

Avoidable deaths in people with intellectual disabilities in England

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Improving Health and Lives:
Confidential Inquiry

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Aim:

In 2010 the Department of Health funded a three year Confidential Inquiry (CI) into the premature deaths of people with intellectual disabilities in England.

The principal aim of the CI was to establish the extent to which people with intellectual disabilities die prematurely and to detect potentially modifiable contributory factors in the care of a person with intellectual disabilities who had subsequently died.

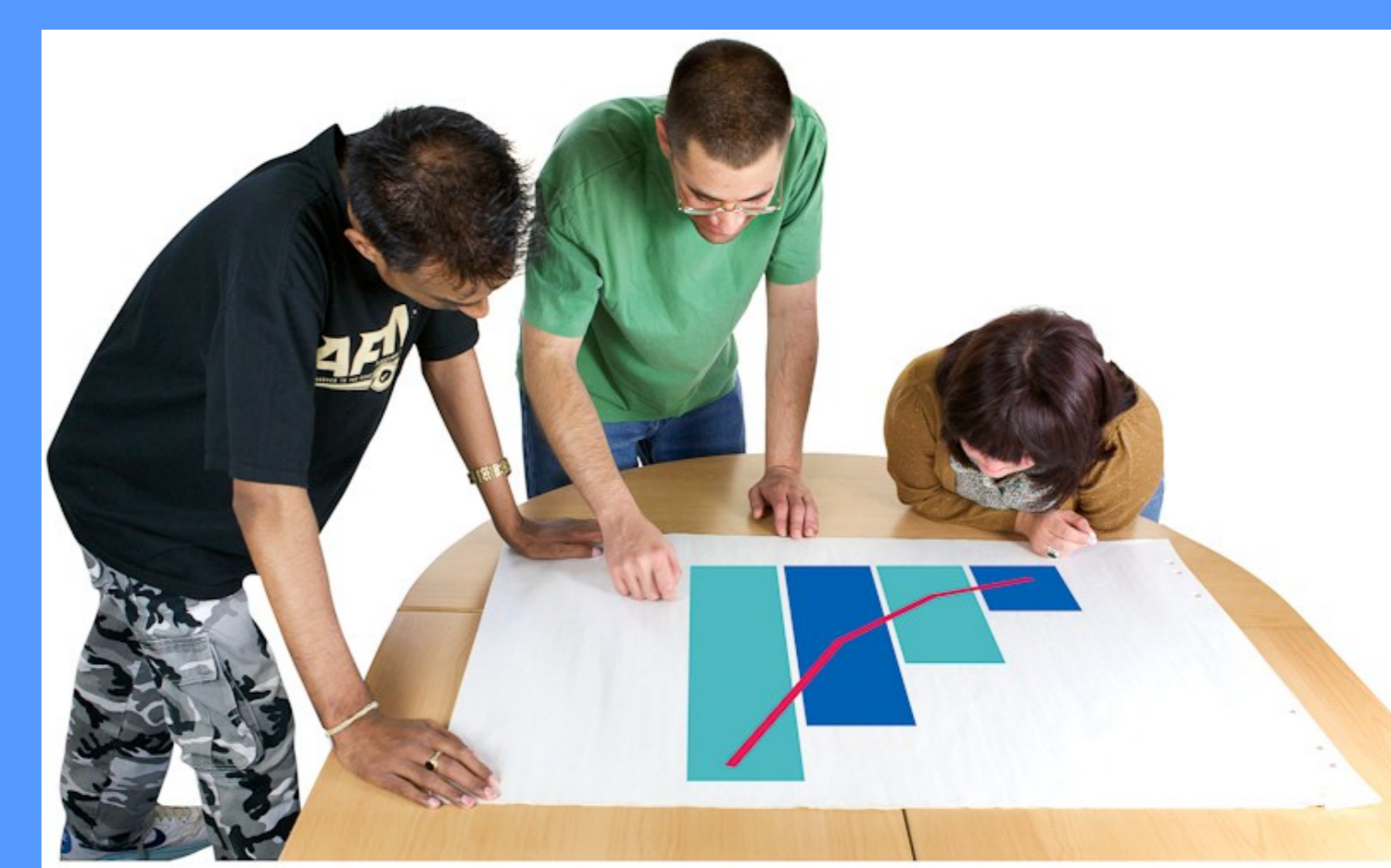


Methods:

The CI investigated the deaths of all people with intellectual disabilities (aged 4 years and older) who died between June 2010 -2012 and had been living in an area of South West England (population of 1.7 million).

We examined avoidable deaths by comparing the ICD-10 codes of underlying cause of death of people with intellectual disabilities and those of deaths of the general population in England and Wales (2011).

Avoidable deaths are defined by the UK Office for National Statistics as those preventable by public health measures, amenable to good quality healthcare, or both preventable and amenable.

