NHS
Northumberland
Clinical Commissioning Group

The Learning Disabilities Mortality Review Programme Annual Report 2019/2020

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*

*Source: Stop People Dying Too Young Group

Glossary of Abbreviations used

CIPOLD	Confidential Inquiry into premature deaths of people with learning difficulties
C(E)TRs	Care (Education) Treatment Reviews
CMB	Clinical Management Board
CNTWFT	Cumbria, Northumberland Tyne &Wear NHS Foundation Trust
DNACPR	Do not attempt cardiopulmonary resuscitation
HQIP	Healthcare Quality Improvement Partnership
IMCA	Independent Mental Capacity Advocate
LeDeR	Learning Disabilities Mortality Review
NECS	North of England Commissioning Support
NHCFT	Northumbria Healthcare NHS Foundation Trust
STOMP	Stopping over medication of people with learning disabilities

Introduction

This is Northumberland CCG's first LeDeR annual report. It has focused on reviews of deaths of people with learning disability completed between 1st April 2019 and 31st March 2020. This report aims to demonstrate actions taken and outcomes from the local LeDeR reviews.

Throughout 2019/20, the CCG has worked in partnership with its stakeholders to ensure progress is made in the delivery of the LeDeR programme and lessons are learnt. The NHS Long Term Plan makes a commitment to reducing the premature mortality of people with a learning disability. The CCG will continue to do that by working with all our statutory partners, service users and their families.

Background

The LeDeR programme is funded by NHS England and commissioned by the HQIP. The overall aims of the programme are:

- To support improvements in the quality of health and social care delivery for people with learning disabilities
- To help reduce premature mortality and health inequalities for people with learning disabilities

The programme was established in response to the recommendations of the CIPOLD. The findings of CIPOLD demonstrated that on average someone with a learning disability dies 15-20 years earlier than someone without. CIPOLD also reported that for every person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so.

The definition of people with learning disabilities as used by LeDeR is the presences of

> *'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development'*

The LeDeR programme supports local areas to carry out reviews of deaths of people with learning disabilities using a standardised review process. This enables identification of good practice as well as where improvements to the provision of care could be made.

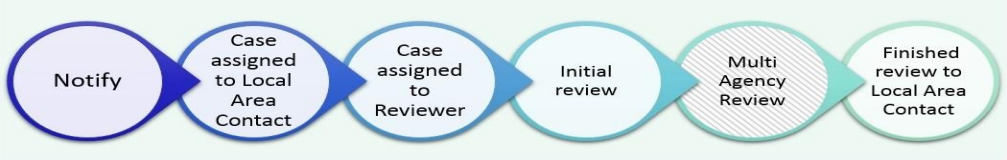


Figure 1: The National LeDeR Process

Figure 1 above illustrates the national process. Anyone can notify the LeDeR programme of someone with learning disabilities who has recently died, and this can be done by telephone or via the website. Every death notified to the programme has an initial review. Some deaths also require a multi-agency review. It is recommended that all families should have the opportunity to be involved in the review of their relatives' death. If a family member is not identified, someone who knew the person well is invited to contribute to the review. Any recurrent themes and significant issues are identified and addressed at a local, regional and national level.

The local process at the CCG for carrying out a LeDeR review is included as Appendix 1.

Northumberland local statement of purpose

Northumberland CCG is committed to the local delivery of the LeDeR programme, and this will continue to be achieved by working with a range of local stakeholders. Local reviews will be promptly allocated and completed within the agreed timescales. Findings will be analysed and learnings will be shared and used to inform service commissioning and delivery, and underpin service improvements.

Governance arrangements

The named person with lead responsibility / Local Area Contact for the CCG is the Executive Director of Nursing, Quality and Patient Safety. She is the link between the LeDeR programme at University of Bristol, the Northeast LeDeR Steering Group, the local Steering Group (Transforming Care Group) and local reviewers. The Executive Director of Nursing, Quality and Patient Safety is supported by two GP clinical leads and they work together to ensure reviews are being carried out in a timely manner and lessons learnt are shared.

