

Bolton LeDeR Steering Group

Annual Mortality Report 2019/2020

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Executive Summary

This is the first annual report of Bolton's Learning Disabilities Mortality Programme (LeDeR) which contains operational information for the period January 2019 to July 2020. The report presents information about the deaths of people with Learning Disabilities aged 4 and over which were notified to the programme from the 1st April 2019 to the 31st March 2020. The report also touches on aspects of learning from previous years since the programme started in Bolton in February 2017.

I would like to extend huge gratitude to the members of Bolton's LeDeR Steering Group who have been actively engaged in the programme and whose positive contributions and enthusiasm are ensuring that we do not waste the opportunities to learn from the review findings. In addition, I would also like to convey special thanks to Bolton's Community Learning Disability Team who have committed time, within their already busy schedules, to complete the reviews. The reviews are very comprehensive, take considerable time to undertake, but have always been carried out to a high standard which has enabled optimal learning. I would also like to thank the team for pulling together this report.

The onset of COVID in 2020 has presented a number of new challenges throughout Health and Social Care. However, I am confident that with the continued commitment and drive of those involved in Bolton's LeDeR programme, we will be able to not only sustain the progress made to date but also drive forward vital improvements in healthcare provision for those living with Learning Disabilities, their families and carers.

Michael Robinson – Associate Director of Governance and Safety, NHS Bolton CCG

Introduction to the LeDeR Programme

The Learning Disabilities Mortality Review (LeDeR) Programme, delivered by the University of Bristol, is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

A review of legislation published over the past 15 years evidences significant health inequalities for adults with Learning Disabilities and a reduced life expectancy, starting with the Mencap, Death by Indifference report in 2007. The Confidential Enquiry into the Premature Deaths of people with a Learning Disability (CIPOLD, 2013) reviewed the deaths of 247 people with a Learning Disability from 5 areas in the South West of England alongside a comparative group of 58 people without Learning Disabilities. The CIPOLD report evidenced health inequalities and premature death in some of the cases reviewed and, as a result, made a number of recommendations, one of which was for all learning disability deaths to be subject to a comprehensive mortality review, this resulted in the LeDeR programme.

The aim of the programme is to drive improvement in the quality of Health and Social Care Service delivery for people with Learning Disabilities and to help reduce premature mortality and health inequalities in this population, through mortality case review.

A confidential telephone number and website enables families and other key people to notify the LeDeR team of the death of someone with Learning Disabilities.

An initial review of the death will then take place. The purpose of this is to provide sufficient information to be able to determine if there are any areas of concern in relation to the care of the person who has died and if indicated, a more in-depth, multiagency review will then be conducted.

As part of the review, the local reviewer would speak to family members, friends, health and care professionals and anyone else involved in supporting the person who has died to find out more about their life and the circumstances leading to their death.

These reviews are intended to support health and social care professionals, and policy makers to clarify the contribution of various causes of death to the overall burden of excess premature mortality for people with learning disabilities; identify variation and best practice; and identify key recommendations for improvement.

Membership of the programme complements and contributes to the work of other agencies such as the Learning Disability Public Health Observatory, academic research studies, NICE, the CQC inspection programme, Local Government Associations, The Transforming Care (Winterbourne View) Improvement Programme, and Third sector and voluntary agencies.

In Bolton we recognise the value and importance of the LeDeR programme and are committed to producing high quality, timely mortality reviews which evidence learning and best practice to support the ongoing improvement of services and healthcare for people with Learning Disabilities.

Co-Production with People with a Learning Disability

We have a multi-agency local steering group with local self-advocates and carer representatives as invited members. We had planned an LD engagement event with health as our key priority for summer 2020 at which we would have presented our LeDeR process, findings, and action plan for service user feedback. Unfortunately, due to the Covid-19 pandemic restrictions, we have been unable to proceed with this event but will offer this level of service user engagement as soon as we are able and currently planned for 2021.

Governance Arrangements

Reviews are completed by a team of multi-disciplinary health professionals who specialise in Learning Disability healthcare. We have an internal, robust quality assurance process which helps to ensure the reviews are a good standard and highlight learning and best practice for every completed review.

