Changing Epidemiology of Abdominal Aortic Aneurysms in England and Wales
Older and More Benign?

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Background—Recent studies from Australia, New Zealand, and Sweden have reported declines in abdominal aortic aneurysm (AAA) incidence, prevalence, and mortality. This finding may have important implications for screening programs. This study determined trends in AAA incidence and mortality in England and Wales.

Methods and Results—Cause-specific mortality data for England and Wales were obtained from UK Office for National Statistics, and hospital admissions and procedures data for England were obtained from Hospital Episode Statistics from 2001 to 2009. Poisson regression models were constructed to estimate the relative change over time. Age-standardized rates for AAA mortality in England and Wales fell significantly by 35.7% from 2001 to 2009, which was largely due to a 35.3% drop in age-standardized ruptured AAA deaths. During the same period, ruptured AAA admissions and emergency AAA repairs in England declined by 29.3% and 35.5%, respectively. In contrast, nonruptured AAA admissions remained static, and nonemergency AAA repairs increased by 17.2%. The average ages for hospital admissions for nonruptured AAAs and ruptured AAAs increased by 0.19 years of age per annum (P<0.001) and 0.09 years of age per annum (P<0.001), respectively. Nonruptured AAA admissions increased by 21.4% in age band 75 years or more but declined by 11.7% in ages <75 years.

Conclusions—AAA mortality, ruptured AAA admission, and emergency AAA repair have declined in England and Wales. However, nonruptured AAA admission has remained steady, with an increasing rate in older population offsetting a decreasing rate in younger population. This suggests a shift in AAA presentation to the older population. Present screening strategies may need reassessment to include consideration for increasing the age at which to screen men for AAAs. (Circulation. 2012;125:1617-1625.)

Key Words: abdominal aortic aneurysms ■ epidemiology ■ incidence ■ mortality ■ mortality rates

Policies1,2 for abdominal aortic aneurysm (AAA) screening were to a large extent driven by historical data that documented rises in both mortality and incidence of AAAs.3-7 Studies published in the 1990s reported an increase in the incidence of asymptomatic AAAs from 7.1 per 100 000 to 25.8 per 100 000 person-years from 1977 to 1990 in Denmark,4 whereas Australian5 and Minnesota6 data reported 4.2% and 11% per year average increase in incidence, respectively.

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However, contemporary data from Western populations have suggested that this trend of rising AAA has not continued, and may in fact be reversing. Norman et al8 reported a declining rate of hospitalization for both ruptured and nonruptured AAA with a 38% decline in AAA mortality in men from 1999 to 2006 in Australia. Similarly, Sandiford et al9 reported a 53% reduction in AAA mortality in men from 1991 to 2007 in New Zealand, and a reduced rate of age-standardized hospitalization rate for AAAs. Both authors cited decreasing prevalence of smoking in their countries as the most likely explanation for the falling incidence of AAAs.

The UK Multicenter Aneurysm Screening Study10 demonstrated that screening for AAA in men aged 65 to 74 years achieved substantial reduction in aneurysm-related mortality. However, this study was conducted between 1997 and 1999, when AAA incidence was still on the rise. Any decline in AAA incidence would be translated into a lower prevalence
and effectiveness of current screening strategies. Preliminary results from the ongoing screening program in the United Kingdom11 have indeed revealed a lower AAA prevalence. Svensjo et al12 described a lowest reported AAA prevalence of 1.7% from their ultrasound-based AAA screening program for 65-year-old men in central Sweden and suggested that the cost-effectiveness of current screening strategies may need to be reevaluated on the basis of modern epidemiological data. If the recent trends continue, Lederle13 advocated that programs that target high-risk populations such as older men who have smoked, in line with US Preventive Services Task Force recommendation,1 are more likely to remain effective.

Contemporary epidemiology of AAA in England and Wales has not been subjected to recent examination. In view of the changing epidemiology of AAAs in other Western populations and its important implications for screening strategies, this study examined the trends in AAA mortality and incidence in England and Wales.

Methods

The International Classification of Diseases, 10th Revision (ICD-10) was used. The incidence of patients with AAA in England for the financial years 2000 to 2009 was estimated by the use of hospital admission counts that had primary diagnosis ICD-10 codes of I71.3, I71.4, I71.5, I71.6, I71.8, and I71.9 from the Hospital Episodes Statistics (HES) data. The primary diagnosis is the main condition treated or investigated during the episode of care. The ICD-10 codes I71.3, I71.4, I71.5, I71.6, I71.8, and I71.9 were abdominal and thoracoabdominal aortic aneurysms, ruptured or otherwise, and aortic aneurysms of unspecified site (ruptured or otherwise), as well.

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Validity of Data

HES data are generated from the hospital records (through the National Health Service hospital trusts) to the commissioners of care. There are >12 million records of admitted patient care each year. Similarly, vast quantities of mortality data are entered into ONS death registration each year. Both HES and ONS data are therefore subjected to a number of complex internal validation processes involving a wide range of people, organizations, and computer systems before becoming usable for analysis. Internal validation processes are present to ensure high quality of data for both HES and ONS, and these processes are summarized in online-only Data Supplement Appendices I and II.

