The burden and impact of measles among the Gypsy–Traveller communities, Thames Valley, 2006–09

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ABSTRACT

Background Outbreaks of measles in Gypsy–Traveller communities are well recognized. Their contribution to the overall burden of disease is less clear.

Methods Measles case-management information was collated retrospectively for the Thames Valley population comprising 2.2 million people over the 4-year period from 2006 to 09. Suspected cases notified by general practitioners and hospital clinicians were sent a saliva testing kit. Cases were defined as those whose measles IgM was positive. Risk factor information was collected and collated including vaccination and membership of the Gypsy–Traveller communities.

Results Of 142 cases of laboratory confirmed measles, 63% were in Gypsy–Traveller communities. These included 10 family clusters and outbreaks confined to the Gypsy–Traveller communities and one with a wider spread. The pattern was consistent across the 4 years studied. Among the Gypsy–Traveller communities 27 of 55 cases eligible for measles, mumps and rubella (MMR) vaccination had received one MMR vaccination. Overall seven cases were admitted to hospital with either pneumonia or dehydration.

Conclusion These findings showed a more than 100-fold higher incidence in the Gypsy–Traveller communities than the rest of the population. The high burden of disease in the Gypsy–Traveller communities highlights the importance of targeting immunization resources towards these communities.

Keywords communicable diseases, public health, social determinants

Introduction

Measles is an acute viral and highly communicable, vaccine preventable disease with an average incubation period of 10 days (typical range of 7–18 days). It is associated with high rates of hospitalization and major complications including pneumonia, encephalitis and, occasionally, death. The UK childhood immunization schedule offers one dose of measles, mumps and rubella (MMR) vaccine between 13 and 15 months and a second dose between 3 and 5 years of age achieving generally good control of these diseases. Vaccination coverage in the UK dropped from 92 to 85% following publication of research suggesting an association with autism. Slow recovery was seen following later evidence that this research was flawed with and further systematic reviews of research showing no support for this association. Restoring vaccination coverage in the UK has been supported by substantial campaigns headed by the Chief Medical Officer in the Department of Health.

Lower vaccination coverage is also identified in some population groups, in particular the Gypsy–Traveller communities. The reasons for the low uptake of vaccination have been shown to be diverse. They include cultural factors, misinformation about the MMR vaccine, lack of targeted catch-up immunization programmes and as observed during these outbreaks, lack of trust in health-care workers (HCWs) and poor access of health services. The numbers of Gypsy–Travellers in Britain are not accurately known due to lack of census data, and surrogate methods...
(e.g. caravan counts) give only approximate numbers. Best estimates suggest that there are around 300,000 Gypsy–Travellers in the UK, implying that this is a significant minority ethnic group which is \(~0.5\%\) of the total population.\textsuperscript{13–15} In 2006, 740 laboratory confirmed measles cases were reported in England and Wales to the Health Protection Unit, with many clusters of cases linked to Gypsy–Traveller communities [9] and it appears that this group bears a substantial, though not precisely quantified, portion of the total burden of measles in the UK. Surveillance has not routinely or reliably identified whether cases of disease are members of the Gypsy–Traveller communities. This study was undertaken to clarify the relative burden and the pattern of measles in these communities over 4 years in the Thames Valley area and to assess the pattern of measles in the Gypsy–Traveller communities.

Methods

The study which was undertaken in the Thames Valley area comprised the counties of Berkshire, Buckinghamshire and Oxfordshire, with a population of 2.2 million and covered the period of 1 January 2006–31 December 2009. The Gypsy–Traveller population is estimated to be \(~0.5\%\) of the total population.

The national caravan survey to allow a comparison between areas of the Thames Valley in 2008 showed that there were 375 caravan sites in Oxfordshire, 340 in Berkshire and 316 in Buckinghamshire.\textsuperscript{14–16} The Gypsy–Traveller caravan numbers in England increased from 12,474 in January 2006 to 14,047 by January 2008 and by January 2011 the number had reached 18,383.\textsuperscript{17} Suspected cases of measles were notified to the Health Protection Unit covering the area by either general practitioners (GPs) or hospital clinicians or were identified as part of cluster investigation. A case of measles was defined as a patient with clinically suspected measles which was confirmed by the national reference laboratory by positive measles IgM or RNA detected in the oral fluid or serum. Each case of suspected measles was sent a saliva testing kit by the local Health Protection Unit in line with national protocols.

