Editorial: Counting the dead properly and promptly

Divergence in death registration between Scotland and the rest of the UK dates from the 1953 Births and Deaths Registration Act. Scotland’s statistical system, as also in the majority (23 of 29) of 30 non-UK European countries surveyed for the Royal Statistical Society (RSS), properly and promptly counts the dead; see http://www.rss.org.uk/site/cms/newsarticle.asp?chapter=15&nid=79.

Without exception, all deaths in Scotland must be registered within 8 days of death having been ascertained so that, for all practical purposes, the death year and registration year are the same. Scotland’s statistical system knows (as it should) for how many deceased persons—by age, gender and region—registration of the cause of death is outstanding and can prompt for the missing information.

In England and Wales, registration of the fact of death has not yet been uncoupled from registration of the cause of death. Until the cause of death has been determined for coroner-referred deaths, or criminal charges are made, fact of death remains unregistered by the statistical system; see Horton (2013) and Oomman et al. (2013).

Consequently, when record linkage or cohort studies seek to establish subjects’ survival status in England and Wales, the information that is received by researchers relates to registered deaths only; not to all deaths that have occurred in a period. Researchers using data on deaths for England and Wales should be fully aware of the limitation of the registration process but readers of their peer-review articles need to be alerted also.

There are around 10,000 deaths per annum in England and Wales for whom the delay in registering the fact of death is at least 6 months. Late registration bedevils premature deaths in particular: a high proportion is subject to inquest (e.g. because accidental, drugs related or suicide) with one in five of all deaths of people aged 5–44 years not registered for at least 6 months (i.e. around 4000 deaths per annum). Until recently, registration delays in England and Wales were underscrutinized: they have lengthened during the 21st century (Office for National Statistics, 2012), and demography also matters. For some major causes of death, notably suicide or drugs related, only half the deaths thus registered in 2011 in England and Wales would have occurred in 2011; the other half in preceding years but were subject to long waiting times until the verdict of an inquest.

Top of the RSS's 10 arguments against late registration of deaths (Table 1) is statistical competence: unless the fact of death is promptly registered, the statistical system is unaware of the number and demography of the deceased for whom the cause of death is outstanding and can neither properly compute contemporary delay distributions nor moderate them, as Bird and Mercer (2008) achieved for military inquests; see also https://consult.justice.gov.uk/digital-communications/coroner-reforms. By nation, the Office for National Statistics (2012, 2013) has summarized registration delays for deaths that were registered in 2011 (say), rather than approximated the likely distribution of registration delays for deaths which occurred in 2011. The latter distributions would enable a harmonized, delay-adjusted estimate (with uncertainty) to be made for the number of suicides (say) which occurred across the UK in 2011.

The second of the RSS's arguments is impedance to the discovery potential from record
Table 1. The RSS’s 10 arguments against late registration of deaths

| i | Statistical competence |
| ii | Impeded discovery potential in record linkage studies |
| iii | Monitoring the lethality of epidemics |
| iv | Hindrance to good clinical practice |
| v | Hindrance to safety monitoring in randomized controlled trials |
| vi | Handicap to monitoring of, and action on, premature deaths |
| vii | Obscured calendar year trends in mortality |
| viii | Inaction on overlong (and lengthening) waiting times to death registration |
| ix | Disharmony across the UK |
| x | Risk of distress to the bereaved |

linkage studies; see also Thomas and Walport (2008), Walport and Brest (2011) and Administrative Data Taskforce (2012). Typically, record linkage studies concern a large ‘virtual cohort’ of many thousands of individuals, whose dated event histories (criminal convictions, infectious disease diagnoses, incarcerations, drug treatment episodes and hospitalizations) have been coalesced into a longitudinal record by probabilistic matching of identifiers which are often non-nominal; see Bird and Hutchinson (2003), McDonald et al. (2009), Cornish et al. (2010), Merrall et al. (2013) and Administrative Data Taskforce (2012). However, in England and Wales, this linkage effort is undermined by the untimeliness of death registrations.

An important consequence of untimeliness is to delay research. For example, to be confident in knowing about actual deaths before April 1st, 2009, for treated opiate users in England who featured in the 2005–2009 drug data warehouse, Pierce et al. (2013) had to delay their check against the deaths register by two and a half years, until October 2011.

The Health and Social Care Information Centre and the Office for National Statistics have now developed an explanatory text which makes clear that requests by research teams for checks against the register of deaths in England and Wales—on whether any members of their study cohort have died by a specified date—can only yield information on deaths that have both occurred by the specified date and been registered by the check date.

Difficulty in monitoring lethality, such as during the 2009–2010 H1N1 pandemic, spurred Sir Liam Donaldson to establish the Chief Medical Officer’s H1N1 Statistical Legacy Group (see https://www.gov.uk/government/publications/pandemic-influenza-preparedness-programme-statistical-legacy-group-a-report-for-the-chief-medical-officer) and constitutes the RSS’s third argument for the registration of fact of death in England and Wales to be uncoupled from (later) registration of cause of death. At least knowing who has died allows further public health inquiries to be made about the likely cause: pandemic influenza or not.

A separate issue is that calendar year trends in cause-specific mortality can be obscured when deaths are tabulated by the Office for National Statistics by registration year. Examples include the 30% decrease in cocaine-related deaths in England and Wales (Bird and Mercer, 2011) in 2009, which was commensurate with uptake of then-legal mephedrone; or the spike in suicides in 2008, following the onset of the financial crisis (Barr et al., 2012; Office for National Statistics, 2013).

Patrick Mercer’s statistically informed parliamentary questions prompted the Office for National Statistics’s recent more comprehensive reporting on the lengthening of registration delays. And the National Statistician has now taken action to ensure full awareness by both the producers and the consumers of official statistics that, in England and Wales, death year and registration year differ importantly, not trivially.
In April 2013, Mercer and Bird (on behalf of the RSS) met Earl Howe (Parliamentary Under-Secretary of State at the Department of Health). Earl Howe generously acknowledged the widespread medical, scientific, policy and statistical support for the RSS’s call for legislation, and the wealth of evidence which now backed it. He asked that the assembled senior officials, from all relevant departments of state, should jointly draw up a plan of action to be presented to him within 6 weeks. What a wonderful celebration of 2013, the International Year of Statistics, it would be if a legislative solution to the late registration of deaths in England and Wales could be set in train in 2013! Prudently, Earl Howe gave no hostages to fortune, but we left in optimistic mood nonetheless.

References

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