Herefordshire and Worcestershire
Clinical Commissioning Group

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

Annual Report 2019 / 2020

June 2020

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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 and to take forward that learning to inform service improvement initiatives.

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 commenced in 2015 and 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, issued by the National Quality Board in England, 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 by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England (NHSE) and during 2019/2020 continued to be hosted by the University of Bristol.

The national LeDeR programme has developed a consistent review process for the deaths of people with learning disabilities. All deaths 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 of the death is facilitated. On completion of the review (Initial or multi-agency), recommendations are made and an action planning process identifies service improvements that may be indicated. More information about the programme can be found on the website for LeDeR hosted by the University of Bristol http://www.bristol.ac.uk/sps/leder/about/ .

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 made across Herefordshire and Worcestershire during the period covering April 2019 to the end of March 2020. It builds on the achievements made up to March 2019 and covers local progress for both Herefordshire and Worcestershire as the programme for both counties moves to become integrated from 1st April 2020 under a single Local Area Contact.

2. Delivery of the LeDeR programme in Herefordshire and Worcestershire

2.1 The local framework for enabling delivery of the programme

Both Herefordshire and Worcestershire, working in partnership with corresponding local authorities, established a Steering Group format to oversee and drive a strong commitment to local delivery of the programme. A key benefit of the way that the programme is delivered locally is our collective capacity to draw themes from learning identified within completed reviews, and to then work together to agree the action that we will take and ensure that progress is made to improve peoples lives.

Within the reporting period the implementation of the programme has been reviewed in response to emerging best practice to support effective delivery. The number of available Reviewers has been consolidated into a smaller but dedicated resource of individual's whose body of work is focused almost solely on the LeDeR programme. In addition to this a small amount of funding was made available by NHS England to enable the continuation of temporary workforce support to the programme to cover the remainder of this reporting period. As part of the staff consultation ahead of the Clinical Commissioning Group (CCG) merger of NHS Herefordshire CCG, NHS South Worcestershire CCG, NHS Redditch and Bromsgrove CCG and NHS Wyre Forest CCG to form NHS Herefordshire and Worcestershire CCG (HWCCG) permanent posts to support the LeDeR programme were agreed.

During the reporting period processes have been refined to support the timeliness of review completion. Administration support is in place to ensure that electronic notes are requested to be available at the commencement of each review. Family and / or residential care provider contact is also initially coordinated by the CCG.

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. The appointment of a LeDeR Clinical Lead and the provision of a regular Reviewer Group has supported Reviewer wellbeing and enabled a consistently high standard of completed reviews.

During this reporting period the process for the scrutiny and approval of all completed reviews was further strengthened. Whilst this has lengthened the time taken between the initial submission and approval of a completed LeDeR review it means 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.

2.2 Notifications

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. During this reporting period the system has received an increase in notifications received from primary care colleagues. 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 1. To the end of March 2020 a total of 113 deaths have been reported to LeDeR for Herefordshire and Worcestershire.

Table 1: Notifications made to Herefordshire and Worcestershire LeDeR

Worcestershire					
Notifications	Q1 (April-June)	Q2 (July-Sept)	Q3 (Oct-Dec)	Q4 (Jan-March)	full year
17-18			5	12	17
18-19	10	3	7	12	32
19-20	7	2	6	8	23

Herefordshire					
Notifications	Q1 (April-June)	Q2 (July-Sept)	Q3 (Oct-Dec)	Q4 (Jan-March)	full year
17-18			2	5	7
18-19	3	3	6	6	18
19-20	6	4	2	4	16

Notifications received for 2017-2018 only included a partial year (1st October 2017 to 31st March 2018). For both counties, but more significantly within Worcestershire, the number of notifications fell overall during 2019-2020. Whereas the number of notifications received each quarter appears to have formed a pattern for Worcestershire (for example consistently lower numbers for Q2 reflecting the general trend for reduced deaths during summer months) this has not been the case in Herefordshire. More work is required to review data over a longer period of time to understand if this has any significance.