A Transforming Care Group is in place in the CCG and its remit including overseeing the delivery of the LeDeR programme in Northumberland. The group is chaired by the CCG's Executive Director of Nursing, Quality & Patient Safety and meets every two months.

The group includes representation from;

- Northumberland CCG
- NHCFT
- CNTWFT
- NECS Medicine Optimisation Team

Exceptions (if any) are escalated to the Quality and Safety Group, which reports to CCG's CMB. The CCG is also accountable to NHS England for the delivery of the programme and the standards/deliverables in the Operational Plan, and regularly provides updates as and when required. .

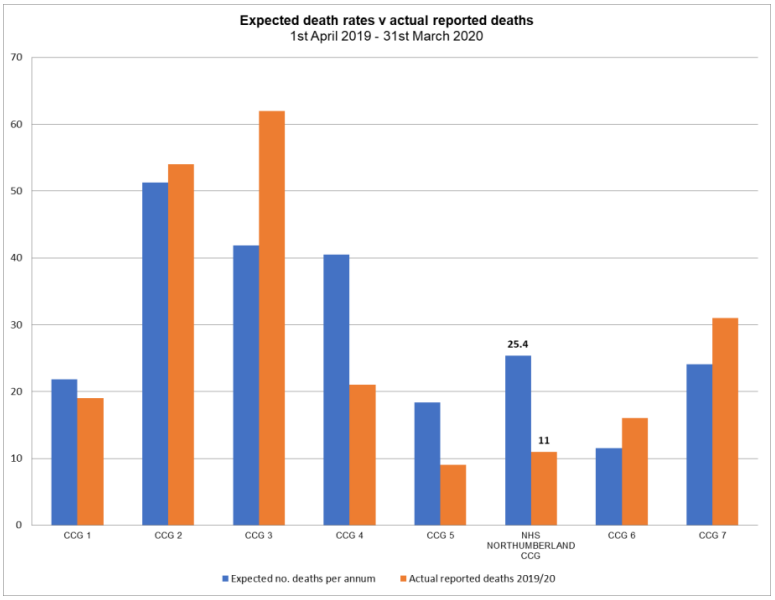
Death notifications and reviews in the Northumberland area

The CCG had reviewed all the cases due to be completed by 31 March 2019 and did not have any backlog cases to carry over.

In the time period of 1st April 2019 – 31st March 2020, 11 death notifications had been received by the CCG;

- 8 reviews were completed
- 1 review was placed on hold due to police investigation
- 2 reviews were unable to start due to the COVID-19 pandemic and they are now completed.

Compared to the expected death rate[1] of 25.4 for Northumberland in 2019/20, the reported number is lower. The chart below shows the comparison of CCGs in the northeast region.



The rest of this report will focus on the 8 reviews which were completed during 2019/20.

The people with learning difficulties included in this report

Gender

3 males (38%)

5 females (62%)

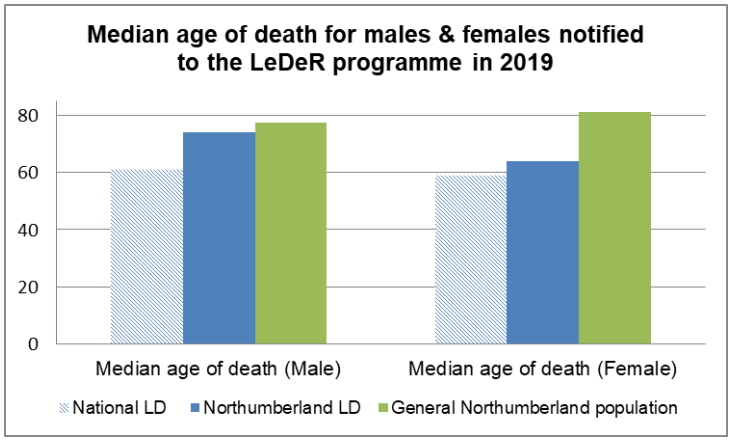
Of the 8 reviews completed in Northumberland, 62% were females. This differs from the national average where over 50% were males

[1] This is based on national analysis on Annual Health Check data, QoF Registers and the age and gender profile of CCGs. The figures are for all deaths not just those 4 or over.

