ROYAL STATISTICAL SOCIETY
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Report for Royal Statistical Society and Deputy National Statistician: September 2019

Availability and accuracy of informal date-of-death from NHS Digital's Personal Demographic Service (PDS-DOD): especially when death-registration at Office for National Statistics (ONS-DOR) is delayed

Sheila M. Bird

Edinburgh University College of Medicine and Veterinary Medicine and MRC Biostatistics Unit at Cambridge University.

1. Background

The 1953 Births & Deaths Registration Act heralded the divergence of death-registration practices in Scotland (where fact-of-death must be registered within eight days of death having been ascertained) versus elsewhere in UK where deaths referred to a coroner need not be registered until inquest-verdict has determined cause of death or criminal proceedings have begun.

A 30-year practice, whereby the National Statistician (formerly known as Director of the Office for Population, Census and Surveys) was simultaneously the Registrar General for England and Wales, began with Arthur Roger Thatcher CB (1978-86)[1] but ended after the tenure of Dame Karen Dunnell (2005-2008). Almost immediately, a problem arose: during the H1N1 influenza pandemic in 2009, the UK's Scientific Advisory Group in Emergencies could not access timely information on the deaths of infants (0-4 years) and young children (5-14 years) in England and Wales because of the late registration of inquest deaths.

The Royal Statistical Society's evidence to the Inquiry in 2010 by the House of Commons Science and Technology Committee into Scientific Advice in Emergencies therefore highlighted the need for England and Wales to achieve the timely registration of all deaths, as in Scotland and most European countries[2]. In addition, Professor Sir Liam Donaldson, then Chief Medical Officer for England, set up an H1N1 Statistical Legacy Group to ensure that statistical lessons were learned, including the need for timely registration of all deaths[3].

The Royal Statistical Society lists 10 arguments supporting its call for legislation to end the late registration of deaths in England and Wales, not least of which is the delay to the discovery-potential from record-linkage studies in England and Wales[4]. But the Royal Statistical Society's call for legislation was twice rejected by David Cameron as Prime Minister respectively of Coalition and Conservative governments.

1.1 Proposed interim solution and analysis plan

An interim solution to assist record-linkage studies was that NHS Digital might release to research-teams the informal dates of death on its Personal Demographics Service (PDS-DOD) if the Office for National Statistics formal date of death (ONS-DOD) had not been registered. However, before doing so, NHS Digital would need to reassure its own head of statistics profession that the release would have approval from the National Statistician and be supported by the Royal Statistical Society.

Approval would be forthcoming if preliminary investigations of PDS-DOD versus ONS-DOD suggested that PDS-DOD was not only more prompt (in terms of reporting-date, PDS-DOR) but also reasonably accurate when compared to ONS-DOD.

An analysis plan, in respect of ONS-DODs in 2011-2015, was formulated by Bird to investigate: first, the availability of PDS-DOD (including by calendar-year, age-group, gender and International Classification of Disease, 10th edition (ICD10) chapter for cause of death); secondly, when both ONS-DOD and PDS-DOD were available, the difference in reporting dates (ONS-DOR minus PDS-DOR): for differences greater than 14 days in magnitude, prior expectation was strongly that the difference would be positive; thirdly, the accuracy of PDS-DOD (including whether influenced by calendar-year, age-group, gender or ICD10 chapter for cause of death).

1.2 Summary findings from earlier report in 2017 for Royal Statistical Society and National Statistician

There are around half a million deaths per annum in England and Wales. Informal date-of-death (PDS-DOD) was missing for a substantial proportion of deaths: 40% in 2011 reducing to 28% in 2015.

Informal and formal dates-of-death agreed exactly for 694 786 (75.7%) out of 918 214 deaths in 2011-2013 for which both were available; to within 7 days for 895 032 (97.5%); to within 28 days for 910 148 (99.1%).

In the event of mismatch by 1-7 days, PDS-DOD was typically **later** than ONS-DOD: of 200 246 such discrepancies in 2011-2013, DOD was **later** according to PDS in 185 303 (92.5%).

For 2011-2015, PDS-DOD was missing for only 22% of late-registered deaths (ONS-DOR more than 28 days after death-date) versus 36% otherwise. However, most gross discrepancies, whereby PDS-DOD was **later** than ONS-DOD by more than 28 days, also occurred in the subset of ONS-late-registered deaths.

Likewise, in the readily-identifiable subset of deaths for which ONS-DOR was more than 90 days later than PDS-DOR, there was no discrepancy in dates-of-death for only 63% of deaths; versus 72% otherwise. Discrepancies of more than 28 days between DODs arose for 7.3% of this subset of deaths versus 0.5% otherwise.

For 2011-2013, the proportion of deaths which lacked ONS-DOD was strongly age-related, being 9.2% at 0-14 years (1 237/ 13 413), dropping to 5.6% at 15-44 years (2 623/47 164), thereafter 2.6% at 45-64 years (4 892/189 694) with further significant reductions in each of the three oldest age-groups to be only 0.5% at 85+ years (2 817/573 518). By contrast, the proportion of deaths lacking PDS-DOD was low at 0-4 years (27.8%, 3 191/11 472) and lowest at 5-14 years (16.3%, 316/1 941).

The percentage of deaths which lacked PDS-DOD was lower, but not overwhelmingly so, in ICD10 chapter 20 [**External causes of morbidity and mortality:** eg 24% of 18 410 deaths in 2013] and chapter 17 [**Congenital malformations, deformations and chromosomal abnormalities**: eg 30% of 1 106 deaths in 2013] versus 36% otherwise in 2013.

1.3 Follow-up actions and other developments

Seven recommendations, see **BOX 1**, were made to shed further light on availability and accuracy. Actions were put in hand by the Office for National Statistics (ONS) and NHS Digital to address these recommendations; and to analyse regional heterogeneity in registration-delays. NHS Digital also delayed its planned release to research-teams of information on informal date-of-death (PDS-DOD and PDS-DOR).

***Office for National Statistics*:** After April 2018, ONS had additional legal powers in respect of record-linkages.

In June 2018, ONS analysed the **Impact of registration delays on mortality statistics: 2016,** see https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/impactofregistrationdelaysonmortalitystatistics2016. The ONS's June 2018 report included for the first time a section on delays in the reporting on infant deaths; and considered whether there were regional differences in registration-delays. For deaths registered in 2017, registration-delays of more than 1 year applied for 0.5% of deaths in England & Wales (roughly 2,600 to 2,700) with notably higher percentages in three regions, namely: 0.7% of deaths in the North West and East Midlands and 1% of deaths in London.

Royal Statistical Society: The Royal Statistical Society (RSS) had advised that research-teams should request ONS-DOR for all deaths for which ONS-DOD is available. This advice has since been endorsed by the UK Statistics Authority and the Clinical Research Practice Database, see https://www.statisticsauthority.gov.uk/correspondence-list/?keyword=Bird&theme=&date.

The RSS has continued to press for legislation to end the late registration of deaths in England and Wales (and Northern Ireland), highlighting the longest delays (see below); and encourages journalists to heed the distinction between registration-year and death-year.

***NHS Digital**:* Computational work was put in hand by NHS Digital to investigate if most discrepancies coded as 1-7 days were in fact 1-day (versus 2 days or 3 days or 4-7 days); and to update the 2017 report using an archive-able snapshot of data items in February 2019 from the Civil Registrations data held by NHS Digital, see Methods. Discrepancies of more than 731 days in dually-recorded dates of death were also scrutinized; and detail provided about the back-office tracing of NHS numbers (for matching of records, see **BOX 2**) by NHS Digital which might shed light on possible reasons for differential availability of dates of death for children under 15 years and, more generally, in respect of premature deaths.

Coroners' rules: The wording of the Coroners and Justice Act 2009 and the Coroners (Inquest) Rules 2013 reflect concern by the public and Parliament that inquest-cases had not, in the past, been completed by coroners in a timely fashion. Rule 8 requests that a "coroner must complete an inquest within six months of the date on which the coroner is made aware of the death, or as soon as reasonably practicable after that date". An adhoc inquiry in respect of deaths registered in England and Wales in 2017 elicited that for 1.6% of 533,252 deaths with calculable-delays, the registration-delay (ONS-DOR minus ONS-DOD) exceeded six months but not 1 year, see https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/009245registrationdelaybyareaofusualresidencepercentagedeathsregisteredinenglandandwales2017.

