Herefordshire and Worcestershire
Integrated Care System

Annual Report 2020/2021

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

June 2021

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Learning Disabilities Mortality Review (LeDeR) Programme

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1. Introduction

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to implement a consistent format for the review of deaths of people with learning disabilities. The key principles of the programme are to identify learning from the review of deaths, for learning to inform service improvement initiatives and for those initiatives to affect meaningful change in improving outcomes for local people.

The LeDeR programme was implemented at a time of considerable focus on the deaths of patients in the NHS. Phased roll-out of the programme reached Herefordshire and Worcestershire in the autumn of 2017. The initial introduction of the programme coincided with the introduction of the Learning from Deaths guidance which made clear the expectation that the LeDeR methodology would be the preferred format for reviewing deaths for people with a learning disability. The LeDeR programme is commissioned on behalf of NHS England (NHSE) and during 2020/2021 continued to be hosted by the University of Bristol.

During 2020/2021 all deaths continued to receive 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 further learning could be gained, a more detailed Multi-Agency Review (MAR) of the person's life and death is facilitated. 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 MAR), recommendations are made and an action planning process identifies service improvements that may be indicated. More information about the national programme can be found on the website for LeDeR hosted by the University of Bristol http://www.bristol.ac.uk/sps/leder/about/ or after 1st June 2021 on the NHS England website https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/ . Easy read information about the programme and its publications can be found at http://www.bristol.ac.uk/sps/leder/easy-read-information/

This report provides an update on the progress and impact made across Herefordshire and Worcestershire during the period covering 1st April 2020 to 31st March 2021, the third full year of programme implementation for our system. It builds on the achievements made up to March 2020, and covers local progress for Herefordshire and Worcestershire in our first year as an integrated programme across both counties within our evolving Integrated Care System (ICS). A new national LeDeR Policy was published in March 2021 and the requirements of this are reflected in appendix 3. The report reflects some of the extraordinary efforts of our partners to work together through a year that many will never forget. This includes the initial and subsequent peaks in the number of cases of the COVID-19 pandemic and some of the consequential implications of 'lockdown'. It will undoubtedly take some time to fully appreciate the impact of COVID-19, on individuals health and on the health inequality of people with a learning disability. We will continue to remain mindful of this as we review lives and deaths during 2021/22 and beyond.

2. Delivery of the LeDeR programme in Herefordshire and Worcestershire

2.1 Our Purpose- what we set out to do

The overriding principle, clearly set out in the Terms of Reference for each forum within the meeting structure that supports the LeDeR Programme across Herefordshire and Worcestershire, is to affect meaningful change and improve outcomes for local people. The outcomes that we are aspiring to achieve include supporting longer, healthier and happier lives for people with a Learning Disability across our Integrated Care System. In each previous year we have set out a work plan, agreed in partnership, based on the thematic recommendations arising from LeDeR Reviews. The infrastructure of the LeDeR programme then works closely with partners from and beyond the infrastructure of the Learning Disability Partnership Board arrangements in each county, to collaborate, to form ideas and action solutions.

Partnerships within the LeDeR programme across Herefordshire and Worcestershire (H&W) are built on the firm legacy of inclusion and placing experts by lived experience at the heart of what we do. The foundations of the Learning Disability Partnership Boards and Transforming Care Partnership infrastructure enable representation from people with a Learning Disability, family carers, advocacy, social care, commissioners, Public Health, Safeguarding, specialist Learning Disability Teams and our Acute NHS Trust providers to contribute to our programme outcomes. Local people inform local outcomes and we each hold each other to account for what we set out to achieve.

2.2 Our Governance - The local framework for enabling and assuring delivery of the programme

Over the course of 2020/2021 our local framework for overseeing and gaining assurance about how our programme operates has evolved. Some of our plans to embed an integrated H&W Steering Group and county-based Learning into Action Groups were interrupted by the COVID-19 pandemic. The newly established Steering Group with revised membership formally met only once. Updates on performance were provided by email and communication was maintained with strategic partners through other forums including the STP Mortality Oversight Group, Learning Disability Partnership Boards and the STP Learning Disability and Autism Board.

A focus was placed on continuing to engage with each county-based Learning into Action Group. Updates were provided to the Adult Safeguarding Board in each county on two occasions during this year, such was the concern regarding the impact of the COVID-19 pandemic on the mortality of people with a learning disability.

The LeDeR Steering Group (Appendix one) and Learning into Action Groups each have clear Terms of Reference, agreed by membership, that reflect:

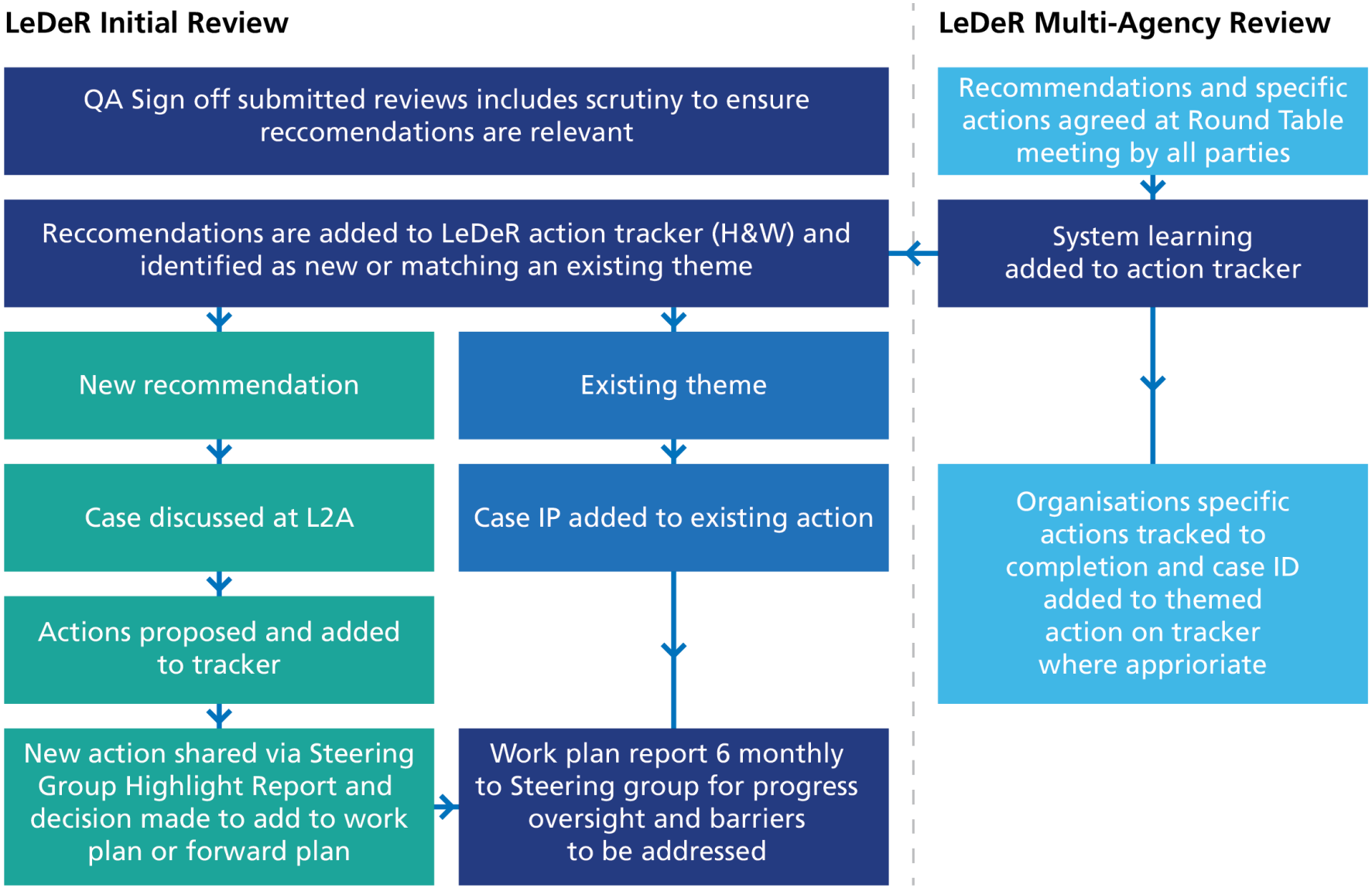
- The scope and purpose of the forum
- Representative membership (predominantly at strategic level for the Steering Group and operational level for the Learning into Action Group)
- Governance arrangements including responsibility, accountability, and reporting arrangements.

The performance of the programme (how well it is meeting NHS England targets for the timely allocation and completion of reviews) and progress with Priority Action workstreams are reported, at different but proportionate levels of detail, to both the Steering Group and the Learning into Action Groups.

The LeDeR Programme Senior Responsible Officer (SRO) is Lisa Levy, HWCCG Chief Nursing Officer. The LeDeR Lead Area Coordinator is Rachael Skinner, HWCCG Associate Director of Nursing & Quality. LeDeR programme updates are reported to the HW Learning Disability and Autism Programme Board. This Annual Report will reported to the Health and Wellbeing Board for each Local Authority in our system, in Public.

Within the reporting period the implementation of the programme has been reviewed and revised in response to emerging best practice to support effective delivery. The consolidated Reviewer group, made up of a dedicated resource of individual's whose body of work is focused solely on the LeDeR programme, has been expanded to ensure consistency across both counties. The Clinical Lead for LeDeR, substantively employed by the CCG, has been joined on an interim basis by a LeDeR Clinical Officer. Their role will be to conduct and lead Review completion, further strengthen Reviewer support and supervision and work with the LeDeR Clinical Lead to oversee and coordinate the sharing of best practice and the progress of Priority Action workstreams in taking forward agreed areas of service improvement. A clear process is in place to ensure that the recommendations arising from LeDeR reviews inform the LeDeR work plan and Priority Action Group themes (see table 1). The LeDeR Team and programme implementation will continue to be supported by an administrative and project support resource.

Figure 1 - How the outcomes of reviews informed H&W LeDeR work plan during 2020/21



Undertaking a review can often result in exposure to distressing details of the circumstances leading up to a person's death. Contact with bereaved relatives and care staff can also be emotionally demanding. It is therefore important that reviewers are supported appropriately in order that they can carry out their role effectively and with compassion. The requirement for remote working and the impact of the pandemic (both emotionally and in terms of the volume of notifications requiring timely completion) has meant that the LeDeR Clinical Lead role has been as vital as ever in supporting Reviewer wellbeing and an outstanding level of timely and consistently high standard completed reviews.

The process for the quality assurance and approval of all completed reviews has been maintained throughout this year, despite periods of redeployment to alternative but vital clinical roles during the pandemic. The length of time taken between the initial submission and approval of a completed LeDeR review is at times longer than we would like and this was particularly true during the period where we worked in close partnership with NHS England and the North East Commissioning Support Unit to address a backlog of reviews to December 2020. The process of quality assurance does however mean that the friends and families of people with a learning disability who lose a loved one can feel confident that relevant aspects of learning are drawn from each LeDeR review with the aim of influencing improvements in the healthy future lives of others. Where the potential for care gaps or failings are apparent within the detail of an individual LeDeR review the LeDeR programme will work alongside colleagues and families to ensure alignment or escalation to appropriate statutory processes including NHS provider Serious Incident reporting, Safeguarding Reviews and Coroners Office proceedings.

Responding to the recommendations of the Oliver McGowan Review

In November 2016 Thomas Oliver McGowan (known as Oliver) died. In May 2017 (when the LeDeR process was in its infancy) a LeDeR Review was commenced by South Gloucestershire CCG following a request by NHS England. Concerns were raised by Oliver's family about the outcomes of the review and the way in which the outcomes had been determined. An independent review was commissioned and in October 2020 the report of that independent review was published. The report made a series of recommendations for the way in which the LeDeR programme should be conducted. Appendix two contains the HWCCG response to these recommendations.

2.3. Collaboration and Partnerships

The contribution of our experts with lived experience, both individuals with a learning disability and family carers, are central to the delivery of the LeDeR programme for H&W. Here is what our partners had to say about how it feels to be involved in LeDeR across Herefordshire and Worcestershire.

'They always ask us what we think - I think it's good they listen to what we have to say.

''Lots of good things have come out of LeDeR and Health Checkers are always involved'.

HealthCheckers, Speak Easy NOW

It's rewarding to sit in LeDeR meetings as equal partners, under inspirational leadership, and to have a voice in making things better for people with learning disabilities. We feel encouraged to use our lived experience to suggest measures to help prevent unnecessary deaths for people with learning disabilities.

Anne Duddington and Alison Price
Family carer representatives,
Worcestershire Association of Carers

'It's not easy to think about dying. It makes me feel sad and a bit upset'.

'Talking about people dying is morbid and makes me sad. I don't want to think about it too much but I know we can learn things from doing it'.

HealthCheckers, Speak Easy NOW

'I liked the lady who made the poo cake. She made me laugh.'

HealthCheckers, Speak Easy NOW

'Some of the information is very complicated.'