An external validity study for AAA data reported by HES has been recently published.16 This multicenter audit on HES AAA data quality assessed the completeness and accuracy of recordings of data in HES in comparison with gold standard data sets from hospital trusts on all elective AAA repairs in England. This study showed that recording within the HES database was 86.0% accurate in comparison with the ONS.

With regard to external validity of ONS mortality data, the United Kingdom was recognized to provide high-quality data on the cause of deaths to World Health Organization in a large review of civil registration systems across the world.17 Among the member states of the World Health Organization, the United Kingdom was among the 31 (13%) countries that provided high-quality data, with data completeness of 90% to 100%. Completeness of statistics on cause of death was defined as the ratio of number of deaths for which cause of death is registered to the civil registration system to the estimated total number of deaths in the population; the latter includes all deaths registered to the civil registration system (whether cause of death is mentioned or not) and those not registered to the civil registration system, as well.

Statistics

Age-standardized rates were calculated by the use of the World Health Organization World Standard Population.18 The relative change in mortality from AAA and the incidence of hospital admissions for AAAs and their association with age, sex, and calendar period were estimated with the use of Poisson regression models. The relative change in age at presentation for nonruptured and ruptured AAA hospital admission was estimated by the use of linear regression. All statistical analysis was performed by using SPSS for Windows version 18.
Results

AAA Mortality in England and Wales

There has been a striking decline of 5.08% per annum ($P<0.001$) in age-standardized AAA mortality in England and Wales. Both age-standardized ruptured and nonruptured AAA mortalities have fallen significantly by 5.03% per annum ($P<0.001$) and 5.56% per annum ($P<0.001$), respectively (Figure 1). Ruptured AAAs (84.6%) was a major contributor of overall AAA mortality, and the sharp decline in overall AAA mortality was largely due to a 54.6% drop in age-standardized ruptured AAA deaths since 2001.

AAA Hospital Admissions and Case Load in England

Age-standardized hospital admissions for ruptured AAAs in England have decreased significantly by a mean 3.62% per annum ($P<0.001$). Age-standardized emergency AAA repairs have similarly decreased significantly by a mean 4.52% per annum ($P<0.001$) (Figure 2A).

Figure 1. Trend in age-standardized AAA mortality in England and Wales. AAA indicates abdominal aortic aneurysm.

Figure 2. Trends in age-standardized ruptured AAA admissions and emergency AAA repair (A) and nonruptured AAA admissions and nonemergency AAA repair (B) in England. AAA indicates abdominal aortic aneurysm.
In contrast, age-standardized hospital admissions for nonruptured AAAs have remained constant (mean change of -0.17% per annum, P=0.58) and age-standardized nonemergency repairs for AAAs have increased significantly by a mean of 1.45% per annum (P<0.001) (Figure 2B).

**Age Stratification**

Both ruptured and nonruptured AAA mortalities declined in all age bands. Ruptured AAA mortality declined by 7.25% per annum (P<0.001) and 3.73% per annum (P<0.001) in those <75 years old and those aged ≥75 years of age, respectively. Nonruptured AAA mortality fell by 7.58% per annum (P<0.001) and 4.43% per annum (P<0.001) in those <75 years of age and those aged ≥75 years, respectively (Figure 3A).

For ruptured AAA admissions, downward trends were seen for both those <75 years of age (decrease of 4.83% per annum, P<0.001) and in those ≥75 years of age (decrease of 2.34% per annum, P<0.001) (Figure 4A). There was a similar downward trend in emergency AAA repairs for both those <75 years old (decrease of 5.07% per annum, P<0.001) and in those aged ≥75 years of age (decrease of 3.97% per annum, P<0.001). When stratified by age bands, a divergence in age-standardized hospital admissions for nonruptured AAAs was seen. In those <75 years of age, this declined by 1.33% per annum (P<0.001). However, in those aged ≥75 years of age, there was an increase of 1.89% per annum (P<0.001) in age-standardized hospital admissions for nonruptured AAAs (Figure 4B). When age-specific rates were analyzed, nonemergency AAA repairs in those <75 years of age increased by 0.17% per annum (P<0.001), with an even larger increase of 4.33% per annum (P<0.001) in those aged ≥75 years of age.

Deaths outside hospitals were counted in the mortality data from ONS. This explains why there were more ruptured AAA deaths than ruptured AAA admissions, because there were a significant proportion of patients who died of ruptured AAA in the community without being admitted to the hospital. Conversely, all deaths from nonruptured AAAs resulted from nonruptured AAA repair in hospital. Therefore, the admissions for nonruptured AAAs must always exceed that of deaths from nonruptured AAAs, which is reflected by Figures 3A and 4B.

The average ages for hospital admissions for nonruptured AAAs and ruptured AAAs have increased by 0.19 years of age per annum (P<0.001) and 0.09 years of age per annum (P<0.001), respectively (Figure 5).

**Sex**

Age-standardized AAA mortality for both men and women declined by 5.90% per annum (P<0.001) and 4.10% per annum (P<0.001), respectively (Figure 3B).

