Llywodraeth Cymru
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# An overview of mortality amongst People with a Learning Disability in Wales, 2012-2022

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# Contents

# Introduction

This report provides an overview of mortality amongst people with a learning disability in Wales over a ten-year period from 2012 to 2022. It is the first report of its kind specific to Wales and a step towards improving mortality reporting amongst people with a learning disability. It is a high-level overview of the scale of mortality, with further detail on a particular set of causes that are held to be overwhelmingly preventable or avoidable.

Gathering, analysing and reporting on this data is part of the ambition contained within the _Learning Disability Strategic Action Plan 2022 to 2026_, where it is recognised that we need to improve our understanding of the needs of people with a learning disability in Wales. This report will contribute evidenced based information to inform our thinking and subsequent action in respects of the health inequalities known to be experienced.

This report is intended to provoke discussion about the appropriateness of the approach taken to the available data sets and importantly generate recommendations as to what future analysis would be most useful. The report is not intended to provide a definitive answer as to whether mortality from these causes has increased or reduced in the last decade. Readers are issued with caution when drawing comparisons with this data and other mortality studies. It is the aspiration of the authors that the targeted improvement work across services for people with a learning disability can in the future be directly informed by such evidence.

# Identifying people with a learning disability from routine health data sets

There are a number of sources of information on which people have a learning disability in Wales, including GP practice- and local authority-held registers. However, for a number of reasons, it remains difficult to make use of these for national secondary analysis across data sets within the NHS itself. Inpatient data provides an alternative approach to identifying people with a learning disability.

The Admitted Patient Care data set (APC Ds) captures information on individuals' stays in NHS Wales hospitals, including diagnoses recorded in their medical records during those stays. Mention of a relevant diagnosis (described in Appendix B) in any stay is considered sufficient to decide that an individual has learning disabilities in this analysis. Similarly, any stay under a specialty of 'learning disability' is considered sufficient. APC Ds records are available from roughly 2010 onwards.

We link the inpatient records with Welsh Demographics Service (WDS) records of GP registration to determine if individuals are alive, aged four years or older, and either resident in Wales or registered with a GP in Wales, at the start of each calendar year from 2012 to 2022. This allows us to identify a set of people with a learning disability (PwLD) at the start of each year, whose mortality we can then investigate in the twelve months that follow.

Deaths were found by linkage in the DHCW Data Warehouse with death certification data from the ONS, for deaths registered on or before 18th May 2023.

# Overlap with other datasets identifying people with a learning disability

Work undertaken during the COVID-19 pandemic found an approximately 50% overlap between individuals identified on GP Learning Disability registers and those identified in the 2020s using the method described above.

Sheehan and others (2023) looked at the recording of learning disability in the English Hospital Episode Statistics (HES) dataset, which is broadly equivalent to the Welsh APC Ds. They compared recording in the HES with the recording of learning disability in an English NHS Trust's case register. They found that approximately two-thirds of patients identified on the case register could also be identified from inpatient diagnoses for the period 2006-2019.

These two findings suggest that the approach of looking for records of learning disability in hospital datasets is likely to find a decent proportion of people identified elsewhere as having a learning disability.

# Possible future improvements in specificity

The method described above is likely to result in some people being incorrectly identified as having a learning disability when they do not. It may be possible to identify some common causes of mislabelling – for example, someone with an acquired brain injury may be mistaken as having a lifelong learning disability – and attempt to detect these within APC Ds.

Future analysis could also look at how consistently different people are identified, recorded and coded as having a learning disability when admitted to hospital – selecting only people who are more consistently coded as having a learning disability may improve specificity of this method.

## Ethnicity and other personal characteristics, autism

The datasets used are limited when it comes to reliably describing some characteristics and conditions of the people identified. In some cases they may allow information to be recorded about an individual, but the usability of the data recorded in practice is extremely limited.

Of particular interest, but that we do not think we can currently describe with good confidence include: a person's ethnicity; whether or not a person has an autism spectrum condition; what sort of residence a person lives in (e.g. a care home, a private residence).

*Appendix A - Stability of the set of PwLD identified over time*, looks at some other characteristics and conditions in more detail and discusses whether observed changes over time in these may relate to changes in recording.

## Medical Examiner Service for Wales database

A future source of data for analysis relating to the deaths of people with a learning disability is the database of reviews of deaths undertaken by the Medical Examiner Service for Wales. It is expected that this will provide a rich and detailed source of data about deaths in Wales, and that it will support the accurate identification of deaths of people with a learning disability.

# Overview of mortality

Between January 2012 and December 2022, 3299 deaths were found, associated with the sets of PwLD identified at the start of each calendar year.

# Age at death

The chart below shows the deaths of PwLD, by age.