Information was obtained from health-care staff and cases or their parents to ascertain whether the case was a member of the Gypsy–Traveller communities; had contact with other measles cases; had travelled abroad and had their vaccination status. Information on whether they had sought medical advice was obtained by interview with patients/cases during public health follow-up of cases and clusters. Vaccination status was validated with GPs and child health information systems where possible.

Results

A total of 142 cases of laboratory confirmed measles were identified over the 4-year period (Table 1). The median age of the cases was 6.5 years (range <1–38 years). Of these, 90 (63\%) were in the Gypsy–Traveller communities, mostly occurring within 10 outbreaks of 2–15 cases on 6 sites in Thames Valley. Cases among the Gypsy–Traveller communities accounted for at least 45\% of cases in the Thames Valley population in each of the 4 years studied (Table 2). 55\% of the Gypsy–Traveller cases were children under the age of 5 years. In view of the reluctance by these communities to seek medical advice, it is possible that the number of cases could have been higher.

Table 1 outlines the distribution of measles outbreaks across the Thames Valley area, according to the county in which the patients were resident at the time of notification and whether the cases were members of Gypsy–Traveller communities.

Most of the confirmed cases occurred within the Gypsy–Traveller family communities based in either Berkshire or Buckinghamshire, with few cases in Oxfordshire.

Of 55 confirmed cases in the Gypsy–Traveller communities eligible for vaccination (aged over 13 months of age), and for whom reliable information was available, 27 had had one MMR vaccination. An additional seven were reported to have had a single measles vaccination, although these reports could not be confirmed. Cases among non-Gypsy–Travellers resulting from transmission in schools and churches were up to date with their immunizations as per the national immunization programme, apart from MMR. The reason given by parents of both cases was a fear of autism associated with the vaccine.

Seven cases were admitted to hospital five of whom were Gypsy–Travellers with either dehydration or pneumonia. The other two were adult cases from a church-associated cluster. No other serious complications were identified. Admission to hospital was the first time that some of these patients sought medical advice, possibly indicating that these patients would not have been identified if they had not suffered severe illness. The main reason given for not seeking medical advice from the GPs was perceptions that GPs were unwilling to attend or listen to them. Many stated a preference for attending acute hospitals when complications developed because ‘hospital doctors know how to treat measles’.

Most identified transmission within the Thames Valley was among Gypsy–Traveller households or close relatives (Table 2). One outbreak was traced to three Gypsy–Traveller households, then to a school setting and from there to a church setting (Fig. 1). External sources of infection were
associated with recent travel within the UK and visits from elsewhere in the UK including one from a relative who travelled from Scotland where there was an outbreak of measles among the Gypsy–Traveller communities. However, travel-related infection was often difficult to confirm as the cases or guardians were unwilling to provide detailed information on their travel history.

Discussion

Main findings of this study

The Gypsy–Traveller communities is widely recognized as having an excess burden of measles infection. The findings of this study are nonetheless striking. It showed that the majority of cases identified over a 4-year period belonged to the Gypsy–Traveller communities which comprised ≈0.5% of the total population. This represents an excess risk of more than 100-fold in these communities. This large proportion of cases was consistent over the 4-year period and not the result of a single or small number of unusual events. This suggests that this is a sustained pattern. In one outbreak, spread to non-Gypsy–Traveller members of the adjacent community was also identified. No other instances of infection spread between the Gypsy–Traveller communities and the non-Gypsy–Traveller communities were identified. The study also identified factors affecting health-seeking behaviour in the Gypsy–Traveller populations.

What is already known on this topic

Earlier studies have also identified widespread communication difficulties between HCWs and the Gypsy–Traveller communities. These include reluctance by GPs to register them or visit caravan sites. Fear of hostility or prejudice from health-care providers including being denied access to GPs by receptionists has been reported to contribute to reluctance by the Gypsy–Travellers’ in accessing or utilizing

<table>
<thead>
<tr>
<th>Year</th>
<th>Berkshire</th>
<th>Buckinghamshire</th>
<th>Oxfordshire</th>
<th>Annual total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not Gypsy–Traveller</td>
<td>Gypsy–Traveller</td>
<td>Not Gypsy–Traveller</td>
<td>Gypsy–Traveller</td>
</tr>
<tr>
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<td>15</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>2007</td>
<td>9</td>
<td>4</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>2008</td>
<td>12</td>
<td>21</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>2009</td>
<td>10</td>
<td>15</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>31</td>
<td>55</td>
<td>19</td>
<td>33</td>
</tr>
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</table>

