Article

Quality of mortality data during the coronavirus pandemic, England and Wales: 2020

Description of changes to death certification and registration under the Coronavirus Act 2020 and the impact they have had on the quality of death registration data.

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1. Main points

- The time taken for deaths to be registered (registration delay) in 2020 decreased compared with the previous year during the first wave of the coronavirus (COVID-19) pandemic; this was because of a combination of factors including a more efficient 'virtual' death registration processes and a reduction in coroner-certified deaths which typically take longer to register.

- The proportion of deaths certified by a doctor increased and the proportion certified by a coroner decreased during the first wave of the coronavirus pandemic.

- Longer delays in coroner-certified deaths are expected, as during the height of the pandemic, the majority of coroner’s inquests were halted; this will especially affect deaths due to suicide and violence.

- The mean number of health conditions mentioned on death certificates involving COVID-19 is greater than on non-COVID-19 deaths, suggesting that certifiers showed care to include all relevant information and conditions.

- Non-COVID-19 deaths saw a small decline in certification quality with an increase in ill-defined causes as the underlying cause of death; this is consistent with our previous finding of increased deaths due to old age and frailty, with more elderly people dying in care homes instead of in hospital.

- Around three-quarters of deaths involving COVID-19 linked to a record of a positive test result (79.2% in England, Public Health England data, 70.4% in Wales, Public Health Wales data).

2. Overview of changes to mortality data

During the first wave of the coronavirus (COVID-19) pandemic period (March to September 2020), there were a variety of changes to the processes in which deaths are certified and registered under the Coronavirus Act 2020. Analysis of the initial impact of these changes shows that registration delays decreased and the median time between deaths occurring and deaths being registered was shorter than in the previous year.

We also find that the proportion of deaths certified by a coroner decreased sharply during the height of the first wave of the pandemic, but then started to return to average levels.

The numbers of conditions recorded on the death certificate are greater for deaths involving COVID-19 than those not involving COVID-19, suggesting higher rates of comorbidities in these deaths and good quality of the certification.

The proportion of deaths not involving COVID-19 that had an ill-defined condition as their underlying cause of death was higher than the average for deaths in 2015 to 2019. This suggests a decrease in the quality of cause of death information recorded for deaths not involving COVID-19 during the first wave of the pandemic, in contrast to COVID-19 deaths.

79.2% (38,907 out of 49,104) deaths involving COVID-19 in England and 70.4% (2,139 out of 3,040) in Wales linked to data indicating the deceased had tested positive for COVID-19. A further 5,193 deaths linked to a positive COVID-19 test result in England but did not have COVID-19 on the death certificate. These deaths are not counted in ONS figures of deaths involving COVID-19 as they do not mention COVID-19 on the death certificate. Of these, 3,352 (64.5%) died more than 28 days after their COVID-19 test. In Wales, 470 deaths linked to a positive COVID-19 test but did not have COVID-19 on the death certificate. Of these 380 (80.8%) had tested positive more than 28 days before death.

In Wales, 470 deaths linked to a positive COVID-19 test but did not have COVID-19 on the death certificate. Of these, 380 had tested positive more than 28 days before death.
Office for National Statistics mortality data

The Office for National Statistics (ONS) is responsible for producing mortality statistics using information collected when a death is certified and registered. We report extensively on the quality of these data in our Mortality Statistics in England and Wales QMI and the User Guide to Mortality Statistics.

During the coronavirus pandemic period beginning March 2020, the processes involved in certifying and registering deaths changed to account for the greater number of deaths occurring, as well as alterations needed to protect staff and the public. For example, registering deaths by telephone was allowed instead of face to face. There have also been changes to the statistics published by the ONS, where far greater information has been published on a provisional basis than during normal times to better inform the public and policymakers.

Prior to the coronavirus pandemic, our weekly reporting of numbers of deaths in England and Wales (weekly deaths) was a simple weekly data table reporting total numbers of deaths registered in a week by age group and region of England and Wales, with a few accompanying main points.

Since the first death involving COVID-19 was registered in England and Wales (Week 11, week ending 13 March 2020), we have vastly increased the information published weekly on death registrations. This includes reporting the numbers of deaths involving COVID-19, excess death calculations, deaths by place of occurrence, and reporting for the whole of the UK. This is in addition to increased commentary and data visualisations produced each week.

We have also published ad-hoc reports periodically since March 2020 analysing provisional data to establish the impact of the coronavirus on different segments of the population, including ethnicity, occupation, religion, disability, and the care sector.

This is in addition to work environment changes for the majority of our staff, shifting from being primarily office-based to working at home. There were also exceptional workloads for our cause of death coders, with double the number of records to code than during normal times. Deaths involving the coronavirus were prioritised for cause coding when capacity was reached. Together, these may have influenced our mortality statistics with fewer fully cause-coded death records being available that did not involve the coronavirus.

