

Learning Disability Mortality Review

Annual Report

2019 - 2020

 Scarborough and Ryedale Clinical Commissioning Group	 Harrogate and Rural District Clinical Commissioning Group
 Hambleton, Richmondshire and Whitby Clinical Commissioning Group	 Vale of York Clinical Commissioning Group

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1.0 Introduction

1.1 The Learning Disability Mortality Review (LeDeR) programme was established in 2015 to drive improvements in the quality of health and social care for people with a learning disability and to help reduce premature mortality and health inequalities. Now, in 2020, the programme nationally provides the largest body of evidence on deaths of people with a learning disability at an individual level anywhere in the world.

1.2 This is the second Annual Report for the Learning Disability Mortality Review (LeDeR) programme compiled on behalf of North Yorkshire and York CCGs.

1.3 The report describes the national update from NHS England / NHS Improvement (NHSE/I) and the local delivery of the programme across the North Yorkshire and York area.

1.4 Notably the report includes the findings and learning from completed reviews; the key achievements; and the challenges and opportunities for the programme in 2020/21.

1.5 The report will reference the challenge of Covid-19 for people with a learning disability and the increased pressure on our health and social care services to manage the pandemic; whilst also acknowledging that the majority of the work described in the report took place before lockdown restrictions were applied in the UK.

2.0 LeDeR Programme National Update

2.1 The NHS Operational Planning and Contracting Guidance 2019/20 now includes four deliverables (key performance indicators) in relation to the LeDeR programme:

- CCGs are a member of a Learning from Deaths report (LeDeR) steering group and have a named person with lead responsibility.
- There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.
- CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.
- An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.

2.2 The Department of Health and Social Care completed its consultation on the proposal to introduce mandatory learning disability and autism training for health and care staff. The recommendation to make this training compulsory was originally recommended in the 2017 LeDeR Annual Report, which was published in May 2018. A final decision about the training has not yet been communicated.

2.3 In May 2019, NHSE/I announced an additional £5 million investment nationally for programme delivery. CCGs were invited to bid for money to address the number of cases that had fallen outside of the 6 month review time frame and money to support the action from learning programme

2.4 NHSE/I commissioned NECS (North East Commissioning Support Unit) to manage the national backlog of reviews that had fallen out of the expected

timeframe for completion. The backlog of reviews for each CCG was identified and any CCG wishing to opt-out of NECS commissioned reviews had to satisfy a framework of quality and performance measures.

2.5 The contract for Bristol University managing the database for the LeDeR programme is in place until May 2020 – discussions commenced as to a likely replacement.

2.6 The Learning Disability Mortality Review (LeDeR) Programme: Action from Learning Report was published in May 2019 <https://www.england.nhs.uk/publication/leder-action-from-learning/>. This was the first report translating learning into action with a focus on national projects to improve practice including: sepsis and the deteriorating patient; constipation; dysphagia; cancer; and the Mental Capacity Act.

3.0 Local Area Opt-Out and Funding Bids

3.1 North Yorkshire and York CCGs were successful in satisfying the required standard of quality and performance to enable an agreed preferred opt-out of the NECS commissioned completion of reviews.

3.2 North Yorkshire and York CCGs were successful in achieving funding awarded by NHSE/I for:

- Continuation of the two day per week post of a LeDeR Specialist Practitioner for Harrogate and Rural District CCG and Hambleton Richmondshire and Whitby CCG until September 2020: with the specific remit to ensure that the backlog of LeDeR reviews was completed by March 2020; to act as Local Area Contact; and to manage the day to day LeDeR Review process for those areas. This post has proven to be successful in meeting the objectives set
- Performance improvement to recruit two LeDeR reviewers on fixed term contract / secondment of 1 year, working 1 day per week with each Local Area Contact.
- Action from Learning initiatives identified by Harrogate and Rural District CCG and Hambleton Richmondshire and Whitby CCG for two specific projects: (1) Prevention, early identification and management of constipation for clients with a Learning Disability; and (2) Early identification and management of sepsis for clients with a Learning Disability. These projects have been managed successfully by the Specialist Practitioner.
- Action from Learning initiative for recruitment to a 12-month service improvement post to work with care providers and families across the Vale of York CCG to provide training and support to improve the health and well-being of people with a learning disability. This post has now been made into a permanent role by the CCG.

