Herefordshire and Worcestershire
Integrated Care System

Annual Report 2021/2022

Learning Disabilities Mortality Review **(LeDeR)** Programme (Herefordshire and Worcestershire)

June 2022

Rachael Skinner – Deputy Chief Nursing Officer and LeDeR Lead Area Coordinator

Imogen Mortiboys- Senior Reviewer and LeDeR Clinical Lead

Table of contents

1. Executive Summary

The programme to drive service improvement by Learning from the lives and deaths of people with a Learning Disability and autistic people for Herefordshire and Worcestershire (HW LeDeR) has been in place since 2017. This is our fourth year of the HW LeDeR programme and our third HW LeDeR annual report. This report summarises the insights we have taken from notifications and completed reviews, what the system focused on and achieved during 2021/22 to improve health outcomes and indicates where we could work together to enable further improvement.

Changes to the national programme during 2021/22 impacted on the timeliness of Review notification and completion and on the format of Reviews (and therefore the type of information collected). Toward the end of 2021/22 notifications could be made for autistic people who had a confirmed clinical diagnosis, for the first time. Anyone can make a notification LeDeR - Home

During 2021/22 the HW LeDeR programme significantly reduced the time taken to allocate a new case to a LeDeR Reviewer and to complete an Initial Review. This has helped to make learning available, to inform improvement measures, in a timelier way. The continued impact of the COVID-19 pandemic on our health and social care services at times delayed access to notes and limited the availability of key people to join multi-agency meetings to talk about more complex Focused Reviews.

The insight that we gained is taken from the detail in notifications made (52 during 2021/22) and Reviews completed (39 in 2021/22). It is important that we are cautious about trying to analyse themes as some data is based on a very small number of cases.

In gaining insight from notifications made to HW LeDeR and Reviews completed during 2021/22 we noticed the following:

- The median age of death was 61 for men and 62 for women. 46% were over 65 years of age when they died and 40% were aged 70 years or older
- Over 70% of those who died before the age of 50 had a profound level of learning disability
- Men were more likely to have mild or moderate learning disability (75% of men) and women more likely to have severe or profound learning disability (60%)
- People are as likely to die in an acute hospital bed than in their usual place of living (50:50)
- The top four recorded causes of death were pneumonia, cancer, cardiovascular disease and dementia.
- In many cases, based on the recorded cause of death, death was considered ‘avoidable’, that is associated with a condition believed to be preventable due to public health intervention or primary prevention, or amenable to treatment to prevent death.

Death from injury or accident were extremely low and LeDeR Reviews completed reflected extremely low numbers of people who smoked, used alcohol to excess or took unprescribed drugs.

- Less than one third of those who died from pneumonia were also considered to be frail. During 2021/22 HW system focused on supporting the uptake of vaccinations for COVID-19 and Flu. COVID-19 vaccination uptake was very good. Flu vaccine uptake improved but we want to do better next year.
- Late stage diagnosis of cancer and carcinomatosis (cancer that is widespread with no clear primary site) is too common. Screening uptake is similar to the general population but we need to do more to identify cancer earlier. Learning events planned for 2022/23 will help share best practice in best interest decision making so that decisions to refer a person for additional tests are informed by those who know the person best and consider a wide range of reasonable adjustments.
- Many of those who died from cardiovascular disease also lived with obesity or diabetes. We need to ensure that measures available enable people with a learning disability to benefit from healthy lifestyle advice and support
- The average age of death from end stage dementia was 58. We need to ensure that those supporting adults are aware of the possible signs of dementia and that access to dementia diagnosis is equitable.
- We do not yet know enough about how to improve the lives of people with a learning disability in HW who are Black, Asian or Minority Ethnic background, or autistic people. This is because we have only been notified of a very small number of deaths and have not yet been able to complete Reviews or identify learning themes.
- Reviews indicate that more people had an Annual Health Check (AHC). Annual Health Check uptake rates overall are high but some people in parts of our system are still missing out on this opportunity to ensure important aspects of health need are addressed and actions coordinated (this includes uptake of cancer screening, healthy lifestyle monitoring and vaccination).

This report sets out what we have noticed from the retrospective review of deaths and how we use information as insights to help inform improvements. We want to do more to support all partners across HW to take action to improve the health of people with a learning disability and autistic people, to enable healthier, happier and longer lives. Our system approach to Population Health Management will enable insight into the health needs of our local population so that people with a learning disability and autistic people are part of wider plans to tackle a range of factors that contribute toward health inequity.

During 2021/22 we published a 3 year HW LeDeR Strategy HW LeDeR Strategy 2022-2025 (herefordshireandworcestershireccg.nhs.uk) which sets out the collaborative and coproduced nature of our programme of work and includes the actions that we plan to take during 2022/23. In autumn 2022/23 we will coordinate a learning event where experts with lived experience and other stakeholders can contribute toward our system plan for improving health outcomes during 2023/24.

2. Introduction to the LeDeR programme and its delivery in Herefordshire and Worcestershire

The programme to enable Learning from the lives and deaths of people with a Learning Disability and autistic people (LeDeR) was initially established to support local areas to implement a consistent format for the review of deaths of people with a learning disability. The key principles of the programme are to identify learning from the review of people's lives after their death, for that learning to inform service improvement initiatives and for those initiatives to affect meaningful change in improving health and wellbeing outcomes for local people.

In March 2021 the first national LeDeR Policy was published. In the summer of 2021, the national LeDeR web-based platform transitioned to be hosted by South West Commissioning Support Unit and the format of reviews changed. From January 2022 the scope of the LeDeR programme included the receipt of notifications of deaths of autistic people who do not also have a learning disability. These changes to the national programme will impact on the nature of data available and therefore what and how we are able to make comparisons with data from previous years, including within this 2021/22 Annual Report.

All deaths continued to receive at least an Initial Review. Where there are areas of concern in relation to the care of the person who has died, or if it is felt that an identifiable feature is worthy of more detailed review as further learning could be gained, a more detailed Focused Review is undertaken.

LeDeR does not replace other statutory formats and processes for reviewing a person's death where concerns exist. On completion of the review (Initial or Focused), relevant learning informs recommendations and system actions. More detail about how we are confident that the Reviews that we complete are of a good standard, and how recommendations are scrutinised and then result in agreed action, can be found within our LeDeR Strategy HW LeDeR Strategy 2022-2025 (herefordshireandworcestershireccg.nhs.uk)

More information about the national programme can be found on the website for LeDeR hosted by NHS England https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/ .

This report provides an update on the progress and impact made across Herefordshire and Worcestershire during the period covering 1st April 2021 to 31st March 2022, the fourth full year of programme for our system. It builds on the achievements made through our partnerships and coproduction in previous years and reflects some of the extraordinary efforts of our partners to work together through another year that many will never forget, under the shadow of the COVID-19 pandemic.