Significant declines were seen for ruptured AAA admissions for both men (decrease of 2.88% per annum, P<0.001) and women (decrease of 2.50% per annum, P<0.001). There was a similar downward trend in emergency AAA repairs for both men (decrease of 3.68% per annum, P<0.001) and women (decrease of 4.53% per annum, P<0.001) (Figure 6A).

In contrast, nonruptured AAA admission in men increased by 0.99% per annum (P<0.001). For women, nonruptured AAA admission declined by 0.25% per annum (P=0.023). Nonemergency AAA repairs in men have increased by 2.69% per annum (P<0.001), and, similarly for women, there has been a rise of 1.66% per annum (P<0.001) (Figure 6B).
Discussion

This study has demonstrated declines in AAA mortality, ruptured AAA admission, and emergency AAA repair across all age bands, and in both men and women, in England and Wales. These data are similar to the Australian\(^8\) and New Zealand\(^9\) data. However, unlike these previous studies, the rate of nonruptured AAA admission has remained steady, with an increasing rate in older population offsetting a decreasing rate in younger population, and the rate of non-emergency AAA repair has increased in both age bands.

Figure 4. Age-specific trends in age-standardized admissions for ruptured and emergency AAA repairs (A) and admissions for nonruptured and nonemergency AAA repairs (B) in England. AAA indicates abdominal aortic aneurysm.

Figure 5. Trend in average age for nonruptured AAA and ruptured AAA hospital admissions in England. AAA indicates abdominal aortic aneurysm.
The question prompted by the present study is whether there has also been a true fall in overall incidence of AAA disease in England, in line with the previous studies from Australia and New Zealand. Sandiford et al described a decline in AAA mortality, AAA hospital admissions, and AAA hospital death rates in New Zealand, but they did not separate ruptured from nonruptured AAAs. Norman et al reported that there have been significant falls in the rates of hospital episodes and mortality for both nonruptured and ruptured AAAs in men and women since 1999 and suggested that the incidence of AAAs may be falling in Australia. Svensjo et al reported that, in their AAA screening program for 65-year-old men in central Sweden, the prevalence of AAAs was only 1.7%, which was the “the lowest reported in a predominantly white population to this date,” and hypothesized that this was caused by an overall decrease of the disease in the population. The current low prevalence of AAAs in the UK screening program would also support the notion of a true fall in incidence of AAAs.

A decline in overall AAA incidence could explain the reduced incidence of ruptured AAAs reported in this study. However, the rate of nonruptured AAA admissions in England has remained unchanged in the past 10 years. One might expect this to decline in parallel with ruptured AAAs if there was a genuine decline in AAA incidence, but this may not necessarily be the case. The underlying causes of the observed changing epidemiology of AAAs are complex, and there are factors that may mask a decline in incidence of nonruptured aneurysms. First, nonruptured AAA admissions and nonemergency AAA repair may have been maintained by evolving clinical practice. Endovascular Aneurysm Repair I (EVAR 1) trial demonstrated that EVAR had significant early survival advantages over open repair, and it is likely that clinical practice has subsequently changed toward the use of minimally invasive endovascular techniques in high-risk patients who would otherwise have been precluded from AAA repair. In the United Kingdom, the rate of endovascular repair for intact aneurysms has increased significantly from 20.2% in 2005 to 58.9% in 2009. Furthermore, data from the present study (Figures 2, 4B, and 6B) demonstrated that the increases in overall, older age group and male nonemergency AAA repairs coincided with the publication of the EVAR I trial in 2004. Second, if medical management such as increased use of statin therapy and decline in smoking have successfully reduced the risk of AAA rupture, patients who would otherwise have presented with ruptured aneurysms may now present with intact aneurysms, and this effect may also obscure a fall in incidence of nonruptured AAAs. Third, an increased availability of imaging techniques may contribute toward an increased diagnosis of incidental nonruptured AAAs in older men. Taking all these factors into account, it is likely that the trends in England and Wales are trailing behind those of Australia and New Zealand, and, after this plateau stage, it is anticipated that there will be a decline in overall nonruptured AAA admissions and nonemergency AAA repairs in the coming years.

Another consideration in terms of the complexities underlying the changing epidemiology of AAAs is the possibility of less intervention for small AAAs in response to the publications of the small AAA trials in 2002. This could explain some of the fall in admissions for nonruptured AAAs in the <75 years of age group. However, this cannot wholly...
explain the trend, because the falling rates in this age group were already seen before the publication of these studies. Second, the older age group has resisted the falling trend; therefore, changing clinical practice of less intervention was unlikely to have played a significant role.

