NHS
Tees Valley
Clinical Commissioning Group

LeDeR Local Area Annual Report 2019/20 (in partnership with Durham Clinical Commissioning Group)
(A summary of this report will be available in Easy Read format)

Acknowledgements

Thank you to all those family members, carers, reviewers and providers of services across health and social care who have taken part in LeDeR reviews and thank you to all those who have contributed toward this report.

The *Stop People Dying Too Young Group* is a confirm and challenge group made up of self-advocates and family carers, supported by Inclusion North. The things the *Stop People Dying Too Young Group* want us to remember and think about:

"All people should be given the same respect, value, access to treatment and rights. Our lives are not valued as much as other people's. This has to change and it starts with you. You need to understand our rights and know the Law. Start by listening to us - hear our worries but also what we want from our life. Listen to the people who know us best. This might be our family, friends or paid support. Know how to make reasonable adjustments so that it is easy for us to get health care. Information, information, information - make it Easy Read and don't use jargon. Don't let us die too young"

1. Introduction

1.1 The Learning Disabilities Mortality Review (LeDeR) programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. A key part of the programme is to support local areas in reviewing the deaths of people with a learning disability (aged 4 years and over) and take forward necessary improvements in provision of services.

1.2 The local area within this report refers to populations and stakeholders within County Durham CCG (formerly Durham Dales, Easington and Sedgefield and North Durham CCGs) and Tees Valley CCG (formerly Hartlepool and Stockton-on–Tees, South Tees and Darlington CCGs).

1.3 We know from the LeDeR Bristol report[1] that people with learning disability can die up to 27 years sooner than that of the general population, often from preventable causes. The Clinical Commissioning Groups (CCGs) and local area are committed toward learning from deaths to reduce premature mortality and address inequalities faced by many people with a learning disability.

1.4 The purpose of this report is to provide an update on how LeDeR has been implemented with partners across County Durham and Tees Valley locality, including information on the number of completed reviews against national targets, the learning, recommendations and action planning up to 31st March 2020.

2. Background Information

2.1 National deliverables within NHS Operational Planning and Contracting Guidance 2019/20[2] relating to transforming care for people with learning disabilities include the following stipulations:

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

3. Current Position

3.1 The local area is compliant in being members of the Cumbria and North East LeDeR steering group, which is currently chaired by the Director of Nursing for County Durham CCG. The DON has lead responsibility for LeDeR across the local area, alongside the deputy local area contact (LAC), Head of Quality and Development for County Durham CCG.

3.2 The local area has put measures in place to ensure the nationally agreed targets of allocation of reviews within three months of notification and completion within six months are met, through the successful recruitment in January and April 2020 of four highly experienced staff, sharing three whole time equivalent LeDeR reviewer posts. Difficulties were experienced in the past in being able to identify reviewers who were able to undertake reviews on top of current roles.

3.3 The table below illustrates the number of notifications, number of completed reviews and information on outstanding reviews:

[1] l http://www.bristol.ac.uk/university/media/press/2018/leder-annual-report-final.pdf
[2] https://www.england.nhs.uk/publication/preparing-for-2019-20-operational-planning-and-contracting/

2019/20	NHS County Durham CCG	NHS Tees Valley CCG	Total
Notifications (deaths reported to LeDeR)	88	81	169
Completed Reviews	48	37	85
In progress	16	16	32
Unallocated	24	21	45
To be completed by 31st December 2020	40	37	77
Awaiting CDOP Report	0	2	2
Awaiting Coroner's Inquest	0	2	2
Overdue NECs cases (notified to LeDeR on or before 31st Dec 2018)	0	24	24

3.4 The CCGs aim to have 100% of reviews completed by 31st December 2020 i.e., all those notifications received before 1st July 2020, in order to meet the six month completion deadline. The total of 77 cases means that each reviewer is working toward completion of 4-5 cases per month. In addition to this, the learning disability liaisons lead from County Durham and Darlington NHS Trust has committed to completing one review per month within her substantive role.

3.5 The current process of allocating reviews involves North England Commissioning Support (NECS) data team notifying the deputy LAC of a death, who then enters the information onto the LeDeR notification system checking for any duplication. Notifications of death are received by LeDeR from a variety of sources, including family members, key workers, local authority and NHS Foundation Trusts. The case is then allocated to one of the four LeDeR reviewers working across the local area in order of chronological priority to ensure the six month completion target is met.

3.6 County Durham has consistently received the highest number of notifications in the region and achieved the highest number of completed reviews due to having robust systems in place. Tees Valley has the third highest number of notifications and completed reviews. This does mean however that the actual numbers of reviews due for completion is greater than in neighbouring areas.

