

## **Response to Department of Health consultation on reforms to Death Certification in England and Wales**

### **Please choose the capacity in which you are responding**

- Other

Learned Society and Professional Body

### **If you are responding for an organisation please say which one**

The Royal Statistical Society

### **Q 22 Do you have any other comments about the regulations?**

The Royal Statistical Society would like to highlight the issue of delayed registration of deaths, reasons for delays, and changes that could be made to improve this situation. Our briefing below from pp. 4-7 sets out ten reasons to make improvements to this, in greater detail.

At the meeting of its Council on 30 January 2013, the Royal Statistical Society re-affirmed its concern (as set out in its statement of 25 January 2012) that delayed registration of deaths in England and Wales poses a risk to public health by potentially undermining the evidence-base for epidemic monitoring, record-linkage research and policy development.

Late registration of deaths in England and Wales occurs because registration of the fact of death is coupled with the registration of cause of death. In England and Wales, if a death is referred to the coroner and subject to an inquest, no registration of the fact of death need be made until the coroner's verdict is given. This may be months or even years later.

The Royal Statistical Society (RSS) therefore calls for the registration of deaths to be uncoupled from the registration of cause of death in England and Wales – as in Scotland and in a majority of 30 non-UK European countries surveyed on the RSS's behalf. Uncoupling requires legislation.

While cause of death information can be legitimately delayed (by awaiting an inquest-verdict), the Society believes that, without any exception, registration of the fact of death should occur promptly.



The Society highlights that:

- There is a delay of at least six months in the registration of 10,000 deaths per annum in England and Wales. Registration-delay of at least six months affects one in five of all deaths at 5-44 years of age<sup>1</sup>.
- England and Wales are out of line with other European countries. A survey conducted by the Society showed that prompt registration of fact of death occurred in the majority (23/29) of non-UK European countries whose national statistician responded (29/30).

In support of its position the Society has published a document setting out ten arguments against late registration: 1) statistical competence, 2) impeded discovery-potential in record-linkage studies, 3) monitoring the lethality of epidemics, 4) hindrance to good clinical practice, 5) hindrance to safety monitoring in randomized controlled trials, 6) handicap to the monitoring of, and action on, premature mortality, 7) obscuring of calendar-year trends in mortality, 8) inaction on overlong waiting-times for registration of cause of death, 9) disharmony of death-registration across UK, and 10) risk of distress to the bereaved.<sup>2</sup>

The Society hopes that the necessary legislation in England and in Wales to uncouple the registration of the fact of death from the registration of cause of death can be laid in 2013, which is the International Year of Statistics.

Until the necessary legislation is enacted, the Society has identified two actions to be taken without delay.

The first will ensure full awareness by both the producers and consumers of official statistics that, in England and Wales, death-year and death-registration-year differ importantly, not trivially.

The second will ensure that research teams who seek to verify the survival-status of patients or study-participants clearly understand that they are informed not about deaths which have occurred (which is generally what they want to know) but about deaths which have occurred and been registered as having occurred. The two differ importantly because the registration-delay is at least six months for around 10,000 deaths per annum in England and Wales, 4,000 of them at ages 5-44 years.

The two urgent actions that the Royal Statistical Society commends are:

- the National Statistician, and heads of statistical profession in government departments, should ensure that all official statistical tables on deaths in England and Wales make crystal clear whether tabulation is by death-year or by death-registration-year and give an explanation that these differ, and the extent to which they do; and
- the Office for National Statistics and the Health and Social Care Information Centre should develop a brief explanatory text which makes clear that requests by research teams for checks against the register of deaths in England and Wales on whether any

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<sup>1</sup> Parliamentary questions by Patrick Mercer OBE MP revealed that one in five deaths of 5-44 year olds in England and Wales is not registered for at least six months. Late-registration bedevils premature deaths, in particular.

<sup>2</sup> See appendix below, pp. 3-7



members of their study-cohort have died by a specified date can only yield information on deaths that have both occurred and been registered by the date of interest. (It should be noted that researchers are required to pay for these checks and that they may currently be unaware that the data they purchase may not be what they were expecting. Typically, researchers expect to be informed about all deaths that have occurred by the date of interest.)

Age-group at death	<i>Registration-delay (%) for deaths which occurred in 2005+2006+2007+2008 in England &amp; Wales and were ONS-registered by the end of 2011</i>			Number of registered deaths by age-group
	<i>91 days or more</i>	<i>183 days or more</i>	<i>366 days or more</i>	
0 - 4 years	2 715 (17%)	1 496 (10%)	497 (3.2%)	15 702
5 – 14 years	869 (30%)	527 (18%)	176 (6.1%)	2 865
15 – 44 years	27 806 (39%)	15 531 (22%)	4 277 (6.0%)	70 721
45 – 59 years	15 810 (10%)	7 588 ( 5%)	1 939 (1.2%)	157 493
60 - 69 years	10 353 ( 4%)	4 829 ( 2%)	1 205 (0.5%)	244 440
70 + years	26 746 ( 2%)	12 467 ( 1%)	3 072 (0.2%)	1 542 900
<b>All ages</b>	<b>84 297 ( 4%)</b>	<b>42 438 ( 2%)</b>	<b>11 166 (0.5%)</b>	<b>2 034 121</b>



## Appendix:

### Ten arguments against late registration of deaths in England and Wales

Produced by The Royal Statistical Society, February 2013

#### 1) *Statistical competence*

Timely registration of births and deaths is a basic function that any well-developed national statistical system should have in place as a matter of competence.

See Royal Statistical Society's policy statements at

<http://www.rss.org.uk/site/cms/newsarticle.asp?chapter=15&nid=33>

<http://www.rss.org.uk/site/cms/newsarticle.asp?chapter=15&nid=79>

#### 2) *Discovery-potential impeded*

Late-registration of deaths seriously impedes the discovery-potential from record-linkage studies in England and Wales.

