County Durham Care Partnership

NHS County Durham Clinical Commissioning Group

Official

Learning Disabilities Mortality Review (LeDeR) Local Area Annual Report 2020/21 (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.

1. Introduction

1.1 This is the second annual LeDeR Local Area report on behalf of County Durham Clinical Commissioning Group (CDCCG) and Tees Valley Clinical Commissioning Group (TVCCG) 2020/21. The CCGs and colleagues within the local area of County Durham and Tees Valley remain fully committed toward learning from the reviews of deaths of people with a learning disability to influence change and implement service improvements across health and social care where necessary.

1.2 This report needs to be read in conjunction with the University of Bristol 4th Annual LeDeR Report & corresponding NHS Action from Learning Report 2019
http://www.bristol.ac.uk/sps/leder/resources/annual-reports/
https://www.england.nhs.uk/publication/leder-action-from-learning-report/

2. Background Information

2.1 Health inequalities and poor health outcomes for people with a learning disability have been well documented. The LeDeR programme was set up in June 2015 in response to ongoing concerns about the likelihood of premature death for people with a learning disability. The programme has been commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and led by the University of Bristol.

2.2 The LeDeR programme supports local areas in England to review the deaths of all people with a learning disability over the age of 4 years, using a standardised review process. Statutory processes such as the Child Death Overview Panel (CDOP), Safeguarding Adults review, Domestic Homicide, Serious Incident, or complaints investigations take precedence over the LeDeR process although the learning is including within LeDeR reports.

2.3 The LeDeR programme is currently undergoing significant change, as detailed within the national LeDeR policy, published in March 2021. Changes include a new data base run within the NHS, a two-stage review process and later in the year reviewing the deaths for people with autism.

2.4 Work is underway to consider how the new policy will be implemented within the CCGs and emerging integrated care systems, however the purpose of this report is to share the learning and recommendations from LeDeR reviews completed between 31st March 2020 - 1st April 2021 by CDCCG and TVCCG, the action planning and achievements to date.

3. Local Arrangements

3.1 There are four experienced members of staff (x3 WTE posts) employed by CDCCG whose primary role is to ensure mortality reviews for people with a learning disability are completed within nationally agreed targets. They work across County Durham and Tees Valley and have a sound breath of local knowledge and established relationships across health and social care from their previous roles within Safeguarding, Continued Health Care, Learning Disability teams, NHS Trusts and Royal College of Nursing Learning Disability forums. This has been hugely beneficial when gathering necessary information for the reviews and providing both challenge and support. Unfortunately, these are fixed term posts which will expire in April 2022 when the additional NHSE funding will expire.

3.2 The reviewers are supported by the CCG Quality and Development Manager who has responsibility for the local area contact (LAC) role, alongside the Director of Nursing who chairs the regional LeDeR steering group. The North England Commissioning Support (NECS) data team contacts the LAC following the death of a person registered on the Primary Care learning disability register and the process of allocation to reviewer begins. CDCCG and TVCCG have consistently had the highest number of notifications in the region due to robust systems in place and the highest number of completed reviews.

4. Governance Arrangements

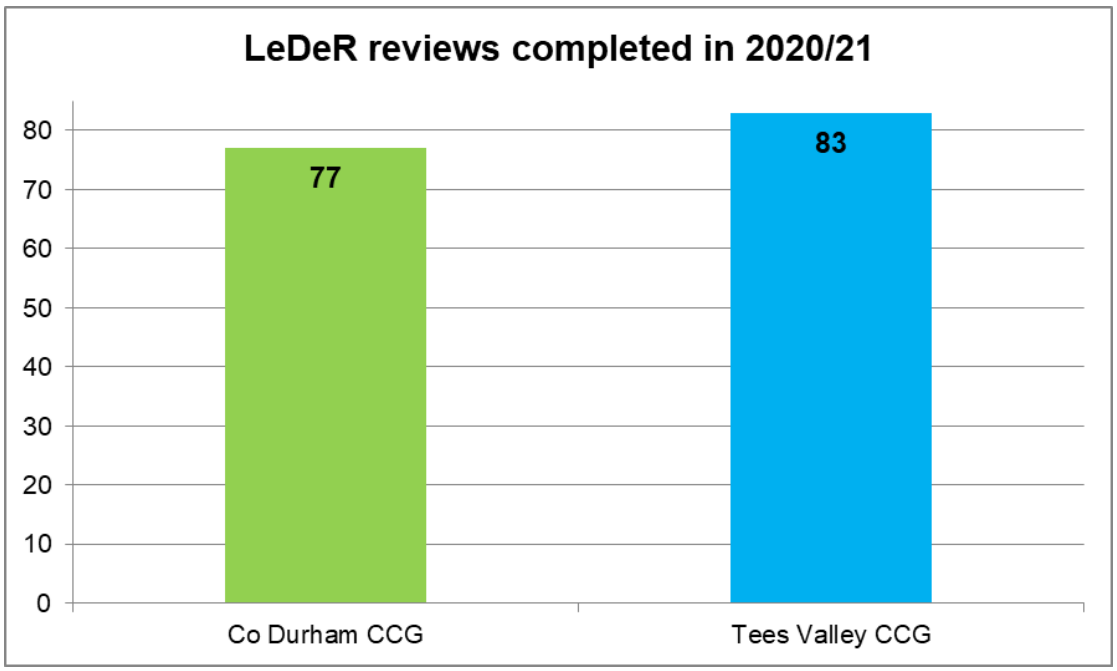
4.1 Both CDCCG and TVCCG have established multiagency Service Improvement groups (SIG) with lay representation from the Partnerships & Engagement Learning Disability groups and Durham Carers. The groups meet monthly to quality assure LeDeR reviews and progress service improvement workplans. The SIG is accountable to the Learning Disabilities Commissioning group and the NHS Durham Darlington and Teesside Learning Disability and Mental Health Partnership.

