Annual Report

Wirral Health and Care Commissioning

Learning from Lives and Deaths (LeDeR)

1st April 2020- 31st March 2021

Report compiled by:

Lorna Quigley: Director of Quality and Safety (Local Area Contact for LeDeR)

Simon Garner: Lead Commissioner Wirral Council (Local Area Contact for LeDeR)

Vicky Palmer: Performance Management Lead for Quality Improvement and Safeguarding (Local Area Contact for LeDeR)

Contents

1.0 Executive Summary

Wirral Health and Care Commissioning (WHCC) are working across NHS and Local Authority services to strengthen learning from LeDeR reviews and support those undertaking reviews on our behalf. As Local Area Contacts we acknowledge the commitment from reviewers to provide comprehensive insight into the circumstances of each case in a way that we can learn from and develop services going forward.

Lorna Quigley Director of Quality and Safety (WHCC)

Simon Garner Lead Commissioner, All Age Independence (WHCC)

1.1 Background

The LeDeR program was established in response to the recommendations of the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD 2013).

This annual LeDeR report presents information from 1st April 2020 to 31st March 2021 about the deaths of people with learning disabilities in Wirral, aged 15 years and over. As this is the second annual report, this report is able to offer some comparison to previous local findings.

1.2 Introduction

People with Learning Disabilities (LD) have an average life expectancy that is 20 years less than the general population and are three times more likely to die from a preventable cause of death. The Learning from Lives and Deaths (LeDeR) Programme was therefore introduced in 2015, delivered by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

All deaths of people with LD aged over four years are notified to the LeDeR programme. Cases where there may be concerns or opportunities for learning are taken forward for a multi-agency review. The reviews aim to highlight best practice, areas where care could be improved and any gaps in service. The ultimate aim is to improve the quality of life and quality of care experienced by people with LD and reduce the health inequalities and gap in life expectancy we see in this cohort of the population.

In Wirral, LeDeR case reviews are coordinated by the Local Area Contacts (and generally undertaken by staff who have received LeDeR reviewer training, within the local system. This report considers Learning from Lives and Deaths case reviews performed between 1st April 2020 to 31st March 2021.

1.3 Governance and Structure

Wirral Health and Care Commissioning (WHCC) is a Commissioning partnership that incorporates NHS Wirral Clinical Commissioning Group (CCG) and Wirral Borough Council. As a requirement of the programme Wirral has identified a Local Area Coordinator (LAC) who is the Director of Quality and Safety, and a Deputy LAC who is the Lead Commissioner for All Age Disabilities.

Their role is to coordinate the reviews, ensure they are completed within a timely manner and ensure that lessons learnt are identified and fed through the organisation to affect change and commissioning pathways. To support this process, last year WHCC appointed a LeDeR lead practitioner for a period of four months. Their role was to work on developing quality assurance processes which support the following areas:

- Identify lessons learnt from reviews
- Identify themes and trends effectively
- Identify actions and develop SMART action plans
- Ensure actions are delivered within the timescales identified. Actions will be monitored and barriers/blocks to deliverability addressed and managed
- Demonstrate effective outcomes through the completion of actions
- Co-production with key stakeholders, including families and clinicians on actions to ensure sustainability of solutions and high-quality care provision
- Develop a quality assurance process aligned with current systems which allows for the monitoring and implementation of actions and the sharing of good practice

Unfortunately, due to the short nature of the post less work was carried out than was expected.

Identify key preventive actions and activities **PROCESS**

2.0 Deaths Notified in Wirral

Notifying the LeDeR Programme of a death

The Learning from Lives and Deaths (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The LeDeR Programme aims to guide improvements in the quality of health and social care services for people with learning disabilities across England. It will do so by supporting local reviews of deaths of people with learning disabilities aged 4 years and above across England.

Notification of a death

Families, friends, professionals, and other key people can notify us of the death of someone with learning disabilities. This can be done via the programme website Report the death of someone with a learning disability (leder.nhs.uk) or a confidential telephone number (01278727411).

