

Meeting: Governing Body			
Meeting Date	22 July 2020	Action	Approve
Item No.	6	Confidential	Yes
Title	Learning Disabilities Mortality Review (LeDeR) programme annual report 2019/20		
Presented By	Catherine Jackson, Director of Nursing and Quality Improvement		
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Executive Summary

The Learning Disability Mortality Review (LeDeR) programme is a national improvement programme to reduce the premature mortality and health inequalities for people with a learning disability.

NHS Clinical Commissioning Groups (CCGs) are responsible for implementing the LeDeR programme in their locality, carrying out local reviews of deaths of people with a learning disability; identifying and acting on the learning to improve local services.

This report outlines Bury CCG's performance of and progress with the LeDeR programme to date.

Recommendations

It is recommended the Governing Body:

- Approve this report for publication

Links to CCG Strategic Objectives

<p>SO1 People and Place To enable the people of Bury to live in a place where they can co-create their own good health and well-being and to provide good quality care when it is needed to help people return to the best possible quality of life</p>	<input checked="" type="checkbox"/>
<p>SO2 Inclusive Growth To increase the productivity of Burys economy by enabling all Bury people to contribute to and benefit from growth by accessing good jobs with good career prospects and through commissioning for social value</p>	<input type="checkbox"/>
<p>SO3 Budget To deliver a balanced budget for 2019/20</p>	<input type="checkbox"/>

SO4 Staff Wellbeing To increase the involvement and wellbeing of all staff in scope of the OCO.	<input type="checkbox"/>
Does this report seek to address any of the risks included on the Governing Body Assurance Framework? If yes, state which risk below:	
GBAF	

Implications						
Are there any quality, safeguarding or patient experience implications?	Yes	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input type="checkbox"/>
Improve the health care provided to those residents of Bury who have a learning disability.						
Has any engagement (clinical, stakeholder or public/patient) been undertaken in relation to this report?	Yes	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input type="checkbox"/>
The bereaved families and the health and social care providers who cared for the deceased persons were key partners and actively involved in the local review process.						
Have any departments/organisations who will be affected been consulted?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input checked="" type="checkbox"/>
Are there any conflicts of interest arising from the proposal or decision being requested?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input checked="" type="checkbox"/>
Are there any financial Implications?	Yes	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input checked="" type="checkbox"/>
The ongoing funding of Bury's LeDeR programme.						
Has an Equality, Privacy or Quality Impact Assessment been completed?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input checked="" type="checkbox"/>
Is an Equality, Privacy or Quality Impact Assessment required?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>	N/A	<input type="checkbox"/>
Are there any associated risks including Conflicts of Interest?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>	N/A	<input type="checkbox"/>
Are the risks on the CCG's risk register?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>	N/A	<input type="checkbox"/>
<i>If you have ticked yes provide details here. If you are unsure seek advice from Lisa Featherstone, Email - lisafeatherstone@nhs.net about the risk register.</i>						

Governance and Reporting		
Meeting	Date	Outcome
Quality and Performance Committee	10/06/2020	Recommend this report to the Governing Body for publication

Learning Disability Mortality Review (LeDeR) programme Annual Report

April 2019 – March 2020

Author

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Section number	Section title	Page number
1	Introduction	3
2	Background	3
3	Challenges	4
4	Number and status of LeDeR reviews	5
5	Underreporting	6
6	Findings	6
6.3	The people whose deaths were notified	7
6.5	Age at death	7
6.8	Month of death	8
6.9	Place of death	8
6.10	Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order	8
6.11	Antipsychotic medication	8
6.14	Multimorbidity	9
6.16	Cause of death	9
6.20	Cancer screening	9
6.22	Quality of care	10
6.23	Overall assessment of the quality of care provided	10
6.25	Best practice	10
6.30	Concerns	11
7	Summary	12
8	Recommendation	13

Learning Disability Mortality Review (LeDeR) programme Annual Report 2019/2020

1. Introduction

- 1.1. This is the first annual report of the Learning Disability Mortality Review (LeDeR) programme being delivered by NHS Bury Clinical Commissioning Group (CCG).
- 1.2. It presents information about the LeDeR programme and its findings to date regarding the deaths of people who have a learning disability aged 4 years and over that have been notified to the programme. This includes both national and Bury specific data, summarising the quality of health care received. Positive practice and areas for improvement are detailed, with recommended actions to implement this learning.
- 1.3. The period covered for Bury residents is for reviews completed between the 1st March 2017 to 31st March 2020¹.

