

Title of report: Herefordshire and Worcestershire Learning from Lives and Deaths- People with Learning Disability (HW LeDeR) Annual Report 2020/21

Meeting: Health and wellbeing board

Meeting date: Monday 26 July 2021

Report by: Associate Director of Nursing and Quality, NHS Herefordshire and Worcestershire Clinical Commissioning Group

Classification

Open

Decision type

This is not an executive decision

Wards affected

All Wards

Purpose

The Health and Wellbeing Board Strategy and the Learning Disability Strategy for Herefordshire recognise that people with a learning disability are one of the groups within our local communities who are vulnerable to experiencing health inequality. The purpose of sharing this Annual Report for 2020/21 is to raise awareness of the LeDeR programme with a view to providing opportunity for the key objectives and priorities of the programme to be aligned with Health and Wellbeing Board priorities and workstreams.

Recommendation(s)

THAT:

- a) **the Health and Wellbeing Board note the Herefordshire and Worcestershire Learning from Lives and Deaths- People with Learning Disability Annual Report for 2020/21 and the programmes key findings for people with a learning disability in Herefordshire.**

Alternative options

1. There are no alternative options. In the national LeDeR Policy published in March 2021 NHS England require that NHS Clinical Commissioning Groups share the Annual Report for the system LeDeR Programme at each Health and Wellbeing Board in public aligned to their Integrated Care System footprint. Partners across the health and social care system are committed to working together and in collaboration with people with lived experience, to improve health outcomes and achieve healthier, longer and

happier lives for local people. Consideration of the social determinants of health is a fundamental element for consideration when addressing health inequality and premature death.

Key considerations

2. People with a Learning Disability continue to be some of the most marginalised individuals within our local communities and experience some of the greatest health inequalities. Data to the end of 2019 (latest available national data) confirms that men with a learning disability die on average 22 years younger than men in the general population and women die on average 27 years younger. The median age of death across England is 60 years.
3. LeDeR is a national service improvement programme commissioned by NHS England. The programme was developed following a recommendation of the Confidential Inquiry into the Premature Deaths of People with Learning Disability published in 2013. The programme roll-out was phased across England and commenced in the Midlands during late 2017. The purpose of the programme is to identify and implement learning that will prevent premature death and reduce health inequality for people with a Learning Disability.
4. The programme provides an infrastructure for reviewing the life and death of individuals notified to our system by the national LeDeR web-based platform. Learning, good practice and recommendations are collated from each individual LeDeR Review and analysed into themes to form system priorities for action.
5. The NHS Long Term Plan and the NHS 2021/22 Priorities and Operational Planning Guidance requires that systems demonstrate evidence of implementing actions arising from LeDeR Reviews and that individual reviews are completed within 6 months of notification to enable timely learning to be extracted.
6. A new national LeDeR Policy was published in March 2021. Implementation of the Policy is required during 2021/22 and includes revised governance and Integrated Care System (ICS) workforce arrangements and a broadening of the scope to include adults with a diagnosis of Autism.
7. A 3 minute youtube video by Dr Roger Banks on the revised LeDeR Programme can be viewed here <https://www.youtube.com/watch?v=v2b9ZU-4tRM>
8. The LeDeR Policy 2021 requires that each ICS develop a 3 year LeDeR Strategy. Learning from LeDeR and our priorities for change are a key thread that runs through the Learning Disability and Autism 3 Year Plan approved by the Learning Disability Partnership Board and ICS Learning Disability and Autism Programme Board in April 2021.
9. The HW LeDeR Annual Report for 2020/21 outlines how as a collaborative partnership we have learnt from the outcomes of reviews, since 2017 and specifically over the last 12 months to April 2021, and how we have started to influence the shaping of services to achieve improvements in outcomes.

Key points of learning from 2020/21 data about the lives and deaths of people with a Learning Disability within Herefordshire

10. The number of notifications made for Herefordshire dropped during 2020/21. There were no confirmed or suspected COVID related deaths of a person with a learning disability reported for Herefordshire during wave 1 or 2 of the COVID pandemic.
11. LeDeR performance measures improved during 2020/21 across the ICS. For Herefordshire significant improvements were made in the average time to complete reviews. Metrics for the whole programme (performance since 2017) were influenced by legacy workforce arrangements that were resolved in 2019. Authorship of reviews continues to rely upon a small, dedicated resource and the majority of reviews are now completed within 7 months.
12. 86% of people who died in Herefordshire were aged over 50 years- this compares to an England average of 72%. 46% of people who died were over 65 years compared to 38% for England. 6% of deaths reported were for those aged 24 years or younger, compared to 11% across England. Overall people with a learning disability are living longer lives in Herefordshire compared to the England average.
13. In Herefordshire the median age of death for men with a learning disability is 64 years, compared to a median age of 61 years for England. The median age for women is 61 years, the same as that for England.
14. The achieved place of death (people spending their last days in their usual place of residence or not in an acute hospital bed) has consistently been better in Herefordshire than for the England average. Many examples of personalised end of life care were of a very good standard.
15. Underlying health conditions recorded within completed LeDeR Reviews reflect that people who have died in Herefordshire had a higher recorded rate of epilepsy, cardiovascular disease and mental health condition than those recorded across England. Diabetes was recorded for 14% of individuals and obesity for 16%.
16. Deaths from cancer accounted for 11% of notifications (lower than the England average) and deaths from cardio-vascular disease accounted for 20% (similar to the England average). The most frequently listed cause of death was pneumonia (same as England average).