3. Performance of Herefordshire and Worcestershire (HW) LeDeR

Notifications

Notifications of the deaths of people with a learning disability or autistic people registered with a Herefordshire or Worcestershire GP continue to be predominantly made by Community Learning Disability Nurses or Learning Disability Acute Liaison Nurses. During 2022/23 we received our first notifications from West Midlands Ambulance Service. Any person (for example GP, social worker, care setting manager or worker, family member) can make a notification by accessing LeDeR - Home

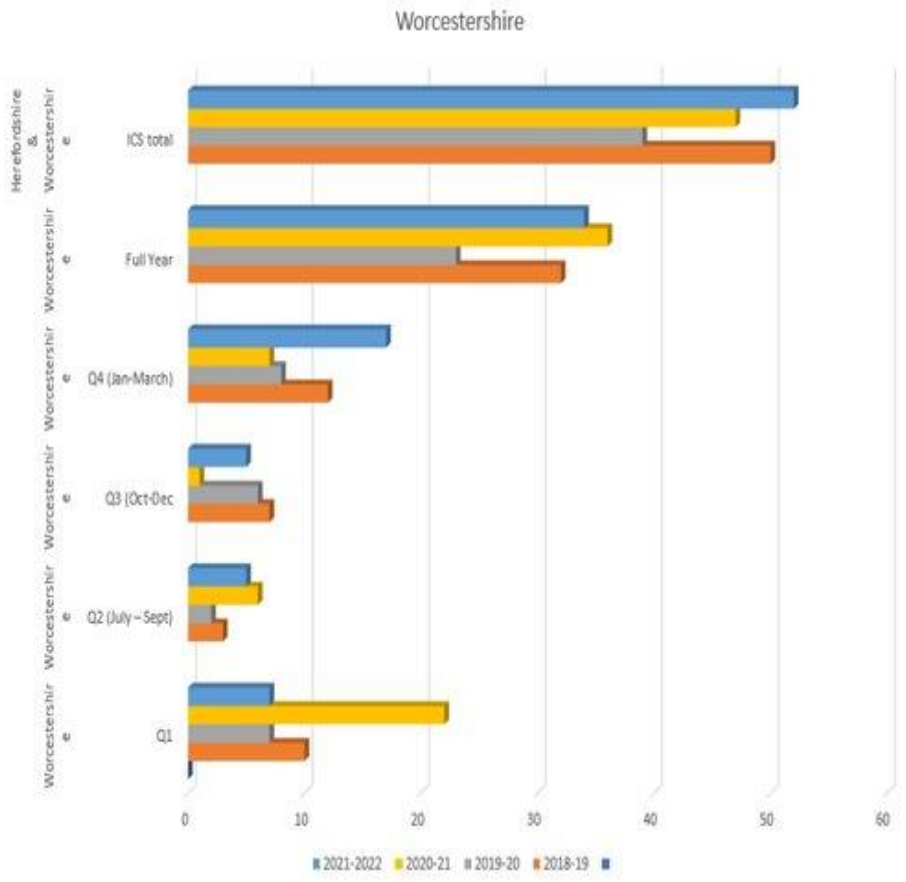
The pattern of notifications received by Herefordshire and Worcestershire is detailed in table 1 and figure 1. During 2021/22 we worked closely with all partners to refresh awareness of LeDeR to ensure that all parts of our system understand the importance of making LeDeR notifications, to increase our confidence that we are taking every opportunity to learn from people's lives and deaths.

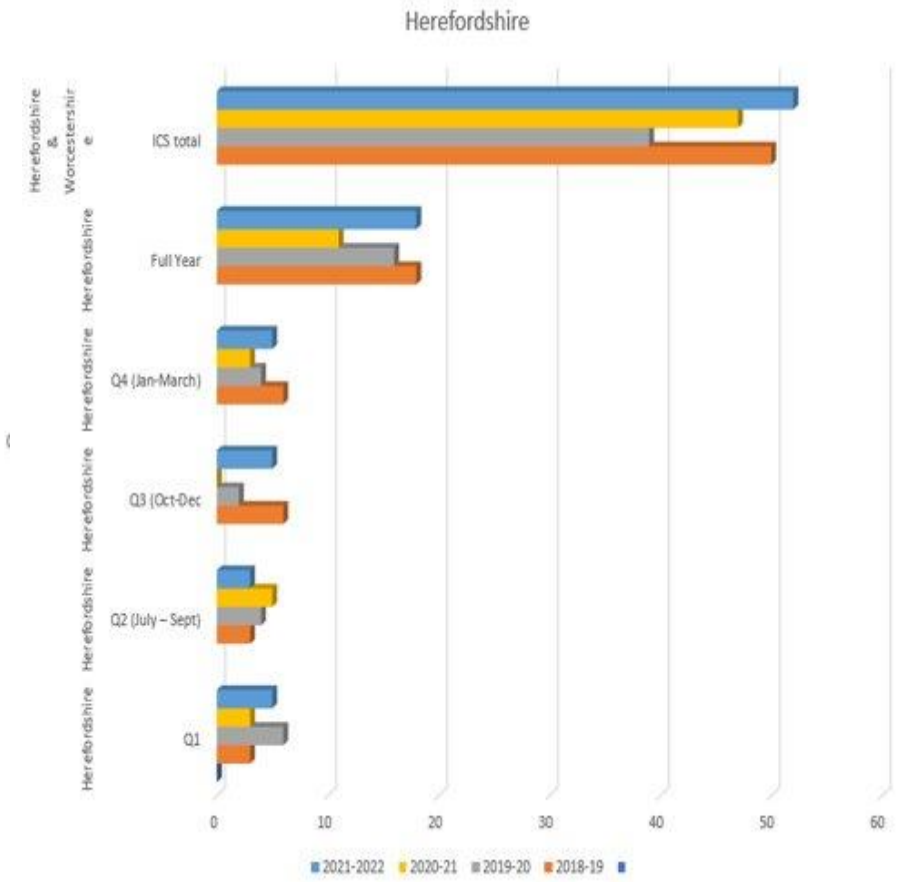
April to June 2020 and January to March 2022 saw unexpected variations in the numbers of notifications received, compared to patterns seen in previous years. COVID-19 accounted for much of the variation seen in April to June 2020. There is no clear explanation yet available for the variation in January to March 2022. Two notifications were received for autistic people as the scope of LeDeR changed to include autistic people from January 2022. We will need to await the completion of these reviews to understand any trends. The overall number of notifications is similar to most of the previous four years and most deaths occur in winter and spring months.

***Table 1**: Notifications made to Herefordshire and Worcestershire LeDeR. 2018/19 – 2021/22*

Herefordshire						Worcestershire						
Notifications received	Q1 (April – June)	Q2 (July – Sept)	Q3 (Oct-Dec	Q4 (Jan-March)	Full Year	Notifications received	Q1 (April – June)	Q2 (July – Sept)	Q3 (Oct-Dec	Q4 (Jan-March)	Full Year	ICS total
2018-19	3	3	6	6	**18**	2018-19	10	3	7	12	**32**	**50**
2019-20	6	4	2	4	**16**	2019-20	7	2	6	8	**23**	**39**
2020-21	3	5	0	3	**11**	2020-21	22	6	1	7	**36**	**47**
2021-2022	5	3	5	5	**18**	2021-2022	7	5	5	17	**34**	**52**

***Figure 1** Notifications made to Herefordshire and Worcestershire LeDeR. 2018/19 -2021/22*


Worcestershire
Herefordshire & Worcestershire
ICS total
Full Year
Q4 (Jan-March)
Q3 (Oct-Dec
Q2 (July – Sept)
Q1
0
10
20
30
40
50
60
2021-2022
2020-21
2019-20
2018-19


Herefordshire
Herefordshire & Worcestershire
ICS total
Full Year
Q4 (Jan-March)
Q3 (Oct-Dec
Q2 (July – Sept)
Q1
0
10
20
30
40
50
60
2021-2022
2020-21
2019-20
2018-19