Reporting to the Chief Coroner: Since 2014, coroners in England and Wales have been required to inform the Chief Coroner if an inquest is ongoing more than one year after date-of-death. See https://www.judiciary.uk/wp-content/uploads/2017/11/chief-coroner-report-2017-web.pdf.
However, the RSS has pointed out that, due to late registration of deaths, the Chief Coroner has no means of checking whether coroners are compliant.

The Chief Coroner's Annual Report for 2016-2017[5] noted that there had been a marked decrease in cases outstanding: down from 2 473 as first reported in 2014 to 1 508 cases reported in 2017. Around 45% of all deaths are reported to coroners **but** the number of cases that require investigation and inquest is much lower, having been 40 504 in 2016. Deprivation of Liberty Safeguards (DoLSs),

including for persons with Alzheimer's Disease, accounted for over 11,300 inquests in 2016. Removing the DoLS cases, there remained 29,128 other inquests in 2016 so that cases outstanding represented around 5% of non-DoLS-inquests; or 4% of all inquests.

The RSS has proposed that ONS could inform the Chief Coroner about all deaths (or all inquest-deaths) with ONS-DOR at least one year later than ONS-DOD. The Chief Coroner's office could then back-check on whether the Chief Coroner was informed that the inquest had not reached its verdict by one year after date-of-death. Such back-checking remains outstanding: neither offered nor requested by the Chief Coroner.

***Suicides*:** More recently, in 2019, Channel 5 News - assisted by Bird - asked ONS for information on suicide deaths by death-year (2007 to 2016), gender, broad age-group and registration-delay, see https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/010218numberofsuicidesbysexbroadagegroupandregistrationdelayenglandandwalesdeathsoccurringbetween2007and2017. **BOX 3** summarizes these data for suicides in 2007-10, 2011-2013, 2014 and 2015, and confirms, inter alia, a marked reduction in registration-delays at 6-months and 1-year after death-date for suicides that occurred in 2014. Prior to 2014, the registration-delay distributions for suicides in 2007-2013 were broadly stable, albeit different by gender and age-group at suicide.

***Longest delays*:** England and Wales have nine to 10 times as many deaths per annum as Scotland. Bird's requests to Office for National Statistics and to National Records of Scotland about their 10 and five longest registration-delays for deaths in five recent registration-years (2013-2017) revealed that Scotland's five longest delays (out of 25 listed) were: 401 days (adult male, unspecified drowning and submersion), 590 days, 632 days (infant male), 746 and 948 days (very old female, atherosclerotic heart disease). By contrast, the shortest five of the 50 listed longest registration-delays in England and Wales were: 3055 days, 3218, 3347, 3366 and 3385 days, see https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/009058top10registrationdelaysinenglandandwales2013to2017). The five longest in England and Wales all exceeded 7000 days. This inquiry prompted the adoption of additional checks by ONS on its exceptionally long registration-delays, greater than 5-years (see below) or than 2-years. However, unlike National Records of Scotland, ONS is handicapped from making pre-emptive checks because fact-of-death is not mandated to be registered within eight days of death having been ascertained. For the subsequent, detailed investigation by National Records of Scotland into Scotland's longest registration delays for births as well as deaths, see https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-background-information/births-and-deaths-days-until-registration.

Follow-up inquiry about deaths registered in England and Wales in 2013-2017, see https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/009162numberandpercentageofdeathsthatwereregisteredmorethan1826daysafterthedeathoccurredasaproportionofalldeathsregisteredintheyears2013to2017, elicited the number (and percentage) of deaths for which calculable registration-delay had been 1826 days or more (5 years or more). The numbers were: 66 and 67 out of 1, 008,189 in 2013+2014, or 13.2 per 100,000 deaths; 45, 42 and 39 out of 1,587,953 in 2015-2017, or 7.9 per 100,000 deaths.

1.4 Current report

The current report shows the results of the NHS Digital computational work, as referred to above.

Briefly, **Section 2** outlines the data accessed and the analysis plan. **Section 3** sets out findings on the availability and accuracy of PDS-DOD, now updated to include 2016 deaths; and from analyses to

follow up on some of the earlier recommendations, see **BOX 1**. Some summaries in **Section 3** focus on deaths in 2011-2014 to minimize the impact that very late registration of deaths at ONS has on the inferences drawn. **Section 4** concludes with a brief discussion.

2. Methods

The Personal Demographics Service (PDS) is a national database of NHS patient details.

Deaths are medically certified, typically by general practitioners or in hospital. A person's record in PDS can be updated with a death notification from any care setting which has PDS-update-access to the Spine, a secure NHS information sharing system. There are no rules or guidance covering the timeliness of updating a patient's record in PDS following the patient's death.

Death-notifications from care settings are marked as "informal" on PDS, but PDS only accepts valid dates; and will accept neither future-dated deaths nor death-dates earlier than the corresponding birth-date.

'Date of registration' for PDS (PDS-DOR) is a system generated date that reflects when the update to a person's record was received in PDS. PDS-DOR is therefore not subject to data entry errors. PDS-DOR may legitimately be the same as PDS-DOD.

Death-registrations in accordance with Births and Deaths Registration Act are made at the local Register Office (RO), where a registrar enters the data electronically. Date of registration (ONS-DOR) is keyed-in by the registrar and hence is potentially liable to data entry error. Data-entry is subject to validation checks, but these are not necessarily programmed - as ONS does have occasion to query dates with the General Register Office (GRO).

The death-registration by GRO is passed to NHS Digital where it is used to update the PDS-record to reflect that a formal death-registration has been received. When a formal death registration has been added to a PDS record, no further informal death notifications will be added.

Matching of death-registrations to PDS-records uses a multi-step deterministic algorithm to identify the correct match. Any death-registrations which cannot be matched to a unique NHS number are submitted for manual tracing by NHS Digital's National Back Office. The traced NHS number is returned to ONS to update ONS's systems.

For dates of death in 2011 -2015, the earlier 2017 analysis investigated:

i) the availability of PDS-DOD (including by calendar-year, age-group, gender and ICD10 chapter for cause of death);
ii) when both ONS-DOD and PDS-DOD are available, difference in dates of death as a measure of the accuracy of PDS-DOD;
iii) when both ONS-DOD and PDS-DOD are available, the difference in registration dates (ONS-DOR minus PDS-DOR); and whether influenced by calendar-year, age-group, gender and ICD10 chapter for cause of death. Differences greater than 14 days in magnitude were strongly expected to be positive;
iv) the availability of PDS-DOD and difference in dates of death for two sub-groups:
    A. Deaths with "ONS-DOR minus ONS-DOD" greater than 28 days: to check if availability and accuracy of PDS-DOD were acceptable for deaths for which ONS-DOR was delayed by more than 4-weeks.

B. Deaths for which "ONS-DOR minus PDS-DOR" exceeded 90 days: to test if availability and accuracy were superior for the subset of deaths with long-delayed ONS-DOR, which record-linkage teams are particularly concerned about.

The current update replaces the earlier 2017 report by:

i) adding data on 2016 deaths and refreshing the 2011-2015 deaths-data (which may bring in additional very late registered deaths);
ii) more detailed analysis of differences between ONS-DOD and PDS-DOD;
iii) investigation of potential data entry errors such as transposition or date of registration as date of death as explanations for differences between ONS-DOD and PDS-DOD;
iv) more detailed breakdown by age for deaths found only in PDS or only in ONS.

Numbers in this report for 2011-2015 may differ from those reported earlier for at least two reasons. Firstly, the 'ONS deaths' data asset available to NHS Digital analysts has changed since the 2017 analysis, and this report has been produced using the new asset (Civil Registrations). Secondly, even for the earliest years considered, registrations and notifications will have been added, or errors corrected, in the interval between the two sets of analysis.