'I don't always understand what they're talking about but it's OK to say that. They try to make hard things easier for us to understand'

'LeDeR people talk to us in ways we can tnderstand. I like that,'

HealthCheckers, Speak Easy NOW

"Carer representatives, with a variety of support from WAC, give up huge amounts of time to support the LeDeR work. In recognition of this input, the growing opportunities of carer involvement within LeDeR and the value of being experts by experience in this role, it would be positive to give consideration to offering some sort of honorarium or additional support to continue to fulfil this and future roles."

Jenny Hewitt, Carer Engagement Lead, on behalf of Carer Reps, Worcestershire Association of Carers (WAC).

"Supporting carer reps as part of this work, demonstrates a real sense of collaborative working and really taking on board the views of carers. The co-productive approach is to be celebrated. It is an outstanding approach to collaborative working and sets a standard to other areas of work."

Jenny Hewitt, Carer Engagement Lead, on behalf of Carer Reps, Worcestershire Association of Carers (WAC).

2.4. Performance of Herefordshire and Worcestershire LeDeR

The system for receiving notifications of the deaths of people with a learning disability registered with a Herefordshire or Worcestershire GP went live on 1st October 2017 Notifications continue to be predominantly made by Community Learning Disability Nurses or Learning Disability Acute Liaison Nurses. Unlike in the previous year no family members have initiated a notification during this reporting period.

Any person can make a notification by accessing http://www.bristol.ac.uk/sps/leder/notify-a-death/ The pattern of notifications received by Herefordshire and Worcestershire is detailed in table 2. To the end of February 2021 a total of 160 deaths have been reported to LeDeR for Herefordshire and Worcestershire (due to the transition of the LeDeR platform hosting arrangements no notifications have been received for March 2021 and reported notifications for March will be visible to each CCG on 1st June 2021)

Table 1: Notifications made to Herefordshire and Worcestershire LeDeR. 2018-2021

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
2018-19	3	3	6	6	**18**	2018-19	10	3	7	12	**32**
2019-20	6	4	2	4	**16**	2019-20	7	2	6	8	**23**
2020-21	3	5	0	3	**11**	2020-21	22	6	1	7	**36**

For both counties, but more significantly within Worcestershire, the number of notifications fell overall during 2019-2020. During the first quarter of 2020-21 the COVID pandemic impacted mortality across the UK and the number of notifications for Worcestershire were almost equal to the total number of notifications for the whole of the preceding year. Notifications made from Herefordshire did not increase during the COVID pandemic and were actually lower than the previous year. 2021/22 will bring new opportunities to ensure that all parts of our system are aware of the importance of making notifications to the LeDeR programme. This will strengthen confidence that we are taking every opportunity to learn from peoples lives and deaths.

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 able (excludes those cases open to the Coroner or subject to Safeguarding processes, provider Serious Incident investigation or Complaints processes or Child Death Overview panel review).

Before the beginning of this reporting period processes had been refined to support the timeliness of review completion. Administration support was secured to ensure that electronic notes were requested to be available at the commencement of each review. Family and / or residential care provider contact was coordinated by the CCG. In March 2020 however the LAC and LeDeR Clinical lead were redeployed to a COVID Infection Prevention and Control (IPC) cell as part of the Incident Control response. This resulted in delays in allocation with a knock-on impact for timely review completion. Rather than focusing on Review completion the CCG LeDeR Team worked proactively with care settings to support the minimisation of outbreaks and its impact on mortality.

Performance of the Herefordshire and Worcestershire LeDeR programmes is important because of its ability to support the completion of timely mortality reviews to affect meaningful change in areas where contributory or modifiable factors influencing avoidable or premature mortality are identified. Rapid Review templates were completed for all confirmed or suspected COVID-19 deaths to enable the identification of learning to inform the ongoing efforts of the IPC cell.

For cases notified up to 30th June 2020 there was a requirement to complete 100% of reviews by 19th December 2020. H&W achieved this requirement within the agreed timescale.

Figures 2-4 reflect our performance to allocate notifications to Reviewer within 3 months and to complete a review within 6 months.

The time taken to complete reviews varies and a number of cases continued to be on hold due to statutory processes (for example pending Coroner's Inquest or Child Death Overview Panel processes). During 2020/21 the impact of reduced contact for those who lost loved ones who died in a care setting or hospital that they were unable to visit until a dying persons final hours, affected families significantly. The impact on bereavement response led some families to need some time to be able to engage with the LeDeR process. The timeliness of allocation to a Reviewer is also impacted by Reviewer capacity. Performance for timely allocation to a Reviewer and the completion of Reviews has improved significantly over 2020/21. Whole programme performance will continue to reflect challenges experienced in the early stages of the programme and the impact of the pandemic in Q1 of 2020/21. From 1st June 2020 72% of reviews have been completed within 182 days and 90% completed within 190 days.

Figure 2 - Notification to allocation - % within 91 days (Herefordshire and Worcestershire)

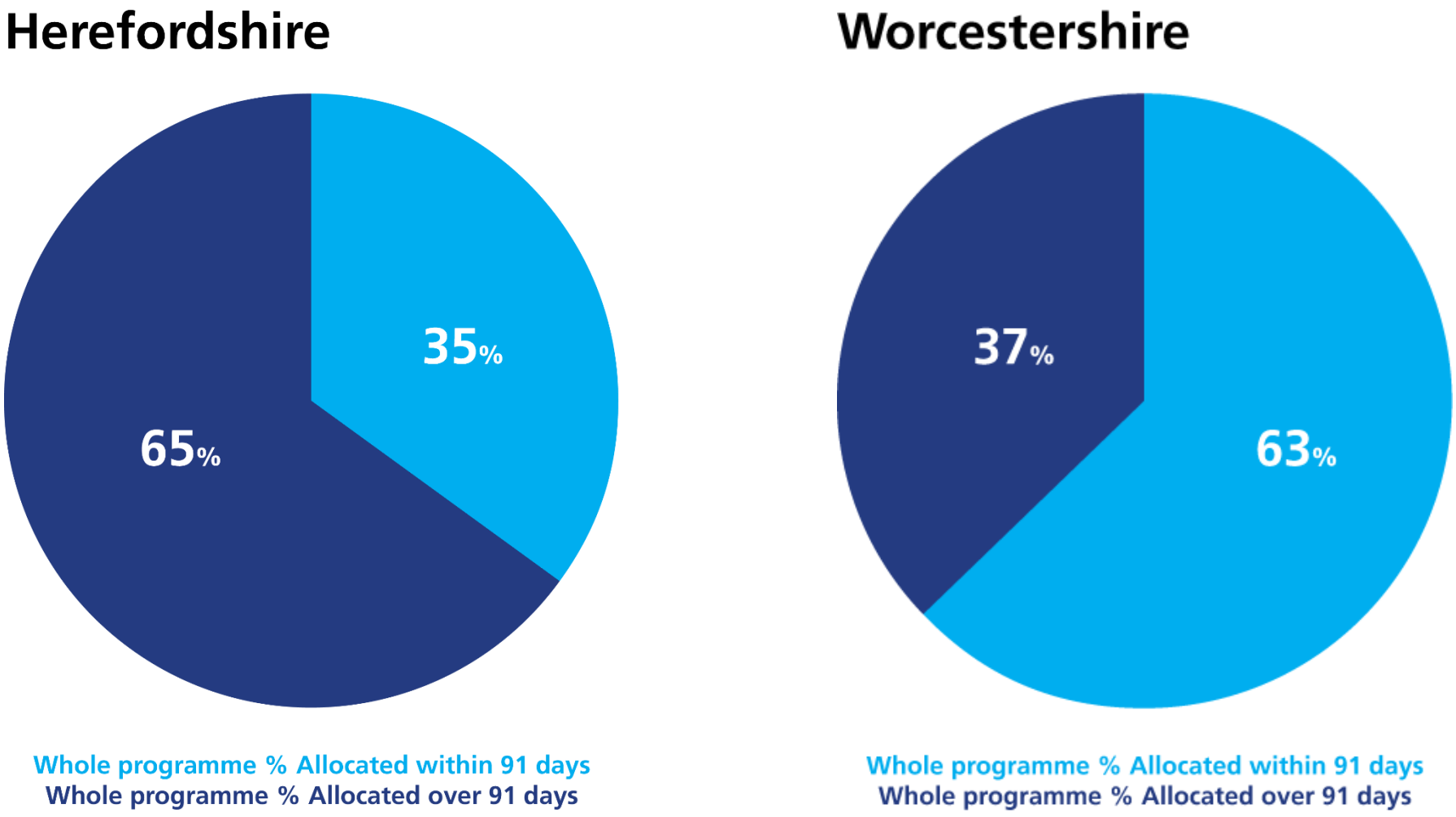


Figure 3 - Average number of days to allocation

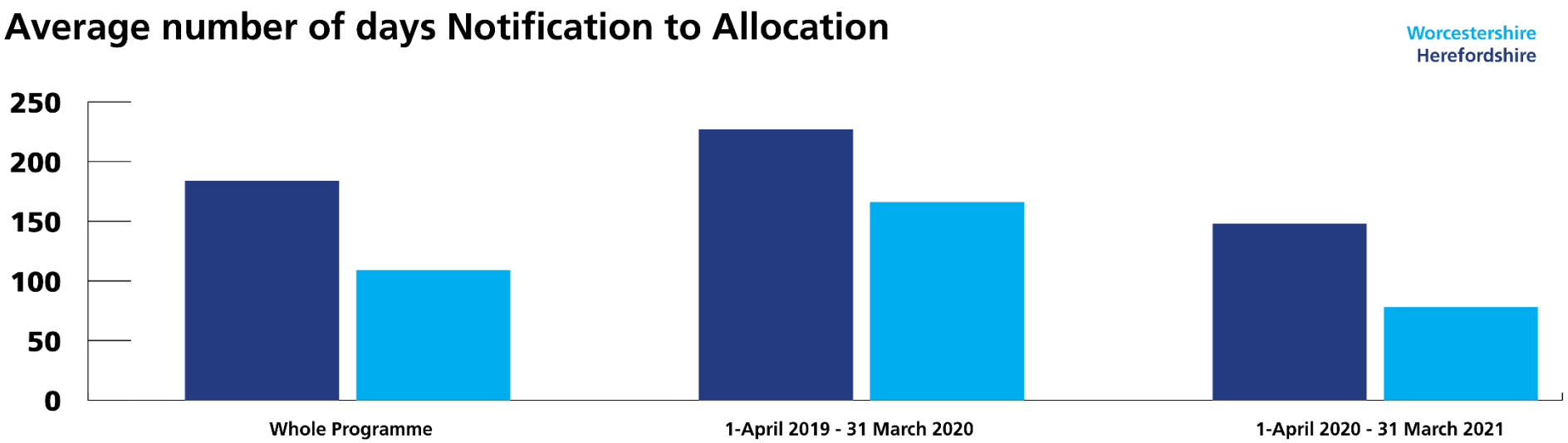
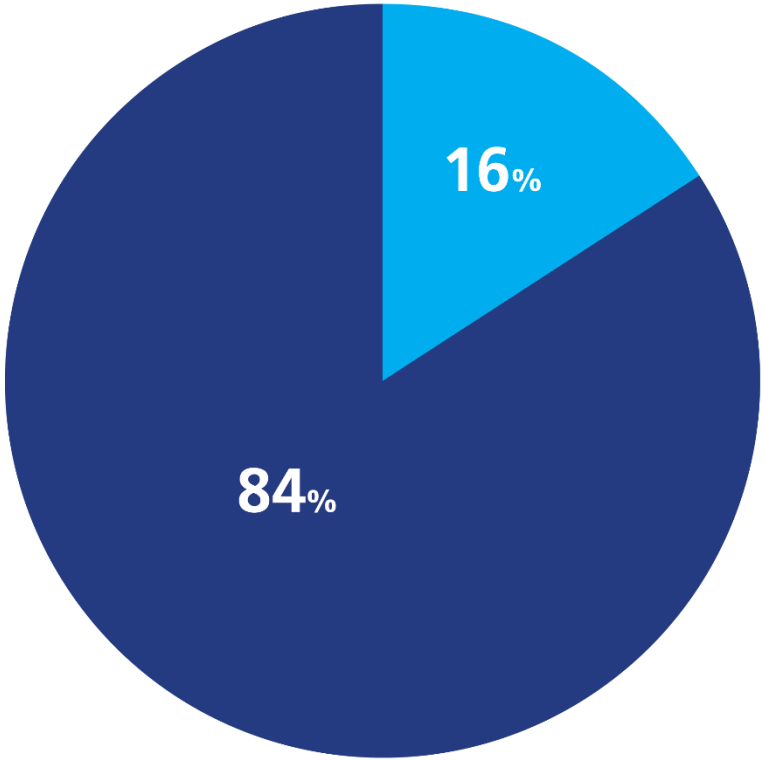


