

**NHS DORSET CLINICAL COMMISSIONING GROUP**  
**GOVERNING BODY MEETING**  
**LEARNING DISABILITY MORTALITY REVIEW (LEDER) PROGRAMME**  
**ANNUAL REPORT 2019/20**

<b>Date of the meeting</b>	15/07/2020
<b>Author</b>	S Hawkins – Patient Safety & Risk Manager
<b>Purpose of Report</b>	To provide an overview and assurance of the local LeDeR programme for 2019/20.
<b>Recommendation</b>	The Governing Body is asked to <b>note</b> the report.
<b>Stakeholder Engagement</b>	N/A
<b>Previous GB / Committee/s, Dates</b>	N/A

**Monitoring and Assurance Summary**

<b>This report links to the following Strategic Objectives</b>	<ul style="list-style-type: none"> <li>• Prevention at Scale</li> <li>• Integrated Community and Primary Care Services</li> <li>• One Acute Network</li> <li>• Digitally Enabled Dorset</li> <li>• Leading and Working Differently</li> </ul>		
	<b>Yes</b> [e.g. ✓]	<b>Any action required?</b>	
		<b>Yes</b> Detail in report	<b>No</b>
All three Domains of Quality (Safety, Quality, Patient Experience)	✓		✓
Board Assurance Framework Risk Register	✓		✓
Budgetary Impact	✓		✓
Legal/Regulatory	✓		✓
People/Staff	✓		✓
Financial/Value for Money/Sustainability	✓		✓
Information Management & Technology	✓		✓
Equality Impact Assessment	✓		✓
Freedom of Information	✓		✓
<b>I confirm that I have considered the implications of this report on each of the matters above, as indicated</b>	✓		

Initials: SH

## 1. Introduction

- 1.1 The NHS 2019/20 Operational planning and contracting guidance states that, to support the local delivery of the LeDeR programme, an annual report must be submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.
- 1.2 This report is the first annual report of the Dorset LeDeR programme.

## 2. Background and context

- 2.1 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.
- 2.2 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.
- 2.3 Each local area has a designated 'Local Area Contact'. Within Dorset, the Local Area Contact is employed by NHS Dorset CCG. Every CCG across England is accountable for the local delivery of:
  - LeDeR reviews of deaths of people with a learning disability aged four and above who are registered with a GP in their locality;
  - Collating learning from completed reviews and developing and delivering strategic and operational actions to address themes and individual recommendations.
- 2.4 More information about the programme and the review process can be found at: <http://www.bristol.ac.uk/sps/leder/about/>

## 3. Programme notifications and activity

- 3.1 Between 01/04/2019 and 31/03/2020 the Dorset LeDeR programme was notified of 44 deaths and completed and closed 28 reviews.
- 3.2 The following table summarises the activity of the Dorset programme, at the end of Q4 2019/20. All data is cumulative.

	2017/18			2018/19				2019/20			
	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Total notifications	41	49	56	73	75	81	83	95	105	116	128
Notifications awaiting reviewer allocation	31	32	15	17	14	13	9	15	16	22	15
Completed reviews	5	7	9	15	16	23	36	49	51	53	64*
Reviews awaiting Assurance panel sign off	2	0	0	0	0	0	3	2	5	4	5**

\*This includes those reviews undertaken by NHS England as part of the initial 'backlog' ('Backlog 1') and have all been approved by the LeDeR Bristol team and five reviews that were completed by the North of England Commissioning Support Unit (CSU).

\*\*These five reviews were submitted to the August, September, November, January and March (2019/20) Assurance Panels and are awaiting actions to be completed by the Reviewers prior to closure and/or the review is progressing to a Multi-Agency Review.