3.7 The local area has improved compliance in having systems in place to analyse and address themes and trends from completed reviews, by taking the

decision to enter all completed LeDeR reviews onto the local Safeguard Incident and Risk Management System (SIRMS). This was considered to be necessary in the absence of local learning intelligence being available from the University of Bristol.

3.8 Bi-annual SIRMS reports highlighting the learning and recommendations from reviews are presented at the local multiagency service improvement group (SIG) to facilitate discussion and agree priority areas for improvement. The SIG also has responsibility for taking part in the quality assurance process for completed LeDeR reviews.

3.9 There have been at least six LeDeR update reports shared with various CCG executive committees and local adult safeguarding boards across the local area since 2017, highlighting progress to date, the learning from completed reviews and the challenges ahead regarding implementation of the LeDeR programme locally. It needs to be noted that the future of the LeDeR has been unclear in the past, but we have now received clear direction from NHS England that the LeDeR programme will continue, albeit with some changes in the management of the system regionally.

4. Governance Arrangements

4.1 Governance relates to how organisations are managed, directed and held accountable for achieving strategic and operational objectives. Appendix 1 demonstrates the local arrangements within the terms of reference for both the Cumbria and North East Learning Disability Mortality Steering Group and Service Improvement Groups (SIG) across the local area. There is lay representation on all groups from the learning disability community and more recently Durham Carer's association.

4.2 Members of the multiagency SIG are responsible for ensuring the learning from LeDeR reviews is shared within their respective learning disabilities teams and that they contribute toward improvement plans. Minutes from SIG, including updates on the thematic action plan are shared within the Durham, Darlington and Teesside Mental Health and Learning Disabilities Partnership, highlighting any recommendations and escalating any concerns regarding the provision of services as necessary.

4.3 Learning from reviews, concerns and recommendations are also escalated to the local safeguarding adult boards (SAB) via annual reports and referral into Serious Adult Review panel as necessary.

5. Local Area Deaths

5.1 The main causes of death as described in Part 1(a) of the death certificate from completed reviews was predominantly pneumonia or aspiration pneumonia and various types of cancer. To a lesser extent, cause of death was described as sepsis, heart failure, pulmonary embolism, frailty of old age, dementia, epilepsy and multi organ failure. Further learning and analysis regarding cause of death for people with a learning disability is awaited from the fourth annual LeDeR

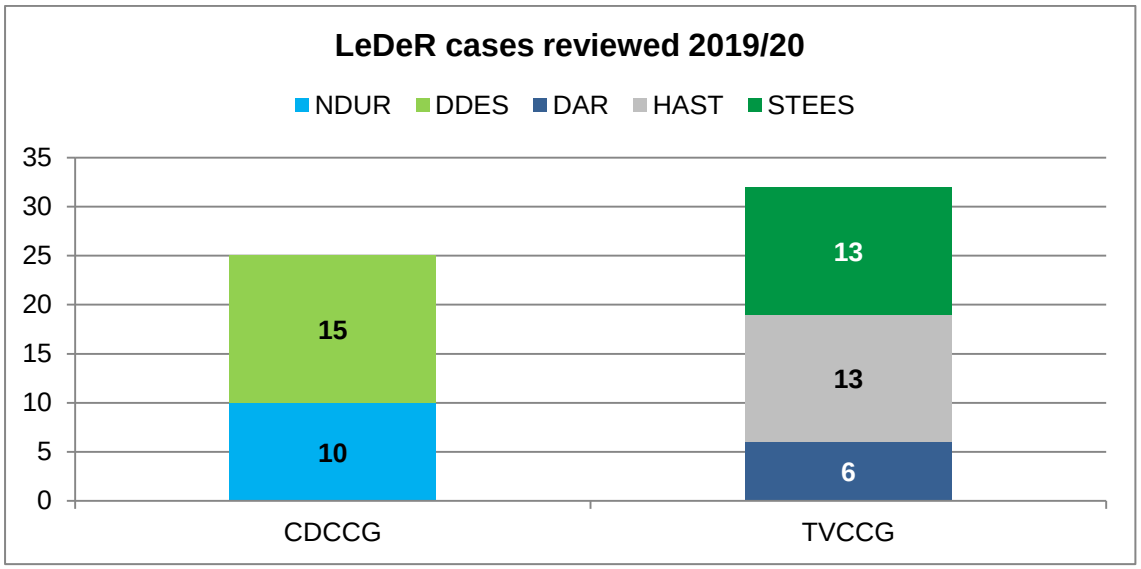
report, due to be published imminently.

