Norfolk and Waveney Clinical Commissioning Group

Learning Disabilities Mortality Review (LeDeR) Programme

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Norfolk and Waveney Learning Disability Mortality Review (LeDeR) Programme

Annual Report for April 2020 to March 2021

1. Introductions from the Learning Disability Mortality Review Steering Group Chair and Co-Chair

Sarah Jane Ward

Chair, Learning Disability Mortality Steering Group
Associate Director of Quality in Care NHS Norfolk and Waveney Clinical Commissioning Group.

1.1 Welcome to the fourth annual report of the Norfolk and Waveney Learning Disability Mortality Review (LeDeR) Steering Group. This report outlines the work during the period 1 April 2020 to 31 March 2021 You will find information on the LeDeR activity, functions, processes and analysis.

1.2 It has been evidenced that people with a Learning Disability die younger than the population as a whole. Overall, people with learning disabilities currently have a life expectancy at least 20 years shorter than other people.

1.3 This year has seen continued commitment to ensure effective communication and good working relationships. The Norfolk and Waveney LeDeR Steering Group have been working hard to decrease the number of reviews outstanding over the past year, employing additional reviewers to support our work.

1.4 We have seen an unusual year for all of us resulting in many changes to our lives during the COVID-19 pandemic. This has impacted on our delivery of the LeDeR programme with changes to how we worked to support the people of Norfolk and Waveney.

1.5 **Final thoughts.**

We have all experienced the challenges of living through the COVID-19 pandemic and wish to thank everyone for the care and support they have shown each other and wish to extend our thoughts and wishes to those who died and to their families.

Andrew Borrett

Co-Chair Learning Disability Mortality Steering Group
Expert by Lived Experience

1.6 Hello, my name is Andrew Borrett I am an Expert by Lived Experience as I have a learning disability and autism.

1.7 I am the Co-Chair with Sarah Jane Ward in Norfolk and Waveney.

1.8 The pandemic means it has been a very difficult year for people with learning disabilities. I have found it hard having limited support, not going to work or seeing my family and friends. I learnt how to use video conferencing to keep in touch with people which helped my mental health.

1.9 I would like to thank all NHS staff and volunteers who have supported people with learning disabilities to get our Covid 19 Vaccines. Especially the James Paget Hospital for their early dedicated vaccine clinic spearheaded by Rebecca Crossley. I would like to say a big thanks to Hayley and Kenny who agreed to be on posters promoting vaccinations for people with learning disabilities.

1.10 It is sad to learn that 20 people with learning disabilities in Norfolk lost their lives to this awful virus.

1.11 It is important to thank Trish Hagan (Senior Nurse for Learning Disability Improvement) for her hard work and guidance over the time she has spent working on LeDeR before and during the pandemic, I was sad to see her move on.

1.12 I was pleased to be asked to interview candidates for the position of the Senior Nurse for Learning Disability Improvement. I would like to welcome Rachel Garwood into that role and looking forward to us working together.

1.13 As part of my role I was asked to interview for the new team set up to help people with learning disabilities to get a health check. I am happy to say that I received a very good support from the new team when I had my first LD health check this month, I know they will continue to support people to get good quality health checks from GP surgeries not just a quick check over.

1.14 I am glad that we have 3 full time reviewers and I would like to thank them and other social care and health staff who do this on top of their normal work.

1.15 Over the next 12 months I would like to see more opportunities for people with learning disabilities to talk about their health concerns and for health providers to work together in ICS to hear and respond to our needs.

1.16 Drawn from my own experiences I feel very committed to delivering good quality accessible training to my colleagues with learning disabilities on what makes a good learning disability health check, what to expect before you go and during your health check.

1.17 I wish everyone a better Happy healthy and safe year ahead.

Final thoughts:

I would like to personally thank all the investigators as I know they are doing this on top of their day-to-day work which is truly amazing.

2. Summary

2.1 Whilst writing this report the University of Bristol published its final report as its current involvement with the English Learning Disabilities Mortality Review (LeDeR) programme on 31st May 2021 ended, five years since the inception of the programme.

2.2 The Norfolk and Waveney LeDeR reviews show there are no reported deaths for people from an ethnic minority for 2020-2021, we are not clear if this is an issue with how we record people's information and work is underway to seek to ensure our reporting is accurate. This is of significance because it is noted that people from an ethnic minority group are disproportionately affected by health inequality.