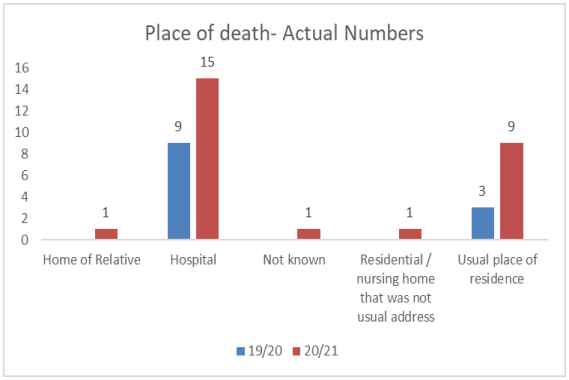
3.0 Summary of Findings

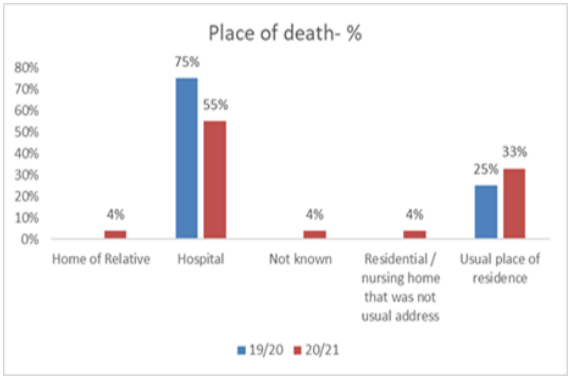
A summary of the findings is presented below:

From 1st April 2020 to 31st March 2021 there were a total of **28** deaths, this is an increase of **16** from the previous year.

- The majority (**55%**) of these deaths occurred in Hospital, in 2019/20 it was more (**75%**). The most common place of death for the last two years has been either in hospital or the usual place of residence.
- In 2020/21 there have been **17** male deaths (increase of **12** from the previous year) and **11** females deaths (increase of **4** from the previous year)
- Ethnicity was recorded in **93%** of cases as white British with **7%** not recorded.
- Although the average age of death during 20/21 was **63** years this should be read with caution due to the small number evidenced. This is an increase of **10.5** years from the previous year.
- Of the proportion of deaths where the reason was provided- during 2019/20 both cancer and pneumonia (**16%**) were identified as the highest cause of death. In 2020/21 pneumonia (**15%**) has again been highlighted as a significant cause of death closely followed by Covid 19 (**12%**). However, in 58% of the cases no cause of death was given within the recoding system. This has been identified as an area for improvement going forward.
- Those who lived through and then died during the pandemic were very clearly affected mentally by the restrictions in place. Evidence to support there was an increase in people socially withdrawing and isolating themselves.
- Consideration needs to be given to the relevance of placement. When considering placements educating other residents who do not have a disability about living alongside those who do.