Deaths amongst PwLD (n=3299) by age, 2012-2022



PwLD identified from inpatient diagnoses in APC Ds
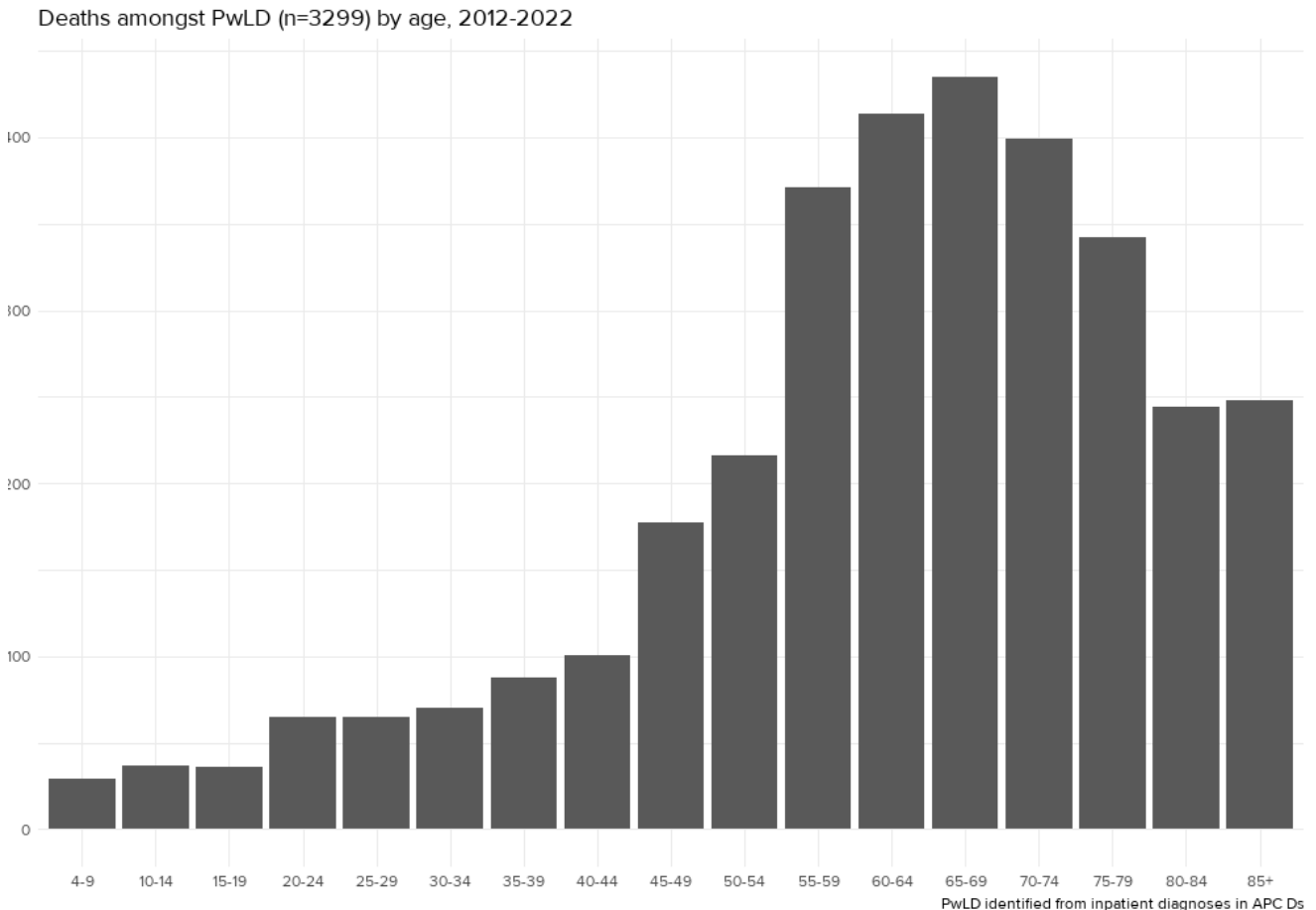
Half of the deaths occurred in people aged 65 or under; this is the median age of death.

The most common age at death was 67; this is the modal age of death.

In England, the *LeDeR* 2021 report by White and others found a roughly similar median age at death of 61 years old amongst people with a learning disability aged 4 and over. The approach taken by *LeDeR* to discovering the deaths of people with a learning disability is *very* different to the approach taken in this this paper and the difference in median ages should not be considered meaningful.

In Scotland, Cooper and others analysed deaths between 2004 and 2018 of a set of adults with a learning disability and found a *mean* age of death of 61 years old. Again, their approach to discovering people with a learning disability and their deaths is different to the approach taken in this paper (and also different to *LeDeR*'s approach in England) and the difference in average ages should not be considered meaningful.

These figures compare with median age of death of around 83 and modal age of death of over 87 in the wider population, according to ONS analysis by Buxton and others of deaths in people aged over 8 years old in England in 2020. The validity of this comparison is limited greatly by the approach taken to identify people with a learning disability in this report. Future analysis could attempt a fairer

comparison by looking only at deaths amongst people *without* a learning disability who had been admitted to hospital in the last ten years.

