

Using ONS mortality data – taking account of changes to cause of death coding from 2011

Background

The Office for National Statistics (ONS) uses software to automate the translation of cause of death information on death certificates from text to International Classification of Diseases (ICD) codes. The Tenth Revision of the ICD (ICD-10) was introduced for coding deaths in England and Wales in 2001. Up to and including 2010, ONS were coding deaths with a version of the ICD called **ICD-10 v2001**. During this period, the World Health Organization (which publishes the ICD) has issued updates of ICD-10, including corrections to the software for automated coding, codes for new conditions (such as swine flu) and changes to the rules used to select the underlying cause of death. From January 2011, ONS has adopted a new version of the coding software which incorporates the majority of these updates included in versions up to 2009 (**ICD-10 v2010**). This change has an impact on cause of death information, but this impact can, in general, be quantified and adjusted for, and this document offers guidance on how to do so.

Changes in 2011

The mortality data from ONS for 2011 will not look any different to the data for 2010 (unlike the major revision from the ninth to tenth revision of the ICD when the codes for all causes of death changed). The new version has a small number of new codes and some expansions of existing codes, at the fourth digit level of the ICD code (which may possibly change the definition of some existing codes). The main change in the new version is in the rules which govern which cause is selected from the death certificate as the underlying cause of death. The underlying cause of death is defined by WHO as:

(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury.

If a death certificate is completed correctly, the causes of death should be entered in a causal sequence, with the immediate cause of death at the top of Part I of the certificate, and working backwards through the chain of events leading to the underlying cause. The underlying cause is therefore normally what is entered on the lowest completed line of Part I of the certificate, as this should be the disease or injury which initiated the sequence of events that led to death. In Part II of the certificate, certifiers may enter diseases or conditions which they believe contributed to the death, but did not form part of the causal sequence leading to the immediate cause. In some circumstances (if the recorded sequence of events is not clear, for example, or if the underlying cause has been entered incorrectly in Part II), selection rules are used to decide what the underlying cause should be. There are other circumstances and conditions where the underlying cause may be selected from Part II of the certificate, as in this example:

| Cause of death the disease or condition thought to be the underlying cause should appear in the lowest completed line of part <i>I</i> | | | | | | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|---------------------|--|--|--|--|--|
| Ι | (a) Disease or condition leading directly to death | Bronchopneumonia | | | | | |
| | (b) other disease or condition, if any, leading to I(a) | | | | | | |
| | (c) other disease or condition, if any, leading to I(b) | | | | | | |
| Π | Other significant conditions contributing to death but not related to the disease or condition causing it | Parkinson's disease | | | | | |
| ICD-10 v2001 – 'old version' – underlying cause of death = Parkinson's disease | | | | | | | |
| ICD-10 v2010 – 'new version' – underlying cause of death = Bronchopneumonia | | | | | | | |
| | | | | | | | |

In the above example, only bronchopneumonia is recorded in Part I of the certificate but coding rules in ICD-10 v2001 allowed Parkinson's disease to be selected from Part II as the underlying cause. A change to the selection rules in ICD-10 v2010 means, however, that Parkinson's disease can only be selected as the underlying cause from Part II of the certificate if it is described as 'grave', 'severe' or 'advanced'. So in the years 2001 to 2010, the underlying cause for this death would have been Parkinson's disease, but in 2011 the underlying cause is bronchopneumonia. In 2010, ONS reported 5,021 deaths with an underlying cause of Parkinson's disease, but in 2011 they reported only 3,701. As ONS also reported 4,789 deaths

with an underlying cause of Parkinson's disease in 2009, and 4,744 in 2008, it is likely that the sudden fall in deaths from this cause in 2011 is related to the coding change, rather than a genuine drop in deaths of people from Parkinson's disease.

Bridge coded data

To understand the impact of the change in coding, ONS have bridge coded a set of mortality data, i.e. records were independently coded using the old version (**ICD-10 v2001**) and the new version (**ICD-10 v2010**). To quantify the change from ICD-9 to ICD-10, ONS bridge coded a complete year of death records. For the 2011 change, ONS have bridge coded only a sample of records, drawn from deaths in England and Wales in 2009. About 11% of deaths in that year were bridge coded: just over 55,000 records. These deaths were selected from a sample of registration districts. Within each sampled registration district, all deaths at ages under 65 were selected for bridge coding and 1 in 4 deaths were selected for ages 65 and over.