3 . Changes during the coronavirus pandemic

Easements under the Coronavirus Act 2020

The Coronavirus Act 2020 introduced changes to the legislation about how deaths can be certified and registered during the height of the coronavirus (COVID-19) pandemic. The Department for Health and Social Care (DHSC) published an impact assessment of the legislative changes to accompany the act. This was prior to implementation and detailed the likely economic cost of the easements made.

The changes were introduced to ease the burden of the likely increase in number of deaths on the current systems, to protect the workforce from infection of COVID-19, and redeploy medical staff to focus on treating COVID-19 patients rather than spending time on death certification.

Guidance by the National Medical Examiner and Chief Coroner

The NHS has published guidance (PDF, 133KB) for medical practitioners for completing death certificates under the easements introduced by the Coronavirus Act. This summarises the main changes implemented during this emergency period. More detailed guidance for medical practitioners (PDF, 372KB) from the Office for National Statistics (ONS) and HM Passport Office includes examples for completing the medical certificate of cause of death (MCCD).
Certification by a doctor or medical professional

During normal times, the doctor who cared for the deceased during their last illness (which led to death) has the responsibility of completing the MCCD and sending this to the relevant registrar for death registration to take place. The attending doctor must have seen the deceased within 14 days of death or after death and be able to determine the cause of death.

During the emergency period for the pandemic, the attending doctor may have cared for the deceased during their last illness in person (as normal times) or via video or visual consultation, but not via audio only (for example, via telephone).

The length of time for a doctor to have seen the deceased has increased from 14 days to 28 days during the emergency period. Furthermore, if the doctor who would normally certify the cause of death is not able to complete the MCCD, as the result of sickness, self-isolation or some other reason, another doctor can complete the certificate as long as they can certify the cause to the best of their knowledge and belief. However, if there is no doctor who can certify the cause, or the cause appears to be unknown, the registrar will be obliged to refer the death to the coroner before they can register the death.

Where there is no certifying doctor, the death is referred to the coroner with any accompanying information. The coroner may from this information determine no investigation is needed and inform the registrar that the death can be registered. This information will be used for mortality statistics, but the death will be legally "uncertified" if the coroner does not determine the cause of death. However, once the registrar has received the coroner’s notification, the death may be registered.

If a doctor was awaiting test results to determine whether a patient had the coronavirus (COVID-19), in order to avoid delay in registration they are able to circle “Option 2” in the MCCD (“information from post-mortem may be available later”) or tick “Box B” on the reverse of the MCCD for ante-mortem investigations.

In cases where the patient has displayed symptoms consistent with COVID-19 but had no swab taken, it is acceptable for the doctor completing the MCCD to apply their clinical judgment and record COVID-19 on the death certificate. Doctors are legally required to complete the cause of death on the MCCD “to the best of their knowledge and belief”.

As a result of these changes, we may anticipate seeing an increase in the number of ill-defined and vague conditions recorded on the death certificate if the doctor completing the MCCD has not been the attending doctor and known the patient’s case well. We may anticipate an increase in the number of cases where additional information was not available in time for death registration. We may also see a change in the number of conditions mentioned on the death certificate.

Certification by coroner

The coronavirus (COVID-19) is a notifiable disease, so has to be notified to the public health authorities. Ordinarily an inquest where a notifiable disease is suspected has to be held with a jury (under section 7(2)(c) of the Coroners and Justice Act 2009). However, Section 30 of the Coronavirus Act 2020 modifies the 2009 Act to disapply the requirement that coroners must conduct any inquest with a jury where they have reason to suspect the death was caused by COVID-19. A death from COVID-19 is regarded as a death of natural cause and therefore should not of itself be referred to the coroner.

A suspected COVID-19 death may still be referred to the coroner if a doctor had not seen in person (or via video call) the deceased within 28 days prior to death or following death. It may also be referred to the coroner if the death was violent, or of unknown cause, or occurred in custody or other state detention.
During the emergency pandemic period, guidance from the Chief Coroner (PDF, 314KB) states only inquests that are of urgent and essential business should be held. This may affect our mortality statistics by further delays in deaths referred to coroners requiring inquests and hearings being registered. We understand that in the recovery period, coroners have been able to hear the majority of their routine inquests but there have been particular issues in hearing jury inquests and non-jury complex inquests because of social distancing restrictions.

Increasing the window of time that a doctor must have seen the deceased from 14 to 28 days prior to death should reduce the number of deaths that are referred to a coroner for not satisfying these criteria. However, there may remain a proportion of suspected COVID-19 (to a greater or lesser degree of confidence) deaths where a report of death is likely to be made to the coroner because a doctor is unable to sign a MCCD.

The Chief Coroner’s guidance also states that it may not be feasible to conduct post-mortem examination where COVID-19 is the suspected cause or was involved in the death, or cannot be ruled out because of a risk of infection, but also because of exceptional pressures on the pathology services and NHS overall. Therefore, is it possible we may see a reduction in deaths registered following post-mortem examinations both certified by a coroner and by doctors.

