Deaths from pertussis are underestimated in England

N S Crowcroft, N Andrews, C Rooney, M Brisson, E Miller

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Mortality statistics are used to evaluate the impact of immunisation programmes and must be accurate for this purpose. A previous study identified 12 deaths from pertussis in England and Wales in 1995–97 through enhanced surveillance of laboratory confirmed cases, compared to only five in Office for National Statistics (ONS) mortality data from death registration. This study examines death registrations in greater detail and compares these with deaths identified from enhanced laboratory surveillance and hospital episode statistics (HES) for the period 1994–99. The objectives were to improve estimates of deaths from pertussis in England and to identify reasons for underascertainment.

Aims: To improve estimates of deaths from pertussis in England and to identify reasons for underascertainment.

Methods: Comparison of deaths identified from enhanced laboratory pertussis surveillance, hospital episode statistics (HES), and Office for National Statistics (ONS) death registrations in England, 1994 to 1999.

Results: A total of 33 deaths were identified, 88% of infants less than 4 months old. There was overlap between all sources; 22 deaths were identified in the enhanced pertussis surveillance system, 18 in ONS mortality data, and nine in HES. Children who had died from pertussis without mention of pertussis on the death certificate were more likely to have been certified by coroners than those with mention of pertussis \((p = 0.0005)\). Using capture-recapture analysis, the total number of deaths from pertussis in the five and a half year period is estimated to be 46 (95% CI 37 to 71), or around nine deaths per year.

Conclusions: National mortality statistics significantly underestimate deaths from pertussis in England and are inadequate for monitoring the national immunisation programme. The largest number of deaths is identified through enhanced laboratory surveillance. Death registration systems should take into account available microbiological information to ensure that cause of death is accurately assigned.

RESULTS

Five deaths from delayed effects of pertussis were excluded. For four of the five individuals, all aged over 50 years, the final underlying cause of death was bronchiectasis.

In total, 33 deaths were detected from the three sources during the six years. There was overlap between all the sources (fig 1); 22 deaths were in the enhanced pertussis surveillance system, 18 in ONS data, and nine in HES. Hospital episodes for all but one of the infants missing from HES could be found, but they were not coded as having died during the admission. From the death certificates, all 33 infants died in an NHS hospital.

The median age at death was 1.7 months (range 2 weeks to 17 months). Twenty nine of the 33 deaths (88%) were of infants aged less than 4 months, too young to have been fully immunised.

None of the three possible two-way interactions were significant, but in view of the likelihood of interaction, that between ONS and HES which was close to significance...
For 15/33 deaths (45%) the medical certificate of cause of death did not mention pertussis. This occurred for 13 deaths identified through enhanced surveillance, one death in the HES, and one death of an infant who was identified in both. Of these 15 infants, eight (53%) had been certified by coroners. In contrast, all of the 18 infants with a mention of pertussis on the death certificate had been certified by doctors (Fisher’s exact test, p = 0.0005). In four (22%) of these 18, the cause of death had been amended to pertussis after the original death registration. Table 1 shows the causes of death on the death certificates of the 15 infants for whom there is no mention of pertussis. This includes the 14 from whom *Bordetella pertussis* had been cultured, of whom seven were certified by coroners. None of the deaths certified by coroners had indicated that bacteriology might be available later and none had been amended.

In the period 1993–99, certificates which included any mention of the causes in table 1 gave it as the underlying cause of death for 273/834 (33%) infants less than 28 days old and 549/625 (88%) infants aged 28 days to 1 year old (table 2). Coroners were more likely to assign cause of death to pneumonia, organism unspecified (ICD9 486), given in 68% of deaths certified by coroners for infants less than 28 days old compared with 24% by doctors (p < 0.0005), and in 39% of deaths certified by coroners in infants 28 days to 1 year old compared with 21% by doctors (p < 0.0005). Doctors were more likely than coroners to ascribe the cause of death to primary pulmonary hypertension (60% versus 11% in neonates, and 13% versus 7% in infants 28 days to 1 year old, p < 0.0005). In infants 28 days to 1 year old, doctors were more likely to assign cause of death to infantile cerebral palsy (17% versus 7%,

### Table 1  Final cause of death in infants who were identified as having pertussis in other data sources, but certified without mention of pertussis