4.2 The annual report and learning from LeDeR updates are presented to the respective CCG's Executive Committee, Governing Body, Safeguarding Adults Board and the local Health and Wellbeing Board. Local updates and case studies are also shared with the Cumbria and North East Learning Disability Mortality Steering Group.

5.0 Learning from Reviews

5.1 Information is gathered from a variety of sources by the CCG reviewers who highlight lessons learnt and make recommendations. Completed reviews are then submitted into the University of Bristol data base. To date, there have only been four national LeDeR reports since the programme began in 2015, so a decision was made to utilise the local Safeguard Incident Reporting and Management System (SIRMS) to interpret data at a local level to provide intelligence which can be used by the CCGs to inform improvement. This has enabled the CCGs to undertake analysis, identify the learning, note recommendations, and track implementation of improvement.

5.2 During 2020/21 a total of 160 cases have been entered onto the SIRMs system following completion of the LeDeR review. The table below shows the number of reviews per CCG undertaken during 2020/21.

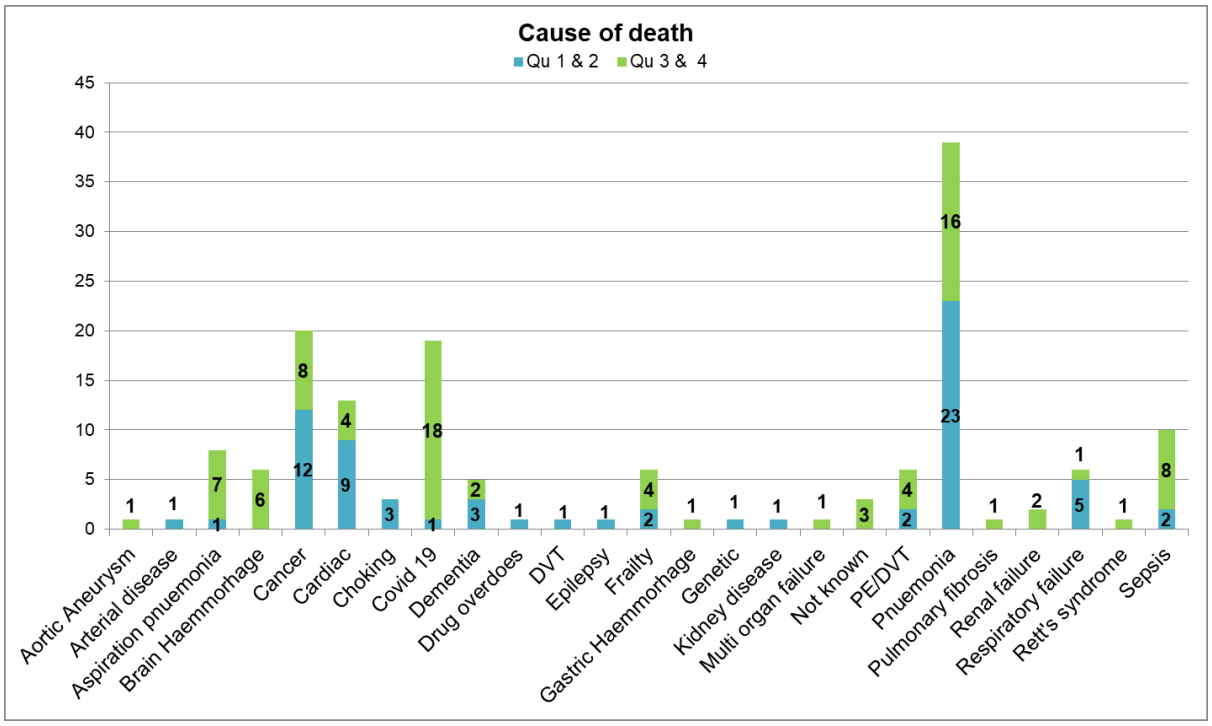


5.3 The purpose of the LeDeR reviews is to understand the care received by patients and their families, identify areas of good practice which can be replicated and share areas of poor practice which can be challenged and improved through the

recommendations made by the reviewers. The focus of LeDeR is that of service improvement and should not be viewed as an incident management process or complaint process but as a service improvement process.

6. Cause of death

6.1 The causes of death from the reviews undertaken by the CCG LeDeR team can be seen in the graph below. In line with the national trend Pneumonia is recorded as the highest cause of death, followed by Cancer (20) and then Covid 19 (19) of the total cases reviewed (88).