What we achieved during 2020/21

17. Learning and recommendations extracted from completed reviews are themed to help our LeDeR Learning into Action Group determine key priorities. A workstream (Priority Action Group) is developed for each key priority area. During 2020/21 we were able to increase the input of carers and experts by experience from Herefordshire into workstreams to inform and shape service improvement.

18. The COVID-19 pandemic resulted in some aspects of workstream activity being paused to enable a focus on emerging areas of significant need including COVID-19 guidance, vaccination access and Annual Health Checks.
19. Actions taken (detailed within the Annual Report on pages 34-36) supported the following outcomes:
- 84.9% uptake of Annual Health Checks across the ICS (within Herefordshire over 80% of GP Practices undertook Annual Health Checks for at least 75% of their Learning Disability population and over 35% of GP Practices exceeded 90%).
 - a coproduced resource pack to support Primary Care Networks to sustain high completion rates and high levels of quality of Annual Health Checks
<https://herefordshireandworcestershireccg.nhs.uk/our-work/learning-disabilites-and-autism/annual-health-checks>
 - an increase of 14-25 year olds on GP Learning Disability Registers
 - 88% uptake of COVID-19 vaccination for people with a Learning Disability by the end of March (including uptake across care settings ahead of the national offer) with further increases to exceed 90% into April and May.
 - COVID-19 testing in Learning Disability care settings ahead of the national offer to support the management and reduction of outbreaks.
 - increased assurance and confidence that national media reports of the discriminatory application of Do Not Resuscitate decisions for people with a learning disability were not widespread within our system.
20. Our priorities for supporting people to develop longer, healthier and happier lives have been co-produced and will form the basis of our LeDeR Strategy. These are outlined below and in table 6 on page 38 of the Annual Report:
- Emotional well-being and good mental health
 - Choice and shared decision making for periods of acute ill-health or toward end of life.
 - Recognising and responding to health need through Annual Health Checks
 - Maximising protection from respiratory conditions
 - Good bowel health
 - Preventing health needs associated with obesity.

All priorities are underpinned by the following enabling principles:

- people with lived experience remain at the heart of the LeDeR programme
- Meaningful inclusion and choice inform better health outcomes and decisions (including mental capacity assessment and best interest decisions)
- our system workforce needs to be equipped to recognise and respond to the personalised adjustments that enable access and equity
- collaborative working and information sharing achieve great things.

Community impact

21. The LeDeR programme, its achievements to date and its priorities for further improvement align with the intentions of the Health and Wellbeing Board Strategy for Herefordshire and with priority 3 of the Herefordshire Learning Disability Strategy. Learning and themes extracted from LeDeR reviews enables health and social care partners to evaluate the expectation that people with a learning disability will achieve access to good standards of healthcare and live healthy and longer lives. There is opportunity, through evolving models of Population Health Management within Integrated Care Partnership arrangements for Herefordshire, to address health equity for people with a Learning Disability or Autism and in doing so develop transferable ways of delivering health and social care that meet the needs of other marginalised groups.

22. The collaborative development of a LeDeR Strategy will be based on the LeDeR learning and themes identified to date, the identified needs of the population (including data available from Learning Disability Needs Assessment) and will be informed by the lived experience of people within Herefordshire and Worcestershire.

Environmental Impact

23. The implementation of the LeDeR programme supports the Councils commitment to the environment by making best use of technology to support experts by experience, family carers and other partners to contribute to LeDeR reviews and engage in LeDeR forums and workstreams without the need for travel. During the course of 2020/21 this has strengthened the capacity of experts with lived experience to engage more frequently. Technology advances this year have also increased capacity for reviewing care records remotely when undertaking LeDeR reviews, reducing the frequency for copying and posting paper care records to reviewers quite significantly.

Equality duty

24. Under section 149 of the Equality Act 2010, the 'general duty' on public authorities is set out as follows:

A public authority must, in the exercise of its functions, have due regard to the need to

- a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;
- b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

The public sector equality duty (specific duty) requires us to consider how we can positively contribute to the advancement of equality and good relations, and

demonstrate that we are paying 'due regard' in our decision making in the design of policies and in the delivery of services. All partners within the LeDeR Steering Group are committed to narrowing the gap in health inequality experienced by people with a learning disability and have confirmed, through a shared terms of reference, that this is one of the main principles at the heart of what we set out to do.

Resource implications

25. The LeDeR programme workforce is currently funded by the Clinical Commissioning Groups and Herefordshire and Worcestershire Health and Care NHS Trust. The ICS is required to review the workforce supporting this programme during 2021/22. There are no anticipated funding implications for the Council. Improvement workstreams that form part of the 3 Year Learning Disability and Autism plan will be overseen by the Learning Disability and Autism Programme Board, chaired by the Director of Adult Services for Herefordshire Council.

Legal implications

26. There are no legal implications. The Health and Wellbeing board are being asked to note the contents of the report accordingly.

Risk management

27. Any risks associated with the performance of the LeDeR programme or a failure to progress the implementation of learning identified from LeDeR reviews will be escalated to the Learning Disability and Autism Programme Board and onto the ICS Executive. Due to delays in the roll-out of the revised national LeDeR platform some metrics will be suspended for part of 2021/22. Potential risks relating to the implementation of the new national Policy are expected to be resolved ahead of the required implementation date of 1st April 2022.

Consultees

28. The LeDeR Programme has a solid foundation of consulting with experts with lived experience, family carers and advocacy organisations. The Annual Report sets out how we engage with partners within LeDeR and Partnership Board forums to consider learning and decide what action to take in response to learning identified. We are currently consulting with experts by experience on the co-production of an Easy Read version of the Annual Report.

Appendices

Appendix A: Herefordshire and Worcestershire LeDeR Annual Report 2020/21.

Background papers

None.