5.2 Issues regarding inaccurate reporting of the cause of death nationally are well recognised, hence the new medical examiners role and whole programme of work led by NHS Improvement[3]. The role of the national medical examiner is to provide professional and strategic leadership to regional and NHS Trust based medical examiners.

6.0 Learning from Reviews

6.1 The information entered onto SIRMS can be interrogated for local information on lessons learnt and recommendations. The system has been configured to capture relevant information taken directly from completed LeDeR reviews. This has enabled the CCG to undertake analysis, identify the learning, note recommendations and track implementation of improvement.

6.2 There have been 57 completed LeDeR reviews recorded into SIRMS during 2019/20. The graph below shows the number of LeDeR reviews grouped by predecessor CCG areas:



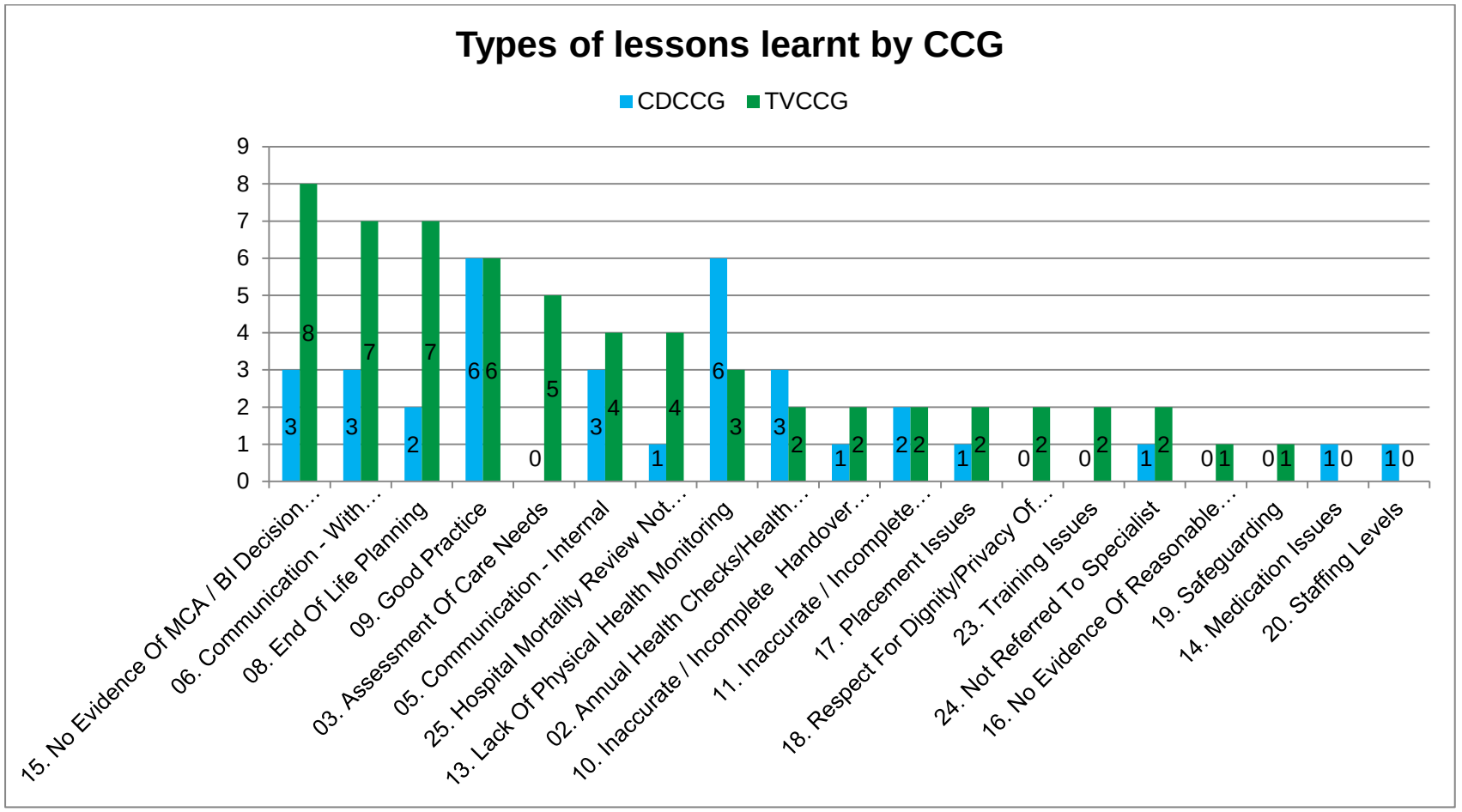
6.3 The lessons learnt taken from each completed review is categorised into the following 25 areas:

Lesson learnt	
01. Advocacy Issues	14. Medication Issues
02. Annual Health Checks/Health Action Planning	15. No Evidence Of Mental Capacity Assessment / Best Interest Decision
03. Assessment Of Care Needs	16. No Evidence Of Reasonable Adjustments Being Made

[3] https://improvement.nhs.uk/resources/establishing-medical-examiner-system-nhs/

04. Communication - External	17. Placement Issues
05. Communication - Internal	18. Respect For Dignity/Privacy Of Patients
06. Communication - With Patients/Carers	19. Safeguarding
07. Delayed Discharge - Care Package Not In Place	20. Staffing Levels
08. End Of Life Planning	21. System/IT Issues
09. Good Practice	22. Timeliness Of Review
10. Inaccurate / Incomplete Handover Information	23. Training Issues
11. Inaccurate / Incomplete Documentation/Assessment	24. Not Referred To Specialist
12. Incorrect Diagnosis	25. Hospital Mortality Review Not Completed
13.Lack Of Physical Health Monitoring	

6.4 The graph below shows the number of lessons learnt per category type for each predecessor CCG



6.5 The information gathered from SIRMS indicate there are 8 categories which make up 80% of the lessons learnt. The numbers of lessons learnt are shown in brackets below, with examples taken directly from individual LeDeR reviews in italics:

No evidence of Mental Capacity Assessment (MCA)or Best Interest (BI) Decision Making (11)

"Care providers reported informal discussion being held with family members, however there was a lack of any evidence regarding mental capacity assessment being carried out or how much XX was involved in his treatment options"

"No evidence of MCA forms 1 and 2 Best Interest Decision Making forms being completed. Confusion about capacity across the different care sectors and who has responsibility for this"

"Capacity assessments not carried out when fast tracked to CHC funding"

"Best interest decision was made in hospital with clinicians and family but no record of a mental capacity assessment ever been completed"

"DNACPR in place, but no record of mental capacity status or assessment. Best interest discussion held with family member by telephone call, other professionals not involved"

Communication - With Patients/Carers (10)

"No evidence that XX was ever told that his cancer was now terminal, as it was felt he probably wouldn't understand, despite having some insight when originally diagnosed"

"XX did not receive any interventions or advice around stopping smoking or help with withdrawal symptoms which clearly had a massive impact on his behaviour when he could no longer go outside for a smoke"

"The family want to share that the weekend staffing at XX hospital was visibly reduced which had an impact on quality of care and communication"

"XX must have been very frightened during his stay in hospital. He had no communication or very little and appeared to go in on himself/give up. Staff kept calling him by his first name as opposed to preferred name"

"Although the care provided by the Care Home was good, there were problems with communication and being kept up to date as XX had lots of different Social Workers"

End Of Life Planning (9)

"XX was admitted to hospital needlessly due to not having an emergency health care plan. Primary health care professionals completed a DNACPR but no EHCP to accompany it"

"Families perception that they have to battle for their loved ones to stay in their usual place of residence or "home" environment as needs increased toward end of life"

"Care Home felt unable to meet XX's increasing physical health needs so he was moved to another Care Home weeks before his death"

"XX was never told of her diagnosis or that she was nearing the end of life. Lack of confidence on behalf of the nursing and medical staff"

"The ECHP could benefit from improvement to ensure that sufficient details are included to support carers accessing it have all the details that they require to provide good care and respect the wishes of XX and their family"

Good Practice (12)

"As part of the multiagency Herbert Protocol, XX had a completed identification proforma which was available for the care home to use if ever she was lost. This helped to minimise risk and keep her safe"

"Reasonable adjustments XX was always seen by the same gastro-intestinal consultant at Hospital and was always allocated an appointment slot at the end of clinic to allow for more time for him and his mother and letters appear to have been written in Easy Read format" .