Practical steps taken by the GRO, local registration services, and the ONS to cope with the volume of registrations

In order to cope with the increased number of death registrations that would likely occur because of the coronavirus pandemic, the General Register Office (GRO) and local registration services made alterations to the services provided. The registration of births and marriages was halted during the height of the pandemic to divert staff resources to the registration of deaths.

During normal times, it is required that the informant attend a local register office in person with the medical certificate of cause of death (MCCD) to register the death. The informant also completes additional information about the deceased such as their occupation and marital status. Under the easements of the Coronavirus Act, this process has been allowed to take place remotely where the MCCD can be emailed or faxed to the local register office and the informant can complete the registration via telephone.

Guidance provided to medical practitioners (PDF, 372KB) states that emailed MCCDs must be sent from a secure email address to another secure email address. The original signed MCCD must be securely retained and delivered to the registrar as soon as possible following registration and this process must be agreed with the registration service.

Where the deceased’s family or informant are having to follow self-isolation procedures, it is acceptable for an alternate informant, including a funeral director, to be appointed to register the death. A funeral director must only act as an informant with the agreement of the family.

The easements made to the registration process may result in a change in the delay between a death occurring and a death being registered. In normal times the median death registration delay is five days (impact on registration delays on mortality statistics). This may increase if register offices are struggling to keep up with demand and if informants are having to self-isolate. Alternatively, the option to use remote registration and diversion of resources to solely focus on death registration may speed up the process and decrease median registration delay.

4. Possible impact of changes

In this section, we describe possible effects of the changes made during the coronavirus (COVID-19) pandemic period on mortality statistics.
Registration delays with and without COVID-19

The pandemic may have affected the time between a death occurring and a death being registered (registration delay) in two ways.

Firstly, it may have increased the time to registration if the informant responsible for registering the death were infected with COVID-19 and they were required to self-isolate. It may also have lengthened because of the increased demand on death registration services and potentially reduced registrars available to register deaths.

Alternatively, registration delay may have decreased. There was increased capacity for registering deaths at local registry offices through diversion of resources, increased opening hours and virtual rather than face-to-face registration as part of the easements under the Coronavirus Act 2020, potentially allowing informants to register a death faster than usual.

This is in addition to the alterations made to the certification process where dedicated medical practitioners were established to certify deaths, reducing the burden on the attending medical practitioners.

During 2018, the median registration delay for all deaths was five days. We have found when reporting elsewhere on non-COVID-19 excess mortality that there was an overall decrease in the time between death occurrence and registration.

We also have reported in monthly COVID-19 publications, the median registration delay for both all-cause mortality and specifically for COVID-19. We find this to be four days for both deaths involving COVID-19 and all-cause mortality. This is faster than the annual median registration delay recorded for 2018 of five days. The proportion of deaths registered within seven days was greater for deaths involving COVID-19 (86.3%) than all-causes of death (82.1%).

Looking at data between Week 11 (week ending 13 March) and Week 36 (week ending 4 September) 2020, the median registration delay was four days for both deaths from all causes, and for deaths involving COVID-19. However, deaths involving COVID-19 had a greater proportion registered within seven days (85.8%) than deaths from all causes (77.3%).
Table 1: Median registration delay, lower and upper quartiles, minimum and maximum delay, proportion of deaths registered within seven days for deaths registered in England and Wales, Weeks 11 to 36 2020

<table>
<thead>
<tr>
<th>Statistic</th>
<th>All causes of death</th>
<th>Deaths involving COVID-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median registration delay</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Lower quartile</td>
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<td>2</td>
</tr>
<tr>
<td>Upper quartile</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Minimum delay</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Maximum delay</td>
<td>4,384</td>
<td>218</td>
</tr>
<tr>
<td>% registered within 7 days</td>
<td>77.3</td>
<td>85.8</td>
</tr>
</tbody>
</table>

Source: Office for National Statistics

Notes

1. Data are provisional
2. Data include deaths of non-residents
3. Deaths involving COVID-19 are deaths where U07.1 or U07.2 were mentioned anywhere on the death certificate
4. Includes death registered between week ending 13 March and 4 September 2020 that occurred any time.

The easements introduced by the Coronavirus Act have overall reduced registration delay, where average times between death occurrence and death registration have decreased. It is also likely that a reduction on the proportion of deaths certified by a coroner has affected this decrease as these deaths typically take longer to be registered.

Changes to coroner registrations

It is possible to determine from information held by the Office for National Statistics (ONS) from death registration whether a death was registered by a coroner or by a doctor. We can compare the numbers of deaths, and proportion of all deaths that were registered by a coroner with the same period over the previous five years.