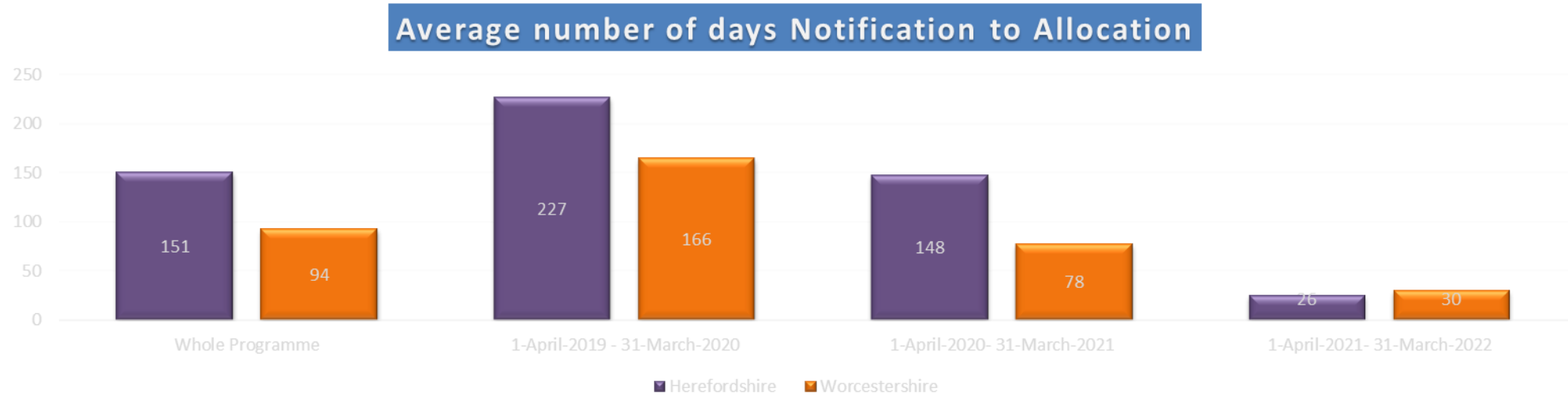
The timely allocation of notified deaths to a LeDeR Reviewer (within 3 months)

During 2021/22 we added to our substantive LeDeR Reviewer team. This enabled 100% of notifications to be allocated to a LeDeR Reviewer within the required timeframe of 3 months.

This is a big improvement on performance for 2020/21 where only 60% of notifications were allocated to a Reviewer within 3 months.

Across 2021/22 over 90% of notifications were allocated to a LeDeR Reviewer within one month of the case becoming visible to HWCCG.

Figure 2 - Average number of days to allocation



LeDeR Reviews

Review completion by type

In March 2021 a LeDeR Policy was introduced. This outlined the new format of reviews. Initial Reviews would be the standard for most notifications. Where the notification, or initial gathering of information, indicated a concern (for example a safeguarding alert) or a condition that required a more detailed review (for example the death of a person who had been detained under the Mental Health Act in the previous 5 years or the death of an autistic person) then a Focused Review would be undertaken.

During 2021/22 39 Reviews were approved as complete. Some of these reviews were commenced before the review format changed. For notifications received during 2021/22 there have been 6 identified as requiring a Focused Review. None of these Focused Reviews have as yet been completed.

The Timely Completion of Reviews (within 6 months)

As part of the LongTerm NHS Plan CCGs are monitored for the number of reviews that are completed within 6 months of notification.

Herefordshire and Worcestershire LeDeR are committed to ensuring that reviews are completed within 6 months. Where cases are open to the Coroner's Office or subject to Safeguarding processes, NHS Trust Serious Incident investigation, Complaints processes or Child Death Overview processes it is rare that LeDeR Reviews can be completed within this timescale. It is important that Reviews are informed by all relevant and available detail and so completion must take the outcome of other processes into account.

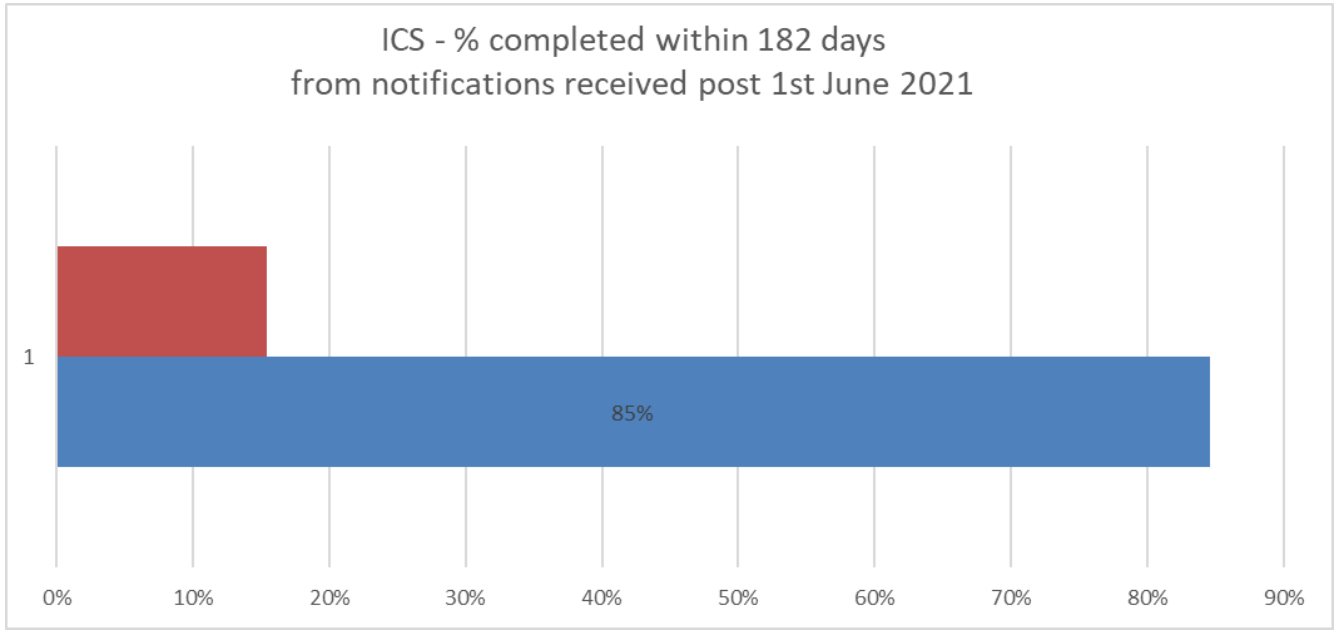
Delays with the completion of LeDeR Reviews have been experienced during 2021/22 due to changes impacting on the availability of the national LeDeR platform and the format of LeDeR Reviews, but also due to the continued impact of the COVID-19 pandemic on the availability of Primary Care and Acute Hospital Care clinicians to provide access to notes, conclude organisation specific mortality reviews and contribute to multi-agency meetings and processes. When we undertake a Focused Review we ensure that we make time to have conversations with all key health and social care workers involved in someone's life and care, so that we can make sure we are identifying any learning that will help influence improvements in services and outcomes for local people.

Due to the transition of the LeDeR platform hosting arrangements no notifications received for April 2021 were visible to each Integrated Care System until June 2021. This created some additional unexpected delays.

For Reviews completed within 2021/22 50% (20 Reviews from 39 Reviews completed) were approved within 6 months. Of the 19 Reviews completed in more than 6 months; 7 were completed by the Commissioning Support Unit after additional support was provided to address the backlog created by the pause in LeDeR Review System availability (notifications made from end of March to end of May 2021); 3 Reviews were subject to Coroner's Inquest; 5 Reviews were completed within 7 months.

For Reviews notified in 2021/22, and visible to HWCCG from June 2021, 85% of Reviews completed were approved within 6 months.

Figure 3- For notifications made from 1st June 2021 time to completion - % within 182 days



4. Learning from LeDeR Reviews

Generating learning from the information and recommendations provided by notifications and completed LeDeR Reviews is the main focus of the LeDeR programme for Herefordshire and Worcestershire system. It enables us to understand the experience of local people, recognise good practice and supports us to understand if we are making progress over time about the things that we want to improve.

4.1 Reflections on the characteristics of deaths notified to LeDeR Herefordshire and Worcestershire.

Age profile of notifications

*Table 2 - age group at death as a percentage of all notifications made during 2021/22 (** denotes number too small to be meaningful)

Age bracket	4-17 yrs	18-24 yrs	25-49 yrs	50-64 yrs	65 yrs and above
England (last available for 20/21	7%	4%	16%	35%	37%
ICS	6%	2%	16%	32%	46%
Male	*	*	6%	20%	22%
Female	*	*	10%	12%	24%

What does this tell us about the age of death within our system?

The percentage of deaths reported to H&W for those aged17 years or younger is similar to that for England and the percentage of young adult deaths is smaller but this difference is marginal and based on very small numbers.