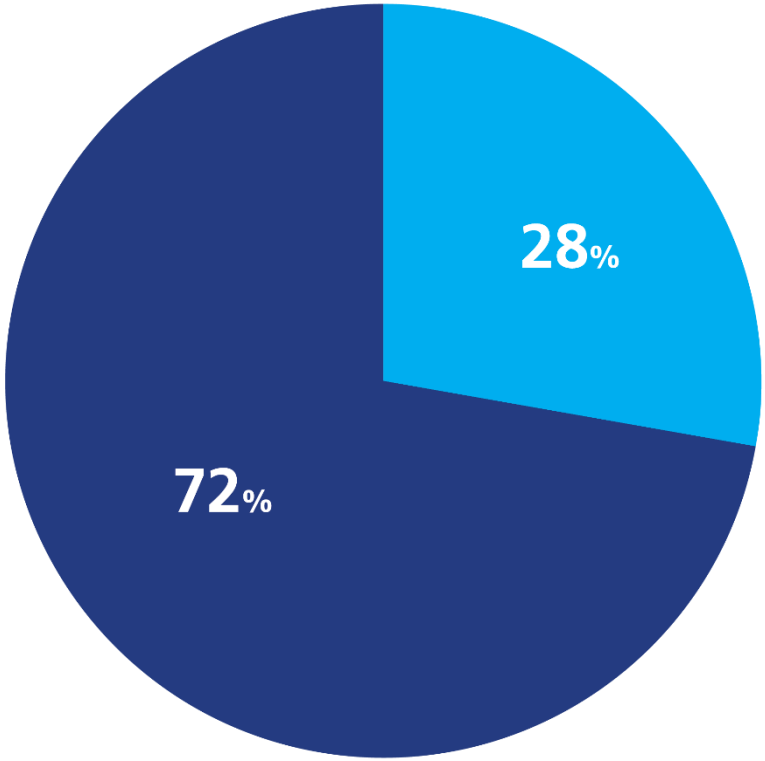
Figure 4 - Notification to completion - % within 182 days

Herefordshire



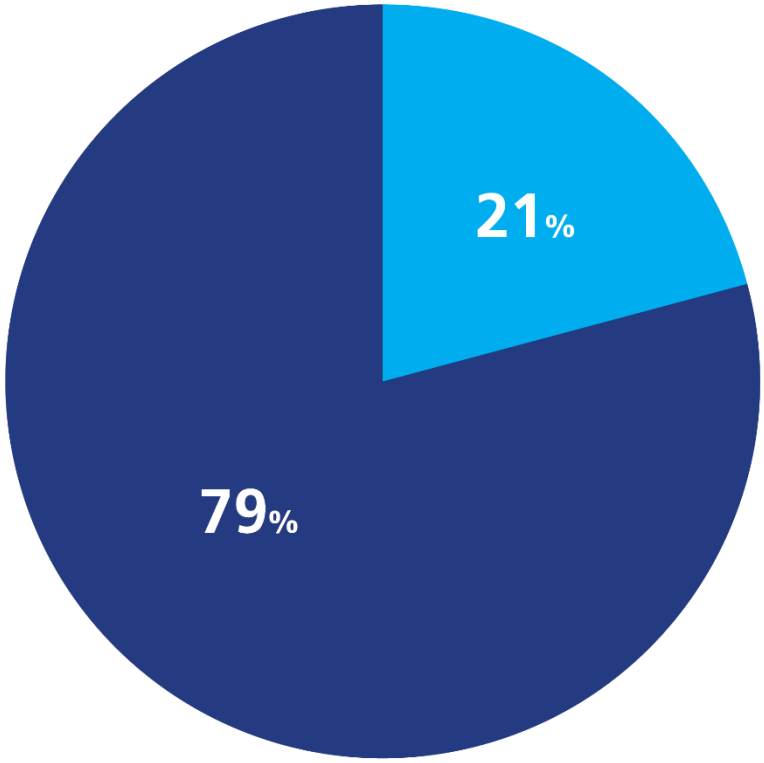
Whole programme % Completed within 182 days
Whole programme % Completed over 182 days

Worcestershire



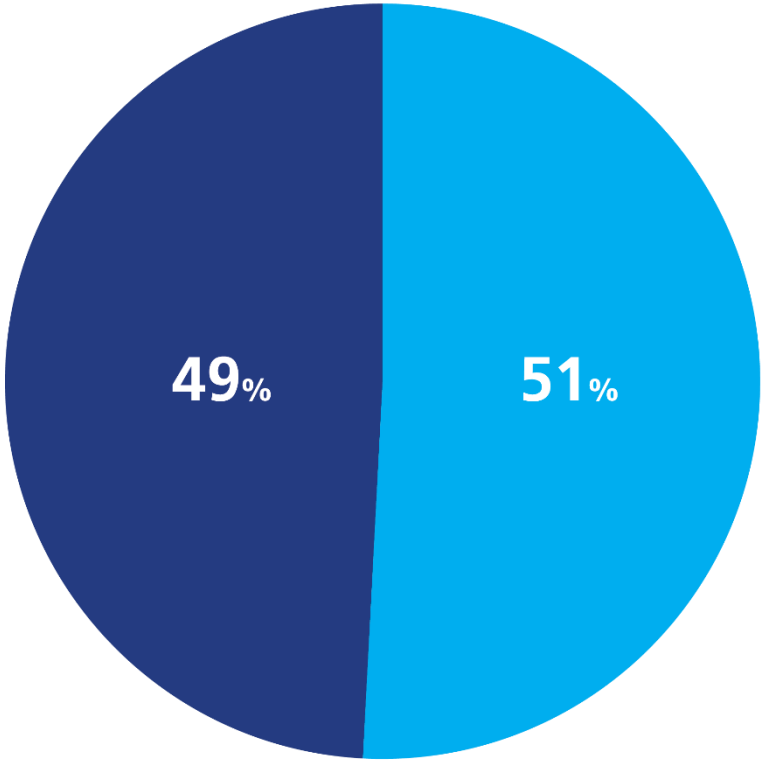
Whole programme % Completed within 182 days
Whole programme % Completed over 182 days

ICS - % Completed within 182 days from notification - 2019/20



April19 - March20 % Completed within 182 days
April19 - March20 % Completed over 182 days

ICS - % Completed within 182 days from notification - 2020/21



April20 - March21 % Completed within 182 days
April20 - March21 % Completed over 182 days

3. Learning from LeDeR Reviews

Learning from the information and recommendations provided by initial notifications and completed reviews is a key focus of the LeDeR programme implementation for Herefordshire and Worcestershire system. It enables us to, where possible, benchmark outcomes or experiences for people within our system compared to the regional or national average and supports us to understand if we are making progress over time. The national LeDeR Annual Report (latest available is for 2019 and was published during 2020) will be used as a benchmark throughout this section where data is available.

3.1 Reflections on the characteristics of deaths of people with a learning disability from Herefordshire and Worcestershire, notified to LeDeR.

Age profile of notifications

Table 2 –median age of death for men and women

	Median age for women (2017-2020)	Median age for men (2017-2020)	Median age for women (2020-2021	Median age for men (2020-2021)
England (2019)	59 years	61 years	Not yet available	Not yet available
Midlands (2019)	59 years	60 years	Not yet available	Not yet available
ICS	61 years	61 years	64 years	63 years
Herefordshire	61 years	64 years	71 years *	67 years
Worcestershire	61 years	60 years	61 years	62 years

*Based on very small numbers of deaths

Table 3 - age group at death as a percentage of all notifications made

Age bracket	4-17 yrs	18-24 yrs	25-49 yrs	50-64 yrs	65 yrs and above
England	7%	4%	16%	35%	37%
ICS	2%	5.6%	13%	40%	39.4%
Herefordshire	2%	4%	12%	40%	46%
Worcestershire	2%	6.5%	14%	40.5%	37%

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

For notifications made between 2017 and March 2021 the median age of death across H&W is marginally higher than the Midlands and England average for women with a learning disability and has improved over the period of the programme.

For notifications made between 2017 and March 2021 the median age of death across H&W for men with a learning disability is marginally better than the median for the Midlands region and the same as the England median age.

The median age of death for those residing in Herefordshire continues to be significantly better for both men and women.

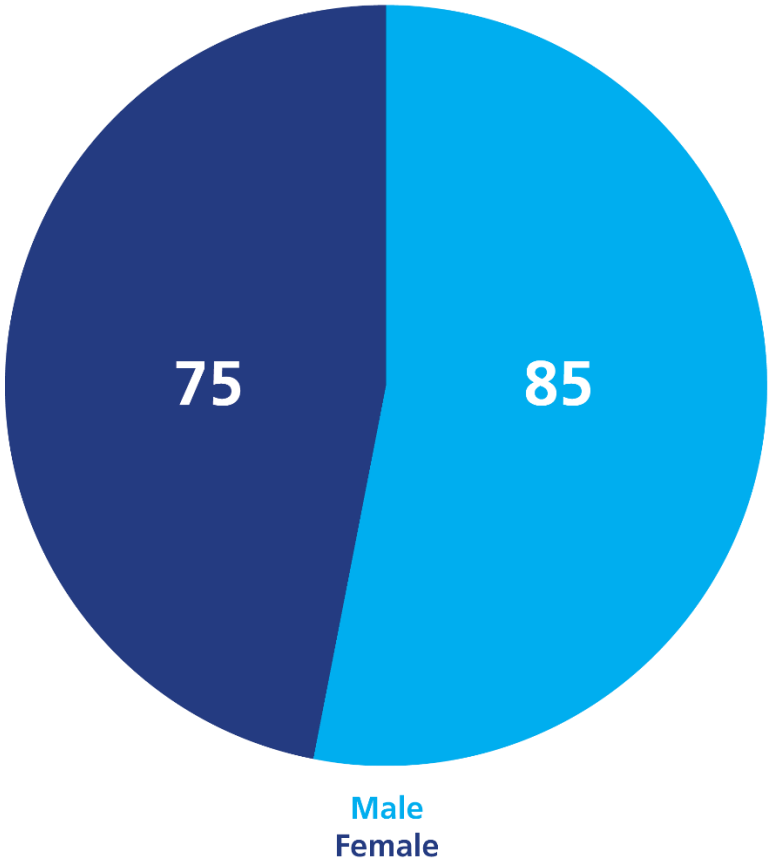
The Midlands and England median age reflects data to 2019 and does not therefore reflect the impact of the COVID-19 pandemic.

The percentage of deaths reported to H&W that are for those aged under 17 years is smaller than for England. The percentage of deaths for those aged 18-24 years in H&W is greater than the England position. This could indicate that either child deaths are under reported to H&W LeDeR or that those with life limiting conditions live into their early adult years. To 31st March 2021 only a very small number of child deaths (4-17 years) have been reported to H&W LeDeR. No concerns have yet been raised for any child death reported to H&W LeDeR and deaths were expected as part of a complex life limiting medical condition. The percentage of deaths for 4-24 year olds is smaller than the England average.

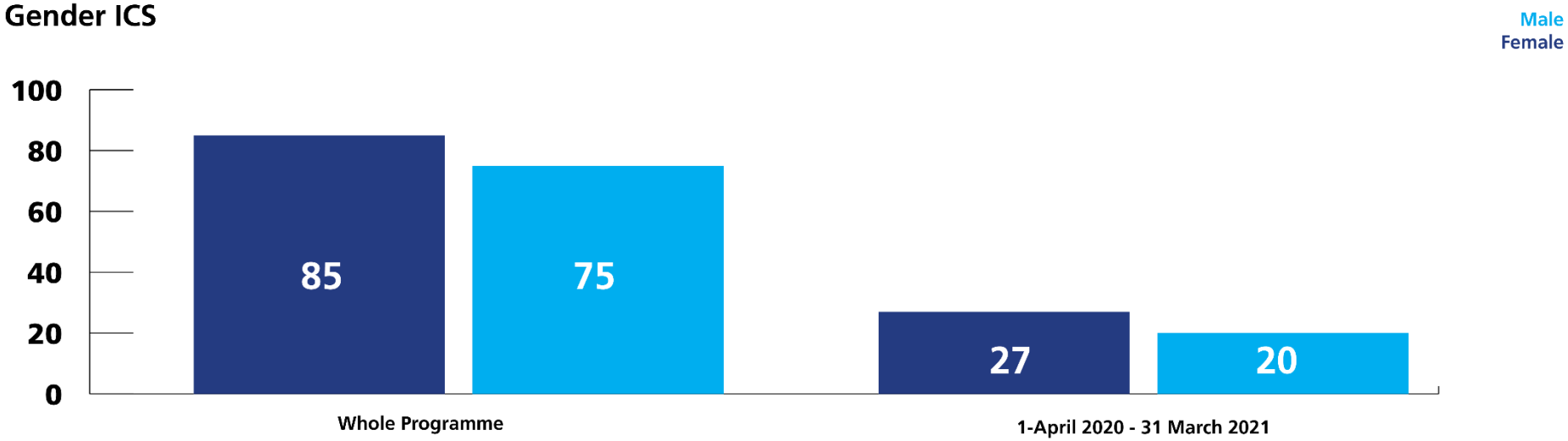
For H&W notifications the percentage or those aged 50-64 years and 65 years and above is greater than the England position, particularly for those residing in Herefordshire. Further analysis is required and caution needs to be applied due to small numbers.

