NHS
Wigan Borough
Clinical Commissioning Group

Learning Disabilities Mortality Review (LeDeR) Programme

Assurance Report

15 August 2017- 30 June 2020

Wigan Borough

Clinical Commissioning Group

Introduction

1. This assurance report is the first written in respect of the Learning Disabilities Mortality Review Programme (LeDeR) within Wigan Borough. The report covers the period from 15/08/17 until 01/07/20.

2. Given that this is the first assurance report in respect of LeDeR for Wigan Borough, the decision was taken to report for the period from notification of the first review (15/08/17) up to and including the period covering the Covid 19 pandemic (01/07/20). The reason for reporting on the extended period as opposed to just the past year is simply to provide an overview of LeDeR activity for the entire period which the programme has been running for the purpose of completeness.

3. The reason to include the period covering the Covid 19 pandemic is solely to include figures for that period and discussion regarding the same in real time.

4. Moving forward an annual report will be written for the period 01 April – 31 March each year in order to provide an overview of LeDeR activity for that year and discussion and analysis regarding the same.

Background Information

5. The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP). It is delivered by the University of Bristol and follows the Confidential Enquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) that took place between 2010 – 2013. CIPOLD reported that for every person in the general population that dies from a cause of death amenable to good quality care, three people with learning disabilities will do so. CIPOLD also reported that on average, people with a learning disability live 20 years less than people without a learning disability.

6. One of the key recommendations of CIPOLD was for greater scrutiny of the deaths of people with learning disabilities. In this way, potentially modifiable circumstances leading to a death could be identified and avoided in the future through improvements to health and care services.

7. Reviewing the deaths of people with learning disabilities (aged 4 years and over) enables us to examine the circumstances leading to a death, identify best practice and the learning necessary to make improvements to health and social care, improve access to health and social care services and address the inequalities experienced by the learning disabled.

8. It is important to emphasise that the review process applies to all people with learning disabilities and not just those known to health and social care services. Work has taken place both nationally and locally with community based voluntary organisations and family/carer forums to notify and inform them of the LeDeR Programme.

9. The causes of death identified within the National LeDeR Annual Report alongside the findings from local reviews reflect the many challenges that people with a learning disability face. The National LeDeR Annual Report for 2018 released in May 2019 reported that women with learning disabilities died 27 years earlier and men with learning disabilities died 23 years earlier when compared to the general population. Sadly, the report also found continuing evidence of bias in the care of people with learning disabilities resulting in unequal treatment.

10. Nationally and regionally work continues in respect of sharing the learning and directing services to address the themes that arise from mortality reviews with stakeholders working together with a view to improving services and reducing premature deaths. From a local perspective, data in respect of and learning from reviews has been presented to the Wigan Safeguarding Partnership and Mental Health Programme Board.

11. Local reviewers are responsible for undertaking reviews of the deaths of people with learning disabilities, who are registered with a GP within Wigan Borough. Reviewers come from a variety of different backgrounds although the majority are nurses (either mental health or learning disabilities). Unfortunately, NHS England (NHSE) and NHS Improvement (NHSI), have been unable to pay reviewers for this work or provide back fill to their respective organisations meaning that reviews were undertaken in addition to reviewers' substantive role and existing duties. This has resulted in Local Area Contacts experiencing difficulties in assigning reviews due to reviewers' limited availability resulting in a national backlog of reviews requiring completion.

12. Recognising the delay in the completion of reviews, NHSE and NHSI have invested £5million to address the backlog of cases identified as being over 12 months old. The investment has also been used to drive and improve the quality of reviews and application of LeDeR methodology.

13. In 2019 NHSE and NHSI identified further short- term funding for the LeDeR programme in order to address the national backlog of reviews. This money was apportioned to individual CCGs with a Memorandum of Understanding to ensure any backlog of reviews not being undertaken by the backlog team, are completed by 31 March 2020. However, there are currently ongoing national discussions regarding the future sustainability of the programme in respect of funding as the University of Bristol will, from May 2020, cease to support the programme.

14. The NHS has committed to renewed national action to tackle serious conditions identified as contributing to or causing deaths in people with a learning disability. NHSE and NHSI have commissioned a review of the alignment of the LeDeR process with other statutory processes such as coroners' inquests and safeguarding investigations, to inform guidance for CCGs and providers alike.