Deaths that have been referred to a coroner typically take longer from time of death to be registered than deaths not referred to a coroner. For example, in 2018, deaths certified by a coroner that required an inquest had a median registration delay of 146 days, and those not requiring an inquest had a median registration delay of 12 days, compared with a median registration delay of four days for doctor-certified deaths. This is because it takes time for the coroner to investigate the circumstances surrounding the death. There is also additional processing time once the data is received by the ONS.

Therefore, deaths that occurred during the first wave of the pandemic period and were referred to a coroner might not be registered for weeks, months and in a few cases even years afterwards. Deaths that required an inquest hearing that were not considered essential business would have had their hearing postponed until restrictions eased to allow some partially remote hearings with the video presence of witnesses from June 2020.

Consequently, these registrations would be delayed more than usual. As all deaths due to suicide are referred to a coroner, we anticipate there to be longer registration delays for suicides in 2020.
The types of deaths that doctors are obliged to refer to coroners are where the death was unnatural, unexplained, violent, or where the death occurs in prison or otherwise in state detention. Deaths occurring during an operation, or before full recovery from an anaesthetic should also be referred.

In addition, there will always be cases which may in one view be “natural” that have some other element (for example, neglect concerns), which brings them within the orbit of the coroner. Deaths for which the cause is not known must be reported to the coroner.

Proportion of deaths referred to coroners registered with and without an inquest

Looking at deaths that did not involve COVID-19 (non-COVID) in 2020 and comparing these with all-cause deaths in 2015 to 2019, we can see that the proportion of deaths certified by a doctor increased during Weeks 11 to 36 and is at a higher level than all-cause deaths in the same period between 2015 and 2019 (Figure 1a). During 2015 to 2019, around 70% of deaths from any cause were registered by a doctor and did not require a post-mortem. During 2020, this increased to around 75%, and during some weeks reached 80%.
Figure 1a: The proportion of deaths certified by a doctor were greater in 2020 than the 2015 to 2019 average

Percentage of deaths not involving COVID-19 by certification type, doctors, England and Wales, Weeks 11 to 26 2020 and 2015 to 2019 average

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths of non-residents
3. Based on date of registration rather than date of death
When looking at deaths certified by a coroner, Figure 1b shows the proportion of deaths certified by a coroner and whether an inquest or post-mortem was required. The chart shows that in 2020 there was a decrease in the proportion of deaths that did not require a post-mortem or inquest during the height of the first wave of the pandemic (Weeks 11 to 18) and again during Weeks 28 to 33 2020.

Deaths certified by a coroner that involved an inquest and no post-mortem, or both an inquest and a post-mortem, were below the proportion shown in the five-year average from Week 14 onwards.

This is likely a result of a combination of factors. Firstly, as shown in Figure 1a, a greater proportion of deaths were being certified by doctors during this time than compared with the five-year average. The increase in total numbers of deaths due to the coronavirus pandemic altered the composition of those certified by doctors and those certified by coroners to shift toward more doctor certifications so that fewer coroner investigations were needed.

Secondly, a decrease in the proportion of deaths registered and certified by a coroner during this time is also likely a result of the restrictions placed on coroners with fewer inquest hearings being held and difficulty obtaining post-mortems.

Also, fewer registrations from coroners will reduce the overall average registration delay because these registrations typically take longer than those certified by doctors. This will in part explain the reduced registration delay we observed for this period.
Figure 1b: Percentage of deaths not involving COVID-19 by certification type, coroners, England and Wales, Weeks 11 to 26 2020 and 2015 to 2019 average

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths of non-residents
3. Based on date of registration rather than date of death
4. Data from the most recent weeks for deaths certified by a coroner with inquest and post-mortem will be an underestimate as there is a delay in processing these records

For both younger and older age groups there has been an increase in the proportion of deaths certified by a doctor without a post-mortem, with the greatest proportion of deaths those involving COVID-19 (see Figures 2a and 2b). For both age groups, as expected, there has been a decrease in the proportion of deaths registered by a coroner in 2020 compared with the previous five years.
Figure 2a: Proportions of deaths of those aged 0 to 64 years by certification type, with and without COVID-19, 2020 and all-cause deaths for 2015 to 2019, England and Wales Weeks 11 to 36

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths from non-residents
3. Based on date of death rather than date of occurrence
Figure 2b: Proportions of deaths of those aged 65 years and over by certification type, with and without COVID-19, 2020 and all-cause deaths for 2015 to 2019, England and Wales, Weeks 11 to 36

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths from non-residents
3. Based on date of death rather than date of occurrence
Proportion of deaths referred to coroners with COVID-19 and ill-defined conditions

For deaths involving COVID-19, the majority of those registered between Week 11 and Week 26 were certified by a doctor with only up to 4% being certified by a coroner (Figure 3).

While COVID-19 is a notifiable disease, this does not automatically mean the death needs to be referred to a coroner. If a death involving COVID-19 is referred to a coroner this is because the certifying medical professional is unable to determine the cause of death or there were suspicious circumstances surrounding the death.

