



Mortality in people with learning disabilities

Introduction

Research studies have shown that people with learning disabilities die at younger ages than other people. However, death certificates and population data for England do not regularly record whether people have learning disabilities. This makes it difficult to measure precisely how much younger or from what causes. The Department of Health has recognised the importance of this issue in assigning a 'placeholder' in the set of NHS outcome indicators but it has not yet been possible to produce numbers for this indicator. Recent developments in one of the UK general practice research databases now show how this can be done. This factsheet gives outline findings.

Where the data comes from

The Clinical Practice Research Datalink (CPRD), maintained by the Medicines and Healthcare Products Regulatory Agency, collects detailed and carefully anonymised clinical notes from several hundred general practices located around the UK for research studies. Using special techniques to ensure patients' identities can never be revealed, these general practice records are linked to death certificate data. This is available to accredited researchers in the CPRD-GOLD database. This database is able to report both the population numbers (by age group and gender) and the number of deaths for patients who have been recorded by their GP as having a learning disability. Deaths and population numbers for people not recorded as having a learning disability can be used for comparison. Public Health England's recent study compared rates and causes of death for these two groups. It used records for the four years from March 2010 to April 2014. A fuller account of the work is published in the *Journal of Intellectual Disabilities Research*.¹

¹ Glover, G., Williams, R., Heslop, P., Oyinola, J. & Grey, J., 2016. Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*.

Key findings

Among the 2.8 million people registered with participating general practices 0.53% were recorded as having a learning disability - 664 people with learning disabilities and 97,371 others died in the four years covered by the study. The crude death rate for people with learning disabilities was 11.2 deaths per 1000 population per year (95% confidence interval 10.4 to 12.1). This was 27% higher than the crude death rate for others (8.8 deaths per 1,000 per year). However, this simple comparison does not allow for the fact that smaller proportions of people with learning disabilities are in the older age groups where death rates are normally higher. Table 1 shows death rates for each age/sex group for people with and without learning disabilities and the ratio of the two. Death rates were higher for those with learning disabilities at all ages and for both sexes, in most cases statistically significantly so (Table 1). Generally, the difference was more marked in younger age groups, although the actual numbers of deaths were relatively small.

To make allowance for the differences in death rates at different ages, mortality in population sub-groups with a distinctive age and gender profile is usually reported as standardised mortality ratios (SMRs). The SMR for a group is the ratio of the number of deaths observed to the number that would have occurred if the age and sex-specific death rates of the general population had applied. SMRs for people with learning disabilities were, for males 3.03 (95% confidence interval 2.73 to 3.35), for females 3.40 (3.02 to 3.81) and for persons 3.18 (2.94 to 3.43).

An alternative single summary statistic is life expectancy at birth. This is the greatest age that would be reached by half of a theoretical population which experienced the current age and sex-specific death rates at successive stages of their lives. For people with learning disabilities life expectancies were, for males 63.8 years (95% confidence interval 57.7 to 69.9), for females 66.7 (63.4 to 70.0) and for persons 65.5 (61.9 to 69.2). Corresponding figures for people without learning disabilities were, for males, 83.6 years (83.4 to 83.7), for females 86.9 (86.8 to 87.0) and for persons 85.3 (85.2 to 85.4). This represents a shortfall in life expectancy for people with learning disabilities of 19.7 years for males, 20.2 years for females and 19.7 years for persons.

Table 1. Age specific death rates per 1000 population per year from all causes by sex and age group and by whether or not recorded as having a learning disability; ratio of death rates for people with/without recorded learning disability

