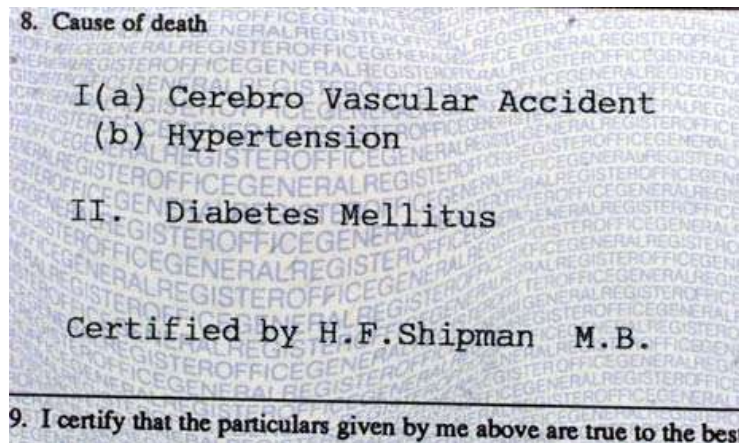


Certified causes of death inaccurate in fifth of cases, study suggests

Cancer and heart disease death rates may be higher than thought and lung deaths lower, according to ONS findings



A death certificate signed by Harold Shipman. The changes to the certification regime are partly the result of an inquiry into the Shipman case. Photograph: Don Mcphee for the Guardian

The causes of death certified by doctors may be inaccurate in more than a fifth of cases, according to a study carried out for the Office of National Statistics.

Thousands more people than previously thought might be dying each year from cancer and heart and circulatory diseases such as strokes, the study suggests, while lung and other respiratory conditions might cause fewer fatalities than presently recorded in England and Wales.

The study, which took in data on 5,112 deaths in 2010 and 2011, assessed the impact that a planned new system of certifying deaths would have on causes of death reported in annual statistics. The indications are that it will be significant and will make difficult any comparisons between annual figures before and after the changes are introduced in April 2014. The findings suggest that at present families in a significant minority of cases are not being told the correct cause of death of their loved ones. About half a million people die in the two countries each year. Cases certified by coroners – about a fifth of the total – will not be affected by the changes. The measures are intended to improve scrutiny of doctors by new medical examiners double-checking death certificates. These are signed by relatively junior doctors with little or no training in procedures. Ministers say the changes will make determination of cause of death more robust, provide more information for bereaved families, better inform public health monitoring and help detect poor-quality care. Doctors are expected to detail on certificates the chain of events directly leading to death, although selection of the underlying cause is made by statisticians following international rules. There is increasing concern that some medics do not provide sufficiently accurate information for this cause to be properly identified. The examiners will ensure they do.

The ONS looked at certificates before and after being checked by examiners in five pilot areas: Brighton, mid-Essex, Gloucestershire, Powys and Sheffield. It found the exact underlying cause of death was changed after scrutiny by a medical examiner in 22% of cases, and the broad category of disease as classified by the World Health Organisation was changed in 12%.

Deaths with the underlying cause of cancer rose by 1% and diseases of the circulatory system by 6%. Deaths attributed to respiratory disease decreased by 7%. In general, more conditions contributing to deaths were mentioned on certificates after scrutiny by medical examiners. There were limitations in the small case study. Pilots tried the system in different ways, meaning statistics were not directly comparable, nor were they representative of England and Wales. The deaths checked were also heavily weighted towards hospitals, when 49% of people die elsewhere, including 22% at home, 19% in care homes and 5% in hospices. The process required doctors and examiners to discuss causes of death, and this sometimes happened before different certificates were completed by doctors and examiners.

However, the ONS said the new system was "likely to affect trends in causes of death in mortality statistics". Its verdict comes three months after the Guardian reported on four years of figures, covering more than 8,000 certificates, from the Sheffield pilot, where inaccurate causes of death were recorded for about one in four patients and the wrong type of disease blamed in one in 10.

Cancer Research UK said 138,000 people died from cancer in England and Wales during 2010. Prof Peter Johnson, its chief clinician, said the study "emphasises the importance of obtaining accurate data about diseases and the results of treatment in the health service. It's important to recognise that many patients – especially the elderly – have more than one medical problem at a time and it can sometimes be difficult to be entirely precise about the cause of death. But we still need to make death certificates as accurate as possible."

Figures collected under the present regime suggest there are about 158,000 deaths from heart and circulatory diseases. By contrast, more than 67,000 people died in 2010 from respiratory diseases excluding lung cancer. Peter Weissberg, medical director of the British Heart Foundation, said changes would "inevitably bring about a shift in the numbers". It could often be "something of a judgment call" for doctors, especially GPs, to decide cause of death without a postmortem, which families often opposed when older relatives died, he said. Certificates "are more often right than wrong but there are always going to be a few cases where (cause of death) was slightly misjudged or miscalculated".

Richard Hubbard, medical adviser at the British Lung Foundation, said ONS data only allowed for one underlying cause of death, "which does not necessarily paint the most accurate picture". It recorded lung cancer as a cancer rather than a respiratory disease, "which distorts the figures somewhat, given lung cancer kills more people each year than any other form of respiratory disease", Hubbard said. "Although the report doesn't tell us what forms of respiratory disease or neoplasm [cancer] these cases involve, it is likely that a fair proportion of the reclassified causes of death were from pneumonia to lung cancer – both respiratory diseases in real life, but only one recorded as such in the ONS data."

The changes are partly the result of an inquiry into how the GP Harold Shipman managed to kill a suspected 260 people without authorities detecting his actions.

The public health minister Anna Soubry said: "It's good to see progress being made in the accuracy of information recorded on death certificates. This is not only important for families but critically it will also help local areas identify areas of need." The new system has been delayed twice, partly because of the controversial way it might be funded – making bereaved families pay a fee collected by councils. A consultation is expected next year.