## 4. Demographics and data

4.1 Of the 44 notifications received during 2019/20:

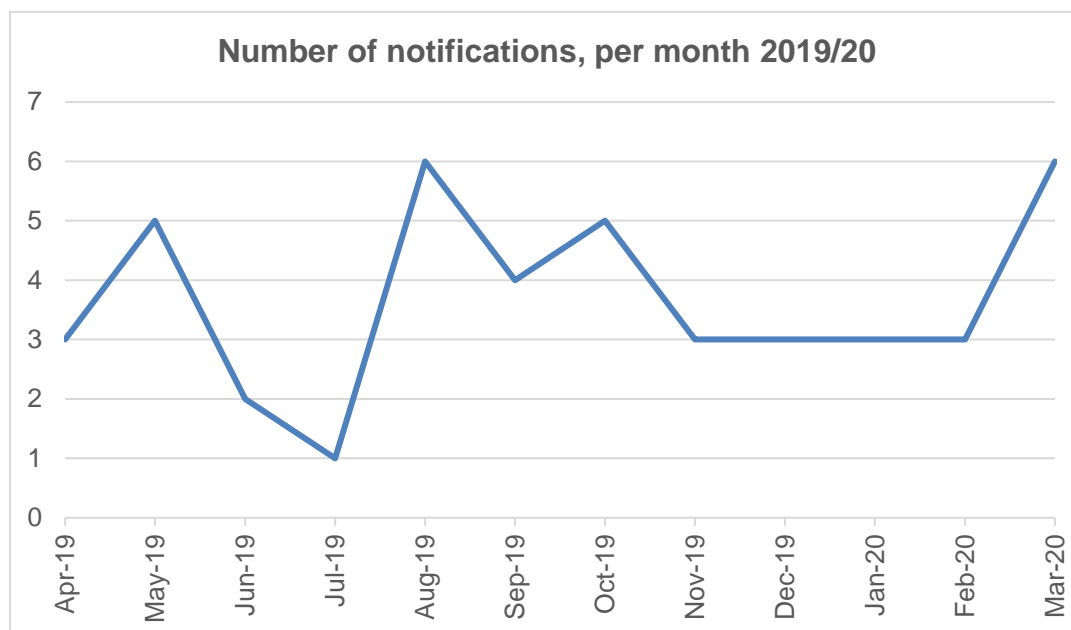
Age at death	0-17	18-24	25-29	30-39	40-49	50-59	60-69	70-79	80-89
	4	2	0	1	9	6	77	10	1

Gender	Male	Female
	27	17

Ethnicity	White British	Gypsy/Irish Traveller	Indian	Blank (no response)
	40	1	1	2

Place of death	Hospital	Usual residence	Hospice/Palliative care unit	Home of friend or relative	Blank (no response)
	21	20	1	1	1

4.2



4.3 The below data relates to the 28 reviews closed during 2019/20.

Level of disability	Mild	Moderate	Severe	Profound/ multiple
	5	16	5	2
Multi-morbidity	Yes	No	Unknown	
	25	1	2	
In contact with specialist services	Yes	No	Not known	
	25	1	2	
Did the individual have an end of life plan?	Yes	No	Not known	
	22	4	2	
Deaths with a DNACPR or decision to AAND	Yes	No	Not known	
	19	7	2	
Death of people taking antipsychotic medication	Yes	No	Not known	
	10	13	5	
Reported to the Coroner	Yes	No		
	4	24		

Causes of death			
Aspiration pneumonia	5	Chest infection	1
Pneumonia	4	Haemoptysis	1
Bronchopneumonia	3	Intracerebral haemorrhage	1
Renal failure	2	Pulmonary haemorrhage	1
Community acquired pneumonia	2	Cirrhosis of the liver /hypertension	1
Head injury	1	Leukaemia	1
Ischaemic heart disease	1	B-Cell lymphoma, renal failure	1
Alcohol intoxication	1	Respiratory failure/epilepsy	1
Myocardial Infarction	1		
<b>Total</b>			<b>28</b>

## 5. Child deaths

5.1 Four cases were reported to the LeDeR programme relating to the deaths of individuals under the age of 18, between 01/04/2019 and 31/03/2020. All four cases remain open whilst the Child Death Overview Process is completed.

Age at death	0-5	6-9	10-12	13-16	17-18
	0	1	2	0	1

Gender	Male	Female
	3	1

Place of death	Hospital	Usual residence
	3	1

5.2 Concerns relating to the care were raised in relation to one of these deaths. CDOP currently await the completion of a Serious Case Review. No concerns were raised in relation to the other three deaths.