6.2 During 2020/21 there has been an unprecedented high number of deaths due to the Coronavirus (COVID 19) pandemic. A study undertaken by Public Health England, published in November 2020, concluded that people with a learning disability in England were up to six times more likely to die from COVID 19. The report from this review can be viewed at: https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary

6.3 Alongside colleagues within the CCG and across the local area, the LeDeR reviewers needed to prioritise other areas of work due to the COVID pandemic during 2020/21. This included support for primary care and social care colleagues in a variety of ways not limited to but including specialist infection prevention and control advice, ensuring the adequate supply of personal protection equipment, providing additional clinical support with vaccination capacity and the supply of easy read information

specifically targeted at people with a learning disability to support their understanding of the pandemic and vaccination programme.

7. Lessons Learnt

7.1 The following graphs outline the information collected in SIRMs relating to the lessons learnt during the review process as identified by the CCG LeDeR reviewers.

The top ten lessons learnt for 2020/21 were:

Lesson	Total
Good Practice	**76**
Lack of Physical Health Monitoring	**33**
Inaccurate / Incomplete Documentation/Assessment	**29**
No Evidence of MCA / BI Decision Making	**28**
Annual Health Checks/Health Action Planning	**26**
Assessment of Care Needs	**22**
Communication - Internal	**21**
End of Life Planning	**20**
Not Referred to Specialist	**17**
Communication - With Patients/Carers	**16**

Good practice was the most frequently identified lesson learnt (76) which is positive. Lack of physical health monitoring (33), inaccurate/incomplete documentation (29) and no evidence of MCA/BI decision making (28) and annual health checks/health action planning (26) the next highest. A total of 48 lessons learnt related to communication (internal, external or communication with patients and/or carers). The information gathered from SIRMS indicate the top 10 categories make up 80% of the lessons learnt.

7.2 Examples of lessons learnt cited by LeDeR reviewers:

Good Practice

"Good primary care support to care home. Good communication with relatives. Relatives views fully respected and considered. XX died at usual place of residence with those known to her and able to best meet her needs. Good advocacy enabled best interest decision to be adhered to allowing all nursing care to be provided in the home. Staff were trained by hospital to administer buccal midazalom used for seizure control to prevent further hospital admissions which were becoming very distressing.

DNs were on call and supportive. Nurses at attached nursing unit also provided advice and support to enable continuity of care for XX until her death".

"Good relationship between care home and GP for accessing GP advise quickly for XX"

"Good safety net advice from hospital - dysphagia letter came with clear warning signs both acute and chronic to alert carers and primary care as to what to look out for and when to refer back"

"Each person in residential care has their own key worker, own goals agreed and set, regularly reviews and individualized care which includes choosing own décor for bedroom and extended family being part of the wider community and central to decision making"

Lack of Physical Health Monitoring:

"XX did not receive regular age relative cancer screening. Care Home and GP surgeries to focus on ensuring age relative cancer screening for those with a learning disability to ensure screening appointments are attended and/or appropriate capacity assessment or best interest assessments completed. To consider reasonable adjustments that may be required to ensure attendance"

"XX had a significant number of respiratory /chest inflections in 12-months preceding death, combined with unintentional weight loss. Combination of clinical indicators should have alerted consideration of lung cancer diagnosis."

"There were many professionals involved in XX's care. There did not appear to be any evidence of one person leading the care or MDT's being held in relation to the deterioration in his physical health"

"XX did not appear to have appropriate pain relief prior to or following her diagnosis of bowel carcinoma"

Inaccurate/ Incomplete Documentation/assessment

"DNACPR form completed by the Consultant without any discussion with advocate, social worker or care provider "

"Staff not feeling confident in following EHCP as feel it is too vague resulting in her being admitted to hospital"

"Hospital passport not present during admission, which would have resulted in XX receiving more appropriate personalized care"

"Despite her terminal illness there is no evidence of a DNACPR or EHCP being completed"

No Evidence of MCA / BI Decision Making: *"There did not appear to be any capacity assessment before consent procedures for endoscopies or prior to surgery. The risks and benefits of surgery were explained on the day of surgery"*
"No evidence of capacity assessment when completing a DNA CPR and/or EHCP"

"The best interest framework did not appear to have been evidenced within the records for XX The use of an IMCA would have safeguarded XX and the health care professionals"

Annual Health Checks/Health Action Planning:

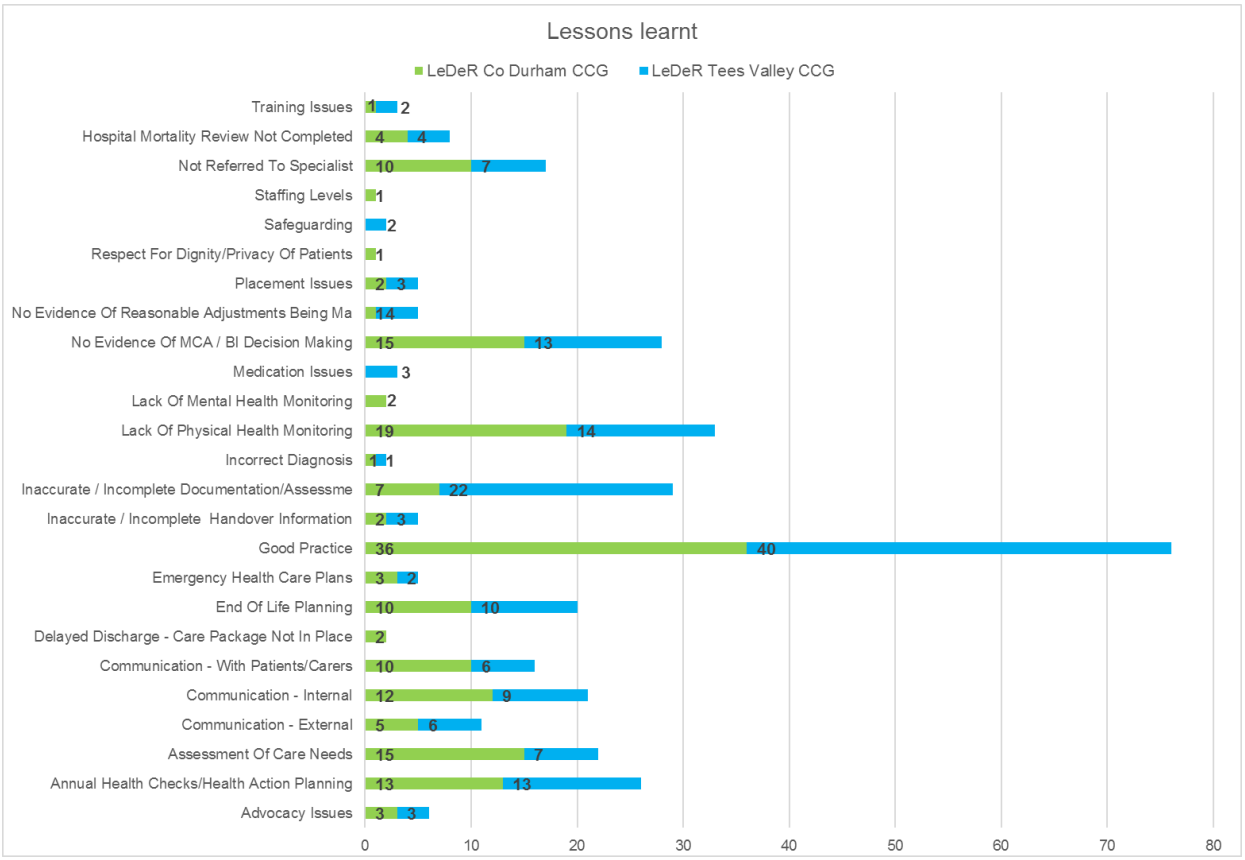
"There were no reasonable adjustments made for XX to assist him through the process of understanding what was going on with his health. This was a missed opportunity"

"AHC - no apparent action plan, which could have clarified what to do in the case of XX having an epileptic seizure or who to contact for advice"

" XX did not have an annual health check within the last 12-months prior to her death. People with learning disabilities are not always able to identify changes in their health or long-term conditions and rely on the support from Primary Care. AHCs are an important process and should include families and other services involved in a person's care. GP practices should take steps to ensure that those who have not attended for an annual health check are contacted to discuss the reasons why"

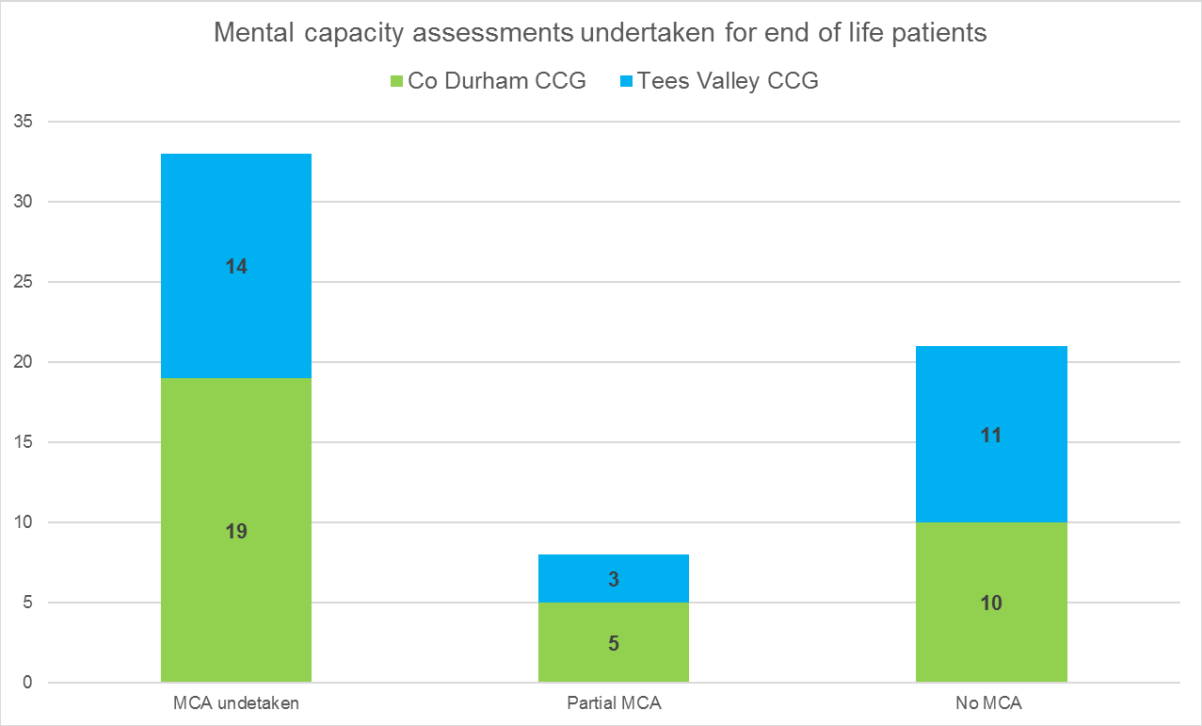
"XX did not attend any annual reviews or cancer screening appointments. There does not appear to be a follow up process if cancer screening is not attended for people with a learning disability. Additional support from community services may be required with the appointment and reasonable adjustments to increase compliance"

7.3 The graph below shows the number of lessons grouped by patient's CCG and by type as categorised by the reviewer based on the information obtained by a variety of sources.

