workstream for the Northwest. This identified 21 recommendations and the local system response to these. Many recommendations were specific to Covid measures i.e., shielding, and visiting restrictions.
Several key examples are detailed below for assurance of local oversight and action. The full report and local response can be found in Appendix 2.

Table 12

No	Learning/Recommendation	Halton/Warrington Response
1	Age thresholds for shielding people from COVID-19 would disproportionately disadvantage people with learning disabilities. This needs to be taken into account of the implementation of key programmes e.g., Covid oximeter@home/virtual wards.	Working with the National team for the roll of Covid-Oximeter@Home to also be offered to people with a learning disability over the age 18. Shielding advice reviewed at national level.
2	Close to a third of those who died from COVID-19 lived in residential care homes and a third in supported living settings. Priority must be given to supporting measures to prevent the spread of COVID-19 in these settings.	All CQC registered providers and LD supported living included in Care Home Workstream. Lead GP identified. Supplied PPE, Thermometers, Medicines Rescue packs, Ipads, pulse oximeters and IPC training to staff.
5	Lethargy and tiredness were more frequently reported in people who died from COVID-19 (39%) compared with other causes (23%), so greater attention may need to be paid to this symptom in people with learning disabilities.	LD LES put in place during Covid as health and wellbeing checks. Diagnostic overshadowing included in LeDeR reviews. We have had a system learning event to feedback the findings including a Video of case studies that has been shared across the system.
6	Train both health and care staff in the use of tools such as RESTORE2™ which help them to identify the soft signs of deterioration in health.	RESTORE 2 currently being rolled out across Halton and Warrington CCGs. Pulse oximeters provided to all learning disability providers
19	Make it clear to all doctors who complete death certificates that a learning disability should never be included in a medical certificate as cause of death.	This has been completed across Primary Care in verification of death training and during safeguarding education session.

7.3 LeDeR Audit- Bristol University

The University of Bristol audit focused on a sample of 50 reviews of deaths attributed to Covid 19. Whilst this is not a representative sample some of the key learning is detailed below in tables13-15 with the local detail, as known as these remain ongoing reviews, provided in Table 16.

Table 13- National learning

All data from deaths between 19th March and 19th May 2020.

- Midlands 28; London 19; Northwest <10.
- 30 males; 20 females.
- 35 aged 50-74 years. <10 aged under 50 years; <10 aged 75 or over.
- 30 white British; 20 from BAME groups.
- 14 mild; 11 moderate; 10 severe learning disabilities; 15 unknown.
- 15 own or family home; 13 supported living; 10 residential home; <10 nursing home; <10 other usual residence.
- 15 had Down's syndrome.

Table 14- National Learning

Pre-existing long-term health conditions:

- Mobility impairment - 64%
- Cardiovascular problems - 54%
- Epilepsy - 36%
- Mental Health - 34%
- Obesity - 30%
- Dementia - 28%
- Respiratory conditions - 24%
- Diabetes - 20%

Table 15- National Learning

Symptoms of Covid 19

Difficulty breathing – 26
Cough – 26
Fever – 25
One or more of these three symptoms - 43
Two or more of these three symptoms – 27
All three symptoms <10 people
None of these symptoms <10 people

Other symptoms (<10 people): generally unwell; loss of appetite, lethargy/tiredness, recent urine or chest infection, diarrhoea, or vomiting.
None reported altered sense of smell or taste.

7.4 Local Learning – Halton and Warrington Covid deaths notified to Leder 2020-2021

From 2020-21 reporting there have been 3 confirmed Covid deaths and 1 suspected. The detailed learning from these reviews remains ongoing as they were notified in Q4, but initial detail is provided as known however this is limited. Learning from the completed reviews will be reported in full in the 2021-2022 Annual report.