4.0 Place of Death



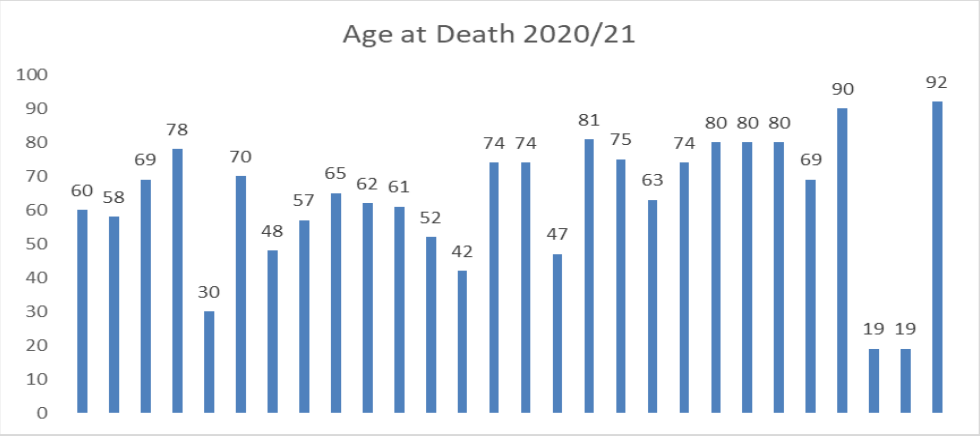


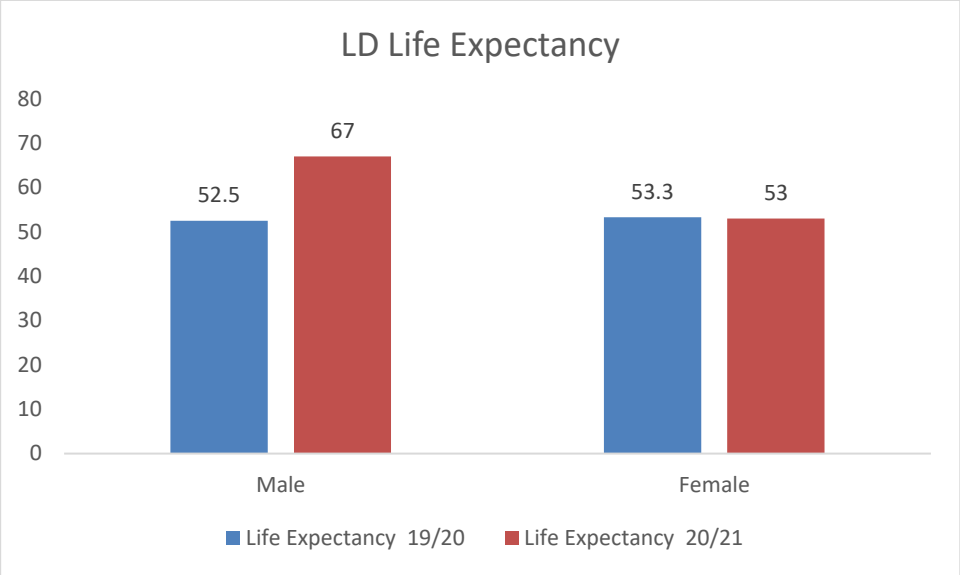
These two graphs show the number and percentage of the place of death for the twenty-eight individuals. From 1st April 2020 to 31st March 2021. As the graphs show, hospital is the most common place of death followed by the person's own home. This was reflected within the previous annual report.

4.1 Age at Death

According to the Office of National Statistics (National life tables – life expectancy in the UK - Office for National Statistics (ons.gov.uk)) the life expectancy at birth in the UK in 2017 to 2019 was 79.4 years for males and 83.1 years for females. However, these figures are lower for someone who has a learning disability. The following information relates specifically to the deaths in Wirral. This information should be read with some caution because the number of deaths is quite low (28 deaths) and the age range is so large. To average out the deaths in this manner can be misleading. For example, we can see the average age of death during the time frame of 2020/21 is 63 years. However, the graph below shows the full figures for this. The average age of life has improved from 2019/20 by 10.5 years.

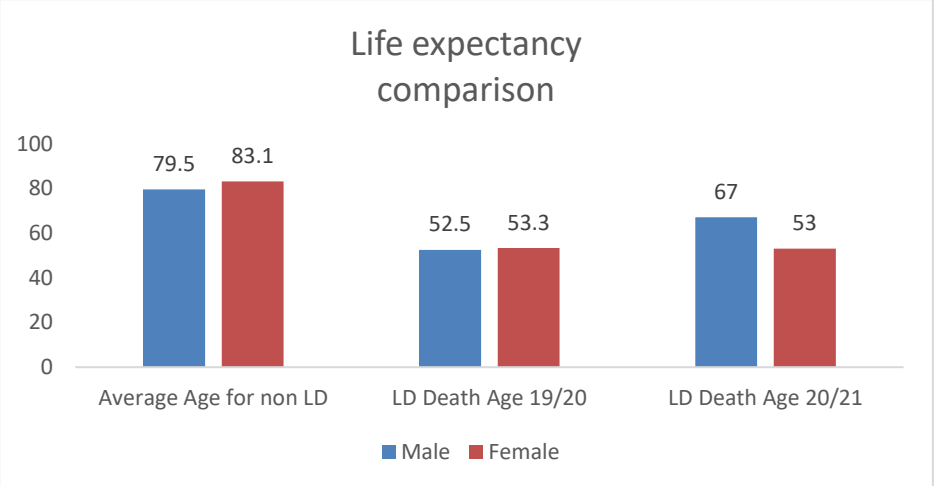
2019/20	**2020/21**
• Age range 15 years – 70 years • Average Age 52.5 years	• Age range 19 years – 92 years • Average Age 63 years
Male = 52.5 years	**Male = 67 years**
Female = 52.4 years	**Female = 53 years**