5.3 There was one completed review of a child with Learning Disabilities between 01/04/2019 and 31/03/2020 by the Child Death Overview Panel (CDOP). No modifiable factors were identified in relation to this death, however incidental learning in relation to pain management in children lead to recommendations.

## 6. LeDeR programme assessment of the quality of care

6.1 The Dorset LeDeR Assurance panel meets at least monthly to review and sign off completed reviews. The panel members include the CCG LeDeR team, representative from Personal Health Commissioning and Dorset Council Mental Capacity Act team and a Lead Safeguarding GP.

# 9.10

6.2 The Assurance panel also request further investigation into certain aspects of reviews and/or further clarification prior to sign off.

Score and score description		Pre-31/03/2019	2019/20	Total	% of cases
1.	This was excellent care and met current best practice	8	3	11	17%
2.	This was good care, which fell short of current best practice in only one minor area.	20	17	37	58%
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).	1	6	7	11%
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	1	2	3%
5.	Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person some learning could result from a fuller review of the death.	3	0	3	5%
6.	Care fell far short of expected good practice and this contributed to the cause of death.	0	0	0	0%
7.	This review was done prior to 1-6 care scoring; deemed unavoidable	2	0	2	3%
8.	This review was conducted via an external process and has therefore not been scored (e.g. CDOP, DHR)	1	1	2	3%
<b>Total</b>		36	28	64	100.0%

## 7. Sharing Learning

7.1 Not all reviews generate learning, with a significant number of reviews demonstrating good care throughout the life, and end of life, of the individual. To 31/03/2020, 8% of closed reviews have indicated that care fell short of expected good practice (scored 4, 5 or 6).

- 7.2 All reviews which score 4, 5 or 6 are shared with the Business Managers of the Adult Safeguarding Boards (BCP Council and Dorset Council) to ensure that identified concerns are shared appropriately.
- 7.3 Learning from reviews is circulated via a quarterly report to an extensive distribution list across the CCG, the Acute Hospitals, Dorset HealthCare NHS Foundation Trust, BCP Council, Dorset Council and NHS England. This report includes a case study summary (with recommendations) of all reviews which score 3, 4, 5 or 6. A separate Appendix includes the recommendations from all reviews. This Appendix from the Q4 2019/20 report is included within this report as Appendix 1.
- 7.4 The national team, based in Bristol, have produced five '[Action into Learning](#)' newsletters since July 2018, sharing the national learning associated with aspiration pneumonia, sepsis, recognising deterioration, constipation and the Mental Capacity Act. These are shared via the quarterly report.

## 8. Affecting Change

- 8.1 The LeDeR programme collates and shares the anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.
- 8.2 During the first 'Learning Disability and Autism Programme Board' on 27/01/2020 the overarching governance arrangements across Bournemouth, Christchurch and Poole and Dorset for the NHS Learning Disability and Autism Programme (as part of the NHS Long Term Plan (2019)) were discussed, along with the mechanism by which learning from the LeDeR programme will feed into quality improvement work and commissioning decisions during 2020/21.
- 8.3 The subsequent meeting of the Joint Commissioners Officers Group (JCOG) was postponed due to the outbreak of the COVID-19 pandemic, however the May 2020 took place. JCOG will be responsible for:
- the delivery of the 'Dorset Learning Disability and Autism Delivery Plan';
  - ensuring that themes identified through the LeDeR programme and Care and Treatment Reviews (CTR) will influence the direction of service and quality improvement.

## 9. Recommendation

- 9.1 The Governing Body is asked to **note** the LeDeR Annual Report 2019/20.

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**Date: 25/06/20**

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<b>APPENDICES</b>	
<b>Appendix 1</b>	<b>LeDeR Annual Report 2019-20 summary of learning</b>



The following is a summary of learning from all cases closed to date, irrespective of their 'score'. It is clearly marked when:

- there has been new learning from the last quarterly report - 'new';
- previous learning has been repeated in this cohort of reviews - 'recurrent'.