Over the period Week 11 to Week 32, the number of deaths involving COVID-19 that were certified by a coroner increased from 0% to 13%.

Figure 3: Percentage of deaths involving COVID-19 by certifier type, Weeks 11 to 36, 2020, England and Wales

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths of non-residents
3. Based on date of registration rather than date of death
Figure 4 shows deaths with an underlying cause of an ill-defined condition in 2020 (for list of all causes included in this definition see Table 3), a slightly higher proportion of deaths being certified by a doctor when compared with the average for 2015 to 2019. This is reflected in the proportion of deaths from ill-defined conditions certified by a coroner being lower than the average for 2015 to 2019.

Figure 4: Percentage of deaths due to an ill-defined condition by certifier type, England and Wales, Weeks 11 to 36, 2020 and the 2015 to 2019 average

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths of non-residents
3. Based on date of registration rather than date of death

Quality of certification

Number of mentions per certificate with and without COVID-19

The number of causes recorded anywhere on the death certificate provides some indication of the quality of completion of the MCCD. It also provides information about possible multimorbidity of the deceased.

Looking at Weeks 11 to 36 of 2020, we can see that the average number of mentions recorded for deaths involving COVID-19 were higher than for those not involving COVID-19.
The numbers of deaths involving COVID-19 were small during Weeks 11 and 12. Figure 5 shows that the mean number of conditions mentioned on these death certificates were particularly high, and then dropped in subsequent weeks as more deaths involving COVID-19 were registered.

We can conclude from this that those deaths first registered involving COVID-19 had a greater number of conditions recorded on their death certificates. It is also possible that doctors were unsure of the clinical features of COVID-19 at first, so reported more symptoms or other features in case they were relevant. It also may not have been clear at the start who was most clinically vulnerable so more pre-existing conditions were recorded.

For deaths not involving COVID-19, the average number of causes recorded on the death certificate was comparable to deaths recorded during the same time period in previous years. Therefore, it appears that the reporting of additional conditions contributing to a death that did not involve COVID-19 has remained unaffected by easements introduced because of COVID-19.

Deaths involving COVID-19 had considerably more numbers of conditions recorded on the death certificate than non-COVID deaths. This is in line with statistics we have reported on pre-existing conditions in deaths involving COVID-19, where 90% of deaths involving COVID-19 have at least one pre-existing condition.
Figure 5: Mean number of conditions mentioned on the death certificate, deaths involving COVID-19, non-COVID-19 deaths and all-causes of death

England, Weeks 11 to 36, 2020 and 2015 to 2019 average

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Data include deaths of non-residents
3. Based on date of registration rather than date of death

Proportion of ill-defined conditions with and without COVID-19

There are a number of International Classification of Diseases (ICD-10) codes that can be classified as ill-defined conditions. These conditions include those in the ICD-10 chapter “Signs, symptoms and ill-defined conditions” (codes R00 to R99) as well as a selection of other vague terms that either are ill-defined or describe a mode of dying rather than a cause of death.

In the guidance provided to medical practitioners completing death certificates, doctors are encouraged not to use the following terms as the only cause of death – “old age”, “senility” or “frailty of old age”. These terms should only be given as the sole cause of death in very limited circumstances for example if the deceased was 80 years or older, the doctor is not aware of any identifiable disease or injury that contributed to the death and they are certain that there is no reason that the death should be reported to the coroner.
See Table 3 for a full list of ICD-10 codes and conditions included in our definition of ill-defined conditions.

Figure 6 shows that during 2015 to 2019, the average proportion of all deaths with an ill-defined condition as the underlying cause of death was around 6.5%.

For deaths not involving COVID-19 registered during Weeks 11 to 36, the proportion of deaths with an ill-defined condition as the underlying cause of death increased over the time period from 6% in Week 11 to a high of 8% in Week 16. For most weeks in the period Week 11 to Week 36, the proportion of deaths with an ill-defined condition as the underlying cause of death was higher than the average of the previous five years.

For deaths involving COVID-19, a very small proportion have an ill-defined condition as the underlying cause of death. This is because around 90% of deaths involving COVID-19 have COVID-19 as the underlying cause of death.

Overall, these figures show that there may have been a decrease in the quality of information recorded on the MCCD, particularly during the peak weeks of the pandemic (Week 16, week ending 17 April 2020), as indicated by an increase in the proportion of deaths due to an ill-defined condition.