Life expectancy in Wirral September 2016 produced by Wirral Health intelligence Team:

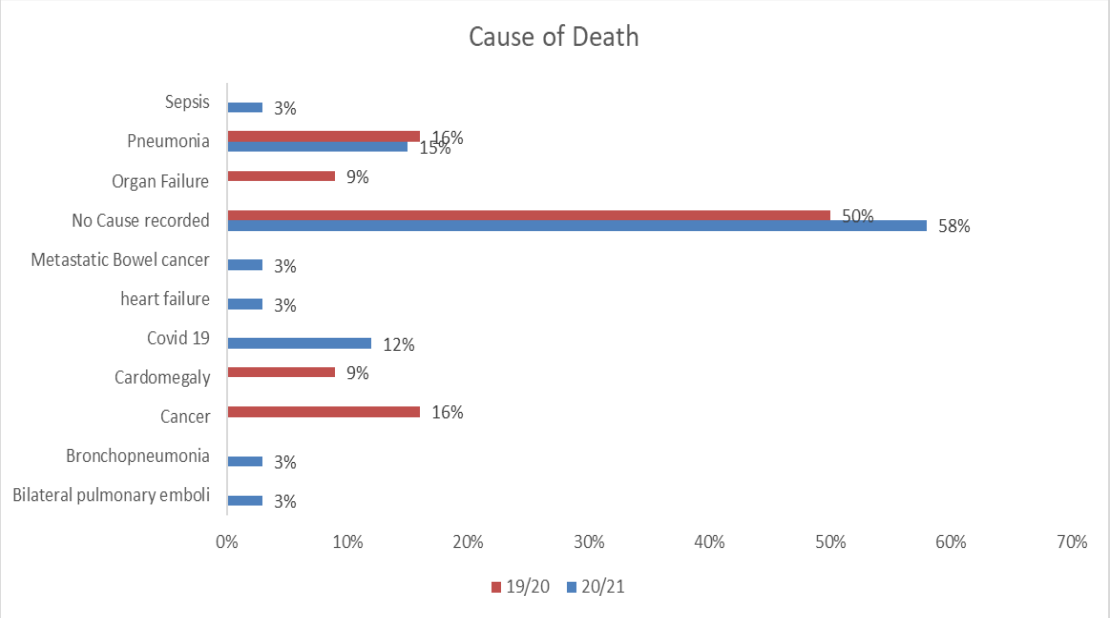
Male 79.5 years and Female = 83.1 years



From these statistics during 2019/20 males with a learning disability have a life expectancy that is approximately **27** years shorter than someone who does not have a learning disability. In 2020/21 this has decreased to **12.5** years. In 2019/20 females had a life expectancy approximately **29.8** years shorter than that of the general population and during 2020/21 this has remained unchanged.

4.2 Cause of Death

During 2019/20 both cancer and pneumonia (16%) were identified as the highest cause of death within the identified group. In 2020/21 pneumonia (15%) has again been highlighted as a significant cause of death closely followed by Covid 19 (12%). However, as the graph below shows, the gaps in data is significant with a gap of 50% in 2019 and 58% in 2020 and without these figures the report can only focus on less than half of the deaths.



