NHS
Trafford
Clinical Commissioning Group

Learning Disabilities Mortality Review (LeDeR) Programme Trafford Annual Report 2019/2020

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Responsible committee:	Trafford LeDeR Steering Group Trafford review group
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Policy Impact:	The National Learning Disability Mortality Review Programme (LeDeR) was established to drive improvement in the quality of health and social care service delivery for people with learning disabilities, by looking at why people with learning disabilities typically die much earlier than average.
Policy Area:	Nursing, Quality and Safeguarding
Issued by:	Nursing, Quality and Safeguarding
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Learning Disabilities Mortality Review (LeDeR) Programme
Trafford Annual Report 2019/2020

This report is the first annual report on the learning from deaths of those with learning disabilities within Trafford. The report covers from April 2019 up until the end of March 2020.

Background

The LeDeR Programme (Learning from Deaths Review of People with a Learning Disability) is being led by the University of Bristol and follows on from the Confidential Enquiry into Premature Deaths of people with Learning Disabilities (CIPOLD). The findings demonstrated that on average, someone with a learning disability lives 20 years less than someone without.

Reviewing all deaths of anyone aged 4 years of age and over allows us to examine the circumstances leading to a death. It will also identify any good/best practice to be shared or learning to make improvements to health and care services, improve access to social and health care and address inequality for people with a learning disability.

It is important to stress that the review process applies to all people with learning disabilities, not just those currently known to health and care services. Work has also taken place with community organisations and family/carer forums to notify them of the LeDeR programme.

The issues and 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.

Nationally and regionally work is already happening to help share learning and better direct services to address the themes which arise from mortality reviews. Different stakeholders are working together focusing on their priorities with a view to improving services and reducing premature deaths throughout the area.

Many areas, including Trafford, initially asked for volunteer reviewers. These local reviewers are responsible for undertaking reviews of the deaths of people with learning disabilities, who are registered with a GP within Trafford. Unfortunately NHS England (NHSE) and NHS Improvement (NHSI) were unable to pay reviewers for taking on this role or provide back fill to their organisations, so reviews had to be done as an 'extra' to their substantive role. This meant Local Area Contacts found it difficult to assign reviews due to the reviewers' limited availability, which then created a backlog list of reviews requiring completion.

NHSE and NHSI recognised the delay of reviews and nationally, £5 million investment had been identified to address the review backlog of cases over 12 months old. The money was also identified to improve the quality of reviews and the consistency of the application of the methodology.

The NHS has committed to renewed national action to tackle serious conditions identified as 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 (e.g. coroners' inquests and safeguarding investigations), to inform guidance for CCGs and providers.

In 2019 NHSE and NHSI identified further short term funding for the LeDeR programme for the national backlog of reviews. This money was apportioned to individual CCGs and Trafford CCG received a total of £48,400 (23,400-(May 2018), 25,000 (Oct 2019). A Memorandum of Understanding was issued to ensure any backlog of reviews not being undertaken by the backlog team, were completed by 31 March 2020. However, there will be GM wide and national discussions regarding the future sustainability of funding the programme. In May 2020 the University of Bristol will cease to support the programme, which means NHSE and NHSI will take over the LeDeR database.

LEDER Rapid Review Process

It was determined by the National LeDeR team that in most cases, the review takes place with full access to at least one set of case notes. Within Trafford in all cases, reviewers have to retrieve information from a variety of sources to gain the whole picture of the person's care and treatment. This can take a significant amount of time on the reviewer's part and impact on the completion of a timely review.

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 provides an interim solution to aid the reviewer in completing a LeDeR review.

The Rapid Review process 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, current or indicated.

Multi-Agency Reviews

The purpose of the multi-agency review 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.

There are a number of circumstances that would indicate that a multi-agency review is required. These may be identified very early on in the initial 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 5 or 6
- When any red flag alerts are indicated in the initial review
- If there have been any concerns raised about the care of the person who has died

Confidentiality and Data Sharing

The National LeDeR Programme applied to the national Confidential Advisory Group (CAG) for Section 251 (of the NHS Act 2006) approval for the use of patient identifiable information, in order that reviews can be undertaken of the deaths of people with learning disabilities.

The 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 CAG. The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the 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. More information about Section 251 approval is available at:www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/

Child Death Overview Panel (CDOP)

Local Safeguarding Children Partnerships are required to review the deaths of all children who normally reside in their area. The regulations 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 normally resides in Trafford 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 which centre on the review of deaths or particular types of child death including the LeDeR process. As such, CDOPs are advised to complete the child death review process rather than the LeDeR review.