2.3. Performance of Herefordshire and Worcestershire LeDeR

Performance of the Herefordshire and Worcestershire LeDeR programmes is important because of its ability to support the completion of timely mortality reviews in order to affect meaningful change in areas where contributory or modifiable factors influencing avoidable or premature mortality are identified. Table 2 presents the number and percentage of completed reviews. From August 2019 NHS Midlands provided some support to CCGs to complete cases that had not been completed within 8 months of notification. Each CCG had cases allocated to a Commissioning Support Unit (CSU)to complete.

Table 2: Performance for the completion of Herefordshire and Worcestershire LeDeR cases by CCG and CSU

Worcestershire					
Performance period	Total number notifications	Completed by CCG	% CCG	Completed by CSU	% NECS
17-18	17	17 of 17	100%	N/A	N/A
18-19	32	25 of 27	93%	0 of 5	0%
19-20	23	7 of 19	37%	0 of 4	0%
Programme total to 31st March 2020	72	49 of 63	78%	0 of 9	0%
Programme total excluding those open to CDOP/Coroner	70	49 of 61	80%	0 of 9	0%

Herefordshire					
Performance period	Total number notifications	Completed by CCG	%CCG	Completed by CSU	% NECS
17-18	7	7 of 7	100%	N/A	N/A
18-19	18	11 of 12	92%	2 of 6	33%
19-20	15	8 of 15	53%	N/A	N/A
Programme total to 31st March 2020	40	26 of 34	76%	2 of 6	33%
Programme total excluding those open to CDOP/Coroner	40	26 of 34	76%	2 of 6	33%

On four occasions initial scoping undertaken at the beginning of a review has identified that the notification of death was made for a person who did not have a learning disability. Where this occurs, the death is out of scope for the LeDeR programme and the case is removed from the database and from baseline figures. It is too early to determine if these reduced number of notifications are due to improvements in care enabled by the programme.

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 at least 90% of all reviews notified after July 2019 be completed within 6 months where able (excludes those cases open to the Coroner or subject to Child Death Overview panels). For cases notified between 1st July 2019 and 31st December 2019 this has been achieved for 75% of cases, in part due to the impact of the start of the coivd-19 pandemic toward the end of this reporting period.

To support local LeDeR programme delivery assurance four statements were included in the NHS 2019/20 Operatiional Planning and Contracting Guidance issued in January 2019. Table 3 details Herefordshire and Worcestershire’s position statement.

Table 3: Herefordshire and Worcestershire position on the achievement of the NHS 2019/20 Operating Planning and Contracting Guidance statements for delivery of the LeDeR programme.

Statements in the NHS 2019/20 Operating Planning and Contracting Guidance	Herefordshire and Worcestershire's position
CCG's are a member of a Learning from Deaths report (LeDeR) Steering Group and have a named person with lead responsibility	A Steering Group for Worcestershire and for Herefordshire has been in place during 2019/2020 and each include key CCG representatives. Each Group has been chaired by the Local Area Contact who is a CCG employee.
CCG has systems in place to analyse and address the themes and recommendations from completed LeDeR reviews	Each LeDeR Steering Group has a system for analysing the themes of recommendations arising from completed reviews, for agreeing system action and for tracking the progress of actions agreed. Action taken and progress made in response to themed analysis is included in the annual report.
An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews	LeDeR updates are reported to the Safeguarding Adults Board for each Local Authority by exception or as requested. A presentation of this Annual Report will be made to the Learning Disability Partnership Board of each county and to the Governing Body of the CCG. Terms of Reference for the Steering Group will continue to detail reporting arrangements in place.