Additional contextual information is available on request.

### END OF LIFE CARE AND PLANNING

- **NEW:** End of life care plans should be reviewed annually, as a minimum.
- **NEW:** DNACPRs should be registered with the ambulance service.
- **NEW:** For anyone who has a DNACPR in place there should be an 'Advanced Care Plan' sitting alongside it so that there is absolute clarity at the point the DNACPR comes into effect.
- **NEW:** When a decision is made for a patient to stay at home, this must be done via an MDT approach to confirm that everyone is happy with the plan, the level of risk, and what is being proposed. A training needs analysis must also be undertaken to ensure no gaps in training or expertise. Decisions should not be made without involving all parties involved in the delivery of care and an end of life care plan should then be documented and available to all.
- **RECURRENT:** Particular emphasis must be placed on ensuring that early conversations relating to 'end of life' and 'DNAR status' must take place with the individual or with their representative where they may lack capacity to have that conversation. Delaying the conversation can lead to poor end of life care.
- **RECURRENT:** Whilst appropriate and involving those who needed to be involved, there were many examples of poorly completed DNACPR documentation.
- **RECURRENT:** Reviews evidenced a need for care home staff to have end of life training and guidance in how to provide the planned care, and in what circumstances to seek help from other professionals.
- A learning disability is not a reason for not attempting resuscitation.
- Whilst someone may have capacity, it is still important to encourage the person to involve their circle of support when completing their End of Life Care Plans.
- There were examples of individuals who were identified as requiring end of life care but there was no evidence that a referral was ever made.
- Families reported that, whilst they knew the individual was at the end of their life, they felt unprepared and didn't know what to expect. Although every death is different, a leaflet or a conversation with families about what to expect might be helpful.

### DOCUMENTATION

- **NEW:** When individuals move localities/different care providers and/or from out of area, a comprehensive health and social care history should always be shared.
- **NEW:** Social care reviews should always take place within an agreed timeframe (e.g. six weeks), following a placement move.
- **NEW:** Eating and drinking care plans should be updated every time there are changes, ideally with a version number and date for added clarity.
- **NEW/RECURRENT:** All documentation, including care plans, DNACPR, best interest decisions and MCA documentation should be uploaded to the relevant clinical system and should be accessible to all involved. Care providers should make sure that key pieces of information, particularly legislative information should be easily accessible even if archived.

## MENTAL CAPACITY AND BEST INTEREST DECISIONS

- **NEW:** Clinicians need to be really clear in their approach to best interest decision making in all areas (including screening) to demonstrate adherence to Principle 2 of the MCA and demonstrate the steps taken to maximise capacity ahead of any decision not to proceed.
- **NEW:** Ensure hospital teams and community teams are aware of the MCA principles and Deprivation of Liberty Safeguards and consider all less restrictive options, consistent with the wishes of the individual and/or their advocate. The starting point should be the individual's wish. The teams should explore the viability of this wish and then give a rationale for more restrictive options. Keeping someone in hospital would be a deprivation of liberty and could be legally challenged unless less restrictive options have been explored and a justification given for not agreeing to the less restrictive option.
- **NEW:** Best interest decision meetings must take place, and be fully documented and involve all professionals involved in the care.
- **NEW/RECURRENT:** An IMCA referral is essential when making end of life decisions. Independent mental capacity advocates (IMCAs) are mainly intended to be a safeguard for people who do not have family or friends who can represent them. The Mental Capacity Act (MCA) identifies this as having no one other than paid staff with whom it would be appropriate to consult. This is for decisions about where the person lives, serious medical treatment and care reviews.
- If medications are to be administered covertly in someone's best interest, there needs to be evidence of the appropriate documentation to support this decision.
- **RECURRENT:** Ensure all conversations and decisions around mental capacity and best interests are clearly documented.
- **RECURRENT:** Ensure that decisions made in the best interests of the individual are backed up by demonstrable processes, meetings and documented outcomes.
- **RECURRENT:** Decisions that individuals are not going to participate in screening programmes should be backed up with the appropriate documentation. Each screening programme should be considered separately as they involve different approaches.
- Health and social care professionals need to be considerate of families and carers if they disagree with the decisions made in relation to mental capacity and best interests. Do not make them feel "brushed off".
- Ensure a robust assessment for individuals with a mild learning disability who may give the impression that they are 'coping'.
- Ensure individuals are informed honestly about their health and procedures, unless a best interest meeting decides otherwise.