The profile of notifications by gender

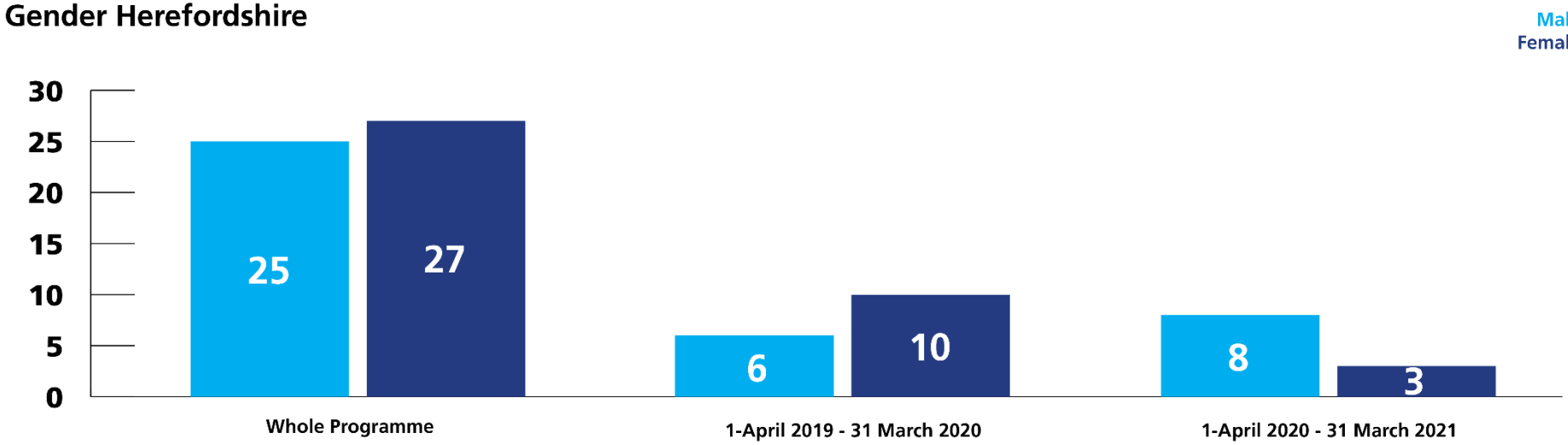
Figure 5 - notifications made for men and women

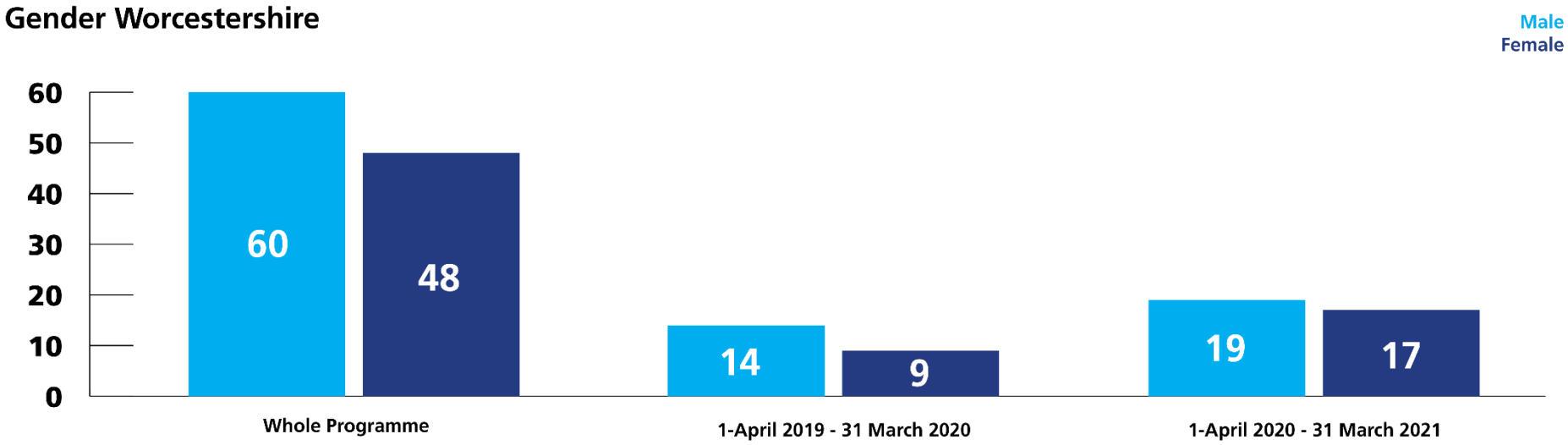


Gender ICS



Gender Herefordshire



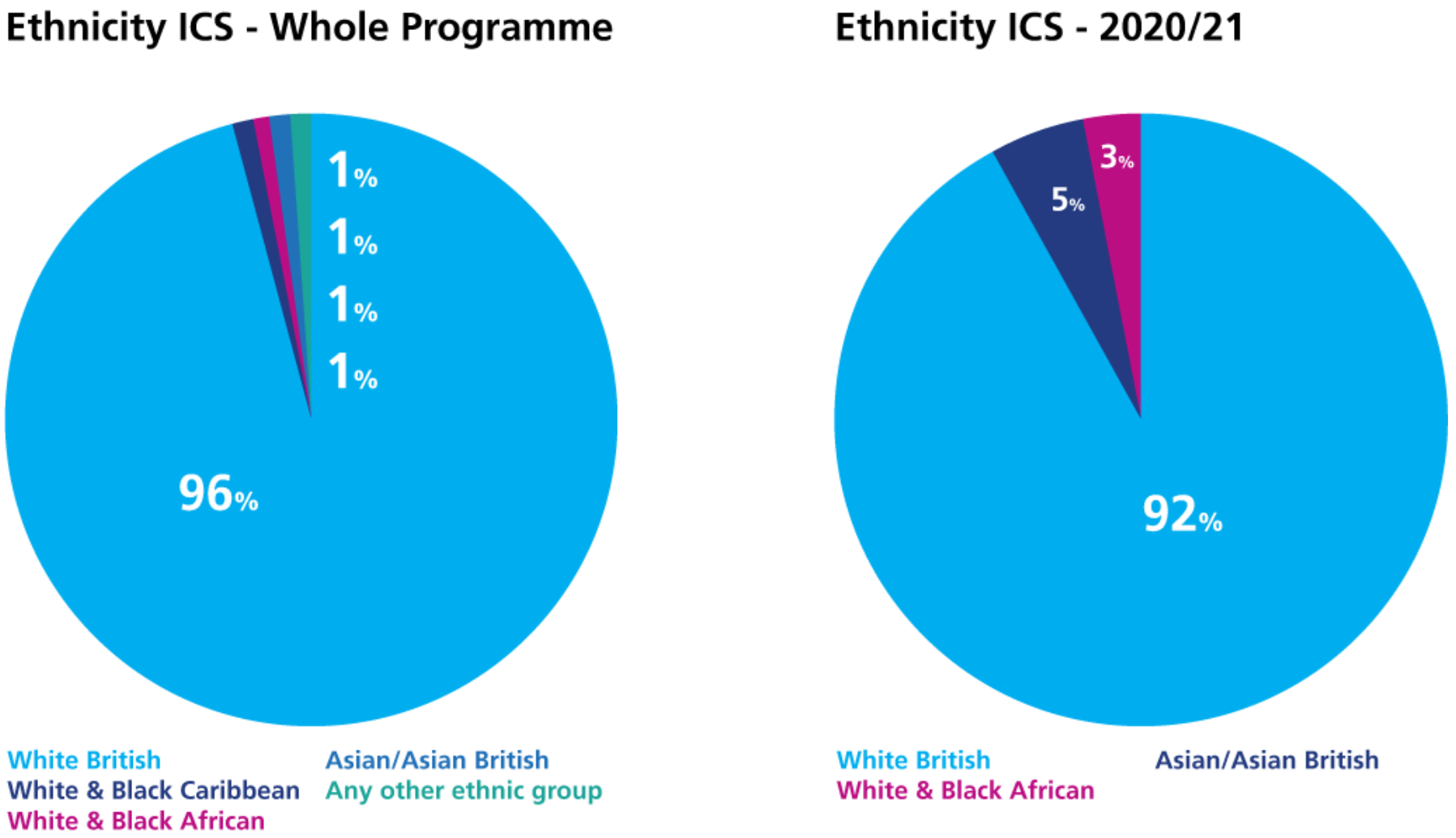


What does this tell us about the impact of gender on lifespan?

The median age of death for men and women is reflected in table 2 and 3. The national report reflects that 58% of notifications were for men. Whilst the overall profile across the ICS since 2017 reflects a more equal distribution (53% men : 47% women), there has in previous years been a higher ratio of notifications for women in Herefordshire. The 2020/21 H&W profile more closely reflects the national distribution of notifications (57% men : 43% women). Data for England across 2020 will be reflected in the national report expected by September 2021.

The ethnicity profile of notifications made to H&W LeDeR

Figure 6 – the ethnicity profile of notifications made to H&W LeDeR since 2017 and for 2020/21

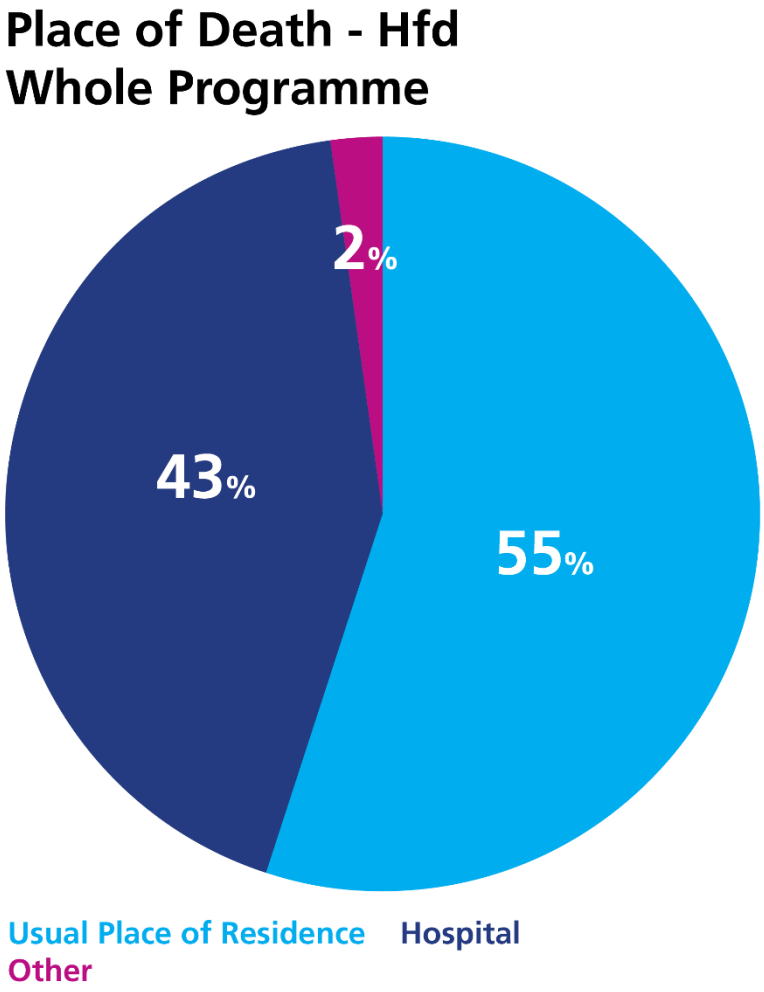


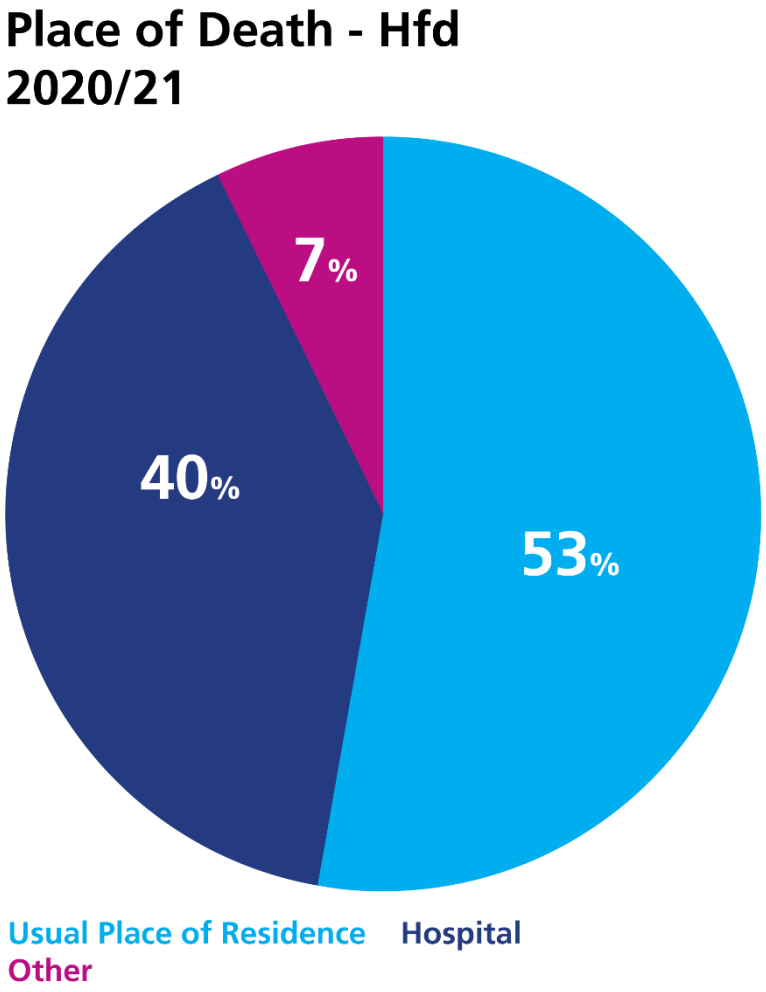
What does this tell us about the impact of ethnicity for deaths reported to H&W LeDeR?