The percentage of individuals aged 25-29 years and 50-64 years on notification of death is similar to the England position. For those aged 65 years and above the percentage is greater than the England position. The percentage of people aged 65 years and over at time of death has increased to 46% and is greater than the England position. 40% of all deaths were aged 70 or above.

Generally, many people whose lives are reviewed by the LeDeR programme in our ICS are able to live long and happy lives. We will continue to do all that we can to address the modifiable factors that help people achieve this.

Average and median age of death for notifications made in 2021/22

	Median age of death (excluding death before age 17 years)	Average age of death (excluding death before age 17 years)
Men	61	62
Women	62	59

The median age of death for men and women is similar to the England figure reported by the LeDeR programme in 2021.

Age of death and level of disability

For those who die before their 50th birthday, over 70% had a severe or profound level of learning disability.

Level of disability	Mild	Moderate	Severe	Profound
Age range at death	55-71 years	37-84 years	48-77 years	25-53 years

The gender profile of notifications

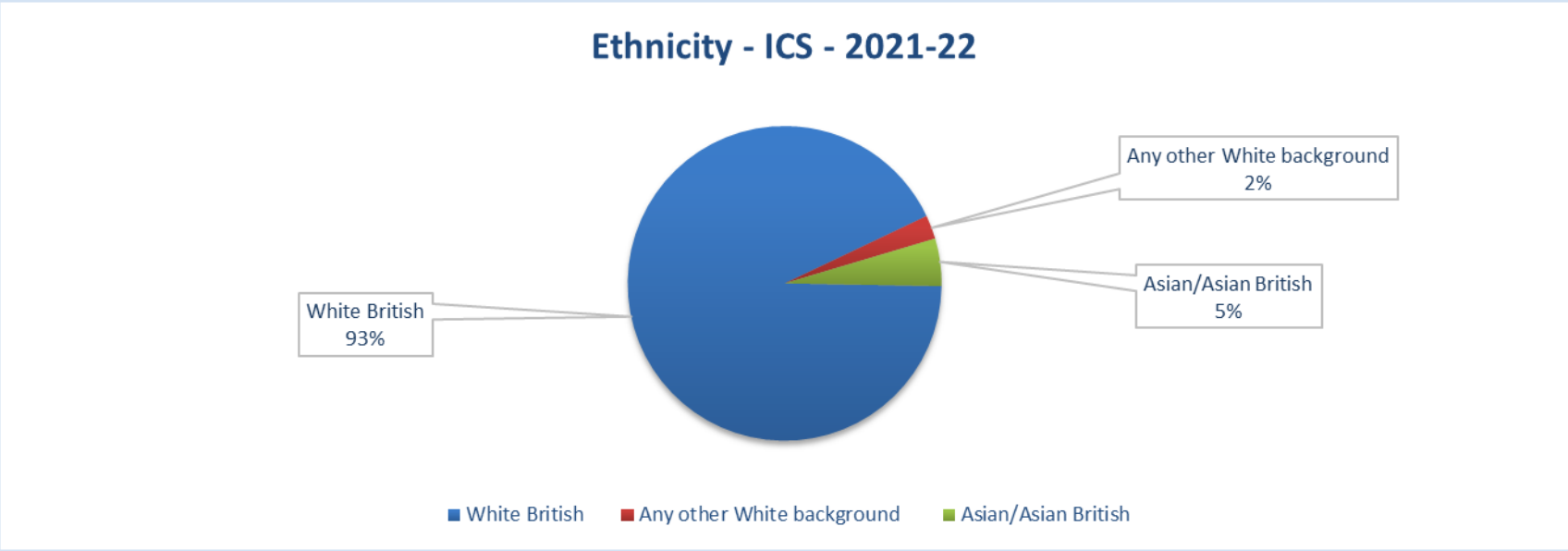
The percentage of notifications during 2021/22 that were of men or women was very similar- 54% men (28 notifications) to 46% women (24 notifications). This ratio was reflected across all groups of age range. In previous years HW LeDeR has received more notifications for men than for women but variation is accounted for by relatively small numbers of cases.

Men and women were not represented equally across the range of level of disability. This may be important if we want to influence health improvement measures for a specific gender group.

	Mild or Moderate learning disability	Severe or Profound learning disability
Men	75%	25%
Women	40%	60%

The ethnicity profile of notifications made to H&W LeDeR

Figure 4 ethnicity recorded on notification or on completion of Review during 2021/22



The ethnicity profile of notifications made to HW LeDeR has remained consistent with the profile over the course of the programme since 2017.

The HW general population is 97% white British with 0.5% of Asian or Black origin. Available data, to understand the ethnicity profile of people with a learning disability or autistic people in our ICS, is not sufficiently accurate and so we are unable to confirm if the pattern of notifications is reflective of our expected local population.

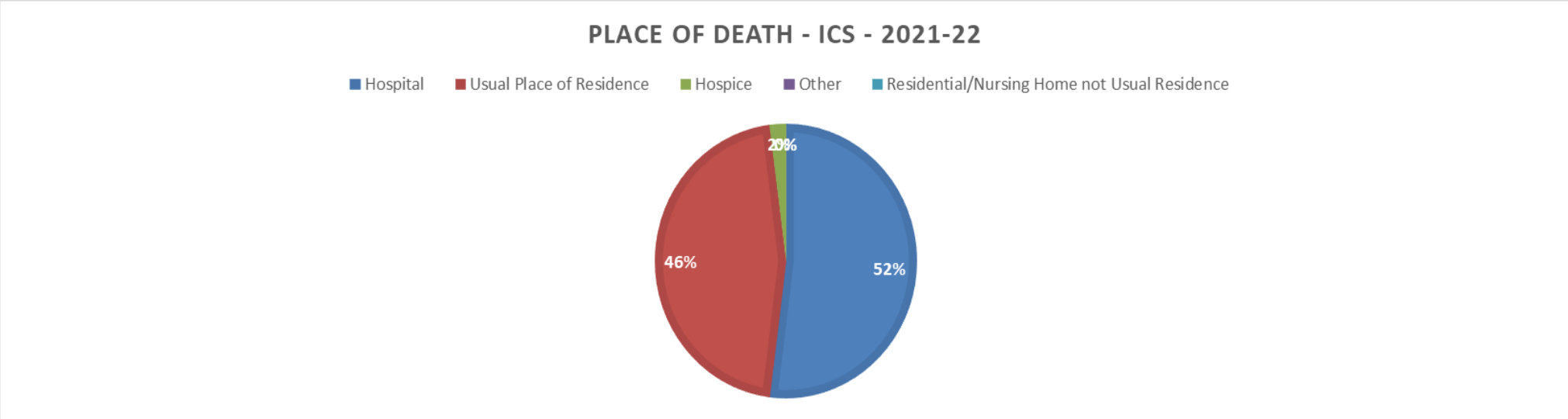
From all notifications received for H&W LeDeR since 2017, 25% of those aged 24 years or younger reported the persons ethnicity as Asian, White and Black African, White and Black Caribbean or other. As an ICS we need to do more to ensure that are receiving notifications for our whole community and try to understand more about the potential impact of ethnicity on the health equity and life chances of people with a learning disability or autistic people.

Place of death

Just over half of all notifications indicate that the person died in an acute hospital bed. Improvements in supporting people to die in their 'usual place' have been sustained for Worcestershire. LeDeR Reviews continue to show examples of satisfactory experience that could have been improved if the person was supported to die in their usual bed with those who know and love them close by.

This year, people whose death was notified to LeDeR from Herefordshire were as likely to die in an acute hospital bed as in their usual place of living. The small increase in deaths occurring in a hospital bed may be linked to improved reporting within that sector, but case numbers are very small and so firm conclusions cannot be made.

Figure 5 recorded place of death on notification during 2021/22



4.2 Learning from the outcomes of completed reviews – key data

Data from completed LeDeR reviews are collated into a matrix to support us to notice patterns worthy of further analysis.