Updated versions of all tables from the 2017 report are presented here so that readers can make consistent comparisons. Analysis by ICD10 chapter of records lacking PDS-DOD was discussed in the 2017 report but no table was included – these data are now provided.

The findings in **Section 3** highlight new analyses or findings from adding 2016 deaths to the tables.

The Civil Registrations data held by NHS Digital are updated weekly, but the available PDS data are updated more frequently. In order to use a consistent data-set throughout for the tables presented in this report, a snapshot of data items from each source in late February 2019 was created and retained.

The data items used to produce the tables in this report were:

Year of date of death – from ONS death registration record; otherwise from PDS informal death notification record when ONS-DOD is not available

PDS-DOR (date of earliest received informal notification about subject's date of death in PDS)

PDS-DOD (date of death as notified to PDS on earliest informal notification)

ONS-DOR (date of registration by GRO, on behalf of ONS, of subject's date of death)

ONS-DOD (date of death as registered by GRO on behalf of ONS, gold standard)

Gender of deceased – from ONS death registration record; otherwise from the PDS informal death notification record when ONS-DOD is absent

Age of deceased - from ONS death registration record and calculated from date of birth and date of death; otherwise from PDS informal death notification record when ONS-DOD is not available. Age is grouped as 0 days (to differentiate deaths on day of birth from other deaths under 5 years), the rest of 0-4 years, 5-14 years, 15-44 years, 45-64 years, 65-74 years, 75-84 years, 85+ years.

ICD10 chapter for underlying (main) cause of death – from ONS death registration record.

Between 2011 and 2016, 138 deaths were excluded from analysis due to missing or partially complete data items. Differences in death-date are calculated as ONS-DOD minus PDS-DOD i.e. a positive difference arises where ONS-DOD is later than PDS-DOD, and a negative difference arises where ONS-DOD is earlier than PDS-DOD. Similarly, differences in registration-date are calculated as ONS-DOR minus PDS-DOR.

The magnitude of the difference between ONS-DOD and PDS-DOD is categorised in **Table 1** as: ZERO, 1-7 days as single-day intervals, 8-28 days, 29-90 days, 91-365 days, 366-730 days, 731+ days. Differences of 1-7 days are grouped in subsequent tables.

3. Findings

3.1 Availability and accuracy of date of death according to PDS (ie PDS-DOD)

Table 1 shows both availability of PDS-DOD and the extent of differences between ONS-DOD and PDS-DOD for 2011-2016. As ONS-DOD is assumed to be correct, differences are treated as a measure of the accuracy of PDS-DOD.

Informal date of death (PDS-DOD) is missing for 28% to 40% of all deaths per year, the percentage decreasing from 40% in 2011 to 28% in 2015 and 29% in 2016 - but remaining substantial.

Secondly, there is apparently no ONS date of death (ONS-DOD) for around 1.35% of all 2011-2016 deaths (95% CI: 1.34% to 1.37%), which may be due to limitations on the matching of deaths between the two data-sources or to data-entry errors, see below. The missing-rates for ONS-DOD were highest at 1.5% in 2011 and 2016.

Third, in the case of 1 265 369 deaths for which both PDS and ONS dates-of-death (DOD) were available in 2011-2014, informal and formal DOD agreed exactly for 930 964 deaths (73.6%).

The additional analysis in **Table 1** of differences between 1 and 7 days in single day intervals shows that, for 2011-2014, informal and formal DOD were within 1 day of each other for 1 072 763 (84.8%) and within 2 days for 1 131 299 (89.4%). Summarily, for 2011-2014, the proportion of differences of 1-7 days that were 1 day only was 47.3% (141 799/299 707).

Among the 25 291 deaths in 2011-2014 for whom PDS-DOD was earlier than ONS-DOD, 16 134 (63.8%) were earlier by 1 day only. When PDS-DOD was later than ONS-DOD in 2011-2014, the proportion that had only 1 day of difference was much smaller (125 665 of 309 114, or 40.7%).

The proportion of non-zero differences that exceeded 90 days was substantially higher when PDS-DOD was earlier by d days than when PDS-DOD was later by d days, see **Table 1**, which could suggest different underlying reasons.

Table 1A reveals that when the delay in formal death-registration [ONS-DOR] is more than 28 days after ONS-DOD (**Subset not-A**), exact agreement between formal and informal death-dates drops to 67%. **Subset not-A** also accounts for most of the deaths for which PDS-DOD is later than ONS-DOD by more than 28 days.

Table 1B focuses on the readily-identifiable subset B of dually-recorded deaths for which ONS-DOR is more than 90 days after the PDS-DOR. There is zero difference in death-dates for only 66% of **Subset B** deaths. Despite being outnumbered 18:1 by subset not-B deaths, **Subset B** accounts for around half of the deaths for which PDS-DOD is later ONS-DOD by more than 90 days (1514/3070, 95% CI: 47.5% to 51.1%).

Subset B also accounts for nearly 70% (95% CI: 67.2% to 70.8%) of 2 496 deaths in 2011-16 for which PDS-DOD was earlier than ONS-DOD by 731 days or more.

3.2 Further analysis of discrepancies between ONS-DOD and PDS-DOD

Further analyses by NHS Digital explored the extent to which the largest discrepancies between ONS-DOD and PDS-DOD could potentially be explained by different types of data entry error.

First, for deaths in 2011-2014, there were 3 536 discrepancies where PDS-DOD was earlier than ONS-DOD by 91 days or more, including 1 564 where PDS-DOD was at least 2 years earlier. One possible explanation would be if death-year was incorrectly entered as an earlier year on a healthcare provider's systems and uploaded to PDS. Alternatively, the discrepancy could also be created by recording ONS-DOD as an incorrectly-late year at GRO, provided that the erroneous ONS-DOD remained prior to ONS-DOR.

Table 1C shows that for 1 221 of the 3 536 (34.5%) deaths in 2011-2014 wherein PDS-DOD was earlier than ONS-DOD by at least 91 days, ONS-DOD and PDS-DOD had the same day and month of death but different death-years, see **Subset C**.

Subset D was defined as deaths for which ONS-DOR was the same as ONS-DOD. While both dates may be correct, this pattern combined with a PDS-DOD earlier than ONS-DOD could reflect an erroneous entry of ONS-DOR as ONS-DOD.

Table 1C shows that **Subset D** includes only 73 (2.1%) of the 3 536 deaths in 2011-2014 with PDS-DOD earlier than ONS-DOD by at least 91 days but **Subset D** includes a substantially higher number and percentage, 812 (4.2%), of 19 376 deaths in 2011-2014 with PDS-DOD earlier than OND-DOD by just 1-7 days.

Second, for deaths in 2011-2014, there were 6 217 discrepancies whereby PDS-DOD was later than ONS-DOD by 29 days or more.

A data entry error in a healthcare provider's system could record the date of data-entry as death-date. For this to be seen in the PDS data, the entry would need to have reached PDS as an informal notification ***prior to*** the patient's record being updated with the formal notification from matched ONS data. Evidence of this as a potential data entry error is more difficult to assess, as PDS holds only the date of the effective change in PDS, not the local data-entry-date. **Subset E,** defined as deaths for which PDS-DOR was the same as PDS-DOD, may undercount records with the local data-entry error of interest and will, of course, also include many accurate records whereby a death is both recorded on local systems and updated in PDS on the day of death.

Table 1C shows that **Subset E** includes 945 (15.2%) of the 6 217 deaths in 2011-2014 in which PDS-DOD was later than ONS-DOD by 29 or more days versus 18.8% of 930 964 deaths in 2011-2014 with zero difference in death-dates.

Transposition errors in data entry at either healthcare providers or GRO could also result in discrepancies between ONS-DOD and PDS-DOD. NHS Digital analysed the number of deaths with a discrepancy between ONS-DOD and PDS-DOD where there would be no difference if day and month were swapped (e.g. 09/12/2013 changed to 12/09/2013); and also where there would be no difference if the day digits were transposed (e.g. 03/04/2013 changed to 30/04/2013).