Rapid Review Process

15. The National LeDeR team determined that in most cases, reviews are conducted with full and complete access to at least one set of case notes. However, the Wigan experience is that in order to develop a full, holistic picture of an individual's care and treatment it is necessary to retrieve information from a variety of sources. This can take a significant amount of time on the reviewer's part and can impact negatively on the completion of a timely review.

16. For the purposes of completing backlog reviews, NHSE and NHSI identified that any review waiting over 60 days, could be completed by a Rapid Review (table top) process, which provided an interim solution to aid reviewers in completing LeDeR reviews. The Rapid Review process is only used for the purpose of progressing delayed review cases and cannot be used for anyone who would trigger a Multi-Agency Review or where concerns about the death are already known or a statutory process has been in place currently or is indicated.

Multi-Agency Reviews

17. The purpose of multi-agency reviews is to include the views of a broader range of people and agencies who have been involved in supporting the person who has died, where it is felt that further learning could be obtained from a more in-depth analysis of the circumstances leading up to the person's death.

18. Several circumstances indicate that a multi-agency review is required. These may be identified early in the review process or may emerge as the review progresses. A multi-agency review is always required:

    - Where the assessment of the care received by the person is graded as falling short of expected good practice and his significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death or care fell far short of expected good practice and this contributed to the cause of death.

    - When any red flag alert is indicated in the initial review and/or if there have been any concerns raised about the care of the person who has died.

Confidentiality and Data Sharing

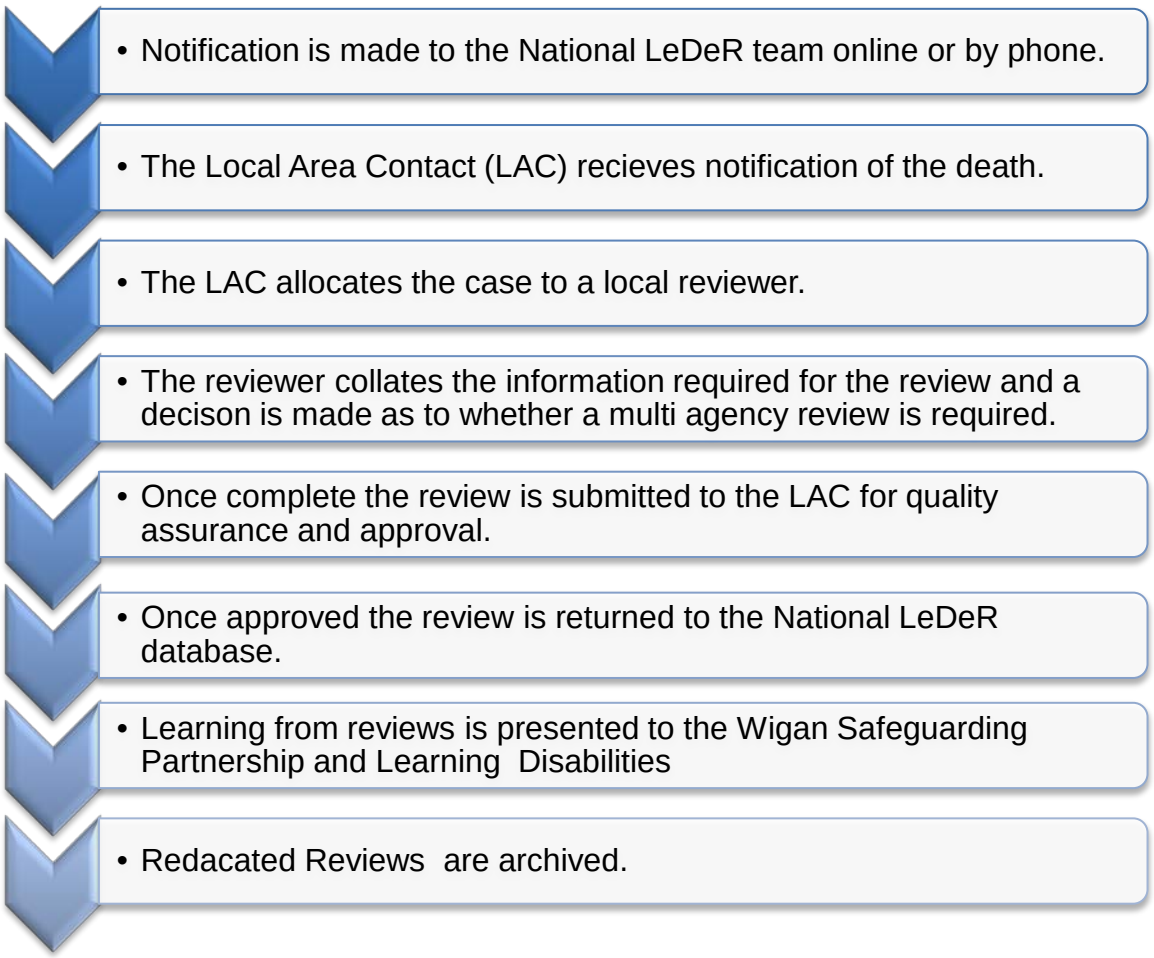
19. The LeDeR programme has been given full approval to process patient identifiable information without consent. Specifically, this provides assurance for health and social care staff that the work of the LeDeR Programme has been scrutinised by the national Confidential Advisory Group (CAG). The CAG is appointed by the Health Research Authority to provide expert advice on the uses of data as set out in the relevant legislation and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved. The key purpose of the CAG