2.4. Challenges to the timely completion of reviews.

The timely completion of LeDeR reviews has been highlighted as a national issue in each of the LeDeR (England) Annual Reports published for 2017 and 2018. NHS Herefordshire and Worcestershire CCGs and Worcestershire Health and Care NHS Trust are committed to work in partnership to continue to ensure that the LeDeR programme achieves meaningful change and enables improvements in outcomes for local people. Reviewers have historically found the tension between completing a review and responding to operational pressures challenging. The local LeDeR programme therefore moved to securing postholders who are dedicated to focusing solely on the LeDeR programme and the completion of reviews. NHS England supported the predecessor organisations of NHS Herefordshire CCG, NHS Redditch and Bromsgrove CCG, NHS South Worcestershire CCG and NHS Wyre Forest CCG to complete a small backlog of reviews that had not progressed toward completion within 12 months of the notification being received. Due to a number of challenges the Commissioning support Unit commissioned to undertake these reviews were not able to make progress and at the time of this report of 15 cases allocated from across H&W only 2 have been completed.

The time taken to complete reviews varies and a number of cases continue to be on hold due to statutory processes (for example pending Coroner's Inquest or Child Death Overview Panel processes).

Challenges may also be faced when attempting to completed review in a timely manner due to difficulties in accessing care notes or in securing family involvement to contribute toward a review. During 2019 the CCG continued to strengthen processes to reduce these barriers. This included securing dedicated administration resources in order to ensure the coordination of retrieval of care notes from GP Practices, care home settings and Subjective Judgment Reviews completed for episodes of acute care where this was the place of death. The coordination of contact with family members was also improved in alignment with good practice identified from other parts of the region. The provision of written information about the LeDeR programme, ahead of the Reviewer making contact, has always been a key feature of local processes. The timing of both written and telephone contact has been adjusted to ensure that an appropriate level of sensitivity and expectation can be provided, with the aim of minimising distress and supporting maximum engagement.
Toward the end of 2019/2020, at the end of January 2020, a Level 4 Major Incident was declared by NHS England in response to the threat of a COVID-19 pandemic. As the health and social care system responded to the developing public health crisis, the necessary restrictions put into place to minimise the risk of the transmission of the virus impacted further on both the completion of reviews and the notification of deaths for the H&W LeDeR programme. The outcomes of this will be reported in June 2021.

3. Learning from LeDeR Reviews

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

Table 4 provides an indication of the characteristics of deaths notified to the LeDeR programme in the total period from 1st October 2017 to 31st March 2020 and in this reporting period. Characteristics are compared for Herefordshire (Hfd) and Worcestershire (Worc). It may be too early in the programme to determine if any of the actions implemented have started to have impact

Table 4: Characteristics reflected in the notification of deaths to LeDeR

Characteristics	England 2016-18	Hfd (2017-20)	Worc (2017-20)	Hfd (2019-20)	Worc (2019-20)
Notifications made		40	72	16	23
Median age (age range)	59 years (4-98)	61 years (18-88)	60 years (7-90)	62 years (40-88)	61 years (16-83)
Deaths that occurred outside of a hospital setting	48%	62.5%	35%	67%	40%

The median age of death within H&W is marginally higher than the national average and has marginally improved during the period of the programme. To 31st March 2020 no child deaths had been reported to LeDeR for Herefordshire and a very small number of child deaths have been reported to LeDeR for Worcestershire. The outcome of the Child Death Overview Panel for one case was that evidence of good multi-disciplinary communication and care coordination was evident.

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. There is a significant difference in this characteristic between both counties and so additional analysis and learning is required to determine whether access to acute care or the model of end of life care for both counties can inform improvement.

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

	England 2016-18	**Hfd 2017-20**	**Worc 2017-20**	**Hfd 2019-20**	**Worc 2019-20**
Cause of death related to respiratory system	41%	57%	30%	60%	26%
Cause of death cancer	14%	10%	18%	13%	12%
Cause of death related to bowel obstruction	>1%	0%	8%	0%	4%
Grading of care for completed reviews - good or excellent (grade 1/2)	48%	71%	31%	87%	28%
Grading of care for completed reviews – care significantly fell short of expected practice (grade 5/6)	8%	15%	8%	0%	0%

The relatively higher rate of respiratory related deaths for Herefordshire requires further analysis and may be related to how the cause of death has been recorded on the LeDeR platform. Bowel related deaths in Worcestershire have significantly reduced since the first year of the programme. No bowel related deaths have been reported for Herefordshire. A review of interventions across both counties may identify additional learning to further embed good practice.