LeDeR Process in Trafford

Trafford Activity

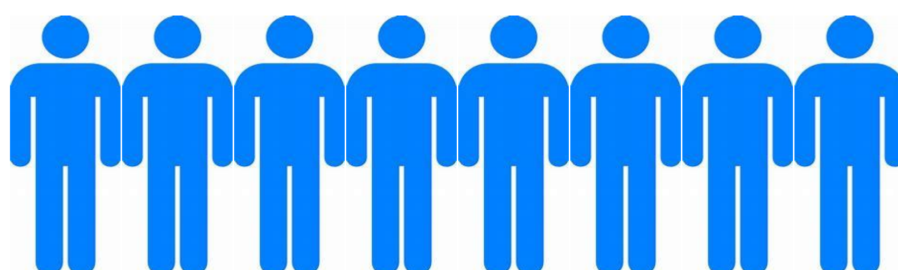
The LeDeR programme is aimed at making improvements to the lives of people with learning disabilities. Reviews are being carried out with a view to improve the standard and quality of care for people with learning disabilities. People with learning disabilities, their families and carers have been central to developing and delivering the programme. Within Trafford, the programme is led and managed by NHS Trafford CCG but is delivered in conjunction with health, social care, families, carers, advocates and providers within Trafford.

Overall there have been 50 notifications in Trafford since 2017. From the 1st April 2019 to the 31st March 2020 there were 15 LD deaths within Trafford. The table below demonstrates the Trafford progress to date since the LeDeR programme commenced.

	2017	**2018**	**2019**	**2020**	**Total**
No of Notifications	13	16	14	7	**50**
Local Reviewer in progress	5	6	4	7	**22**
North of England Commissioning Service (NECS)	4	6	9	0	**19**
Completed	4	4	1	0	**9**

NHSE have recognised the need to improve care for people with a learning disability and as a result allocated an additional £5 million nationally to fund reviews. A portion of this has been allocated to the national backlog project, allowing NHSE and NHSI to employ a pool of temporary reviewers to allocate reviews to those that are over 12 months old. An agreement of once-only funding was also allocated to the CCG, which has enabled us to tackle the backlog of outstanding reviews requiring completion by local reviewers. This was supported by paying a flat rate to reviewers per completed review which enabled them to complete the review in their own time, as all our local reviewers have substantive, full time posts.

Trafford 2019/2020



53 % of reviews were male (8 people)

47 % of reviews were female (7 people)

Ethnicity

In Trafford 7% (one case) of deaths were from a Black and Minority Ethnic background (BAME), which is lower than the national average. The ethnic diversity of Trafford is in line with a lower figure. Low numbers for deaths in Trafford residents with a learning difficulty also reduce validity of data comparison.

Nationally, children aged 4-17 years had a high proportion as 42% were from BAME groups. In Trafford we had no deaths from a BAME background, which is lower than the national average.

Nationally 26% of 18-24 year olds were BAME (0% in Trafford).

73 % of deaths ethnicity was given as white British (11 out of 15 reviews)

7% of deaths ethnicity was given as Black/African/Caribbean/Black British (1 out of 15 reviews)

20% of deaths ethnicity was unknown (3 out of 15 reviews)