This is consistent with our published findings on death registrations not involving COVID-19, that there was an excess of deaths in this period certified as due to old age and frailty. It is also possible that some deaths may have been certified less precisely than normal because of reduced recourse to post-mortems or other pathology investigations, or certification by a doctor with less familiarity with the patient.
1. Data for 2020 are provisional
2. Data include deaths of non-residents
3. Based on date of registration rather than date of death

Proportion of ill-defined conditions by place of death

Figure 7 shows all settings except hospitals saw an increase in the proportion of deaths with an ill-defined underlying cause of death in 2020 compared with 2015 to 2019 for deaths not involving COVID-19. In hospitals there was a decrease, at the same time as an overall reduction in the proportion of deaths that occurred in hospitals not involving COVID-19. This may reflect the reduction in hospital capacity for elderly people, such as care home residents.
**Figure 7: Proportions of deaths with an underlying cause of death as an ill-defined condition, with and without COVID-19 2020, and average for 2015 to 2019, England and Wales, Weeks 11 to 36**

Source: Office for National Statistics

Notes:

1. Data for 2020 are provisional
2. Figures exclude non-residents.
3. Hospital includes acute and community hospitals, but does not include psychiatric hospitals
5. Certification and coding issues

Issues in coding confirmed (U07.1) and suspected (U07.2) COVID-19

At the start of the coronavirus (COVID-19) pandemic, there were no automated algorithms for coding text recorded on the death certificate to ICD-10 codes U07.1 (COVID-19, virus identified) or U07.2 (COVID-19, virus not identified). To determine which texts and phrases should be coded to which code we referred to World Health Organisation (WHO) guidelines and consulted with medical and epidemiological experts. We also consulted with colleagues in other English-speaking countries to discuss ambiguous terms. We kept a log of coding variations to inform later decisions and analysis.

Our final coding rules are to use U07.1 (confirmed) for COVID-19 (not otherwise specified; NOS) and U07.2 (suspected) for stated as suspected or similar terms.

Text or phrase examples coded to U07.1: “COVID-19”, “COVID-19 positive”, “COVID-19 confirmed”. A trickier example of “COVID-19 clinically” would also result in a U07.1 code. This is because a statement of clinical evidence of COVID-19 is interpreted the same as the certified stating “COVID-19”.

Text or phrase examples coded to U07.2: “Suspected/Probable/Possible/Likely Covid-19”. Again, a more complicated example would include “Pneumonia in the setting/context of a COVID-19 outbreak”. This is coded as U07.2 (suspected COVID-19) and J18.9 (Pneumonia) because it is interpreted that the certifier is saying that COVID-19 is suspected by association with the setting.

Additionally, “COVID-19, swab negative” would be coded as U07.2. This is because it is interpreted that the certifier has stated COVID-19 is clinically present but it downgrades to “possible/suspected” because the result of the swab test was negative.

Text or phrase example that would result in neither code: “COVID-19 negative”, “COVID-19 swab negative”. In both these cases no code is recorded. The lack of a comma in the second example is important. Unless there is also a separate mention of COVID-19 as the example for U07.2, it is taken that COVID-19 was not a cause of death.

Underlying cause rules and “due to” or “involving”

This section explains how the underlying cause of death is determined for COVID-19 cases and clarifies the difference in our terminology to describe deaths “due to” and deaths “involving” the coronavirus (COVID-19) but can be applied to any condition.

Determining the underlying cause of death

To determine the underlying cause of death from all the causes recorded on the death certificate, we use coding rules provided by the World Health Organisation.

The international rules and guidelines for selecting the underlying cause of death for statistical tabulation apply when COVID-19 is reported on a death certificate but, given the high priority public health requirements for data, COVID-19 is not considered as due to, or as an obvious consequence of, anything else in analogy to the coding rules applied for influenza.
Difference between deaths due to COVID-19 and deaths involving COVID-19

We refer to both the number of deaths “due to” COVID-19 and the number of deaths “involving” COVID-19. These are two different numbers.

Deaths due to COVID-19 are those where COVID-19 has been recorded on the death certificate and has subsequently been selected as the underlying cause of death using the rules outlined in “Determining the underlying cause of death” section.

Deaths involving COVID-19 are those where COVID-19 has been recorded anywhere on the death certificate but does not have to be the underlying cause of death. Therefore, deaths due to COVID-19 are a subset of deaths involving COVID-19. Around 90% of deaths involving COVID-19 have COVID-19 as the underlying cause of death.

There are situations in which the deceased had COVID-19 that contributed to the death but was not the underlying cause. For example, if COVID-19 aggravated the consequences of an accident, COVID-19 may be reported in Part 2 of the death certificate (contributory factors). This would be counted in our statistics as a death involving COVID-19 but not a death due to COVID-19.

Changes to registrations resulting from further information

In order to prevent delays to death registration, if a certifying doctor knows in broad terms the disease or condition which caused the patient’s death but is awaiting results from laboratory investigations, they are still able to complete the Medical Certificate of Cause of Death (MCCD).

For example, with COVID-19, the patient may have been clinically presenting with symptoms consistent with COVID-19 but died before results of a swab test were returned. Therefore, the doctor would complete the MCCD with suspected COVID-19 and then indicate that information from investigations may be available later. They do this by either circling “Option 2” on the front of the MCCD for autopsy information available later or ticking “Box B” on the back of the MCCD for results of investigations initiated prior to death. The registrar who registered the death would then write to the certifying doctor to obtain this information later. This additional information is then passed on to the Office for National Statistics (ONS) and received by post.