2. Background

- 2.1. The LeDeR programme was established by NHS England (NHSE) to improve the standard and quality of care for people with a learning disability².
- 2.2. The programme introduced a new review process for deaths of people with a learning disability aged 4 years and over³. All deaths, regardless of where they took place and whether expected or not, are required to be locally reviewed.
- 2.3. The drivers for the LeDeR programme were, and still are, the persistence of health inequalities between the general population and people with a learning disability. People with a learning disability are three times more likely to die from causes that could have been avoided with access to good quality healthcare and die on average, 15-20 years sooner than the rest of the population. The need to act to address this disparity was a key recommendation of the Confidential Inquiry into Premature Deaths of people with a Learning Disability (CIPOLD)⁴. The LeDeR programme aims to reduce these health inequalities and avoidable deaths by informing public policy through a better understanding of the care provided and the causes of death.
- 2.4. The University of Bristol run the LeDeR programme⁵ funded by NHSE. The university holds the national LeDeR database and receives all death notifications, allocating them out to local areas for review. To prompt local and national system-wide change, the university produces learning briefs and an annual national report to government.
- 2.5. The LeDeR programme is part of a wider national Learning from Deaths framework⁶, bringing greater scrutiny of deaths and standardisation of mortality review processes.

¹ The national LeDeR data cover deaths notified to the programme from 1st July 2016 to 31st December 2018.

² The definition of learning disability used by the LeDeR programme is from the 'Valuing People - A New Strategy for Learning Disability for the 21st Century' (2001) report and includes the presence 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.*'

³ An initial upper age limit of 74 years was later removed to bring the LeDeR programme in line with the wider Learning from Deaths framework.

⁴ CIPOLD (2013) was itself a key recommendation of Mencap's 'Death by Indifference' report; its purpose to review if the learning from premature and preventable deaths of people with a learning disability was being implemented.

⁵ NHSE were due to take over the LeDeR programme from 1st June 2020, with the NHS Long Term Plan supporting its continuation. Due to the COVID-19 pandemic, this has been postponed to 31st May 2021.

⁶ National Guidance on Learning from Deaths 2017, 2019 (National Quality Board).

Acute, mental health, community and ambulance trusts are all now required to improve how they learn from the deaths of patients, including how they engage with bereaved families. The new medical examiner system is bringing a further layer of independent scrutiny, confirming cause of death for non-coronial deaths.

- 2.6. Introduced at a similar time, this wider Learning from Deaths framework and the LeDeR programme are interlinked, with both gaining momentum over the past few years.
- 2.7. The LeDeR programme was introduced in England in 2017 via a phased national roll-out, going live across Greater Manchester in February 2017. CCGs are responsible for its implementation and running; both the completion of reviews and the collation of subsequent learning, developing and delivering strategic and operational improvements. Health and social care commissioners and providers are required to work together, in partnership with families of the deceased and with people with a learning disability, to identify and act on learning from reviews.
- 2.8. The CCG's Quality Team is responsible for the programme in Bury. With the support of Local Authority and provider colleagues, the Quality Team launched the programme on 27th February 2017 via communication packs, e-newsletters, site visits and formal training sessions. To support the continued commitment to and understanding of the programme's aims, GP practices and providers receive targeted support from the Quality Team, particularly when participating in their first review.