Trafford LD deaths

Average age of death was 48 years old for LD deaths

Average age for males 50 years old

Average age for females 46 years old

National LD deaths

Average age for males 60 years old

Average age for females 59 years old

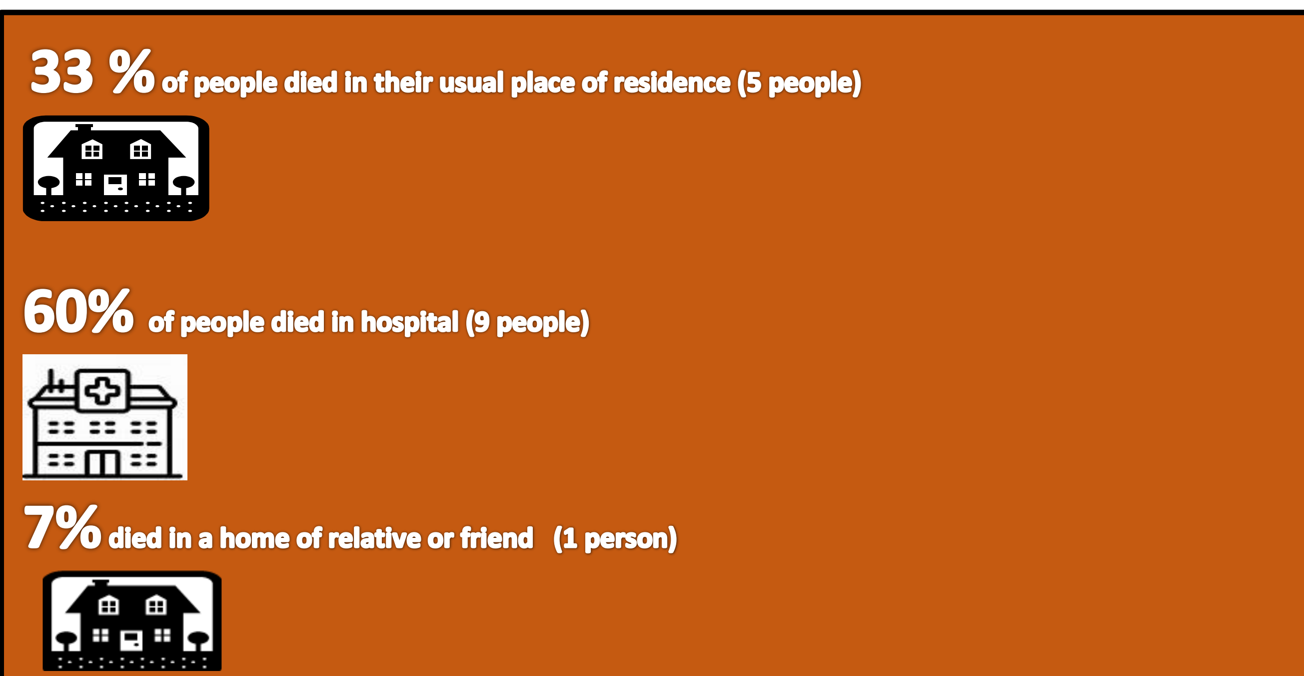
ONS data for general population deaths

Average age for males 83 years old

Average age for females 86 years old

The Trafford data suggests that the disparity between the age at death for people with a LD (aged 4 years and over) and the National LD deaths (all ages) is 10 years for males and 13 years for females. The Trafford data also highlights the disparity between the ONS data for the general population which is represents 33 years for males and 40 years for females.

Place of Death



Grading of Care
At the end of a review, having considered all of the information available to them, reviewers are asked to provide an overall assessment of the care provided to the individual and provide a grade. The table below shows the grading of care and the LeDeR Reviewers' overall assessment of the care received that have been completed. Trafford have 4 reviews that have completed this stage, the other 11 are awaiting the reviewer to complete the grade of care.

Grading of Care in Adult Cases	Number of Reviews
1 = Excellent Care	1
2 = Good care	2
3 = Satisfactory	1
4 = Care fell short of current best practice in one or more significant areas	0
5 = Care fell short of current best practice and some learning could result from Multi agency review	0
6 = Care fell short of best practice resulting in potential for, or actual adverse impact 3	0

Trafford Annual Health Checks

Learning Disability (LD) Register Annual Health Checks	This is an NHS Oversight Framework (NHSOF) indicator that is reported annually with latest data from 2017/18 and ranking the CCG 147 out of 191. This has also been implemented as CCG planning indicator which allows for quarterly reporting. Quarter 3 targets were met with 144 patients receiving LD health checks, (Table below). Work continues to ensure improvement with LD health checks with a working group in place. Other measures put in place include working with Cheshire, Wirral & Partnership to support delivery of KPIs around LD health checks, as well as communications to GP practices and indicators built into Tableau to support GP practices in reviewing the health checks. This has demonstrated a marked improvement.

Aside from the NHS Oversight Framework (NHSOF) performance, the CCG monitors the progress of this indicator via the 19/20 CCG Planning guidance, and there are internal targets around this which are reported on quarterly. The latest data available takes us up to the end of Quarter 3 19/20 where there has been some improvements made and the target for the quarter has been achieved. We are awaiting publication of the Q4 performance at this time which has been delayed due to COVID-19 priorities within the CCG BI team.

LD () = Targets %	Jun 19 (20.2%)	Sept 19 (20.5%)	Dec 19 (20.6%)
Annual Health Checks	13.1%	18.85%	21.52%

Themes of the National LeDeR Report (2018)

The six most common conditions reported in the latest national report include:

- Pneumonia.
- Aspiration pneumonia.
- Sepsis.
- Dementia (syndrome).
- Ischaemic heart disease.
- Epilepsy

Trafford are committed to ensuring that the health inequalities reported in the National Annual report (2018), are embedded in all areas of the Trafford Learning Disability work stream. The use of a newly developed Trafford dataset will allow Trafford, to identify its position in line with the National data to steer the direction of required commissioning and provide a much clearer understanding in next year's annual report.

