COVID-19-related deaths in Wales amongst People with Learning Disabilities from 1st March to 26th May 2020

Author Adam Watkins, Improvement Cymru

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This paper is for information only

Requested by Sharon Williams, Learning Disabilities Programme Lead, Improvement Cymru

Next update Not agreed at this time

Introduction

People with learning disabilities are often subject to more health inequalities than the wider population, and they are often more vulnerable to wider variety of health issues, including acute respiratory illnesses. Consequently, people with learning disabilities may be particularly vulnerable to COVID-19.

This paper attempts to look at COVID-19-related deaths amongst a subset of people with learning disabilities using existing data, and consider whether there is evidence of a disproportionately high number of deaths in this group.

Summary of findings

Using information routinely collected by NHS Wales on the diagnoses people receive as inpatients, we can identify approximately 15,000 people with a learning disability who were either resident in Wales or registered with a Welsh GP on the 29th February 2020. Those identified are likely to be individuals with relatively severe learning disabilities and those with relatively poor physical health statuses.

According to death registration data, at least 31 of these people have since died from COVID-19 between 1st March and 26th May 2020.

Comparison with deaths amongst all Welsh residents, suggests that the age-standardised rate of deaths involving COVID-19 is around 3x to 8x higher in this cohort than the population as a whole.

Despite this, the proportion of deaths in this cohort involving COVID-19 remains similar to that in the population as a whole. This is because this cohort has a persistently higher mortality rate from causes other than COVID-19.

Identifying people with learning disabilities from inpatient data

We can identify around 15,000 individuals with a learning disability by looking at the diagnoses that they have received during hospital stays over their lifetime to date.

Existing work suggests that this approach is unlikely to pick out all people with learning disabilities. It is liable to be biased towards picking out people with relatively severe and readily identifiable learning disabilities or conditions associated with learning disabilities. At the same time, people picked out by this approach may not be known to specialist learning disabilities services.

Furthermore, this approach will be biased towards people who have relatively poor health, independent of their learning disability; more frequent inpatient admissions make someone more likely to appear in this data.

More information on this approach, and the people identified by it, is given in Appendix A. The figures from this approach are not comparable with figures from other sources; this is discussed in more detail in Appendix C.

Deaths since 1st March 2020 amongst those identified

Deaths are discovered by linkage with ONS death registration data, for deaths occurring between 1st March and 26th May (and registered on or before the 8th June). At least 123 of the 15,294 have since died.

Deaths mentioning COVID-19 amongst those identified

Of these deaths, 31 had an underlying cause of death of COVID-19 (ICD-10 code U07) according to the death certificate. In 25 of these cases, it is indicated that the individual had a positive laboratory test confirming this diagnosis (ICD-10 code U07.1). More information on the characteristics of these people are given in Appendix B.

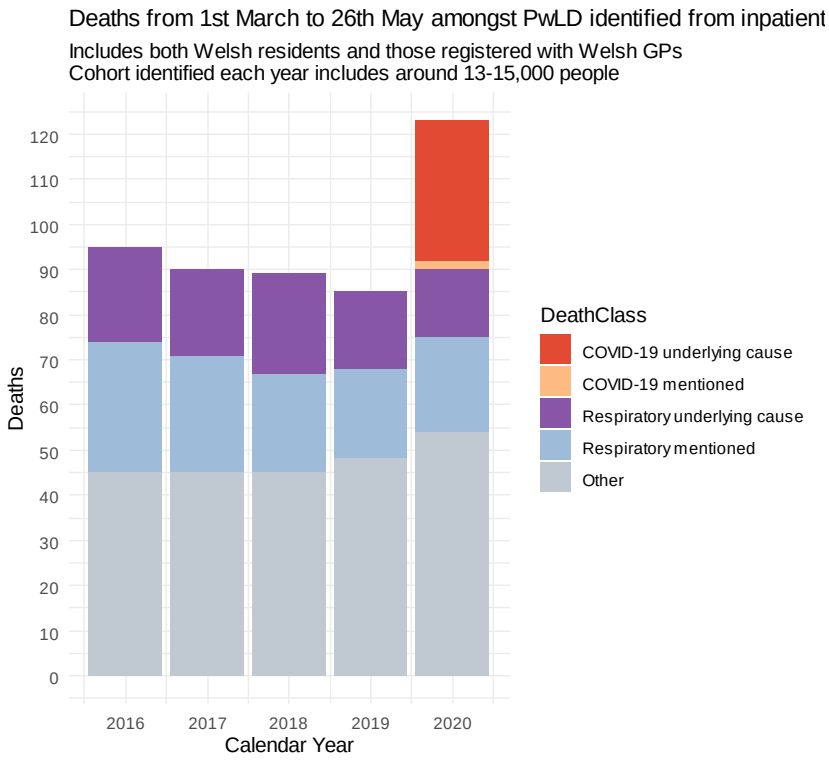
Two further deaths mentioned a laboratory confirmed case of COVID-19 on the death certificate, but did not have COVID-19 as the underlying cause.
(These deaths are included later in this report as deaths “involving COVID-19”.)