Table 16

Known factors	HALTON	WARRINGTON
Number of Covid deaths	1	2 1 suspected
Male/female	M	F, F F
Age	52	71, 70 51
Level of learning disability	Mild	1) Await information 2) Moderate 3) Level not stated
Long Term Conditions	Epilepsy Obesity Schizophrenia	1)Await information 2)Asthma Behavioural disorder 3)Downs syndrome Congenital heart disease Thyroid disease
Covid symptoms	Persistent dry cough Breathlessness High temperature	1) Await information 2)Covid positive test Low temperature Oxygen level slightly low 3) Lethargic Pale Tiredness
Other	DNACPR	1) Await information 2) DNACPR

Observation:
Whilst the data from the local Covid deaths reported to LeDeR for 2022-21 is limited due to the reviews being ongoing it does show some alignment with the national reporting:

- Covid deaths have occurred in Q4 of the reporting period- thus later into the pandemic
- None reported altered sense of smell or taste
- Generally reported as unwell and lethargic

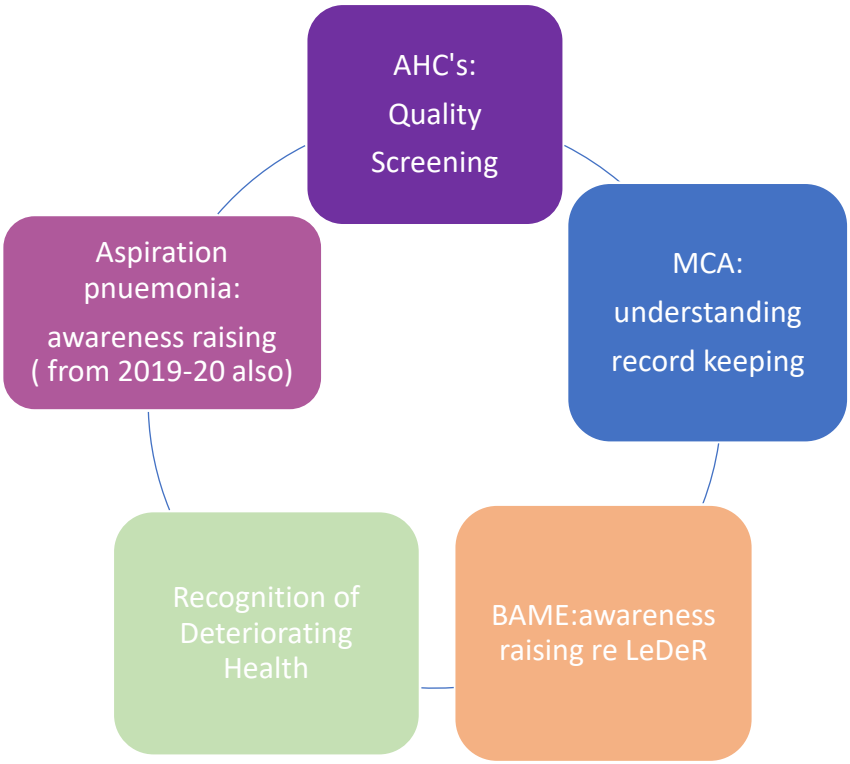
7.5 Covid Impact upon LeDeR delivery for Halton and Warrington

During 2020-2021 the Covid restrictions and need for business prioritisation did impact upon the LeDeR panel. The panel continued as frequently as possible with 9 panels being held across the year. The panels were adapted to run via a virtual platform to enable continuity however it is noted this does bring some challenges to information sharing and review of the available information on screen and remains subject to continuous development.

In addition, there was a noted impact upon the capacity of services to provide information towards the LeDeR reviews. HCCG/WCCG supported services where possible and ensured that NHSE/I was aware of the competing demands across the system. Whilst national business prioritisation plans were in place for services to enable the required Covid response, the national LeDeR timescales remained unchanged throughout the pandemic. Reviews were maintained throughout this period and a flexible and pragmatic approach applied in respect of the information gathered for a review.

8.0 Learning into Action themes:

The most reported themes for 2020-2021 noted for targeted learning into action were reasonably consistent across both Halton and Warrington and relate to:



9. Progress from 2019-2020

In 2019-2020 the LeDeR panel was a new process, and the panel members were adjusting to the multi-agency approach. For 2020-2021 the LeDeR panel is now established and functions well. The panel is very well supported across the system from both Halton and Warrington with members from a range of providers and HCCG/WCCG. The reviews are

subject to multi-agency scrutiny for every review, and this has on many occasions highlighted issues and learning that would not have been noted with the previous single reviewer process.