"Following non-attendance for cancer screening, one Care Home had been taught on how to do simple breast examinations which was then taught to the residents"

"Excellent examples of cross specialty working with the family of a young person with extremely complex needs, requiring specialised equipment and a complicated care package. Mum was actively involved with all aspects of XX's care and supported by professionals to take the lead via personal health budget. Mum identified that excellent support had been provided to her by the CHC team, who she said organised XX's care package in such a way that it provided clarity to everyone involved"

"Staff used pictures cards and a pictorial planner when XX was first diagnosed, his care was consistent from the Day Centre through to 24 hour care. Within the service the staff turnover was very low and many of them had known XX for 15-20 years. This gave them the knowledge to provide consistent person centred care, using previous experience to enrich his life once he was diagnosed with dementia"

“Support during hospital admission by the residential care home who went above and beyond, even when XX had been discharged from their care as they knew he had no family involvement”

"Staff at the supported living unit went above and beyond to provide support for XX. When XX wanted to go to college they advocated on his behalf. When XX was in hospital, they stayed with him in case he woke up and was frightened. When he died the staff picked out clothes for him to wear and asked for his favourite food, a pork pie, his watch and radio be placed in the coffin. Family stated that XX loved the staff and they loved him and treated him as a member of the family”

Assessment Of Care Needs (5)

“Care home staff did not recognise the overall decline in XX condition and that they were approaching end of life, therefore there was a delay in being on end of life pathway”

“Poor uptake of cancer screening because client did not attend, but no evidence of follow up or what measures were taken to improve attendance or consideration of reasonable adjustments”

“Lack of monitoring of weight and no referral to SALT or dietician to optimise health outcomes”

“No record of why XX did not attend for Annual Health Check or what reasonable adjustments had been considered to support him with attending the surgery”

Communication – Internal (7)

“Phobia to needles and physical examinations not communicated to health facilitation team who may have been able to do some desensitising work with XX”

“Communication between the hospital and his carers and care coordination team could have been improved. Confusion about why he was being admitted to the Care Home”

“Poor communication during respite care at home which meant staff did not know how poorly XX had been and that he had been treated by GP as temporary patient”

“Poor communication with the Care Home on discharge from hospital which meant that there was a delay in XX getting his new medication”

“Lack of clarity around EHCPs and discussion with the patient and their families/carers about what they want to happen in the event of deterioration”

"Poor planning at 6 monthly care reviews, especially around the accumulated personal finance and how this could have been spent to enrich XX life prior to his death"

"XX did not receive a full health check on transfer to his new GP practice however it had been some time since his last annual health check and this resulted in a delay in XX having his bloods rechecked"

Hospital Mortality Reviews Not Completed (5)

"Lengthy delays in getting any information on the hospital mortality review"

Lack of Physical Health Monitoring (9)

"*No evidence of re- referral to SALT or dietician to optimise health outcomes, XX died from community acquired pneumonia"*

"Whilst it is optional for GPs to do a health check for new patients, this should happen for vulnerable groups as soon as they are registered. This might have picked up the health problems earlier"

"The residential home did not refer to dietician when weight was below healthy BMI"

"Did not attend annual reviews at GP surgery - father wrote to surgery declining. No capacity or assessment undertaken to ascertain XX's views or referral made to Health Facilitation team who may have been able to discuss with XX and his family to alleviate anxieties"

"XX had a significant number of respiratory/chest inflections in the 12 months preceding his death combined with unintentional weight loss. Combination of clinical indicators should have indicated further investigation, XX died from lung cancer"

6.6 It is interesting to note from the data that there have been more lesson learnt identified in relation to the 8 categories above (apart from lack of physical health and good practice), in the Tees Valley CCG compared to County Durham CCG. This may be due to more learning being captured within Tees Valley, by the designated reviewer.

6.7 We also know from the more recent learning from LeDeR that a range of issues have come to light regarding inappropriate use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders, which can be associated with MCA/BI decision making processes. A regional letter from NHSE/I has been circulated to all Chief Officers and a further letter from the Director of Nursing (appendix 2) has been cascaded to local teams, in addition to NICE guidelines.

7.0 Grading of Reviews

7.1 University of Bristol adopts the following criteria for grading LeDeR reviews:

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.