Comparison with previous years over the same period

It is possible that some deaths involving COVID-19 do not identify it in the causal chain leading to death on the death certificate, particularly in the absence of a positive laboratory test.

One approach to investigating this is to see if there have been significantly more deaths than we would expect, beyond those described above, by identifying similar cohorts for previous years, at the end of February, and looking for deaths in the following weeks.

It looks as though the number of deaths for the period under investigation is notably higher than in the last 4 years or so, but that the number of deaths with an underlying cause of COVID-19 accounts for much of this difference, but perhaps not all of it. Further investigation of ‘excess mortality’ in this group may be warranted.



Comparison of mortality rate involving COVID-19 with all Welsh residents

Population	Age-standardised rate of deaths involving COVID-19 for the period 1st March to 26th May, per 100,000 person-years	
People with learning disabilities identified from inpatient data, February 2020	1429	(941 – 1917, 95% CI)
All Welsh residents	277	(266 – 289 , 95% CI)

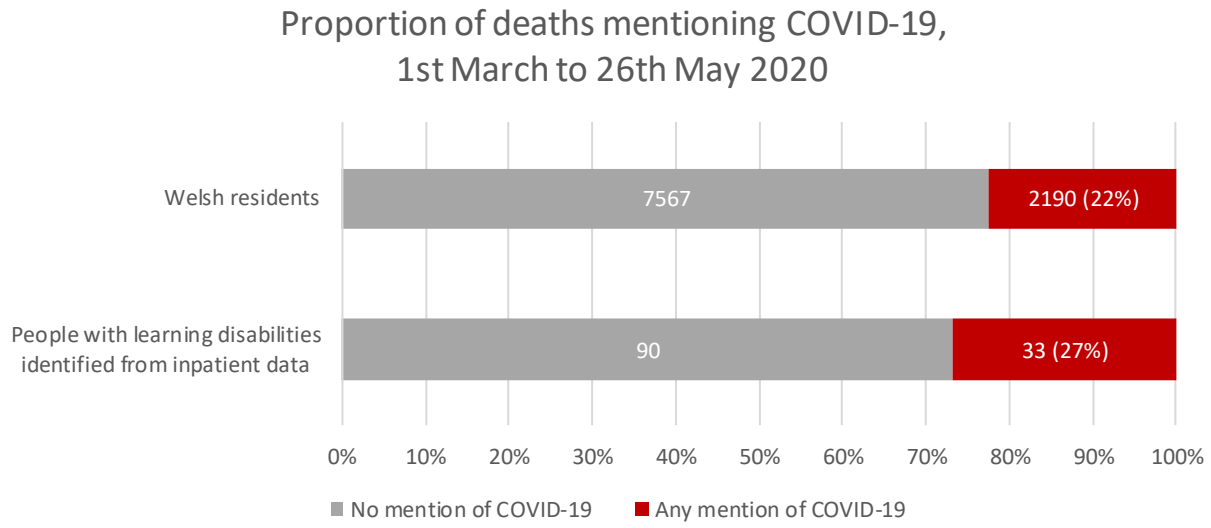
Only includes deaths registered on or before the 8th June 2020
The populations do overlap, as most of the people identified from inpatient data are Welsh residents.

This suggests that the age-standardised mortality rate is around 3x to 8x higher in the cohort identified than the total population, although the small number of deaths of people in the cohort identified limits the reliability of this analysis.