The ratio of care graded as poor is influenced by small numbers. Both counties have had four cases where a multi-disciplinary panel agreed that care received was poor. It appears that care has been graded as good or excellent for some Herefordshire case reviews that have resulted in recommendations including the absence of recording of an Annual Health Check or the absence of reasonable adjustments to enable access to national cancer screening programmes. From 1st April 2020 a consistent quality assurance process will eb applied for cases across both counties.

3.3 Learning from the outcomes of completed reviews- evolving themes

LeDeR Reviewers are encouraged to make recommendations from 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 from the recommendations of completed reviews. The recommendations that have been reported with the greatest degree of frequency are included in the table below.

Recommendation theme	Actions and progress during 2019/2020
1.The quality of Annual Health Check completion is variable. It would be of benefit if the Annual Health Check was used as an opportunity to promote and record the use of other aspects of access to health service provision, including access to screening programmes and dental examinations, in order that additional support could be organised if access has been absent or problematic.	A Priority Action Group has been established to oversee an improvement programme of work to enhance the quality and frequency of completion of Annual Health Checks for those eligible. The Group is led by a Lead Commissioner and includes a Public Health Registrar with Primary Care experience, Primary Care Learning Disability Liaison Practice Nurse, family carer representation and strong links to a consultative group of experts by experience. Key aspects of learning identified from completed reviews has informed an improvement plan led by this group. Community Learning Disability Team members review available Annual Health Check and Health Action Plan documents as part of their initial assessment.
2.The system roll out of the ReSPECT programme, including documentation and agreed processes, should include reference to and be informed by the needs of people with a learning disability and learning arising from LeDeR Reviews. This should include consideration for mental capacity assessment and best interest decisions in the last weeks and days of life.	The ReSPECT Programme Board and Palliative Care Network include a Community Learning Disability practitioner and Advocacy organisation representation to ensure that the needs of people with a learning disability are reflected. The CCG LeDeR Clinical Lead attends the STP End of Life work stream group to share learning from LeDeR reviews. A collation of learning was due to be presented in May 2020 but was deferred due to the covid-19 pandemic. Integrated and multi-disciplinary partnership working has been key in enabling personalised care. 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.

Recommendation theme	Actions and progress during 2019/2020
3.Training for medical staff, on the communication needs of people with a learning disability, should be prioritised and promoted in acute hospital settings	Acute Liaison Nurses are now in place within acute settings across both counties. A local programme of Learning Disability awareness education/ Transforming Patient Experience events, led by the Acute Liaison Nurses, has been established. A system is in place to support improvements in communication in each ward and outpatient area to further support the development of good practice and reasonable adjustments. This has been enabled through the development of 'champion' roles or specific communication resources. Both Worcestershire Acute Hospitals NHS Trust and Wye Valley NHS Trust are committed to making improvements and acting on the findings of reviews. Executive Leads have been established within each organisation to drive and oversee improvement. Quality Priorities for each organisation support the promotion of equality and high standards of care for those who are at risk of experiencing discrimination. Worcestershire Acute Hospitals NHS Trust hosted a Learning Disability Awareness event during 2019/2020 that welcomed Paula McGowan to share the acute care experience of her son, Oliver, prior to his death.
4.Social care providers should ensure that guidance and education is available to staff to support them to identify when urgent medical advice is required, including the recognition of potential sepsis.	The Worcestershire Steering Group commissioned Inclusion North to work with local family members, experts by experience and clinicians to co-produce and deliver a series of workshops to raise awareness of the LeDeR programme and share some of the early findings. The workshop included access to information and resources to aid staff in supporting essential aspects of a healthy lifestyle and how to recognise the signs of deterioration that may require urgent medical advice, including sepsis. The workshops evaluated very highly. In Herefordshire the Lead Sepsis Nurse delivered training and education to staff in community teams and care settings, to promote early recognition of deterioration.