We have developed a multi-agency review process to have a more detailed discussion for reviews that require additional consideration to determine learning.

Our local multi-agency LeDeR steering group meets regularly to support the mortality review process and ensure learning is captured and progressed via a clear action plan.

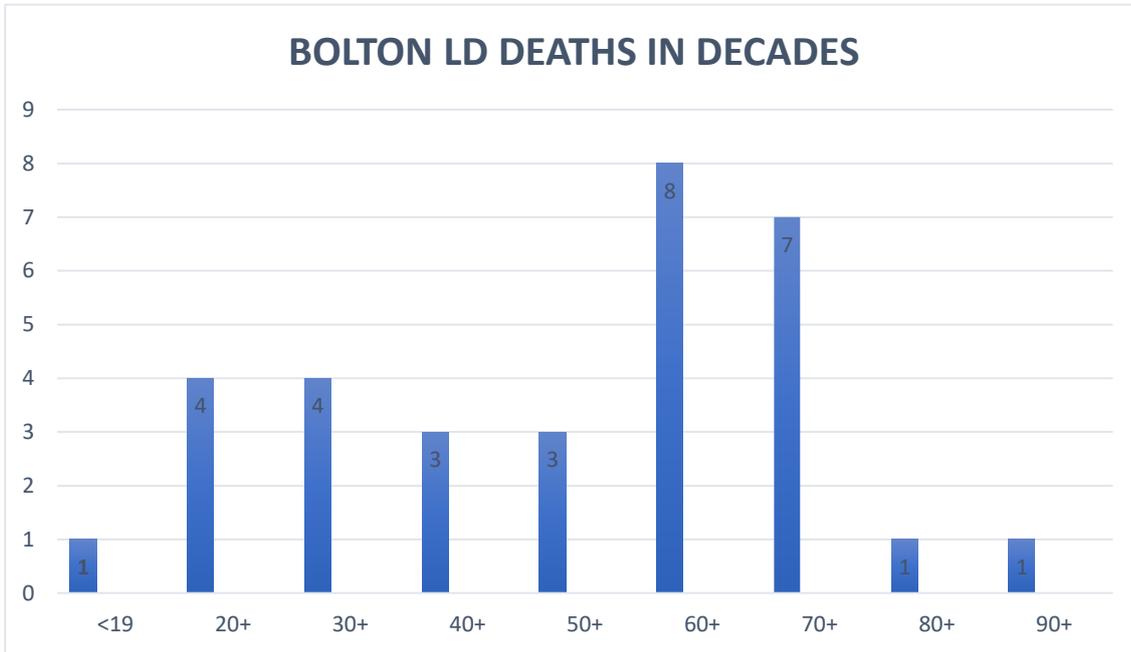
All completed reviews are presented to Bolton CCG's Serious Incident Review Group meeting to ensure high level oversight and sign off. This provides appropriate quality assurance for all learning disability death reviews.

Once we have satisfied the local governance requirements, the reviews are submitted on the LeDeR platform to inform Regional and National learning.