We call these deaths “B cases”. We can identify which deaths had either of these options selected on the death certificate. Sometimes, the additional information is not received by the registrar and subsequently the ONS. If it is sent on, we then use this information to determine whether the cause of death changed as a result of the additional information.
Table 2: Number of deaths where the certifier indicated additional medical information was outstanding at time of certification, England and Wales, 2019 to October 2020.

<table>
<thead>
<tr>
<th>Year of registration</th>
<th>Number of B cases</th>
<th>Number of deaths with revisions to causes of death</th>
<th>Number of deaths where revision changed underlying cause</th>
<th>Involving COVID-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019</td>
<td>1,183</td>
<td>42</td>
<td>20</td>
<td>n/a</td>
</tr>
<tr>
<td>2020 (until 30/10/20)</td>
<td>1,116</td>
<td>60</td>
<td>32</td>
<td>17</td>
</tr>
</tbody>
</table>

Source: Office for National Statistics

Notes

1. Data for 2020 are provisional

Of the 17 “B cases” that involved COVID-19, 12 changed to include COVID-19 (U07.1), one changed from U07.1 to U07.2, one changed from U07.2 to U07.1 and three changed from U07.1 to not include COVID-19. These changes have therefore had only a very small effect on the statistics.

Linkage of death registration data at the ONS with COVID-19 test data held by Public Health England and Public Health Wales

It is possible to link the death registration data held by the ONS with coronavirus test data held by public health bodies such as Public Health England (PHE) and Public Health Wales (PHW). An NHS number is used as the identifier to join these datasets. This is a further way in which we can corroborate the quality of our mortality statistics.

This data linkage allows us to determine the proportion of deaths with COVID-19 mentioned on the death certificate (deaths involving COVID-19) that had a positive test result at any point prior to death. We can also find out how many had a positive test result then subsequently died but did not have COVID-19 on the death certificate, and the possible reasons why.

England

Between Week 11 (week ending 13 March) and Week 35 (week ending 28 August) 2020 there were 49,104 deaths involving COVID-19 registered in England.

Of these, 79.2% (38,907 deaths) linked to a record of a positive test result held by PHE. The remaining 10,197 deaths mentioning COVID-19 did not link to a record of a positive test result. In these cases, the certifying doctor clinically determined COVID-19 to be present at the time of death. It is possible that these cases were more common towards the beginning of the pandemic where widespread testing has not been established.

Additionally, there were 5,183 deaths that linked to a record of a positive COVID-19 test but did not have COVID-19 mentioned on the death certificate. Of these 5,183 deaths, 74 were “B cases” where the certifying doctor indicated that additional information was sought and would be available later, possibly explaining why COVID-19 was not recorded on the death certificate.

Of the 5,183 deaths, 442 had a date of death after the result of the test was available, so the certifying doctor did not have the information that the deceased was COVID-19 positive when they wrote the death certificate.
There are also deaths where the result of the positive COVID-19 test preceded the death by significant period of time and are likely to represent deaths due to other causes. Of the 5,183 deaths where COVID-19 was not mentioned but linked to a positive test result, 3,352 died more than 28 days after their positive test and of these 2,128 died more than 60 days after their positive test result.

In such cases the deceased may no longer have been suffering clinically from COVID-19, so there would be no need to mention it on the death certificate. Conversely, the contribution of COVID-19 on the death certificate may not have been recognised by the reporting clinician. However, further research is needed to determine whether the long-term effects of COVID-19 may have played a role in their later death. There were a remaining 1,831 deaths that tested positive within 28 days of death and did not have COVID-19 recorded on the death certificate.

We can also look at the underlying cause of death of these 5,183 deaths that do not involve COVID-19 but had a positive test result. We can assess whether the underlying causes of death vary by the length of time between positive test and death.

Dementia and Alzheimer’s disease was the most common underlying cause of death for those who died within 28 days of positive test result. For those who died within 60 days of a positive test result or more than 60 days after a positive result, malignant neoplasms were the most common underlying cause of death.

Figure 8 shows the ten most common underlying causes of death where the death registration did not involve COVID-19 but the individual had a positive COVID-19 test result.
Figure 8: Number of non-COVID-19 deaths with a positive COVID-19 test, by underlying cause of death and time from positive test result to death

England, March to August 2020

Source: Office for National Statistics

Notes:

1. Linked death registration data with positive COVID-19 test result data, deaths where COVID-19 (ICD-10 codes U07.1 or U07.2) were not recorded on the death certificate

2. Underlying cause of death grouped by leading cause of death list

3. Deaths exclude non-residents

4. “Other” includes both conditions not on the leading cause of death grouping list and leading causes of death with deaths not ranked in the top 10 causes.