4.0 Key Achievements in the programme 2019/20

- ✓ The system of quality assurance for completed reviews by the monthly CCG Serious Incident Panel has proven to be successful. The process ensures appropriate scrutiny of reviews by senior quality leads from each CCG and enables learning and actions to be agreed and formally recorded.
- ✓ Improved programme performance against agreed KPIs i.e. completed reviews within agreed timescales (6 months from referral); increased numbers allocated within agreed timescale (3 months from referral).
- ✓ Increased evidence of highlighted learning from completed reviews beginning to be embedded into practice.
- ✓ Valued contribution of the GP Learning Disabilities Lead as a key member of the steering group and a knowledgeable resource to support training and share learning with Primary Care.
- ✓ Learning from the programme has been included in the Protected Learning workshops for primary care in addition to inclusion in the annual programme of Safeguarding 'Hot Topic' events attended by primary care staff.
- ✓ Additional opportunities taken to strengthen links with local Advocacy and Self-Advocacy Groups.
- ✓ Established links with care providers and partnership forums utilised to share programme learning and training opportunities e.g. React to Red training; End of Life Care-planning.

5.0 NHSE/I Regional Steering Group

The Regional Steering Group meeting is held on a quarterly basis. Chairing arrangements have transferred from NHS England's Director of Nursing (Yorkshire & the Humber) to the Transforming Care Strategic Resettlement Lead – establishing the programme firmly in the Transforming Care Programme pathway.

The group is attended by the Regional Coordinator and the Local Area Contacts from each CCG. Speakup Self-Advocacy and Inclusion North provide the voice for people with a learning disability at the meeting. The meeting offers the opportunity to hear updates from the regional and national team; share information, best practice and challenges from across the region.

Resources shared have included:

- Ask, Listen, Do <https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>
- Diabetes Research and improved accessible information for diabetes care www.diabetes.org.uk/learning-disability
- Cancer Screening information http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN_cancer_pack_2.pdf

6.0 CCG Local Steering Group

6.1 The North Yorkshire and York LeDeR Steering Group has continued to strengthen its membership from across the North Yorkshire Transforming Care Partnership (TCP) footprint. The group provides oversight, support and governance for the local delivery of the programme, operating within the CCG Constitution and aligning with relevant CCG policies and procedures.

6.2 Meetings have moved from bi-monthly to quarterly with membership made up from the partners and relevant stakeholders from across the health and social care economy.

6.3 The Group is an established pathway for exchange of information with the Transforming Care Partnership Board and the Mental Health Partnership Board.

6.4 In 2019/20 the Group has achieved: robust Terms of Reference detailing a strong core membership; systems in place to analyse and address the themes and recommendations from completed reviews; and a communication strategy to disseminate learning.

7.0 LeDeR Methodology

7.1 LeDeR reviews continue to be conducted either by individual reviewers or utilising a panel approach. We listened to feedback from colleagues in Primary Care and have now streamlined the process for obtaining information from GP records.