Despite the issues in comparability between the diverse approaches involved, the findings described above reinforce the view that across Britain, including in Wales, there is a disparity in age of death of roughly two decades between people with a learning disability and the wider population.
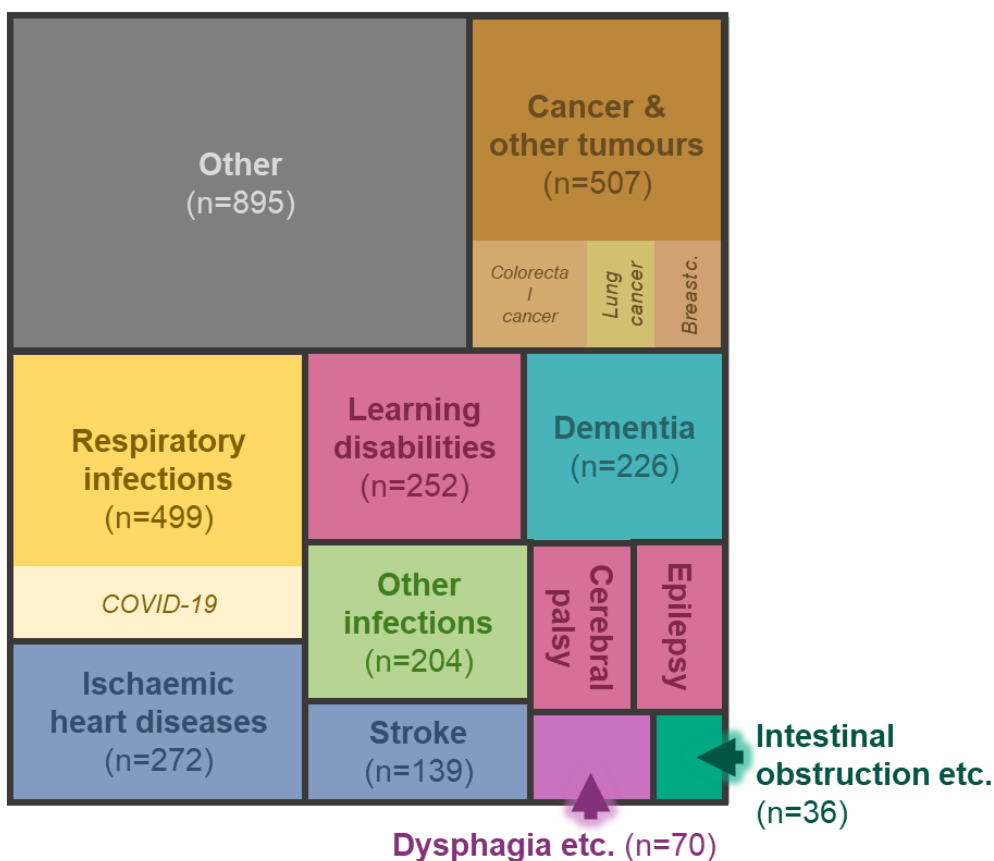
## Underlying causes of death

The 'tree map' chart below shows some selected rough groupings of the underlying cause of death for the deaths identified. (The sets of codes used for each grouping are given in *Appendix B*. *Appendix D* provides an overview of death certification and the determination of an underlying cause of death, with particular reference to people with a learning disability.) The selection and definition of these groupings has involved a degree of judgement; other ways of grouping these underlying causes of death are possible.

The groupings chosen cover around 73% of the 3299 deaths. 'Other' includes deaths from a diverse set of causes; a breakdown of these by ICD-10 chapter and, where appropriate, sub-chapter, can be found in *Appendix E*.

## Underlying causes of death amongst PwLD, 2012-2022
### (n=3299, PwLD identified from APC Ds)



The majority of the "Learning disabilities" grouping in the above chart are deaths where Down's syndrome was identified as the underlying cause of death. *Appendix D* discusses how more meaningful causes of death (e.g. respiratory infection) can be masked in cases like these.

The chart below shows deaths by underlying cause of death grouped as above, but split between deaths of people aged under 65 and deaths of people aged 65 and over.

At the top of the chart are groupings of underlying cause of death which were more often found in deaths of younger people than older people. These included Cerebral palsy, Epilepsy, Learning Disability, and Intestinal obstruction and constipation.

At the bottom of the chart are groupings which were more often found in deaths of older people than younger people. These include Dementia, Stroke, Ischaemic heart diseases, and both Respiratory and other infections.