Ethnicity

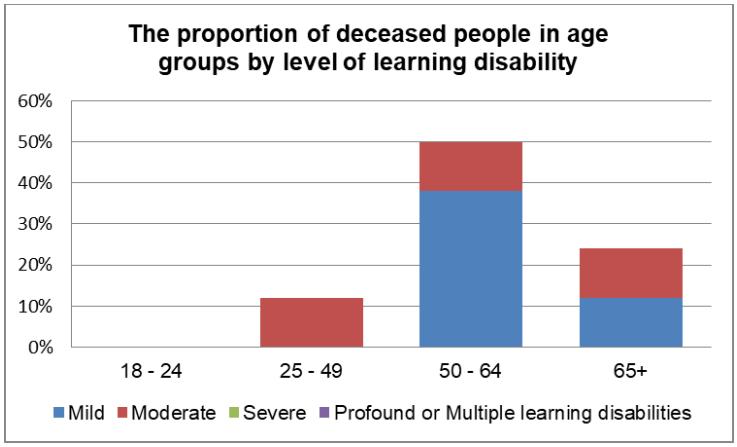
For the completed reviews, all people (100%) were white British ethnicity compared to 90% nationally.

Age

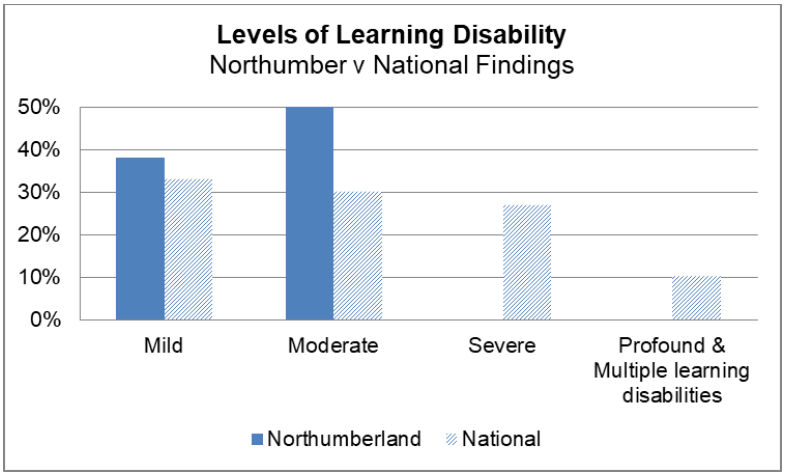


The median age of death for both male and females with learning disabilities was higher in Northumberland than the national median age. Across the North East, the median age for both male and females was 59 showing Northumberland as reported above the median age across the region.

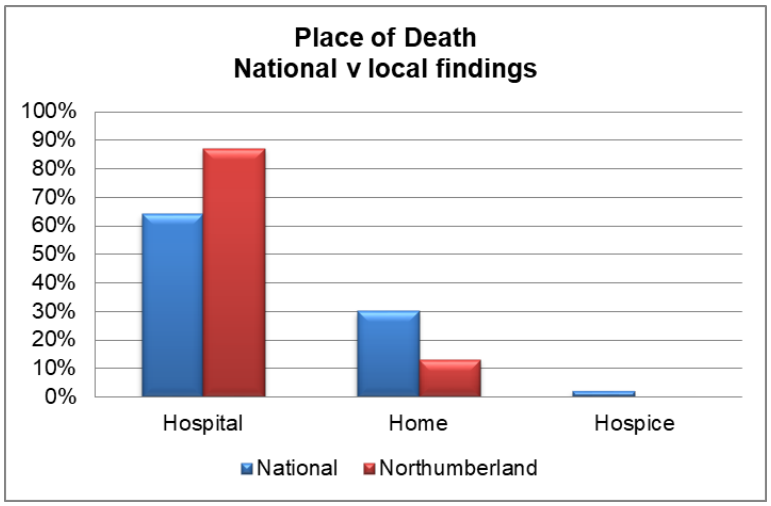
Level of learning disabilities



The level of a person's learning disabilities was reported for all deaths reviewed. It was unclear for one person what their level of learning disability was. Of the other 7, 38% were classed as having mild learning disabilities and 50% were classed as having moderate.