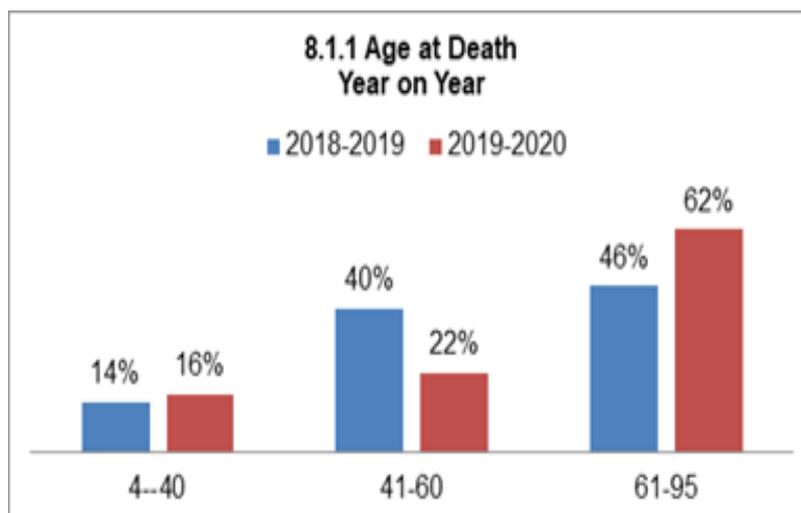
7.2 The LeDeR panel approach utilised as a methodology for oversight of reviews for Vale of York CCG and Scarborough and Ryedale CCG continues to meet on a monthly basis and has been enhanced in 2019/20 by membership from Tees, Esk, and Wear Valleys Mental Health NHS Trust.

7.3 The statutory Child Death Review process continues as the primary review method for children with a learning disability. Closer working relationships between local LeDeR processes and the Child Death Overview Panel (CDOP) have been established. Any learning is shared through the LeDeR programme network in the usual way. To date, the CDOP Reviews have not identified any additional learning.

8.0 Programme Statistics

8.1 The figures in tables 8.1.1 to 8.1.3 are reported from the total number of deaths (age 4 years and over) reported to the programme between April 1st 2019 and 31st March 2020 (n = 45). Where possible we have compared local data to the national statistics reported in the national LeDeR Annual Report 2018-19 published May 2019

8.1.1 Age at death



The age range with the highest reported deaths in York and North Yorkshire was 61-95, with 28 of the 45 reported deaths in 2019-2020 within this cohort. There has been an 18% decrease of reported deaths in the mid age bracket, 41-60 from the previous year; with a 16% increase of people dying in the highest age bracket of 61-95 years old. The youngest age bracket remains comparable with the previous year's data.

Locally the average age at death for people with a learning disability is 60 years: for males 60 years; for females 61 years. This average figure has risen from the reported 54 years in North Yorkshire and York in 2018-2019 and now exceeds the national average of 59, reported in 2018-2019.

The Specialist Practitioner is now a member and contributes to the North Yorkshire Live Well Live Longer Group.

8.1.2 Place of Death

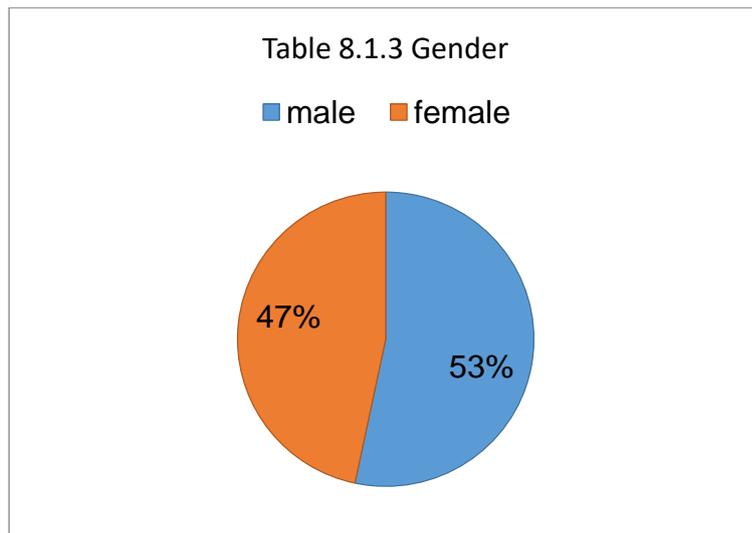
Place of death	Hospital	Usual place of residence	Residential or Nursing Home/Hospice/ Not usual place of residence/Community/Other
Local nos. (19-20)	21	17	7
Local % (19-20)	46%	38%	16%
National % (18-19)	62%	n/a	n/a

The percentage of people with learning disabilities dying in hospital nationally in 2018-2019 was 62%; in the general population it was 48%; locally hospital deaths in 2019-2020 represented 46% of those reported, this is a decrease from 2018-2019 when locally hospital deaths were 62%.