Causes of death

Cause of death, as listed on death certification, is compiled into themes once the LeDeR Review has been completed, to ensure that data is accurate. Where an underlying condition is felt to have been a significant contributory factor in the persons death this is reflected (for example end stage dementia might be listed within themed analysis as opposed to pneumonia).

Figure 6 - most frequently reported cause of death for people with a learning disability

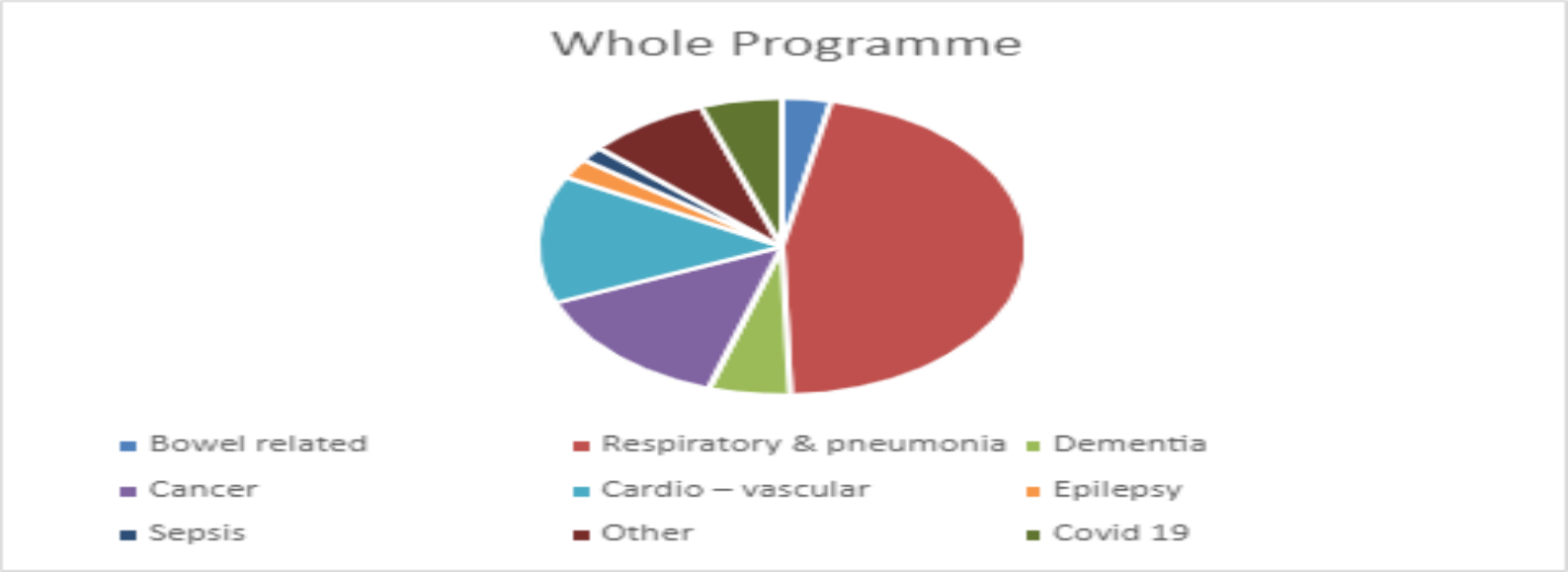
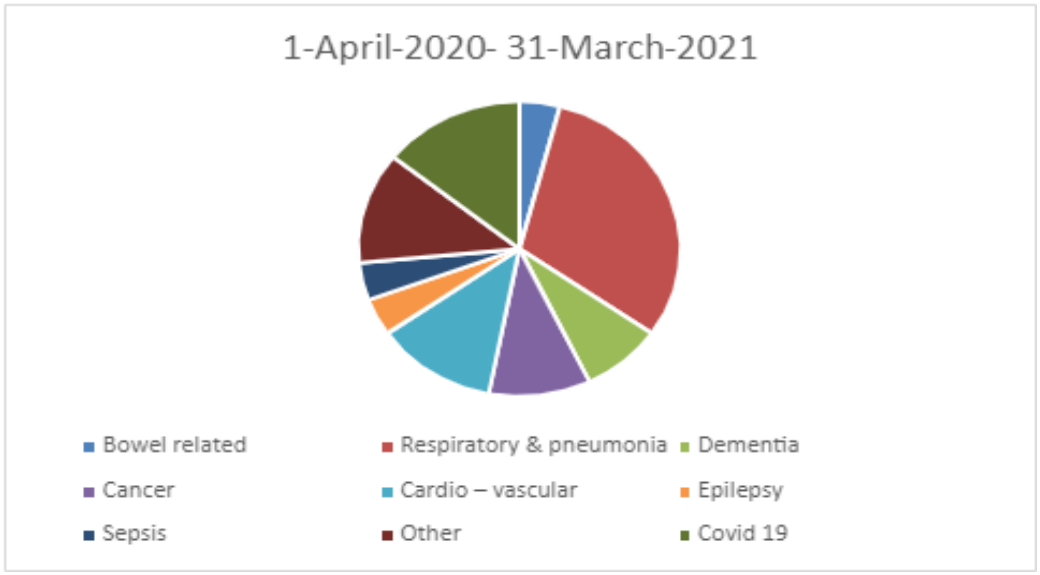
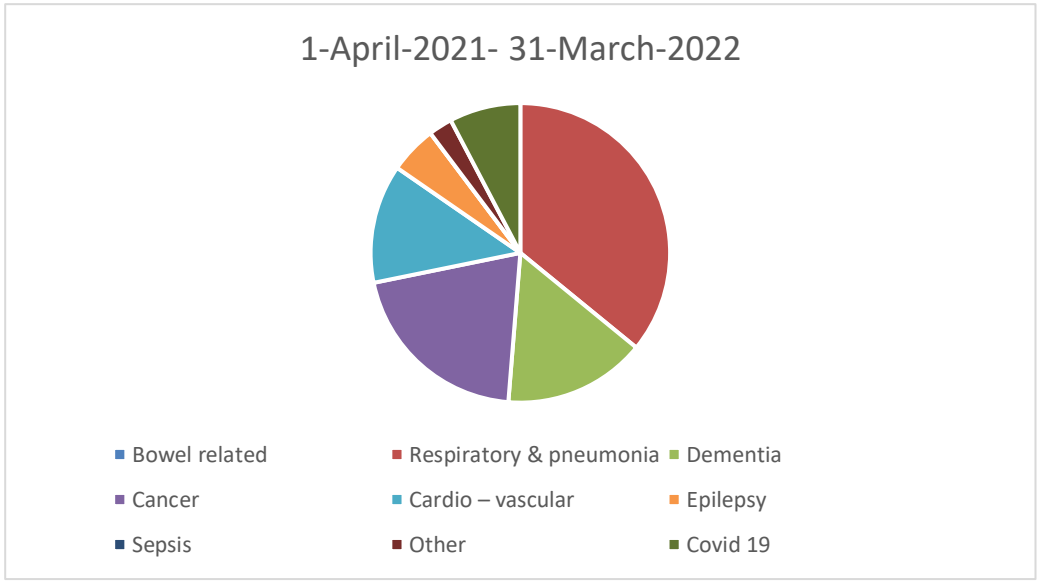


Figure 7 & 8- most frequently reported cause of death for people with a learning disability for 20/21 and 21/22





What does this tell us about the cause of death for people with a learning disability across our ICS?
Cause of death themes for each county are not reported here as some themes reflect very low numbers or single figures.

Respiratory system related deaths

Pneumonia continues to be the most frequently reported cause listed on death certification. Deaths related to COVID-19 reduced significantly this year. COVID-19 deaths, although very small in number, continued to reflect previous themes of moderate learning disability, living in care setting with history of cardio-vascular health needs. No Reviews completed during 2021/22 indicated that poor care was contributory. 27% of those who died from pneumonia were also noted to be very frail. For 15% the underlying cause of pneumonia was believed to be aspiration.

What action did we take during 2021/22?