Place of death



The majority of people whose deaths were reviewed in Northumberland died with a hospital setting – with 7 out of 8 (88%) completed reviews indicating this. This is above the national findings which reported 64%.

Causes of death

Of the 8 reviews completed in Northumberland the causes of death were as follows:

- Pneumonia (2)
- Sepsis (1)
- Alcohol related ketoacidosis (1)
- Heart Failure (1)
- Calciphylaxis and infection of the skin (1)
- Cardiac arrest (1)
- Intracerebral Haemorrhage (1)

DNACPR

Of all reviews completed where DNACPR information is available, 72% nationally had such a decision. In Northumberland 5 out of 8 of the reviews completed (63%) had DNACPR decisions in place. Each of these reviews documented that DNACPR documentation was correctly in place and followed. Although there were no issues regarding the documentation, some learning was identified with regards to the reason that a DNACPR was in place and communication with the person's family. This has been included in the recommendation section of this report.

Medication

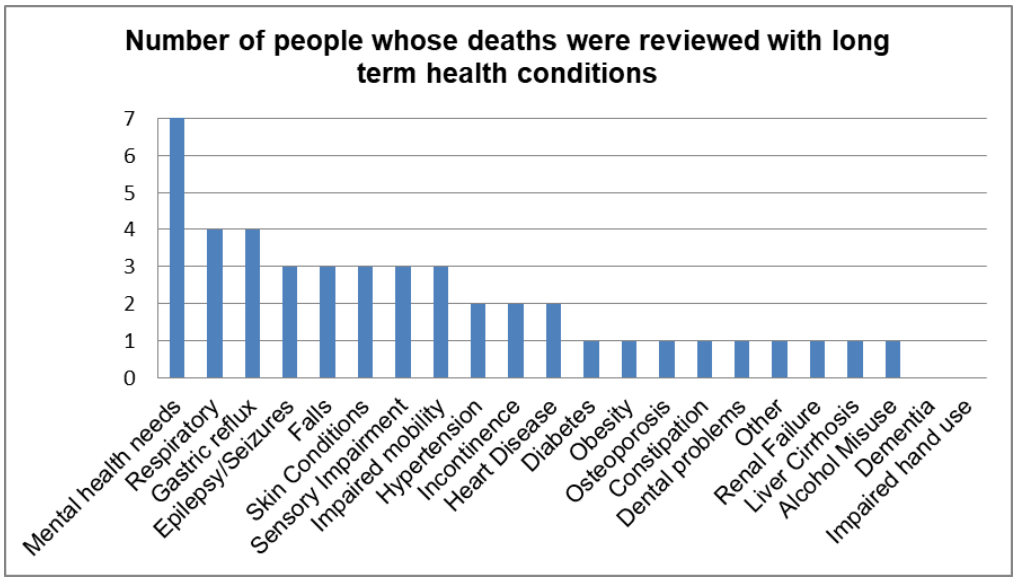
Nationally 97% of people whose deaths were reviewed had one or more medications prescribed. The mean number of medications prescribed in Northumberland was 5.3 which is slightly below the national average of 5.8. There appeared to be little difference between the number of medications prescribed by gender or level of learning disabilities.

Number of Medications prescribed	People prescribed this number	% of people prescribed this number	National % of people prescribed this number
0	0	0	3%
1	0	0	5%
2	1	12%	9%
3	1	12%	10%
4	2	25%	12%
5	0	0	11%
6	3	38%	13%
7	0	0	19%
8	0	0	7%
9	0	0	6%
10	0	0	4%
11 or more	1	12%	10%

The most common usual medications prescribed were lansoprazole, Accrete d3 and Atorvastatin.

