NHS
Heywood, Middleton and Rochdale
Clinical Commissioning Group

HEALTHIER PEOPLE,
BETTER FUTURE

Learning Disability Mortality Review (LeDeR)

Annual Report

2019/20

EXECUTIVE SUMMARY

This is the second annual report of the Heywood, Middleton and Rochdale (HMR) Learning Disabilities Mortality Review (LeDeR) Programme for 2019/20.

It presents information about the death of people in HMR with learning disabilities notified to the LeDeR programme between 1 July 2019 to 31 March 2020

LeDeR Steering Group

HMR Clinical Commissioning Group (CCG), co-ordinates the LeDeR programme across the borough and has, in collaboration with other key stakeholders, agreed the process of undertaking reviews and putting the learning into action.

The HMR LeDeR multi-agency Steering Group was established in January 2018 to have strategic oversight of the programme locally.

The HMR CCG Executive Nurse is the LeDeR Local Area Contact (LAC) and also chairs the Steering Group. Membership of the Steering Group 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.

Review Process & local learning

Notifications of deaths submitted to the Bristol LeDeR Team are received by through the LeDeR Review System. These are then allocated by the LAC to a LeDeR reviewer for an initial review. If the initial review indicates a fuller review is likely to identify further learning, the review progresses to a multi-agency review.

Of the 18 deaths notified to HMR between 1 July 2019 to 31 March 2020, the majority have shown examples of good practice across Learning Disability provision; these include:

- Medication Reviews
- Reasonable adjustments
- Use of hospital passports
- Use of familiarisation and de-sensitisation techniques
- Individual GP practice relationships with their patients with LD

Three reviews identified satisfactory practice and one fell short of expected practice. Areas for improvement emerging from the reviews and recommendations include:

- Learning Disability Awareness training for practitioners
- Annual Health Checks (AHCs)
- Mental Capacity assessment and best interest decisions
- Reporting of deaths among people from Black, Asian and Minority Ethnic (BAME) groups

Introduction

The LeDeR programme was established in 2015 as a response to the recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013). CIPOLD reported that people with learning disabilities are three times more likely to die from causes of death that could have been avoided with good quality healthcare. The purpose of the programme is to:

- Support improvements in the quality of health and social care delivery for people with a learning disability;
- Reduce premature mortality and health inequalities for people with a learning disability.

The programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The aim of a LeDeR review is to identify potentially modifiable factors which contribute to the premature mortality of people with a learning disability. The most critical part of the programme is for local area partners including CCG's, NHS providers, Local Authorities and independent sector organisations to work in partnership with families and people with a learning disability to address the learning and recommendations emerging from LeDeR reviews.

More information about the programme, national findings and the review process can be found at http://www.bristol.ac.uk/sps/leder/about/

Child Death Overview Panel (CDOP)

The child death review process is the primary review process for children with a learning disability, or likely to have had a learning disability, aged between 4-17 years.

The CDOP Panel responsibilities are to collect, collate and analyse information about the death of each child who normally resides in HMR with a view to identifying any matters of concern or risk factors affecting the health, safety or welfare of children, or any wider public health concerns. making recommendations to relevant organisations where actions have been identified to prevent future child deaths.

There were no Rochdale deaths for children over the age of 4 considered by the CDOP Panel during the timeframe of this report.

HMR LeDeR Reviews 1 July 2019 to 31 March 2020

HMR Clinical Commissioning Group (CCG), co-ordinates the LeDeR programme across the borough and has, in collaboration with other key stakeholders, agreed the process of undertaking reviews and putting the learning into action.

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In total, 18 cases were notified to HMR between 1st July 2019 and 31st March 2020. In one case, where the death had been notified in
Of the notifications received:

Age at death	**0-17**	**18-24**	**25-29**	**30-39**	**40-49**	**50-59**	**60-69**	**70-79**	**80-89**
	0	4	0	3	0	6	2	3	0

National LD deaths

Average age for males 60 years old
Average age for females 59 years old

ONS data for general population deaths

Average age for males 83 years old
Average age for females 86 years old

Gender	**Male**	**Female**
	14	4

Ethnicity	**White British**	**Asian British**	**Chinese**	**Not known**
	12	4	1	1

Level of disability	**Mild**	**Moderate**	**Severe**	**Profound /Multiple**	**Not known**
	5	7	3		3

Place of death	**Hospital**	**Usual residence**	**Outside** of UK
	10	**7**	**1**

Causes of death			
Myocardial Infarction	7	COPD	1
Ketoacidosis	1	Oesophogeal cancer	1
Pneumonia	1	Covid 19	1
Aspiration pneumonia	1	Type 2 respiratory failure	1
Pulmonary Bronchitis	1	Alzheimer's Disease	1
Intracranial hemorrhage	1	Vascular Dementia	1

At the end of a review, reviewers are asked to provide an overall assessment of the care provided to the individual and provide a grade. The table below shows the grading of care and the HMR LeDeR Reviewers' overall assessment of the care received:

Grading of Care	Number	Percentage
1. This was excellent care and met current best practice	**0**	**0%**
2. This was good care, which fell short of current best practice in only one minor area.	**13**	**72%**
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).	**3**	**16%**
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.	**1**	**5%**
5. Care fell far short of expected good practice and this contributed to the cause of death.	**0**	**0%**
Unable to grade as information not available	**1**	**5%**

Sharing Learning

Not all reviews generate learning, with a significant number of reviews demonstrating good care throughout the life, and end of life, of the individual.

Examples of good practice have included:

- Evidence of regular medication reviews
- Reasonable adjustments made for individuals
- Use of hospital passports

- Use of familiarisation and de-sensitisation techniques
- Individual GP practice relationships with their patients with LD

Between 1 July 2019 and 31 March 2020 one review was completed which indicated that care fell short of expected good practice.

Areas for improvement and recommendations:

- Learning Disability Awareness training for practitioners
- Improving take up of Annual Health Checks (AHCs)
- Mental Capacity assessment and best interest decisions
- Reporting of deaths among people from Black, Asian and Minority Ethnic (BAME) groups

Learning from reviews is circulated via the HMR LeDeR Steering Group and is also shared with the Rochdale Borough Safeguarding Adult Board.

The national team, based in Bristol, produce ‘Action into Learning’ publications , sharing the national learning associated with aspiration pneumonia, sepsis, recognising deterioration, constipation and the Mental Capacity Act. These are shared with the LeDeR Steering Group for wider circulation.

References

Care Act (2014) HMSO London

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

LeDeR 2019 Annual Report http://www.bristol.ac.uk/sps/leder/resources/annual-reports/