(Performing the calculation without age-standardisation shows that the *crude* mortality rate is also higher in this cohort, but that the ratio is smaller.)

Comparison of proportion of deaths involving COVID-19 with all Welsh residents

Another approach to comparing the impact of COVID-19 on this group with the wider population is to consider the proportion of deaths involving COVID-19. Despite the higher age-standardised rate of deaths involving COVID-19, described above, the proportion of deaths are fairly similar - as shown in the graph below.



This is because the mortality rate for this group relating to causes other than COVID-19 is also higher than the general population's.

Discussion

The findings above suggest both that:

- the rate of deaths involving COVID-19 is higher amongst people with learning disabilities,
- this higher rate is in line with the higher mortality rate generally experienced by this population

These findings must be interpreted with some caution, given the issues with reliably identifying people with learning disabilities using this approach.

Appendix A
Identifying people with learning disabilities from routine health data sets

There are a number of sources of information on which people have learning disabilities 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 learning disabilities.

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 (given in a section below) 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 for roughly the last decade.

We link the inpatient records with Welsh Demographics Service (WDS) records of GP registration to determine if individuals are alive and either resident in Wales or registered with a GP in Wales, on the 29th February 2020.

Existing work suggests that the sensitivity of this approach is relatively poor; it is liable to be biased towards picking out people with relatively severe and readily identifiable learning disabilities or conditions associated with learning disabilities. However, at the same time, people picked out by this approach might well not be known to specialist learning disabilities services.

Furthermore, this approach will be biased towards picking out people who have relatively poor health, independent of their learning disability; more frequent inpatient admissions make someone more likely to appear in this data.

Very rough pre-COVID-19 work based on similar cohorts from previous years suggests that people picked out using this approach had around a 5x higher annual risk of admission for a respiratory infection than the general population, matching with controls on age and sex.

Inpatient diagnoses indicating the presence of a learning disability

ICD-10 codes	Diagnoses (as named in ICD-10) and notes
F70-F79	*Mental retardation*
F81.9	*Developmental disorder of scholastic skills, unspecified* (More frequently used than F70-F79 codes for a learning disability of unspecified severity. Use of this code is advised by the LeDeR programme in England.)
F84.2	*Rett syndrome*
Q90	*Downs syndrome*
Q91	*Edwards syndrome, Patau syndrome*
Q93.3	*Wolff-Hischorn syndrome*
Q93.4	*Cri-du-chat syndrome*
Q93.5	*Other deletions of part of a chromosome, including Angelman syndrome*
Q99.2	*Fragile X syndrome*

Comparison of size of cohort

This approach picks out 15,294 people.

Approximately 12,450 of these people are aged 18 or older. We can compare the size of this cohort with a number of other cohorts of adults with learning disabilities or estimates of population size:

Cohort/Estimate of PwLD aged 18 or older	Size (people)
Identified from inpatient data, aged 18 and older, February 2020	12,452
Predicted number of adults with a moderate or severe learning disability, 2020 (Daffodil, after Emerson & Hatton, 2004)	12,203
People on GP QOF/QAIF "Learning Disability" registers, April 2019 (although this can now include people aged under 18)	15,197
People on LA "Learning Disabilities" registers, April 2018	14,456

Approximately 2600 of these people are aged under 17 or under. We can compare the size of this cohort with a number of other cohorts of children with learning disabilities or estimates of population size:

Cohort/Estimate of PwLD aged under 17 or under	Size (people)
Identified from inpatient data aged 18 and older, February 2020	2584
Predicted number of children with a severe or profound learning difficulty, 2020 (Daffodil, after Emerson & Hatton, 2008)	3727

Some early analysis, using the SAIL Databank, suggests both that approximately half of the people identified from inpatient data are found on GP registers and vice-versa.

Comparison of size of Down's syndrome sub-cohort

Of the 15,294 people picked out by this approach, 1,835 had a recorded diagnosis of Down's syndrome.

Approximately 1250 of these people are aged 18 or older.
We can compare the size of this cohort with predictions based on estimates of prevalence.