Recommendation theme	Actions and progress during 2019/2020
5.All health and social care staff must act in accordance with the Mental Capacity Act in situations where an individual's capacity to make decisions regarding their own care are to be established and this should include decisions to refuse care. Examples have included reluctance to engage in cancer screening programmes, attendance for an Annual Health Check and tolerance of post-surgical aftercare.	Health and Social care senior partners have worked together to strengthen the training offer for front line staff. Training and education sessions have been enhanced to provide examples of complex scenario's to support staff to make decisions and implement the necessary action to intervene. The importance of ensuring that decisions to engage with or refuse health care interventions are fully informed, or made in a person's best interests, will form part of guidance that will be developed by local LeDeR Priority Action work groups developed to focus on improving outcomes for the most common underlying causes of premature death identified by LeDeR programme. This includes Bowel Health and Respiratory conditions. Community Learning Disability Nurses developed tools, display materials and ran workshops to improve awareness of cancer screening.
6.People with a learning disability and their families / carers need to be aware of the risks of bowel obstruction and what can be done to support people to maintain a healthy bowel. This includes responding to the signs of constipation and how to support the essential aspects of a healthy lifestyle.	Community Learning Disability Nurses have worked with colleagues in the Continence Team to develop a package of education to improve awareness of the recognition and response required for those who experience constipation. This includes greater recognition that those who are prescribed regular laxatives require support to monitor the effectiveness of this medication. In Worcestershire a 'bowel management' template has been created to support social care staff to deliver appropriate care. A system has been put into place so that the Community Learning Disability Team are alerted to those attending urgent care due to bowel impaction. This enables follow up care and advise to be provided to support improvements in condition management.

3.4 Sharing examples of good practice

Throughout the programme of work to complete LeDeR reviews and extract recommendations to improve areas of practice, the Steering Group and Reviewers have maintained an important focus on recognising good or excellent practice. A number of examples have been shared and some of these examples are included in table below- all names are fictitious. A framework for sharing good practice, as a commitment to 'growing excellence,' will be rolled out during 2020 to ensure the most effective format and channels of communication are in place for each intended stakeholder group.

Mary and Eileen had known long term conditions and had steadily become increasingly frail. Both individuals lived within a Care Home (with Registered Nursing care) where the skill mix of Learning Disability Nurses was high. District Nurses were able to provide support for the Learning Disability Nurses to acquire skills in delivering anticipatory medication and care to maintain comfort in their last weeks and days of life. Care notes evidenced proactive planning and liaison between members of the multi-disciplinary team, coordinated by the care home staff. Both individuals were supported to remain at home throughout their deterioration and received exceptional care. Relatives and visiting professionals were highly complementary of the care delivered

Tim acquired drug induced Parkinson's disease after many years of taking psychotropic medication. He was enabled to move into supported living accommodation when his mobility deteriorated. As the symptoms of Parkinson's disease experienced by Tim became more problematic it became increasingly challenging to minimise his symptoms whilst treating Tim's long term mental health needs. Evidence within care records detail the frequent liaison between care staff, the Neurologist, Tim's GP and the Learning Disability Psychiatrist, all coordinated by the Specialist Parkinson's Nurse. Great care was taken to monitor the intended impact and expected side effects of prescribed medication. Tim sadly died unexpectedly during his sleep. Every effort was made by the multi-disciplinary team to manage his needs and work tirelessly to titrate his medication to attempt to relieve the physical and mental health symptoms that caused him distress. His care team supported him to continue to do as many of the daily activities that brought him joy as often as he was able.

Rebecca had lived in the same residential care setting for a number of years before she was diagnosed with cancer. She had developed close relationships with many of her carers. Rebecca's care needs increased as her illness progressed and she was admitted to hospital to help stabilise her pain. To enable Rebecca to return home, her preferred place of death, the provider agreed to support care staff to acquire new skills outside of their usual practice. Residential care workers learnt how to administer injections and worked with District Nurses to keep Rebecca comfortable. Some staff supported Rebecca for hours beyond their paid rota, on a voluntary basis. Rebecca died peacefully, within the privacy of her home, comforted by carers who knew her well.

