Annual Report
North Cumbria CCG
Learning Disability
Mortality Reviews
(LeDeR)
1st April 2018- 30th March 2019

Report compiled by;- 

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&

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Introduction

This is the first annual report presented by North Cumbria Clinical Commissioning Group (NCCCG) as required by the ‘The NHS Long Term Plan January 2019’.

The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities. Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It was implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017.

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death.

Key processes to deliver mortality reviews of people with learning disabilities have been established, North Cumbria have held a local steering group since February 2018 with the Director of Nursing from the Clinical Commissioning Group (CCG) chairing and taking the Strategic lead. The CCG has developed a robust quality assurance process to ensure that reviewers are supported, and that ultimately the system delivers high quality reviews and shares the lessons learned across the both North East and Cumbria and Nationally.

The most significant challenge to the delivery of the programme has been the timeliness with which mortality reviews have been completed, largely driven by four key factors: a) large numbers of deaths being notified before capacity was in place locally to review them b) the limited resources available to undertake reviews and the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review c) trained reviewers having sufficient time away from their other duties to be able to complete a mortality review and d) the process not being formally mandated.

Deaths notified in North Cumbria to the LeDeR programme

Table 1 below details deaths reported by year, the numbers of reviews completed, numbers still with a reviewer and reviews awaiting allocation. It should be noted that 3 additional reviews were completed in 2016 by CPFT prior to the start of the National programme
making a total of 45 deaths notified. As such figures extrapolated for this report need to be taken in the context of this relatively small number.

To date out of reviews undertaken 2 patients were flagged as having a Learning Disability in the local systems and a LeDeR review was undertaken, the findings of the reviewers were that there was no strong evidence that a Learning Disability was present and thus a request was made to the national programme to have them removed from the data base. The learning will not form part of the LeDeR Programme but will instead be captured in standard NHS mortality reviews.

Table 1

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of deaths notified</th>
<th>Completed reviews</th>
<th>Reviews allocated</th>
<th>Awaiting allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1/04/16 - 30/3/17</td>
<td>7</td>
<td>6+1*</td>
<td>-</td>
<td>0</td>
</tr>
<tr>
<td>1/4/17 – 30/3/18</td>
<td>17</td>
<td>8+1*</td>
<td>6+1**</td>
<td>1+1***</td>
</tr>
<tr>
<td>1/4/18 – 30/3/19</td>
<td>19</td>
<td>1</td>
<td>3</td>
<td>14</td>
</tr>
</tbody>
</table>

(*completed but removed as no learning disability **safeguarding adult review in progress ***reallocated to another CCG)

It should be noted that additional pressure has again been put on the North Cumbria LeDeR system as a case file audit was completed in the local NHS Acute services that established a number of previously unreported yet eligible deaths. This has significantly contributed to the backlog of unallocated cases as well as the time delay between deaths, notification and allocation. *(8 reviews were notified from 6 to 11 months after the person’s death and 6 reviews notified between 3 to 5 months after the person’s death).*

The most frequent reporter of deaths was the North Cumbria Acute Hospital Trust (NCUH) followed by the Learning disability nursing team then 3rd sector providers.
# North Cumbria context versus National Findings

<table>
<thead>
<tr>
<th></th>
<th>National Findings</th>
<th>Local Findings (North Cumbria)</th>
<th>General Population (North Cumbria)</th>
</tr>
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<tbody>
<tr>
<td><strong>The median age of death for people</strong></td>
<td><strong>with learning disabilities</strong></td>
<td><strong>Average is:- 61 years</strong>&lt;br&gt;Men it is 56 years&lt;br&gt;Women it is 66 years&lt;br&gt;NB: Removing the 4 male children recorded from this calculation creates a median of 60 years which would increase the average above by another 2 years to 63yrs.&lt;br&gt;18 people or 42% were over the national medium age of 58 years.&lt;br&gt;15 people or 35% were 70+ years significantly over the national average.</td>
<td><strong>Average age:- 81.8 years</strong>&lt;br&gt;Men it is 79.4 years&lt;br&gt;Women it is 82.8 years.</td>
</tr>
<tr>
<td><strong>Setting of Death</strong></td>
<td>Hospital - 64%&lt;br&gt;Home - 30%&lt;br&gt;Hospice- 2%</td>
<td>Hospital - 70%&lt;br&gt;Home 25%&lt;br&gt;Hospice – 5%</td>
<td></td>
</tr>
<tr>
<td><strong>Top Causes of Death</strong></td>
<td>1) Respiratory 31%&lt;br&gt;2) Circulatory 16%&lt;br&gt;3) Sepsis 11%&lt;br&gt;4) Cancer 10%</td>
<td>1) Respiratory 21%&lt;br&gt;2) Bowel related 10%&lt;br&gt;3) Cancer 9%&lt;br&gt;4) Sepsis 7%&lt;br&gt;5) Epilepsy 5%&lt;br&gt;6) Circulatory 5%</td>
<td></td>
</tr>
</tbody>
</table>
Themes, Learning points and recommendations from reviews