2.3 Norfolk and Waveney met the requirement set by NHS England/Improvement of completing 94% of the backlog of review by December 2020.

2.4 From the LeDeR reviews completed in Norfolk and Waveney during 2020/21, 90% of people with a learning disability died younger than the general population with the median age of death being 61 years old compared to the national median age of 62 years.

2.5 The majority of people reviewed died in hospital, with the most frequently themes of cause of death being as a result of respiratory conditions. Just over half of the people whose lives and deaths were reviewed received satisfactory or above care with 24 adults identified where their care fell short of current good practice.

2.6 Covid-19 and the effects it had on people with learning disabilities have been reviewed by Public Health England and as part of the LeDeR national work and is mentioned in more detail within the report. Within Norfolk and Waveney, we supported people to access their vaccinations, travel more freely during the restrictions, provided advice and support and held some live video events which enabled us to receive feedback to inform our service provision.

Our priorities for 2021/22

- 100% reviews to be completed within 6 months of notification.
- Development and implementation of the new LeDeR policy which now includes the review of people with autism
- Continue to take forward the learning into action and monitor outcomes
- Implement learning from the Annual Health Check exemplar to support people from ethnic minorities
- People with learning disabilities in their health care increase their life chances and life expectancy by service improvements and learning from our citizens.

3. Background

3.1 The University of Bristol published its final report this year as its current involvement with the English Learning Disabilities Mortality Review (LeDeR) programme on 31st May 2021 ended, five years since the inception of the programme. The programme is now run by NHS England and is named Learning from Lives and Deaths – People with a learning disability and autistic people (LeDeR) Programme. The aim of the programme is to reduce the health inequalities faced by people who have a learning disability and drive quality and improve health outcomes for this group. The programme has been implemented in Norfolk and Waveney since 2017 and this is the fourth annual report.

3.2 The LeDeR programme has reported on deaths of people with learning disabilities aged 4 years and over.

3.3 The definition of 'learning disabilities' as used by LeDeR is the presence of: 'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.'

3.4 The recently published LeDeR Policy 2021 has stated that those with a confirmed diagnosis of Autism (recorded within clinical records) will also be incorporated into this programme of work.

3.5 Deaths of all children, including those with learning disabilities are reviewed by the statutory Child Death Review programme; completed reviews and thematic learning are shared with the LeDeR programme. The LeDeR Local Area Contact and Child Death Review Team work together to ensure there is shared learning and actions.

3.6 A key part of the Learning from Lives and Deaths – People with a learning disability and autistic people (LeDeR) Programme is to support local areas to review the deaths of people with learning disabilities. The purpose of the LeDeR reviews is not to hold any individual or organisation to account. Other processes exist for that, including criminal proceedings, disciplinary procedures, employment law and systems of service and professional regulation. It is vital, if individuals and organisations are to be able to learn lessons from the past, that reviews are trusted and safe experiences that encourage honesty, transparency and sharing of information to obtain maximum benefit from them.

3.7 In order to do this in a timely manner and to avoid duplication, the LeDeR process links with other review or investigation processes. Other investigations or reviews may include, for example: Serious Case Reviews, Safeguarding Adult Reviews, Safeguarding Adults Enquiries (Section 42 Care Act) Domestic Homicide Reviews, Serious Incident Reviews, Coroners' investigations and Child Death Reviews. During the course of a review concerns about the death of the person with a learning disability may emerge, for which an agency or individual should be called to account. Reviews may be escalated to different agencies utilising usual process and protocols. In 2020 Norfolk and Waveney LeDeR Steering Group finalised a process with Norfolk Safeguarding Adult board to

formalise how LeDeR Reviews will be reported when a safeguarding concern is highlighted.

3.8 The programme receives notification of deaths of people with learning disabilities, and supports local areas to conduct standardised, independent reviews following the deaths of people with learning disabilities aged over four years of age. These are conducted by trained reviewers. The purpose of the local reviews of death is to identify any potentially avoidable factors that may have contributed to the person's death or any gaps in provision leading up to their death and to develop plans of action that individually or in combination, will guide necessary changes in health and social care services, in order to reduce premature deaths of people with learning disabilities.