Underlying Cause of Death of PwLD split by aged under 65 (n=1647) or aged 65 and over (n=1652)
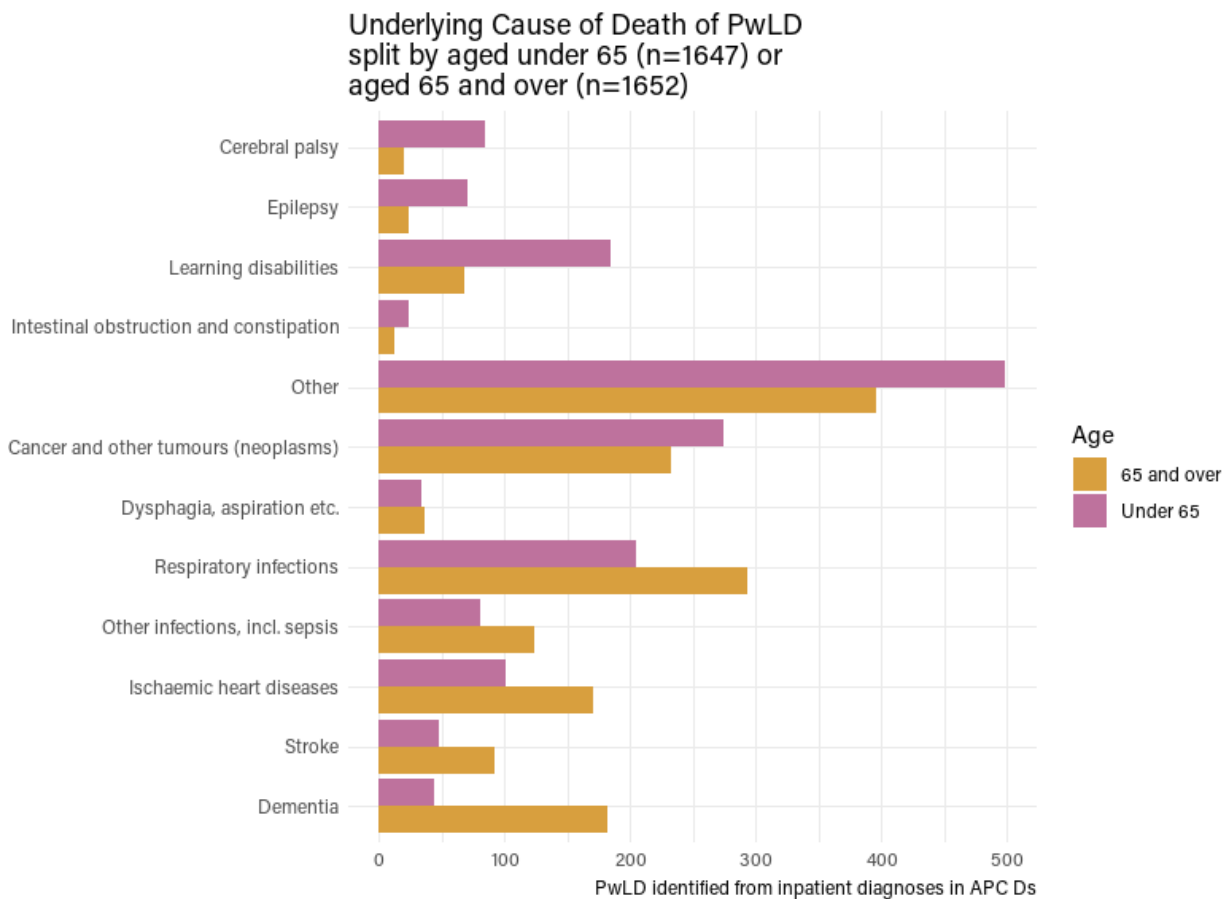
# Deaths involving selected causes

This section of the report looks in more detail at deaths that involved one of three different sets of causes of mortality:

1. Respiratory infections
2. Dysphagia, aspiration pneumonitis and choking on food or vomit
3. Intestinal obstruction and constipation

These sets of causes have been chosen on the basis that they are often preventable and/or treatable in people with a learning disability and that they are generally believed to be more common in the deaths of people with a learning disability than the general population.

The sets of codes used for each set of causes are given in *Appendix B. Appendix D* provides an overview of death certification and the distinction between underlying causes of death and "any mention" of a cause involved in someone's death, with particular reference to issues in deaths of people with a learning disability.

The table below shows some summary statistics about the number of deaths of people with a learning disability involving these causes, and the median age of those people.

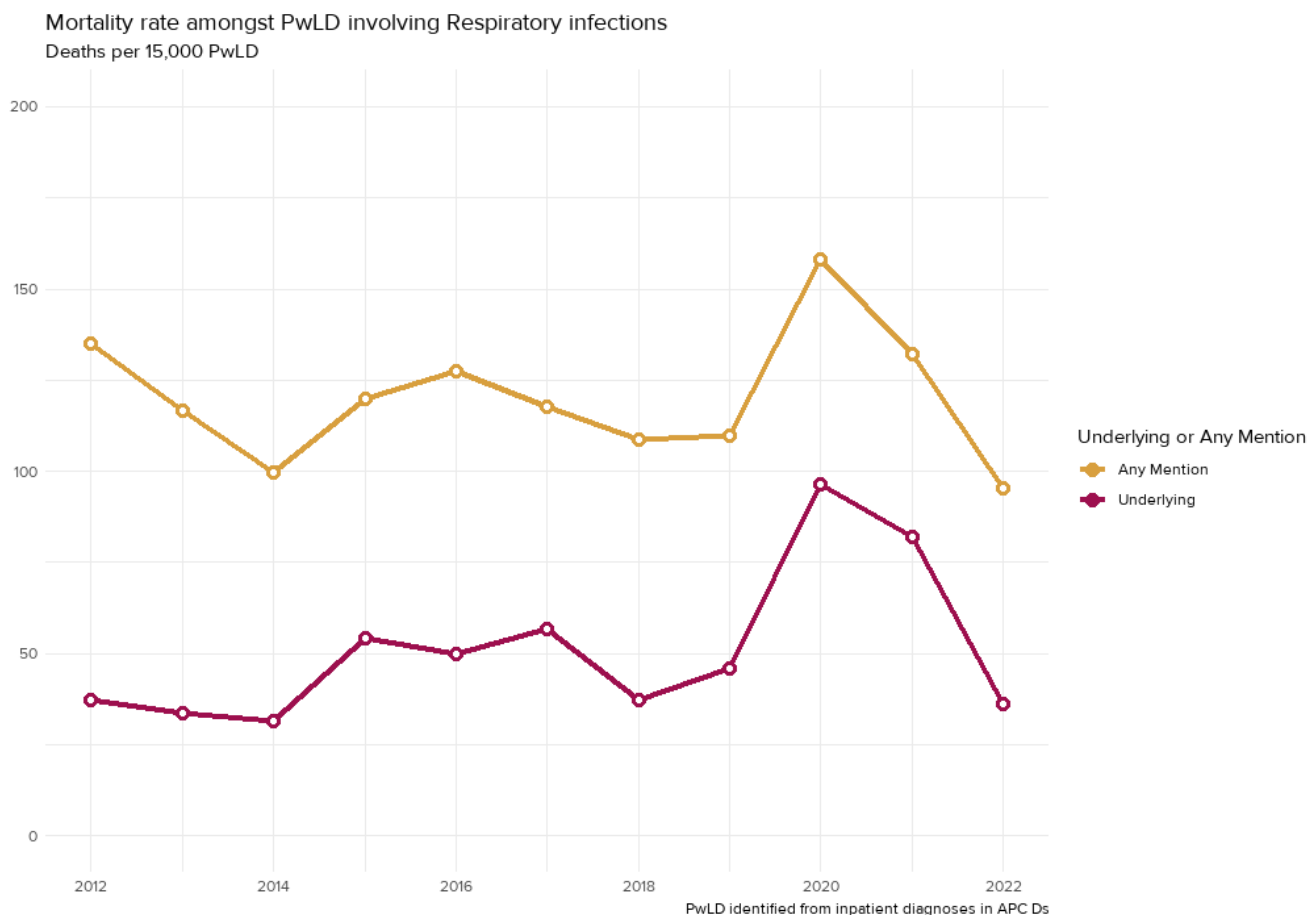| Cause of death group | Deaths with any mention | ... where this was the underlying cause | Median age of death with any mention |
|---|---|---|---|
| Respiratory infections | 1138 deaths | 499 deaths | 66 years |
| Dysphagia, aspiration pneumonitis and choking on food or vomit | 342 deaths | 70 deaths | 63 years |
| Intestinal obstruction and constipation | 77 deaths | 36 deaths | 62 years |