In accordance with NHS England's End of Life Programme (<https://www.england.nhs.uk/eolc>) persons receiving end of life care are afforded the opportunity of having choice, with more supported planning around the place where they are looked after at the end of their life.

Whilst the decrease of 16% of people with a learning disability dying in hospital will not all relate to expected deaths we have seen an increase over the last 12 months in numbers of people being supported to make their own choices of where they want to be cared for. This reflects the work being done by providers of health and social care regarding end of life care planning. Our local NHS mental health and learning disability service provider has developed an accessible 'Supporting Choices' document which has been shared through our communications network.

8.1.3 Gender of Deaths Notified to LeDeR in NY &Y Between April 2019- April 2020



The national information reported the gender split as 58% male, 41% female and less than 1% as other (National LeDeR Annual Report 2018). Locally gender was recorded in all cases and reports as 53% male and 47% female this is the opposite to local figures in last year's report which showed 47% male and 53% female. We do not have the statistics to know whether the figures are reflective of the gender split in people with a learning disability in our local populations.

8.2 Reported deaths per CCG area and progress of reviews.

The table and narrative below illustrates the number of reported deaths per CCG area and the progress of those reviews for the financial year 1st April 2019 – 31st March 2020.

Table 8.2.1 Deaths notified per CCG	
HaRD	15
HRW	13
VOY	10
SCR	7
Total reviews notified 2019-2020	45
Total reviews notified 2018-2019	45

Table 8.2.2 Review progress per quarter 2019/2020				
	Notified	Awaiting Allocation	In Progress	Completed
Q1	5	45	20	6
Q2	18	25	39	2
Q3	11	27	32	11
Q4	11	16	27	29
Cumulative	45	n/a	n/a	48

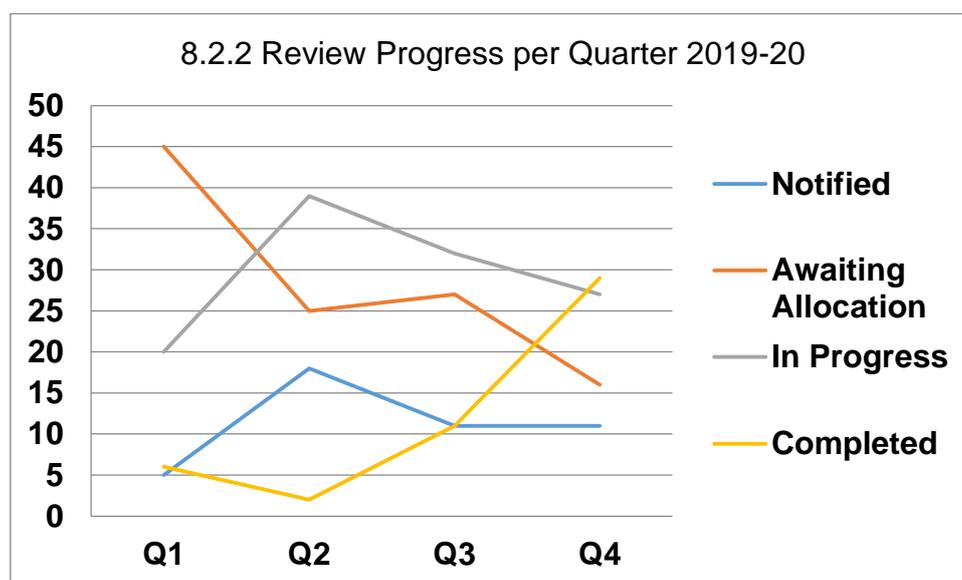


Table 8.2.2 demonstrates the upward trend in completion of reviews, with a considerable increase in Q4 following the local increase in resource. This directly correlates with the reduction in reviews awaiting allocation and an increase in the number of reviews in progress. Reviews awaiting allocation reduced from 45 in Q1 to only 16 by the end of Q4 2020. The number of reviews notified to LeDeR remains relatively stable throughout 2019-20; and there was only one more review notified in 2019-20 than the previous year.