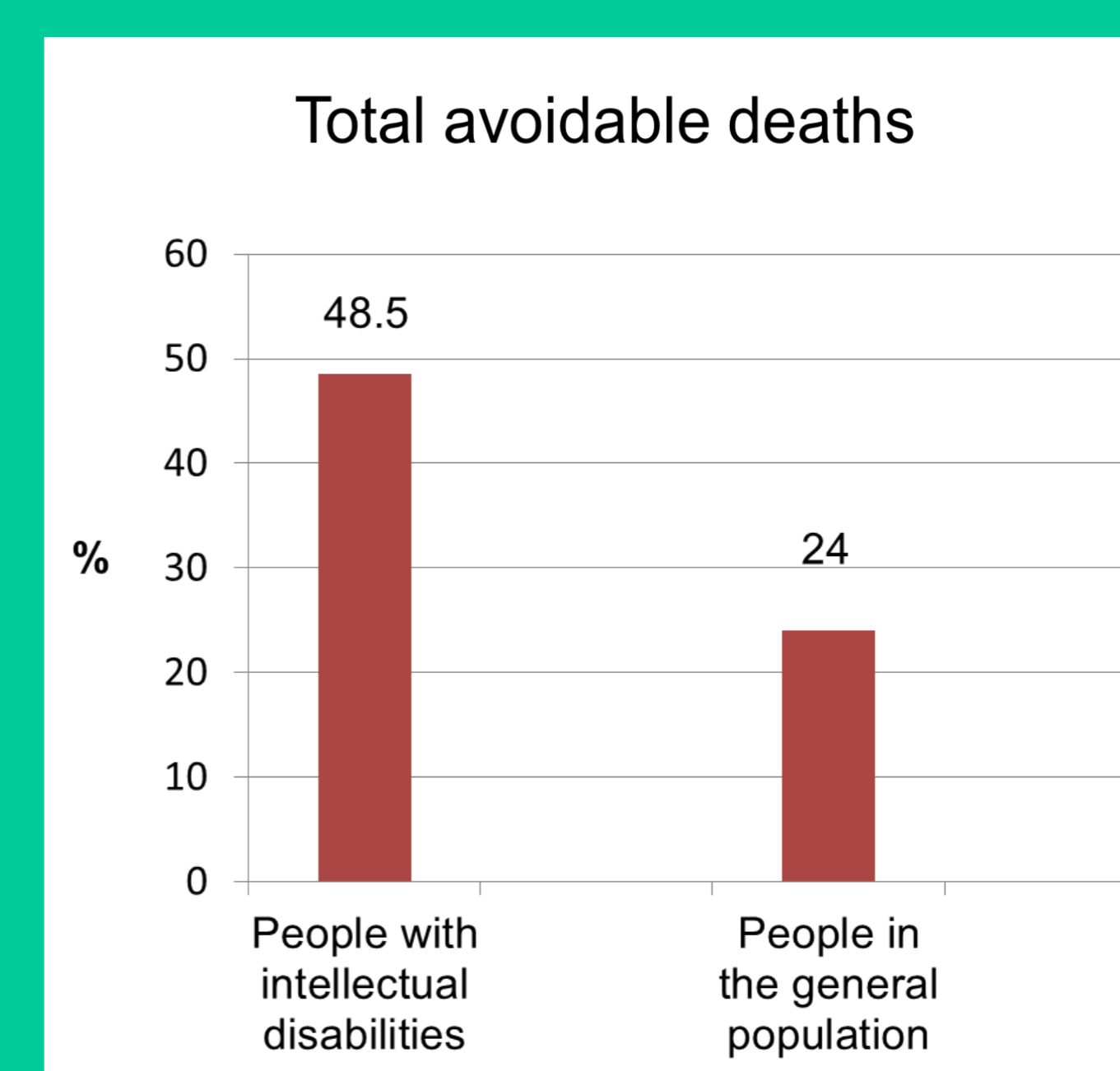


Results:

The CI reviewed the deaths of 247 people with intellectual disabilities, approximately 2½ times the number expected. The median age of death for people with intellectual disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women.

Using the UK's Office for National Statistics's agreed definition of avoidable deaths, 48.5% of the 244 people with intellectual disabilities, for whom final ICD-10 coding of their cause of death was available, were classified as having an avoidable death. This is more than twice the percentage of avoidable deaths in the general population in England and Wales (24%).

In the general population avoidable deaths are likely to occur because of lifestyle factors related to smoking, drinking and diet, or due to intentional and unintentional injuries. In people with intellectual disabilities avoidable deaths relating to accidents and DVT were common.



The proportion of deaths amenable to good quality healthcare was significantly different between the two groups. For people with intellectual disabilities, over a third (37%) of the deaths were amenable to good quality healthcare – almost three times the proportion found in the general population (13%).

People with intellectual disabilities had more deaths related to epilepsy, congenital malformations and pneumonia than the general population.

Conclusions:

This is the first UK mortality study of people with intellectual disabilities which has gone beyond age and cause of death data, as it has identified potentially contributory factors in relation to the deaths.

Mortality in people with intellectual disabilities could be reduced by paying attention to specific causes of death, and improving the quality of healthcare.

The CI made 18 key recommendations which, were they individually and collectively implemented, would decrease the risk of premature death in people with intellectual disabilities.



The full report and recommendations, and easy read versions of these can be found at:

<http://www.bris.ac.uk/cipold/fullfinalreport.pdf>

<http://www.bris.ac.uk/cipold/easyreadfullreport.pdf>