



Heywood, Middleton
and Rochdale
Clinical Commissioning Group

HEALTHIER PEOPLE,
BETTER FUTURE

Learning Disability Mortality Review (LeDeR)

Annual Report
2018/19



LeDeR Annual Report - Executive Summary

Introduction

The LeDeR program was established in response to the recommendations of the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD 2013).

This is the first annual report of the Heywood, Middleton and Rochdale (HMR) CCG Learning Disabilities Mortality Review (LeDeR) program.

It presents information about the deaths of people with learning disabilities in HMR, aged 4 years and over, notified to the LeDeR program between 1st June 2018 and 31st July 2019. The report includes a comparison of the findings of CIPOLD with HMR evidence.

LeDeR Steering Group

The HMR CCG Executive Nurse is also the Local Area Contact and chairs the multi-agency LeDeR Steering Group. Membership includes representatives from Adult Social Care and Commissioning, Reviewers, Continuing Health Care and the GP lead. Steering group members hold each other to account so that learning from reviews is translated into measurable improvement actions.

Deaths notified to the program

Within Heywood Middleton and Rochdale, a total of 21 reviews have been undertaken in an 18-month period. The reviews have yielded a picture of predominantly good practice across the Learning Disability provision.

This report covers the period between June 2018 and July 2019. A total of 4 reviews were completed during this timeframe.

The people whose deaths were notified

All the cases reviewed the individuals had a host of health conditions ranging from cardio-vascular conditions to life limiting ones such as Duchenne Muscular Dystrophy. 3 individuals had a diagnosis of dementia.

7 individuals lived in supported living arrangements with a care package. 1 individual lived in a residential care home. 2 individuals lived independently and the remaining 4 lived in the care of family.

Age at Death

71% of deaths reviewed were of people aged 50 years or over.

Quality of care provided

Of the 14 cases reviewed locally treatment and intervention was of an appropriate and expected standard. All except one case had documented evidence of annual health checks and a good overall picture of co-morbidities and/or emotional health issues. GP practices locally use coding on the system to easily identify patients with a learning disability.

There was no evidence of the over use of anti-depressants or psychotropic drugs. Medication prescription was found to be appropriate.

In all but one case where, despite reasonable adjustment, the individual would not engage with health services,

care packages were based on need and delivered appropriately.

No safeguarding concerns were raised in respect of these 14 cases.

Local Learning

As with the general population, the most common underlying causes of death in the Learning-Disabled Population is heart and circulatory disorders (22%) and cancer (20%)

The final event leading to death is most frequently a respiratory infection in the people with learning disabilities. There was no significant difference in relation to premature deaths between people with learning disabilities and the general population. The contrary was seen in that individuals had far outlived their expected life span and within these cases good medical care

was seen with all but one individual receiving a yearly health assessment with an appropriate and implemented action plan.

Fewer than a quarter (23%) of cause of death certificates noted that the person had learning disabilities.

Fewer deaths of people with learning disabilities (38%) were reported to the coroner compared with the general population (46%).

When deaths were reported to the coroner, people with learning disabilities were more likely to have a post-mortem and were as likely to have an inquest opened.

The issue of Mental Capacity, particularly in terms of documentation around DNAR was an issue in some cases reviewed locally.

Introduction

The Learning Disabilities Mortality Review (LeDeR) program is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). It is the first national program of its kind in the world.

Its overall aims are:

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

The program was established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD 2013).

CIPOLD 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. People with learning disabilities have a life expectancy 19.7 years lower than people without learning disabilities.

The LeDeR program contributes to improvements in the quality of health and social care for people with learning disabilities in England by supporting local areas to carry out reviews of deaths of people with learning disabilities (aged 4 years and over) using a standardised review process. This enables them to identify good practice and what has worked well, as well as where improvements to the provision of care could be made. Recurrent themes and significant issues are identified and addressed at local, regional and national level.

The core principles and values of the LeDeR program are as follows:

- The program overall must effect change and make an identifiable difference to the lives of people with learning disabilities and their families.
- We value the on-going contribution of people with learning disabilities and their families to all aspects of our work and see this as central to the development and delivery of everything we do.
- We take a holistic perspective looking at the circumstances leading to deaths of people with learning disabilities and don't prioritise any one source of information over any other.
- The key principles of communication, cooperation and independence will be upheld when working alongside other investigation or review processes.
- The program overall strives to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.

A key part of the LeDeR program is to support local areas to review the deaths of all people with learning disabilities aged 4 years and over, irrespective of whether the

death was expected or not, the cause of death or the place of death. This enables them to identify good practice and what has worked well, as well as where improvements to the provision of care could be made.

What do local reviews of deaths consist of?

- An initial review of each death.
- A fuller multiagency review of deaths that meet the criteria for this.

Following reviews of deaths, local areas discuss learning and recommendations identified in reviews of deaths and translate these into improvements in the delivery of health and social care for people with learning disabilities as appropriate.