It is anticipated that with continued investment in the programme in 2020/21 the percentage of reviews completed within the target timeframe of six months will be achieved.

8.3 Data reported below is taken from reviews that were completed and approved (n = 48) in York and North Yorkshire between April 1st 2019 – 31st March 2020. Where available, local data is compared with data from the 2018-2019 National LeDeR Annual Report. This data does not include child deaths, which are undertaken through CDOP. Any learning from CDOP would be shared in the local LeDeR Steering Group.

8.3.1 Causes of death

Nationally Pneumonia and Aspiration Pneumonia were the most common causes of death in a person with a learning disability, reported as Pneumonia (25%) and Aspiration Pneumonia (16%). Locally Aspiration Pneumonia (28%) is reported as our highest cause of death with Pneumonia as a close second (24%). Aspiration Pneumonia has increased slightly from last year's report (25%) and Pneumonia has shown a decrease when compared with the same period (34%).

Other reported causes of death in the LeDeR reviews completed in 2019-2020 (fewer than five cases each) were: Cancers; Dementia; Frailty; Sepsis and Epilepsy.

With chest conditions reported as accounting for over half of local deaths and the current situation of Coronavirus it is increasingly important that annual health checks are completed in primary care to pick any early indicators of health concerns. NHS England have updated supporting information available for practices including an easy read adaptable letter template which explains the importance of attending and what to expect.

<https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

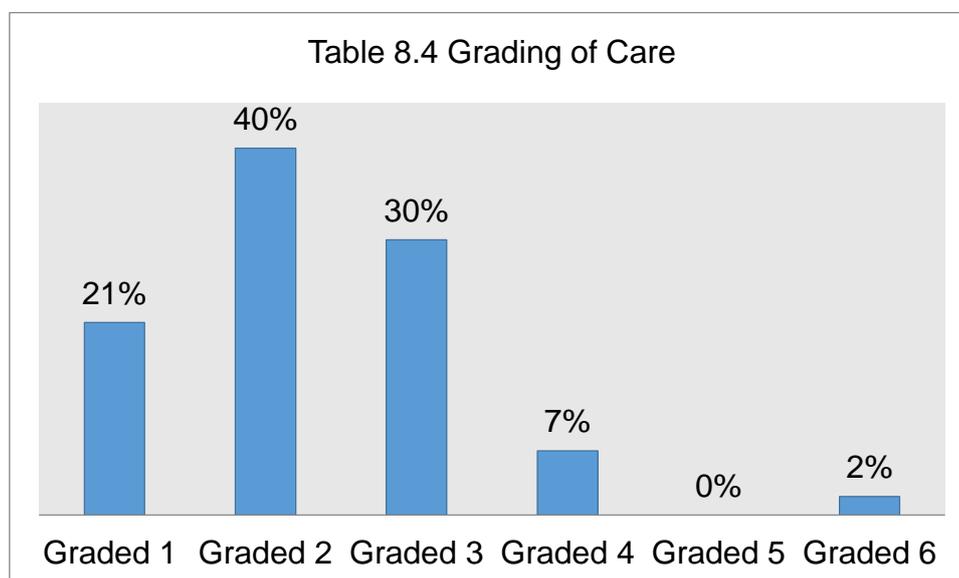
<https://www.england.nhs.uk/wp-content/uploads/2020/06/Letter-what-to-expect-from-your-doctor.pdf>

8.3.2 Indicators of the quality of care provided

At the end of the review, having considered all of the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person. The following are the possible gradings:

- 1) This was excellent care (it exceeded expected good practice).
- 2) This was good care (it met expected good practice).
- 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).
- 4) Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.

- 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) Care fell far short of expected good practice and this contributed to the cause of death.



Locally 91% of the reviews completed were graded as satisfactory and above (1-3).