As the graph shows there are still too many gaps therefore evidencing the commonest cause of death is difficult. A recommendation from this report will be to ensure that the reporting structure is robust and cause of death recorded.

5.0 What has been learned from local reviews of deaths

A major finding from reviewers is that families are very often unhappy to be contacted in the majority of instances. Clearly it is a difficult time and is often difficult to talk about a loved ones passing. It appears, unfortunately that the families who are more willing to discuss the death are families who wish to discuss bad experiences and need to formalise complaints. The complaints are often not necessarily related or used to inform reviews.

The majority of the complaints relate to financial issues especially when certain benefits cease due to the death and the detrimental effect this has on the family financially as a whole. In relation to the collection of information to inform the reviews the Local authority in the vast majority of cases were very difficult to obtain any information from.

Depending upon the provider reviewers found it difficult to ascertain who the main contact was when requiring information from the hospitals. Reviewers have experienced being sent to different departments in order to access the relevant records. Care homes were usually very prompt with the information but in many cases held very limited records. This is a common feature across many reviews.

However, it must also be acknowledged that any safeguarding issues or mental health records

were difficult to obtain information on.

The reviewers found that in Wirral the care that has been commissioned appears to be very relevant to need and well planned. It also appeared to provide more funding and be more supportive at providing equipment than other areas.

5.1 What has been learned from local reviews of COVID deaths

Those who lived through and then died during the pandemic were very clearly affected mentally by the restrictions in place. There was a great deal of evidence to support this and in many cases resulted in a very rapid decline in health.

There was a lot of evidence to support that in some cases there was an increase in people socially withdrawing and isolating themselves so much so that it was difficult for professionals and family to persuade people out of their rooms. GP surgeries were restricted to video calls and phone calls to assess people and in some cases referrals on to other professionals were taking longer. This also had a detrimental affect on people's mental health and ability to get help earlier.

5.2 Recommendations made by reviewers for local actions

Wirral reviewers have found that the CCG was very helpful and when a case was allocated they provided a pre-prepared list of GP contact details, care providers, hospital contact numbers, letter templates, leaflets and other sources of help. This really speeded up the process. Some even pre-warned GP practice etc that they would be contacted. This is something that can be classed as good practice and could be shared with other CCGs.

Certain GP surgeries where unaware of what LeDeR was but when they were made aware they were exceptionally quick to respond to requests for records. They also responded well to any queries regarding records. Similarly, the Coroner's office was extremely supportive and helped wherever they could. It was not difficult to obtain full transcripts of postmortems, inquest and any other requests for information.

However, it was also clear that younger adults who were still under children's services appeared to have better access to services than adults. This could be attributed to the multiple funding sources (health, education, social). Referrals from care homes to outside services were not always as prompt as they should have been. Some care providers were not as concerned about an individual with behavioural issues for example or being referred to dieticians when losing weight.

When they were questioned about this some of the responses were that the individual would not comply so that it was a waste of time and resources. Similarly, there were a number of care providers who did not refer on to tissue viability services or contact with district nurses for support. These referrals were often made when things had become too advanced rather than at first signs. A very clear recommendation is that as soon as issues arise support must be requested.

5.3 What has been done /planned to address learning from local reviews of deaths

It has become clear that those most recently deceased cases were showing a marked improvement in the need to socialise. There was more evidence of for example obtaining a mobility vehicle and extra staff on duty to ensure the person was taken out to shops, parks ,

community events etc. There is more evidence of a focus on the individuals needs and wants than what is or was traditionally provided.

There was evidence that many residents / service users went lengthy periods without family visits. One care provider had linked in with a befriending service who visited and befriended those with little or no visitors. This appeared to work really well.

5.4 Local priorities for delivery in 2021/22 and the evidence base that supports them

The specialist facilities appeared to be more supportive of the holistic needs of clients than the general Care homes. Specialist facilities have more structured support and more appropriate activities available so that individuals can participate and be interested /motivated into joining in. A lot of general care facilities tend to offer the more typical activities such a bingo sessions and similar. This means that there is less interest by many residents and the activities tend to be more appropriate for people who are in later years of life or advanced in a disease process.