<table>
<thead>
<tr>
<th>Final underlying cause of death (ICD9)</th>
<th>Cause of death</th>
<th>Number of deaths certified by coroner</th>
<th>Number of deaths certified by doctor</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>420</td>
<td>Acute pericarditis</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>343.9</td>
<td>Infantile cerebral palsy</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>481</td>
<td>Pneumococcal pneumonia (lobar pneumonia, organism unspecified)</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>416.0</td>
<td>Primary pulmonary hypertension</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>425.4</td>
<td>Other primary cardiomyopathies</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>427.5</td>
<td>Cardiac arrest</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>466.1</td>
<td>Acute bronchiolitis</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>482.3</td>
<td>Pneumonia due to streptococcus</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>486.0</td>
<td>Pneumonia, organism unspecified</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>747.0</td>
<td>Patent ductus arteriosus</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>8</td>
<td>7</td>
<td>15</td>
</tr>
</tbody>
</table>

### Table 2  Number of deaths in 1993–99 in infants where one of the causes of death in table 1 was given as the final underlying cause of death

<table>
<thead>
<tr>
<th>Final cause of death (ICD9)</th>
<th>Infants less than 28 days old</th>
<th>Infants 28 days to 1 year old (total 549 infants)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number certified by coroner</td>
<td>Number certified by doctor</td>
<td>Number certified by coroner</td>
</tr>
<tr>
<td>343.9</td>
<td>0</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>416.0</td>
<td>6</td>
<td>132</td>
<td>3</td>
</tr>
<tr>
<td>425.4</td>
<td>4</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>427.5</td>
<td>1</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>466.1</td>
<td>1</td>
<td>4</td>
<td>50</td>
</tr>
<tr>
<td>486.0</td>
<td>36</td>
<td>52</td>
<td>75</td>
</tr>
<tr>
<td>Others</td>
<td>5</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>53</td>
<td>220</td>
<td>193</td>
</tr>
</tbody>
</table>

Figure 1  Overlap between deaths in enhanced pertussis surveillance system (ES), ONS mortality database (ONS), and hospital episode statistics (HES).
DISCUSSION

As diseases become rarer with successful immunisation programmes, inaccuracies in the mechanisms for monitoring the burden of disease become more important. Laboratory surveillance of pertussis is known to be incomplete because culture is at best 80% sensitive, and not all infants are investigated. Deaths may not be detected through HES because the infant died before they could be admitted or after leaving hospital, because the diagnosis was not suspected, or because of data errors. As expected, all of the identified deaths from pertussis took place during a hospital admission, so the incompleteness of HES is likely to be caused by error. Some deaths will not be identified as being caused by pertussis in any routine system. Sudden infant death syndrome may be caused by pertussis but is unlikely to be accurately ascribed to pertussis and unlikely to be detected through HES, laboratory, or ONS mortality data.¹

Death registration only identified 18 deaths from pertussis in 1994–99. This is 55% of the deaths identified using multiple sources, and only 40% of the estimated total of 46 deaths. Under ascertainment of pertussis in mortality statistics is a long standing problem.² Virtually all deaths are registered in England and Wales, which requires a certificate of cause of death from a doctor or a coroner. Thus if deaths from pertussis do not appear in the mortality database, this is because of the culture is at best 80% sensitive, and not all infants are investigated. Some of these results, particularly microbiological investigations, may only become available some time after death. In most of the cases certified by doctors, antemortem bacteriology established the cause as pertussis, either before the death was certified or subsequently. In the eight deaths certified by coroners, the postmortem examinations did not include bacteriological examination. In seven of these, bacteriology showed pertussis. However, the coroners and their pathologists apparently did not have access to this information, either at the time of certification or later. Whoever certifies the cause of death, whether doctor or coroner, should ensure that they obtain the results of any relevant bacteriology investigations. If these cannot be obtained quickly, and the death is not suspicious, they can certify it with the most accurate cause they know, but should indicate that further information may be available later. If the certifying doctor or coroner indicates that results may be available later, ONS will write to them to get this information and amend the coded cause of death on the mortality database. Similar problems may affect other infectious diseases such as meningococcal infection. Coroners should be enabled and encouraged to provide an accurate cause of death for infectious diseases where the data are used for the surveillance of major public health interventions such as mass immunisation programmes.

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Authors’ affiliations

N S Crowcroft, C Rooney, Demography and Health, Office for National Statistics, 1 Drummond Gate, London SW1V 2QX, UK

N Andrews, M Brisson, E Miller, Immunisation Division, Public Health Laboratory Service Communicable Disease Surveillance Centre, 61 Colindale Avenue, London NW9 5EQ, UK

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