Table 1C shows that the number of discrepancies that may be due to either type of transposition error to be small.

3.3 Difference in the dates of registration of death according to PDS (ie PDS-DOR) and their matched ONS-DOR

See **Table 2** for 2 015 199 matched-deaths between PDS and ONS in 2011-2016, for which the effective date of informal death notification in PDS (PDS-DOR) was within 28 days of ONS-DOR for the majority: 1 859 707(92.3%). For registration differences up to 28 days, ONS-DOR was the later in 2011 for 59.3% of 2011 deaths but the percentage rose each year thereafter, reaching 77.9% by 2016.

The majority of registration-differences of more than 28 days are on account of ONS-DOR being later than PDS-DOR: in 2011-14, only 129 (0.14%) of 93 775 registration-differences in excess of 28 days were because PDS-DOR was later than ONS-DOR whereas 2 771 (3.0%) were occasioned by ONS-DOR being more than 2 years later than PDS-DOR.

3.4 Absence of ONS-DOD or PDS-DOD by age-group; and by gender within age-group

Table 3 shows the number of deaths in 2011-2014 that lacked ONS-DOD or PDS-DOD by age group, with deaths at zero days of age separated from the rest of the under 5 years age-group.

The high proportion of deaths with age at death of zero days (i.e. date of death = date of birth) that appear in PDS only (21.1%) is likely to reflect various data entry errors in PDS, for example a healthcare provider inadvertently amending date of birth at the same time as adding a date of death.

The earlier report had noted that the proportion of deaths which lacked ONS-DOD was highest for children aged under 15 years at 9% than for 15-44 year olds at 5%. Now, setting aside the deaths at zero days, the proportions lacking ONS-DOD for 2011-14 are actually very similar: 5.2% for 0-14 years (668/12 752) and 5.3% for 15-44 years (3 280/62 435). The age-related pattern whereby the proportion of deaths lacking ONS-DOD falls within increasing age group above 45 years remains visible in the updated 2011-2014 data.

The pattern noted in the earlier 2017 report, of the lowest percentages lacking PDS-DOD being the 5-14 year olds (15.1%) followed by the 0-4 year age group (24.9%), remains true for the 2011-14 data after separating out the deaths at zero days.

Table 3A provides further important detail by gender and age-group. Whereas the percentage of deaths at zero days with missing ONS-DOD is significantly higher for females than for males, the reverse holds systematically for each of the age-groups from 45-64 years to 85+ years. There are no important differentials by gender in the percentage of deaths with missing ONS-DOD for the intermediate age-groups: under 5 years excluding zero days, 5-14 years and 15-44 years. The only striking disparity by gender is the higher percentage of male deaths with missing PDS-DOD at age 15-44 years.

3.5 Absence of PDS-DOD by ICD10 Chapter: ICD10 chapter is available via ONS-registered deaths

Summed for 2011-14, **Table 4** shows that the top seven ICD10 chapters in terms of underlying cause of death differed in their percentage of absent PDS-DOD as follows: **neoplasms** (chapter 2: PDS-DOD was missing for **35.4%** of 581 422 chapter 2 deaths, 95% CI: 35.3% to 35.5%); **diseases of the circulatory system** (chapter 9: PDS-DOD was missing for **38.6%** of 558 169 chapter 9 deaths, 95% CI: 38.5% to 38.7%); **diseases of the respiratory system** (chapter 10: PDS-DOD was missing for **37.1%** of 280 085 chapter 10 deaths, 95% CI: 36.9% to 37.2%); **mental and behavioural disorders** (chapter 5: PDS-DOD was missing for **39.3%** of 147 002 chapter 5 deaths, 95% CI: 39.1% to 39.6%); **diseases of the digestive system** (chapter 11: PDS-DOD was missing for **36.3%** of 97 781 chapter 11 deaths, 95% CI: 36.0% to 36.6%); **diseases of the nervous system** (chapter 6: PDS-DOD was missing for **36.2%** of

86 919 chapter 6 deaths, 95% CI: 35.9% to 36.5%); and, least often in the top set, for **external causes of morbidity and mortality** (chapter 20: PDS-DOD was missing for **25.1%** of 71 430 chapter 20 deaths, 95% CI: 24.8% to 25.4%).

4. Discussion

The data presented in **Tables 1-3** do not give grounds for optimism that PDS-DOD is sufficiently available (missing for 28% to 40% of deaths) or sufficiently accurate (74% exact agreement; 85% within 1 day) to compensate for the late registration of deaths in England and Wales. Worse, when the delay in formal death-registration (ONS-DOR) was more than 28 days after ONS-DOD, exact agreement between formal and informal death-dates dropped to 67%.

Likewise, when ONS-DOR was more than 90 days later than PDS-DOR (**Subset B**), exact agreement between formal and informal death-dates dropped to 66%. **Subset B**, although outnumbered 18:1 by other dually-recorded deaths, accounted for half (95% CI: 47.5% to 51.1%) of 3 070 deaths in 2011-16 for which PDS-DOD was later than ONS-DOD by more than 90 days. **Subset B** also accounted for nearly 70% (95% CI: 67.2% to 70.8%) of 2 496 deaths in 2011-16 for which PDS-DOD was earlier than ONS-DOD by two years or more.

A third (95%CI: 33.0% to 36.1%) of 3 536 deaths in 2011-14 with PDS-DOD earlier than ONS-DOD by at least 91 days were accounted for by ONS-DOD and PDS-DOD having the same day and month of death but *different death-years*.

For 2011-14, deaths for which *ONS-DOR and ONS-DOD were identical* accounted for 4% of 20 462 differences in death-dates when PDS-DOD was earlier by 1-28 days but for only 1% of 302 897 differences when ONS-DOD was earlier 1-28 days.

For registration differences up to 28 days, ONS-DOR was the later in 2011 for 59.3% of 2011 deaths but the percentage rose each year thereafter, reaching 77.9% by 2016. Most registration-differences of more than 28 days are, of course, on account of ONS-DOR being later than PDS-DOR.

The nature of the differences between ONS and PDS dates may be explained partly by the purpose and circumstances in which an informal PDS-DOD is created in advance of the ONS-DOR. NHS staff submit a known or estimated date of death with the administrative purpose of closing an episode of care and/or to ensure the cancellation of services to the deceased and prevent unwanted contact (such as appointment letters) reaching bereaved families. Estimation by NHS staff, in respect of day of death, can occur when a family-member informs the healthcare team about the patient's death.

Formal death registration creating a record at ONS takes place only when death occurs in England and Wales. Therefore, plausible reasons for there being no ONS-DOD for 1.3% of 2.02 million deaths in 2011-14 include patients being present in PDS who died in Scotland, Northern Ireland or outside the UK, as well as individuals being unidentified or wrongly identified after death, and failures in the tracing and matching processes.

Particularly striking in **Table 3** was the absence of ONS-DOD for 21% of 4 673 deaths at 0 days of age versus for 5.3% for 75 187 other premature deaths (ie under 45 years of age) in 2011-14. We conjectured that the high proportion of deaths with age at death of zero days (i.e. date of death = date of birth) appearing in PDS only may reflect various data entry errors in PDS, for example a healthcare provider inadvertently amending date of birth at the same time as adding a date of death. However, further investigation is warranted especially as the proportion was shown to be significantly higher for females (24%) than for males (19%). For the four older age-groups (45-64 years to 85+ years), the

percentage of deaths with missing ONS-DOD decreased steadily but was always significantly higher for males than for females in the same age-group.

Finally, we documented differences (35% to 39%) of little practical importance in the absence-rate for PDS-DOD among the six leading ICD10 chapters for cause of death (neoplasms, diseases of the circulatory, digestive and respiratory systems, mental and behavioural disorders, disease of the nervous system) but the seventh leading cause, external causes of morbidity and mortality, lacked PDS-DOD in only 25% of its deaths.

Recommendations for further analysis were made primarily to arrive at a better understanding of the possibility for mis-matching of cases and limitations on data-entry checks which gave rise to the phenomena in **Tables 1-3** than in expectation that the additional analyses would alter conclusions greatly.