# Respiratory infections

These deaths include those involving seasonal flu, COVID-19, pneumonia of various other infectious origins and so on.

Between 2012 and the end of 2022, we identified 1138 deaths with any mention of respiratory infection; therefore respiratory infections were mentioned in over a third of all deaths.

In 499 of these deaths, this was selected as the underlying cause of death. The chart below shows the yearly mortality rate.

Mortality rate amongst PwLD involving Respiratory infections
Deaths per 15,000 PwLD



PwLD identified from inpatient diagnoses in APC Ds

There is no indication that the mortality rate involving these causes has decreased over the period shown. Indeed, a substantial increase in the mortality rate, both with any mention or with a respiratory infection identified as the underlying cause, can be seen in 2020 and 2021.

Over the decade as a whole, half of the deaths with any mention of a respiratory infection were amongst people aged 66 and under. A quarter were amongst people aged 56 and under.

# COVID-19

The chart below shows whether deaths with any mention of a respiratory infection also mentioned COVID-19.

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Deaths amongst PwLD involving Respiratory infections and COVID-19
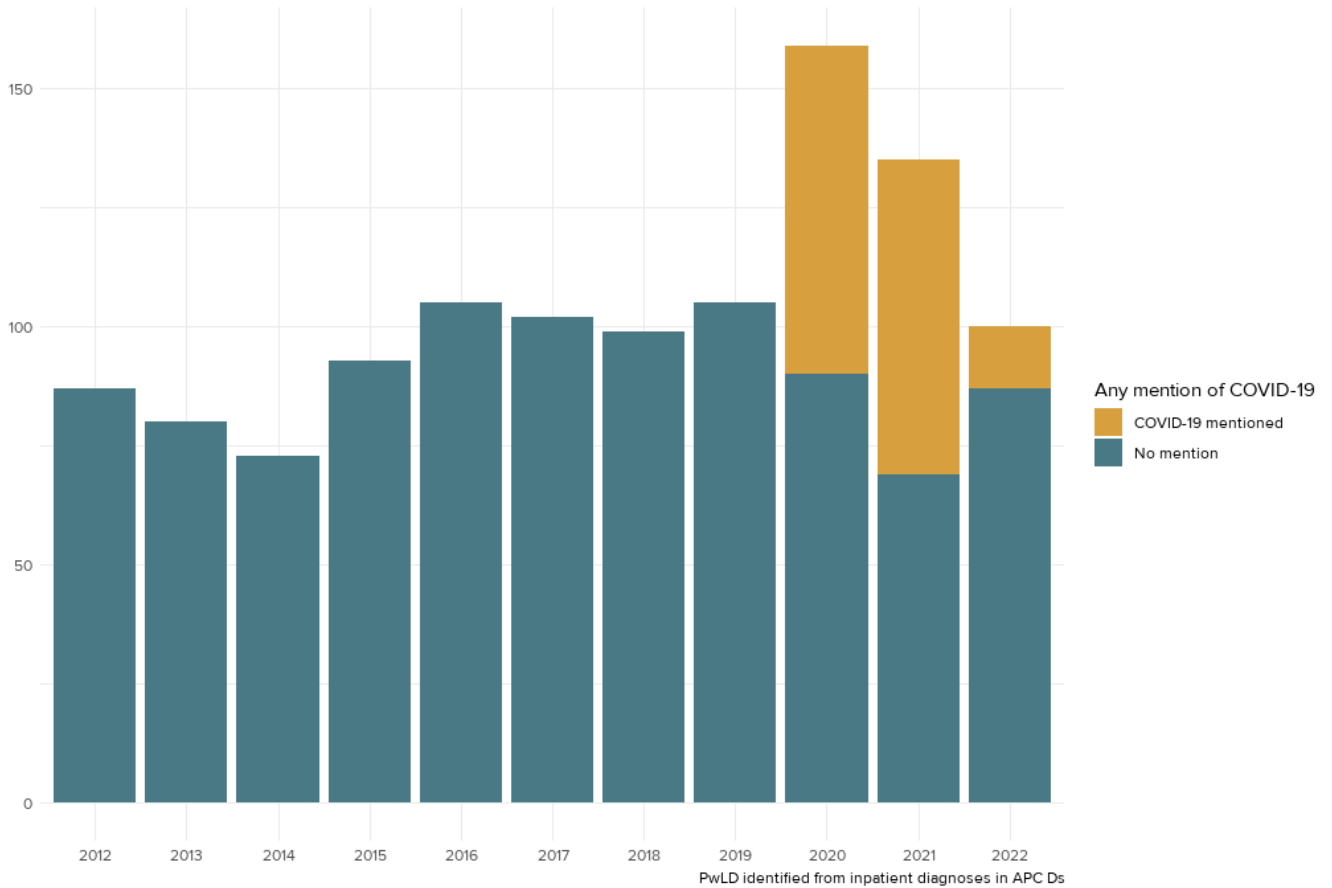