9% of care was graded in categories 4-6 – falling short of an acceptable standard. In 2% of reviews a contributory factor from care was found to have impacted on the person's death.

No local reviews in 2019/20 identified care which had a direct contribution to the cause of death.

The local figures have not been compared to the national data as the categories have changed since last year's report and are therefore not directly comparable.

9.0 Local Performance against National Key Performance Indicators (KPIs)

1. *CCGs are a member of a Learning from Deaths report (LeDeR) Steering Group and have a named person with lead responsibility.*
 - ✓ The CCG chairs the North Yorkshire and York LeDeR Steering Group. The named person with responsibility for LeDeR is the CCGs Chief Nurse

2. *There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.*
 - ✓ A robust plan is in place to achieve this target with additional monies from NHSE.

3. *CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.*
 - ✓ The CCG's analyse and address the themes of recommendations from completed reviews through the LeDeR Steering Group. Learning is shared through the communications network.

4. *An Annual Report is submitted to the appropriate Board/Committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.*
 - ✓ The 2018-2019 North Yorkshire and York Annual Report was submitted to the CCG Governing Bodies and Local Safeguarding Adult Boards

	Reviews notified and completed 2018-2019	Reviews notified and completed 2019-2020
Assigned within 3 months	53%	56%
Completed within 6 months	7%	89%

There has been a significant improvement in achieving the second NHSE KPI due to the additional resource; at the end 2019 - 2020 financial year the CCGs were on target to complete all reviews within 6 months. Rates of completion then slowed due to the lockdown restrictions imposed by the global pandemic.

10 Themes from reviews completed in 2019/20

10.1 The following are examples of identified best practice reported in one or more reviews:

- ✓ Compassionate, person centred care which provided a good quality of life.

- ✓ Care Providers acting as effective advocates and involving families in care.
- ✓ Excellent care packages provided and training undertaken to further support people.
- ✓ Good collaborative multi agency work and communication; regular contact between health care professionals to provide a wrap around service.
- ✓ Support, coordination and regular reviews by the Community Learning Disability Team (CLDT) and effective multi agency working between CLDT and Acute Trusts.
- ✓ Regular and flexible GP consultations.
- ✓ Effective advocacy by acute hospital Learning Disability Nurses and effective admission alerts.
- ✓ Supportive end of life planning to allow people to be cared for in their home environment and take into account their wishes.
- ✓ Recording of the involvement of the person, the care staff and the family in best interests decisions.
- ✓ Good record keeping and comprehensive hospital passports.
- ✓ Care Provider support with appointments and hospital admissions.
- ✓ Prompt diagnosis and relevant care pathways followed.

10.2 The following are examples of reasonable adjustments identified in reviews:

- ✓ Easy read appointment letters and information
- ✓ Reserved parking, longer consultation appointments and appointments in side rooms.
- ✓ Support to attend all health appointments and hospital appointments by residential care staff.
- ✓ Involvement of the Learning Disability Liaison Nurses to ensure that reasonable adjustments were made when secondary services were required and support provided to the ward staff in caring for the person.
- ✓ GPs making home visits to reduce a person's anxiety of attending the surgery
- ✓ Clustering of appointments/investigations to minimise anxiety.
- ✓ Learning Disability Passports in place.
- ✓ Staff support to access activities and ensure person centred care.
- ✓ Ensuring the person could see a named GP who could make adjustments and see the person promptly.
- ✓ End of life care managed by the care provider to keep the person at home.

- ✓ Adaptations such as automated and widened doors and adapted bathrooms; allowing the person to stay at home.
- ✓ Personalising of the persons environment when their conditions changed.
- ✓ Specialist seating and beds sourced.
- ✓ Care provider arranging for additional training for staff e.g. dementia training and end of life care training.
- ✓ Arrangement with the acute provider to ensure regular hospital attendances, rather than going through the Emergency Department.
- ✓ Offer of sedatives prior to treatments and tests to reduce anxiety.
- ✓ Reminders, alerts and evidence of the person's learning disability in their records to ensure reasonable adjustments are offered.