7.2 The following table illustrates the overall grading of reviews 2019/20 for the local area:

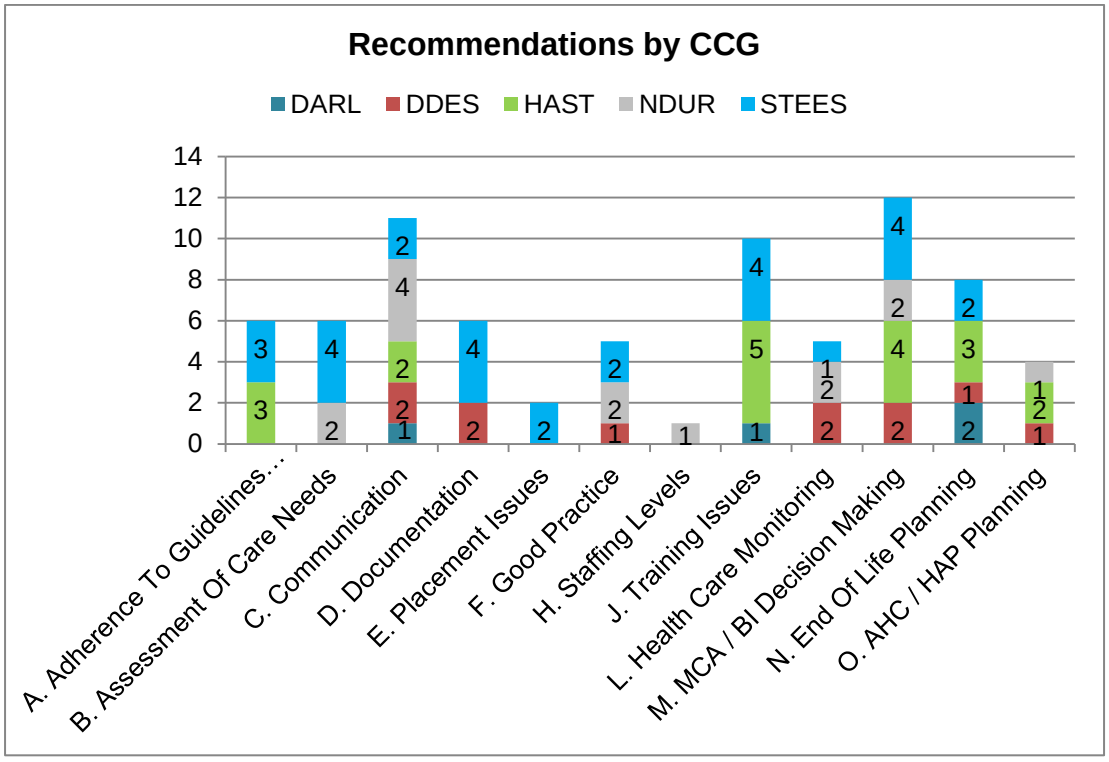
Overall number of reviews	Grading 1	Grading 2	Grading 3	Grading 4	Grading 5	Grading 6	Not specified on LeDeR system
X 85	4	41	18	4	1	0	16

Whilst it is pleasing to note the majority of reviews are graded "good care" the local area is committed toward improving the number of "satisfactory" episodes of care and fewer episodes whereby care fell short of expected good practice for people with a learning disability, by raising awareness to the issues identified within the reviews and progressing the local area action plan (appendix 3)

8. Recommendations and Priority Areas

8.1 It is from the lessons learnt that the recommendations emerge and the priority areas for improvement are identified. The recommendations are tracked via the SIRMS system and themes and trends discussed at both the SIG Group meeting and local LeDeR reviewer team meetings. Case studies and learning are also shared at the North East & Cumbria Learning Disability Network.

8.2 The graph below outlines the recommendations made by respective predecessor CCG locality:



From the data above it is possible to identify key areas for the CCGs to inform the development of actions, which are also in keeping with national directives. The four most prevalent are:

- MCA/BI Decision Making
- Communication
- Training Issues
- End of life planning

8.3 In the main the recommendations from completed reviews are reflected within the priority areas of work currently underway as demonstrated in the Strategic and Local Area Action plans (appendix 3).

8.4 The local priorities have been driven by the intelligence taken from the LeDeR database, information collated from the SIRMS system and local soft intelligence. This informs discussion at the SIG Group who then agrees priority areas of work. The key areas for improvements have been identified as:

- Improving the understanding and implementation of MCA/BI decision making processes in both primary and secondary care
- Improving communications and raising awareness of the issues identified within LeDeR reviews to further increase the uptake of annual health checks and cancer screening
- To implement a training programme for health and social care workforce, to embed training into practice, in particular with regards to MCA/BI and specific health conditions prevalent to cause of death such as pneumonia, dysphagia, acute illness, sepsis, alongside national initiatives

- Improving End of Life Care for people with a Learning Disability

9. Achievements to date

9.1 The process for completing reviews within specified targets is clearly starting to improve, following the successful recruitment of 3 whole time equivalent LeDeR reviewers in January 2020 and April 2020, although during the COVID-19 pandemic, these staff were redeployed and the SIG temporarily suspended. The local area is now back on track to meet the specified target of completing all reviews within 6 months of notification.