Table 1 Confirmed measles cases, 2006–2009, Thames valley, UK by county and whether a member of the Gypsy–Traveller communities

<table>
<thead>
<tr>
<th>Date of notification</th>
<th>Primary care trust</th>
<th>Cases</th>
</tr>
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<tbody>
<tr>
<td>May–June 2006</td>
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<td>15</td>
</tr>
<tr>
<td>May–June 2006</td>
<td>Buckinghamshire</td>
<td>12</td>
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<tr>
<td>June 2006</td>
<td>Oxfordshire</td>
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</tr>
<tr>
<td>June–August 2007</td>
<td>Berkshire East</td>
<td>4</td>
</tr>
<tr>
<td>April–June 2007</td>
<td>Buckinghamshire and Milton Keynes</td>
<td>9</td>
</tr>
<tr>
<td>March 2008</td>
<td>Buckinghamshire</td>
<td>5</td>
</tr>
<tr>
<td>August 2008</td>
<td>Berkshire West</td>
<td>3</td>
</tr>
<tr>
<td>October 2008</td>
<td>Berkshire East</td>
<td>5</td>
</tr>
<tr>
<td>December 2008</td>
<td>Berkshire West</td>
<td>13</td>
</tr>
<tr>
<td>January–February 2009</td>
<td>Berkshire West</td>
<td>12</td>
</tr>
<tr>
<td>February–March 2009</td>
<td>Berkshire East</td>
<td>3</td>
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<tr>
<td>May 2009</td>
<td>Buckinghamshire</td>
<td>7</td>
</tr>
<tr>
<td>May 2009</td>
<td>Oxfordshire</td>
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</tbody>
</table>

Table 2 Gypsy–Traveller confirmed measles cases grouped by outbreak, Thames Valley, 2006–09

Fig. 1 Time course and transmission events for measles cases in Gypsy–Traveller communities and a wider community cluster showing the week of onset and age (inside each box) of cases, Thames Valley, 2008–09.
health services. These were also some of the reasons given by cases or their parents for not seeking health-care advice from their GPs. Some of our cases additionally cited a belief that GPs do not know how to treat measles. Earlier studies have also shown that health professionals, for their part, lack knowledge about the beliefs and culture of the Gypsy–Traveller communities.12,24,26

What this study adds
The main information added by this study is a quantitative estimate of the scale of excess burden of illness suffered by the Gypsy–Traveller communities. It additionally demonstrated that a substantial minority of cases occurred in those who had been partially but not completely vaccinated. Although Oxfordshire has the largest number of caravan sites, only two small outbreaks occurred as compared with seven relatively large outbreaks in Berkshire and four in Buckinghamshire (see Table 2). This may have been attributed to Oxfordshire having a longstanding provision of targeted immunization services for Gypsy–Traveller communities. Taken together these findings suggest that there is a substantial preventable burden of disease in these communities that can be addressed by appropriate health-care services.

The very high burden of disease in the Gypsy–Traveller communities argues for targeting of immunization resources on this community, so long as effective interventions are possible. Locally the data from this study are leading to a range of interventions. The same issues are likely to apply in other areas.

More widely than measles and the Gypsy–Traveller communities, this work highlights the importance of the intelligence gained by robust surveillance systems to understand the distribution of disease in the community. This intelligence can allow targeting of interventions and improvements of health equity.

Limitations of the study
The study was confined to the Thames Valley and is not quantitatively representative of the national or international population. However, the recurrence of similar patterns across the 4-year study period in the relatively large background population of 2.2 million makes it unlikely that this is a temporary or purely local phenomenon. Our findings are likely to be relevant to many other parts of the UK and possibly more widely.19–21

A possible bias in our study is that case ascertainment may have varied between the Gypsy–Traveller and non-Gypsy–Traveller communities. Reluctance to present measles to GPs by the Gypsy–Traveller communities may have decreased the probability of identification and reporting. This was evidenced in this study by some parents who reported being unable to read immunization reminders sent by their general practices. In contrast, other factors may have increased the probability of identification and reporting of cases among the Gypsy–Traveller communities including:

(i) awareness of measles among these communities;
(ii) awareness of the increased risk of measles in this community among HCWs;
(iii) the occurrence of cases in clusters, with new cases coming to light during the public health follow-up of these clusters.

Therefore there may be some overestimate of the relative excess of cases that this community suffers. However, given the strength of the association observed this bias is not likely to alter the substantive conclusion of a very marked excess or the public health implications arising from this.

Acknowledgements
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References