Cohort/Estimate of People with Down's syndrome aged 18 or older	Size (people)
Identified from inpatient data, February 2020	1255
Prediction of adults with Down's syndrome, 2020 (Daffodil)	1021

580 of these people are aged 17 or under.
We can compare the size of this cohort with predictions based on estimates of prevalence.

Cohort/Estimate of People with Down's syndrome aged 17 or under	Size (people)
Identified from inpatient data, February 2020	580
Prediction of children and young people with Down's syndrome, 2020 (Daffodil)	346

It is interesting that the number of individuals identified is substantially higher than the total number predicted. It is possible that the prevalence estimates used by Daffodil are now outdated, and fail to reflect ongoing increases in both the incidence of Down's syndrome amongst live births and increased lifespans of people with Down's syndrome.

Comorbidities of those identified

It is also possible to identify comorbidities from inpatient diagnoses. As with the approach as a whole, the sensitivity of this is likely to be poor, as comorbidities may not be recorded during an inpatient stay unless they are relevant.

The table below gives the *recorded* prevalence of certain comorbidities from inpatient diagnoses:

Comorbidity	Individuals	Prevalence	ICD-10 codes
Diabetes	1485	9.7%	E10-E14
Congenital circulatory problems	1255	8.2%	Q20-Q28
Congenital circulatory problems of the kinds registered by CARIS	422	2.8%	Q23.4, Q20.3, Q21.0
COPD, bronchitis and emphysema	531	3.5%	J40-J44
Asthma	2718	17.8%	J45-J46
Ischaemic heart disease	574	3.8%	I20-I25
Epilepsy	4218	27.6%	G40
Cerebral palsy	1527	10.0%	G80

These figures are likely to be lower than the true prevalence of these comorbidities in this cohort.

Appendix B
Characteristics of those who have died from COVID-19 amongst people with learning disabilities identified from inpatient data (n=31)

This appendix gives a brief overview of characteristics of people with learning disabilities identified from inpatient data who have died from COVID-19 in the period 1st March – 26th May 2020, and whose death was registered by the 8th June 2020.

Health board of residence	Deaths
Aneurin Bevan	8
Betsi Cadwaladr	9
Cardiff & Vale	<3
Cwm Taf Morgannwg	5
Hywel Dda	<3
Powys	3
Swansea Bay	3

By gender	Deaths
Men	23
Women	8

By age	Deaths
Under 60	8
60-79	16
80 or over	7

20 individuals died in an NHS hospital. Of those, fewer than five were residents in a care home prior to admission.

The remaining 11 individuals all died in a care or nursing home.

Appendix C
Comparability with other approaches to collecting data on COVID-19 deaths amongst people with learning disabilities

England has published data about COVID-19-related deaths amongst people with learning disabilities based on two approaches. It is **not** possible to meaningfully compare the number of deaths involving COVID-19 described in this paper with these approaches.

The fundamental issue is that these approaches determine the presence of learning disabilities in very different ways, and so they may discover deaths amongst quite different sets of people.

Our approach identifies a set of people that we believe have learning disabilities, and then attempts to discover if these people have died from COVID-19.

Both English approaches are roughly the reverse of this – given someone's death, they attempt to determine if the person had learning disabilities. The upshot of this is that we do not know the exact populations that the English approaches are effectively drawing from, how large they are, and how they compare to the cohort identified by our approach. (LeDeR's 2019 annual report includes mortality rates calculated using English GP Register populations, but the report does not discuss this approach in detail.)

The table below provides a brief overview of the criteria used by the three approaches.

Country	Approach	Criteria for determining deceased had learning disabilities	Criteria for determining death involved COVID-19
Wales	*As described in this paper*	Relevant inpatient diagnoses or specialty during lifetime. About 15,000 people in cohort.	Mention of COVID-19 on the death certificate, with or without positive test.
England	NHS England's in-hospital COVID-19 deaths	Presence of "learning disabilities or autism" is reported alongside the death using NHS England's COVID-19 notification system (CPNS).	Died in hospital, and tested positive for COVID-19
England	COVID-19 deaths notified to LeDeR	Non-mandated notification of death (by anyone) to LeDeR. LeDeR then validates the presence of learning disabilities according to broad criteria.	COVID-19 is suspected or confirmed as the cause of death