Local Reviews

Within Heywood Middleton and Rochdale 21 reviews have been undertaken in an 18-month period.

What the reviews have yielded is a picture of good practice across the Learning Disability provision.

Gaps in practice, identified in a minority of cases, related to application of DNAR and use of effective capacity assessment.

Aims of this report

This report will look at a period between June 2018 and July 2019 considering 14 reviews against national evidence, perceptions and the local dynamic.

The Heywood Middleton and Rochdale Process

The embedded documents outline process locally:



Flowchart
DRAFT.pdf



LeDeR Local
Information Sharing



7MB LeDeR
Learning .pdf

Steering Group

The steering group drives the LeDeR process and puts challenge back into the system.

The group is made up of:

- CCG
- Local Authority
- Primary and secondary healthcare
- Regional Safeguarding Board (children and adults)
- Community Learning Disability Team
- Representative of people with learning disabilities and their families.
- Advocacy organisation
- Provider organisation
- Public Health

The HMR Steering group accesses the opinion of people with learning disabilities via the Learning Disability Partnership Board where LeDeR is a fixed agenda item.

The Terms of Reference ([Appendix 1](#)) outlines the function of the Steering Group

CIPOLD Findings vs HMR evidence

As with the general population, the most common underlying causes of death in the Learning-Disabled Population is heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively).

The final event leading to death is most frequently a respiratory infection in the people with learning disabilities. That a person had learning disabilities was mentioned on few (23%) cause of death certificates.

Fewer deaths of people with learning disabilities (38%) were reported to the coroner compared with the general population (46%). When deaths were reported to the coroner, people with learning disabilities were more likely to have a post-mortem and were as likely to have an inquest opened. Of note is that the CIPOLD Overview Panel identified some additional deaths that they thought should have been reported to the coroner and expressed concerns about some coroners' reviews of deaths. (CIPOLD 2013)

In considering the 14 deaths reviewed locally it can be seen that 10 of the 14 had deaths attributed to pulmonary disease/infection. Breaking this down further 2 individuals have a host of cardio vascular issues which also contributed to their deaths. Lung infection secondary to a fracture was a feature in 2 more.

In 2 patients the death was because of cancer. A further two patient had complex health needs from birth and died because of these. Of the cases reviewed 5 are within the coronial process.

There was no significant difference in relation to premature deaths between people with learning disabilities and the general population.

In the CIPOLD study, a death was considered as premature if, *'without a specific event that formed part of the "pathway" that led to death, it was probable that the person would have continued to live for at least one more year'*. This allowed the Overview Panel to take account of both lifestyle and co-morbidity in assessing the potential significance of events or omissions in the care of the person concerned, regardless of their age. Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.

Within HMR cases there were no 'premature deaths' fitting the category above. The contrary was seen in that individuals had far outlived their expected life span and within these cases good medical care was seen with all but one individual receiving a yearly health assessment with an appropriate and implemented action plan.

The age range of the deaths reviewed were

1 aged 20 years

1 aged 21 years

1 aged 31 years

1 aged 49 years

3 between 50-59

5 between 60-69

2 between 70-79

In terms of health screening/prevention all the 14 individuals received a flu vaccination. All were offered bowel screening if age appropriate which amounted to 7 people of these 3 chose to be screened. Of the females eligible all were offered breast screening and 2 of the eligible 4 attended

In comparison to the rest of the population in HMR whereby 57% of those eligible in 2016/17 attended for bowel screening in our cases 42% of those eligible attended

In terms of breast screening the rest of the eligible population in Heywood Middleton and Rochdale 66% attended within the cases reviewed 50% of those eligible attended

When considering the health and social care needs in the CIPOLD report of the people with learning disabilities, it was apparent that they were a very vulnerable group. Significantly more (17%) were underweight than the general population (2%), even after excluding those who had lost weight in their final illness. Two-thirds lacked independent mobility, half had problems with vision, a quarter had problems with hearing, over a fifth (21%) had problems with both vision and hearing, 30% had limited verbal communication, and 22% did not communicate verbally at all. Almost all (97%) had one or more long-term or treatable health condition, including 43% with epilepsy (31% had had a seizure in the previous 5 years), 39% with cardiovascular disease, 22% with hypertension, 14% with dementia and 13% with osteoporosis.

Of people known to be on GP learning disability registers, 71% had received an annual health check in the year before death, but 12% had never had an annual health check. More than a third were reported as having difficulty in communicating their pain, but a pain assessment tool such as DisDAT3 had been used with only 4 people. Engagement in the bowel cancer screening program was problematic.

At the time of their deaths 64% lived in residential care homes, most with 24-hour paid carer support. For 20% of the people with learning disabilities, safeguarding concerns had previously been raised; for a further 8% safeguarding concerns were raised to the CIPOLD review retrospectively – these had not been reported or investigated at any time previously. (CIPOLD....)