Caution should be applied when making interpretations of the impact of ethnicity due to the small numbers reported for H&W. Within the notifications of individuals who reported their ethnicity as Asian, White and Black African, White and Black Caribbean or other the age range was 18-60 years. From all notifications received for H&W 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 from those with an ethnicity profile that matches our general population and understand more about the potential impact of ethnicity on the health equity and life chances of people with a learning disability.

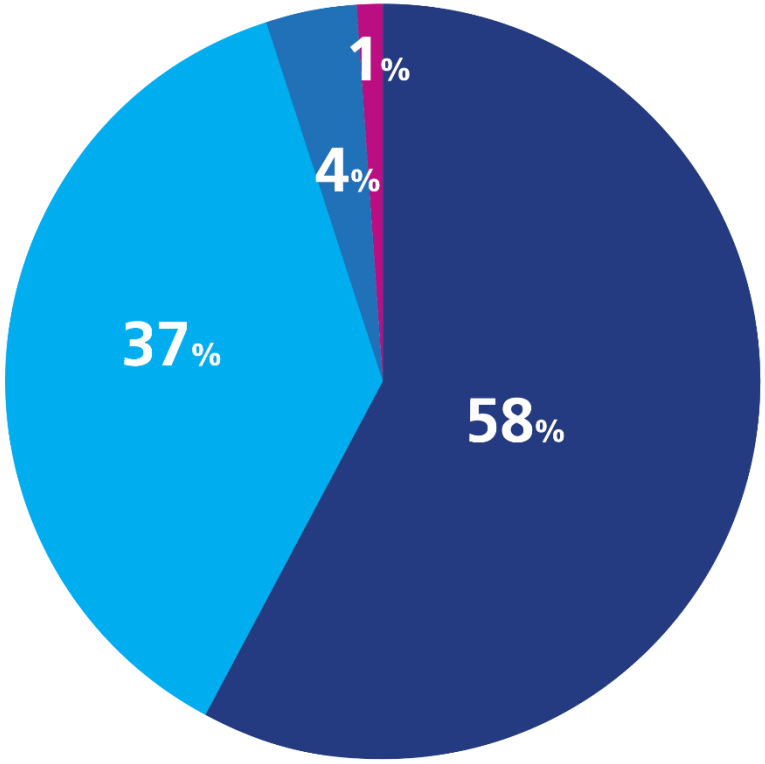
Place of death

Figure 7 – place of death in each county for 2017-2020 compared to 2020/21

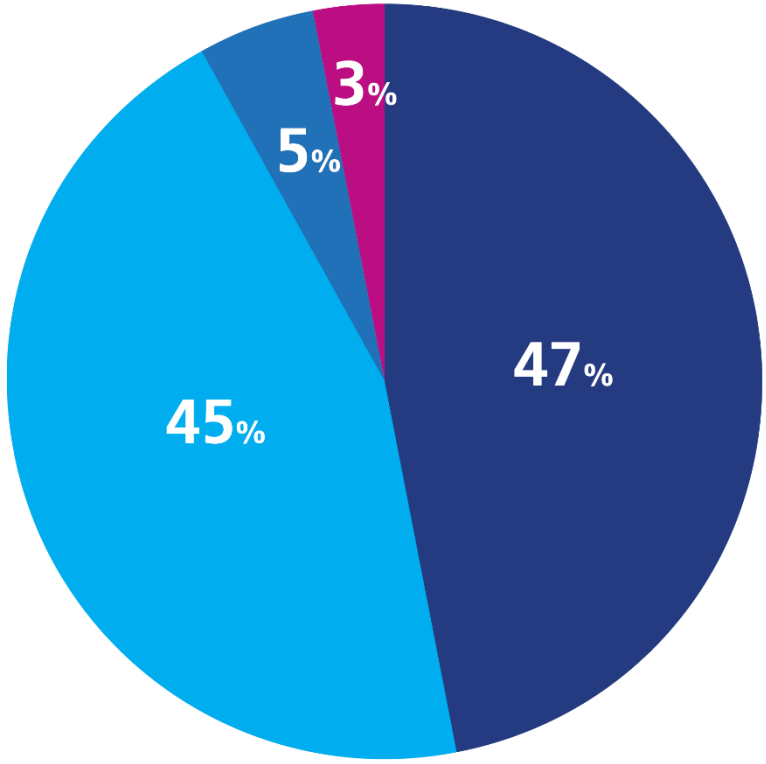




Place of Death - Worcs Whole Programme



Place of Death - Worcs 2020/21



What does this tell us about where people die within our system?

The extent to which deaths occur outside of an acute hospital bed, for people with a learning disability, has improved for both counties across the period of the programme. Worcestershire data for 2020-21 would have reflected a more significant difference were it not for the impact of COVID; 86% of people with a learning disability whose death certificate confirmed COVID-19 in part 1 died in an acute hospital bed but this was likely influenced by the context of testing availability. Additional analysis is required to review if people are achieving death in their 'preferred place'. No completed reviews have identified that acute care was required but was not accessed or the decision to not convey to hospital was found to be contributory to death in any way. Recommendations predominantly support that more people could achieve a different or preferred place of death if the timeliness of the identification of irretrievable deteriorating health or processes for planning and coordinating end of life care, were different. This includes examples where a return to home or an alternative care setting is considered.

3.2 Learning from the outcomes of completed reviews – key data findings

Data from completed LeDeR reviews are collated into a matrix to enable a level of analysis.

Causes of death

Cause of death, as listed on death certification, is compiled into themes. 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 8 - themes for most frequently reported cause of death for people with a learning disability

	Bowel Related	Respiratory & Pneumonia	Dementia	Cancer	Cardio-vascular	Epilepsy	Sepsis	Other	Covid-19
Cause of death – Hfd & Worcs Whole Programme	*7*	*73*	*9*	*20*	*21*	*3*	*3*	*15*	
Cause of Death – Hfd & Worcs Apr19–March20	*2*	*17*	*2*	*5*	*6*	*1*	*1*	*4*	
Cause of Death – Hfd & Worcs Apr20–March21	*1*	*16*	*5*	*4*	*4*	*1*	*1*	*7*	*8*

What does this tell us about the cause of death for people with a learning disability across our ICS?

Respiratory deaths continue to be the most prominent cause listed on death certification. Deaths due to aspiration pneumonia make up 35% of deaths for all respiratory causes. Of deaths where aspiration pneumonia is listed within part of the death certificate care was rated as poor or of concern (grades 4-6) for 30%. A Priority Action Group will continue to focus on the modifiable factors that can contribute toward aspiration pneumonia so that the ICS can have confidence that aspiration pneumonia need not be seen as an inevitable cause of death for many. Cause of death themes for each county are not reported here as some themes reflect very low numbers or single figures.

Very low numbers of deaths are recorded as being due to sepsis. The ICS has also seen very low numbers of deaths reported due to Sudden Death in Epilepsy (SUDEP) or epilepsy related.

Bowel related deaths have significantly reduced since the first year of the programme (overall less than 2% compared to 6% of all England LeDeR notifications). A review of interventions across both counties is the focus of a Priority Action Group and may identify additional learning to further embed good practice.

Deaths where the cause is listed as due to cancer remain fairly static and reflect a broad range of primary sites. Late stage diagnosis is not uncommon. Death due to cancer appears to be reflected less often for people with a learning disability than for the general population. We do not know how many people may be dying from undiagnosed cancer. Further analysis of screening access is underway and equity of uptake will be a key priority over the next 2-3 years.

Deaths where the cause of death is listed as due to cardio-vascular disease also remain static however all deaths were exclusively compatible with individuals who had a recorded high Body Mass Index.

COVID-19 Pandemic

During 2020/21 a new health condition and cause of death emerged, COVID-19. The pandemic had an unusual impact on the pattern of reported notifications (see figure 9). Only 1 death was notified to LeDeR during quarter 3. Between May 2020 and March 2021, but particularly between October 2020 and March 2021, death notifications were below expected levels.

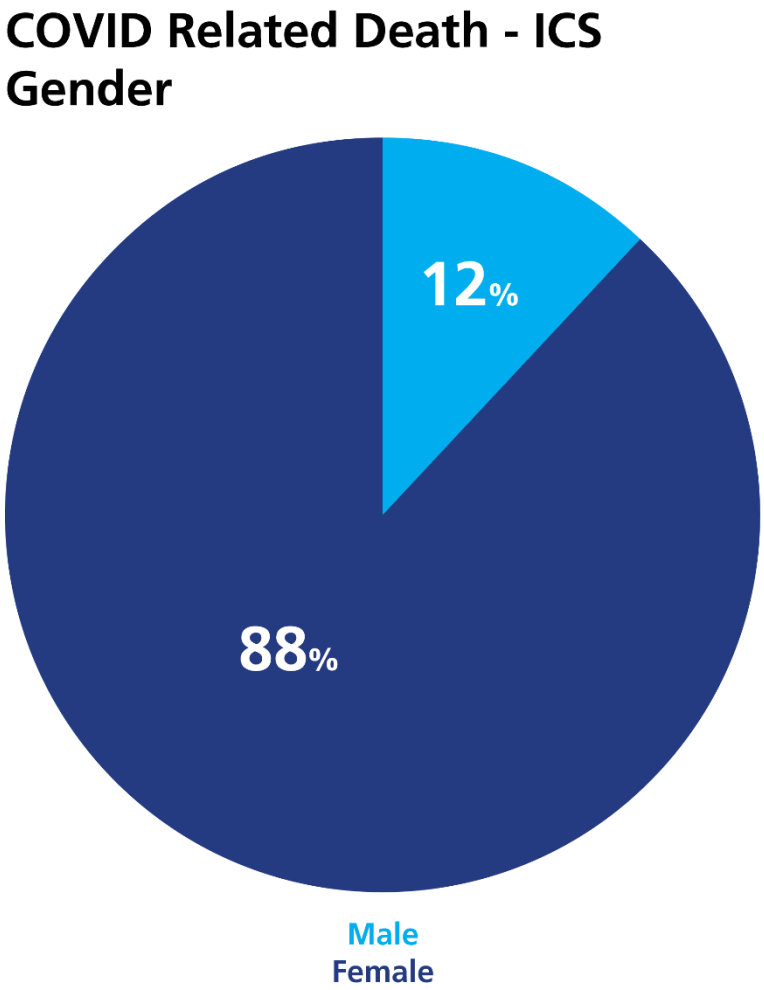
Figure 9 - cause of death profile, by month of the year during 2020/21

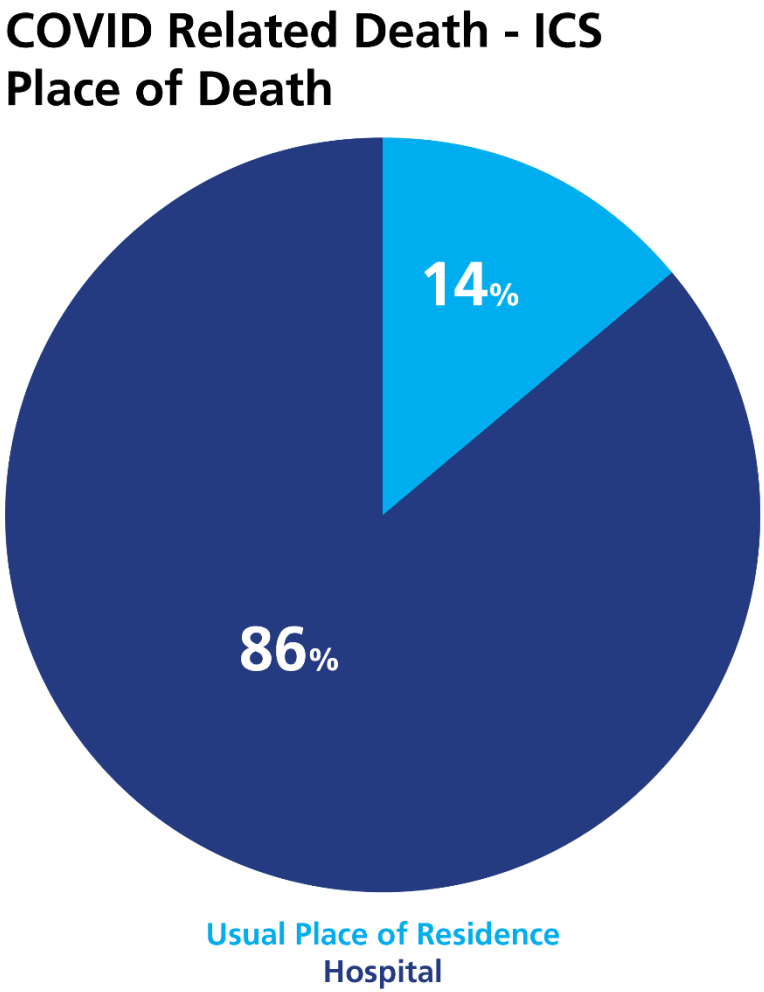
	Mar20	Apr20	May20	Jun20	Jul20	Aug20	Sep20	Oct20	Nov20	Dec20	Jan21	Feb21	Mar21
Respiratory	3	7	0	1	1	1	1	0	0	0	4	2	0
COVID related Death	0	6	0	1	0	0	0	0	0	0	0	1	0
Cardio Related Death	1	2	0	2	0	0	0	0	0	0	0	0	0
Other COD	2	3	2	2	3	2	3	0	1	0	0	3	0

The characteristics and health needs of individuals who had died from confirmed or suspected COVID-19 were subject to an initial Rapid Review to enable the extraction of key learning points in a timely manner. Where a completed review confirmed the cause of death as COVID-19 further analysis of associated factors was undertaken.