ONS have reported in more detail on the bridge coding study, in a statistical bulletin, which also summarises the impact of the coding change for each chapter of the ICD:

http://www.ons.gov.uk/ons/rel/subnational-health3/results-of-the-icd-10-v2010-bridge-coding-study-england-and-wales--2009/2009/index.html

Comparability ratios

The bridge coded data can be used to calculate comparability ratios which allow the impact of the coding change to be adjusted for. The ratio is simply the number of deaths coded to an underlying cause in the new version of ICD-10, divided by the number of deaths coded to the same underlying cause in the old version of ICD-10. For example:

ICD-10 v2001 – Number of deaths coded to Parkinson's disease = 397

ICD-10 v2010 – Number of deaths coded to Parkinson's disease = **287**

287/397 = 0.723

In this example, only 72.3% of deaths coded to Parkinson's disease in the old version, were coded to the same underlying cause in the new version. If the ratio had been 1, the number of deaths coded to Parkinson's disease would have been the same in both versions. That may not necessarily mean that no changes took place, however. Some causes of death in the new version may 'gain' some deaths from some causes and in turn 'lose' some deaths to other causes. If these movements in and out are balanced, the number of deaths in both v2001 and v2010 will be the same.

ONS has used their bridge coded data to publish comparability ratios for all chapters in ICD-10, based on data for all persons and all ages. These ratios give a broad indication of the impact of the change in coding. ONS have also released their bridge coded data on their website:

http://www.ons.gov.uk/ons/rel/subnational-health3/results-of-the-icd-10-v2010-bridgecoding-study--england-and-wales--2009/2009/index.html

These data include both 'old' and 'new' ICD codes, as well as the age and sex of the deceased. These data have been used by the London and East Midlands Knowledge and Intelligence Teams of Public Health England (PHE) to calculate a set of comparability ratios (provided in an accompanying table to this report). These were calculated for each sex rather than for all persons. As the ONS sampling strategy also included all deaths under 65, but only 1 in 4 deaths for those aged 65 and over, age-specific ratios have been calculated for those broad age bands, rather than ones for all ages (to avoid giving too much weight to the under 65s). Ratios have been calculated for indicators included in the Public Health Outcomes Framework, local authority Health Profiles and the Health and Social Care Information Centre's Indicator Portal. They could, however, be calculated for any other cause (or group of causes) as needed. The ratios are presented with 95% confidence intervals, which were calculated using the same method used by ONS (Rooney, Griffiths and Cook, 2002).

While the ONS comparability ratios provide a broad indication of change, they have been calculated without taking into account the different sampling ratios for deaths under 65 and those aged 65 and over. The PHE ratios take this into account and allow a more detailed assessment of the impact of the coding change to be made. They should be used to adjust numbers of deaths (and to calculate adjusted mortality rates), by sex and broad age group, using the methods described in this report. This detailed adjustment is particularly important as for some causes the bridge coded data indicates differences between the sexes, or between age groups. For example, the PHE comparability ratios for respiratory disease are 0.98 for males under 65, and 1.03 for males aged 65 and over. The coding change thus led to a decrease in respiratory disease deaths at younger ages, and an increase at older ages. The ONS ratio based on all persons and all ages is 1.02.

How to apply the comparability ratios

It is normally recommended that comparability ratios are applied to historic data, to make them comparable to data coded in the most recent version of the ICD. It is only necessary to use comparability ratios if we are looking at trends in causes of death, or grouping years of mortality data together.

In reporting cause-specific trends, ONS have generally taken the position that they do not report adjusted numbers of deaths. Instead they have tended to report actual numbers of deaths and added warnings to users to note the likely impact of ICD revisions. Where comparability ratios are applied, it should be made clear that these are 'adjusted' numbers.

The ratios can be applied to mortality data in England and Wales back to 2001, the year that ICD-10 was introduced. It should be remembered, however, that the ratios are based on data for 2009. Changes in the distribution of deaths between cause groups in other years may mean that the ratios are less accurate when applied to data not from 2009. This should be considered if, for example, adjusted trend data do not appear plausible or consistent.

The comparability ratios can also be used to adjust mortality rates. The ratio can either be applied directly to the rate or the numbers of deaths can be adjusted before the adjusted rate is calculated. It is recommended that the latter option is used, so that the adjusted rate and its confidence interval, are both based on adjusted numbers of deaths. Since the ratios are different for different age groups and for males and females, applying an overall single comparability ratio to the calculated rate would require this to be calculated taking into account the age/sex distribution of deaths by cause. If the numbers of deaths are adjusted, however, the appropriate ratio can be applied to each age/sex-specific count.

Table 1 includes an example of how deaths can be adjusted by the application of age/sexspecific comparability ratios. The age-specific ratios should be used to adjust deaths for under 65s and those aged 65 and over separately. In the example in Table 1, deaths for 2009 and 2010 are aggregated with deaths for 2011. Deaths for the earlier two years therefore require adjustment, while deaths for 2011 do not. Once the adjusted deaths have been calculated, they can be used to calculate either directly or indirectly age-standardised rates, or crude or agespecific rates. For an SMR, deaths should be adjusted for both the reference population and study populations being compared to the reference group.