Looking at the chart above, it seems likely that from 2020 onwards that COVID-19 has both:

1. caused a substantial increase in the overall mortality associated with respiratory infections, particularly in 2020 and 2021, and
2. displaced some mortality associated with respiratory infections involving other organisms alone.

# Dysphagia, aspiration pneumonitis, and choking on food or vomit

Between 2012 and the end of 2022, we identified 342 deaths with any mention of dysphagia, aspiration pneumonitis, and choking on food or vomit. In 70 of these deaths, this was selected as the underlying cause of death. The chart below shows the yearly mortality rate.

Mortality rate amongst PwLD involving Dysphagia, aspiration pneumonitis, and choking on food or vomit
Deaths per 15,000 PwLD
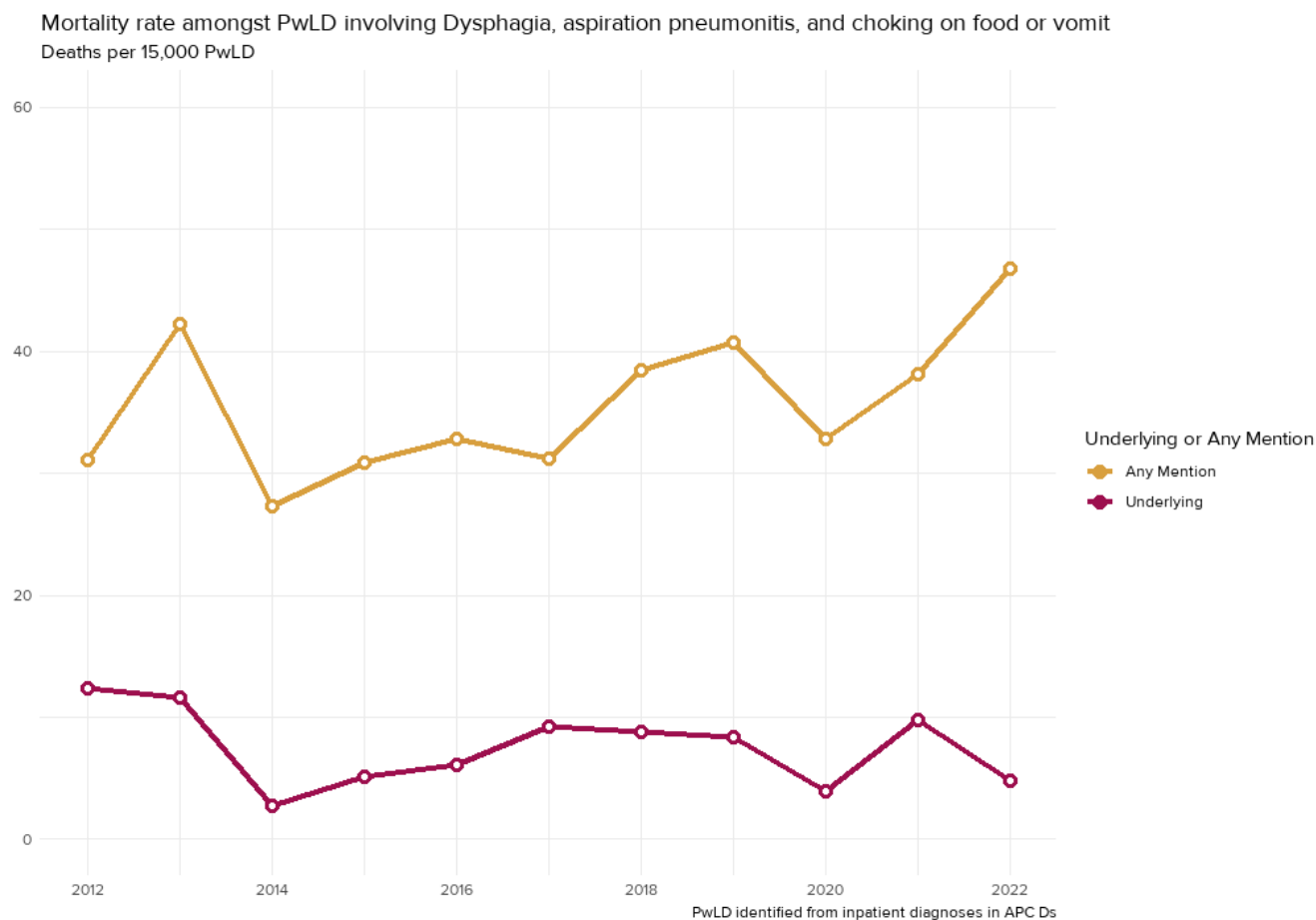