HCCG/WCCG remain committed to this approach for 2021-2022 until the move to the Integrated Care System model (ICS). LeDeR will become a shared ICS function with a dedicated team from April 2022 (refer to section 12).

All national learning and key messages have been cascaded during this reporting period via System Partners, Safeguarding Adult Boards, and local groups and forums as appropriate.

Covid has impacted upon the system capacity to hold local learning into action groups however lots of the learning and measures implemented due to Covid align to the LeDeR learning and health inequalities workstreams for people with a learning disability as reported in **Appendix 2.**

Key partners continue to support all workstreams for people with a learning disability and examples are detailed in Table 18.

10.0 National Independent Review into the Oliver McGowan's Learning Disabilities Mortality Review (LeDeR) process (October 2020)

10.1 Background:

An in-depth and detailed review of the Learning Disabilities Mortality Review (LeDeR) process for a young man- Oliver McGowan, was undertaken following concerns raised by his family. The review was shared for national learning and awareness across the LeDeR system and recommendations identified for local consideration.

10.2 Key Findings:

Oliver was a healthy teenager who died of a relatively rare condition, known as neuroleptic malignancy syndrome (NMS). Throughout the complaints, safeguarding and root cause analysis (RCA) process, Oliver's parents consistently voiced their dissatisfaction with the care and treatment he received. RCA notwithstanding, the review found that the initial response to Oliver's death should not have been the instigation of an LeDeR review but an independent serious investigation.

In addition, the independent review found there were delays and difficulties in completing the LeDeR process for Oliver and this was characterised by poor governance contributed to by poor leadership, reorganisation, changes in personnel and lack of oversight by the relevant CCG. The review highlighted numerous learning points and has been shared nationally. Independent Review- full details of the report can be found at **Appendix 3.**

10.3 Recommendations:

The independent review made a number of recommendations, included in the full report, to ensure that:

- all CCG's take their leadership responsibilities in respect of LeDeR seriously
- the national LeDeR processes are more robust
- learning is taken forward nationally and not continually repeated.

HCCG/WCCG has reviewed all recommendations as indicated for the CCG, LeDeR Local Area Contact (LAC), or reviewers. Compliance against these recommendations has been assessed and actions identified where required and this will be subject to quarterly review or until compliance is met.

11. Next Steps in 2021-2022

A key priority for 2021-2022 is to commence the local LeDeR Learning into Action Group. The governance and membership are in place however the implementation has struggled due to the on-going Covid impact upon system capacity in 2020-2021.

HCCG/WCCG are an active member of the Cheshire/ Merseyside steering group and contribute to the delivery of the regional learning and shared action plan.

Learning from the reviews in 2020-2021, and from the Covid focused learning has informed the development of priority areas of focus for 2021-2022. This has been incorporated into a local action plan for assurance, oversight, and delivery by the local LeDeR Learning into Action group.

The key areas of focus have been identified for each quarter in 2021-2022. Some aspects may require system assurance of actions undertaken/ongoing- especially where part of existing Learning Disability workstreams, and for other areas these have been planned to be the subject of a quarterly focus topic at the Learning into Action Group.

Table 17 Workplan for the Learning into Action Group

Quarter	Focus Area- awareness raising and promotion	Deep dive topic for Learning into Action Group
Quarter 1	BAME groups- awareness of LeDeR	• Covid learning • Aspiration pneumonia
Quarter 2	Recognising deteriorating health- Speak up video. Z cards	• Recognition of signs of deteriorating heath in people with a learning disability
Quarter 3	Nursing Homes- awareness of LeDeR (from 2019-20)	• MCA - scoping
Quarter 4	LeDeR delivery in the ICS	• AHC and access to screening

12. National LeDeR Policy

A national LeDeR policy was developed for the first time in March 2021, the key implications are:

- The most important focus of the new policy is that there is a stronger emphasis on the delivery of the actions coming out of the reviews and holding local systems to account for that delivery, to ensure that there is evidence of service improvement locally. NHSE/I regional teams will hold integrated care systems to account for the delivery of the actions they identify.

- From the 1 June 2021, there will be a new process for reviewers to follow, including a new computer system ('web- based platform'), and new training for the LeDeR workforce.