3. Challenges

- 3.1 As with the introduction of any new national process the LeDeR programme has taken time to become established. However, from its launch the programme has had two significant difficulties. Firstly, the review process it introduced is not a statutory requirement. Secondly, there continues to be no recurrent funding, resulting in a lack of resources and reviewers. Review completion was initially an additional task within existing roles. Consequently, reviewers had minimal capacity and when able to complete a review, it would often be as a one-off, which in turn impacted on their ability to increase in confidence and pace. In some areas, large numbers of deaths were also notified before capacity was in place to review them. These factors have resulted in a national, regional and local backlog of reviews waiting to be completed.
- 3.2 Different national initiatives have been introduced to address the backlog - a rapid review process, non-recurrent funding and the reallocation of historic reviews to a national team (hosted by the North East Commissioning Support (NECS) unit).
- 3.3 Bury CCG has a current backlog of 8 reviews, the majority from 2018. All are now with the NECS unit. This backlog is consistent with the GM, regional and national picture. The CCG has had eight reviewers over the past four years, four of whom had full-time substantive posts and were only able to complete one review each. Following two separate national funding allocations, the CCG employed four dedicated reviewers on fixed term contracts, enabling a further seventeen reviews to be completed over the past two years. The CCG currently employs one reviewer on a part-time basis.
- 3.4 To embed and drive the LeDeR programme (and support the backlog reduction), from April 2019 the NHS planning and contracting guidance for both CCGs and for NHS

Trusts has included expectations regarding mortality reviews. Trusts must comply with the National Guidance on Learning from Deaths, which requires their mortality processes to be compliant with the LeDeR programme. New learning disability improvement standards have also been introduced, requiring Trusts to monitor and review the quality of care they provide to people with a learning disability.

- 3.5 Regarding expectations of CCGs, Bury CCG is currently compliant, with a local LeDeR group in place⁷, an identified executive lead and reviews being undertaken in a timely manner with a robust system to collate and act on local and national learning.⁸
- 3.6 Regarding the timeliness of review completion, two national performance measures have been introduced for CCGs, one for review allocation and one for review completion (with NECS back log cases excluded). As a region, the North West was aiming to achieve 100% in both by July 2020. With the impact of the COVID-19 pandemic, this has been amended to the end of the year, with the expectation to achieve completion of all reviews reported up to June 2020 by the 31st December 2020.

4. Number and status of LeDeR reviews

- 4.1 The number of deaths notified to the LeDeR programme nationally and across Greater Manchester and the number of reviews completed are detailed in table one below.

Table 1 - Number and status of notifications to the LeDeR programme (01/07/16 to 31/12/18 for England, 27/02/17 to 30/04/20 for Greater Manchester)

Total notifications received		Closed notifications (review completed)	Percentage of closed notifications (review completed)
England	8733	4353	50%
Greater Manchester	520	249	48%
Bolton CCG	53	20	38%
Bury CCG	36	21	58%
Heywood, Middleton, Rochdale CCG	39	30	77%
Manchester CCG	83	48	58%
Oldham CCG	47	18	38%
Salford CCG	58	40	69%
Stockport CCG	71	38	54%
Tameside and Glossop CCG	46	24	52%
Trafford CCG	50	5	10%
Wigan CCG	37	5	14%

The current position of Bury CCG's notifications and reviews is detailed in table two below.

⁷ Bury CCG's LeDeR Steering Group was incorporated into the CCG's Transforming Care Group last year (November 2019).

⁸ The publication of this annual report will satisfy the final requirement, with an easy read version also required.

Table 2 - Number and status of death notifications to Bury CCG (27/02/17 to 28/05/20)

	Notified				Total
	2017	2018	2019	2020	
	3	15	11	7	36*
Status	closed	8 closed 7 reallocated to NECS	10 closed 1 reallocated to NECS**	open	
Assigned within 3 months of notification	n/a	n/a	n/a	Target achieved (100%, n 7)	
Review completed within 6 months of notification	n/a	n/a	Target achieved (100%, n 10)	Target predicted to be achieved (100%, n 7)	

*Bury CCG has received 38 notifications, 2 were later withdrawn as the persons did not have a learning disability.