Adult

• There was a need for more formal joint working between District Nurses & Learning Disability Nurses. As such Learning Disability Awareness sessions offered with plans to offer the same to local General Practice (GP). This aligns to a National Recommendation

• Better recording and Implementation of Mental Capacity Act. This aligns to a National Recommendation

  i) DNACPR was in place and properly completed except: there was no separate assessment of capacity in notes as per policy. No attempt to discuss with patient was recorded, although it was discussed with family.

  ii) Decisions made in earlier life by family could have been reviewed under MCA to reduce risk of aspiration. This would have required a detailed & holistic review of the care being predominantly provided by the family & best interest decision making evidenced. It is hoped this would now take place.

Child

• Clear end of life pathways to be recommended from Children Death Overview Panel (CDOP)-Children’s services: Education and healthcare plans

• Cumbria Partnership Foundation Trust (CPFT) and NCUH to formally recognise the importance of advance care planning at annual reviews and definitely by age 14.

• Ensure that the possibility of Sudden Unexpected Death in Epilepsy (SUDEP) is discussed with families of children with epilepsy

• Local Safeguarding Childrens Board (LSCB) to consider- When does a parent’s decision not to follow a therapist’s advice become a safeguarding issue? Children with disabilities policy taken into account for all cases where there could be a potential safeguarding concern - e.g. when families/child disagrees with their recommendations.

• North West Ambulance Service (NWAS): To always inform the police of child deaths (already actioned).

• CPFT: consider training re advance resus planning (recognising that most parents will want everything possible done to save their child)

• LSCB to produce a leaflet for families specifically re the Post mortem process and the fact the child has to go to Newcastle (or Alder Hey/Manchester)
• LSCB to produce a “poor reader” version of the CDOP leaflet or ask the Lullaby Trust to produce a YouTube explanation of the SUDICYP process.

**Good practice examples from completed reviews**

1. Reported by frontline care providers that NWAS had instigated reasonable adjustments being made to facilitate transfer to hospital.

2. It was identified that GP’s had regularly viewed epilepsy medication & had undertaken annual health checks.

3. A hospital passport was in place and shared appropriately.

4. Hospital staff held best interest meeting around feeding options (ie Percutaneous endoscopic feeding tube PEG)

5. Good practice was noted in that advanced care planning was in place and parents had been involved in the planning and agreed with it.

**North Cumbria LeDeR Activity/ Achievements in 2018-2019**

NCCCG has taken a system leadership role and established and embedded its own local steering/implementation supported by the North East and Cumbria Learning Disability Network (NE&CLDN), group to oversee the LeDeR programme of work and in particular action local improvements based on the evolving National and Local picture. This is chaired by the Director of Nursing within North Cumbria CCG and supported practically and strategically by the NE&CLDN. The steering group is well represented by health, social care and the 3rd sector.

The CCG has formally aligned to the North East Regional steering group; between these two groups priorities for service improvements are agreed based on interpretation of the nation and local themes arising for this programme.

NCCCG consistently receives all notifications of deaths of those with a Learning Disability from the national system and coordinates all the LeDeR Reviews across North Cumbria. To address the challenge of the backlog of reviews / limited resources to complete reviews the CCG have recently increased the number of trained reviewers to deliver more capacity to complete reviews; this included third sector partners.

Despite a significant backlog of LeDeR cases awaiting an in-depth review for all those who die when in the care of NHS providers a rapid mortality review does take place and forms a part of the providers own internal mortality governance and learning arrangements. Thus ensuring any key quality and safety issues relating to clinical practice are reviewed and acted
upon in a timely fashion. These rapid reviews are then also available to LeDeR Reviewers to support their work.

The CCG has strong links with the Child Death Overview Panel and has influenced the alignment of this with the LeDeR Methodology so that learning is shared across the county in relation to Childrens services, Generic Health services and Specialist Learning Disability Services.

To ensure robust oversight of quality and governance processes all completed LeDeR reviews are scrutinised by the CCG internal Serious Incident/Soft Concerns Operational Group. In addition the panel also receives thematic information that arises from the programme. Bristol University no longer quality assures any of the LeDeR Reviews captured in the programme website.