- Local Integrated Care Systems (ICSs) will become responsible for ensuring:
  a) that LeDeR reviews are completed for their local area
  b) that actions are implemented to improve the quality of all mainstream services for people with a learning disability to reduce health inequalities and premature mortality.
  c) that local actions are taken to address the issues identified in reviews.
  d) that recurrent themes and significant issues are identified and addressed at a more systematic level.
  e) within the ICS reviewers will work in teams so that no reviewer will work alone, everyone will have the time they need to do reviews and support to do them.

- The policy introduces the need to commence reviewing the deaths of adults who have a diagnosis of autism but no learning disability. All reviews of people who are autistic without a learning disability will be focused reviews initially.

- All notifications of a person's death will receive an initial review including talking to their family or people who knew them well, talking to their GP or looking at the GP records, and talking to at least one other person involved in the person's care. If the reviewer feels a more detailed review is needed, a focused review will follow. Families can say if they think a focused review is needed.

- All people from Black Asian and Minority Ethnic communities (BAME) will get a focused review because the evidence so far shows that the health inequalities experienced by people from these communities are very significant, and there is also under reporting of deaths from these communities.

The above will therefore need to be a major focus for 2021-2022, both as local delivery and for active future planning for the transition to the new model within the ICS. A key consideration will be how to ensure completion of the newly required LeDeR reviews for people with a diagnosis of Autism in 2021-22 whilst this remains with HCCG/WCCG accountabilities.

13. Local Actions

Key partner organisations across Halton and Warrington have shown commitment and support for the LeDeR programme in this reporting period.
Highlights of the development work undertaken that aligns with LeDeR priorities, and supports reducing health inequalities, improving accessibility, quality, and the experience of services for people with a learning disability is detailed below:

Table 18

Organisation	Key Developments
St Helens and Knowsley Acute Trust (STHK)	St Helens & Knowsley NHS Teaching Hospital (STHK) employed a Learning Disability Specialist Nurse in March 2020 to provide specialist support to lead on the implementation of the Learning Disability/ Autistic Spectrum Disorder Strategy across the Trust. This

	has enabled the Trust to meet the NHS Improvement objective set out in the Improving Standards for patients with Learning Disabilities NHS 2018. Links have been made with local networks and community teams to support information sharing and liaison and virtual meetings have taken place to engage with people who have a learning disability. The Learning Disability Specialist Nurse has also made links with IMCA services locally to ensure that people with a learning disability, who lack capacity, have an independent advocate involved with Best Interest decision making discussions. The Trust has updated the STHK Health Passport to ensure that reasonable adjustments are considered. Reasonable Adjustments included during the Covid pandemic, allowing care staff or family members to visit or stay with the patient whilst in hospital. Over the last twelve months over 300 STHK staff and key departments have received face to face Introduction to Learning Disability Awareness & Autism Training. Coordination of care for those with a Learning Disability has received very positive feedback with one family responding post-surgery with the following comment, ***"We express sincere appreciation for the concern and tremendous support".***
Warrington and Halton Hospital Foundation Trust	A Learning Disability / Autism Practice Development Nurse trainer has been appointed into a fixed term full time band 7 post. Her role is to support WHH training requirements, support incidents and the wider LD/Autism agenda. Do Not Attempt Cardiopulmonary Resuscitate (DNACPR): following the letter from NHSE chief nurse Ruth May and medical director Stephen Powis regarding DNACPR decisions for patients with an LD being shared throughout WHH it was noted that there were no reports of inappropriate DNACPR decisions, for assurance an audit of all DNACPR decisions regarding patients with LD is underway. During the Covid-19 period, safeguarding adult and community Learning Disability teams have worked together to share hospital passports of patients with a learning disability to proactively support any admissions. WHH have an LD action plan that is directly linked to the outcomes of the National Learning Disability Improvement Standards and contains learning actions from incidents and investigations. This is updated and monitored via the LD /Autism steering group, which has a trust wide attendance. Twice daily welfare checks are undertaken by the Matron/Lead Nurse which includes a review of reasonable adjustments. During the month of July 2020, the WHH Safeguarding Team launched a 3-week event 'Spotlight on Safeguarding' including sessions on learning disability, autism, and the additional impact of covid. A weeklong hot topic was delivered at trust wide safety brief that included discussion and information on Learning disability or Learning Difficulty? What is autism? Health inequalities in people with a learning disability and autism