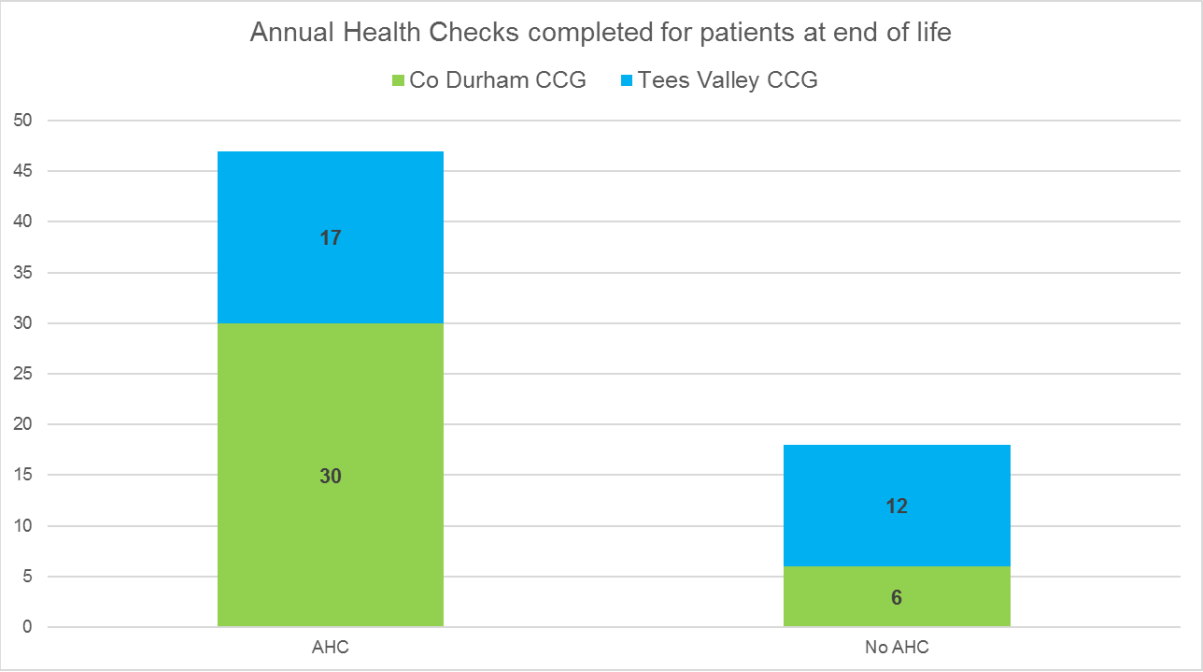


7.4 Good practice is a theme which emerged as the highest reported lesson learnt throughout 2020/21 and is reflective of the areas of care as reviewed by the LeDeR reviewers. It is important to note that both lessons learnt, and recommendations can be very individual to the case being reviewed so it is important to understand the data and review themes and trends emerging as part of this process, often there maybe links between areas and therefore more complex than first thought. For example, a lesson learnt relating to end of life care may also relate to documentation, communication, Mental Capacity Assessment (MCA), and Best Interest (BI) decision making so it is important to understand the detail to support the correct improvements.

7.5 The table below show the number of people identified as being on an End-of-Life pathway out of the total number of completed reviews and the number of MCAs undertaken as evidenced within care records viewed.



7.6 This table shows how many people who were recorded as being on an End-of - Life pathway and had received an annual health check within the last year of life.



7.8 End of life care (EoLC) is often complex and difficult, involving multidisciplinary care coordination to facilitate a positive experience for patients, their families, and carers. It is pleasing to note that of 65 reviews, 47 people had received an AHC within the last 12 months of their life.

7.9 In 33 cases there was evidence of a mental capacity assessment having been undertaken by a healthcare professional and 8 cases of a partial MCA having been undertaken. This would usually indicate that mental capacity had been considered but no formal documentation was available to the reviewer in the persons healthcare record relating to that assessment but rather a record in the notes indicating it had been considered.

7.10 MCA is an identified area of improvement for the CCGs and there has been work ongoing across the year to improve EoLC planning and MCA understanding and application of due process through mandatory safeguarding training sessions and the "Act on Capacity – it's in everybody's best interest" campaign.

8. Grading of Reviews

8.1 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.

8.2 The following table illustrates the overall grading for the 160 completed reviews completed by CDCCG and TVCCG during 2020/21:

Grading of care	**2020/21**
1. This was excellent care (exceeded good practice)	**8**
2. This was good care (met expected good practice)	**89**
3. This was satisfactory care (it fell short of good practice in some areas, but this did not significantly impact on the person's wellbeing)	**44**
4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to cause of death	**17**
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 cause of death	**2**

8.3 Whilst it is pleasing to note most reviews are graded as “good care” the local area is committed to 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 work plans.