We had a key focus this year on supporting the uptake of vaccination for COVID-19, Influenza and pneuomococcal infection. This reflects recent learning from a Scottish Learning Disability Observatory study on reducing deaths from Pneumonia in the learning disability population. HW ICS supported a decision to enable people with a learning disability of all ages living in communal residential settings to be prioritised for COVID-19 vaccination alongside older adults. This influenced earlier access to booster doses for people with learning disability living in residential settings. Vaccination status is checked as part of the Annual Health Check and support to make reasonable adjustments made. COVID-19 vaccination rates were again equitable to the general population and Influenza vaccination rates improved this year. The small number of people who were notified to LeDeR because they died of COVID-19 during 2021/22 had each received all eligible doses of vaccine. Pulse Oximetry at Home and a proactive COVID Management Service was also available during 2021/22 and ICS guidance specifically encouraged the use of close monitoring for those with a learning disability who tested positive.

What action will we take going forward?

We will continue to focus on the importance of vaccination and do all that we can to enable uptake. We will each case of pneumonia against recommended best practice to determine any emerging themes. We will continue to support care settings to identify deterioration early so that necessary intervention isn't started too late. We will also work with partners to review how we support good oral health and to review the Specialist Dental pathway following the conclusion of a Review related to full dental extraction.

To date no reviews have identified a gap in dysphagia assessment or in plans/ guidance to support safe eating and drinking to reduce the risk of aspiration. We want to ensure that this continues.

Cancer related deaths

Deaths related to cancer and cardio-vascular disease account for the next two most frequently recorded causes of death notified to HW LeDeR

Deaths where the cause is listed as due to cancer remain fairly static and reflect a broad range of primary tumour sites. In the general population deaths due to cancer are most commonly lung and bowel cancer. For people with a learning disability late stage cancer diagnosis is not uncommon and for around a quarter of all cancer deaths notified to HW LeDeR the primary site of the cancer could not be identified. Where a primary cancer site could be identified bowel and breast cancer are those most frequently reported to HW LeDeR. An equally low proportion of deaths from cancer have been reported to HW LeDeR for lung, pancreatic, renal and lymphoma.

What action did we take during 2021/22?

Cancer screening access for people with a learning disability appears to be comparable to that of the general population. LeDeR Reviews have indicted that more people could be supported to access bowel screening if they, and the care staff that support them, knew more about what screening involves and were supported to complete it. This year we started to test how many more people would access bowel screening if they were contacted in the year before their screening was due and received extra information and support to make reasonable adjustments. We also led an education event that included information on the importance of accessing bowel screening.

What action will we take going forward?

We want to understand screening uptake in more detail as uptake for breast and bowel screening will be a key priority over the next 2-3 years. Early cancer detection is a key priority for the NHS and we want to make sure that people with a learning disability and autistic people have equitable access to measures being taken to increase this early recognition. We will work through our ICS Cancer Leads, and with other systems that form part of the West Midlands Cancer Alliance, to inform the further roll-out of the NHS Galleri test over the next 3 years.

Heart disease and stroke related deaths

Deaths where the cause of death is listed as due to cardio-vascular disease also remain static however many deaths were consistent with individuals who had a recorded high Body Mass Index or diabetes. Over the course of the programme 20% of completed reviews recorded the presence of obesity. 3 out of every 4 individuals with obesity had a mild or moderate learning disability and 2 out of every 3 were women.

What action did we take during 2021/22?

Public Health funded additional advocacy support to enable Lifestyle Advisor teams to make reasonable adjustments to improve the measures that can be offered to people with a learning disability who need advice and guidance to reduce their body weight. LeDeR Reviews indicate that most people who had a history of heart disease or who were prescribed medication that may affect their cardio-vascular health had a good level of monitoring by their GP, including support to have regular blood tests. Community Learning Disability Teams, who are working to ensure that medication prescribed for mental health needs or distressing behaviour is appropriate and proportionate, will continue to promote best practice in the monitoring of cardio-vascular health.

What action will we take going forward?

Referrals to the Lifestyle Advisor groups for weight management of people with learning disability were low. We need to understand why this was and what measures would be most effective in providing the right support. Through the use of an Annual Health Check template, and ICS work to further enhance Population Health Management, we will be able to better understand how many people with a learning disability have cardio-vascular disease. This will support plans for improving earlier recognition and intervention for obesity and cardio-vascular disease.

Dementia
Deaths recorded as related to dementia are a smaller proportion of all deaths compared to the extent of dementia related recorded deaths in the general population. The average age of death for those with end stage dementia was 58 years; Most people also had Downs Syndrome. We want to be sure that people with a learning disability have equitable access to diagnosis services

Other causes of death

Very low numbers of deaths are recorded as being due to sepsis or Sudden Death in Epilepsy (SUDEP) / epilepsy related. Bowel obstruction related deaths have significantly reduced since the first year of the programme. A review of interventions across both counties has continued to be the focus of a Priority Action Group

What action did we take this year?

We continue to want to focus on ensuring that no-one experiences premature death due to avoidable bowel impaction. A learning event took place early in 2022 and will be followed up by a further event linked to Learning Disability Awareness week 2022. LeDeR Reviews and care staff conversations told us that those supporting people with a history of constipation did not always know how to use laxatives effectively. People also said that they were sometimes embarrassed to talk about poo and care staff said they found it difficult to support people in a way that also respected their privacy. A Healthy Bowel Management plan template and education about lifestyle choices to support bowel health is being promoted by Community Learning Disability Teams, working with Continence Team colleagues.

What action will we take going forward?

We will roll-out the use of the Healthy Bowel Management plan more widely and link this work to the promotion of bowel cancer screening.

Whilst the numbers of people in our ICS experiencing Sudden Death in Epilepsy is low, care staff and families who experienced this were not aware of the possible risk of sudden death. We want to do more to raise awareness of SUDEP and help people plan or prepare for this possibility. We will also ensure that any deaths listed as related to Epilepsy are reviewed against a best practice checklist.

The overall grading of care provided

During 2021/22 the system of undertaking Reviews and the Review template changed. Reviews no longer require a decision to grade the overall standard of care provided to the person. Where care falls short of the expected standards of good practice, and this was suspected as influencing the cause or timing of death, a more detailed Focused Review may be completed. Due to changes in the Review format occurring partly within 2021/22 no Focused Reviews were fully completed ahead of the end of March 2022. At the time of the report (June 2022) 6 individual cases are being considered as requiring Focused Reviews and 3 of these have been considered by the HW LeDeR Learning into Action Group membership and are near completion. No Focused Reviews have yet indicated care so poor that there are clear factors that may have avoided death.

In early 2021 the Coroner concluded an inquest for a lady who died in 2018 following a full dental extraction. Following the Inquest a Regulation 28 Report to Prevent Future Deaths was issued. The Inquest identified failings in the care home to monitor, recognise and respond to deterioration following Rachel's discharge from hospital after the dental extraction Rachel-Johnston-2021-0090-Redacted.pdf (judiciary.uk).

What action did we take during 2021/22?
HW LeDeR held a further round table event in April 2021 to share final learning identified from each partner organisation's review. Training and support to embed assessment and monitoring tools, to identify and respond to deterioration early was promoted across the ICS as part of a programme to Enhance Health In Care Homes.

What more will we do going forward?
Health Checkers (Experts by Experience) will lead a review of the Specialist Dental pathway to review improvements that were made following Rachel Johnstons death.

During 2021/22 Herefordshire were selected to be part of a LeDeR funded programme , coordinated by the West Midlands Academic Health Science Network, to test tools for identifying deterioration within Supported Living settings for people with a learning disability. During 2022/23 we will evaluate, build on and extend this work to cover Herefordshire and Worcestershire.

The underlying health conditions of people whose deaths were notified to H&W LeDeR Programme

During 2021/22 the template and format for LeDeR Review changed which influenced the extent to which underlying conditions were recorded and captured. All Reviews completed for HW LeDeR include review of the GP notes and underlying health conditions listed in the GP summary are transferred onto a recording spreadsheet, irrespective of whether the condition was felt to be associated with the cause of death.