** Received late as incorrectly allocated by the national LeDeR team to Manchester CCG.

5. Underreporting

- 5.1 There is no accurate record of the total number of people with learning disabilities in England, nor of the number of deaths each year. Estimates from Public Health England suggest the approximate number of deaths of people with learning disabilities of all ages each year to be more than 3,400. Using this figure, approximately 86% of deaths were notified to the LeDeR programme in 2018⁹. The assumption is the underreporting reflects the lack of a statutory requirement to notify deaths to the programme.
- 5.2 However, the number of notifications has increased over time as the programme has become more established. Between 2017 to 2018, they nearly tripled from 1,274 to 3,413 in England and increased five times from 3 to 15 in Bury.

6. Findings

- 6.1 The national LeDeR programme has started to generate significant amounts of data. Local information, from completed reviews of Bury residents with a learning disability, is also available, although on a smaller scale.
- 6.2 However, as detailed above in table one, 50% of all national reviews and 42% of Bury reviews are waiting to be completed. Once this backlog has cleared and current reviews are completed timelier, the value of the information and learning generated will increase. As the number of completed Bury reviews is so small this will provide greater confidence in interpreting the findings and understanding the experiences of local

⁹ A further difficulty is the data are indicative but not directly comparable as the general population data are from 0 upwards and LeDeR data are from 4 years and over.

people with a learning disability and how these compare across Greater Manchester and England, and to those of the general population.

The people whose deaths were notified

- 6.3 The deaths of children with a learning disability are reviewed by a separate process, the statutory Child Death Review programme, and do not have a LeDeR review. Any learning identified is fed back to the relevant CCG and to the national LeDeR team. There has been one death of a Bury child (aged 17 years) notified to the LeDeR programme, with no concerns identified.
- 6.4 The LeDeR programme has a specific focus on the deaths of two groups - young people aged 18 to 24 years and the deaths of people from Black, Asian, Minority Ethnic (BAME) groups. This reflects concerns in the transition from children's to adults' services and the ongoing additional inequality of health care experienced by people with a learning disability from BAME groups. To generate maximum learning, the programme required a more in-depth, multi-agency LeDeR review for any death in these two categories. However, due to the backlog, this automatic additional scrutiny has been suspended (and is only triggered if concerns are identified). To date, the proportion of deaths notified of people from BAME groups in England has been lower than expected (10% compared to 14%). Of the 36 deaths notified to date of Bury residents, 3 people were Asian / Asian British, with one person identifying as Indian, one as Pakistani. Of these 3 notifications, 1 review has been completed and found no concerns linked to the deceased's ethnicity.

Age at death

- 6.5 To date, the average age at death for people with a learning disability notified to the programme is 59 years, with 59 years for women and 60 years for men. The current disparity between these and the general population (all ages) is now 23 years for men and 27 years for women.
- 6.6 The average age at death of Bury residents notified to the programme is currently 55.5 years¹⁰, with 49.5 years for women and 56 years for men. This is nearly 10 years earlier for women than the national figure and 4 years earlier for men. However, as the number of Bury notifications is so small (36), these differences should be interpreted with caution.
- 6.7 There is a considerable difference in the national LeDeR data for the average age at death between white British people compare to people from BAME groups. For people of BAME groups it is 35 years compared to 61 years for people of white British ethnicity. The Bury data show 23 years as the average for the 3 people of BAME groups compared to 56 years for the 33 people of white British group. Again, although in keeping with the national data, these differences should be interpreted cautiously due to the small numbers involved.

Month of death

¹⁰ Of 36 deaths notified to Bury, 26 were men and 10 were women, with the youngest 17 years and the oldest 81 years.

- 6.8 The national LeDeR data shows a rise in deaths through autumn and early winter, earlier than the winter peak of deaths in the general population. Of the 36 deaths of Bury residents notified to the programme, 64% (23) occurred between October and March, and 36% (13) between April and September.

Place of death

- 6.9 The national LeDeR data show more people with a learning disability die in hospital than the general population (62% compared to 46%). Of the Bury notifications, place of death is currently unknown for 4 people. For the remaining, 23 people died in hospital. Nine people died at home, with 3 of these deaths reflecting the person's and their family's wishes regarding their preferred place of death.