9.2 Training on MCA is included within mandatory safeguarding training for all practitioners, however County Durham CCG has complemented this by providing training sessions for Practice Managers on how they can support MCA/BI decision making processes within Primary Care to ensure this is "everybody's business". The session included a presentation from a Practice Manager based on a patient story following "did not attend" record and was very well received. Planning is also underway to initiate an 'Act on Capacity' awareness raising campaign to include information leaflets and adding MCA prompt onto the Annual Health Check template with links to the MCA1/2 forms.

9.3 There has also been numerous other training sessions held throughout the year in a wide variety of settings to increase the understanding and objectives of the LeDeR programme and share the learning. Examples include dedicated sessions on dysphagia, pneumonia, sepsis and constipation for Care Homes and the "Staying Alive Event" held in Redcar in February 2020. Regional initiatives such as the *"Stop and Watch" and "Let's talk about Poo"* are widely shared at such events and health inequalities highlighted.

9.4 Local authorities have included health colleagues in their training for local providers, in particular to raise awareness around Annual Health Checks and Cancer Screening and local groups such as the "Staying Alive" and "Patients Congress" have received updates on LeDeR, the learning to date and recommendations.

9.5 Approximately 2.0 % of the population will have a learning disability[4] and we know through our learning disability registers that only 0.5% on average have been identified. It is vitally important that those who need additional support are recognised in order to achieve positive health outcomes. A top tips guide to understanding the classification of a learning disability, identification tools and how to use them in primary care to ensure registers are refreshed and kept up to date has been produced by the CCG clinical lead for learning disabilities. This has been widely circulated, well received and will be reiterated in future training sessions.

[4] https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability

9.6 Work is underway to ensure that EHCPs (Emergency Health Care Plans) are clinically appropriate, accurate and timely to improve communication across the local area. We know that well written EHCPs can enable the individual wishes of patients to be respected, including their choices around end of life planning. The LeDeR review team, clinicians and commissioning delivery team have worked together to undertake a review of the current practice and design a revised process.

This work includes the development of County Durham and Darlington NHS Trust wide standard operating procedure, roll out of electronic EHCP template across clinical systems, improving the recording of EHCPs within ambulance systems, developing a competency framework for clinicians around EHCP decision making (which will include MCA/BI considerations) and a training package delivered to community nursing staff.

In addition to this, the learning disability health facilitation team have been working with the local authority to identify those most vulnerable with profound learning disabilities to undertake specific work on their EHCPs and support decision making around DNACPR during the COVID -19 pandemic.

9.7 Acute liaison work around flagging of learning disability patients within NHS Foundation Trusts and analysis of admissions and trends in health at point of admission has been undertaken. This includes frequent attender multiagency meetings; follow up of patients recently discharged from hospital and the development of clinical pathways for such conditions as epilepsy and constipation.

9.8 A comprehensive and user friendly “Cancer Screening Resource for people with Learning Disabilities” for primary care in partnership with the northern alliance and learning disability network has been devised, professionally edited and well received.

9.9 North Tees and Hartlepool NHS Foundation Trust has worked hard to ensure that learning disability training is in place (face to face and e-learning) and mandatory for all staff. This action was taken following a LeDeR review which highlighted the need for all clinical staff to have greater understanding of learning disabilities. The LeDeR reviews also demonstrated that the Deprivation of Liberties Safeguards (DoLs) process was robust and embedded into practice within the Trust, who have also made funds available to enable supported carers to stay in the hospital with patients with a Learning Disability during their hospital stay.

9.91 There has been recognition that practice nurses may benefit from additional training around physical examinations for people with a learning disability at their annual health checks. Work is in progress with the CCG Practice Nurse Links in conjunction with Teesside University to ensure this is rolled out locally.

9.92 Following the issues raised by a family regarding accumulated personal finance not being spent to enrich her brother’s life, Hartlepool Borough

Council property and finance team devised a more robust system to monitor a person's finances and avoid where possible a client accumulating too much capital in preference to this money being used to improve quality of life. Middlesbrough Council have also committed to improving their care home quality assurance processes to include review of respite clients' documentation, following the learning from a LeDeR review and all councils recognised the need for more joined up communications around welfare benefits advice.

9.93 There has been extensive work undertaken by the Macmillan Cancer Support team in collaborative with the North East and Cumbria Learning Disability Network and local area (appendix 6) to ensure the learning from LeDeR is taken forward. This includes "Margaret's Story" co-produced training which was a powerful example of how participants need to stop and think about how we can better support people with a learning disability and what good quality care looks like.