3.9 When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so does not have complete coverage of all deaths of people with learning disabilities in Norfolk and Waveney and therefore some data may be missing, and that numbers in some sub-categories are small so must be interpreted with caution.

4.0 Annual LeDeR Report

4.1 The Fourth National LeDeR **Annual Report** 2020-21 was published in June 2021-21. **Easy Read Annual Report 2020-21.** The University of Bristol published its final report this year as its current involvement with the English Learning Disabilities Mortality Review (LeDeR) programme on 31st May 2021 ended, five years since the inception of the programme.

5.0 Governance

5.1 Norfolk and Waveney Clinical Commissioning Group Chief Nurse is the Senior Responsible Officer for the LeDeR programme in Norfolk, strategic oversight is through the monthly meeting of Learning Disability and Autism Programme Board, the bi-monthly LeDeR Steering Group which also supports the Action into Learning Group.

5.2 The quarterly meeting of the LeDeR Steering Group continued via Microsoft teams during the COVID-19 pandemic. Although it must be noted that there were changes to attendees as organisations responded to the challenges of the work changes due to the pandemic.

5.3 Performance against trajectory targets is currently monitored by NHS England/Improvement. The LeDeR Steering Group monitored the thematic learning and actions. The Norfolk and Waveney Clinical Commissioning Group (NWCCG) Quality and Performance Committee

and the system wide Learning Disability and Autism Programme Board monitored the work of the NWCCG team who support the LeDeR programme on behalf of the system.

5.4 The **LeDeR Policy 2021** was revised and published by NHS England on 23 March 2021

5.5 Norfolk and Waveney Clinical Commissioning Group will be working alongside the Integrated Care System (ICS) to implement the changes of the governance arrangements as the LeDeR process moves from NWCCG to the ICS. This will include the formation of a new local Governance Panel replacing the Steering Group.

6.0 Equality Impact

6.1 Learning from national LeDeR reviews is that ethnic minority groups are disproportionately affected by health inequality. More work is required to support people from ethnic minorities and in recognition of this Norfolk and Waveney CCG were successful in their bid to become an exemplar site to support people with learning disabilities access their annual health checks.

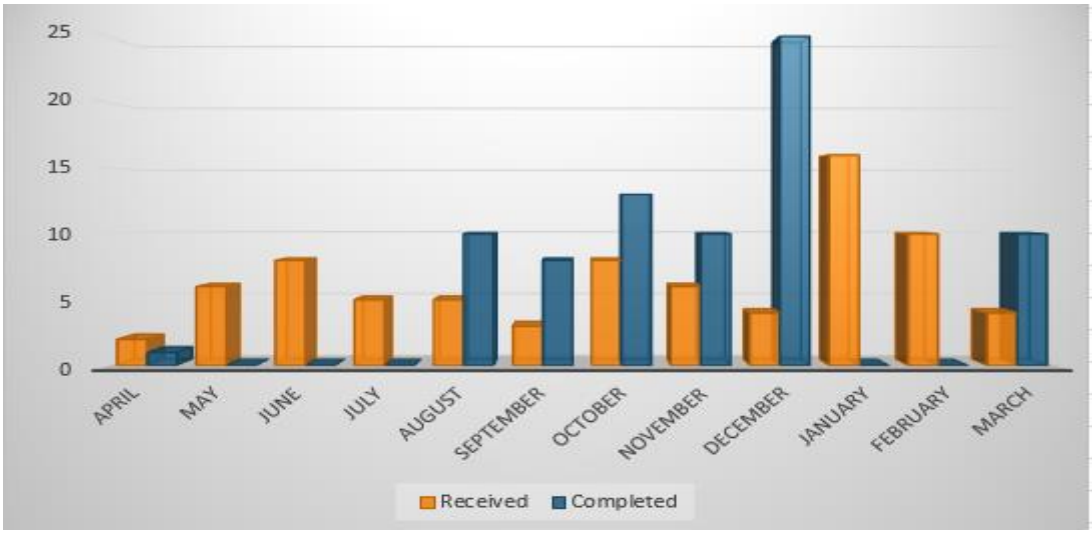
6.2 Norfolk and Waveney reported zero deaths of people with a learning disability with an ethnic minority to the local LeDeR programme and it is not currently clear whether this is a reporting issue. Work is underway within the health and care system to identify those from ethnic minorities backgrounds which may see a change of notifications received.