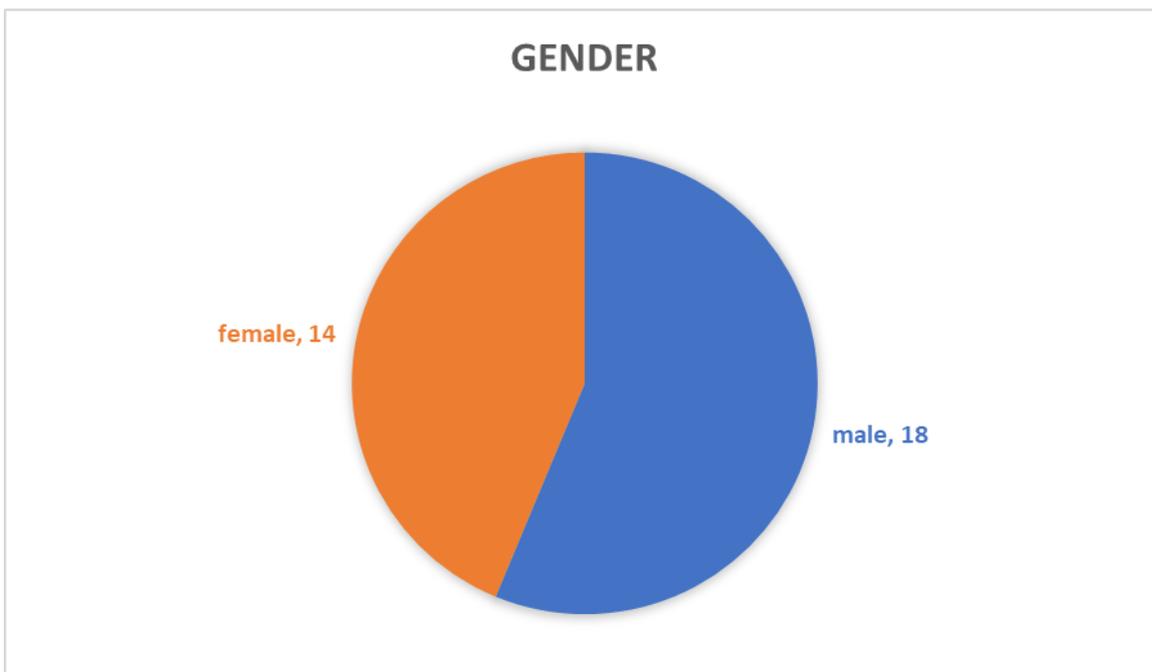
There is a Bolton LD strategic action and delivery plan, LeDeR is a key component of this and feeds into the LD Partnership Board to provide an additional layer of governance and hold agreed actions to account.