Next Steps for Trafford

Trafford CCG have recently formed (December 2019) a quality assurance process for reviews thus ensuring that the learning from the reviews is shared both locally and nationally. The review system has been modelled on the Serious Incident process and the reviews will be carried out by the Trafford CCG team.

The membership of the review team consist of:

- Deputy Chief Nurse (Chair)
- Designated Nurse for Safeguarding Adults
- LD Commissioner
- Administrative support
- CHC lead
- Contracting representation (optional)
- Quality and performance team support
- Representative from Adult Social Care
- Representative from Local Authority Commissioning
- Lay member

The outcomes of the reviews will be reported to Senior Leadership Team in the first instance in a thematic format and then onto Governing body. Thematic analysis of the reviews will influence commissioning decisions where necessary and may also influence commissioning and contracting intentions.

Trafford CCG have also recently joined the Manchester CCG LeDeR Steering Group to support the implementation of the review findings and provide a governance forum for the reviews. The Manchester and Trafford LeDeR Steering Group's activities and outputs will complement and contribute to:

- ensuring appropriate safeguarding pathways as agreed with the individual Safeguarding Partnerships, informing commissioning plans and arrangements in both localities for People with Learning Disabilities, contributing to the GM Learning Disability Strategy
- Support the development of quality indicators and appropriate standards across acute, community and third sector services and engage with service user groups and their families to ensure service improvements positively affect patient experience.

The LeDeR Steering Group provides independent scrutiny and challenge to monitor and develop the effectiveness of mortality review processes across providers in Trafford. The purpose of having one Manchester and Trafford group, reflects the joint commissioning arrangements between Manchester and Trafford. This collaborating working model ensures that all the jointly commissioned providers are all represented in one meeting, thus ensuring the learning identified is shared in the most effective way.

The proposed Trafford representation in this group would be:

- Deputy Chief Nurse (Chair)
- Designated nurse for Safeguarding Adults
- Representative from the quality team

Steering group members will review programme direction and make decisions to ensure:

- Findings of reviews are clear and accurate and form the basis of recommendations to the various committees & Boards within member's respective organisations
- Communication across and between members respective organisations reflect the plans and objectives of the steering group
- The progress of the overall programme is monitored and any remediable action is undertaken as soon as possible
- There is an agreed mechanism to assure all Boards and committees that service improvements are being conducted that will have real impact on reducing premature and avoidable deaths of people with learning disabilities and/or autism
- Open and honest communication is maintained in order to progress mutual objectives

- All risks are assessed and managed well, putting in place actions and contingency plans for all high impact risks
- The time and resources needed for the programme objectives are available
- Recording of programme information is accurate and coherent
- Support is available for the Local Area Contact
- The progress of the overall programme is monitored and any remediable action is undertaken
- Learning found from the reviews is disseminated across the Trafford Health and Social Care system
- Scrutiny of anonymised case reports pertaining to deaths or significant adverse events relating to people with learning disabilities, for publication in the LeDeR Programme repository in order to contribute to collective understanding of learning points and recommendations across cases

Greater Manchester (GM) Learning Disability Strategy Implementation

As part of the Learning Disability Strategy Implementation, each locality has now submitted their draft delivery plan and 'Good Health' is one of the 10 priorities within the Strategy. The good health strategy includes:

- Reviewing the GP learning disability registers and set targets for more people to access good quality annual health checks
- Reviewing and embedding the learning from mortlity reviews across GM
- Embedding STOMP (Stopping the over medication of people with a learning disability, autism or both) into the GM medicines management strategy and increase awareness of peoples rights for medicaiton reviews

- Work with the GM Cancer Leads to improve cancer screening rates for people with a learning disability

These plans will be monitored quarterly via the GM Learning Disability Delivery Group and will also provide an assurance to the wider system that as GM, we are delivering on our commitments. The plans will be scrutinized by the Confirm and Challenge Group on a regular basis. All ten of the GM localities are part of a collaborative process whereby colleagues leading on different priorities share and learn from each and actively identify an opportunity to work together on certain priority areas. The work of the GM Health Inequalities Working Group is one of the mechanisms to provide GM solutions to problems and challenges identified in individual localities.