6.3 The local LeDeR Steering Groups were asked by the National NHS England/Improvement LeDeR team to identify an ethnic minority lead for people to sit on our steering group. We are pleased to report we have a person who is able to undertake this role.

7.0 Programme performance data including the current trajectory against national targets

7.1 Within Norfolk and Waveney during 2020/2021 there was an increased focus on completing the outstanding reviews.

7.2 The graph below shows the reviews received and those completed. Please note that some reviews of will be completed into the next reporting year



7.3 Norfolk and Waveney met the requirement of completing 94% of backlog reviews by December 2020. The reporting platform was closed for a new launch and the reviewers are now being trained to use it and there is a plan to focus on the reviews paused during this transition.

7.4 Since the Covid-19 pandemic, many of the reviewers were deployed to front line services, however three reviewers were able to continue, and they were supported by CCG employees who were also allocated to undertake reviews.

8.0 Analysis of those deaths notified to the programme in Norfolk and Waveney during 2020/21

8.1 For 2020-21 we received 77 notifications which is an increase of 26 cases compared to the previous year. Of those, 2 notifications were for children and young people.

8.1.2 In Norfolk and Waveney the average age of death in 2020-21 was within the age bracket of 45-64 for females and 65+ for males. With a median age of 61 compared to the England average of 62 years of age.

8.1.3 In Norfolk as reflected within the national report the majority of people have died within a hospital setting. With 54% of deaths reported within a hospital setting, 36% at home and 10% in other settings.

8.1.4 The reason(s) for death recorded is limited as not all reviewers had access to the cause of death, however of the deaths reviewed, 20 cited COVID 19 as the primary cause and 15 cited a respiratory condition (3 of which were aspiration pneumonia) as the primary cause.

8.1.5 From the reviews completed for this reporting year, the recommendations were themes and show that reasonable adjustments, mental capacity act assessments and annual health

checks, softer signs of deterioration were of concern. It is not to say these themes were not in place for the person but the reviews of the supporting evidence available gave rise to these recommendations

Reasonable Adjustments	17%
Mental Capacity	16%
Annual Health Checks	14%
Softer Signs	12%
Staff/Training	8%
Dysphagia	7%
End of Life Pathway	5%
DNARCPR	5%
Bowel Care	5%
Transition	3%
STOMP	3%
Safeguarding	3%
Advance Care plans	2%

8.2 Consideration and learning from COVID-19 deaths

8.2.1 Since the start of the pandemic the Norfolk and Waveney CCG LeDeR team closely monitored all notifications for those people with a learning disability who died as a result of Covid-19. These reviews were prioritised (20 in total) to ensure any learning was identified and shared across the system as a priority.

8.2.2 The national data on recorded deaths was shared with Public Health England to help better understand the impact of COVID-19 on people with a learning disability. The aim was to understand the reasons for the increased rate of deaths during the pandemic and what recommendations reviewers suggested. There were two national studies completed into the deaths of people with a learning disability as a result of COVID-19. A small study was conducted by Bristol University and Public Health England published a wider analysis of COVID-19 deaths of people identified as having a learning disability. Covid-19 Deaths Report

Key findings and conclusions were:

- There is a striking difference in age at death between COVID-19 deaths in the general population compared with people with learning disabilities. Just 4% of LeDeR deaths were aged 85 and over; in the general population of England and Wales, 47% of deaths from COVID-19 were in people aged 85 years and over.

- Of those people with a learning disability who died from COVID-19, 37% had all three symptoms of cough, fever or difficulty breathing; 39% had two of the symptoms and 21% had one of these symptoms. No one reported a loss of sense of smell or taste, suggesting that this symptom is more difficult to identify in people with learning disabilities than in the general population.

8.2.3 In Norfolk and Waveney there were 20 confirmed cases aged 19 to 86 during the 2020/21 period.

8.2.4 During the pandemic the team at James Paget Hospital set up an accessible access clinic for people to receive their COVID -19 vaccination. **Setting up a Covid Clinic**

Other accessible clinics were set up across Norfolk and Waveney to support people with learning disabilities and autistic people to receive their vaccination

8.2.5 NWCCG joined LD&A support groups to discuss COVID-19 concerns and hear about their health concerns generally and provide support to the members of these groups with access to senior clinicians.