Smoking is the single most important risk factor for AAA. Declines in smoking rates have been identified as the most likely cause of the declining incidence of AAAs in previous studies. The adult prevalence of smoking in Australia declined from 35% in 1980 to 23% in 2001, and Statistics Sweden reported that daily smoking among 65-year-old men in Sweden decreased from 32% in 1980 to 11% in 2007. In England, the historical rise in the rate of AAA mortality from the 1950s to 1980s has been attributed to a cohort effect of tobacco addiction in the 20th century. The highest recorded level of smoking among men in England was 82% in 1948, of which 65% smoked manufactured cigarettes. Smoking prevalence among women in 1948 was 41% and remained fairly constant until the early 1970s, peaking at 45% in the mid-1960s. Overall prevalence among adults then fell steadily between the mid-1970s and early 1980s. It is possible that faster rates of decline in smoking in Australia may explain why Australian data have shown a clear decline in rates of hospital admissions for nonruptured aneurysms, whereas data from England have not. After 1982, the rate of decline in smoking slowed in England, with prevalence falling to ~1 percentage point every 2 years until the early 1990s when it leveled out. Since 2000, overall adult smoking rates have only been declining by ~0.4% per annum, and, between 2007 and 2008, overall smoking prevalence among adults remained the same at 21%. For those >60 years of age, the rate of smoking in England was 16% in 1998 in comparison with only 10% in Australia in 2001.

The overall mortality from AAA in England and Wales has declined sharply since 2001. Aneurysm rupture was a major contributor of AAA mortality, and the sharp fall in overall AAA mortality was principally due to decreasing mortality from ruptured AAA, for which there are 2 explanations. First, the incidence of ruptured AAA has declined, as evident from declines in hospital admissions for ruptured AAA and falls in emergency AAA caseloads in the present study. This declining incidence of ruptured AAAs was probably due to a combination of reduced overall incidence of AAAs and of better control of risk factors for AAA rupture. Improvement in uptake of statin therapy, decline in smoking, and better control of blood pressure are all potential factors that can reduce the incidence of AAA rupture. Second, there is recent evidence for improved perioperative outcome for ruptured aneurysm repair. The recently published Vascunet registry AAA data (from 9 participating countries) reported that in-hospital mortality has decreased significantly from 42.5% in 2005 to 28.5% in 2009 for ruptured aneurysm repairs in the United Kingdom.

An appealing explanation is that there may be evidence that elective (prophylactic) repair of AAAs is achieving its aim. The combination of increased elective workload, better case selection, and better elective perioperative outcome may have contributed to the decline in incidence of ruptured AAAs and overall AAA mortality. As previously alluded, elective AAA workload has increased and was temporally related to the publication of the EVAR 1 trial in 2004. The UK Small Aneurysm Trial (SAT) and the Aneurysm Detection and Management (ADAM) trial have improved case selection to AAAs >5.5 cm. The Vascunet registry data reported that in-hospital mortality has decreased from 5.5% in 2005% to 3% in 2009 for elective aneurysm repairs. It is important, however, to note that the declines in incidence of ruptured AAAs and AAA mortality were already present before the publication of the UK SAT and ADAM trials in 2002 or the EVAR 1 trial in 2004. Therefore, increased elective workload and better case selection cannot wholly explain the trend.

Regardless of whether there has been a true accompanying decline in overall incidence of AAAs, mortality has unquestionably declined sharply in the past 10 years, and any continuing trend of declining AAA mortality may challenge the cost-effectiveness of AAA-screening programs. It is therefore crucial that these recent trends be monitored and screening strategies reevaluated accordingly on the basis of these trends to maintain their effectiveness. On the basis of the present change in epidemiology, data are emerging from age band and sex analyses that may be imperative to optimization of strategies for screening.

When stratified into age bands, the most striking finding was an increase in nonruptured AAA hospital admissions and nonemergency AAA repairs in those aged ≥75 years. In those <75 years, the opposite was true, in that hospital admission rates declined for nonruptured AAAs. The average age for AAA hospital admissions also increased significantly from 2000 to 2009. The most likely explanation is that declining smoking rates shifted the age of AAA presentation to the older population. AAA is a multifaceted disease with multiple risk factors including a strong association with genetic factors. Although smoking is a key risk factor for AAA, it is possible that the decline in smoking may serve to delay the onset of the disease in genetically predisposed individuals rather than reduce its incidence altogether. This would explain the decreasing prevalence of AAAs among men aged 65 years screened for AAAs. As aortic aneurysms primarily affect the elderly population, the increase in life expectancy over time in England may also result in a longer lifespan to develop the disease and therefore increase the age at which AAAs become clinically significant. Over the past 3 decades, the average life expectancy of a man aged 60 years in England has increased significantly, from 16.4 years in 1981 to 21.7 years in 2008.

Because of the increasing incidence of nonruptured AAAs in those aged ≥75 years, it might be necessary to rescreen the entire population at a higher age. However, the cost-effectiveness of such a strategy must be balanced against the reduced gain in life years in the older cohort. If incidence of nonruptured AAAs in population <75 years of age continued its downward trend, it is possible that the prevalence of AAAs in men aged 65 years will fall below the threshold needed to make screening at this age cost-effective.
It is difficult to explain why male admissions for nonruptured AAAs have increased, whereas female admissions have fallen. Regardless of causation, this again has important implications for AAA-screening program and with the current trend, limiting AAA screening to men only remains appropriate. With regard to smoking data in England, limiting AAA screening to male smokers (as suggested by Lederle13 and as per previous US Preventive Service Task Force recommendation) may become necessary, if reduced rate of smoking continues to cause further reductions in the incidence of AAAs. In this respect, a cautious approach is necessary, because current evidence suggests that rates of decline in smoking are slowing26 and may eventually level out. Furthermore, the reduced life expectancy among smokers will reduce any gains from limiting screening to male smokers only.