Figure 9 – Ratio of recorded underlying health conditions detailed within completed LeDeR Reviews across 2020/21 and 2021/22

What does this tell us about underlying health conditions and their contribution to premature or avoidable death?

For 2020/21 the percentage of notifications received that reflect a long-term health condition for individual's with a Learning Disability residing within our ICS appeared to be high and many reflected multiple co-morbidities. This may have been a reflection of a good standard of health surveillance through General Practice that recognises and records long term conditions for people with a learning disability, compared with the average position across England.

For Reviews completed during 2021/22 the most frequently recorded long term conditions continued to be constipation, mental illness, epilepsy, dysphagia and cardio-vascular disease. A mental health diagnosis (or the proxy of a prescribed medication associated with mental illness) was less frequently recorded in Reviews completed during 2021/22. This may be related to efforts to promote appropriate prescribing and reduce

over-medication (STOMP). The percentage of completed reviews for those with obesity reduced significantly this year. This may be because 2020/21 reflected COVID-19 related deaths where obesity appeared to be a consistent underlying condition.

What did we do during 2021/22?

Our work to support good quality Annual Health Checks has focused on promoting the use of a template that recognises these commonly reported underlying health conditions, to ensure early recognition and support links to health promotion measures in the person's Health Action Plan.

During 2021/22 the ICS has made great steps in supporting General Practice to work with partners to improve health by having a greater understanding of the most prevalent health need in their registered population to enable focused action (Population Health Management). The dashboard in development includes 'learning disability' and will enable Primary Care Networks (PCN- groups of General Practice surgeries working together) to understand the patterns of health needs for their learning disability population. This will support earlier intervention and help us move away from relying on understanding health need through the review of those who have already died. Our aim is to make addressing the health equity and needs of people with a learning disability everyone's business, not just the work of the LeDeR programme.

What will we do going forward?

Health surveillance data will inform Population Health Management that recognises local health need and empowers each PCN to work with partners in their locality to address health equity for those who may be more vulnerable to experiencing barriers to happy and healthy lives, including access to programmes aimed to support prevention, diagnosis, earlier intervention or treatment.

4.3 Learning from the outcomes of completed reviews - key themes in Review recommendations

During 2021/22 the format of Reviews changed and so the option and likelihood of multipole recommendations changed. Initial Reviews were limited to a make only 1 or 2 key recommendations. Where significant learning was to be gained a Focused Review would be triggered. No Focused Reviewed were completed to the point of Learning into Action membership approval during 2021/22 and so no new action plans were finalised. Detail of how we agree actions arising from learning recognised at Focused Reviews is included within our Strategy HW LeDeR Strategy 2022-2025 (herefordshireandworcestershireccg.nhs.uk)

Reviewers continued to be encouraged to make recommendations from the information made available to them when completing an Initial Review. As the Review template changed, we initiated a Reviewer checklist to prompt the identification of learning for themed areas of improvement that had previously been recognised. Themed areas of focus included Annual Health Check completion, the understanding and use of the Mental Capacity Act, the completion of ReSPECT plans and where they were completed.

New recommendations continue to be added to a tracker that has bene in place since the start of HW LeDER in 2017. The frequency with which a recommendation category is made, and the seriousness of the potential outcome enable recommendations for key priority areas for improvement to inform an annual Delivery Plan. The Delivery Plan for 2022/23 is embedded within our LeDeR Strategy. New themes and priorities that arise from this Annual Report will be considered at our Annual Report learning event in the autumn of 2022 and will inform our Delivery plan for 2023/24.

During 2021/22 the key areas of focus to support improvement were:

- equity of access to vaccinations (COVID-19, Influenza, Pneumococcal)
- supporting measures to improve the uptake and quality of Annual Health Checks and resulting Health Action Plans
- promoting bowel cancer screening, supporting reasonable adjustment and improving awareness of good bowel health
- improving practice in assessing and planning to meet the needs of people who cannot make decisions about care and health for themselves or without the right support (Mental Capacity assessment and best interest decisions)
- increasing awareness of the use of a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) for people with a learning disability and promoting its completion ahead of a last episode of care in a hospital

One of the ways that we can determine if the actions that we are collectively taking are making a difference for local people are through the extent to which the frequency of specific recommendations are made. Whilst we need to keep in mind that the overall number of recommendations reduced this year due to report format changes some changes have been noticed.

Reductions have been seen, compared to previous years, in the number of recommendations reported for:

- Mental Capacity assessment and Best interest decision making
- Gaps in Annual Health Checks being completed
- Annual Health Check recognition of gaps in screening uptake
- Completion of a ReSPECT plan
- Notification to and involvement of LD Liaison Nurses in Hospital admissions, Emergency Department Attendances or Outpatient appointments
- The use of a completed Hospital Passport during an inpatient stay

Some thematic areas have remained the same or have emerged as new areas for focused improvement:

- Processes for engaging a person and their carers if they fail to attend or respond to an invitation for an Annual Health Check
- Access to or offer of a Pneumococcal vaccine
- Reference to personalised approaches to managing obesity in a person's Health Action Plan
- ReSPECT form completion during a person's last episode of hospital care, by healthcare professionals who know the person least well. This impacts on the quality of detail and involvement of the person, their family and close carers.
- Support to enable a person to die in the preferred place of the individual and their family or carers
- The timely notification of and review of a care package when an individual's needs change (often due to deterioration in health or increase in dependency).
- Coordinated discharge planning to enable effective onward care when a person has had a stay in hospital, at the point that their medical care has been optimised

Updates on progressing plans to inform improvements in outcomes have bene reported after each quarter of 2021/22 to NHS England Regional Learning Disability and Autism Programme team, our ICS Learning Disability and Autism Tackling Health Inequalities Board and our ICS Learning Disability and Autism Programme Assurance Board. Table # summarises our key actions and what we have collectively achieved.

Table 3 – Actions and outcomes of Priority Action workstreams during 2021/22

Priority Action focus	Actions during 2021/22	What we achieved.
The uptake and quality of Annual Health Check completion.	The Priority Action Group, established earlier in the HW LeDeR programme, was coordinated during 2021/22 by a new LDA Programme Lead. The group continued to include a broad range of partners from Public Health, Primary Care, Learning Disability Community and Liaison teams, family carers and strong links to a consultative group of experts by experience. During 2021/22 the Group: • Aspired to support the system to achieve an uptake rate of 85%, 15% above the national expected target • Co-produced sustainable education and training materials to support Annual Health Check delivery. Materials were based on examples of national best practice and informed by local people's experience. Training uptake covered 100% of PCNs • Oversaw progress with the completion rates of Annual Health Checks by establishing and sharing frequent data updates on progress made. This involved PCN level data shared every two weeks to compare current position and progress made over time. • Informed recruitment for an Access Worker to enable our ICS to learn about and influence the factors that support people who have not engaged with Annual health Checks.	A co-produced learning resource available to all Primary Care staff across HW ICS. Coproduction of resources to promote autism awareness and autism -friendly environments across our ICS, starting in General practice. Herefordshire and Worcestershire ccg - Learning disability and autism By 31st March 2022 a completion rate across H&W of 80%, with 59% of GP Practices exceeding the aspirational 85% uptake target. 84% of individual GP Practices in HW exceeded the national uptake rate of 70%. The uptake rate across our Primary Care Networks ranged from 58-95%, with some of the highest areas of deprivation for our ICS achieving some of the lowest rates of uptake. Achievement of uptake rates, in the context of excessive demand across Primary care services and of the COVID-19 vaccine booster programme in the winter of 2021/22, exceeded what we thought might be possible. Uptake rates declined with age (75% for 18-24 year olds and 67% for 14-17 year olds) and we still have little understanding about uptake for people from Black, Asian and other ethnicity groups.