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order¹¹

- 6.10 The national LeDeR data indicate the majority (79%) of DNACPR orders are appropriate and are correctly completed and followed. Although 'learning disabilities' is never an acceptable rationale for a DNACPR order, a small number (19), incorrectly recorded 'learning disabilities' or 'Down's syndrome' as the reason for the DNACPR order being in place. To date, of the 11 in place for Bury residents, all have been appropriately and correctly completed.

Antipsychotic medication

- 6.11 There is a higher rate of prescribing medicines that affect mental processes and behaviour (psychotropic medication) for people with a learning disability than amongst the general population, with 30,000 to 35,000 adults taking them when they do not have the health conditions the medicines are for¹². Psychotropic medicines can cause serious physical health problems if taken for too long, or at too high a dose or for the wrong reason.
- 6.12 The national LeDeR programme looks at the prescribing of one type of psychotropic medication, antipsychotics. Data for 2018 found a fifth (19%) of adults were prescribed antipsychotic medication at the time of their death, with an increase with age, with 90% aged 50 or over. Contrary to national guidance for only one antipsychotic medicine to be prescribed at a time, the national data found a small number of people (20) taking two different types, 6 three different types, and 1 person four different types.
- 6.13 To date, Bury's LeDeR data show of the 21 completed reviews, 8 people were prescribed antipsychotic medicine¹³. Regular medication reviews took place for all, with attempts to reduce antipsychotic medicine for several people. Three people were taking 2 different types of antipsychotic medicine.

Multimorbidity¹⁴

¹¹ Cardio-pulmonary resuscitation (CPR) is the chest compressions and artificial breaths given when a person's heart has stopped. A decision not to attempt, a DNACPR, is made and recorded in advance when it is not in the best interests of the person if they are near the end of their life or unlikely to be successful. Decisions about DNACPR must not be based on assumptions related to the person's age, disability or the professional's subjective view of a person's quality of life.

¹² Stopping over medication of people with a learning disability (STOMP) is a national campaign to reduce the over use of these medicines.

¹³ The national LeDeR review template has had several iterations, with questions changed. Due to the small number of completed Bury reviews and different reviewers completing a changing template over time, the current findings are limited in some areas.

¹⁴ Multimorbidity is the presence of two or more long-term health conditions.

- 6.14 People with a learning disability are significantly more likely to have another long-term health condition. The national LeDeR programme has found over half (57%) of the people whose deaths have been reviewed have three or more other long-term health conditions in addition to a learning disability. The most common is epilepsy (39%), followed by swallowing difficulties (dysphagia) (38%), heart (cardiovascular) problems (28%), dementia (25%) and mental illness (23%). No link was found between the medium age of death and having additional long-term health conditions.
- 6.15 Of the 21 completed Bury reviews, 17 (81%) people had additional health needs. As per the national LeDeR data, epilepsy was the most frequent followed by dysphagia and then diabetes.

Cause of death

- 6.16 The national LeDeR data show the most frequent cause of death as pneumonia, followed by aspiration pneumonia, sepsis, dementia (syndrome), ischaemic heart disease and epilepsy. The Bury data provide a similar picture. Of the 36 notifications received, the cause of death is currently known for 27. The most frequent is pneumonia (14), followed by liver disease (3), aspiration pneumonia (2), heart disease (2), sepsis (1), dementia and epilepsy (1), cardiac arrhythmia (1), shock (1), multiorgan failure (1) and cancer (1).
- 6.17 As pneumonia is one of the respiratory problems where mortality can be avoided, there is a national focus on increasing the number of people with a learning disability who receive an influenza (flu) vaccination. National figures show only 44.7% of GPs' patients with a learning disability received a flu vaccination in 2018. Of the 21 completed Bury reviews, 4 identified the person had regular flu vaccinations, with unclear information in the other reviews.
- 6.18 Aspiration pneumonia is the second most frequent cause of death nationally and the third in Bury. Some of these deaths will have resulted from dysphagia. As with pneumonia, mortality from swallowing difficulties can be avoided with better management and support.
- 6.19 The underlying cause of death is also considered under the LeDeR programme. CIPOLD found cancer was one of the most common underlying causes of death for people with a learning disability. Access to cancer screening services for people with a learning disability is variable and engagement in the bowel screening programme is especially problematic. To date, the LeDeR programme has found people in the general population die more frequently from cancer than people with a learning disability. In Bury there have been 3 deaths where there was a cancer diagnosis, although this was not necessarily the direct cause of death.