Changes to data-entry or data-checking practice, or to back-office procedures, that these further analyses might give rise to include the following: additional back-checking when PDS-DOD and ONS-DOD have the same day and month of death but *different death-years*; data-entry confirmation required by registrar *when ONS-DOR and ONS-DOD are the same*; back-office investigation of *gender and age-relatedness* of 1.3% of all deaths and *gender-relatedness* of 21% of deaths at 0 days of age that lack ONS-DOD. *Location of death* (England, Scotland, Wales, Northern Ireland, outside of UK) is a possible explanation for absence of ONS-DOD but cannot be further investigated as location of death is not recorded when PDS-DOD is registered.

The Royal Statistical Society's case for legislation to address the late registration of deaths in England and Wales (and Northern Ireland) must now be heeded We have exhausted alternative solutions.

We have, however, learned a lot about the practicalities of death-registration – formal and informal – and the value-added, in terms of quality assurance, that systematic comparison of the two and querying of outliers afford.

September 2019.

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Table 1: Difference between informal (PDS) and formal (ONS) date of death, as revealed by counts of death-dates (DOD) which are tabulated by [ONS-PDS] difference.

YEAR	**2011**	**2012**	**2013**	**2014**	*Summed for 2011-14*	**2015**	**2016**	**Summed for 2011-16**
ZERO difference in death-dates (% both present)	217 945 (76.3%)	239 712 (77.6%)	237 384 (73.3%)	235 923 (68.0%)	*930 964 (73.6%)*	245 222 (65.1%)	309 706 (83.0%)	**1 485 892 (73.7%)**
PDS-DOD is later by d days: ie [ONS-DOD minus PDS-DOD] is negative								
1 day	25 852	26 721	32 235	40 857	*125 665*	49 325	27 170	**202 160**
2 days	11 189	11 274	14 766	19 780	*57 009*	24 111	9 435	**90 555**
3 days	7 472	7 431	9 963	13 612	*38 478*	16 173	6 194	**60 845**
4 days	4 599	4 536	6 230	8 268	*23 633*	10 313	3 554	**37 500**
5 days	3 243	3 077	4 153	5 683	*16 156*	6 886	2 326	**25 368**
6 days	2 181	2 229	3 086	4 113	*11 609*	4 644	1 608	**17 861**
7 days	1 458	1 567	2 058	2 698	*7 781*	3 042	1 144	**11 967**
1- 7 days	***55 994***	***56 835***	***72 491***	***95 011***	***280 331***	***114 494***	***51 431***	***446 256***
8- 28 days	4 078	4 369	5 867	8 252	*22 566*	9 128	3 388	**35 082**
29- 90 days	772	831	1 058	1 240	*3 901*	1 319	548	**5 768**
91-730 days	500	567	697	530	*2 294*	529	222	**3 045**
731+ days	6	7	5	4	*22*	3	0	**25**
PDS-DOD is earlier by d days: ie [ONS-DOD minus PDS-DOD] is positive								
1 day	4 116	4 203	4 090	3 725	*16 134*	3 807	5 220	**25 161**
2 days	412	373	391	351	*1 527*	333	447	**2 307**
3 days	181	186	190	142	*699*	122	203	**1 024**
4 days	87	72	90	78	*327*	86	104	**517**
5 days	62	70	65	52	*249*	61	82	**392**
6 days	47	54	50	37	*188*	34	54	**276**
7 days	68	53	71	60	*252*	78	104	**434**
1- 7 days	***4 973***	***5 011***	***4 947***	***4 445***	***19 376***	***4 521***	***6 214***	***30 111***
8- 28 days	309	241	258	278	*1 086*	221	304	**1 611**
29- 90 days	311	349	317	316	*1 293*	276	342	**1 911**
91-730 days	464	465	576	467	*1 972*	512	518	**3 002**
731+ days	294	405	445	420	*1 564*	477	455	**2 496**
No ONS-DOD (%)	**7 287 (1.5%)**	**6 205 (1.2%)**	**6 355 (1.2%)**	**6 713 (1.3%)**	***26 560 (1.3%)***	**7 241 (1.4%)**	**8 059 (1.5%)**	**41 860 (1.4%)**
No PDS-DOD (%)	198 567 (40.4%)	194 259 (38.1%)	181 557 (35.5%)	155 674 (30.6%)	*730 057 (36.1%)*	150 770 (28.2%)	156 697 (29.1%)	**1 037 524 (33.5%)**
Both present	285 646	308 792	324 045	346 886	*1 265 369*	376 702	373 128	**2 015 199**
TOTAL	**491 500**	**509 256**	**511 957**	**509 273**	***2 021 986***	**534 713**	**537 884**	**3 094 583**

Table 1A: Subset-A, formal date of death-registration [ONS-DOR] within 28 days after death-date [ONS-DOD]. Difference between informal (PDS) and formal (ONS) date of death, as revealed by counts of deaths when tabulated by difference [ONS-DOD minus PDS-DOD] in death-dates

YEAR:	**2011**	**2012**	**2013**	**2014**	*Summed for 2011-14:* *Subset A*	**2015**	**2016**	**Summed for 2011-16:** **Subset A**	**Summed for 2011-16: Subset Not-A**
ZERO difference in death-dates	202 906	223 455	220 613	219 321	*866 295 (74.2% of deaths with both DODs)*	226 772	283 497	**1 376 564** (74.3% of deaths with both DODs)	**109 328** (67.0% of deaths with both DODs)
PDS-DOD is later by d days: ie [ONS-DOD minus PDS-DOD] is negative									
1- 7 days	52 108	52 819	67 488	88 439	*260 854*	105 907	46 670	**413 431**	**32 825**
8- 28 days	3 060	3 281	4 477	6 569	*17 387*	7 092	2 551	**27 030**	**8 052**
29- 90 days	13	5	11	29	*58*	35	18	**111**	**5 657**
91-730 days	2	0	3	6	*11*	8	1	**20**	**3 025**
731+ days*	3	1	2	2	*8*	2	0	**10**	**15**
PDS-DOD is earlier by d days: ie [ONS-DOD minus PDS-DOD] is positive									
1- 7 days	4 441	4 483	4 354	3 996	*17 274*	3 981	5 441	**26 696**	**3 415**
8- 28 days	254	192	214	239	*899*	180	252	**1 331**	**280**
29- 90 days	272	306	283	288	*1 149*	242	301	**1 692**	**219**
91-730 days	427	420	507	413	*1 767*	466	462	**2 695**	**307**
731+ days	274	382	419	387	*1 462*	443	427	**2 332**	**164**
No PDS-DOD (%)	191 377 (42.0%)	187 164 (39.6%)	174 537 (36.9%)	148 724 (31.8%)	*701 802 (37.6%)*	143 284 (29.3%)	148 735 (30.5%)	**993 821 (34.9%)**	**43 703 (21.1%)**
TOTALS: both DODs present	263 760	285 344	298 371	319 689	*1 167 164*	345 128	339 620	**1 851 912**	**163 287**
TOTAL	455 137	472 508	472 908	468 413	*1 868 966*	488 412	488 355	**2 845 733**	**206 990**

Table 1B: Subset-B, formal date of death-registration [ONS-DOR] is more than 90 days after informal death-registration-date [PDS-DOR]. Difference between informal (PDS) and formal (ONS) date of death, as revealed by counts of deaths when tabulated by difference [ONS-DOD minus PDS-DOD] in death-dates