8.4 There were two cases where the care fell short of good practice which impacted on the person’s well-being and/or had the potential to contribute to the cause of death. One of these cases involved a care home in Durham and the other involved South Tees Hospitals, although it needs to be noted other agencies also had key roles. Both cases were considered not to meet the criteria for a Serious Adult review and were therefore progressed to the LeDeR next stage multiagency review. This involves holding information sharing meeting with key professionals and family members and agreeing specific actions relevant to the specific review.

8.5 The 17 cases where care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to cause of death involved the following settings:

Setting	**Qu 1-2**	**Qu 3-4**
Care home / home care	4	0
Patient's home	1	1
CDD FT	3	2
NTH FT	2	1
ST FT	1	2

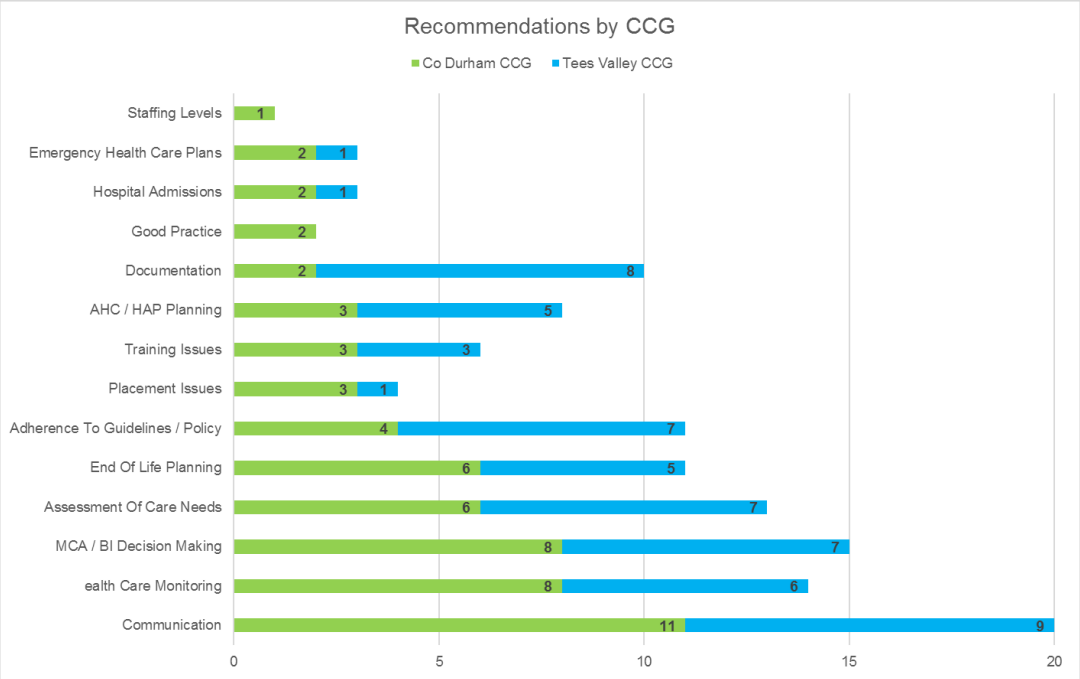
9. Recommendations from completed LeDeR reviews

9.1 The most frequently identified recommendations made by the reviewer relate to communication (20), MCA/BI (15), healthcare monitoring (14), assessment of care need (13) and adherence to guidelines/policy and EoLC planning (11). The frequency of types of recommendations are shown in the table below:

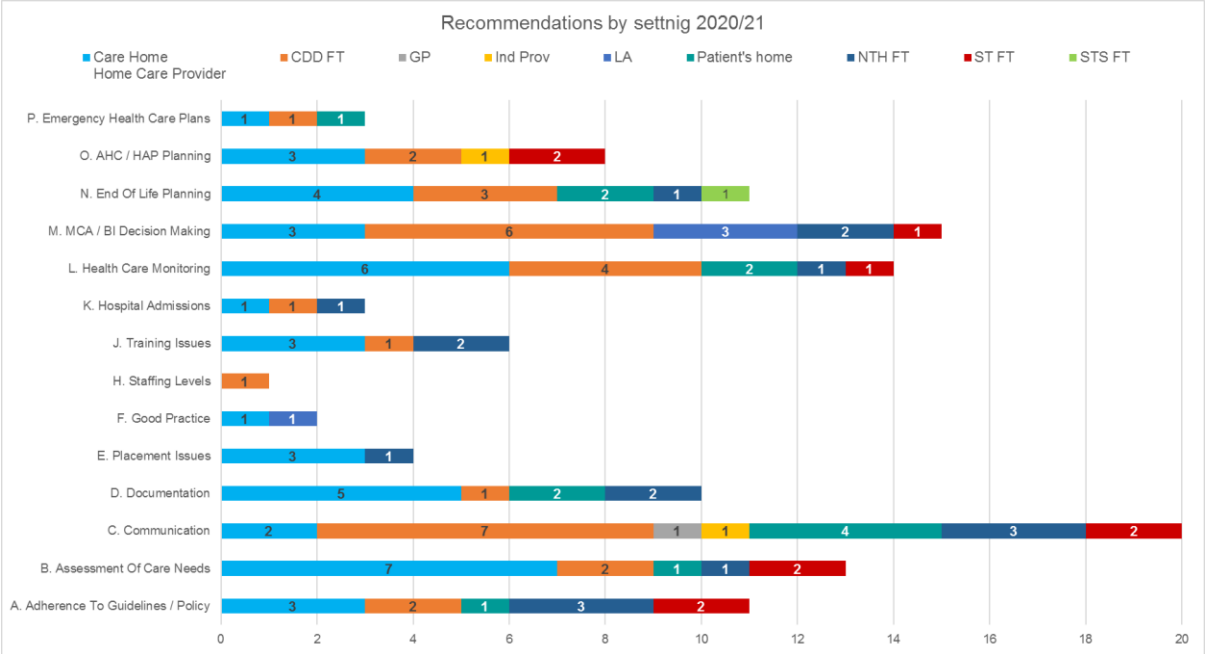
Recommendation 2020/21	Total
Communication	20
MCA / BI Decision Making	15
Health Care Monitoring	14
Assessment of Care Needs	13
Adherence to Guidelines / Policy	11
End of Life Planning	11
Documentation	10
AHC / HAP Planning	8
Training Issues	6
Placement Issues	4
Hospital Admissions	3
Emergency Health Care Plans	3
Good Practice	2
Staffing Levels	1