The HMR cases 7 individuals lived in supported living arrangements with a care package. 1 individual lived in a residential care home. 2 individuals lived independently and the remaining 4 lived in the care of family.

All the cases reviewed the individuals had a host of health conditions ranging from cardio-vascular conditions to life limiting ones such as Duchenne Muscular Dystrophy. 3 individuals had a diagnosis of dementia.

There was no evidence of the over use of anti-depressants or psychotropic drugs. Medication prescription was found to be appropriate.

In all but one case where, despite reasonable adjustment, the individual would not engage with health services, care packages were based on need and delivered appropriately.

No safeguarding concerns were raised in respect of these 14 cases.

While the great majority (86%) of the illnesses that led to the deaths of people with learning disabilities reviewed by CIPOLD were promptly recognised and reported to health professionals,

for 29% there was significant difficulty or delay in diagnosis, further investigation or specialist referral, and for 30% there were problems with their treatment. The lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths. GP referrals commonly did not mention learning disabilities, and hospital 'flagging' systems to identify people with learning disabilities who needed reasonable adjustments were limited. People with learning disabilities had a considerable burden of ill-health at the time of their death. Key issues that appeared to be problematic were the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision. (CIPOLD)

Of the 14 cases reviewed locally treatment and intervention was of an appropriate and expected standard. All except one case had documented evidence of annual health checks and a good overall picture of co-morbidities and/or emotional health issues. GP practices locally use coding on the system to easily identify patients with a learning disability.

Further to the review of the deaths locally a dip sample audit of five practices has taken place to evidence practice.

In addition, CIPOLD found, professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular, assessments of capacity, the processes of making 'best interest' decisions and when an Independent Mental Capacity Advocate should be appointed. Many instances were identified of inappropriate or poorly documented DNACPR4 orders.

Record keeping was commonly deficient – particularly in relation to fluid intake, nutrition, weight and seizures, and little attention was given to predicting potential problems, e.g. when a person was fearful of contact with medical professionals. A lack of recognition of the approaching end of life commonly led to problems in coordinating end-of-life care and providing support to the person and their family. Difficulties in obtaining Continuing Healthcare funding were also reported. (CIPOLD...)

The issue of Mental Capacity particularly in terms of documentation around DNAR was an issue in some cases reviewed locally. 5 cases were subject to 'end of life plans' 'DNAR' instruction however best interest assessment was not evident within the records. In the case of one individual there was documentation of self-neglect in 2016 however capacity was not assessed at this time and could on further exploration led to unwise decision making.

LeDeR Backlog Project

There is a significant backlog in the completion of LeDeR reviews, both nationally and across Greater Manchester, linked to lack of specific funding and capacity.

The Backlog Project is intended to enable local areas to focus on more recent deaths to get to a position where the rate of notifications and completed reviews are balanced.

Heywood Middleton and Rochdale CCG have no such backlog.

To ensure timely completion of the reviews in the best interests of the family and to implement actions a band 7 ex-Learning Disability Nurse is employed on a 'bank' contract within the CCG.

This affords timely allocation and commencement of reviews and best use of finances as currently there is no specific funding for LeDeR.

Reviewing the deaths of children

Reviews of deaths up to the age of 18 is undertaken by the Child Death Overview Panel.

The new safeguarding arrangements (Children and Social Work Act 2017 Working Together to Safeguard Children 2018) place child death review outside of Safeguarding. The new arrangements place child death reviews within a child death review process. However, a Child Death Overview Panel still reviews child deaths which fulfil LeDeR criteria

A member of the CDOP attends the LeDeR Steering Group quarterly to provide child death oversight in terms of Learning Disability.

This process is in it's infancy and there is no specific data at this point to add to this report.

Conclusion

The LeDeR process looks at the deaths of all people over the age of 4 with a Learning Disability

There have been some issues across Greater Manchester about completing reviews considering funding and capacity issues

In Heywood Middleton and Rochdale a process has been devised to ensure timely allocation and completion of LeDeR reviews using a cost effective model

Learning from the reviews locally has shown good and expected practice across the Borough with good compliance across Primary Care.

The process of mortality review has sparked wider work across the Borough in relation to Learning Disabilities and there is an appetite locally to progress this work

Priorities

- Inclusion of people with Learning Disability in all ongoing campaigns/LeDeR work
- Development of alert checklist for physical health to be used by relatives and carers as an early identification tool
- Development of links with the Child Death Overview Panel and attendance of a CDOP representative at LeDeR Steering Group quarterly to provide a child death analysis in terms of learning disability
- Audit across the health economy to evidence compliance with reasonable adjustments

References

Care Act (2014) HMSO London

CIPOLD (2013) Confidential Inquiry into Premature Deaths of People with Learning Disabilities Bristol University