3.5 Developing a LeDeR Priority Work Plan to affect meaningful change

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 each LeDeR Steering Group. Steering Group members agreed that to have effective and sustained influence it was crucial to focus on a relatively small number of key priorities. An emerging priority work plan was approved by the Worcestershire LeDeR Steering Group in September 2018. This plan informed the priorities of a H&W Learning Disability and Autism Programme Board during 2019/2020. The plan is informed by the key themes emerging from completed LeDeR reviews and by the lived experience of family carers and experts by experience. Action plans for each focused area of improvement are being driven by a Priority Action work group and are reported to the Steering Group on a rotational basis. The Priority Work Plan and progress made during 2019/ 2020 is included as appendix one. The plan, and each Priority Action work group, will be reviewed early in 2020/2021 to ensure reflection of learning opportunities and key representative membership from across all of H&W.

4. Conclusion and next steps

The NHS Long Term Plan, published during 2019, and the NHS Oversight Framework for 2019/2020, provided a welcome focus on reducing the health inequalities experienced by people with a learning disability. The remit of Clinical Commissioning Groups, as key partners and system leaders, will be to continue to support partnership working to deliver the LeDeR programme. The NHS Operational Planning and Contracting Guidance 2020/21, issued in January 2020, demonstrates that there will be a continued focus on enabling reductions in health inequalities for people with a learning disability and autism and a focus on the timely completion of LeDeR reviews to ensure that learning is extracted and informs meaningful change.

Outcomes will only be realised where partners successfully work together to review and learn from premature deaths and make sustainable changes to local practice. 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 will be integrated under one single Local Area Contact to form a cohesive partnership. A proposal to form a single H&W LeDeR Steering Group, with a Learning into Action Sub Group for each county, will be discussed with key members during the summer of 2020 with the intention of implementing a revised meeting format by the end of September 2020.

The H&W LeDeR Steering Group will continue to oversee the characteristics of notifications and the recommendations of completed LeDeR reviews in order to inform an evaluation of the Priority Work Plan during 2020. Systems for the wider dissemination of learning and the promotion of good practice will be strengthened.

The drawing together of data from Worcestershire and Herefordshire for the purposes of this integrated report has enabled the identification of areas for further review and consideration. During 2020/2021 there will be a key focus to ensure:

- The grading of care of completed reviews is consistent across H&W
- Models of end of life care within each county are reviewed to ensure that people with a learning disability and autism can die with dignity in their preferred place of death wherever possible
- Awareness of the system for notifying deaths to the LeDeR programme is well embedded across H&W to ensure that the system is capturing and learning from all relevant deaths.

In February 2020 NHS England and NHS Improvement published the content of Primary Care contract guidance for the Quality Improvement domain 2020/21 – Supporting people with learning disabilities. The guidance outlines a number of areas that align to HWCCG LeDeR Priority Action work plan. The LeDeR Steering Group membership therefore look forward to proactively working with GP Practices across Herefordshire and Worcestershire to further enhance service delivery for people with a learning disability and together improve health outcomes for local people.

Toward the end of 2019/2020 the covid-19 pandemic was declared. Initial data appeared to suggest that the first wave of infections resulted in a significant increase in notifications for Worcestershire, but not for Herefordshire. A Rapid Review format was introduced so that early learning could be extracted and shared in an attempt to minimise avoidable transmission of the virus, particularly within communal care settings. HWCCG will be contributing toward a national LeDeR report during 2020 that identifies themed learning from completed covid related reviews. A detailed update will be a key feature of the Annual Report for 2020/2021.

HWCCG and the H&W 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 a successful year of driving change to enable improved outcomes so that local people can live longer, happier and healthier lives.

