

Data Quality Statement: LeDeR Notifications and Reviews

From 1st July 2016 deaths of people with a learning disability have been notified to the Learning Disability Mortality Review (LeDeR) programme. This information covers deaths of people with a learning disability aged 4 years and over. Reviews of deaths of children with a learning disability are completed as part of the Child Death Review programme and are shared with the LeDeR programme.

Accuracy and Reliability

Accuracy and reliability define the underlying detail behind the data capture methods and the reporting assumptions.

Data from the LeDeR programme are recorded by the University of Bristol. The data are captured and summarised such that:

- The definition of 'learning disability' for the LeDeR programme is the presence of 'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.'
- The total number of people who have died with a learning disability where the death has been notified to the LeDeR programme. Deaths do not have to be reported to LeDeR so the LeDeR data only contains deaths that have been notified. There may have been more deaths that have occurred and Public Health England has estimated that around 65%¹ of deaths are notified to the programme.
- Delays in notifying deaths to LeDeR may also affect weekly figures. Deaths can be notified several weeks after they have happened.
- More than one person might report the same person's death. If so, the programme tries to make sure the person's death is not counted more than once.
- Reviews should be completed within 6 months of notification. Therefore, percentages on reviews completed in this document are calculated from notifications received 6 months ago or more.

The data in this report excludes notifications relating to children and some reviews that are 'on hold':

- Notifications of deaths of children under 18 years are not included as Clinical Commissioning Groups (CCGs) are not responsible for the completion of reviews of child deaths - these are part of the Child Death Review programme.
- 'On hold' notifications are not included where these deaths cannot be investigated by the CCGs at the present time due to coronial or other legal processes.

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From mid-2018 onwards a quality assurance process has been carried out by CCGs and reviews are not recorded as 'completed' until the CCG has agreed they meet their quality assurance criteria. Some caution should therefore be used in comparing figures over time.

Relevance

Relevance is the degree to which the statistical product meets user needs in both coverage and content.

NHS England has published data on reviews that are unallocated, in progress or completed as at 30th September 2020. Data are presented at region and CCG level as well as national level:

<https://www.england.nhs.uk/learning-disabilities/learning-disability-and-autism-programme-data-and-information/>

Annual reports from the LeDeR programme are also published each year by the University of Bristol and available here:

<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>

Alongside these reports, NHS England also publish an 'Action from Learning' report on the LeDeR programme. The latest report is available here:

<https://www.england.nhs.uk/publication/leder-action-from-learning-report/>

Weekly counts of all reported deaths (including those where the cause of death is Covid-19 or suspected Covid-19) are reported by NHS England here:

<https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/>

Accessibility

Accessibility is the availability and ease with which the data can be accessed; largely reflecting the format in which the data are available.

Data in this report are presented in graphs and tables. An Easy Read version of this report is also available.

Comparability

Comparability refers to the way data changes over time.

The data presented in this publication will change over time due to live data capture and processing. Deaths may be reported late to the programme and there can be a lag between reviews being allocated and completed and this being reported on the system.

Timeliness

Timeliness refers to the time gap between publication and the data capture period.

Data as at 30th September 2020 have been published in December 2020.

Confidentiality

To reduce risk of disclosure reported data are aggregated and counts less than 5 are suppressed and shown with an * symbol. Counts of 5 or more are rounded to the nearest 5. Percentages are banded.