The CCG worked closely with the Local Adult Safeguarding Board to host a local event to share countywide learning in October 2018 and improve awareness of LeDeR across user groups, provider organisations and families. At this event the proposal was presented and unanimously supported to develop ‘STOP AND WATCH’, a tool to support carers, families and the non-registered workforce spot the signs of deterioration. A further event was held in March 2019 called ‘Don’t let me die too young - Mortality Conference’. It focused on learning in to action and supported the North East and Cumbria launch of ‘Stop and Watch’ and tool.

The CCG has secured additional funding through support from the NE&CLDN this will facilitate the development of an advocacy based confirm and challenge group to both challenge and support the local programme of work related to LeDeR. Whilst this is a new initiative it will form part of the programme of work in the coming year.

**Objectives and plans for 2019-2020**

The NHS Operational Planning and Contracting Guidance 2019/20 (10 year plan) now include four deliverables in relation to the LeDeR programme: North Cumbria CCG aligns as follows to these.

1. **CCGs are to be a member of Learning from Deaths report (LeDeR) steering group and have a named person with lead responsibility.**
   
   **NC-CCG Action:** - Director of Nursing & Quality is the named lead and retains strategic oversight of LeDeR with operational support from within the Nursing, quality and Safeguarding Team. There are formal links both local and regionally to implementation and steering groups.

2. **There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.**
   
   **NC-CCG Action:** - The CCG is prioritising and tracking all new notifications to ensure this expectation is achieved. The CCG is using staff from across its internal directorates to address outstanding reviews with an aspirational target of clearing all reviews this coming year.
3. CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.
   **NC-CCG Action:** - The CCG contributes learning from reviews to the Regional Steering Group where themes are collated and then priorities set for service improvements. Completed and anonymised reviews are shared in a sub-group of the adult safeguarding board alongside similar reviews completed by a neighbouring CCG. This enables a countywide view to be taken on peoples experiences of care prior to their death.

4. An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.
   **NC-CCG Action:** - The CCG has already provided a number of reports through its internal governance arrangements. This annual report will also be shared in the same way and across partner agencies through the local safeguarding boards.

In addition to the actions above the North Cumbria Steering group have agreed the following local priorities:

5. The CCG aims to continue supporting, developing and integrating the Local Confirm and Challenge Group in to the LeDeR Steering Group and associated programme of work. This group will be led by people with a Learning Disability and have appropriate Family member representation too.

6. The CCG will prioritise all new notifications in to the LeDeR System to ensure learning can be taken forwards in a timely manner. There will still be a parallel commitment from the CCG towards clearing the backlog of cases and work will continue with NHS England and regional colleagues to develop strategies to best to achieve this.

7. The CCG will continue to work with local providers across both Health and Social Care services through Cumbria LeDeR Steering Group to continue improving the general physical health of local citizens who also have a Learning Disability.

8. The CCG commits to continue the local implementation of ‘Stop and Watch’ see Appendix 1

9. The GP lead for learning disability at the CCG and members of the primary care team will ensure that the learning from LEADER is disseminated to GP practices in North Cumbria. Workshop dates have already been set for 2019 for the Learning disability leads in GP practices which will include an item on LEADER. Information is also disseminated in the regular primary care newsletters.
10. The CCG will support the planned communication campaigns that are being led by the NE&CLDN. These campaigns are focused on the prevention of early death in those with a learning disability and include:

- AAA screening campaign (planned for summer)
- Flu immunisation campaign (planned for late summer/autumn)
- Sepsis campaign (planned for winter)
- Constipation (planned for autumn/winter)

**Conclusion**

North Cumbria CCG continues to be committed to delivering the LeDeR programme. The past year has been exceedingly challenging due to the lack of resources such as the availability of trained reviewers, time for reviewers to undertake the reviews due to competing work priorities. To support future delivery and recover the position additional reviewers have been trained from across the system and within the CCG. Robust governance systems have been embedded to ensure the quality assurance process and share learning from the reviews across the system.

**Recommendation**

The committee are asked to:

1. Note the content of the report
2. The ongoing challenges to complete timely reviews
3. Approve the annual report
Appendix 1

Recognising Deterioration

Early Warning Tool

S - Seems different to usual
  Think 'Is that normal?'

T - Talk - can't communicate
  Or changes

O - Overall mental state
  Good or worse

P - Pain (new or worsening)
  Participating
  Weakness
  Activities

A - Aims to the usual
  Lack

N - No bowel movement
  in 3 days or diarrhoea

D - Drink
  Increase
  Hydration

W - Weight
  Losing weight without trying

A - Agitation
  Drowsy
  Sleep

T - Tired weak
  Confused

C - Change skin
  Colour
  Condition

H - Help with washing
  Transferring
  Urine

Everyone can spot the signs
If you notice an important change make sure
you talk to the right person about this without
delay. This could be your manager, healthcare
professional, the family or the out of hours
health service.