Appendix one: Priority Action work plan

Key	Action	Progress during 2019/2020
1.Annual Report recommendation- Inter-agency collaboration	.1 Learning Disability service specifications will include a key expectation to promote inter agency communication.	National guidance on care coordination was expected during 2019. The Long Term NHS Plan has now made a clear expectation that care coordination roles will be in place by 2023/24 and that funding linked to the Long Term Plan will support this. The Learning Disabilities and Autism Improvement workstream for Herefordshire and Worcestershire include the planning and implementation of these roles as a key deliverable . This action will therefore be closed for action by the LeDeR Steering Group but will remain a fundamental part of the Improvement workstream.
	1.2 Commissioners will consider how NICE Quality Standard 142 and the requirement for a named health care coordinator for those with two or more long term conditions, as a conduit for promoting coordination of communication, can be implemented locally. Consideration will be given to understanding how many people with a learning disability have two or more long term conditions, the emerging role of Neighbourhood Teams, the number of people whose care is coordinated by Continuing Health Care and the national review of best practice in care coordination (due to report March 2019)	
	1.3 Ensure that the Steering Group are kept updated on progress with a review being undertaken, by NHSE and NHS Digital, to promote and extend the use of the Summary Care Record and Care Record Exemplars, to support information sharing.	Update was published in an 'Action from Learning' report by NHS England and the NHS Long Term Plan and shared with the Steering Group. The H&W Digital workstream will now oversee progress for this action.
	1.4 Ensure that Sustainability and Transformation Partnership sub groups, working to find solutions to promoting better communication across Health and Social Care agencies, take the needs of people with a learning disability into account.	The H&W Learning Disability and Autism Improvement workstream plan has been agreed and includes oversight of the implementation of NHSI Learning Disability standards, including 'alert flags' to enhance communication and care continuity.

Key	Action	Progress during 2019/2020
2. Annual Report recommendation – reasonable adjustments	2.1 Worcestershire Acute Hospitals NHS Trust will provide assurance to the Steering Group of progress in meeting NHSI Improvement Standards for the provision of reasonable adjustments. This will include ensuring processes are in place that support and enable the provision of reasonable adjustments, including how reasonable adjustments are identified (ie Hospital Passport), recorded and assurance of regular audit of this provision.	The implementation of NHSI Improvement Standards for Learning Disability services now forms part of the H&W Learning Disability and Autism Improvement workstream and the milestones of the programme plan. Executive engagement at Trusts across H&W was confirmed during early 2020, with a commitment to ensure that progress made during 2019/20 is reflected within respective Quality Accounts published on NHS Choices and continued progress is made during 2020/ 2021. The format of Hospital Passports was reviewed and relaunched during 2019/2020, informed by learning identified through LeDeR reviews.
	2.1.1 Assurance of meeting the NHSI standards for reasonable adjustment will be evidenced in the Quality Account for 2019/2020, published by the end of June 2020.	
	2.2.1Assurance of meeting the NHSI standards for reasonable adjustment will be evidenced in the Quality Account for 2019/2020, published by the end of June 2020.	
	2.3 Ensure that the LeDeR Steering Group are kept appraised of national progress in developing guidance for how 'flagging' systems may be used, on the Summary Care Record and other applications, for the need to make reasonable adjustments.	Progress update reported in the national Action from Learning report May 2019. Guidance on 'flags' within primary care is expected but not yet published.
3. Annual Report recommendation- mental capacity	3.1 CCG Designated Nurse will confirm assurance, through provider Integrated Safeguarding Committees, that compliance with MCA training and principles, is audited and reported.	Confirmation received. Learning form LeDeR Reviews will continue to inform training and education plans to improve compliance with the Mental Capacity Act.