Cancer screening¹⁵

- 6.20 People with a learning disability participate less in the three national cancer screening programmes than the general eligible population. In the most recent year for which data are available (2015/16), there was an 8% lower uptake rate for bowel cancer screening and 16% and 46% lower uptake rates for breast and uterine cervical cancer screening

¹⁵ Bowel cancer screening is offered every 2 years to all men and women aged 60 to 74. Breast cancer screening is offered every 3 years for women aged 50 and over and cervical screening is offered to women at different intervals depending on age.

respectively (compared to the eligible population). Local information is limited, with only 4 people known to have participated in a national screening programme.¹⁶

Quality of care

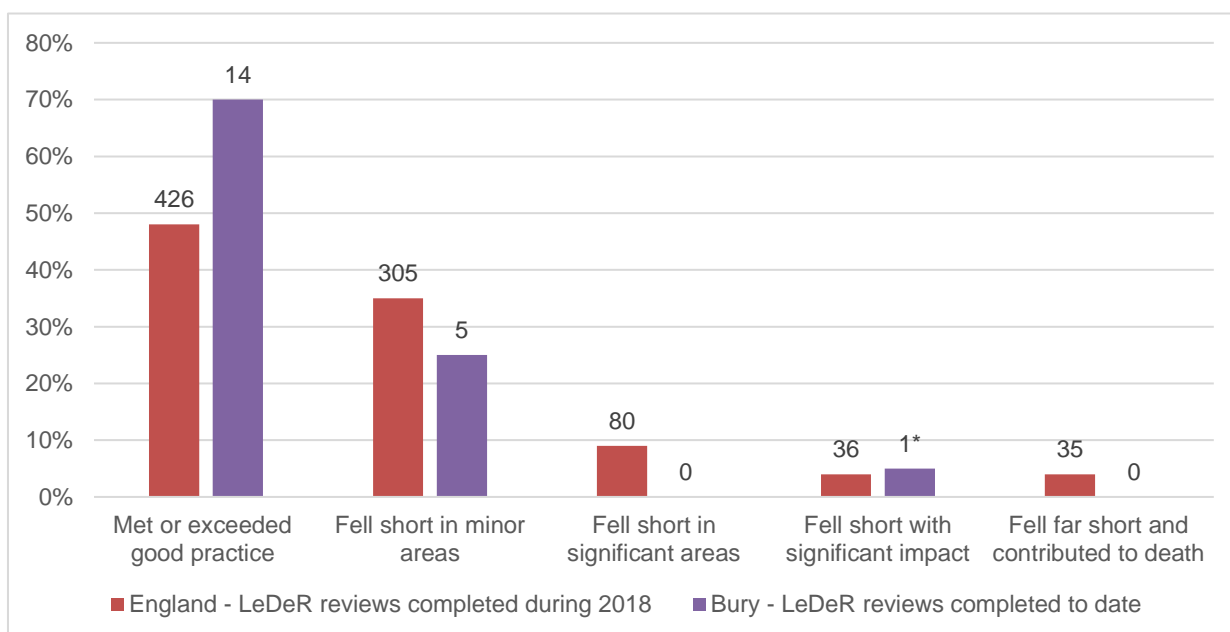
6.22 The LeDeR programme asks reviewers to rate several aspects of the quality of care.

Overall assessment of the quality of care provided

6.23 At the end of the review, an overall assessment is made of the quality of care provided, whether it exceeded or met expected good practice or whether it fell short. The national LeDeR data show almost half (48%) of the deaths reviewed in 2018, the person received care that met or exceeded good practice. People whose reviews had either rating were more likely to be on an end-of-life care pathway, for any DNACPR documentation to be completed correctly and to have had a health check in the last 12 months.