A conclusion might be that in some area's consideration needs to be given to the relevance of placement. Whilst the whole idea is to integrate the various services, this cannot happen until all sectors are fully aware of what is available. How to meet the needs of people with learning disabilities within a general environment rather than socially isolating them. Also, when considering placements, educating the other residents who do not have a disability whether it is a learning, physical or mental need into living alongside those who do have. This appears to be a social issue in society in general and the more education into acceptance the better.

5.5 What have you put in place to monitor and review action plans/ service improvements to ensure that they are implemented and effective in improving care, reducing inequalities & saving lives

In Wirral there is now a full time LAC who supports and oversees the allocation of all LeDeR reviews. Part of this role will be to prepare reports for the senior leadership team about themes and trends learned. This learning is then fed into the safeguarding adults framework so that learning can be disseminated in a timely manner.

6.0 Summary

- Over the past year Wirral have been doing a lot of work with partners including with bereaved families and people with a learning disability, around what has worked well with LeDeR and what we need to do differently and better in the future, and making sure it results in improvements to services that will save lives.
- The most important focus of the new policy is that there is a stronger emphasis on the delivery of the actions coming out of the reviews and holding local systems to account for that delivery, to ensure that there is evidence of service improvement locally. NHS England and NHS Improvement regional teams will hold integrated care systems to account for the delivery of the actions they identify and ICSs (Integrated Care Systems) will report to them every quarter on progress.
- From the 1 June, there will be a new process for reviewers to follow, including a new

computer system ('web based platform'), and new training for the LeDeR workforce. Over the next year the workforce will change and reviewers will work in teams so that no reviewer will work alone, everyone will have the time they need to do reviews and support to do them.

- For the first time we will be reviewing the deaths of adults who have a diagnosis of autism but no learning disability. All reviews of people who are autistic without a learning disability will be focused reviews initially.
- All notifications of a person's death will receive an initial review including talking to their family or people who knew them well, talking to their GP or looking at the GP records, and talking to at least one other person involved in the person's care. If the reviewer feels a more detailed review is needed, a focused review will follow. Families can say if they think a focused review is needed.
- All people from Black Asian and minority ethnic communities will get a focused review because the evidence so far shows that the health inequalities experienced by people from these communities are very significant and there is also significant under reporting of deaths from these communities.
- In response to this change and stakeholder engagement the new name for the LeDeR programme is 'Learning from Life and Death Reviews – people with a learning disability and autistic people'. We will still use the name LeDeR.
- Sessions have been arranged with each ICS (via the Local Area Co-ordinators) to talk through the policy, changes and implementation of the new policy over the next year.
- Reviewers who completed the LeDeR reviews for this period were contacted to ask about themes that arose from the reviews. At the time of publication we are still pursuing feed back and acknowledging that for a period recently there has been no access to the LeDeR system.

7.0 Recommendations

It is clear from the report that there are areas of learning for commissioners and providers in relation to ensuring isolation does not impact on this group. It has also been established that delays in asking for help and putting in referrals can have a significant detrimental effect on people and that this is unacceptable, and that support must be requested at the earliest time to ensure the best outcome.

There are too many gaps evidencing the cause of death and reporting mechanisms would benefit from strengthening this so it is robust and any themes in this area can be scrutinised. As the new system becomes 'live' from 1st June it is anticipated the gaps of this nature will cease. However, this is something that has been escalated.

In future the LeDeR reviewers that are commissioned will ensure that the reason for death is recorded within the system before submitting the review. This information comes from the death certificate which they should see before submitting the review. They can also access this information from the medical record or from the coroner if it was a sudden death.

We have established a learning and development steering group across Wirral Health and Care Commissioning to ensure that themes from reviews are reported in centrally and actions arising from them are monitored in terms of completion and impact.