There is no indication that the mortality rate involving these causes has decreased over the period shown.

Half of the deaths with any mention of these causes were amongst people aged 63 and under. A quarter were amongst people aged 54 and under.
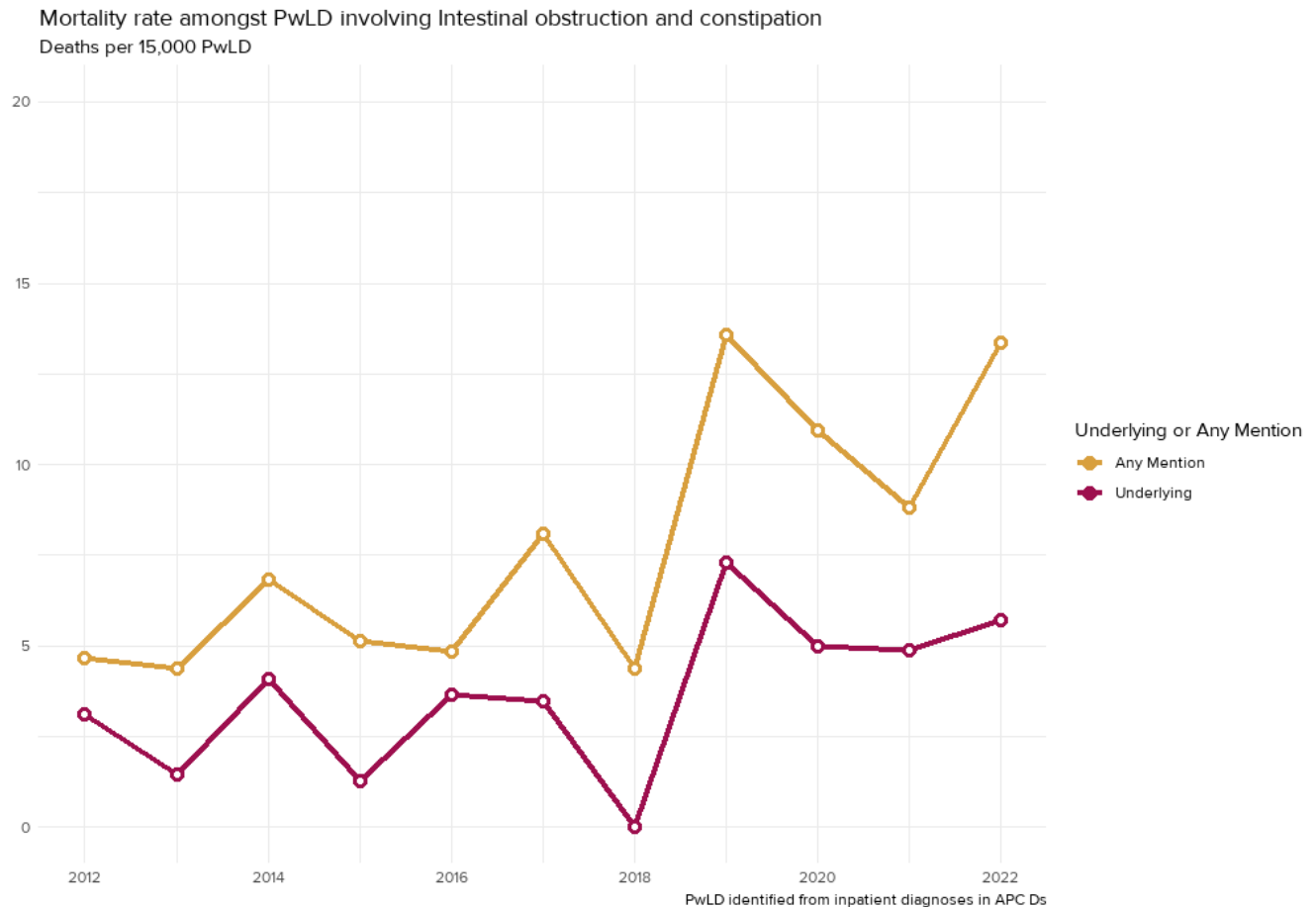
## Overlap with seizures or convulsions

These deaths include those where persistent swallowing issues were involved, but they may also include some deaths from choking where the person had no prior swallowing difficulties or that were the result of an unrelated incident (for example, a seizure).

Of the 342 deaths with any mention of dysphagia, aspiration pneumonitis, and choking on food or vomit, 76 also mention seizures or convulsions (epileptic or otherwise). This leaves 266 deaths with *no* mention of seizures or convulsions.

# Intestinal obstruction and constipation

These deaths include those involving hernias and constipation.