	What are reasonable adjustments?
Bridgewater Community Healthcare Trust	Bridgewater have established a Learning Disability Working Group for the purpose of improving the service offer to people with learning disabilities across the Trust. Bridgewater have taken part in the Learning Disability Improvement Standards review and undertaken an internal gap analysis of service provision for people with learning disabilities and developed an action plan based on the findings, the workplan includes: • Recording and flagging reasonable adjustments plan to be developed in collaboration with IT and BI. • Developed feedback form for people with LD. • Completion and launch of best practice guidance. • Provision of an LD training offer Bridgewater have implemented a part-time post to sit within the Safeguarding Team who will take on a lead role for people with learning disabilities, supporting, and advising the trust workforce. Bridgewater have undertaken an internal gap analysis of service provision for people with learning disabilities and developed an action plan. Bridgewater have developed a friends and family test (FFT) feedback form for people with a learning disability to support quality feedback. Bridgewater are currently in the process of developing best practice guidance for trust staff who are working with people who have a learning disability. Other key contributions include: • Learning Disability Community Matron in post supporting people with complex health conditions in Halton completing joint work with Halton Council and Northwest Boroughs as a co-located multidisciplinary team. • Improving End of Life Care for people with a Learning Disability with monthly advanced planning meeting where patients in last 12 month of life are discussed and MDT approach to care and issues surrounding end of life and advanced planning can be brought to this monthly meeting. Community matron is link from this group to mainstream services. • Contribution to the external review of End-of-Life Care Design in Halton to ensure the needs of people with a Learning Disability are considered. • All death of people with a Learning Disability are reviewed for lessons learned, and in addition the Trust has quarterly Learning from Deaths meeting to review learning and identify and themes / trends. Where issues are identified from partner agencies these are shared via safeguarding or incident reporting process. • Support to local LeDeR panel on a monthly basis • Safeguarding Adults Team representatives attend all patient safety meetings to support decision making and practice re Mental Capacity Act compliance COVID specific contributions: • Provided challenge and escalation for DNAR decision where these were felt to be clinically inappropriate.

	• Flexibility and adjustments to services provision during COVID for people with a Learning Disability • Provision of COVID vaccine support through facilitation and direct care and clinical holds
Halton Local Authority	Halton's Model of Care takes a whole systems approach to supporting Adults with Learning Disabilities and is built on strong Partnership Working across agencies. Halton Clinical Commissioning Group and Halton Borough Council have entered into a Section 75 Partnership Agreement which establishes a framework for integrated commissioning to achieve better outcomes for local people. The model supports all Halton adults with learning disabilities, their family and carers, plus young people with learning disabilities in transition to adult services with their family and carers. The Communities Directorate has responsibility to support, care for and protect its most vulnerable residents. It also offers information and signposting to enable its residents to make informed choices to help them maintain their independence, health, and wellbeing. Halton Supported Housing network run by HBC is part of 19 properties registered supported living service where support is provided for up to 54 adults with LD living in the Runcorn and Widnes area to live as independent as possible in their local community, access various day services or make use of a direct payment. Over the last 12 months it has been a difficult time due to the pandemic but as usual the tenants have been resilient to the change and now looking forward to getting back towards normality. Also, part of a registered shared lives scheme, the scheme was on a massive recruitment drive for carers to offer long term placement to residents of Halton in 2020 as the pandemic hit. Only very recently did the service resume a limited day care provision and look to set dates for completing new carers application and supporting them through the induction panel process.
Halton Learning Disability Nursing Team	Pro-active and reactive dementia screening processes for adults with downs syndrome has been revamped and has continued throughout the pandemic supporting early identification and treatment of suspected dementia (alongside identifying any unmet health needs as part of the health screening section of this assessment). This is now completed via the Learning Disability nurses without the need for referral to psychology speeding up the process and any signposting/health support needed for individuals. Learning Disability Nurses have been pro-actively updating and sharing hospital passports for the known Learning Disability population in Halton as part of reasonable adjustments and linking in with hospital safeguarding teams at STHK and Warrington Hospitals. Learning Disability nurses have been maintaining contact as GP liaison nurses throughout the pandemic to ensure Annual Health Checks are maintained throughout the pandemic. Support also provided to facilitate reasonable adjustments and access to vaccinations for individuals with a Learning Disability and complex needs.