10.0 Local Incentive Scheme and National Comparison of Data

10.1 To further improve outcomes for people with learning disabilities and in addition to the national targets set for annual health checks and cancer screening, the local area has included the following criteria within the Local Incentive Scheme:

- All GP practices must have an identified clinical lead for learning disabilities
- Learning Disability registers must be updated in accordance within Royal College of General Practitioners guidance
- 100% uptake for flu vaccine for people with learning disabilities

It needs to be noted however, that suspension of the 2019/20 Quality Outcomes Framework and Local Incentive Schemes (LIS) was agreed locally due to the increasing pressure on practices due to COVID-19

10.2 The table below illustrates comparison data regarding nationally agreed performance indicators:

Summary of 2019/20 LD activity

	County Durham		Tees Valley		National Data 2018/19	
Population	551031		705081		with LD	no LD
LD Register	3764	0.68%	4451	0.63%	0.50%	
LD Annual Health Checks	2282	66%	2571	64%	56.10%	
Bowel screening	441	65%	534	63%		61%
Breast screening	217	53%	240	49%	49%	64.30%
Cervical screening	364	41%	374	34%	33.70%	74.70%
Flu vac	2040	54%	2391	54%	44%	60%

(Source: NECs Primary Care Data Quality Team 6th July 2020)

10.3 Whilst pleasing to note the local area is achieving above the national average in all areas, there are stark difference in the number of people with learning disabilities attending for breast and cervical screening in comparison to the general population and significant challenges regarding flu vaccination.

11.0 STOMP

11.1 Stopping the overprescribing of psychotropic medication (STOMP) is a long-running national campaign to review the inappropriate use of therapeutic treatments in people with learning disabilities[5]. The CCGs have commissioned a specialist service from our local Mental Health Provider (TEWV) to review adult patients with a learning disability and/or autism solely under the care of primary care who are prescribed a psychotropic medication for the management of behaviours that challenge.

11.2 A key line of enquiry for LeDeR reviews is exploring whether a person is either currently or has historically been prescribed antipsychotic medication and whether there has been an active attempt to reduce or withdraw this treatment where it may not be clinically necessary. The learning disability nurse recently employed by the CCGS as a LeDeR reviewer is able to provide advice and appropriate challenge regarding the use of psychotropic medication and in the case of XX to explore the rationale of prescribing psychotropic medication as part of their care.

12.0 COVID- 19 Pandemic

12.1 As the COVID-19 pandemic unfolded toward the end of 2019/20 LeDeR reviews were temporarily suspended as staff were redeployed to front line duties, however a great amount of work was undertaken during this time to protect our already vulnerable learning disability community. This involved the regional network, CCGs, acute learning disability teams, health facilitation team and local authorities all working together to ensure appropriate measures were in place such as communications, shielding and wrap around support. Daily then weekly calls were made to all specialist care providers, with support from a learning disability nurse. Examples of work undertaken during this time can be seen in the Covid-19 Resource pack (appendix 5)

13.0 Resources and Funding

13.1 The local area is fully committed toward learning from deaths for people with learning disabilities, however there have been issues with identifying available reviewers, who primarily have been asked to complete reviews in addition to their substantive posts. Various pockets of funding have been made available to the CCG by NHS England, which has been utilised to pay clinicians to undertake reviews in their own time.

[5] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

13.2 Following a successful business case proposal to the CCG and Mental Health and Learning Disability partnership commissioning group, funding was agreed for 2.0 WTE Band 7 Leder reviewer posts. In addition to this, funding was also agreed for another 1.0 WTE Band & LeDeR reviewer post from the successful bid submitted to NHS England North.

13.3 It needs to be noted that funding for the above posts have been agreed for a 2 year period only and will expire 1st April 2022 which will pose a significant risk to the local area going forward. We have received clear direction from NHS England that the LeDeR programme is to continue and that local areas need to ensure sustainability in the implementation of the programme. A further paper will be taken to Executive Committees for decision regarding future funding of these posts.

14.0 Summary

14.1 The local area has undertaken a comprehensive programme of work in relation to implementing the LeDeR programme and learning from deaths in order to address premature mortality and challenge inequalities faced by many people with a learning disability. The CCGs are able to demonstrate compliance with the NHS Operational Planning and Contracting Guidance and have better systems in place to compare findings with next year's annual report to see whether lessons have actually been learnt and improvements made where necessary.

15.0 Recommendations

15.1 The CCG Quality Committee is asked to:

- Note how LeDeR has been implemented with partners across County Durham and Tees Valley
- Acknowledge the learning, recommendations and progression of action planning
- Approve the report for submission to respective Governing Body, Safeguarding Adult Board and Health and Wellbeing Board.

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Date: 10th July 2020