Between 2012 and the end of 2022, we identified 77 deaths with any mention of intestinal obstruction and constipation. In 36 of these deaths, this was selected as the underlying cause of death. The chart below shows the yearly mortality rate.

**Mortality rate amongst PwLD involving Intestinal obstruction and constipation**
Deaths per 15,000 PwLD



Legend: Underlying or Any Mention — Any Mention; Underlying

PwLD identified from inpatient diagnoses in APC Ds

There is no indication that the mortality rate involving these causes has decreased over the period shown.

Half of the deaths with any mention of these causes were amongst people aged 62 and under.
A quarter were amongst people aged 50 and under.

# Overlap with cancer and other tumours

Of the 77 deaths with any mention of intestinal obstruction or constipation, 8 also mentioned cancer or other tumours – in these cases, the obstruction may well be related to the growth of a tumour.

This leaves 69 deaths without any mention of a tumour. (Other intestinal conditions may still be implicated in these deaths.)

# Interaction with healthcare services immediately prior to death

Of the 77 people whose death certificates mentioned intestinal obstruction or constipation, 59 died during a stay in an NHS hospital.

A small number of people (fewer than five) also had one or more stays in an NHS hospital in the 30 days in the prior to their death but were discharged before they died.

Of those with a stay in an NHS hospital, 14 people had surgery potentially related to intestinal obstruction during their stays. (The procedures searched for are described in *Appendix C*.)

Future analysis could look at whether or not people who died from intestinal obstruction had presented to emergency healthcare services (e.g. ambulance services, emergency departments) shortly prior to their death.

Future analysis could look at outcomes of surgery for intestinal obstruction in people with a learning disability, including emergency abdominal surgery (laparotomy). Notably, information collected as part of the National Emergency Laparotomy Audit (NELA) supports the identification of people with learning disabilities who have undergone laparotomy.

## Conclusion & Recommendations

This report is a first in providing an overview of mortality amongst people with a learning disability in Wales. Whilst there exists particular complexity attached to this reporting, there are a number of meaningful conclusions we can consider from this report.

- Using the Admitted Patient Care data set, we have found an approach to examining mortality together with future suggestions for improvements in specificity.
- There is limited meaningful data available in respects of ethnicity and other personal characteristics.
- Collaboration with the new Medical Examiner Service for Wales could provide a future source of data for analysis relating to the deaths of people with a learning disability.
- Data shows a fairly steady rise in recorded prevalence over the last decade or so in some specific comorbidities, including asthma, diabetes, and hearing impairment.
- The most common age at death was 67; this is the modal age of death
- There is a disparity in age of death of roughly two decades between people with a learning disability and the wider population.
- Over the decade, respiratory infections were mentioned in over a third of all deaths and a quarter of these were amongst people aged 56 and under.
- Dysphagia, aspiration pneumonitis, and choking on food or vomit were mentioned in over one in ten of all deaths, and a quarter of these were amongst people aged 54 and under.
- Intestinal obstruction and constipation were mentioned in around one in forty-two of all deaths, and a quarter of these amongst people aged 52 and under.
- Consideration needs to be given to death certification processes and guidance therein of recording appropriate causes of death.

Finally, it is recommended that an overview of mortality of PwLD in Wales is reported upon on an annual basis. Feedback from key stakeholders subsequent to the release of this report will help us shape the contents of future reporting, which could include spotlight analysis of specific issues for example a deeper analysis of mortality from cancer. It is also proposed that in addition to this high-level overview for Wales, we explore the appetite for local level data reports, to help inform specific services of their local trends and patterns, e.g. by Health Board region.

Further work is being considered in respects to a data improvement strategy for learning disabilities, the learning from gathering, analysing and reporting this mortality report specific data is key to this wider strategy.

# Glossary

| | |
|---|---|
| PwLD | People with a Learning Disability<br><br>The term "intellectual disability", instead of "learning disability" is more common outside of British English and in academic literature. |
| APC Ds | Admitted Patient Care Data set<br><br>This data set covers all inpatient and day case activity undertaken in NHS Wales, and inpatient or day case activity relating to Welsh residents treated in English NHS hospitals.<br><br>Information from the APC Ds is used to update a very similar but longer-existing data set known as the *Patient Episode Database for Wales* (PEDW). The names APC Ds and PEDW are sometimes used interchangeably.<br><br>More information about the APC Ds and PEDW can be found at https://dhcw.nhs.wales/information-services/information-delivery/archived-pedw-data-online/ |
| ICD-10 | International Classification of Disease, 10th Edition<br><br>This is a classification system for diseases and other health conditions – it is used to describe what health conditions, including reasons for admission, someone has while in hospital, in a structured, consistent way. |
| OPCS-4 | OPCS Classification of Interventions and Procedures, version 4<br><br>This is a classification system for interventions and surgical procedures – it is used to describe what has been done to someone during their time in hospital in a structured, consistent way.<br><br>("OPCS" stands for the name of a UK government department that originally managed this classification system.)<br><br>More information about clinical classification systems can be found at: https://digital.nhs.uk/services/terminology-and-classifications/clinical-classifications |
| WIMD2019 | Welsh Index of Multiple Deprivation, 2019 update<br><br>More information about WIMD can be found at https://www.gov.wales/welsh-index-multiple-deprivation |