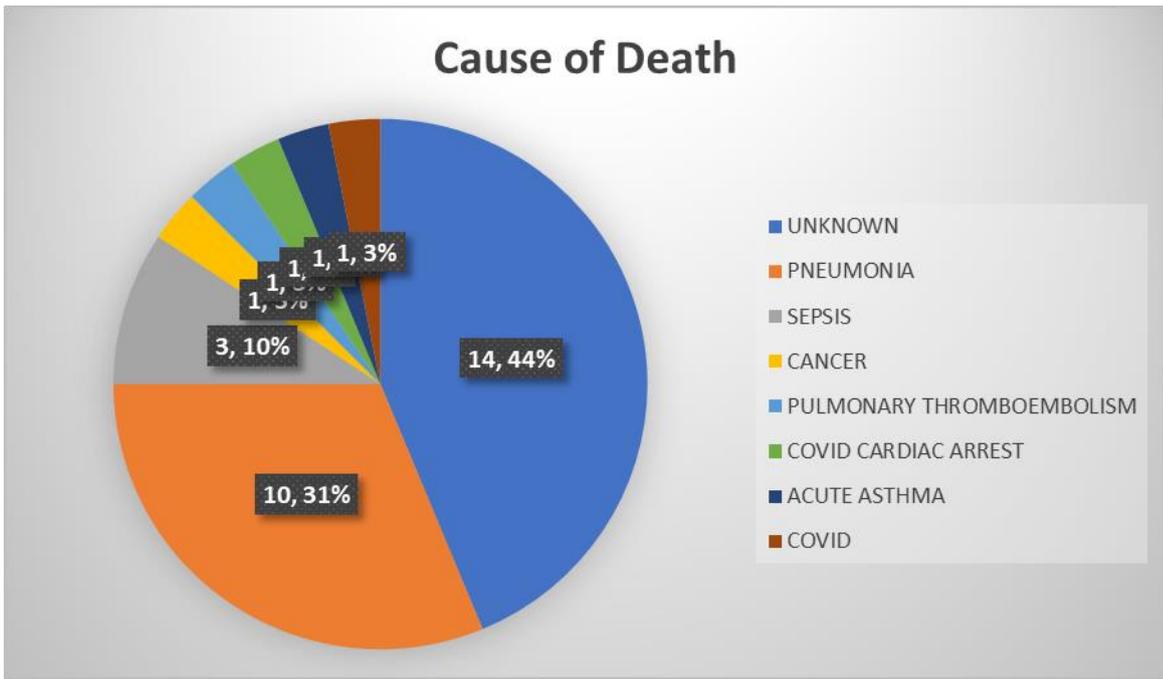
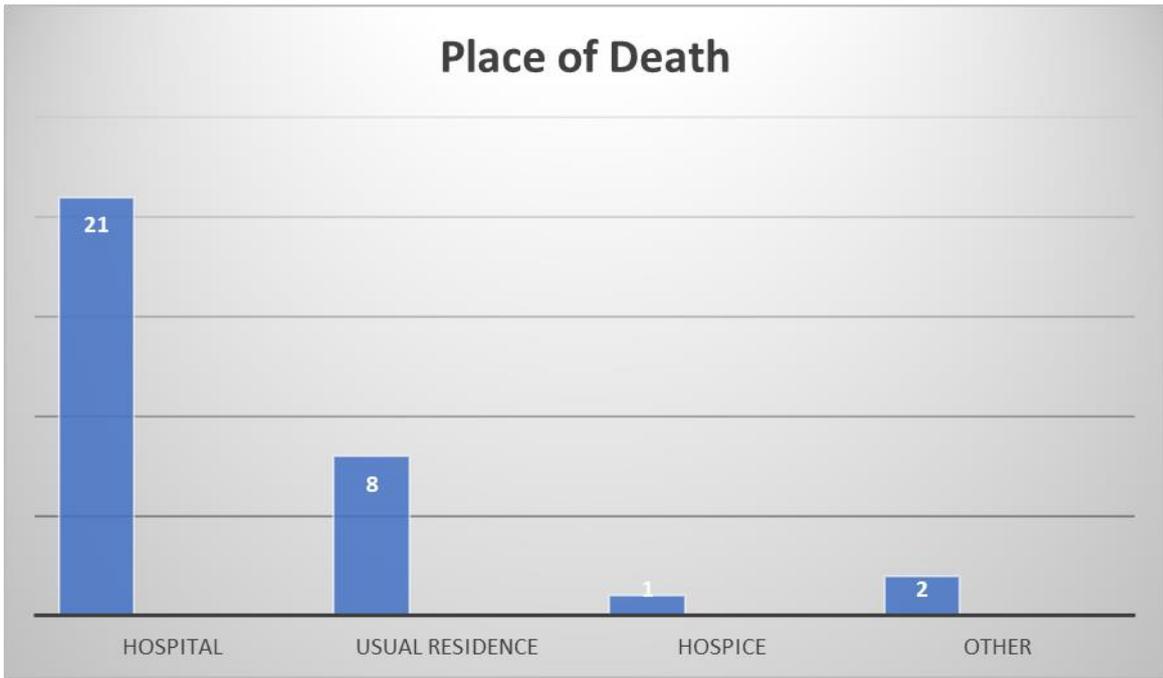
Local Data

Between January 2019 and July 2020 there has been 32 Bolton deaths reported to LeDeR.



In Bolton the average of death of people with learning disabilities is 56.3 years for women and 52.2 years for men compared to data in the LeDeR National report which shows the average age of death of adults with learning disabilities is 59 years for women and 61 years for men. Within the general population the average of death is 27 years older for women and 22 years older for men.





The figures relating to unknown cause of deaths are the reviews still in progress where we have not yet determined or confirmed cause of death.

The Pneumonia deaths can be further broken down as 40% pneumonia (not classified), 40% Covid related Pneumonia and 20% Aspiration Pneumonia.

The percentage of total confirmed cause deaths (Jan 19 – July 20) that had Covid included as a contributing factor to death is 18.75%.

Recommendations from LeDeR Reviewers for Local Action

The following table identifies the key recommendations made by the Bolton LeDeR reviewers taken from four completed reviews during 2019/2020.