6.24 Of the 21 Bury completed reviews, an overall quality rating is available for 20¹⁷. As detailed in figure one below, most (70%) found the care the person had received met or exceeded good practice. Of this group, 12 of the 14 had a health check in the last year¹⁸ and 5 were on an end-of-life care pathway with correctly completed DNACPRs.

Figure 1 Assessment of the quality of care provided



*The local multi-agency panel for the Bury review where care fell short of expected good practice with significant impact, identified learning actions for systems and staff training.

Best practice

6.25 Most (75%) completed Bury reviews have one or more examples of best practice, compared to 33% of national reviews. Both groups have similar themes of excellent person-centred care, strong inter-agency work and effective end-of-life care. The

¹⁶ As noted, the national LeDeR review template has had several iterations and a cancer screening question was not initially included.

¹⁷ The statutory child death review process (CDOP) does not assess quality of care in the same way, so the death of the 17 year old Bury young person is not included.

¹⁸ One person, with capacity, had declined and another person was new to Bury, with past medical records unclear.

provision of 'reasonable adjustments'¹⁹, often small changes to make appointments and health care work better, were absolutely key.

- 6.26 Local examples of person-centred care are best and most frequently demonstrated through positive relationships with Bury GP practices. These include flexible, consistent support from practice staff who know the person and their additional needs; home visits and telephone support; active follow up if an appointment is missed or a health invitation not responded to; and referral letters detailing how to support a person when invited to attend for an outpatient appointment or a hospital stay.
- 6.27 Local examples involving other health services and settings include referrals to a specialist nurse for additional help with intimate self-care, reducing lighting in A&E cubicles to lessen anxiety and health professionals taking the time to gain a person's trust and confidence, resulting in treatment being received when previously there had been no engagement.
- 6.28 The second theme of strong, effective inter-agency work is best demonstrated locally when either Pennine Care Foundation Trust (PCFT) Community Learning Disability Team are supporting a person (and their family, GP practice and care provider) or if the person is a patient in Fairfield General Hospital and the hospital's Learning Disability Liaison Nurse is involved in their care. Complex health care needs are met, specialist advice and support provided, and independent advocacy and additional medical opinion arranged.
- 6.29 Local reviews also provide examples of highly personalised end-of-life care. Care providers and District Nursing and Palliative Care teams providing support with dignity and compassion, enabling people to die in their preferred place at home (avoiding stressful hospital admission), regardless of complex health conditions. Support includes familiar, reassuring items nearby and staff rotas adjusted so the person is cared for by staff well known to them.

Concerns

- 6.30 The national LeDeR data indicate most (89%) reviews do not identify any concerns. Where they are noted (11%), they generally relate to families' concerns about delays in diagnosing and treating illness and in the quality of care received. Of the 21 completed Bury reviews, 9 identify concerns, 2 of which were looked at more in-depth via local multiagency LeDeR review panels.
- 6.31 Of the 9 local concerns, four themes are evident. The first is a lack of consistency and continuity when the person accesses General Practice. People are being seen by too many different GPs, even when they have a named GP and the practice knows they have a learning disability. This hinders a relationship developing, which as seen above, can impact on a person's willingness to engage with health procedures and health checks. It also limits a GP's ability to understand and meet the specialist communication needs of the person and their required reasonable adjustments.
- 6.32 The second theme is staff knowledge, confidence and competence in caring for people with a learning disability. This includes considering the expert knowledge family carers

¹⁹ Under the Equality Act 2010, all public bodies must make reasonable adjustments to ensure people with learning disabilities can use their services and are not disadvantaged.

and paid carers usually have about the needs of people with profound learning disabilities, particularly when medical and treatment decisions need to be made. Subtle ('soft') changes recognised by a family or an established paid carer can be a better and an earlier indicator if a person with profound learning disabilities is in pain or their health is deteriorating than formal health assessment tools.²⁰