9.2 The graph below shows the number of recommendations made by patient's CCG area.

Official



9.3 The graph below shows the total number of recommendations by setting. The most highly recorded recommendations relate to communication (20) across all of providers. Assessment of care needs (7) and health care monitoring (6) are highest in the Care home/Home care settings. Communication (7) and MCA / BI decision (6) are the recommendations made most frequently within Co Durham and Darlington NHS Foundation Trusts. The table below demonstrates the recommendations per organisation:



9.4 Recommendations related to Care Homes/Home Care settings total 42 notifications. The number of recommendations relating to Co Durham and Darlington NHS Foundation Trusts total 31 recommendations. South Tees NHS Foundation Trust have 10 recommendations and North Tees NHS Foundation Trust have 18. All these organisations are represented on the relevant CCG working groups to progress improvements.

9.5 The key areas for improvement identified from the recommendations are:

- Communications
- MCA/BI decision making
- Health care monitoring
- Improving assessment of care needs
- End of life care /Adherence to guidelines and policy

9.7 The areas of improvement are complex and cross cutting and often there is overlap between improvements required which will lead to improvement in communications related to specific areas of care. It is therefore impossible to separate out communication; assessment of care needs, adherence to guidelines and policy and healthcare monitoring as individual areas for improvement but rather better to include them in all areas of improvement as requirements for success.

9.8 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 work plans going forward.

10. Achievements to date

8.1 The multiagency Service Improvement Groups have agreed workplan/action plans in place which have been developed by the group from the learning from LeDeR reviews and local intelligence to improve care in the areas identified. Both TVCCG and CDCCG have representatives from local NHS Trusts, local authorities, CCG, primary care, commissioning support and lay representatives on their respective SIG groups.

8.2 Tees Valley achievements to date during 2020/21 include the following:

- Well established SIG to discuss key topics related to learning disabilities, local and regional LeDeR updates, BAME and national developments and reports. Five LeDeR cases are reviewed at each meeting and the themes have been used to inform the development of the Tees Valley LeDeR strategy.

There are 15 key areas of development:

  - Targeted approach to increase Annual Health Checks
  - Improve advanced care planning / end of life care.
  - Complete Best Interest meetings.
  - Complete Capacity assessments.
  - Ensure correct learning disability GP coding.
  - Ensure robust DNACPR.
  - Implement reasonable adjustments.
  - Avoid Covid-19 care complications.
  - Follow-up 'Did not attend' appointments.
  - Avoid where possible, changes in care providers late in life.
  - Confirm correct funding process whilst in hospital.
  - Ensure family involvement in planning care.
  - Complete timely medication reviews.
  - Improve hospital learning disability patient information.
  - Improve the sharing of information between health and social care partnerships.

- North Tees and Hartlepool NHS Foundation Trust working towards the nationally recognised learning disability diamond standards which is a training package and pathways of care for people with a learning disability. A recent LeDeR case review identified outstanding care in relation to support and family care needs.

- South Tees Hospital NHS Foundation Trust employs 15 Learning Disability Registered Nurses (LDRN), 14 of these are employed in an adult nurse role on the wards within neurology, neuro surgical, neuro rehabilitation and spinal

specialities. This has proved such a successful model, with some of the wards going on to employ more than one LDRN. Recently a LDRN was employed to work with the therapeutic care team supporting patients with mental ill health.

- Both North Tees and Hartlepool NHS Foundation Trusts have updated their external website with an 'easy read' button, with the minimum of clicks, people have access to information on Covid-19, Keeping Well for Winter Bulletins and websites providing easy read information/videos.

- In October 2020, a summary report with a gap analysis was compiled, which took the national concerns for people with a learning disability as highlighted in the 4th LeDeR report, looking at the concerns from the Trust's perspective, with relevant action plans.

- In November 2020, an independent review of the learning disability and autism service model used at the Trust was undertaken by NHS England and Improvement in collaboration with local agencies and people with lived experience. Based on these findings and the results of the 2020 NHS improvement learning disability audit, an improvement plan for the Trust's learning disability service is to be presented to the Trust's Learning Disability Partnership Group for approval, before further distribution following the Trust's governance process.