There are a number of limitations to this study. First, fluctuations in the HES data collection from year to year can happen for a number of reasons, such as organizational changes, reviews of best practice within the medical community, the implementation of new coding systems, and data quality issues that are often year specific. Second, HES records describe episodes (periods) of continuous admitted patient care under the same consultant. In cases where responsibility for a patient’s care is transferred to a second, or subsequent, consultant there will be 2 or more HES records relating to the patient’s stay (spell) in hospital. The HES data also fail to distinguish between possible multiple admissions for the same patient with the same principal diagnosis within any 1 year. Third, autopsy rates in the United Kingdom have declined from 42.7% in 1979 to 15.3% in 2001.28 Although there have not been any reports on recent trends of autopsy rates in the United Kingdom, it is likely that autopsy rates have continued to fall, and to fail to pick up sudden deaths caused by ruptured aneurysms may exaggerate the decline of the disease. Finally, EVAR procedures were given specific codes only after 2006, and it is likely that EVAR procedures may not have been completely captured on the HES database before 2006. As a result, this study may underestimate the decline in AAA repairs between 2000 and 2009.

Conclusions
This is the first study to provide direct evidence for a shift of AAA presentation to the older population. Taken together with declining AAA mortality, it may be appropriate to reassess present screening strategies, and this may include consideration for increasing the age at which to screen men for AAAs. Further trends for smoking in England need to be ascertained before selectively screening male smokers only.

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Disclosures
None.

References
CLINICAL PERSPECTIVE

Policies for abdominal aortic aneurysm (AAA) screening were principally influenced by historical data of rises in both mortality and incidence of AAAs. However, recent data from Western populations including Australia, New Zealand, Sweden, and the United States have suggested that this trend of rising AAA has not continued and may in fact be reversing. Similarly, this present study reported declines in AAA mortality, ruptured AAA admission, and emergency AAA repair in England and Wales. One may consider the emergence of these data to be ill-timed, because many countries are now priming to roll out AAA-screening programs, including plans to fully implement the screening program by 2013 in England. A decline in smoking is likely to have contributed to the reversal of the AAA epidemic. This study also reported a delayed presentation of nonruptured AAAs to the older population (>75 years of age). These changes in the epidemiology of AAA disease underlined the need to reevaluate different screening strategies that take into account these emerging contemporary epidemiological data. Such strategies may include screening the entire population at a higher age or limiting screening to older men who smoke. AAA screening is more than just the identification of asymptomatic AAAs; proponents will argue that it also provides valuable opportunities for research on small AAAs. Although it is too early to revise AAA screening at this stage, there is no doubt that screening programs will now need to work harder to prove their worth to the health economists if these trends were to continue.
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Appendix 1. Internal and External validation of Office for National Statistics mortality data

Mortality statistics in England and Wales are derived from the registration of deaths certified by a doctor or a coroner. The data pass through a number of complex processes involving a wide range of people, organisations and computer systems before becoming usable for analysis.

Completing medical certificates of cause of death

In England and Wales, it is a legal requirement to register all deaths, locally within five days of the death. Most of the deaths are certified by a doctor attending the deceased. This Medical Certificate of Cause of Death (MCCD) records the cause of death according to the attending doctor. The majority of registrations (75%) are carried out in this way.

In cases of deaths which are not attended by a doctor during their last illness such as sudden or unexpected deaths and deaths due to violence, such cases will be referred to the coroner directly. The coroner has various courses to follow. If he is satisfied that the death has occurred due to a natural cause and does not need post-mortem examination, he issues the certificate of death and instructs the registrar to record the cause of death according to the issued certificate.

If the coroner is unsure regarding the cause of death as is common in cases of sudden deaths or deaths due to unknown causes, he may order a post-mortem examination. He then issues the certificate of death based on the pathologist’s report and the registrar records the cause of death as issued by the coroner.

If an inquest is needed, then the registration of death will only occur once the inquest into the cause of death is completed. In almost all cases, inquests follow post-mortem examination and the registrar records the cause of death based on the inquest findings.

Very rarely, some cases may be recorded as “uncertified”. This happens when the MCCD does not meet all the legal requirements and the coroner issues the certificate without post-mortem examination. This may include deaths of foreign military personnel in England and Wales, when the certifying doctor has not been registered in England and Wales for issuing death certificates.

Checks at registration service


1. Entry of data

Registration Service Software (RSS)

The deaths statistical fields used in RSS were validated in three respects:

a) range: checking that codes fall into an expected range of values
b) data type: checking that text appears where it should, and numeric values appear where they should, and

c) logic: cross-checking with values in one or more other fields

Cross-validations are carried out by checking logical consistency between various items recorded by the registrar. These include information collected on type of certification, referral to coroner, and whether a post-mortem was carried out.