- 6.33 The need for mandatory learning disability awareness training for all health and social care staff, including General Practice and hospital staff, has been a key recommendation of the national LeDeR programme²¹. As noted above, having access to and support from a specialist resource, such as PCFT Learning Disability Team or a Learning Disability Liaison Nurse, is also key. Completed Bury reviews have identified when this is present, a higher quality of care is more likely.
- 6.34 The third theme concerns systems and processes, information sharing and communication needs, with both national and local difficulties. Completed Bury reviews found key information such as a patient's learning disability diagnosis is not always shared between General Practice, care providers and hospitals²². In General Practice, texts and letters are sent to people who cannot read or write, resulting in them not responding or attending for appointments and health checks. This can happen even when it is noted on the system that verbal communication is preferred. Information about who supports a person is also not recorded or missed, particularly if a person has more than one supporter (family member, close friend or partner and paid carers).
- 6.35 In hospitals, there is disparity in systems and processes to ensure reasonable adjustments can be made, such as the first outpatient appointment of the day being routinely offered to avoid a noisy, busy waiting room. Consequently, some people do not attend, missing health care appointments and treatment or stop attending as it is too stressful. Information about additional needs is also not shared between departments and wards when a person with a learning disability is staying in hospital.

7. Summary

- 7.1 People with a learning disability have poorer health and are more likely to die at a younger age than people in the general population, in part because of poor access to health services. The national Learning Disability Mortality Review (LeDeR) programme was established to improve the standard and quality of care for people with a learning disability. This report presents national and local findings from the programme's reviews of notified deaths of people with a learning disability.
- 7.2 The LeDeR programme is well established across England and in Bury, with reviews producing valuable information and learning. Whilst local findings need to be interpreted cautiously, due to low review numbers, Bury's evidence base is growing. This local

²⁰ Using their knowledge of a resident, carers in care homes have identified illness 5 days earlier than clinical observations did. Monitoring of soft signs in hospital can also be a better indicator of the health of a person with profound learning disabilities than the national clinical system used by nursing and medical staff (the National Early Warning Score system) (LeDeR Learning into Action Bulletin 'Recognising deterioration' November 2018).

²¹ Trials of a mandatory training package are currently taking place across health and social care sectors. In the meantime, providers are still expected to provide training that meets the revised Core Capabilities Education and Training framework for people with a learning disability. This details 3 levels of skills, knowledge and behaviours required in a range of settings, from general awareness to expert.

²² From 1st August 2016, all organisations which provide NHS care and publicly-funded adult social care are required to follow the Accessible Information Standard; identifying, recording, flagging, sharing and meeting the information and communication support needs of patients with a disability or impairment to ensure they get the information they need to stay healthy and in a format they can understand. NHS England and NHS Digital are working on national digital integrated 'flagging' project.

information will enable local commissioners and providers to understand how best to act on the national data and it will evidence the standard and quality of care in Bury.

- 7.3 As seen regionally and nationally, there continues to be challenges with the programme - ensuring all deaths of people aged 4 years and over are being notified and having the capacity to review them in a timely manner. Bury CCG has made considerable progress in completing reviews and benefits from a skilled and knowledgeable reviewer. National review timescales are being met and more importantly, learning generated.
- 7.4 Findings from local reviews are very positive, with Bury CCG significantly above the national average for good or excellent practice being identified. There are substantial examples of skilled and person-centred care, of complex needs being met and of effective collaboration between providers.
- 7.5 Areas of learning are also identified. General Practices need to improve continuity of care and meet the communication needs of patients with a learning disability. Training for both General Practice and hospital staff is needed so they understand the specialist needs of people with a learning disability and the expert knowledge held by their families and carers, including awareness and use of reasonable adjustments.
- 7.6 In General Practice, these areas for improvement are being supported by a current quality improvement programme. This focuses on improving the accuracy of information held about patients with a learning disability and increasing the number and quality of health checks these patients receive. A revised Bury health check template has already been developed by the CCG's Transforming Care Group and is currently being piloted. Such learning actions will make a local difference as better-quality health checks enable health needs to be identified earlier, minimising the risk of people with a learning disability dying from preventable health conditions.

8. Recommendation

- 8.1 Bury CCG to consider the findings of this report, ensuring corresponding targeted learning actions are included in the CCG's Learning Disability work plan, improving health care for Bury residents with a learning disability.