is to protect and promote the interests of patients and the public whilst at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care.

Child Death Overview Panel (CDOP)

20. Safeguarding Children Partnerships are required to review the deaths of all children who reside in their local area and the regulations associated with the same are outlined in Working Together to Safeguard Children and the CDOP statutory and operational guidance. The purpose of the child death review process is to collect and analyse information about the death of each child who resides in Wigan Borough 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. There are a number of national programmes that focus on the review of child deaths or particular types of child death including the LeDeR process. However, CDOP supersedes the LeDeR process and the findings of the same always inform and influence LeDeR reviews in respect of children.

LeDeR Process in Wigan



Wigan Activity

21. The LeDeR programme is aimed at making improvements to the lives of people with learning disabilities. Reviews are conducted specifically with a view to improving the standard and quality of health care for people with learning disabilities.

22. People with learning disabilities, their families and carers are central to developing and delivering the LeDeR programme. Within Wigan, the programme is led and managed by Wigan Borough CCG but is delivered in conjunction with colleagues from health, social care, families, carers, advocates and providers (both NHS and Not for Profit).

23. Overall there have been 48 deaths notified between 15/08/17 – 30/06/20. To date (30/06/20), of the 48 deaths notified 15 reviews have been completed by our 5 local reviewers. There are currently a further 33 reviews in varying stages of progress but not yet completed of which 18 have been allocated to the national backlog project coordinated by NHSE and NHSI. Of the 33 reviews yet to be completed, 15 are being undertaken by local reviewers.

24. The number of notifications of deaths of people with learning disabilities has varied year on year. Given that it takes time for any new system or process to establish itself, it is perhaps not surprising that the first year further to LeDeR being introduced saw the fewest notifications (9). However, the number of notifications since has increased and the reporting of deaths of people with learning disabilities to LeDeR appears to be well established across the Borough. This is best illustrated by example in that, for the period 15/08/17 until 31/03/18, 9 notifications of death were received, for the period 01/04/18 until31/03/19, 17 notifications were received, for the period 01/04/19 until 31/03/20, 14 notifications were received and finally for the period 01/04/20 until 30/06/20 that coincided with the Covid 19 pandemic, 8 notifications were received.

Gender

25. Of the 15 completed reviews, 9 (60%) were in respect of males and 6 (40%) in respect of females although it is believed that the number of completed reviews is too small to draw any meaningful conclusions regarding this data.

Ethnicity

26. The National Annual LeDeR Report 2018 reported that 25% of people from Black, Asian and Minority Ethnic (BAME) groups had a diagnosis of learning disability compared to 11% of people of White British ethnicity. In Wigan, 100% of the completed LeDeR reviews reported the person subject to the review as being of White British ethnicity.

27. In England, the percentage of deaths notified in respect of people from BAME groups was lower at 10% than that of the whole population where 14% of deaths were notified. However, nationally 42% of notified deaths of children aged 4-17 years were reported as being from BAME groups. In Wigan, 2 reviews were

completed in respect of children although neither was reported as being from BAME groups. Nationally for BAME groups aged 18-24 years old, the proportion of notified deaths was 26% although none were notified in Wigan.

Age at Time of Death

28. According to the Office of National Statistics (ONS) 2018, the average age of death in England for the general population is 79.2 years for males and 82.9 years for females. However, in respect of people with learning disabilities, the ONS reports the average age of death in England to be 60 years for males and 59 years for females. Based on the completed reviews in respect of adults in Wigan, the average age at time of death of males is 55 and the average age at death of females is 69.