## NOT KNOWN TO SERVICES

- Processes for recording those with a learning disability has evolved. There are individuals who live with their elderly parents who are not known to services. GP practices should ensure that patients with a learning disability are on the GP register and a referral is made to the Community Learning Disability team, if required.
- For those individuals who become known, having previously been unknown for a significant period of time, it is imperative that any referrals that are made (e.g. to social services) are followed up to ensure that the referral was received and actioned.

## INPATIENT CARE

- **NEW:** In relation to discharge planning, hospital staff should base their decision on clinical presentation AND based on the information provided to them by those advocating for the patient.
- **NEW:** All Trusts have a policy for applying for additional staffing for patients with additional needs. All ward staff to be aware of their Trust procedure for requesting staff for a patient with additional needs, and how to escalate a request for additional staff (both in and out of hours).

## SIGNPOSTING

- **RECURRENT:** There is a need to raise awareness of the role of the Community Learning Disability team.
- **RECURRENT:** The signposting for families could be improved, detailing the services which are available to them.
- Primary Care are often unaware that there is a Speech and Language Therapy (SALT) team specifically for those with a learning disability. Referrals are often made to the wrong team, which then take time to be forwarded on and can cause delays to assessment and treatment.
- Primary Care can be unsure which services to refer to, due to the large and differing number of services available.
- Hospital based learning disabilities facilitators can provide support and care to families, even if the individual is unconscious. If the patient has a learning disability and is an inpatient, contact the hospital learning disability facilitator.

## TRAINING

A large number of reviews indicated a need for specific learning disability training, within both acute hospitals and the community setting. Highlights were:

- Staff need to understand that a change in behaviour and mood can be a sign of an underlying medical condition.
- Staff need to listen to the voice of the family and/or carers when then they are acting as an advocate.
- Medical and nursing staff can struggle with assessment and communication, especially with non-verbal patients. Training regarding the clinical assessment of non-verbal patients would be invaluable.
- Staff should be reminded of the different criteria for learning difficulty and learning disability.

## CAUSE OF DEATH

In three cases the cause of death was “congenital cerebral palsy”. It may be a contributing factor, but it is not the cause of death.

## ADDITIONAL LEARNING

- **NEW:** All care providers (community NHS or other) to routinely check/update diagnosis and medication information, particularly following an inpatient episode. In one case, the Learning Disability team notes (RIO) nor the Provider notes gave 100% accurate diagnoses (4/5 recorded) or medication (7/10 recorded) when compared to the hospital discharge report prior to death.
- **NEW:** Ensure that the patient and/or their family/advocate have a forum to voice concerns about the chosen approach (for example “too many interventions”).
- **NEW:** Particular care should be taken when reviewing medications which individuals have taken for a number of years – research on the links between PPIs and renal function is relatively new.
- **RECURRENT:** Ensure the individuals are on the Learning Disability Register at the GP practice and have annual health checks.
- Particular care should be taken when discharging individuals from hospital to prevent a failed discharge, and subsequent readmission.
- General Practice should offer flu vaccinations to all eligible individuals.
- Ensure there is a process in place to support those with a learning disability (and their next of kin/guardians if appropriate) to access their finances and understand how much they have.
- Consider how individuals with capacity can plan where their money should go following their death, and the options available to them in terms of making a will.
- Be mindful of ensuring continuity of professionals, wherever possible, over short periods of time.
- Should referrals made to the learning disability community team be acknowledged, especially in circumstances when they are not going to be acted on immediately?
- There is still uncertainty over who is on the Learning Disability Register as who is on these registers is not known to the acute providers.
- There should be clear arrangements in place for the monitoring arrangements of home oxygen.