Confidence intervals

When adjusted counts of deaths are used to calculate rates or ratios, there are two potential ways of calculating confidence intervals for the statistics:

- i) The adjusted counts can just be used to determine the confidence intervals as if they were actual observed counts.
- ii) The rate or ratio (R) and its confidence interval (R_L , R_U) can be calculated using the original counts, and the confidence interval applied to the adjusted rate or ratio (R^*) as follows:

$$R^*_L = \frac{R_L \times R^*}{R}$$
 and $R^*_U = \frac{R_U \times R^*}{R}$

While the second method is arguably more accurate, as it uses the actual observed counts to define the confidence interval, it will make little difference as long as the ratios are fairly close to 1, as they are in the majority of cases. Hence it is recommended, pragmatically, that the adjusted counts are treated as if they were observed counts, and the confidence intervals calculated using the standard methods.

Attributable fractions

Comparability ratios can be used to adjust numbers of deaths for the calculation of mortality indicators which involve the application of attributable fractions, e.g. to estimate numbers of smoking-related or alcohol-related deaths. In these cases, the comparability ratios should be used to adjust numbers of deaths separately for each cause, or group of causes, within the definition. Attributable fractions can then be applied to these adjusted numbers.

When do comparability ratios not need to be applied?

Each comparability ratio has a 95% confidence interval. If the interval includes 1, then the difference in the number of deaths coded to a cause in the old and new versions is not statistically significant. Adjustment is therefore not considered necessary for these deaths.

For causes with very large numbers of deaths, ratios close to 1 may still appear significant but adjusting the mortality rate would have little effect. For example, the comparability ratio for cancers for males under 65 is 1.004, with a confidence interval from 1.001 to 1.007. Adjusting for the impact of the coding change would have little effect on mortality rates for this cause

group. It is therefore recommended that deaths are not adjusted where the comparability ratio indicates a change of less than 1%.

The changes to selection rules impact on the selection of the underlying cause of death, but do not affect how causes of death are recorded on the death certificate. For example, the number of deaths where Parkinson's disease was mentioned on death certificates in 2010 will be comparable to the number mentioned in 2011. No adjustment is therefore needed when using multiple cause of death data to look at mentions of causes.

Vascular dementia, Alzheimer's disease and Parkinson's disease

Vascular dementia is usually caused by cerebral damage following strokes. The version of ICD-10 used by ONS in 2001 coded vascular dementia (or cerebrovascular dementia) to F01.9 (vascular dementia unspecified). From 2002 to 2010, however, ONS coded these deaths to codes I67.9 (cerebrovascular disease unspecified) and F03 (unspecified dementia) (Office for National Statistics 2006). In ICD-10 v2010 there is a change to the coding rules for dementia. Deaths previously coded to I67.9 are now coded to F01 or F03 (vascular dementia and unspecified dementia respectively).

This change in coding rules in ICD-10 v2010 onwards has a very big impact on deaths from vascular dementia. In the bridge coded sample, only 37 deaths had an underlying cause of vascular dementia (F01) using ICD-10 v2001. But 478 deaths had an underlying cause of vascular dementia using ICD-10 v2010. Simply adjusting trend data for vascular dementia by applying a comparability ratio based on the bridge coded sample is not recommended. As deaths from dementia, Alzheimer's disease and Parkinson's disease have been particularly affected by changes over time in the rules used to select the underlying cause of death, ONS analysis of trends in these deaths has examined mortality rates based on mentions of these causes on death certificates, rather than just rates based on underlying cause (Griffiths and Rooney, 2006). However, as the effect of the change is to reallocate deaths from cerebrovascular diseases to mental health disorders, comparability ratios would be required if examining deaths by underlying cause for those two broader cause groups.

External causes

The bridge coded data indicate a 12% increase in deaths coded to external causes in ICD-10 v2010. ONS cause coders did not, however, have all the information provided by coroners at death registration during the bridge coding study. ONS therefore advise that the results from the bridge coding study for external causes may not be strictly comparable and should be treated with caution.

ONS has reported separately on the impact on deaths from drug poisoning, as there has been a change in the selection rules which affects deaths where both accidental poisoning and drug dependence are mentioned on the death certificate (Office for National Statistics, 2012). In the old version (ICD-10 v2001), the underlying cause would have been drug dependence and the death would have been assigned an F code – mental and behavioural disorders due to drug use. In the new version, the selection rules now mean that the underlying cause will normally be accidental poisoning, and these deaths will be assigned an external cause code instead. ONS analysis shows that the number of deaths coded as mental and behavioural disorders due to drug use (ICD-10 codes F11–F16 and F18–F19) consequently decreased by 84 per cent in ICD-10 v2010, compared with v2001. The decrease is due to these deaths being allocated instead to accidental poisonings by drugs (ICD-10 code X40–X44), which increased by 44 per cent in v2010. This change will also affect alcohol-related deaths. The number of deaths with an underlying cause of F10 (mental and behavioural disorders due to alcohol) will decrease and the number coded to X45 (accidental poisoning by alcohol) will increase. As long as both are considered together, as in the ONS definition of alcohol-related deaths, the coding change will not impact on the overall number of alcohol-related poisoning deaths.