29. The first thing to be said when considering the Wigan figures for age at time of death for adults is to be mindful that the figures are based on a very small sample size namely 13 adults as child deaths were not included. However, the figures are important in the sense that they provide a benchmark moving forward by which to compare future years data that over time is hoped to be significant.

30. For the purpose of clarity, the method used to calculate the average age at time of death for completed adult reviews was to use the recorded age at time of death in the review itself. In addition, it should be noted that the deaths were recorded throughout the period 15/08/17 until 30/06/20 and were not from a single year as will be the case moving forwarded.

31. On reflection, when considering the Wigan data what can be said with certainty is that the age of death of people with learning disabilities for both males and females is that the figure is far too low when considered against the figures of the general population suggesting perhaps that there remains much work to be done in order to reduce health inequalities.

Wigan LD deaths

Average age of death (excluding child deaths) was 60 years old for LD deaths

Average age for males:	55 years old
Average age for females:	69 years old

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

Cause of Death

Learning Disability Mortality Review (LeDeR) Programme: Annual Report 2018. University of Bristol - Norah Fry Centre for Disability Studies

8.12 As would be expected, the completed adult reviews reported several different causes of death including; Pneumonia, Sepsis, Pulmonary Hypertension, Bilateral Pneumonia, Aspiration Pneumonia, Bronco Pneumonia and more recently Covid 19.

32. Several of the deaths subject to LeDeR review were expected in the sense that the deceased had been in receipt of palliative care. Furthermore, several deaths had been anticipated in that the deceased had experienced complex health needs. In these cases, discussion had taken place with the deceased or a member of their family regarding their wishes as to whether they would want to be resuscitated or not in the event of them experiencing further deterioration in health.

33. It is recognised that it is difficult to draw meaningful conclusions from the data in respect of cause of death given the relatively small number of completed reviews. However, moving forward it is hoped to compare the causes of death (from a greater number of LeDeR reviews) against national data in order to identify whether there are any trends or patterns that could help inform clinical practice.

Place of Death

34. With regard to place of death, the completed adult reviews reported that 5 individuals died in hospital, 5 died in their own home, 2 died in a care home and 1 died in a supported living service. One completed review highlighted the need for paid carers and the families of people with learning disabilities to receive training in respect of end of life care. This is considered a priority because such training would help ensure that wherever possible people with learning disabilities could receive end of life care in their own home surrounded by their family and friends as opposed to being admitted to hospital or a care home.

Child Deaths

35. For the period considered by this assurance report, there have been 2 completed reviews in respect of children. Both cases were subject to the Child Death Overview Panel (CDOP) process, the detail of which helped inform the LeDeR process. Given the small number of reviews in respect of children and the risk that any discussion or commentary regarding the same could potentially identify the deceased the author has decided to provide no further comment. However, moving forward and recognising the need to capture and share the learning from these deaths it is proposed to provide a detailed overview once the risk of identifying individuals has reduced. In reaching this decision, the author has been mindful that some child deaths have previously been reported in the local media. As such, it would be insensitive to comment further as doing so could identify the deceased and in doing so cause distress to their family.

Covid 19 Pandemic

36. In terms of the number of notifications received during the period that has coincided with the Covid 19 pandemic, it is difficult to provide an exact figure due to the lack of clarity regarding the pandemic time frame.

37. It is widely recognised that the pandemic first spread to the United Kingdom in late January 2020. The Department of Health and Social Care launched a public health information campaign to help slow the virus's spread in early February and the Chief Medical Officer for England outlined a four-pronged strategy to tackle the outbreak: contain, delay, research and mitigate. In March, the government imposed a lockdown banning all non-essential travel and contact with people outside one's home, shutting all schools, business, venues, facilities, amenities and places of worship. Those with symptoms and their households were told to self-isolate while the most vulnerable were told to shield themselves.

38. For the period 01/01/20 – 30/06/20, there have been 12 notifications received in respect of adult LeDeR deaths of which 8 were received between 01/04/20 – 30/06/20. Each of the notifications have been assigned to reviewers and in compliance with the directive from NHSE every effort is being made to complete the reviews as quickly as possible.

39. Completion of reviews that have coincided with the pandemic has been challenging largely due to the difficulties experienced in obtaining clinical records during what has been an unprecedented period of activity within the NHS. However, as of 30/06/20, three reviews have been completed for this period two of which the cause of death has been reported as being Covid 19 related. It is possible, indeed likely, that further deaths will be attributed to Covid 19.