Long term health conditions

Nationally, 94% of people with learning disabilities whose deaths have been reviewed had at least one long term health condition. In Northumberland, all people whose deaths were reviewed had at least one long term health condition. The LeDeR reviews listed a number of health conditions which are detailed in the chart below;



Nationally, the five most common long-term health conditions reported in completed reviews were

- Epilepsy (36%)

- Cardiovascular problems (32%)
- Dysphagia (29%)
- Mental Health needs (26%)
- Constipation (23%)

In comparison, the deaths reviewed in Northumberland show

- Mental Health needs (88%)
- Respiratory conditions (50%)
- Gastric reflux (50%)
- Epilepsy (38%)
- Falls (38%)

Grading of Care

From information gathered and analysed, the reviewer is asked to grade the quality of care that the person received. Grading is based on 1 to 6;

1. This was excellent care (it exceeded 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 persons wellbeing but did not contribute to the cause of death
5. Care fell short of expected good practice and this significantly impacted o the persons 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

Of the 8 reviews that were completed, 71% were graded 2 demonstrating good care and meeting expected good practice. 28% were graded 3 demonstrating satisfactory care, whilst also falling short of expected good practice in some areas (although not significantly impacting the person's wellbeing). This is above the grading given nationally, where only 56% of reviews were deemed to demonstrate good care and meet the expected good practice.

Themes, Learning and Recommendations

When analysing the LeDeR cases from last year, communication and multi-agency working, documentation and record keeping and recognition of symptoms of alcohol abuse were identified themes.

Communication and multi-agency working

It was identified in a number of reviews that communication between colleagues across organisations and communication with people with learning disabilities around their care plans could be improved. The importance of liaising with colleagues to improve the overall experience for people was evident. It is imperative that all contact made with colleagues is recorded, and a clear plan of who to pass

information onto is in place. The person needs to be at the heart of any communication with families and at every encounter, the capacity and ability to manage needs to be checked.

The importance of inter-agency working to ensure families get the right support to make decisions was highlighted in the reviews. Potential conflicts of interest should be identified and independent support such as IMCA should be accessed.

Documentation and record keeping

Although overall the DNACPR decisions were deemed appropriate and followed correctly, it was felt that the reasons for DNACPR could have been clearer. Identification of a person's wishes would allow clinicians to address any challenges that may arise. It was recommended that there should be further education and training around completion of the DNACPR form and also assessment of capacity.

Recognition of alcohol symptoms

Symptoms of alcohol misuse are common and important causes of depression, anxiety, general ill health, confusion etc and could be missed. It was recommended that further alcohol misuse training would be beneficial.

Good practice examples from completed reviews

Areas of good practice were identified in 7/8 of the completed reviews.

"Multi-disciplinary teams (MDT) in hospitals have ensured planned care and discharge. These teams involve multiple specialities and look at functional level issues as well as clinical issues"

"Service agreements with care homes were quickly agreed with social care"

"Effective communication between clinical staff in hospital and carers. The involvement of Learning Disability Liaison Nurses has proved to be very effective"

"Good interaction between primary care, ambulance service, Crisis team and secondary care"

"Good practice recognised for end of life care in hospitals, with hospital staff working closely with families and specialist staff to ensure wishes were met"

"Investigations for diagnosis carried out in a timely manner".

"Consideration of legislation given when caring for patient who can not communicate preferences, to ensure appropriate ongoing care"

Outcomes and achievements

The CCG has recognised excellent achievements in primary care and multi-agency working regarding improving the level of care for people with a learning disability. These include;

- Good multidisciplinary working with liaison nurses in secondary care helping with fast track possible cancer referrals through to operations, in acute care
- Good care from social care, working with learning disability nurses, working well with primary care
- Good level of annual health care check uptake from primary care with an adequate level of consistency of care of the checks
- Education annually for practices with a good network of practice leads, open forum for discussion, questions as needed to GP lead.
- Good uptake of flu vaccination with support by learning disability link nurses, and proactive consideration of other vaccines needed.
- Proactive consideration of needs of those who may have a syndrome who may needs specialised care or investigations
- Consideration of those who may be developing a dementia
- Mental health needs proactively managed
- Consideration of holistic other areas of care which would promote health and wellbeing as a region such as diabetes prevention and weight loss programmes. This was unfortunately put on hold due to the COVID-19 pandemic.
- Proactive management of the STOMP agenda.
- Covid health action plans sent to all practices to try to implement to enable carers and families to safeguard patients and have a 'hospital passport'.
- Hospital passport in electronic version in development regionally.