10.3 Where families are involved there is a more rounded review about the person and their life; feedback is provided to families in addition to care providers once each review is completed.

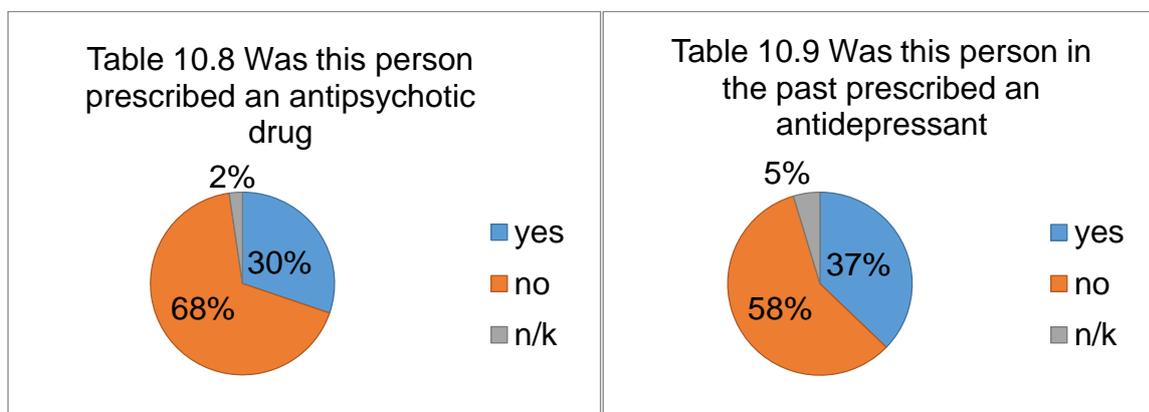
10.4 A small number of families have raised concerns, where this has been the case the reviewer has taken the time to go through the review and they have been helped to understand what other processes are open to them.

10.5 Care Providers were represented in 67% of completed reviews. They have provided positive feedback of involvement.

10.6 42 of the 43 people reviewed had contact with specialist services within the last six months of their life.

10.7 In 30 of the 43 completed reviews the person had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place at the time of their death. Of those 30: 24 were completed correctly; and 6 were either not completed correctly or it was not clear whether they were or not.

10.8 & 10.9



Tables 10.8 & 10.9 shows the number of people prescribed antipsychotic medication or anti-depressant medication at the time of their death.

People with a learning disability, autism or both are more likely to be given these medicines than other people. These medicines are right for some people. They can help people stay safe and well. Sometimes there are other ways of helping people so they need less medicine or none at all.

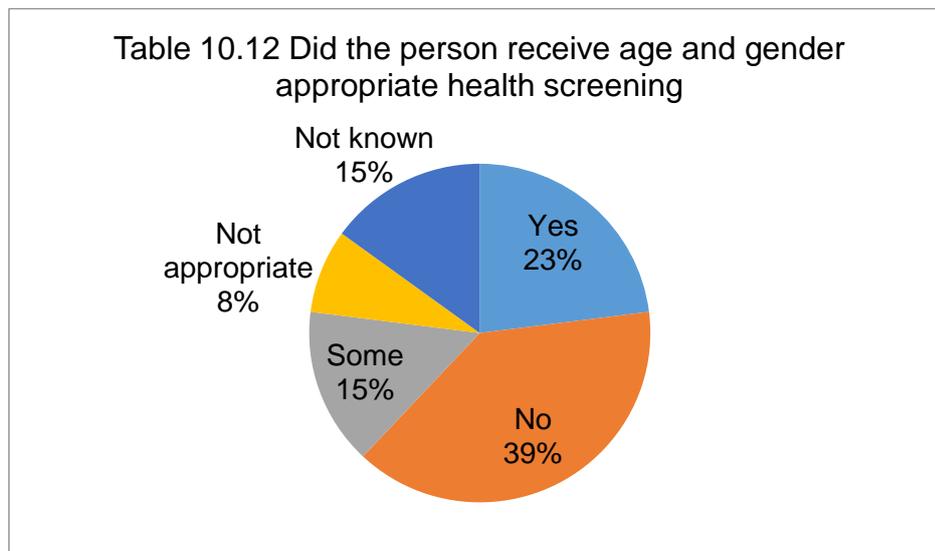
STOMP is a project to stop over medication of people with a learning disability, autism or both