8.3 Quality of care by review

The review process requests the reviewer assesses and rates the care received based on the information they have received, or concerns raised by people who knew the person. In Norfolk and Waveney 69% of the reviews assessed quality of care as being satisfactory or above. 31% fell short of expected good practice with one case where this impacted on the person's wellbeing. Care of children is not graded as the Child Death Review Process has a different way of reporting their deaths.

A break down of the assessments of care and the ratings can be found in the table on page 13

Assessment of Care received of completed reviews (2020-21)		
Rating	**Standard**	**Number of reviews**
1	This was excellent care (it exceeded current good practice).	7
2	This was good care (it met current good practice in all areas).	18
3	This was satisfactory care. (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	28
4	Care fell short of expected good practice but did not contribute to the cause of death.	13
5	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	6
6	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	5

8.4 Level of learning disability by review

The level of learning disability was not always recorded in the case notes which has made analysis difficult.

8.5 Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

8.5.1 Analysis of the reviews concludes that the DNACPRs were appropriately put in place, evidence that mental capacity was considered, and there were no issues raised where family members had not been consulted. In some cases the DNACPR was put in place during the final episode of care. Nationally there has been a focus on DNACPR for people with a learning disability with a number of reports published.

8.5.2 NHS England/Improvement wrote to CCGs, NHS Trusts and primary care reiterating the need to ensure vigilance in the decision-making process and highlighting available resources. Assurances were sought within primary care for review of DNACPRs in place for people with a learning disability. The CQC undertook a review of DNACPR during the pandemic and published a final report with a number of recommendations which will be taken forward by the Learning into Action Steering group over 2021-2022

8.6 Role of cancer screening

Data around cancer screening from the reviews is sporadic, with unclear evidence from the reviewed records regarding the age specific health screening offered to people. Further work will be undertaken by the Learning into Action Group with primary care and community colleagues to support an increase in people access this screening.

8.7 Annual Health Checks

Analysis showed that most people had an annual health check however we are reviewing how we can report this information with a statistical format as retrieving form the data sets was not possible. The current process does not allow for a review of the quality of the annual health checks or whether the annual health check led to a clear health action plan and this being explored as a quality improvement work stream with Primary Care.

8.8 Ethnic Minority Groups

The Norfolk and Waveney LeDeR reviews show there were no reported deaths for people from an ethnic minority for 2020-2021, we are not clear if this is an issue with how we record people's information and work is underway to seek to ensure our reporting is accurate. This is of significance because it is noted that people from an ethnic minority group are disproportionately affected by health inequality

9.0 Action from Learning

9.1 Each LeDeR review provides us information about the cause of death of a person with a learning disability. From all of the information we learn we look at what we can do locally to impact on the health of people with a learning disability and to reduce health inequalities. We call this action from learning.

9.1.1 Recommendations and learning from the reviews are shared by the Steering Group and the Action from Learning Group work across the system to support the improvement actions within services**.**

9.1.2 The work plan for the Action from Learning Group can be found at Appendix 1

9.2 Improving uptake of Annual health Checks:

9.2.1 The Annual Health Check pilot was set to start in March 2021. The team was set up with a GP Clinical Lead and a Registered Nurse (Learning Disabilities) and Health Improvement Support Workers, one of which is focused to support people from ethnic minority groups.

9.2.2 The team work individually with practices to support improvement in the overall outcomes of individuals with learning disabilities.

Examples of areas of focus within each practice are to support the practice:

- to ensure their learning disability registers are up to date
- to identify a learning disability champion
- to consider new ways of inviting and supporting people during their Annual Health Checks.
- to establish good working practices around communication and accessibility for individuals with a learning disability
- to improve the quality of the annual health checks completed.
- establishing a monthly LD champion forum to promote sharing of good practices and supporting the practices.

9.2.3 The NHS England/Improvement National Target for completed Annual Health Checks is set at 67%. Within Norfolk and Waveney the current amount completed is 68.22%. Further work will take place around the introduction of Annual Health Checks for individuals with Autism in 2021.