This change in the coding rules regarding poisonings may also impact on suicide rates, which ONS has reported on separately (Office for National Statistics, 2013). Some acute poisonings, which may previously have been coded to F codes (mental and behavioural disorders), will now be coded to external causes. If the coroner cannot establish the deceased's intent, these deaths will be coded to Y10-Y19 – poisoning of undetermined intent. As ONS includes 'undetermined' deaths in its standard suicide definition, the selection rule change could potentially increase the number of deaths in ONS suicide statistics. ONS analysis of the bridge coded data suggests a 2% increase in the number of deaths coded as an event of undetermined intent. However, the data should be treated with caution due to the bridge coded sample not being strictly comparable between both versions of the ICD for external causes.

Secondary causes

ONS have not released any information on how secondary causes of death (S and T codes) may have been affected by coding changes.

Neonatal deaths and stillbirths

Neonatal deaths (under 28 days) and stillbirths are not certified using the same death certificate which is used for deaths over 28 days. ONS have therefore reported separately on the impact of the coding change on these deaths:

http://www.ons.gov.uk/ons/rel/child-health/results-of-the-icd-10-v2010-bridge-coding-study-forstillbirths-and-neonatal-deaths--england-and-wales/2009/index.html

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Office for National Statistics. *Deaths Related to Drug Poisoning in England and Wales, 2011*. Statistical Bulletin, 29 August 2012: <u>http://www.ons.gov.uk/ons/rel/subnational-health3/deaths-related-to-drug-poisoning/2011/stb-deaths-related-to-drug-poisoning-2011.html</u>

Office for National Statistics. *Suicides in the United Kingdom, 2011*. Statistical Bulletin, 22 January 2013:

http://www.ons.gov.uk/ons/rel/subnational-health4/suicides-in-the-united-kingdom/2011/stb-suicide-bulletin.html

Table 1 - Example: adjusting deaths using sex and age-specific comparability ratios

| Male comparability ratios (CR) for Age cardiovascular group diseases | | Male cardiovascular disease deaths 2009-10 | Adjusted deaths 2009-10: deaths*CR | Male cardiovascular disease deaths 2011 | Male cardiovascular disease deaths 2009-11: adjusted deaths 2009-10 + unadjusted deaths 2011 | |
|-------------------------------------------------------------------------------|--------|-----------------------------------------------------|------------------------------------------|--------------------------------------------------|----------------------------------------------------------------------------------------------------------|---------|
| <0 | CR <65 | 0.98 | 0 | 0.00 | 0 | 0.00 |
| 1-4 | CR <65 | 0.98 | 1 | 0.98 | 0 | 0.98 |
| 5-9 | CR <65 | 0.98 | 0 | 0.00 | 0 | 0.00 |
| 10-14 | CR <65 | 0.98 | 1 | 0.98 | 0 | 0.98 |
| 15-19 | CR <65 | 0.98 | 0 | 0.00 | 1 | 1.00 |
| 20-24 | CR <65 | 0.98 | 2 | 1.97 | 1 | 2.97 |
| 25-29 | CR <65 | 0.98 | 3 | 2.95 | 2 | 4.95 |
| 30-34 | CR <65 | 0.98 | 4 | 3.94 | 2 | 5.94 |
| 35-39 | CR <65 | 0.98 | 7 | 6.89 | 3 | 9.89 |
| 40-44 | CR <65 | 0.98 | 12 | 11.81 | 5 | 16.81 |
| 45-49 | CR <65 | 0.98 | 18 | 17.72 | 7 | 24.72 |
| 50-54 | CR <65 | 0.98 | 26 | 25.60 | 12 | 37.60 |
| 55-59 | CR <65 | 0.98 | 74 | 72.85 | 30 | 102.85 |
| 60-64 | CR <65 | 0.98 | 140 | 137.83 | 65 | 202.83 |
| 65-69 | CR 65+ | 0.94 | 220 | 207.46 | 103 | 310.46 |
| 70-74 | CR 65+ | 0.94 | 330 | 311.19 | 150 | 461.19 |
| 75-79 | CR 65+ | 0.94 | 576 | 543.17 | 254 | 797.17 |
| 80-84 | CR 65+ | 0.94 | 805 | 759.12 | 403 | 1162.12 |
| 85+ | CR 65+ | 0.94 | 999 | 942.07 | 498 | 1440.07 |