In Trafford we have been working closely with the medicines optimisation team to

- Ensure these reviews were part of the services provided by specialist teams and were within the contracts through Mental Health and Children's commissioners
- Identify capacity within our mental health service to commence these reviews in children and adolescents
- Identify new adult patients from GP records, and review their medication in conjunction with specialist services where appropriate

- Embed these reviews as part of ongoing care in Primary Care
- Communicate with other stakeholders outside of clinicians, specialist services about STOMP and STAMP and how we can all contribute to ensuring the safety of children, adolescents and adults with LD, ADHD & autism
- STAMP audits have not been undertaken in Trafford before, and as a result of the previous high quality STOMP review and there has been a local agreement to focus on prevention, and reviews of child and adolescent medication was prioritised for this review period

Progress in Trafford for the Learning Disability Strategy

Trafford is committed to aligning local plans with the GM strategy, whilst acknowledging the specific local challenges we have. The Learning Disability Partnership Board is now operational and has taken the 10 priority areas of the GM plan to form focus groups with self-advocacy and family representation, to drive momentum into the change needed to improve outcomes for people living with a Learning Disability in Trafford.

We have agreed a further two year CQUIN with Cheshire Wirral Partnership (CWP) to improve access to screening and timely treatment for bowel, breast and cervical cancers.

CWP have completed and maintain a dynamic register of risk relating to morbidity which is used in conjunction with other care planning and risk management tools to ensure effective coordination of health.

Health facilitation remains of the two commissioned elements of the Community Learning Disability Team (alongside effective management of challenging behaviour) and there are nurses based at Trafford General Hospital and working into MFT where Trafford residents may access planned and unplanned care.

Trafford's commissioned provider Cheshire and Wirral Partnership (CWP) are undertaking training of GP registrars to undertake annual health checks.

Trafford current STAMP offer:

The majority of children with complex medical needs are on different types of medicine, for example antireflux, antiepilepsy, medicine for constipation, drooling, muscle relaxants etc. These children are reviewed in special school clinics or community clinics every 6 months or annually by the consultants. In each and every visit the consultants or reviewing doctors check the dose of the medicine and review the need of the medicine.

Joint care with tertiary centre – A number of children are under specialist care at Royal Manchester Children's Hospital with cardiac, respiratory, endocrine or gastro team. Their medicines are reviewed by their specialist and the Paediatricians in Trafford to avoid mis-medication.

Children with Autism- If the children with Autism are having difficulties with sleep then they receive input from sleep clinic. If they need medicine for sleep then they get reviewed by Paediatricians every 6 months with shared care protocol with GP. There is also input from tier 3 sleep clinic.

Children with ADHD- These group of children receives Cognitive Behaviour Therapy and majority of them also receives medicine. They get reviewed by Paediatricians and ADHD nurse on a regular visit. The requirement of the medicine and the dose are assessed in each and every visit.

Children with Autism and LD- receive annual health check after 14 years of age.

A number of children with mental health disorders in Trafford are under Healthy Young Minds (HYMS, previously CAMHS) and receives medicine for anxiety, depression, and antipsychotics.

Next Steps in Trafford to implement the GM strategy

Ensure the STOMP and STAMP (Supporting treatment and appropriate medication in paediatrics) is rolled out across Trafford by partners. NHSE and NHSI launched STOMP and STAMP to make sure that people with a learning disability, autism or both are only prescribed the right medication at the right time, for the right reason

- Continue to share the learning into action and consideration of slot on the quarterly GP learning event during 2020/21
- Develop a LD mortality dataset with support from our business intelligence team
- Increase the numbers of reviewers to reduce the length of time it takes for a review to be assigned
- Note the continued backlog and difficulties in allocating reviews within 6 months of them being notified, which is being reduced to 3 months in April 2020. Consideration of a business case to employ a full time reviewer

Conclusion

The LeDeR process is now well established in Trafford. There have been challenges with use of the LeDeR system and capacity of reviewers to complete the work. 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 to NHSE as part of their review of the LeDeR process.

The level of understanding and awareness about care and support for individuals with learning disabilities has improved in Trafford. Over 2019/2020 we have developed better partnership working, which facilitates joint learning and promotes more co-ordinated care for the individuals.

Trafford’s focus remains that the learning and recommendations coming from completed reviews are translated into service improvements and examples of best practice are shared via the LeDeR review group and the LeDeR Steering Group, alongside completing reviews efficiently.

The LACs are proposing a business case for the CCG for a LeDeR Nurse who can complete the reviews, coordinate Trafford’s learning at both the quality assurance and the Steering Group to provide training of the identified learning. Previous years mortality figures suggest that Trafford will receive 16 notifications this year.