Wales

Between Week 11 (week ending 13 March) and Week 45 (week ending 6 November) 2020, there were 3,040 deaths involving COVID-19 registered in Wales. Of these, 70.4% (2,139 deaths) linked to a record of a positive test result held by PHW. The remaining 901 deaths involving COVID-19 did not link to a record of a positive test. In these cases, the certifying doctor would have clinically determined COVID-19 to be present and relevant at the time of death. It is likely these cases occurred more frequently at the start of the pandemic when widespread testing was not established.
Additionally, there were 470 deaths that linked to a record of a positive COVID-19 test but did not have COVID-19 mentioned on the death certificate.

Of these 470 deaths, six were “B cases” where the certifying doctor indicated that additional information was sought and would be available later, possibly explaining why COVID-19 was not recorded on the death certificate.

Of the 470 deaths, two had their sample for the test taken after death; 16 had their test sample taken on the same day as death, or the day before possibly not allowing enough time for a result to be returned to include COVID-19 on the death certificate. A further 380 had their test swab collected more than 28 days before death, of which 281 had their test swab taken more than 60 days before death. Therefore, there were a remaining 90 deaths that tested positive within 28 days of death and did not have COVID-19 recorded on the death certificate in Wales.

We can also look at the underlying cause of death of these 470 deaths that do not involve COVID-19 but had a positive test result. We can assess whether the underlying causes of death vary by the length of time between positive test and death.

Malignant neoplasms were the most common underlying cause of death for those who died within 28 days of positive test result, those who died within 60 days of testing positive, and those who died more than 60 days after a testing positive.

Figure 9 shows the ten most common underlying causes of death for deaths in Wales not involving COVID-19 but with a positive COVID-19 test result.
Figure 9: Number of non-COVID-19 deaths with a positive COVID-19 test, by underlying cause of death and time from positive test result to death

Wales, March to November 2020

Source: Office for National Statistics

Notes:

1. Linked death registration data with positive COVID-19 test result data, deaths where COVID-19 (ICD-10 codes U07.1 or U07.2) were not recorded on the death certificate.

2. Underlying cause of death grouped by leading cause of death list.

3. Deaths exclude non-residents.

4. “Other” includes both conditions not on the leading cause of death grouping list and leading causes of death with deaths not ranked in the top 10 causes.
# 6. Appendix

Table 3: List of conditions and corresponding ICD-10 codes included in definition of ill-defined conditions

<table>
<thead>
<tr>
<th>ICD-10 codes</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>A40-A41</td>
<td>Streptococcal and other septicaemia</td>
</tr>
<tr>
<td>C76, C80, C97</td>
<td>Ill-defined cancer sites</td>
</tr>
<tr>
<td>D65</td>
<td>Disseminated intravascular coagulation [defibrination syndrome]</td>
</tr>
<tr>
<td>E86</td>
<td>Volume depletion</td>
</tr>
<tr>
<td>I10</td>
<td>Essential (primary) hypertension</td>
</tr>
<tr>
<td>I26.9</td>
<td>Pulmonary embolism without mention of acute cor pulmonale</td>
</tr>
<tr>
<td>I46</td>
<td>Cardiac arrest</td>
</tr>
<tr>
<td>I47.2</td>
<td>Ventricular tachycardia</td>
</tr>
<tr>
<td>I49.0</td>
<td>Ventricular fibrillation and flutter</td>
</tr>
<tr>
<td>I51.4</td>
<td>Myocarditis, unspecified</td>
</tr>
<tr>
<td>I51.5</td>
<td>Myocardial degeneration</td>
</tr>
<tr>
<td>I51.6</td>
<td>Cardiovascular disease, unspecified</td>
</tr>
<tr>
<td>I51.9</td>
<td>Heart disease, unspecified</td>
</tr>
<tr>
<td>I70.9</td>
<td>Generalized and unspecified atherosclerosis</td>
</tr>
<tr>
<td>I99</td>
<td>Other and unspecified disorders of the circulatory system</td>
</tr>
<tr>
<td>J81</td>
<td>Pulmonary oedema</td>
</tr>
<tr>
<td>J96</td>
<td>Respiratory failure, not elsewhere classified</td>
</tr>
<tr>
<td>K72</td>
<td>Hepatic failure, not elsewhere classified</td>
</tr>
<tr>
<td>N17</td>
<td>Acute renal failure</td>
</tr>
<tr>
<td>N18</td>
<td>Chronic renal failure</td>
</tr>
<tr>
<td>N19</td>
<td>Unspecified renal failure</td>
</tr>
<tr>
<td>P28.5</td>
<td>Respiratory failure of new-born</td>
</tr>
<tr>
<td>R00-R99</td>
<td>Symptoms, signs and ill-defined conditions</td>
</tr>
<tr>
<td>Y10-Y34, Y87.2</td>
<td>External cause of death not specified as accidentally or purposefully inflicted</td>
</tr>
</tbody>
</table>

Source: Office for National Statistics