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

10.10 There were no reported gaps in service in any of the 43 completed reviews.

10.11 Problems with organisational systems and processes were reported in 9% of reviews.

10.12 From the 37 reviews in which the question was asked 'Had the person received age and gender appropriate health screening? (e.g. breast cancer screening, bowel cancer screening)' the data below was gathered



Less than a quarter of reviews found evidence that appropriate screening had been completed.

Screening can detect a problem early, before there are any symptoms.

A guidance and resource pack has been developed by partners for care providers to support people to access health screening

http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN_cancer_pack_2.pdf

11.0 Recommendations made by reviewers

The following are highlighted as recommendations from the completed reviews. All recommendations are agreed and recorded and their progress into action is monitored by the local CCG LeDeR Steering Group.

- The importance of using appropriate advocates. The Mental Capacity Act 2005 introduced Independent Mental Capacity Advocates (IMCA). It is important to use these services appropriately rather than presume family or friends can adequately fulfil the role.
- The consistent use of hospital passports in order to ensure that patients have their passport when they are admitted to hospital from their care facility.
- The importance of following correct DNA/CPR (do not attempt cardio-pulmonary resuscitation) processes. Forms should be completed clearly and should include discussion with person if they have capacity; and family member or an advocate if they lack capacity.
- End of Life Plans; people with a learning disability are not consistently offered the opportunity to develop an end of life plan.
- Identification of a Learning Disability on all medical records. For good communication and information, it would be beneficial if all medical records indicate that the patient was on the Learning Disability register including the GP summary.
- The importance of the availability and use of easy read health resources which can aide informed choices, for example healthy lifestyle choices, treatments including cancer care, investigations and end of life care.
- The need to increase the uptake of routine cancer screening in people with a learning disability or clear recorded decision making using the best interests principles when not deemed appropriate.
- The need to raise awareness of the importance of recognition of sepsis and its possible consequences at the earliest opportunity with advocates, self advocates and care providers.
- The need to raise awareness of the importance of recognition of constipation and its possible consequences with appropriate actions and treatments available with advocates, self advocates and care providers.

12.0 Summary

In 2019/2020 the North Yorkshire and York CCGs have achieved significant progress in the development and awareness of the LeDeR programme. The information detailed in this report shows the combined commitment from health and social care partners to making a difference to people with learning disabilities, their families and carers. Learning points at individual level have been shared widely across the health and social care economy and taken forward into relevant service improvements by care providers. Continued investment in the programme has enabled a dedicated focus on learning into action to be established.

The local team maintain strong links with both the regional and national team in order to ensure that the progress made with the national action from learning projects is translated across local services.

13.0 Challenges and Priorities for 2020/21

- The programme relies heavily on a small resource of people completing reviews and the goodwill and dedication of many others in supporting the programme to make improvements in the lives of people with a learning disability. Maintaining investment is essential to continuing this.
- Covid-19 has presented a new set of challenges that are expected to emerge over a period of time. Rapid learning from Covid-related deaths is a national priority which will also be supported in the local region.
- The strengthening of existing service user engagement is a priority for the NorthYorkshire and York LeDeR Steering Group in the forthcoming year.
- The need for continued attendance and engagement with the LeDeR Steering Group is vital to translate learning into action and share the learning across the system.

14.0 Acknowledgements

The data presented in this report represents individuals who were loved and supported by their families, friends and carers. On behalf of the CCGs the local LeDeR team would like to pass on sincere condolences to those who are bereaved and also express grateful thanks for the contributions they have made to helping us make improvements in our services to support the lives of others.