Sharing Lessons Learnt

Working with the University of Bristol LeDeR team, NHS England and NHS Improvement have produced a series of learning into action newsletters to communicate key learnings emerging from LeDeR reviews in England. Subjects have included aspiration pneumonia, sepsis, recognising deterioration, constipation and the Mental Capacity Act. These newsletters have been distributed to health and care professionals across Northumberland and GP practices.

A 'Living well with Learning Disability' educational event took place in June 2019 and was delivered by the two GP clinical leads. The event was well attended by GPs and nurses from GP practices and other clinicians in the local health system, and the feedback received was very positive. A range of topics were included in the agenda, included:

- Annual Health Check
- Cancer screening
- STOMP
- Consent and Capacity
- Local learning regarding preventable deaths in Learning disability
- Autism update

At the CCG Primary Care Network Engagement event on the 2nd of October 2019, one of the GP clinical leads delivered a session on 'Learning Disability – preventable illness, avoidable death' to a large audience of primary care clinicians and managers.

A LeDeR learning workshop took place on the 8th October 2019. The aim of this meeting was to gain a better understanding of the learnings and recommendations, so actions can be developed accordingly. The workshop was attended by clinical reviewers in the primary care, community and secondary care settings. An action plan had been developed in response to the findings and the outputs of this workshop had also been incorporated into this annual report.

Throughout the year, GP clinical leads also included lessons learnt from LeDeR reviews in their teaching sessions to doctors and nurses.

Objectives and Plans for 2020-21

The CCG has a robust plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area. Northumberland is one of a small number of CCGs in the northeast and Cumbria region that that has consistently met this standard. The CCG will continue to treat this as a priority so that learning can be translated into effective actions in a timely matter.

The LeDeR Annual Report 2019 has recently been published in July 2020. The CCG will work with its statutory partners to review its local practices against the problematic aspects of care and best practice identified in the report, as well as the relevant recommendations. Action plans will be produced accordingly where appropriate.

Since the beginning of LeDeR programme in 2016, a total of 33 reviews have been completed by the end of August 2020. Further work will be carried out to review and consolidate the recommendations, and maximise the opportunity for learning. Case studies on impacts and service improvements as a result of these reviews will be gathered as evidence of change, as well as helping to spread the learning across the system.

Further work will be carried out to understand the comparatively lower reporting rate of deaths of people with Learning Disabilities in Northumberland. Working with its partners and the regional steering group, actions will be taken accordingly to address the issue/s and continue to promote awareness in Northumberland and beyond.

Finally, building on the successes of the educational events and workshops in 2019, the CCG has plans to organise other similar activities to promote good practices and share lessons learnt across the Northumberland health and care system. As the working relationships continue to develop with other CCGs in the Integrated Care Partnership, joint event/s will be explored to increase the spread and impact.

Conclusion

This is the first annual report on LeDeR and its contents will evolve and further develop in coming years. In particular, evidence of impact and service improvement as a result of learning from reviews will be a key focus in future reports.

This report summarises the development and progress of LeDeR in 2019/20. The local reviews have given CCGs a snapshot of the quality of care received by people with a learning disability in Northumberland. Many good practices have been noted from the reviews, but more still needs to be done to address health inequalities in this group of service users.

It is important to note that the LeDeR programme is only one element of the CCG's improvement programme for people with a learning disability. The wider programme also includes a focus on increasing the uptake of primary care annual checks, stopping over medication, reducing inpatient admissions to specialist mental health services, making sure that physical health is appropriately considered during care, (education) and treatment reviews (C(E)TRs).

The CCG is committed to address the premature mortality of people with a learning disability, as described in the NHS Long Term Plan, and will continue to work with its statutory partners, stakeholders and people with a learning disability and their families to make this happen.

Appendix 1: Northumberland CCG LeDeR process
Appendix 2: http://www.bristol.ac.uk/sps/leder/resources/annual-reports/

Final version / GB / 23/9/20

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