Age group	LD all	No LD	Ratio
Females			
00-09	8.3 (4.2 to 14.9)	0.1 (0.1 to 0.2)	49.9
10-17	3.6 (1.5 to 7.0)	0.1 (0.0 to 0.1)	41.2
18-24	1.6 (0.5 to 3.8)	0.2 (0.1 to 0.2)	8.5
25-34	3.0 (1.6 to 5.3)	0.2 (0.2 to 0.3)	11.6
35-44	4.4 (2.7 to 6.8)	0.7 (0.7 to 0.8)	6.0
45-54	8.2 (5.8 to 11.1)	1.9 (1.8 to 2.0)	4.2
55-64	21.6 (16.6 to 27.6)	4.8 (4.6 to 5.0)	4.4
65-74	35.1 (26.4 to 45.6)	11.7 (11.4 to 12.0)	3.0
75-84	85.7 (63.6 to 113.0)	37.2 (36.6 to 37.8)	2.3
85-99	222.4 (147.8 to 321.5)	131.6 (130.0 to 133.3)	1.7
Males			
00-09	3.8 (1.7 to 7.6)	0.2 (0.2 to 0.2)	19.8
10-17	1.3 (0.5 to 2.9)	0.1 (0.1 to 0.2)	9.7
18-24	1.0 (0.3 to 2.2)	0.4 (0.3 to 0.5)	2.3 [†]
25-34	3.5 (2.1 to 5.4)	0.5 (0.5 to 0.6)	6.6
35-44	4.4 (2.8 to 6.7)	1.1 (1.1 to 1.2)	3.8
45-54	10.8 (8.3 to 13.9)	2.4 (2.3 to 2.5)	4.3
55-64	26.7 (21.5 to 32.8)	6.8 (6.6 to 7.0)	3.9
65-74	45.7 (36.4 to 56.8)	17.3 (17.0 to 17.7)	2.6
75-84	104.3 (79.0 to 135.2)	50.9 (50.1 to 51.7)	2.0
85-99	221.0 (136.8 to 337.9)	152.0 (149.6 to 154.5)	1.5 [†]
Persons			
00-09	5.6 (3.4 to 8.7)	0.2 (0.1 to 0.2)	30.4
10-17	2.1 (1.1 to 3.4)	0.1 (0.1 to 0.1)	17.3
18-24	1.2 (0.6 to 2.2)	0.3 (0.3 to 0.3)	3.7
25-34	3.3 (2.3 to 4.7)	0.4 (0.3 to 0.4)	7.8
35-44	4.4 (3.2 to 6.0)	0.9 (0.9 to 1.0)	4.6
45-54	9.5 (7.8 to 11.6)	2.2 (2.1 to 2.3)	4.3
55-64	24.3 (20.6 to 28.5)	5.8 (5.7 to 5.9)	4.1
65-74	40.8 (34.2 to 48.2)	14.4 (14.2 to 14.7)	2.8
75-84	94.7 (77.6 to 114.5)	43.2 (42.7 to 43.7)	2.2
85-99	221.8 (164.1 to 293.3)	138.5 (137.1 to 139.9)	1.6

[†] rates for people with and without learning disabilities not significantly different.

Causes of death

The CPRD data included medically certified underlying causes of death. SMRs for individual causes of death were calculated where numbers were large enough. Grouping deaths according to the International Classification of Diseases (10th revision) chapters, the largest number of deaths were from diseases of the circulatory system (152 deaths, 22.8%), the respiratory system (114, 17.2%) neoplasms (cancers) (87 deaths 13.1%) and diseases of the nervous system (85 deaths 12.8%). SMRs for these groups were circulatory 2.8 (95% confidence interval 2.4 to 3.3), respiratory 4.9 (4.0 to 5.9) and nervous system 9.8 (7.8 to 12.1). The SMR for neoplasms was 1.1 (0.9 to 1.4), meaning that the overall number of cancer deaths was not significantly different from what would be expected. However several types of cancer stood out as causing deaths more frequently than expected. The most notable was cancer of the colon and rectum (SMR 2.4, 1.3 to 3.8).² Four other individual conditions stood out as causing higher than expected numbers of deaths. These were pneumonia (organism unspecified) accounting for 8.4% of deaths, dementia (5%), epilepsy (3.9%), and pneumonitis due to inhalation of solids and liquids (3.6%).

The NHS Outcomes Framework Indicators

NHS Outcomes Framework indicators were introduced in 2011. From the outset a 'placeholder' for premature mortality of people with learning disabilities was included. This recognised that this was a high priority topic, but one for which there was no immediately available data. NHS Outcomes Framework Indicators are usually reported both nationally and for local areas. At present local data are not available for this indicator as GPs learning disability registers are located in individual practice note-keeping systems. There is currently no central collated national register. Research registers like CPRD-GOLD, with linkage to mortality and hospitalisation data, give a good indication of the national position but are only small samples. The numbers of deaths from this research dataset in its current form is too small for reporting about local areas or likely changes over relevant intervals of time.

Conclusion

The study found that people with learning disability in England have a death rate more than three times that of the general population after allowance is made for their age profile. Many deaths are from causes that could possibly be prevented with improved screening and health care. These data indicate the urgency of obtaining detailed comprehensive mortality for this vulnerable group of individuals.

² The period covered by the study was too early for the effect of the new colorectal cancer screening programme, introduced in 2013, to be apparent.

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First published: February 2017

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