Identified Issues	Learning	Recommendation to address the issue
DNACPR needs to be undertaken in line with the Mental Capacity Act and via a Best Interest meeting.	Clinicians completing DNACPR forms need to be aware of the MCA with associated LD training.	This work is already being done across the health system supported by Safeguarding, Palliative Care and GP's.
Admissions occurring even though the patient is known to be end of life and not for admission following previous recent admission.	Admitting clinicians need to carefully review previous discharge summaries to prevent unnecessary admissions.	Access to the Electronic Patient Record and the Bolton Care Record should support admitting clinicians to have readily available information on patients so as to prevent unnecessary admissions.
Appropriate assessments of pressure damage need to be undertaken with appropriate referral to the Tissue Viability team for onward care and support.	Clinicians need to be trained to ensure that following appropriate pressure assessments referrals must be made on to Tissue Viability should further care needs arise.	Clinical staff must ensure that all appropriate documentation is completed and recorded, and referrals made where appropriate in a timely manner. Further training required for nursing staff in identifying and grading pressure damage categories in patients with a LD.
End of Life care only occurred 24 hours prior to the individual's death despite previous opportunities to commence. No evidence of hospital passport or referral to hospital LD Nurse noted.	Clinical staff, on recognising the appropriateness, need to refer the patient to the hospital LD Nurse to enhance palliative care.	Staff training to recognise the important issues associated with a person with a LD and ensure the LD Nurse is informed of their admission at the earliest opportunity.
Care staff called 999 when they noted a deterioration in the individual's condition which resulted in the admission into hospital although there was a directive in place stating the person was to remain at home.	Care staff to be aware of and understand what the ceiling of care is for a patient who has a directive in place to remain at home and not be admitted into hospital, including who they need to call when they see a deterioration -i.e. not 999.	Enhanced training of care staff to understand what the ceiling of a care plan is for a person who has a directive in place to not be admitted into hospital including clear guidance regarding who to call if they see a deterioration.
A DNACPR remained in place for both their hospital admission, and later discharge to the community without being reviewed.	The DNACPR must be reviewed following hospital discharge.	Enhanced training for clinical staff to fully understand the DNACPR policy and procedures, specifically around reviewing documentation.

<p>Failure to fully document discharge actions on discharge correspondence and within the hospital notes.</p>	<p>There needs to be robust discharge planning and communication in place to ensure optimum care is received after leaving hospital.</p>	<p>Discharge planning meeting to be held prior to discharge for individual's with complex needs, despite the length of stay, involving all relevant MDT members including family, LD team and both hospital and community staff. A robust discharge action plan to be completed with an identified person taking ownership of this e.g. GP or LD nurse, and for this to be reviewed post discharge by the community MDT with timescales set for reviewing the document and the actions set.</p>
<p>Difficulty in undertaking certain diagnostic tests due to challenging presentation and behaviour.</p>	<p>Opportunity for desensitisation work to be carried out with the patient and for them to be placed on an appropriate diagnostic pathway to ensure essential diagnostics are undertaken in a timely manner.</p>	<p>A clear blood taking policy/pathway for both the hospital and community would be beneficial for professionals to have a clear step by step guidance/check list to follow. Reasonable adjustments to be considered by GP, practice staff and hospital staff, and if desensitisation work is required and how the individual is prepared for the appointment - involving family and support staff in this process. Advice to be sought from liaison nurse/learning disability team as and when needed. If unable to take tests, follow up appointment to be made or MDT meeting to discuss next steps rather than no further action.</p>
<p>Reasonable adjustments need to be fully considered and documented.</p>	<p>Whilst some reasonable adjustments were implemented, others which are considered related to e.g. examinations and tests, need to be fully documented.</p>	<p>Reasonable adjustments grab sheets to be available on wards and for the GP service - giving a brief overview of reasonable adjustments and when these should be considered and who to contact if having difficulties or wanting to seek advice.</p>
<p>Unclear messages to family and support staff.</p>	<p>At an understandably distressing time for families they sometimes feel they are not listened too, especially in relation to discharge home for palliative care. Discharge planning meetings need scheduling to which the family can attend to ensure the patient is fit for discharge.</p>	<p>A key person to be identified to liaise with family to ensure key information is shared. In usual circumstances this would likely be the learning disability liaison nurse however if they are not available (as in this case on annual leave) an identified ward staff member will take over this role.</p>

Hospital passport going missing.	The person had a hospital passport which went missing on two occasions - replaced by service provider staff.	An identified system to prevent this happening, i.e. each person with a learning disability to have an identified file with LD information and the passport as part of this. The Hospital passport is now downloaded on to the system and saved on Patient's records.
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Positive Practice That Was Identified During the Reviews:

Positive Practice Identified:	Recommendations from this:
Care staff were aware and alert about the person's particular health needs.	Regular, consistent, dedicated, and knowledgeable care staff are essential to the lives of those with complex needs.
Good Community Learning Disability Team and GP practice links with the staff.	All PMLD clients should have access to specialist CLDT services.
Nursing home tried to get hold of his family whilst they were not in the United Kingdom.	It is important we try to engage family members in the service user's life.
The individual's medication and care were regularly reviewed within the right timeframe.	Having a regular medication and care review ensures that the right support is still being provided.
Whilst due to the individual's physical health it was unfortunately not possible for them to return home, the individual was moved to a side room. This gave the patient and family privacy and time together, it also enabled the environment to be personalised to try and make things as comfortable for the person as they could be.	When discharge home is not a possibility, to look at alternative options such as a private room that can be personalised.
Co-ordinated MDT working: the discharge planning meeting that occurred, whilst not having the desired outcome due to individual's health, was organised at short notice and had good representation from the MDT such as community specialists, discharge coordinator, palliative care team, family and ward staff, ensuring that all avenues were covered and all areas considered.	MDT discharge planning meetings for complex patients to be standard procedure regardless of how long the person has been in hospital and ideally to be arranged prior to the person being deemed medically fit for discharge then there is time for plans to be implemented.

Outcomes and Achievements

- Carers in Supported Living accommodation have been provided with the training and equipment required to assist in monitoring physical health and early identification deteriorating health. All Supported Living properties now have pulse oximeters and infrared thermometers for support staff to utilise to ensure more accurate symptom reporting to healthcare professionals.
- Recruitment of a Health Improvement LD nurse to collate the learning outcomes from the LeDeR reviews and implement changes required, working across the NHS, social services, and independent providers. The Health Improvement nurse will also be looking at devising and implementing relevant training in accordance with national guidance.
- Recently developed diagnostic pathway to ensure timely diagnosis of health conditions. This pathway was devised as a direct result of LeDeR learning and concern that delayed recognition of health issues was leading to delayed treatment and poorer health outcomes. This pathway helps to ensure diagnostic testing is available to all, including those individuals who cannot tolerate investigations in a typical manner. The pathway is currently going through the final stages required to ensure this is embedded into standard practice.

Future Plan

We will continue to complete high quality LeDeR reviews within the allocated timescale of 6 months from date of alert.

We will take objectives and actions agreed as a result of the recommendations from completed reviews and implement them in a timely manner.

We will ensure that the health and wellbeing of people with Learning Disabilities is underpinned by the understanding that a Learning Disability does not in itself make illness and premature death inevitable. It must never be used as a cause of death on a death certificate as stated in Professor Stephen Powis letter to the medical staff in 2019.

We will ensure reasonable adjustments are made for adults with learning disabilities when in hospital as inpatients or outpatients and when accessing health services in the community. We plan to implement a reasonable adjustment care plan in the community and already have this document in place in our acute hospital. Further consideration will also be undertaken regarding the support needed for patients to access virtual clinics in line with COVID restrictions.

In the coming year we will engage in a Queen's Nursing Institute funded project to look at the quality and outcomes of the local annual LD Health Screening programme. This project will involve collaborative working between the GP Federation, extended Primary Care Team and Nurses from the Community Learning Disability Team to explore best practice in LD health screening with a focus on outcomes. Our aim is to ensure that health screening leads to individualised health improvement targets, improved access to national health screening initiatives and a reduction in health inequalities.

To ensure accessible information is available to services users and staff to help people with a LD prevent and respond to illness by way of early identification of health issues. This includes improved uptake of health screening initiatives such as Cancer screening programmes.

We will further support staff training to be able to identify early warning signs of illness and a pathway of actions to follow. This will include consideration of implementation of an early warning indicator system for use in supported living services to ensure timely recognition and action when ill health occurs.

For staff to have training on End of Life Care to help understand the process, and which services are available for support to avoid unnecessary hospital admissions.