9.3 Work that has commenced following the reviews of 2020-21:

- Mental Capacity Act (MCA) multi-agency training event being planned with Norfolk Adult Safeguarding Board.
- Transition group has been established, linking in with SEND priorities.
- A Did Not Attend/was not brought (to an appointment) systemwide policy for adults being developed.
- RESTORE 2 mini for carers/family (identifying the soft signs of deterioration)
- Improving access to cancer screening

- Support for services in understanding reasonable adjustments including coaching staff in how to support people with learning disabilities and/or autism.
- Learning disability improvement standards benchmarking within provider settings

9.4 Work to address national reports

- Flu vaccination information for people who have a learning disability included a communication as part of winter planning. In Norfolk and Waveney, a request to the vaccination programme for people with a learning disability to receive nasal flu vaccination was considered and agreed.

9.5 Recommendations from the Oliver McGowan Independent Review

9.5.1 What has been done (or planned) to fulfil the recommendations identified in the independent review into Thomas Oliver McGowan's LeDeR process. Oliver McGowan Report

- All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process. In Norfolk and Waveney of the current LeDeR reviewers (who are employed to undertake reviews only) they hold a weekly meeting which the local area contact (LAC) attends to offer support and supervision to each other. There is a variety of experience between the team.
- Until the new policy changes are implemented reviewers who are undertaking reviews in addition to their permanent clinical roles are allocated 'buddy reviewers and have the support of the LAC. Recent briefings have been sent to all reviewers updating them on the new Governance Framework and expected standards for the reviews.
- Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs. The CCG employs a full-time LeDeR co-ordinator. LeDeR steering group members who have reviewers completing reviews as well as undertaking reviews, organisations have been requested to ensure they have some dedicated time to complete a review. For the more complex reviews there are some experienced reviewers available to undertake these.

- 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. In Norfolk and Waveney, we have a LeDeR Governance Framework. The LeDeR Steering Group is co-chaired by experts with lived experience. The CCG is looking to co-produce a LeDeR framework for families/carers.
- The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what this should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case). In Norfolk and Waveney, the LAC supports reviewers and receives weekly updates from the core reviewers. Regular team meetings are in place.
- 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 CCG has an executive lead for LeDeR.
- The CCG executive lead for LeDeR will ensure that LeDeRs 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 a LeDeR trajectory in place which is monitored by NHSE/I.
- When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. Norfolk and Waveney have a new governance process and reviewed its processes in undertaking a MAR.
- It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, that they will seek support from a ‘buddy’ who does. 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 invited to attend all or part of the meeting as they wish. Norfolk and Waveney have experienced reviewers and senior nurses who have undertaken MARs to support reviewers who have not.
- There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers. Norfolk and Waveney have a weekly update and/or meeting with the reviewers.
- 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.

We are currently developing supervision documentation and ensuring supervision for reviewers within their organisation.

10 Priorities for 2021/22

- Ensure all reviews are completed within timeframes stated by the LeDeR policy. That is 100% to be completed with 6 months of notification
- Bowel care guidelines – we must ensure these are disseminated across Norfolk and Waveney and that additional learning events are held for carers and providers
- Promote the flu and any associated COVID-19 vaccination campaigns for 2021/22
- Improve assessment and recording of Mental Capacity Assessments / reasonable adjustments and provide a multi-agency training event with the Norfolk Safeguarding Adults Board in 2021/22.
- Improve the support for people with access to their cancer screening invitations.
- Improve uptake and quality of annual health checks by implementing the learning from the exemplar pilot which includes listening and responding to feedback from our people with learning disabilities and autistic people
- To support the roll-out of RESTORE 2 (understanding deterioration of health and to seek medical attention) across Norfolk and Waveney to all carers
- Implementation of new LeDeR policy which will include a new governance process for the integrated Care System, and focused reviews for autistic people and those from an ethnic minority group
- We also wish to support an improvement in transition from children and young people's services into adult services

11 Conclusion

11.1 The year 2020 saw a challenging time for people with learning disabilities and we reported 20 deaths from COVID-19

11.2 Our median age of death for people with learning disabilities is one year less than the national average and we want to improve this by the service improvement priorities mentioned within the report

11.3 We have limited data on our ethnic minority groups and will work to improve our recording to inform our practice

11.4 We value the expertise that the Experts with Lived Experience provide to both our steering group and Action from Learning group. It is important to remember particularly in these challenging times that

each loss was a person and it is important that we continue to improve the services we provide

11.5 With the changes ahead moving into an Integrated Care System we can see a great benefit in the policy changes and the new governance arrangements of the Learning from Lives and Deaths – People with a learning disability and autistic people (LeDeR) Programme.