A basic requirement in health and other record-linkage studies is to establish the survival-status of each individual whose records are analysed.

In Scotland, a check against the deaths-register at the end of January 2013, for example, will correctly identify all deaths that had occurred in Scotland by 31 December 2012. For the corresponding check in England and Wales to achieve an almost-similar level of assurance, researchers have to wait until January 2015.

In England and Wales, record-linkage studies must either be held back by two years or analysts must accept –and explain to the public, editors and research-commissioners - that they have under-counted deaths that occurred up to 31 December 2012 *because not all such deaths would have been registered by the end of January 2015, let alone by the end of January 2013.*

#### 3) *Monitoring lethality in epidemics*

In novel epidemics, Chief Medical Officers in England and Wales (unlike in Scotland) cannot rely on the registration system to tell them quickly how many extra deaths the new disease may have given rise to, nor the demography of those who have died, because not even the fact of death will have been registered if, as is likely for a novel disease, deaths have been referred to coroners.

See Chief Medical Officer's Statistical Legacy Group report:

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_122754.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122754.pdf)

#### 4) *Negative effect on good clinical practice*

In randomized controlled trials (RCTs), or in cohort studies from which patients have been lost to follow-up, the research team may need to verify the survival-status of all originally-consented



patients. However, the deaths-register in England and Wales – which should be the ultimate-check – cannot be relied upon as being authoritative because of delays in the registration of coroner-referred deaths.

### 5) **Adverse effect on safety monitoring**

If a randomized controlled trial (RCT) has a safety concern, and needs urgently to verify the survival status of all patients who were randomized, the deaths-register in England and Wales cannot be relied upon. Hence, Data Safety and Monitoring Committees cannot properly discharge their responsibilities to patients as the public rightly expects. Safety monitoring in mental health trials is particularly undermined.

### 6) **Monitoring of premature mortality**

Each year, there are around 500,000 deaths in England and Wales. For some 10,000 of these deaths (2%), the waiting-time from date of death to death-registration exceeds six months.

However, for specific causes of premature death, such as drugs-related deaths, the waiting time from date of death to death-registration exceeds six months for half the deaths.

See Deaths Related to Drug Poisoning in England and Wales, 2011 at [http://www.ons.gov.uk/ons/dcp171778\\_276681.pdf](http://www.ons.gov.uk/ons/dcp171778_276681.pdf)

In August 2012, for the first time, ONS documented that the median waiting-time to registration of drugs-related deaths in England and Wales had doubled over the past decade. ONS made explicit that half the drug-related deaths registered in 2011 had occurred in years prior to 2011.

On 6 November 2012, ONS published brief similar analyses for each of the major groupings of ICD10 codes that ONS regularly uses when reporting mortality statistics by registration-year. However, age at death matters (see table) and was not taken into account.

Parliamentary questions by Patrick Mercer OBE MP revealed that one in five deaths of 5-44 year olds in England and Wales is not registered for at least six months. Late-registration bedevils premature deaths, in particular.

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## **7) Calendar-year trends obscured**

Calendar-year trends in mortality matter for the public health. Registration delays may themselves alter with time (as they have done for drugs-related deaths, see above). Thus, monitoring cause-specific mortality by registration-year, rather than by calendar-year, distorts the underlying epidemiology.

An example of this obfuscation was when the mephedrone epidemic took off, and there was an associated 30% decrease in 2009 both in cocaine-use and in cocaine-related deaths, an alignment that was obscured by the reporting of cocaine-related deaths on a registration-year basis.

See Straight Statistics article: <http://www.straightstatistics.org/article/mephedrone-and-cocaine-clues-army-testing>

## **8) Action on overlong waiting-times**

The Office for National Statistics (ONS), unlike the General Register Office for Scotland, cannot properly monitor the lengthening waiting-time for cause of death to be registered because ONS does not know about the missing deaths - until their cause of death is eventually determined which may be weeks, months, or years after the fact of death was ascertained.

By contrast, Patrick Mercer MP used an analysis of long waiting-times for military inquest-verdicts to persuade the previous government to make more resources available to coroners which, in turn, dramatically shortened with waiting-times-to-inquest-verdict for military families.

## **9) Harmonization across UK; and across Europe**

Within the UK, it is only in Scotland that registration-year and death-year are, in effect, the same.

In England, Wales and Northern Ireland, the proportion of deaths for which registration-year was also death-year varies by age-group and cause of death; and between the nations.

Good registration-practice in Scotland is undermined when Scotland's data are amalgamated on an UK-basis, as the largest country dominates and so confounds calendar-year trends for the UK as a whole.

See Lords EU Committee recommendations on harmonization of death-registrations in their report on EU Drugs Strategy <http://www.publications.parliament.uk/pa/ld201012/ldselect/ldcom/270/27002.htm> and Government's response to the recommendations on statistics at <http://www.parliament.uk/documents/lords-committees/eu-sub-com-f/EU%20DS/DrugsStrategyGovResp.pdf>



*Good registration-practice was the norm in 23/29 surveyed non-UK European countries whose national statistician responded (29/30). Their legislation, as does Scotland's, requires registration of all deaths within 8 -10 days of the death having been ascertained.*

#### **10) Distress to the bereaved**

When writing to patients who may have been lost to follow-up, or for other reasons, a research team will want to check, as a matter of good practice, that the patient has not died in the interim. However, late-registration of deaths in England and Wales risks that a deceased family-member is written to, for example with an invitation to take part in research on new treatments for the disease from which the person died. Timely registration of all deaths avoids this fiasco.

*Appendix ends*

*Consultation response submitted by RSS' Policy and Research Manager, 15 June 2016*