2. At the time of registration

The registrar makes the following checks when someone attends to register a death:

• the death is in their area
• the death occurred within the last 12 months
• the informant is qualified to give information
• the correct medical certificate has been used
• the certificate relates to the correct person
• the certificate has been filled in properly – that is, it is signed, not amended in any way, the doctor’s qualifications filled in, the last date seen alive and whether or not the certifier saw the deceased after death is shown
• the death does not need to be referred to the coroner

3. Other registration checks

Superintendent registrars carry out the following quarterly checks:

• the Quarterly Certified Copy (QCC) entries agree with each register entry
• the entries appear to be in sequence
• there is a medical certificate/coroner’s form to accompany each death entry, as appropriate
• each entry has been signed by an informant (if required) and by the registrar, and
• a general check on any apparent erasure, illegibility etc

Account managers visit registration districts on a cyclical basis and as part of the process will typically include the following inspection activity:

• sitting in on actual registrations to check questioning technique
• examining a sample of register entries and supporting documentation and draft entries
• checking some QCCs against the register
Once the death is registered satisfactorily, the local registrar then drafts the registration and sends a copy on a weekly basis to the Office for National Statistics (ONS).

**Internal validation of ONS mortality data**


1. Receipt of death registration data at ONS Titchfield

Details of deaths are received from register offices electronically. Routine and automated checks are carried out on each file and the combined data are then loaded on to the deaths database. Regular receipt and diagnostic reports are produced, resulting in weekly contacts with the identified registrars to resolve any problems.

Examples of checks include:

- identification of missing entries, so that death registration details are received in sequence
- checks for duplicate records
- checking for misplaced records, for example, verifying that each registrar is using the register allocated
- for paper records – that date of death and date of registration are in the correct range
- for paper records – records are checked for completeness prior to keying
- checks on registrars whose returns have not been received by the fourth working day after the end of each week

2. Validation processes

Once on the database, the data are passed through a series of validation processes which are carried out automatically with any inconsistencies highlighted. Simple validations include examination of dates or employment status to ensure that they are likely. More complicated validations include checks for consistency between dates of birth, death and registration, or between age and marital status.

3. Routine checks in Titchfield

All deaths accepted onto the database that need routine coding are identified and coded as required by the Survey and Life Events Processing Branch (SALEP). The detailed routine coding falls into five main areas:

- postcoding to give usual residence of deceased
- occupation, that is, the occupation of deceased/spouse/civil partner, where age of deceased is over 16 (last occupation if retired); the occupation of the mother and/or father,
where age of deceased is under 16. The Industry and employment status for the deceased and spouse/partner where the deceased was aged 16 to 74

- communal establishment coding for place of death of deceased
- place of birth of deceased, and
- cause of death

Causes of death are coded either through Automated Cause Coding or by a manual process (for example, coroners’ inquests). There are also routine checks of cause of death data.

Those carried out monthly include:

- checking cause fields against inquest verdict fields for compatibility
- the presence or absence of original and final cause of death fields
- codes for ONS cause groups are present for neonatal deaths, and absent for non-neonatals
- validity of suicides at very young ages
- mentioned conditions on death certificate are compatible with sex

Once coding of the cause of death is complete, checks are carried out on variables such as date of death, sex, year of birth, marital status and communal establishments. These checks evolve continuously during exploratory surveillance of data quality, and some of these are later incorporated as routine checks.

4. Checks before and after extraction of data for analysis

The first of these are carried out as a final check of what is held on the deaths database before an annual extract of data is taken. These comprise frequency checks for a range of fields, covering age, sex, underlying cause, and area of residence. Also checked are possibly incorrect combinations of fields. Any apparent errors or inconsistencies result in checks of individual cases by coders who make amendments, as required. Some of these checks are also carried out routinely every month.

Further examinations are carried out once the data extract has been taken. They include checks similar to those done before extraction, to ensure that corrections made at that stage were properly carried out. After the annual extract used for mortality analyses has been produced as a dataset in a statistical computing package, a further set of frequency counts and two-way tables are prepared to ensure that no new errors have been introduced at this stage. These checks are to ensure that the frequency distributions are both valid and plausible and broadly similar to those for the previous year’s data.

5. Checks on routine outputs

At present these include:
• systematic checks of totals (row, column, and other) against known correct figures, such as frequency counts mentioned above or other outputs already accepted, based on similar data. The ‘known correct’ figures are those extracted from the database and from a SAS dataset. These are checked against each other and against ‘accepted as correct’ figures from previous years. Staff also refer back to original table specifications, where necessary

• checks of individual cells against correct figures, as above

• checking figures are consistent and plausible, that is, that they are what would be expected compared to the previous year’s tables

These checks are carried out by the Primary Mortality Outputs team in Vital Statistics Outputs Branch in consultation with a medical epidemiologist.

**External validation of ONS mortality data**

The UK Statistics Authority is an independent body from government and act as a non-ministerial department, directly accountable to Parliament. It was established on 1 April 2008 by the Statistics and Registration Service Act 2007. The UK Statistics Authority monitors and assesses all UK Official statistics, independently. One of the functions of this authority body is to publish “Codes of Practice for Statistics” which sets out the standard that official statistics must meet before they can be designated as National Statistics.