Both the gender profile and place of death was different to the trend seen for other causes of death (see figure 10).

Figure 10 - gender and place of death for individuals whose completed reviews confirmed a cause of death as COVID-19





Some patterns of health condition were similar to those seen across the full profile of LeDeR reviews for the ICS. This included 71% of people with a Mental Health need and 43% of people with a history of cardio-vascular disease.

Some areas of health need were underrepresented. No-one who died from COVID-19 had diabetes and 14% had asthma.

Other areas of health need were disproportionately represented, and this included epilepsy (57%) and obesity (71%). The rate of prevalence of underlying health condition is however based on small numbers and so should be interpreted with caution.

Of those who died from COVID-19 75% lived in a multi-occupancy care setting and 71% of individuals had mild or moderate levels of learning disability.

Of those reviews completed (87%) 71% have been given a care grading of 4 (poor care) or 5 (areas of significant concern that may have been contributory to death). Where relevant Serious Incident and / or Safeguarding investigations were triggered, and LeDeR Reviewers worked in close alignment with partners.

The overall grading of care provided

Within the current LeDeR system each review, prior to completion, is graded from 1 (excellent) to 6 (where care gaps contributed toward death). Care grading is approved by the LAC prior to final submission. The care grading should reflect the overall quality of integrated care and the number and significance of areas of learning or recommendations made, not purely the final weeks or days of life.

Figure 11 - overall grading of care as a percentage of completed reviews

	Grade of Care – Whole Programme		
	ICS	Herefordshire	Worcestershire
6	3%	4%	3%
5	4%	2%	5%
4	20%	13%	23%
3	31%	22%	35%
2	33%	40%	30%
1	9%	18%	5%

	Grade of care – 2020-21		
	ICS	Herefordshire	Worcestershire
6	0%	0%	0%
5	6%	0%	6%
4	22%	0	26%
3	17%	20%	16%
2	47%	60%	45%
1	8%	20%	6%

NB- 2020/21 only reflect reviews notified within 2020/21 that have been completed to date.

What does this tell us about the grading of care and how this contributes to premature or avoidable death in our system?
The percentage of cases graded as 1 or 2 (met or exceeded good care) has increased over time. The ratio of care graded as poor (grade 4) often reflects poor end of life care. No reviews notified during 2020/21 have yet required a multi-agency review (MAR). The percentage of cases graded as 5 or 6 compare proportionately to the all England position (7%). Cases graded 6 are usually subject to a Coroner's Inquest. Inconsistent methods for the grading of care across both counties were addressed during 2020/21.

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

Underlying health conditions are recorded for each completed review irrespective of whether the condition was felt to be associated with the cause of death.

Figure 12 - themes of common underlying health conditions detailed within completed LeDeR Reviews

Underlying Health Concern - Herefordshire	Whole Programme	1-April-2019 - 31-March-2020	1-April-2020- 31-March-2021
Epilepsy	22	12	5
Cardio – vascular	18	8	5
Dysphagia	15	9	4
Mental illness	27	11	8
Constipation	26	14	8
Diabetes	7	3	2
Obesity	8	4	2
CKD	5	3	0
Asthma	6	5	0

Underlying Health Concern - Worcestershire	Whole Programme	1-April-2019 - 31-March-2020	1-April-2020- 31-March-2021
Epilepsy	55	7	22
Cardio – vascular	47	3	23
Dysphagia	41	4	21
Mental illness	68	4	36
Constipation	72	7	36
Diabetes	21	0	13
Obesity	24	2	16
CKD	8	1	3
Asthma	13	1	5

Figure 13 - the number of health conditions

Number of Underlying Health Concerns - Herefordshire	Whole Programme	1-April-2019 - 31-March-2020	1-April-2020- 31-March-2021
UHC - 2 or less	14	7	4
UHC - 3	11	7	2
UHC - 4 or more	18	8	5

Number of Underlying Health Concern - Worcestershire	Whole Programme	1-April-2019 - 31-March-2020	1-April-2020- 31-March-2021
UHC - 2 or less	22	1	11
UHC - 3	40	5	18
UHC - 4 or more	39	3	19

Table 4 - percentage of individuals notified to LeDeR with specific underlying health conditions recorded (2017 onwards)

Health condition	% of cases England	% of cases Herefordshire	% of cases Worcestershire
Epilepsy	**36%**	**44%**	**51%**
Cardio-vascular disease	**32%**	**36%**	**43%**
Mental Health	**26%**	**52%**	**63%**
Constipation	**23%**	**50%**	**67%**
Dysphagia	**29%**	**33%**	**40%**
Diabetes	**Not available** (general population in UK- 6%)	**14%**	**19%**
Obesity	**Not available** (general adult population UK-26%)	**16%**	**21%**
3 or more long term health conditions	**56%**	**56%**	**72%**

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

The percentage of notifications received that reflect a long-term health condition for individual's with a Learning Disability residing within our ICS appear to be greater across all reported themes compared to those reported within notifications across England. The variance is most significant for Epilepsy, Mental Health and Constipation. This prevalence data reflects health conditions experienced by those who have died and whose deaths have been reported to LeDeR and may not therefore be an accurate reflection of health condition prevalence for the wider population of people with a learning disability. More analysis is required to understand whether the position is reflective of a good level of health surveillance and recording or whether, for example, medication use for severe or enduring mental health conditions is influencing the prevalence of other health needs.

Over the next 2-3 years we will collaborate with partners within the ICS, particularly Primary Care and Public Health, to understand the health needs and inequalities of people with a learning disability in more detail. This will include a focus on the accurate recognition, recording and clinical coding of health needs in the Annual Health Check. Health surveillance data can then inform population health management that recognises local health need and empowers each 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.

3.3 Learning from the outcomes of completed reviews - key themes and what we have achieved during 2020/21

Reviewers are encouraged to make recommendations from the information made available to them when completing an initial review. Recommendations arising from each completed review are then considered by system partners who agree the most effective action that can be taken to improve practice or influence better outcomes for people with learning disability.

Themes have emerged over the course of the programme. The frequency with which a recommendation type is made and the seriousness of the potential outcome supported the Steering Group to agree key priority areas for improvement and the development of Priority Action Groups to take forward each area of required improvement. During 2019/20 there were 5 Priority Action Groups.

- Bowel Health (linked to a key theme of deaths with an underlying factor of chronic mis-management of faecal impaction)
- Respiratory Conditions (linked to the most frequent cause of death and the factors that might influence modifiable factors)
- Annual Health Checks (including a theme in review learning for variability in the uptake and quality of checks)
- Support during an Acute Hospital admission
- Experience of the end of life (including themes relating to ReSPECT and DNACPR decisions and documentation)

In the months prior to the start of 2020/21 the necessary health and social care response to the COVID-19 resulted in the need to quickly review the areas of focus for service improvement linked to LeDeR themes. The work of the Priority Action Groups for Bowel Health was paused.

The focus of group members for ‘Support during a Hospital Stay’ and ‘Experience at end of life’ merged and the focus shifted to respond to growing concerns about the perception of the inappropriate use of ReSPECT forms in acute hospitals and community settings.

The work of the Priority Action Group for Annual Health Checks was temporarily paused during the first few months of 2020/21 but then rapidly gathered momentum in later months during the wave 1 recovery.

The Priority Action Group for Respiratory Conditions rapidly evolved to focus almost solely on COVID-19. Table 5 below summarises what we have collectively achieved during an extraordinary year.

Table 5 – Actions and outcomes of Priority Action workstreams during 2020/21

Priority Action focus	Actions during 2020/21	What we achieved.
The uptake and quality of Annual Health Check completion.	The Priority Action Group, established earlier in the programme, focused on developing an improvement plan based on a gap analysis. The Group is led by the Lead Commissioner for Complex Needs and includes 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 2020/21 the Group achieved: • A co-produced range of accessible resources and guides to support Annual Health Check delivery. Materials were based on examples of national best practice and informed by local people's experience. • Oversight of 'tests of change', funded by LeDeR Learning into Action funds, to support and evaluate effective models and processes for delivering quality Annual Health Checks across Primary Care Networks. This involved examples including the consistent implementation of call, recall and booking processes; the implementation of an MDT approach; the use of a central PCN team; the utilisation of Learning Disability Nurse expertise and support • Oversight of 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.	A co-produced 'resource pack', published at https://herefordshireandworcestershireccg.nhs.uk/our-work/learning-disabilites-and-autism/annual-health-checks By 31st March 2021 a completion rate across H&W of 84.9%. For PCNs involved in 'test of change' projects completion rates exceeded 90%. 91% of individual GP Practices exceeded the national completion rate target of 67% The number of people on the GP Learning Disability Register increased, particularly for people aged 14-25 years, a position that we will build on into 2021/22. This will result in more Annual Health Checks being offered next year.

Priority Action focus	Actions during 2020/21	What we achieved.
The system roll out of the ReSPECT programme.	During wave 1 of the COVID-19 pandemic many were concerned by media reports about the potential for the unlawful use of Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms and Do Not Attempt Resuscitation (DNAR) documentation to justify discriminatory barriers to accessing health care including Intensive care beds. Healthwatch, on behalf of the local population, wrote to the LeDeR LAC to raise these concerns. A review of documentation for people with a learning disability who had died in an acute hospital during wave 1 was undertaken. Areas requiring improvement were noted for some of the ways in which decisions were documented however all decisions were found to have been appropriate to personal need. The ReSPECT Programme Board includes Learning Disability practitioners and Advocacy organisation representation to ensure that the needs of people with a learning disability are reflected. A collation of themed learning from LeDeR reviews was due to be presented in May 2020 but was deferred due to the COVID-19 pandemic. Integrated multi-disciplinary partnership working has been key. Community Learning Disability Teams have been fundamental to raising awareness of ReSPECT for people with a learning disability and their families and have developed accessible information to support the process.	The CCG Medical Director wrote to all GPs and the Trust Medical Directors/ Chief Medical Officer wrote to all clinicians, to reinforce that DNAR and ReSPECT decisions must be individual and personalsied and not be justified solely on the grounds of a person having a Learning Disability. A review of hospital notes determined that all decisions regarding DNAR and access to healthcare intervention during wave 1, for people with a learning disability who had COVID-19 included in part 1 of their death certificate, were appropriate and did not result in discriminatory barriers to healthcare. Completed LeDeR Reviews during 2020/21 have continued to reflect many examples of highly personalised end of life care. Review has also recognised however that most people who required an acute hospital admission during the pandemic had to rely on hospital doctors, who may not have met them before, to make challenging decisions during an emergency situation. 56% of those who died in hospital had a ReSPECT form completed whilst an inpatient. More needs to be done to support people with a learning disability and their families to be encouraged to think about ReSPECT form completion alongside trusted community-based health and social care teams, prior to an episode of deterioration.