YEAR:	**2011**	**2012**	**2013**	**2014**	*Summed for 2011-14:* *Subset B*	**2015**	**2016**	**Summed for 2011-16:** **Subset B**	**Sum for 2011-16: Subset Not-B**
ZERO difference in death-dates	10 398	11 587	11 232	10 037	*43 254 (65.1% of deaths with both DODs)*	11 008	15 321	**69 583** (66.0% of deaths with both DODs)	**1 416 309** (74.2% of deaths with both DODs)
PDS-DOD is later by d days: ie [ONS-DOD minus PDS-DOD] is negative									
1- 7 days	2 835	2 944	3 450	4 047	*13 276*	5 249	2 813	**21 338**	**424 918**
8- 28 days	685	768	954	1 008	*3 415*	1 196	477	**5 088**	**29 994**
29- 90 days	395	472	533	511	*1 911*	579	236	**2 726**	**3 042**
91-730 days	249	332	367	252	*1 200*	194	108	**1 502**	**1 543**
731+ days	2	6	1	2	*11*	1	0	**12**	**13**
PDS-DOD is earlier by d days: ie [ONS-DOD minus PDS-DOD] is positive									
1- 7 days	387	379	393	301	*1 460*	309	452	**2 221**	**27 890**
8- 28 days	36	37	28	20	*121*	21	28	**170**	**1 441**
29- 90 days	26	30	26	18	*100*	20	23	**143**	**1 768**
91-730 days	149	142	172	165	*628*	171	174	**973**	**2 029**
731+ days	182	274	303	290	*1 049*	347	327	**1 723**	**773**
TOTALS: both DODs present	15 344	16 971	17 459	16 651	*66 425*	19 095	19 959	**105 479**	**1 909 720**

Table 1C: Count of deaths when tabulated by difference in death-dates (ONS-DOD minus PDS-DOD) and various potential data quality explanations for the observed [ONS-PDS] differences

YEAR	*Summed for 2011-14*	ONS-DOD had same day and month as PDS-DOD but different death-year (Subset C)	ONS-DOR is the same as ONS-DOD (Subset D)	PDS-DOR is the same as PDS-DOD (Subset E)	Zero days difference if day and month values swapped	Zero days difference if digits of death-day swapped
Row percentages shown are with respect to *Summed for 2011-14*						
ZERO difference in death-dates	*930 964*	0	24 079 (2.6%)	174 793 (18.8%)	0	0
PDS-DOD is later by d days: ie [ONS-DOD minus PDS-DOD] is negative						
1- 7 days	*280 331*	0	2 950 (1.1%)	73 766 (26.3%)	0	0
8- 28 days	*22 566*	0	81 (0.4%)	5 197 (23.0%)	2	287 (1.3%)
29- 90 days	*3 901*	0	0	611 (15.7%)	6	0
91-730 days	*2 294*	22 (1.0%)	1	329 (14.3%)	0	0
731+ days	*22*	1 (4.5%)	0	5	0	0
PDS-DOD is earlier by d days: ie [ONS-DOD minus PDS-DOD] is positive						
1- 7 days	*19 376*	0	812 (4.2%)	109 (0.6%)	0	0
8- 28 days	*1 086*	0	18 (1.7%)	42 (3.9%)	2	37 (3.4%)
29- 90 days	*1 293*	0	26	57 (4.4%)	15	0
91-730 days	*1 972*	869 (44.1%)	34	118 (6.0%)	0	0
731+ days	*1 564*	352 (22.5%)	39	117 (7.5%)	0	0
TOTAL non-ZERO differences	***334 405***	1 244	3 961	80 351	25	324
TOTAL Both DODs available	***1 265 369***	1 244	28 040	255 144	25	324

Table 2: Difference between informal (PDS-DOR) and formal (ONS-DOR) registration-dates, as revealed by counts of death-registrations when tabulated by difference in registration-dates [ONS-DOR minus PDS-DOR].

YEAR:	**2011**	**2012**	**2013**	**2014**	*Summed for 2011-14*	**2015**	**2016**	**Summed for 2011-16**
ZERO difference in registration-dates	53 856	52 020	52 139	52 963	*210 978*	50 008	42 452	**303 438**
PDS-DOR is later by d days: ie [ONS-DOR minus PDS-DOR] is negative								
1- 7 days	82 117	77 439	75 312	73 375	*308 243*	67 174	62 551	**437 968**
8- 28 days	3 710	3 508	3 639	5 286	*16 143*	3 353	3 582	**23 078**
29+ days	35	23	14	57	*129*	66	61	**256**
PDS-DOR is earlier by d days: ie [ONS-DOR minus PDS-DOR] is positive								
1- 7 days	116 440	141 962	154 660	172 075	*585 137*	198 926	198 146	**982 209**
8- 28 days	8 655	11 362	13 774	17 302	*51 093*	27 273	34 648	**113 014**
29- 90 days	5 489	5 507	7 048	9 177	*27 221*	10 807	11 729	**49 757**
91-730 days	14 627	16 218	16 781	16 028	*63 654*	18 443	19 394	**101 491**
731+ days	717	753	678	623	*2 771*	652	565	**3 988**
No ONS-DOD (%)	**7 287 (1.5%)**	**6 205 (1.2%)**	**6 355 (1.2%)**	**6 713 (1.3%)**	***26 560 (1.3%)***	**7 241 (1.4%)**	**8 059 (1.5%)**	**41 860 (1.4%)**
No PDS-DOD (%)	198 567 (40.4%)	194 259 38.1%)	181 557 (35.5%)	155 674 (30.6%)	*730 057 (36.1%)*	150 770 (28.2%)	156 697 (29.1%)	**1 037 524 (33.5%)**
Both present	285 646	308 792	324 045	346 886	*1 265 369*	376 702	373 128	**2 015 199**
TOTAL	491 500	509 256	511 957	509 273	*2 021 986*	534 713	537 884	**3 094 583**

Table 3: Number of deaths in 2011-2014 by age-group together with the number and percentage of deaths which lack i) ONS-DOD or ii) PDS-DOD

AGE-GROUP	**Number of deaths in 2011-14**	No ONS-DOD (as % deaths)	No PDS-DOD (as % deaths)
0 days	**4 673**	984 (21.1%)	1 369 (29.3%)
Under 5 years, excluding 0 days	**10 205**	390 (3.8%)	2 546 (24.9%)
05-14 years	**2 547**	278 (10.9%)	385 (15.1%)
15-44 years	**62 435**	3 280 (5.3%)	20 422 (32.7%)
45-64 years	**251 631**	6 505 (2.6%)	90 615 (36.0%)
65-74 years	**329 500**	5 777 (1.8%)	117 501 (35.7%)
75-84 years	**590 590**	5 817 (1.0%)	213 530 (36.2%)
85+ years	**770 405**	3 529 (0.5%)	283 689 (36.8%)

Table 3A: Number of deaths by calendar-year, sex and age-group together with the number and percentage of deaths which lack i) ONS-DOD or ii) PDS-DOD