UK was recognised to provide high-quality data on the cause of deaths to WHO in a large review of civil registration systems across the world[^3]. Among the member states of the WHO, UK was among the 31 (13%) countries which provided high quality data, with data completeness of 90-100%. Completeness of statistics on cause of death was defined as the ratio of number of deaths for which cause of death is registered to the civil registration system, to the estimated total number of deaths in the population; the latter includes all deaths registered to the civil registration system (whether cause of death is mentioned or not) as well as those not registered to the civil registration system.

References:


Appendix 2. Internal and External validation of Hospital Episodes Statistics data

Hospital Episodes Statistics (HES) data collection, cleaning and processing cycle¹ (from www.hesonline.org.uk)

HES data for admitted patients, outpatients and A&E is derived from the routine release of information from healthcare providers for National Health Service (NHS) patients in England to the commissioners of the care.

Healthcare providers (ie. hospitals) collect administrative and clinical information locally to support the care of the patient. The data is submitted to the Secondary Uses Service (SUS) which makes it available to the commissioners and copies the information to a database.

SUS sends an extract from their database to HES at pre-arranged dates during the year.

HES then validates and cleans the extract, before making the information available in the data warehouse. At various stages in the cleaning and processing cycle, data quality reports and checks are completed.

The HES Data Warehouse also links with the Office of National Statistics (ONS) mortality statistics to include information on the date of death (when a patient with a record in HES dies).

Figure 1. Method of HES data extraction (from www.hesonline.org.uk)
Figure 1 is a simplified version of how HES data is extracted. It can be divided as follows:

PAS (Patient Administration System): system used by healthcare providers (Hospital Trusts) to submit data to SUS.
XML: specification used for submitting and validating data to SUS.
SUS (Secondary Uses Service): a data warehouse used to store information. Extracts are created from this data warehouse for RTT (Referral to Treatment), PbR (Payment by Results), SEM (SUS Extract Mart) and HES.
HES Input Universe: the raw HES data straight from SUS. This is where the data is cleaned and additional fields are derived.
HES Output Universe: cleaned data is stored here and can be accessed by HES users.

The HES Data Quality team are responsible for cleaning the data, enabling the HES Output Universe to be created from the HES Input Universe.

**Internal validation of HES data (the cleaning process)**

Within the HES Input Universe, cleaning is divided into four phases:

1. **Provider mapping**

   During this stage any old or invalid provider codes are changed/merged to new valid provider codes (using reference data based on information from the ODS website).

2. **Automatic cleaning**

   During this stage a pre-defined list of cleaning rules that remove or correct common errors is worked through, including:

   - Sex: changing M, m, F, f entries to 0, 1, 2 and so on
   - Diagnosis codes: changing the capitalisation on entries, such as k40.3.
   - Operation codes: removing excess characters, such as & and -. The introduction of XML validation is helping to improve data quality from the initial submission stage.

3. **Manual cleaning**

   During this stage:

   - Records outside the relevant date range are removed, eg removing November data from the October extract.
   - Duplicate records are removed.
   - Specific requests from providers to remove data are carried out.

4. **Derivation**

   During this stage the following information is derived:

   - Primary Care Trusts (residence, responsibility and treatment) are derived from the appropriate postcode
   - Mentions
Organisation names from reference data
Group fields, such as age
Descriptions, eg procedures and diagnosis
HES ID, a patient unique ID for each HES data year.

Full details of the cleaning process can be found in the Data Cleaning section.

Feedback

An important part of the cleaning process is feedback. The Data Quality team liaise with providers on a range of subjects, including:

- mapping data to specific providers
- missing data
- duplicate data
- queries about specific sections of data, such as maternity data.

They also:
- encourage providers to clean (correct) their data before the next extract is taken, where possible
- offer advice where issues occur in the submission process
- recommend to providers, where necessary, that they request deletions of data from within SUS itself.

The internal data quality framework

Data quality in SUS
Reports are published regularly and providers can access these reports to assess their data quality. Data Quality Dashboards are also published within SUS, which providers can assess the completeness and quality of their data and compare their performance to the national and regional averages.

Data quality during the data processing cycle
The HES Data Quality team investigates and reports on the quality on data regularly. This helps to recognise and rectify any specific issues involved in the processing of data as well as to ensure that the automated cleaning processes are running correctly.

Data quality in HES
Regular reports are published in the database regarding the information on completeness and quality of HES data. When HES publishes its data, explanatory notes and data quality reports are also published along with its publication on its database.

External validation of HES data

An external validity study for AAA data reported by HES has been recently published². This multi-centre audit on HES AAA data quality assessed the completeness and accuracy of recordings of data in HES when compared to “gold standard” data sets from hospital trusts on all elective abdominal aortic aneurysm repairs in England. This study showed that recording within the HES database was 86.0% accurate when compared to “gold standard” data sets from individual hospitals. In addition this study reported a 99.8% accuracy of survival status in HES compared to that of the Office for National Statistics.
References:

1. www.hesonline.org.uk

Résumés d’articles

Prédiction du risque de décès à long terme après réalisation d’une intervention coronaire percutanée chez le sujet âgé

Résultats issus du Registre national américain de données cardiovasculaires

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Contexte—Cette étude avait pour objectif l’élaboration d’un modèle à long terme à même de prédire le risque de décès après une intervention coronaire percutanée (ICP) chez les patients présentant un infarctus du myocarde avec sus-décalage du segment ST et chez ceux atteints d’une maladie coronaire plus stable.