Priority Action focus	Actions during 2020/21	What we achieved.
Respiratory Conditions (focus on minimising transmission of the COVID-19 virus and maximising protection)	Learning from COVID-19 LeDeR Rapid Reviews was used to inform work with partners to provide support to minimise COVID-19 outbreaks in care settings. The LeDeR LAC and LeDeR Clinical Lead worked alongside other Registered Nurses within the CCG Quality Team to form an extended Infection Prevention and Control Clinical Cell, coordinating access to testing in care settings during the 1st wave and supporting LD Care Settings to access testing ahead of the national offer. Learning from initial COVID-19 local and national LeDeR reports were shared with partners across the system. Took action from learning identified from COVID-19 related LeDeR reviews to inform a proposal to offer COVID vaccination to people with a learning disability in care settings, alongside older people in care settings in JCVI 1, and therefore ahead of the national offer. This proposal was supported by the system Ethics Forum (established during the COVID-19 pandemic) and approved by the Clinical Commissioning Executive Committee. Promoted use of the LD Register to identify those in JCVI 6 for vaccination, shared easyread resources with PCNs and worked with family carers to coproduce a FAQ factsheet shared through social media Learning Disability Teams were instrumental in facilitating vaccination for those with the most complex needs, including support to coordinate best interest decisions.	Supported access to the whole home testing for care settings supporting people with a learning disability in the weeks ahead of national offer. This helped to identify asymptomatic cases and contribute toward minimising COVID-19 outbreaks. Maintained virtual Learning into Action Group meetings and updates to engage and sustain partnerships during the pandemic. Supported access to vaccination for people living within learning disability care settings ahead of the national offer, with initiation of vaccination at the early stages of wave 2 offering increased protection for people with a learning disability who were amongst those most at risk. Deaths of all causes for people with a learning disability reduced by 60% from 25 (April- June 2020) to 10 (January to March 2021), with a reduction in notifications with a confirmed cause of death of COVID-19 positive from 7 (wave 1 March -May 2020) to 1 (wave 2 January to March 2021). By 31st March 2021 the vaccination uptake rate for people with a learning disability was 88%. Uptake rates continued to grow after this date thanks to the dedicated work of PCNs and Community Learning Disability Teams.

3.4 Affecting meaningful change in Herefordshire and Worcestershire - Our 3 Year Road Map to Longer, Healthier and Happier Lives

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 the LeDeR Steering Group and Learning into Action Groups for H&W. Steering Group members agreed that to have effective and sustained influence it was crucial to focus on a relatively small number of key priorities.

During 2020/21 the COVID-19 pandemic brought into sharp focus and in many ways compounded the health inequalities experienced by people with a learning disability. Underlying health conditions that had not previously featured as a significant contributory theme for premature mortality were brought to people's attention. Information and learning gathered from the completion of LeDeR Reviews this year contributed to the wealth of information that we have collectively generated now that we have been undertaking learning from LeDeR Reviews for 3 full annual reporting year cycles.

From the themed learning generated up to and during 2020/21 and the feedback of people with lived experience a number of priorities were felt to be of greatest importance. The agreed areas of focus outlined in table 6 will be a key feature of the milestones within our 3 Year Learning Disability And Autism Plan and in the HW LeDeR 3 Year Strategy that will be developed during 2021.

To enable meaningful and sustainable change that impacts on people's health outcomes and starts to address health equity for our local population we must ensure that we also work together to address a number of underpinning determinants of health. For this reason it is essential that our HW LeDeR Strategy is informed by local Joint Strategic Needs Assessments reflective of our local population of people with Learning Disability or Autism led by local experts in Public Health. It is also critical that a Strategy to outline plans for improving health outcomes is shaped in a meaningful co-produced manner by those who are key to delivering services and people with lived experience. National Policy requires that we achieve the development of a Strategy by the end of June 2021. Table 6 sets out our overarching strategic priorities and we will work together during 2021, as our ICS evolves, to clearly set out a Strategy for achieving this.

Table 6 – Our Priorities

Supporting peoples emotional and mental health needs by:

- training staff in mental health services to recognise and respond to the needs of people with a learning disability or autism
- ensuring that services are accessible to all
- ensuring that peoples needs are met in a manner that does not over rely on medication
- ensuring that the move to increase digital services does not exclude access for vulnerable people

Supporting people with learning disability or autism and their loved ones to make and influence choices about their care when they are very unwell or when they are dying by:

- Increasing the meaningful completion of Summary Plans for Emergency Care and Treatment (ReSPECT) before a crisis situation
- informing plans to make access to the detail of ReSPECT wishes available across the health and social care system
- ensuring that training to support the planning and delivery of end of life care reflects the needs of people with learning disability or autism

Recognising and responding to health need through Annual Health Checks by:

Achieving high rates of Annual Health Check completion (85% or more)
Ensuring all those who may be eligible are on the GP Learning Disability Register, particularly young people aged 14-25 years and those who represent the ethnicity of our wider population in Herefordshire and Worcestershire
Annual Health Checks resulting in a meaningful Health Action Plan that reflects wide ranging need including access to dental services, screening programmes and roles aimed to support health and wellbeing (including coach, trainer or social prescriber roles)
The way that Annual Health Check outcomes are recorded are accurate, consistent and support the system to understand health needs of the population in a better way.

Increasing protection from respiratory conditions to include:

Dysphagia assessment, support and training
Pneumococcal, Influenza and COVID-19 vaccinations
Improving oral health and preventing disease
Understanding the impact of long COVID

Taking a zero tolerance to avoidable deaths related to poor management of constipation or bowel impaction by:

- ensuring that Annual Health Checks lead to advise on healthy lifestyle support that reduces the risk of constipation
- Training people to develop and use bowel management plans for chronic constipation
- raising awareness of how to use laxatives
- supporting access to bowel screening and monitoring uptake.

Prevent a deterioration of health needs by recognising and supporting people to understand the impact of obesity by:

- ensuring that Body Mass Index is recorded in the Annual Health Check
- improve data to understand the extent of diabetes in our local population
- ensure that those on medication for emotional or mental health needs have the right health checks to identify and reduce cardio-vascular disease risks

Underpinning features of all improvements

People at the heart of all we do with service design informed by those with lived experience , that responds to their needs
Meaningful inclusion and choice- including Mental Capacity assessment and facilitated Best Interest decisions
A workforce equipped to recognise and respond to personalised adjustments that enable equity of access and opportunity
A way of working that supports people to collaborate and share information and decision making

4. Conclusion and next steps

The NHS Long Term Plan, published during 2019, and the NHS Oversight Framework for 2019/2020, provided a welcome spotlight on reducing the health inequalities experienced by people with a learning disability. From 1st April 2020 the four Clinical Commissioning Groups across Herefordshire and Worcestershire merged to become one single CCG. The two local programmes for LeDeR across H&W were integrated under one single Local Area Contact to form a cohesive partnership. A single H&W LeDeR Steering Group, with a Learning into Action Group aligned to the geography of each Health and Wellbeing Board at county level, was in place by the end of September 2020.

The remit of Clinical Commissioning Groups, as a key partner and system leader during 2020/21 has been to continue to support partnership working to deliver the LeDeR programme. We believe we have achieved this. We have collaborated, during an 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. This included improving the time within which reviews are completed, significant improvements in Annual Health Check completion rates and equitable access to COVID vaccination. The NHS Priorities and Operational Planning Guidance 2021/22, issued in March 2021, demonstrates that in the year to come there will continue to be a significant focus on reducing health inequalities for people with a learning disability and autism and we very much welcome this.

In March 2021 a national Learning from Lives and Deaths (LeDeR) Policy was published. The Policy signals the introduction of new requirements and standards and as we move toward Integrated Care Systems by 1st April 2022 we will work collaboratively to agree and set out how we will take the LeDeR programme forward. Milestone implementation is required from June 2021 and an outline of our current position is included in appendix 2. We will develop a clear summary of this report, accessible to all, that outlines who we are, what we have learnt this year, what action we have taken and what we plan to do going forward into 2021/22 and beyond. This will form the basis for our HW LeDeR Strategy. 2021/22 presents many uncertainties and this includes the impact of the implementation of a new LeDeR platform from 1st June 2021 and the way in which COVID-19 will influence peoples longer term health, the nature of health inequality, peoples day to day lives and premature death.

HWCCG and the HW LeDeR Steering Group members welcome the current national emphasis and focus on the health needs of people with a learning disability and autism, and look forward to another successful year of improving outcomes so that local people can live longer, happier and healthier lives.

Appendix one - LeDeR Steering Group Terms of Reference (V3 approved June 2020)

Terms of Reference

Herefordshire and Worcestershire Learning Disability Mortality Review (LeDeR) Steering Group

Background

The Learning Disabilities Mortality Review (LeDeR) Programme, delivered by the University of Bristol, is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The Programme was established as one of the key recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPoLD) (2013).

The aim of the Programme is to drive sustainable improvement in the quality of health and social care service delivery for people with learning disabilities, to help reduce premature mortality and health inequalities in this population, through mortality case review. Reviews will be undertaken to help clarify contributory factors for the causes of death that contribute to the overall burden of excess premature and amenable mortality for people with learning disabilities; identify variation and best practice; and identify key recommendations where there is opportunity to influence improved outcomes.

The outputs of the Herefordshire and Worcestershire (H&W) LeDeR Programme will contribute toward the national Programme which will complement and contribute to the work of other agencies and workstreams of the Learning Disability and Autism Programme including Transforming Care and other aspects of Building the Right Support.

In March 2017 ‘National Guidance on Learning from Deaths’, published by the National Quality Board, set out a requirement to providers to use the LeDeR methodology to undertake reviews of all deaths for people with a learning disability in contact with their services.

Core shared values

As members of the H&W LeDeR Steering Group we commit to ensuring that local Programme delivery:

- Keeps the experience of people with a learning disability, whose life and death we will become aware of through the course of the Steering Group, firmly at the center of the review and learning process and the forefront of our mind.
- Engage with families and carers in a manner that is inclusive, values their contribution and is respectful of their experience and bereavement.
- Remain focused on celebrating where end of life experiences are managed well, capturing examples of 'reasonable adjustments' and considering how lessons can be learnt following deaths considered to be premature or amenable to improvements in healthcare.
- Remain open minded and agree not to pre-judge outcomes or contributory factors, giving fair consideration to all available information.
- Support an evolving process that will become sustainable and embedded in local culture.
- Uphold the key principles of cooperation and partnership to ensure that the programme of work affects meaningful change on reducing health inequality and increasing the opportunities for the experience of a 'good' death for people with a learning disability.

The scope of the local reviews of deaths

The LeDeR Programme will support the reviews of all deaths of people with learning disabilities aged 4 years and over, irrespective of the cause or place of death. The H&W LeDeR Programme will ensure oversight of the review of all deaths of people with a learning disability who are registered with a Herefordshire or Worcestershire GP and meet the criteria to be listed upon a GP Register for a Learning Disability Annual Health Check. Children and young people, originating from H&W but placed out of area during the time of their death, will be within the scope of reviews for the H&W LeDeR programme (in alignment with the scope of the Child Death Overview Panel).

Purpose / role of the Steering Group

- To work in partnership with the Regional LeDeR lead for NHS Midlands.and the Learning Disability and Autism Programme
- In partnership with stakeholders, ensure that a nominated Local Area Contact has oversight of the programme activities for H&W.
- To guide the implementation of the programme of local reviews of deaths of people with learning disabilities.
- To receive regular updates from the Local Area Contact about the progress and themed findings of reviews.
- To agree the key benchmarks or indicators from which progress and impact of the LeDeR programme will be evaluated. To re-prioritise or modify benchmarks in response to emerging local themes following the completion and reporting of reviews.
- To agree priority recommendations, based on the themes of reviews and contributory factors that have the potential to make the greatest impact.
- To oversee the tracking of progress toward agreed measurable outcomes where local action is recommended through receipt of updates from the Learning into Action Group for each county of Herefordshire and Worcestershire
- To ensure each identified partner agency is accountable for the delivery of action required from the organisation that they represent.
- To ensure agreed protocols are in place and are adhered to, for information sharing, accessing case records and keeping content confidential and secure.

Each county based Learning into Action (LeDeR) Group will

- Receive a summary of anonymised case reports pertaining to deaths relating to people with learning disabilities in order to contribute to a collective understanding of learning points and recommendations across cases.
- To help interpret and analyse information submitted from local reviews, including areas of good practice in preventing premature mortality, and areas where improvements in practice could be made.
- To consider the recommendations made within completed reviews and agree system or partner agency actions to be taken to ensure improvements in health outcomes and experience
- To gain updates from partner agencies on the progress of agreed actions arising from reviews, escalating actions that are not progressing as expected to the Steering Group

Membership - Membership for the H&W LeDeR Steering Group will include broad representation including health and social care; provider and commissioning organisations; people with a learning disability and those who support them, including family carers and advocacy organisations.

Role of Steering Group Members

Members will continuously review the programme direction and make decisions to make sure that:

- Partners work together to support the success of the programme and make sure that the voice of no single interest will dominate.
- All identified risks are assessed, putting in place actions, mitigations and contingency plans for all high impact risks.
- The time and resources needed for the programme objectives are available.
- The Governance of the programme ensures that information available is recorded and stored safely and accurately.
- Support is available for the Local Area Contact to deliver the programme across H&W.
- The progress of the overall programme is monitored and achieves meaningful and measurable outcomes.

Governance

- Steering Group Meetings will be held quarterly and Learning into Action Groups will be held 4-6 weekly
- Meetings will be quorate when representatives or the nominated deputy from the relevant organisation/ forum marked with * are in attendance. Where meetings are not quorate, key decisions will be agreed virtually by email wherever possible to avoid meeting cancellations.
- Meetings will be organised by the Local Area Contact.
- The Chair will be agreed by the Steering Group.
- The Steering Group will provide themed annual reports to the CCG led Mortality Oversight Group and each county Learning Disability Partnership Board,
- High risks identified that cannot be mitigated will be escalated to the CCG Quality, Performance and Resource Committee via the HWCCG Risk Register and to a relevant partner agency forum
- The Steering Group may request that task and finish working groups be established to focus on resolving specific emerging priorities and issues.