Age-group & Sex	2011	2012	2013	2014	2015	2016	*Total for 2011-14*	*95% CIs*
0 days, Female								
# Deaths	548	546	504	521	426	472	*2 119*	
No ONS-DOD	114	136	118	132	40	27	*500 (23.6%)*	***21.8% to 25.4%***
No PDS-DOD	208	131	130	120	79	92	*589 (27.8%)*	*25.9% to 29.7%*
0 days, Male								
# Deaths	714	698	587	555	569	580	*2 554*	
No ONS-DOD	133	118	109	124	51	42	*484 (19.0%)*	***17.4% to 20.5%***
No PDS-DOD	253	221	174	132	116	123	*780 (30.5%)*	*28.8% to 32.3%*
Under 5 years, excluding 0 days, Female								
# Deaths	1 156	1 185	1 097	1 025	967	1 067	*4 463*	
No ONS-DOD	48	44	38	46	49	59	*176 (3.9%)*	***3.4% to 4.5%***
No PDS-DOD	342	293	274	204	180	215	*1 113 (24.9%)*	*23.7% to 26.2%*
Under 5 years, excluding 0 days, Male								
# Deaths	1 543	1 473	1 412	1 314	1 328	1 261	*5 742*	
No ONS-DOD	54	43	47	70	64	78	*214 (3.7%)*	***3.2% to 4.2%***
No PDS-DOD	449	410	305	269	276	252	*1 433 (25.0%)*	*23.8% to 26.1%*
05-14 years, Female								
# Deaths	261	304	292	262	269	254	*1 119*	
No ONS-DOD	32	35	33	31	27	30	*131 (11.7%)*	***9.8% to 13.6%***
No PDS-DOD	41	45	47	30	23	28	*163 (14.6%)*	*12.5% to 16.6%*
05-14 years, Male								
# Deaths	384	370	325	349	344	350	*1 428*	
No ONS-DOD	41	37	35	34	35	38	*147 (10.3%)*	***8.7% to 11.9%***
No PDS-DOD	72	51	55	44	50	48	*222 (15.5%)*	*13.7% to 17.4%*
15-44 years, Female								
# Deaths	5 740	5 586	5 545	5 568	5 516	5 854	*22 439*	
No ONS-DOD	331	317	287	259	297	366	*1 194 (5.3%)*	***5.0% to 5.6%***
No PDS-DOD	1 921	1 742	1 621	1 463	1 334	1 478	*6 747 (30.1%)*	*29.5% to 30.7%*
15-44 years, Male								
# Deaths	10 385	10 015	9 925	9 671	10 128	10 158	*39 996*	
No ONS-DOD	644	504	483	455	537	585	*2 086 (5.2%)*	***5.0% to 5.4%***
No PDS-DOD	3 897	3 534	3 253	2 991	2 907	3 008	*13 675 (34.2%)*	*33.7% to 34.7%*
45-64 years, Female								
# Deaths	25 851	25 629	24 913	24 946	25 421	26 496	*101 339*	
No ONS-DOD	598	552	498	578	594	662	*2 226 (2.2%)*	***2.11% to 2.29%***
No PDS-DOD	10 046	9 329	8 570	7 310	7 055	7 544	*35 255 (34.8%)*	*34.5% to 35.1%*
45-64 years, Male								
# Deaths	38 541	37 244	37 594	36 913	37 998	38 741	*150 292*	
No ONS-DOD	1 148	1 017	1 046	1 068	1 101	1 251	*4 279 (2.8%)*	***2.76% to 2.93%***
No PDS-DOD	15 618	14 350	13 597	11 795	11 355	11 761	*55 360 (36.8%)*	*36.6% to 37.1%*
65-74 years, Female								
# Deaths	32 919	34 139	34 551	34 800	36 250	37 591	*136 409*	
No ONS-DOD	534	479	506	507	622	643	*2 026 (1.5%)*	***1.42% to 1.55%***
No PDS-DOD	13 241	12 932	11 905	10 450	10 168	10 865	*48 528 (35.6%)*	*35.3% to 35.8%*
65-74 years, Male								
# Deaths	47 056	48 317	48 576	49 142	50 637	52 562	*193 091*	
No ONS-DOD	996	892	915	948	1 095	1 146	*3 751 (1.9%)*	***1.88% to 2.00%***
No PDS-DOD	18 919	18 306	16 952	14 796	14 188	15 125	*68 973 (35.7%)*	*35.5% to 35.9%*
75-84 years, Female								
# Deaths	69 976	71 685	71 021	69 904	72 441	71 118	*282 586*	
No ONS-DOD	668	547	552	666	707	788	*2 433 (0.9%)*	***0.83% to 0.90%***
No PDS-DOD	28 789	27 866	25 534	21 720	20 525	20 861	*103 909 (36.8%)*	*36.6% to 37.0%*
75-84 years, Male								
# Deaths	75 176	77 374	78 008	77 446	80 579	80 779	*308 004*	
No ONS-DOD	908	748	841	887	998	1 116	*3 384 (1.1%)*	***1.06% to 1.14%***
No PDS-DOD	30 005	29 104	27 244	23 268	22 416	23 113	*109 621(35.6%)*	*35.4% to 35.8%*
85 + years, Female								
# Deaths	116 110	124 226	125 038	123 133	132 601	130 165	*488 507*	
No ONS-DOD	575	394	440	488	558	676	*1 897 (0.4%)*	***0.37% to 0.41%***
No PDS-DOD	48 677	49 236	46 210	38 927	38 224	39 019	*183 050 (37.5%)*	*37.3% to 37.6%*
85 + years, Male								
# Deaths	65 140	70 465	72 569	73 724	79 239	80 436	*281 898*	
No ONS-DOD	463	342	407	420	466	552	*1 632 (0.6%)*	***0.55% to 0.61%***
No PDS-DOD	26 089	26 709	25 686	22 155	21 874	23 165	*100 639 (35.7%)*	*35.5% to 35.9%*

Table 4: Number of deaths by calendar year and ICD10 chapter of cause of death together with the number and percentage of deaths which lack PDS-DOD

ICD10	2011	2012	2013	2014	2015	2016	*Summed: 2011-14*
1. Certain Infectious and parasitic diseases							
# Deaths	5 391	5 133	5 287	5 198	5 761	5 772	*21 009*
No PDS-DOD	2 216	1 980	1 841	1 580	1 638	1 633	*7 617 (36.3%)*
2. Neoplasms							
# Deaths	143 499	145 834	145 137	146 952	147 488	150 181	***581 422***
No PDS-DOD	57 200	54 500	50 578	43 693	40 890	43 633	***205 971 (35.4%)***
3. Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism							
# Deaths	1 003	939	976	954	1 124	1 066	*3 872*
No PDS-DOD	403	376	344	287	306	298	*1 410 (36.4%)*
4. Endocrine, nutritional and metabolic diseases							
# Deaths	6 477	6 752	6 787	7 218	7 665	7 990	*27 234*
No PDS-DOD	2 570	2 612	2 419	2 145	2 142	2 219	*9 746 (35.8%)*
5. Mental and behavioural disorders							
# Deaths	31 172	36 081	38 128	41 621	48 161	48 769	***147 002***
No PDS-DOD	13 617	15 087	15 082	14 041	14 775	15 762	***57 827 (39.3%)***
6. Diseases of the nervous system							
# Deaths	18 567	21 302	22 445	24 605	28 310	30 673	*86 919*
No PDS-DOD	7 612	8 249	7 979	7 637	7 819	8 881	*31 477 (36.2%)*
7. Diseases of the eye and adnexa							
# Deaths	22	16	11	4	16	12	*53*
No PDS-DOD	10	9	5	1	6	3	*25 (47.1%)*
8. Diseases of the ear and mastoid process							
# Deaths	22	21	21	24	35	29	*88*
No PDS-DOD	7	5	8	5	8	6	*25 (28.4%)*
9. Diseases of the circulatory system							
# Deaths	139 625	142 259	140 012	136 273	138 106	135 045	***558 169***
No PDS-DOD	59 892	57 755	52 779	45 133	41 823	42 138	***215 559 (38.6%)***
10. Diseases of the respiratory system							
# Deaths	67 439	71 402	73 675	67 569	74 623	73 281	***280 085***
No PDS-DOD	28 246	27 807	26 906	20 839	21 402	21 294	***103 798 (37.1%)***
11. Diseases of the digestive system							
# Deaths	24 477	24 802	24 332	24 170	25 005	25 356	***97 781***
No PDS-DOD	10 029	9 533	8 518	7 457	7 064	7 461	***35 537 (36.3%)***
12. Diseases of the skin and subcutaneous tissue							
# Deaths	1 660	1 691	1 713	1 765	1 896	2 006	*6 829*
No PDS-DOD	631	588	610	482	505	548	*2 311 (33.8%)*
13. Diseases of the musculoskeletal system and connective tissue							
# Deaths	4 192	4 340	4 132	3 836	3 997	3 903	*16 500*
No PDS-DOD	1 626	1 503	1 330	1 048	1 044	1 076	*5 507 (33.4%)*
14. Diseases of the genitourinary system							
# Deaths	9 475	9 841	9 568	8 829	9 334	9 193	*37 713*
No PDS-DOD	3 885	3 874	3 500	2 714	2 632	2 642	*13 973 (37.1%)*
15. Pregnancy, childbirth and the puerperium							
# Deaths	62	36	40	36	33	38	*174*
No PDS-DOD	15	11	9	4	8	6	*39 (22.4%)*
16. Certain conditions originating in the perinatal period							
# Deaths	202	201	165	205	201	304	*773*
No PDS-DOD	68	58	42	44	54	78	*212 (27.4%)*
17. Congenital malformations, deformations and chromosomal abnormalities							
# Deaths	1 105	1 163	1 125	1 345	1 251	1 364	*4 738*
No PDS-DOD	374	359	337	357	308	357	*1 427 (30.1%)*
18. Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified							
# Deaths	10 156	10 789	10 993	11 102	11 774	12 013	*43 040*
No PDS-DOD	4 205	4 208	3 940	3 492	3 496	3 713	*15 845 (36.8%)*
20. External causes of morbidity and mortality							
# Deaths	16 762	17 703	18 523	18 442	20 140	20 336	***71 430***
No PDS-DOD	4 763	4 734	4 460	3 981	4 154	4 278	***17 938 (25.1%)***
22. Codes for special purposes							
# Deaths	724	635	604	608	691	715	*2 571*
No PDS-DOD	261	219	221	178	238	221	*879 (34.1%)*
No cause of death on ONS record							
# Deaths	2 181	2 111	1 928	1 804	1 861	1 779	*8 024*
No PDS-DOD	937	792	649	556	458	450	*2 934 (36.6%)*