Key	Action	Progress during 2019/2020
4.Performance improvement for the completion of LeDeR Reviews in a timely manner	4.1 Updates on performance will be shared with the Steering Group to provide assurance and accountability.	NHSE reporting was revised following publication of the NHS Long Term Plan and Planning and Contracting Guidance. Assurance against four standards for LeDeR will now form part of reporting for the Learning Disability Improvement workstream. Performance reporting to the LeDeR Steering Group is a standing agenda item. CLOSE
	4.2 LAC to support WHCT to receive clarification of training expectation from NHS England.	WHCT have received training on the completion of SJRs from another Trust. CLOSE
	4.3 The CCG will undertake an analysis of activity and benchmark analysis with the data available from the national programme. This will be detailed within an annual report presented to the Steering Group and the groups detailed within the governance and reporting section of the terms of reference for the Steering Group.	Data included in annual report. The 2018 report was shared with the Steering Group, Mortality Oversight Group and Worcestershire Safeguarding Adults Board. Further updates on performance are scheduled as a standing agenda item to Steering Group and will feature in each annual report. CLOSE.
5.Priority theme - Annual Health Checks and Health Action Plans	5.1Learning Disability Strategy (Worcestershire) refresh will include key improvement indicators for the completion of Annual Health Checks and the development and use of Health Action Plans.	A trajectory to improve the completion rates and quality of Annual Health Checks is a key feature of the H&W Learning Disability and Autism Improvement workstream
	5.2 A working group will be established to review current practice, agree a development plan and a schedule to monitor and report progress.	This Priority Action work group has been established and an improvement plan is in place.
	5.3 Bi-annual progress with the agreed indicators will be reported to the Learning Disability Partnership Board and LeDeR Steering Group	Progress will now additionally be reported to the H&W Learning Disability and Autism Improvement Board. Progress will be reported to align with NHS Mids data publication.

Key	Action	Progress during 2019/2020
6. Priority theme - Aspiration pneumonia	6.1 Steering Group to be appraised of the extent to which aspiration pneumonia is a key area of risk for Worcestershire residents. Initial benchmark data to be presented in July 2018 and reviewed 6 monthly.	Initial benchmark data reported. Leading causes of death, including aspiration pneumonia, now form part of a standing agenda item to each Steering Group. CLOSE
	6.2 Establish a sub-group of the LeDeR Steering Group to agree and take forward local actions with regard to reducing the incidence of aspiration pneumonia.	Priority Action Group established and improvement plan in place. Key partnership working with Public Health to promote flu and pneumococcal vaccine.
	6.3 Action plan for 'aspiration pneumonia' (to include consideration of actions agreed at LeDeR Steering group in July 2018) to be presented to LeDeR Steering Group and updates on progress agreed.	An overarching plan of action has been presented to the Steering Group. Key elements include flu vaccination uptake, oral hygiene promotion and further roll out of safe eating and drinking education.
7. Priority theme- one to one support in an acute hospital setting	7.1 Priority Action Sub-group to be established to develop guidance, agreed across all stakeholders, for when individuals with a learning disability are admitted to an acute hospital bed and may require additional one to one support as part of a suite of measures to provide reasonable adjustments.	Work group has been established and draft guidance is evolving. Relevant key partners are being consulted. Group to be extended to include members who can facilitate a framework for how additional one to one support may be funded.
	7.2 Guidance produced needs to take account of provider perspective, continuing healthcare funding, existing liaison service and acute trust existing policy and process for agreeing one to one support in specific circumstances.	
8.Priority theme – promoting good practice in end of life care for people with a learning disability.	8.1Working group to be established for improving end of life care for people with a learning disability.	It has been agreed that themes from LeDeR reviews regarding EoL care will be fed into RESPECT Programme Board and existing groups for improving end of life care. The communication interface will be led by the CCG LeDeR Clinical Lead and the CCG GP Lead for EoL care who are both key partners of the LeDeR Steering Group. Community Learning Disability Teams have been fundamental to the roll out of ReSPECT for people with a learning disability and their families and will continue to support this programme.
	8.2Working group to agree a plan for improvement that is based on standards that would be expected for the general population and is informed by the outcomes of local LeDeR Reviews. The plan will include assurance that the roll out of RESPECT will be appropriate and mindful of the needs of people with a learning disability.	

Key	Action	Progress during 2019/2020
9. Priority Theme- promoting bowel health	9.1 Working group to be established for improving bowel health and reducing bowel related deaths	Initial stakeholder engagement has commenced. A template for managing bowel health has been agreed, informed by learning from LeDeR reviews related to bowel obstruction. Additional education has been put into place including targeted sessions for supported living providers and a series of workshops, commissioned by the CCG, delivered in partnership between Inclusion North, family carers and experts by experience. No bowel impaction related deaths were reported during 2019/2020.
	9.2 Working group to agree and present a plan for improvement to the LeDeR Steering Group	