Membership of the Steering Group will include representation from key groups, organisations and forums. Required organisation/ forum representation is outlined below and roles for quoracy indicated *. Where a key representative is unable to attend a suitable deputy should attend.

	Representation
*	HWCCG LeDeR Lead Area Coordinator / CCG Director
*	Safeguarding Adult Board or Child Death Overview Panel representative
	HWCCG LeDeR Clinical Lead
*1	Worcestershire Acute Hospitals NHS Trust Mortality Lead
*1	Worcestershire Health and Care NHS Trust Mortality Lead
*1	Wye Valley NHS Trust Mortality Lead
*1	Primary Care/ CCG GP Quality Lead Worcestershire
*1	Primary Care/ CCG GP Quality Lead Herefordshire
	West Midlands Ambulance Service
*2	Complex Needs Commissioning / Transforming Care Lead
*	Learning Disability Commissioner
*2	Adult Social Care representative
*	Worcestershire Health and Care NHS Trust ,Learning Disability Services
*2	Public Health
*	Speak Easy NOW
*	Family Carer Representatives
	LD Provider Forum
*1 Medical representation from any one agency for quoracy *2 representation of both Herefordshire and Worcestershire County Councils from at least one member	

<u>Experts by Experience</u>

SpeakEasy NOW Worcestershire have consulted with Health Checkers on behalf of the Steering Group to guide a decision about how they may wish to be involved in the work of the LeDeR programme in the most meaningful way. Health Checkers have reached a decision that they would not wish to form part of formal Steering Group meetings where Reviews will be discussed in detail. Health Checkers preference is for a member of Speak Easy NOW to attend the Steering Group and act as a link between the Steering Group and Health Checkers group meetings.

Health Checkers are a key component of the Staying Healthy Sub Group of the Worcestershire Learning Disability Partnership Board. Consultation on the detail of how improved outcomes can be achieved for people with a Learning Disability, as a result of work of Priority Action groups that take forward the themes arising from Reviews, will take place at the Staying healthy Sub Group and LeDeR updates are a standing item on the meeting agenda. The Staying Healthy Sub Group will work closely with the Worcestershire LeDeR Learning into Action Group.

Herefordshire Learning Disability Partnership Board includes key representation of experts by experience including a co-chair arrangement. Consultation is achieved through meaningful engagement with a range of provider supported experts of experience service users between formal meetings. The Herefordshire LeDeR Learning into Action Group will work with the Lead Commissioner for Learning Disabilities to agree the most meaningful way to engage with experts by experience.

Appendix two – HWCCG Response to the Oliver McGowan Independent Review Report Recommendations

Recommendation	CCG Position	Current Gaps	Level of Assurance
All those who are new to the role of reviewer, or Lead Area Coordinator (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process	All reviewers are supported by the LeDeR Clinical Lead, who makes a minimum of weekly contact to ensure that the reviewer is fully supported and supervised. New reviewers are supported through telephone contact and Review template content oversight by the LeDeR Clinical Lead. Supervision on an ongoing basis remains in place until there is mutually agreed confidence that the reviewer can complete a review with reduced frequency of ongoing supervision. Experienced reviewers can also provide peer support and guidance. The LeDeR Clinical Lead receives weekly contact with the Lead Area Coordinator (LAC) for support and supervision.	No gaps identified.	Green.
Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs	Dedicated administrative support (substantive contract) is provided to the LeDeR programme. During 2021/22 a review of analyst support to inform programme oversight and progress will need to be undertaken.		Green
There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes	LeDeR programme processes across H&W ensure transparency in the following ways:- Close working relationships between the LAC, Clinical Lead and Reviewers that enables oversight of progress and process. Multi-disciplinary scrutiny panel sign-off ensures that the correct procedures and processes have been followed and reviews are quality assured. Recommendations and outcomes are shared with county based Learning into Action Groups with recommendations approved and action agreed. Progress is then tracked and reported to the Learning into Action Group and the LeDeR Steering Group. Progress, outcomes and updates are reported through CCG governance structures, including the CCG Governing Body and Safeguarding Boards. Reporting to Health & Wellbeing Boards in 2021.	No Gaps identified	Green

Recommendation	CCG Position	Current Gaps	Level of Assurance
Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.	The Chief Nurse is the Senior Responsible Officer / Executive Lead for LeDeR and ensures that timely updates are provided to the CCG Governing Body and Safeguarding Boards for awareness and assurance.	No Gaps	Green
The CCG executive lead for LeDeR will ensure that LeDeR Reviews are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.	There is an escalation process in place when critical information has been difficult to obtain in a timely manner. The H&W LeDeR Team have developed and maintained positive, collaborative relationships with partners and it is very rare that we encounter difficulty in acquiring information. During 2020/21 the COVID pandemic placed a level of demand upon services and processes that resulted in delays in completing and sharing Subjective Mortality Reviews, gaining access to Care Home notes and in obtaining GP records on occasions. Processes are now in place, should COVID secure measures be required, to support timely access and avoid delays. No significant avoidable delays have been experienced since wave 1 of the pandemic and delays in 6 month completion during 2020 have been largely due to pandemic redeployment or bereavement impacting on family engagement.	No Gaps	Amber
When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer or LAC have no previous experience of a MAR, they will seek support from an experienced 'buddy'	All MARs have been chaired by the LAC who has experience of chairing multi-agency meetings– including those that are highly sensitive. The LAC is supported by the Clinical Lead who is also experienced in chairing highly complex and challenging meetings. Where additional support might be required the Chief Nurse and SRO is available to guide and advise.	No Gaps	Green

Recommendation	CCG Position	Current Gaps	Level of Assurance
In regard to the MAR meeting itself, it is recommended that there is action taken to: -ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of meetings as they wish -review the purpose of the MAR with specific reference to the function of Question 8 (now Question 9 in version R05) and, should this question be retained, provide clear guidance for MAR participants; also, to think through whether this question should be asked in confidence if it is a particularly difficult situation	In all MARs chaired by the CCG to date Family members have been invited and actively encouraged to attend and contribute (in one case the deceased was estranged from their NoK and as this was very well documented it was therefore not appropriate to invite them to the MAR). All LeDeR MAR processes are followed, the meeting documented and shared for accuracy checking before final acceptance/ approval. Much thought and consideration is given to how a MAR will be approached, given the highly sensitive nature of it's purpose. Decisions regarding how Q9 is approached is done on a considered case by case basis, deferring to the Coronial process where relevant and giving due consideration to an organisations capacity to appoint legal representation.	No Gaps	Green

Recommendation	CCG Position	Current Gaps	Level of Assurance
Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	Appropriate support is available to Reviewers, provided by the LAC and the Clinical Lead, prior to approval via a multi-disciplinary quality assurance process. Leder recommendations are endorsed by the Learning into Action Group and actions agreed. An action tracker is reviewed monthly and progress of a themed work plan is overseen by the Steering Group. Lessons are shared regionally through NHSE/I Forums and locally through a network of Forums connected to the Learning Disability Partnership Board in each county .	Re-prioritisation of work due to the COVID pandemic and vaccination programme has resulted in progress in some areas of Priority Action not progressing as we would have hoped – new areas associated with COVID have however made significant improvements. Learning from wave 1 led to a reduction in deaths of people with a learning disability in wave 2 and this is to be celebrated. Despite the delay in some areas of progress the infrastructure is strong.	Green
Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.	This document reflects the review undertaken into systems and processes against the learnings and recommendations arising from Oliver's Independent Review. Further review will be undertaken during 2021/22 in light of the new national LeDeR Policy.	No Gaps	Green

Appendix three- Initial Implementation Plan for the national LeDeR Policy 2021

No	Deliverable and method of measurement	Frequency	Required date of delivery	System position and required action	Lead
1	100% of reviews (both initial and focused) are completed within six months of notification. Monthly dataset will show ICS completion rates. Evidence of robust plans in place to achieve 100% where performance is below this figure.	Monthly	30 June 2021	Reviews notified 1st March to 31st May will not be released to system until 1st June 2021. Twice monthly Review Oversight meeting to be formalised to track progress of each review, monitor days toward deadline and unblock barriers to progress. Data to be collated monthly and reported to Steering Group quarterly. Oversight will monitor and respond to the impact of any 3rd or subsequent waves of the COVID pandemic. Substantial workforce requirements form part of the national Policy. This will be scoped and agreed as part of the implementation plan to be developed by September 2021	LeDeR Clinical Lead
2	ICS will demonstrate each quarter that there is progress against delivery of LeDeR actions which will be monitored using a RAG rating. Quarterly reports to NHS England and NHS Improvement regional teams.	Quarterly	30 September 2021	Agreed reporting template to be in place by end of September 2021, aligned to milestones within LDA 3 Year Plan, themed Priority Actions agreed via Learning into Action Group and in consultation with Experts by Experience.	LeDeR LAC
3	Annual Report agreed at public meeting of CCG/ ICS and local Health and Wellbeing Board by end of Q1 each year. Annual Report, including accessible version published in June each year via ICS website. Documents approved within CCG/ ICS governance and shared with regional teams.	Annually	30 June 2021	Annual Report final draft will be approved by LeDeR Steering Group during May and shared with CCG Governing Body and Health and Wellbeing Boards by the end of June 2021.	LeDeR LAC

No	Deliverable and method of measurement	Frequency	Required date of delivery	System position and required action	Lead
4	A three year strategy demonstrating how the ICS will act strategically to tackle areas identified in aggregated and systematic analysis of LeDeR Reviews and national findings will be shared with NHS England / Improvement and updated annually in June each year. The Strategy will contain section on issues faced by people with learning disability from Black, Asian and minority Ethnic backgrounds who have a learning disability	annually	30 June 2021	Draft three year LDA plan required for submission by 30 April 2021. The plan was informed by LeDeR thematic analysis and consultation with experts by lived experience and family carers. Thematic analysis will be incorporated into a three year Strategy that will include plans to better understand the needs of young people (under 25 years) and people with a learning disability from diverse ethnic backgrounds and ensure equity in uptake of Annual Health Checks and vaccinations.	Lead Commissioner for LDA informed by contribution from LeDeR LAC LeDeR LAC
5	The ICS will demonstrate how they are narrowing the gap in health inequalities and premature mortality. Locally determined targets agreed with NHS England and Improvement regional teams to include measures around: -A reduction in repetition of recurrent themes -Reduced levels of concern and areas for improvement -Reduced frequency of deaths that are potentially avoidable and amenable to good quality healthcare.	Annually	30 June 2021	Key milestones of the three year LDA plan reflect: Reductions in aspiration pneumonia associated with modifiable factors – pneumococcal vaccine, eating and drinking plans, postural care plans Zero tolerance for avoidable deaths Increased uptake and quality of annual health checks Increased vaccination uptake Increased achievement of preferred wishes including place of death and use of ReSPECT	LeDeR LAC
6	Clear and effective governance in place which includes LeDeR governance within ICS quality surveillance arrangements (including minutes of quarterly meeting of ICD governance meeting)	Annually	Plan by 30 September 2021 operational by April 2022	Implementation plan for LeDeR governance and revised Terms of Reference for the LeDeR Steering group will be in place by September 2021 and will take account of evolving ICS governance structures	LeDeR LAC

No	Deliverable and method of measurement	Frequency	Required date of delivery	System position and required action	Lead
7	A named executive lead will act as LeDeR SRO across the ICS by June 2021	Annually	30 June 2021	Existing LeDer SRO is HWCCG Chief Nurse. This position is expected to remain unchanged for 2021/22 but will be reviewed by April 2022.	LeDeR SRO
8	A named lead for Black, Asian and Minority Ethnic inequalities will be part of the LeDeR Steering group. Increased reporting of deaths from people with Black, Asian and Minority Ethnic communities will be proportionate and relative to communities living within the ICS geography (baseline data to be reported by April 2022)	Annually	1 April 2021	The LeDeR Clinical lead is the named Black, Asian and Minority Ethnic Lead for LeDeR and this will continue until the Terms of Reference for the ICS are reviewed during 2021/22. During 2021/22 baseline population data will examine whether the ethnicity profile of deaths reported to LeDeR are proportionate to our local population.	LeDeR Clinical Lead
9	Clear Strategy for the meaningful involvement of people with lived experience in LeDeR governance. Evidence of meaningful engagement in local governance group by September 2021 (including engagement of autistic people proportionately to the number of notifications)	Annually	30 September 2021	Existing arrangements in place are detailed in Terms of Reference for the meaningful engagement of people with a learning disability, in a format determined by individuals themselves. This will be reviewed during 2021/22 to ensure appropriate representation. During 21/22 review Herefordshire expert by lived experience engagement, revise support for family carer involvement and liaise with the Autism Board to ensure proportionate representation for autistic people.	LeDeR LAC
10	Senior ICS leaders, including local authority partners are involved in governance meetings where issues found in local reviews are discussed and actions agreed collaboratively.	Annually	1 April 2022	Terms of Reference for Steering Group and Learning into Action Groups reflect partnerships and collaboration. Review Terms of Reference as ICS structures evolve during 2021/22	LeDeR LAC