	Learning Disability nurses have been the main point of contact for any crisis/mental health concerns/referral for the LD population throughout the pandemic in Halton. Coordination of signposting and maintenance of support for isolated individuals and those at higher risk of hospital admission due to the pandemic. The team complete bespoke training such as autism, behaviour, physical health sessions with individual clients and staff teams. Team are also looking at completing some awareness of LD training for their own organisation Halton Borough Council The team complete sexual health and relationship groups, in addition sessions around personal hygiene and healthy eating. The group sessions have been on hold during Covid but hope to return to them asap. The Team have a weekly walk in the park, run by one of community care workers, to try and encourage exercise, widen clients' social circles. The Team send out client feedback forms once a case is closed and then the feedback is discussed during supervision sessions, looking at any positive or negative comments etc. The team remain link workers for each GP surgery in Halton, offering help and advice, health facilitation with learning disability health checks. The Team are currently involved in end-of-life pathway meetings, parenting pathway, autism meetings all to improve the care that clients with Learning disability receive. Also currently working on a project with Countess of Chester hospital and CCG, to reduce the inequalities in diabetes type 2 in Halton to look at creating accessible education sessions.
Warrington Local Authority	Improving health outcomes and life expectancy in the Learning Disability community has been a key priority: 1. Accurate and effective record flagging, widespread awareness-raising across the workforce and proactive promotion of public health messages using accessible approaches. 2. Enhance preventative community-based approach to health through 'Let's Check'. Improving workforce awareness so that Annual Health Checks and regular screenings are maximised, and transition teams are on Board. 3. Ensure STOMP agenda is understood through audit and addressed through a comprehensive action plan. 4. Communicate and respond to findings from LeDeR reviews. 5. Reasonable adjustments are understood and available as required.
Northwest Boroughs	The learning disability service have undertaken targeted work in relation to Cancer screening for people with a learning disability, and AHC's are a focus area for 2021-22 The learning disability service have worked with Warrington Advocacy service to deliver zoom meetings with their self-advocates on a range of topics relating to health and well- being. LD team will continue with health facilitation to ensure all health inequalities are addressed and promote AHC. I have now offered dates to GP's regarding training regarding Learning Disability and health support etc.

	NWB have undertaken a targeted piece of work in relation to care/residential homes to ensure that any residents who have a learning disability are accessing the right support from specialist services.

14. NHSE/I Assurances

There are four performance indicators NHSE/I requires each CCG to report against when assessing how well we are doing with local delivery of the LeDeR programme.

These are:

• CCGs are a member of Learning from Deaths Report (LeDeR) Steering Group and have a named person with lead responsibility.

HCCG and WCCG are fully compliant with this indicator √

• There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.

HCCG and WCCG are fully compliant with this indicator √

• Each CCG has systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.

HCCG and WCCG are fully compliant with this indicator √

• An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.

HCCG and WCCG are fully compliant with this indicator √

15. Conclusion

2020-2021 has been a challenging year, with the effect of the pandemic being felt upon system capacity and business priorities at times impacting upon LeDeR local delivery. With support of the system partners HCCG/WCCG LeDeR panel has maintained oversight and delivery of LeDeR activity within the agreed standards and worked flexibly to ensure the learning from deaths continues.

The 2020-2021 LeDeR Annual Report provides an opportunity to mobilise engagement across the local system from those whose efforts and actions are needed in the coming year, to drive forward the service improvements required to improve care and reduce health inequalities for people with a learning disability.

Appendices:

Appendix 1

HCCG/WCCG Leder Governance Flow Chart

Flow chart.docx

Appendix 2

Covid National Learning Recommendations

Covid reviews Dec 2020 national learnin

Appendix 3

Oliver McGowan Report

independent review TOM.pdf

Appendix 4

LeDeR National Policy

B0428-LeDeR-policy-2021.pdf