Méthodes et résultats—Les données du registre CathPCI de la Fondation de l’American College of Cardiology ont été confrontées à la base de données des Centres Medicare et Medicaid (NdH : systèmes d’assurance-maladie gérés par le gouvernement des Etats-Unis et respectivement réservés aux personnes de plus de 65 ans et à celles ayant un faible revenu) par appartenance probabiliste. Les caractéristiques démographiques et cliniques préopératoires saisies dans le registre CathPCI ont été utilisées pour prédire la probabilité de décès à 3 ans en ayant recours à la base de données des Centres Medicare et Medicaid pour recenser les décès effectivement survenus. Entre 2004 et 2007, le devenir de 343 466 (66 %) des 518 195 patients âgés de 65 ans ou plus enregistrés dans le registre CathPCI comme ayant fait l’objet d’une première ICP a pu être établi par consultation de la base de données des centres Medicare et Medicaid. Cette population d’étude a été aléatoirement scindée en une cohorte de dérivation regroupant 60 % des patients et une cohorte de validation formée des 40 % restants. La durée médiane de suivi a été de 15 mois, la mortalité observée ayant été de 3,0 % à 30 jours et de, respectivement, 8,7 ; 13,4 et 18,7 % à 1, 2 et 3 ans. Nous avons constaté que le risque de décès avait été sous-tendu par 24 facteurs en rapport avec les caractéristiques démographiques, les pathologies associées, les antécédents d’affections médicales et les degrés de sévérité et d’acuité de la maladie. Dans la cohorte de validation, les statistiques C respectivement obtenues pour les patients qui avaient été victimes d’un infarctus du myocarde avec sus-décalage du segment ST et pour ceux n’ayant pas présenté d’événement de ce type ont été de 0,79 et 0,78. Le modèle s’est révélé bien calibré sur une large fourchette de risques attendus.

Conclusions—En nous appuyant sur le vaste registre CathPCI représentatif du contexte national, nous avons conçu un modèle permettant de prédire les chances de survie au cours des 3 ans faisant suite à une ICP et dont le pouvoir de discrimination, la calibration et la validation se sont révélés excellents. (Traduit de l’anglais : Prediction of Long-Term Mortality After Percutaneous Coronary Intervention in Older Adults: Results From the National Cardiovascular Data Registry. Circulation. 2012;125:1501–1510.)

Mots clés : maladie coronaire | mortalité | intervention coronaire percutanée | registres | revascularisation

Evolution de l’épidémiologie des anévrismes de l’aorte abdominale en Angleterre et au Pays de Galles

Plus tardifs et moins graves ?

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Contexte—De récentes études menées en Australie, en Nouvelle-Zélande et en Suède font apparaître une diminution de l’incidence, de la prévalence et du taux de mortalité des anévrismes de l’aorte abdominale (AAA). Cette observation pourrait avoir d’importantes conséquences pour les programmes de dépistage. La présente étude a donc été entreprise pour examiner les tendances en matière d’incidence des AAA et de mortalité afférente en Angleterre et au Pays de Galles.

Méthodes et résultats—Les données sur les causes des décès survenus en Angleterre et au Pays de Galles entre 2001 et 2009 ont été obtenues auprès de l’Institut national de statistiques du Royaume-Uni et les informations sur les hospitalisations et les interventions enregistrées en Angleterre au cours de la même période l’ont été en consultant les Hospital Episode Statistics (base de données hospitalières du National Health Service). Des modèles par régression de Poisson ont été élaborés pour estimer les modifications relatives intervenues au cours du temps. Nous avons constaté que, tant en Angleterre qu’au Pays de Galles, les taux de décès par AAA ajustés en fonction de l’âge avaient connu une baisse significative de 35,7 % entre 2001 et 2009, laquelle était due pour une large part à la diminution de 35,3 % des taux de décès secondaires à une rupture d’AAA ajustés à l’âge. Au cours de la même période, les hospitalisations pour rupture d’AAA et les réparations d’anévrismes en urgence intervenues en Angleterre ont diminué de, respectivement, 29,3 et 35,5 %. En revanche, le taux d’hospitalisation pour AAA non rompus est demeuré stable et celui des réparations d’AAA non urgentes a augmenté de 17,2 %. L’âge moyen des patients à la date d’admission a augmenté de 0,19 année par an (p <0,001) dans le cas de AAA non rompus et de 0,09 année par an (p <0,001) dans le cas de ruptures d’anévrisme. Les hospitalisations pour AAA non rompus ont augmenté de 21,4 % pour les patients âgés de 75 ans ou plus, mais ont diminué de 11,7 % chez ceux âgés de moins de 75 ans.


Mots clés : anévrismes de l’aorte abdominale | épidémiologie | incidence | mortalité | taux de mortalité

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