40. Although 9 reviews for the period coinciding with the pandemic have yet to be completed, some learning is emerging to suggest that there have been difficulties experienced in managing such a complex and rapidly changing health condition (Covid 19) in terms of assessing the individual's mental capacity and acting in their best interests for example in decisions pertaining to their end of life care.

41. It is recognised that the Covid 19 pandemic has been an extremely challenging and in many ways unprecedented time for all but none more so than the learning disabled who are among the most vulnerable in our society. Rather than wait until the next annual report to report the findings and share the learning to emerge from deaths that have occurred during this period it is proposed to report the same to the Clinical Governance Committee at the earliest opportunity which is envisaged to be in January 2021.

Events

42. Wigan Borough reviewers have attended and participated in two events relating to LeDeR that were held across the Greater Manchester footprint in 2018. Firstly, the Reviewer Bereavement Workshop which shared good practice examples around engaging bereaved families and carers and secondly, the Sharing the Learning to Improve Care Event which focused on key learning disabilities issues such as empowering people with learning disabilities and how to make reasonable adjustments in an acute setting.

Learning

43. A key feature of reviews is identifying and sharing the learning that emerges from reviews in order that it can inform future practice and improve the experience of people with learning disabilities and their families when accessing health care services.

44. The learning from reviews has been presented to the Wigan Safeguarding Adult Board (now the Wigan Safeguarding Partnership) and Mental Health Programme Board. However, moving forward the learning from reviews will be presented to the Learning Disabilities and Autism Health Task Group in order that it can be better translated into meaningful actions to improve the experience of and healthcare delivered to people with learning disabilities.

45. The following learning points (in no particular order of priority) have emerged from the completed LeDeR reviews thus far:

• Good quality GP referrals to other health services where the individual's level of LD is specified and the need for reasonable adjustments is made clear delivers good outcomes.
• Good communication between GP, CLDT and Social Care enables the effective and speedy delivery of services.
• Professionals working in partnership with and supporting families can effectively meet the needs of people with learning disabilities and complex needs enabling them to live in their own homes within their local community.
• Multi-agency partnership working delivers good health outcomes for people with learning disabilities.
• Training regarding "end of life care" is required for families and paid carers in order to ensure that people with learning disabilities are supported in their own home as opposed to being admitted to hospital for palliative care.
• Health Action Plans and Hospital Passports greatly assist the hospital admission process.
• The Complex Care Team plays a valuable role in supporting people with learning disabilities and their families in managing long-term health conditions.
• Paid carers play a pivotal role in supporting people with learning disabilities to attend GP and hospital appointments.
• Medical and nursing staff within the hospital environment need to avoid using jargon when discussing health related issues with people with learning disabilities and their families.

Objectives 2020-2021

46. Moving forward it is important that the LeDeR workstream maintains a sense of momentum in order to build on the learning that has emerged from completed reviews thus far. To this end, the following objectives have been set:

- Increase the number of local reviewers in order to improve the capacity to undertake reviews and reduce the time taken to complete reviews.
- Establish a bi-monthly Local Steering Group.
- Identify and deliver “end of life” training to families and carers.
- Deliver a local Wigan LeDeR event that captures the experience of people with learning disabilities accessing Primary Care services.
- Provide a monthly LeDeR update to the Learning Disability and Autism Health Task Group in order to translate learning into action.
- Present paper to the WBCCG Clinical Governance Committee regarding LeDeR activity during the Covide 19 pandemic (01/01/20 – 30/06/20).
- Increase the awareness of Sepsis in people with a learning disability including prevention, early identification and treatment amongst people with a learning disability, their families and paid carers.

Conclusion

47. The LeDeR process is now well established in Wigan despite challenges with use of the LeDeR system and the capacity of reviewers to undertake and complete reviews. In addition, other statutory processes such as the coronial process have created an unavoidable delay in the LeDeR review timescales. This has been raised by the Local Area Contacts with NHSE as part of their review of the LeDeR process.

48. The level of understanding and awareness about care and support for individuals with learning disabilities has improved in Wigan. During the period of this assurance report, we have along with our colleagues from across health and social care developed better partnership working and facilitated joint learning to improve the experience of people with learning disabilities.

49. Wigan’s priority is that the learning and recommendations from completed reviews are translated into meaningful service improvements and that examples of best practice are shared via the Local LeDeR Steering Group in order to drive the quality of service delivered to people with learning disabilities.
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