BOX 1: Recommendations from 2017 Report

Recommendation 1: For a random 10% of death-records with no ONS-DOD but with PDS-DOD, institute checks, such as on the back-office-tracing of NHS number or by adopting probabilistic matching, to understand the underlying reasons for the apparent absence of ONS-DOD.

Recommendation 2: For a random 1% of matched death-records in 2011-2013, for which ONS-DOD and PDS-DOD differ by 1-7 days, institute checks to understand the reasons that 92.5% of the disparities are because PDS-DOD is **later** than ONS-DOD. Possibilities include: that the majority of discrepancies is by a single day; confusion at data-entry between PDS-DOR (later) and PDS-DOD; mis-matching of cases.

Recommendation 3: PDS–DOD may not be exempt from a confusion of registration and death dates as discrepancies by more than 29 days between the **later** PDS–DOD and earlier ONS-DOD may indicate. For a 10% random sample of over 4 000 dually-recorded DODs in 2011-13 which differ by 29+ days with PDS-DOD as the **later**, institute joint-scrutiny by ONS and NHS Digital.

Recommendation 4: For a 50% random sample of over 1 000 discrepancies by 731 days or more in dually-recorded DODs in 2011-2013 in which PDS-DOD was *earlier* than ONS-DOD [or 25% random sample of the over 2 000 corresponding discrepancies in 2011-2015], joint-scrutiny by ONS and NHS Digital may be worthwhile to understand if there was confusion at GRO between the late ONS-DOR and actual DOD; or if death-year was erroneous.

Recommendation 5: Additional tabulations, as per **Table 1**, by NHS Digital for two subsets of deaths as follows: A) late-ONS-registered deaths for which [ONS-DOR minus ONS-DOD] is more than 28 days; and B) deaths for which ONS-DOR minus PDS-DOR exceeds 90 days.

Recommendation 6: Additional inquiries by NHS Digital and ONS properly to understand the relative lack of ONS-DOD for premature deaths (ie aged 0-44 years), which applies even for deaths in 2011-2013; and for the relatively better availability of PDS-DOD for the age-group 5-14 years than at other ages.

Recommendation 7: Additional subgroup analyses, as in **Recommendation 5**, could additionally take account of ICD10 chapter.

BOX 2: Back-office tracing of NHS numbers by NHS Digital and suggestions for future consideration

The Office for National Statistics confirmed that any migrant who dies in England or Wales and has his/her death registered here will have a record created/entered into PDS even if not previously registered with a general practitioner or PDS was lacking for another reason. In this scenario, no PDS-DOD could be present prior to ONS-DOR. ***Such scenarios should perhaps be explicitly flagged by NHS Digital so that their frequency can be computed****.*

Alternatively, PDS-DOD may be missing if it was apparently erroneous and was subsequently removed through 'logical deletion'.

The reverse scenario, where ONS-DOD is lacking, should also be flagged if it arises because the death occurred abroad but PDS was notified.

NHS Digital provided detailed information on its trace overview which operates in different modes: exact matching, rule-based, probabilistic matching, name-based or alphanumeric (such as Soundex). For example, rule-based might include matching on the first three (or two) letters of family-name. Such rules are ill-suited to Scottish names such as MacDonald, McDonald which Soundex copes well with. Gender code in NHS Digital's trace programs accounts for transitioning from birth-assigned gender. Trace routines also identify potential duplicates and make allowance for babies being identified as "Twin 1" or "Baby Macdonald". ***Further refinements of the trace routines at NHS Digital have been proposed, such as geographic-distance matching, wildcards on postcode and use of mobile phone numbers in match-programs.***

By 2019, NHS Digital had hoped to complete migration of its Medical Research Information Service to a new system. The new system, when operational, should enable research-teams to request PDS-DOD and PDS-DOR in addition to ONS-DOD and ONS-DOR. Users would, of course, be advised of the data quality constraints in respect of PDS-DOD. The new system was not operational by August 2019.

BOX 3: Suicides by sex, broad age-group (10-44 years; 45+ years), registration-delay (under 6 months, greater than 1-year) and death-year (2007-2010, 2011-2013, 2014 and 2015) for England and Wales.

Registration-delays are longer for younger suicides and, within age-group prior to 2014, for females.

Death-year	Total registered	Registered within 6 months after death-date (%); **95% CI**	Registered within 1 year after death-date (%); **95% CI**	Delay of > 2 years (%)	Comment
Male suicides in England & Wales: aged 10-44 years					
2007-2010	7285	4195 (57.6%); **56.4% to 58.7%**	6376 (87.5%); **86.8% to 88.3%**	239 (3.3%)	Stable registration-delay distribution
2011-2013	5483	3130 (57.1%); **55.8% to 58.4%**	4801 (87.6%); **86.6% to 88.5%**	125 (2.8%)	
2014	**1704**	1140 (66.9%); **64.7% to 69.1%**	1569 (92.1%); **90.8% to 93.4%**	25 (1.4%)	**6m & 1st-year improvements**
2015	*1770*	*1194 (67.5%);*	*1642 (92.8%);*		*Total may yet increase*
Male suicides in England & Wales: aged 45 years or older					
2007-2010	6813	4423 (64.9%); **63.8% to 66.1%**	6231 (91.5%); **90.8% to 92.1%**	122 (1.8%)	Stable registration-delay distribution
2011-2013	6140	3866 (63.0%); **61.8% to 64.2%**	5626 (91.6%); **90.9% to 92.3%**	87 (1.4%)	
2014	**1980**	1405 (71.0%); **69.0% to 73.0%**	1860 (93.9%); **92.9% to 95.0%**	13 (0.7%)	**6m & 1st-year improvements**
2015	*2016*	*1494 (74.1%);*	*1916 (95.0%);*		*Total may yet increase*
Female suicides in England & Wales: aged 10-44 years					
2007-2010	1938	1014 (52.3%); **50.1% to 54.4%**	1641 (84.7%); **83.1% to 86.3%**	78 (4.0%)	Stable registration-delay distribution
2011-2013	1402	700 (49.9%); **47.3% to 52.5%**	1183 (84.4%); **82.5% to 86.3%**	51 (3.6%)	
2014	**471**	291 (61.8%); **57.4% to 66.2%**	423 (89.8%); **87.1% to 92.5%**	4 (0.8%)	**6m & 1st-year improvements**
2015	*490*	*294 (60.0%);*	*441 (90.0%);*		*Total may yet increase*
Female suicides in England & Wales: aged 45 years or older					
2007-2010	2594	1559 (60.1%); **58.2% to 62.0%**	2331 (89.9%); **88.7% to 91.0%**	49 (1.9%)	Stable registration-delay distribution
2011-2013	2001	1149 (57.4%); **55.3% to 59.6%**	1788 (89.4%); **88.0% to 90.7%**	29 (1.4%)	
2014	**700**	472 (67.4%); **64.0% to 70.9%**	654 (93.4%); **91.6% to 95.3%**	4 (0.6%)	**6m & 1st-year improvements**
2015	*733*	*502 (68.5%);*	*695 (94.5%);*		*Total may yet increase*