Appendix 1	Action from Learning Quality Improvement Plan Additions from 2020-2021	
Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/2020)	**Recommendations from National and local LeDeR Reports published May 2018 and May 2019**	**Actions included in a quality improvement plan for 2020/2021**
Pneumonia risk.	• Focus on increasing the uptake of the flu vaccine among people with a learning disability alongside other at-risk groups through a targeted awareness campaign.	• Easy read information to made available across the system as part of the winter flu campaign. • Staff being encouraged to ensure people who have a learning disability have a flu vaccine.
Annual Health Check.	• NHS England to report progress on uptake of Annual Health Checks to DHSC via Clinical Commissioning Group Improvement and Assessment Framework.	• Awareness raising re importance of Annual Health Checks. • National target of 75 % people who have a learning disability to have an annual health check. • Primary care to implement quality outcome framework in relation to annual health checks.
Constipation.	• The NHS will launch a national campaign to promote awareness around the risk of constipation including how it can be prevented, recognised and treated to better support families, carers and staff who work with people with a learning disability	• Learning Disability Learning into Action Group established and has developed bowel care guidelines for care home/residential home /supported living settings. • NHSE Easy read constipation information circulated to providers. • Looking to pilot the bowel care guidelines in some care home/residential homes in 2020/2021 • To provide further training to care settings to be co-delivered with Experts with lived experience.

Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)	Recommendations from National and local LeDeR Reports published May 2018 and May 2019	Actions to be included in a quality improvement plan for 2020/21
Reasonable adjustments, record the adjustments that are required and regularly audit their provision	• Implement NHS Digital Reasonable Adjustment Project rollout and as part of this align with the LHCREs to ensure the same information is being used in both. NHS Digital/NHS England, 2020	• Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families. • Ensure organisations are regularly auditing their provision of reasonable adjustments. • To explore possibility of further training on reasonable adjustments being co-delivered with Experts with Lived Experience to primary care settings in 2020/2021.
Dysphagia assessments and training.	• Recognising deteriorating health or early signs of illness in people with learning disabilities and minimising the risks of pneumonia and aspiration pneumonia.	• Dysphagia group established being led by the acute hospital. Planning to develop on pathway across the system and develop a training package for staff. • To link with the National learning into action group that is currently looking at this area and review dysphagia training and assessment across the local system, ensuring reasonable adjustments are made and easy read information available. • To explore possibility of introducing RESTORE2 training in care home/residential settings.

Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)	Recommendations from National and local LeDeR Reports published May 2018 and May 2019	Actions to be included in a quality improvement plan for 2020/21
Strategic approach to be taken for the delivery of learning disability mortality reviews with Executive level leadership and ownership across all providers and health and social care commissioners.	• Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme. • NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.	• The CCG to ensure LeDeR reports are completed within six months and monthly reporting to NHSE/I against trajectories. • To ensure the learning is included within the actions for the steering group and the learning into action group. • New N&W LeDeR framework produced.
Knowledge and correct application of the Mental Capacity Act	• Local services must strengthen their Governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role	• MCA training and monitoring required across the system. • Multi-agency Safeguarding event to be planned to include MCA
Cancer Screening	• Screening programmes should identify patients with learning disabilities in advance and ensure that a) their correspondence is accessible • they make adjustments in terms of following up/supporting understanding • they consider mental capacity in cases in which a patient has an impairment of the mind or brain as per mental capacity act 2005	• To be actioned by the LeDeR steering group working collaboratively with organisations. • Learning into action group along with support from the Experts with Lived • Experience to prioritise improving access to cancer screening for 2020/21.

Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)	Recommendations from National and local LeDeR Reports published May 2018 and May 2019	Actions to be included in a quality improvement plan for 2020/21
End of life care	• The Department of Health and Social Care, working with a range of agencies and the Royal Colleges are to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part 1 of the Medical Certificate Cause of Death. • People with LD should be fully informed of conditions and diagnoses particularly those that are life limiting to enable involvement in EOL care planning. Best interest decisions	• Letter sent in 2019 to all Chief executives/Director Nurses informing them that 'downs syndrome' is not a rationale for DNACPR-providers to report action taken via quality forums. • To be included as part of the actions for the LeDeR steering group.