Priority Action focus	Actions during 2021/22	What we achieved.
Respiratory Conditions (focus on minimising transmission and maximising protection and modifiable factors)	Learning from COVID-19 continued to inform work with partners to provide support to minimise COVID-19 outbreaks in care settings, to reduce the severity of illness and to identify deterioration in order to ensure that people received timely treatment. During 2021/22 the COVID Management Service were able to monitor people with a learning disability within residential settings (highest area of risk) using Pulse Oximetry. An ICS agreement in 2020/21, to offer COVID vaccination to people with a learning disability in care settings, alongside older people in care settings in JCVI 1, enabled earlier access to a complete primary course of vaccination and access to booster doses. We worked together to continue to promote vaccination, have discussions to reduce fear and hesitancy and find solutions for those who would find vaccination difficult to tolerate. Vaccination Centres introduced 'Quiet Hour' sessions to support autistic people and others who found crowds difficult or needed more space and time to tolerate vaccination. We worked together to promote the Flu vaccination toolkit. Learning Disability Teams and GP's who embraced 'reasonable adjustments' were instrumental in facilitating vaccination for those with the most complex needs, including support to coordinate best interest decisions.	Maintained virtual LeDeR Learning into Action Group meetings and updates to engage and sustain partnerships during the pandemic. By early 2021/22 uptake rates for COVID vaccination exceeded 93%, comparable with rates for the general population and uptake rates of booster doses were comparable with the general population. Flu vaccine uptake to January 2021 for people with LD achieved 66%, an increase on previous years. For 2021/22 this marginally increased again to 68% across HW (with 2/3 of Primary Care Networks achieving uptake over 70% and Herefordshire achieving an uptake of 73%) We ensured that each completed LeDeR Review for someone who died from pneumonia checked if access to a Pneumococcal vaccine had been offered -this was found to be the case for over 80% of cases reviewed. All LeDeR Reviews for those who died from aspiration pneumonia identified a dysphagia assessment had taken place and a clear Eating and Drinking plan was available for those at risk of aspiration.

Priority Action focus	Actions during 2021/22	What we achieved.
Bowel	During 2021/22 we followed up on previous work to raise awareness of the factors that lead to bowel impaction for people with a learning disability and measures that can be taken to improve a healthy bowel. A learning event was held online in March 2022 (due to the extent of COVID-19 transmission at that time). This event was coproduced with experts by experience (individuals with LD and family carers) and involved a wide range of health and social care practitioners. Work commenced on supporting early intervention to engage in bowel screening in the 12 months ahead of an expected invitation. A Bowel Management Plan for those with a history of constipation was further reviewed and work commenced to ensure all people living across HW are able to benefit from this resource to inform their care and support.	No deaths were reported related to bowel impaction that was avoidable. Bowel cancer screening uptake in the learning disability population achieved an uptake rate of 67% compared to 62% for the general population in HW ICS. Whilst bowel screening uptake is favourable to uptake rates for the general population this still means that one third of people are not accessing tests for one of the highest areas of cancer for people with a learning disability. A further face to face learning event, to promote awareness and reduce embarrassment for talking about poo and bowels, will be held in the summer of 2022 around Learning Disability Awareness week. Following this event an impact evaluation will be undertaken to understand what changes people, care staff and families have made as a result of these learning events.

Priority Action focus	Actions during 2020/21	What we achieved.

MCA awareness	During 2021/22 we continued to ensure that LeDeR Reviews identified where there was learning regarding how mental capacity assessment and best interest decision making could impact on the identification and recognition of health need and on intervention to prevent deterioration and improve outcomes. Our local NHS Trusts worked together to ensure that clinicians had the right access to support to develop their awareness. Learning Disability Liaison Teams ensured that they continued to support awareness and decision making in individual circumstances. We worked together with Safeguarding Adult Boards to plan a learning event for the autumn of 2022 and commissioned Inclusion North to coproduce additional learning material to further promote awareness of the impact of involving people and their family/ carers in decisions that can improve the outcome for people's health.	Fewer recommendations were made from LeDeR Reviews to improve Mental Capacity Act awareness and decision making and good examples of coordinated multi-agency decision making were seen. NHS Trusts in Worcestershire worked together to further strengthen and make clear the way in which best interest decisions are communicated prior to dental extraction.

Priority Action focus	**Actions during 2020/21**	**What we achieved.**
ICS implementation	During 2021/22, in order to strengthen our local programme and adhere to the national LeDeR Policy we:	We received more LeDER notifications during 2021/22 that for any previous year.

of key aspects of the national LeDeR Policy and transition to a new national platform and Review format	• Appointed more LeDeR Reviewers into dedicated roles in HWCCG • Ensured that all Reviewers undertook training on the new LeDeR system and Review format • Supported Reviewers to prepare for undertaking LeDer Reviews for autistic people. • Ensured that processes for supervising and supporting Reviewers were maintained or strengthened • Worked with partners to plan for ways of further promoting LeDeR to ensure that all possible deaths (and therefore opportunities for learning) are notified to LeDeR. • We reintroduced multi-agency meetings ahead of Focused Review report scrutiny at LeDeR Learning into Action meetings to ensure that all involved had opportunity to benefit from the learning opportunity and ensure that all relevant learning was identified. • We worked closely with NHS England to inform improvement in the functioning of the new LeDeR platform • Committed to undertaking Focused Reviews for all autism notifications • Commissioned a short video to raise awareness and promote notifications to LeDeR for autistic people	We improved the extent to which Reviews were completed within 6 months. We retained confidence that the most complex LeDeR Reviews were able to extract learning to inform service improvement and of our processes for working alongside other statutory processes. We received our first notifications for autistic people (without additional learning disability).

5 Affecting meaningful change in Herefordshire and Worcestershire - Our Strategy for enabling Longer, Healthier and Happier Lives for local people and next steps

The capacity and opportunity to influence meaningful improvements for the health outcomes of people with a learning disability has always been the main driving force and key priority of LeDeR Reviewers and the members of HW LeDeR Learning into Action Group

and other key forums. We believe that the way that we work together to deliver HW LeDeR is in line with the NHS Patient safety Strategy to enable Insight through learning from the completion of Reviews, Involvement through key engagement and the coproduction of outputs alongside people with lived experience, to inform experienced based Improvement that matters to local people.

During 2021/22 we coproduced a LeDeR Strategy and on 31st March 2022 the final version of the HW LeDeR Strategy (2022-2025), including a Delivery Plan for 2022/23, was published HW LeDeR Strategy 2022-2025 (herefordshireandworcestershireccg.nhs.uk) . Progress with key actions in our Delivery Plan will be reported each quarter and we will monitor how these actions are influencing measurable outcomes by reporting a dashboard of indicators to our Assurance Board. The way that Groups and reporting work together across LeDeR and the Learning Disability and Autism Programme are shown in appendix one.

The NHS Priorities and Operational Planning guidance 2022/23 continues to direct a welcome spotlight on reducing the health inequalities experienced by people in our local communities, including people with a learning disability and autistic people.

The remit of Clinical Commissioning Groups, as a key partner and system leader during 2021/22 has been to continue to support partnership working to deliver the LeDeR programme. We believe we have achieved this. We have collaborated, during another extraordinary year, to start to see improvements across programme performance and key outcomes that experts with lived experience and family carers tell us are important to them.

From 1st July 2022 NHS Herefordshire and Worcestershire CCG will be abolished and NHS Herefordshire and Worcestershire Integrated Care Board will be formed. The local programme for LeDeR across H&W will have new opportunities to work together in an integrated way, across health and social care, to maximise benefit for our population.

HWCCG and the members of HW LeDeR Learning into Action Group and LDA Tackling Health Inequalities Board welcome the continued focus and emphasis on the health needs of those who experience health inequity and look forward to another successful year of improving outcomes so that local people can live longer, happier and healthier lives.

Appendix one – HW LeDeR within the context of the overarching Integrated Care System Learning Disability and Autism Programme