8.3 County Durham achievements to date during 2020/21 include the following:

- Well established SIG chaired by CDCCG to discuss topical issues related to learning disabilities, local and regional updates (including LeDeR), national developments and reports. Five LeDeR cases are also reviewed at each meeting which are used to inform the SIG Workplan (appendices A). There are also monthly LeDeR reviewers' meetings in addition to the SIG, to quality assure reviews and provide clinical supervision/support for the reviewers.

- Work on Emergency Healthcare Plans (EHCP's), as identified within LeDeR reviews as being key to making a difference in the quality of care and assessment of care needs within LeDeR reviews. Following a CCG audit of the quality of EHCP's, subsequent work has been commissioned in CDCCG to improve the quality and accessibility of EHCP's, with the primary objectives being to:

1) Implement systems that facilitate consistent and effective completion of EHCP documentation
2) Create a more coordinated mechanism for sharing EHCPs between care settings

3) Education and training to support the effective creation and use of EHCPs across the system

Improvements to date regarding the EHCP work include:

- A Trust-wide Standard Operating Procedure/policy for creation and effective communication of EHCPs
- Quick reference guideline for tackling EHCPs
- Improved creation of the EHCP
- Pre-population of EHCP template for community services via System One
- Template created for use by the acute hospital (WinDip)
- Mechanism to prompt and code NEAS Special Patient Notes on SystemOne
- Access to patient records via SystmOne in nursing homes included as part of Digital work programme
- Self-assessment competency framework developed for clinicians completing EHCPs
- Locality based alignment of Palliative Care Consultants
- Regular support sessions for community nurses
- Palliative Care on call advice line extended to care homes (part of COVID response)

The Integrated Learning Disability Teams have also been working with Primary Care colleagues to make improvements in the quality of EHCPs specifically for patients with a learning disability both in supporting the development of plans and with training and support for primary care colleagues.

There is still further work to be done focussing on education and training and improved communication with patients and their families and carers to ensure understanding of the use and application of EHCPs.

- Improving the understanding and legal requirements in relation to MCA and BI decision making processes and highlight how this can be empowering for all concerned. To support improved awareness CDCCG developed a 7minute "*Act on Capacity, it's in everybody's best interest*" briefing for primary care colleagues which was widely circulated across the local area. A logo relating to this was created by the CCG communications team and used within e-mail signatories. Work to improve the understanding of MCA/BI decision making is ongoing with training and education for front line staff supported by the local mental health trust colleagues and Safeguarding teams.

- Supporting the local area during the Coronavirus pandemic which for some staff included returning to front line practice and supporting primary care with

the delivery of the vaccination programme. This also involved sharing a vast array of available resources related to learning disabilities with providers from all sectors across the local area, such as the Keeping Well for Winter Bulletins and websites providing easy read information/videos aimed at explaining the rules and guidance related to COVID

- There has been continued efforts to ensure Annual Health Checks (AHCs) for people with a learning disability remain high priority during 2020/21 in order to ensure that people with a learning disability are as healthy as they possibly can be, especially during the COVID pandemic. A national risk stratification tool was utilised locally, and additional resources allocated to the learning disability nursing team, to support primary care and ensure AHCs continued using a bespoke model. Pleasing to note that CDCCG has exceeded the national target of completing 67% AHCs during 2020/21.

- It has been identified within LeDeR reviews that following the AHC, the areas of need are not always communicated effectively within the subsequent personalised Health Action Plan (HAP). The Royal College of General Practitioners has produced a AHC toolkit to support GP's in undertaking the reviews with their patients. This includes ideas on how to make reasonable adjustments for patients with a learning disability. The Integrated Learning Disability Team have been working closely with GPs to improve the uptake and quality of the AHC's, which includes having a robust HAP in place. Further work is planned for 2021/22 to continue with this work and improve the quality of both the AHC and HAPs further.

- County Durham Council have been undertaking work on the roll out of Health Call Digital Work Plan which enables all 95 care homes within the county to monitor and share information about a resident's physical health with health care professionals who can treat, advice and support the care staff in managing the person's physical health. This work is supporting early detection of deteriorating health and enabling health professionals to support care staff in more robust ways than previously they were able and is currently being rolled out to all learning disability providers.

- A pilot of 'Stop over medication of people with a learning disability, autism or both with psychotropic medicines' (STOMP) has been completed and funding received to continue with the work to manage patients on psychotropic medication. Further work is now underway to progress this across the CCG areas.

- We know from LeDeR the most common cause of death for people with a learning disability are related to respiratory conditions. CDCCG have commissioned a local drama group to produce a *"Healthy Happy Lungs"* video in which people with a learning disability present fun exercises to music which

can be done to improve respiratory function. This will be widely shared with all learning disability providers and relevant groups across the local area.

9.0 Recommendations – the quality committee are asked to:

- Note the content of the report and learning/recommendations to date
- Acknowledge the achievements during the last year and progression of workplans
- Agree that health outcomes for people with a learning disability will be a strong focus in the coming year
- Approve the report for submission to respective Governing Body, Safeguarding Adult Board and Health and Wellbeing Board
  CDCCG

Author: *Kim Lawther, Head of Quality & Development CDCCG*
Liz Ward, LeDeR Reviewer CDCCG

Sponsor: *Anne Greenley, Interim Director of Nursing and Quality CDCCG*

Date: *May 2021*