Mapping the Gypsy Traveller community in England: what we know about their health service provision and childhood immunization uptake

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ABSTRACT

Background A series of reports over the last two decades have concluded that the overall health status of UK Gypsy Traveller Community is very poor when compared with the general population and relatively poor in comparison with other disadvantaged groups. Despite a government commitment to reducing health inequalities, differences in health outcomes and in healthcare access and service provision have persisted.

Methods In order to understand immunization services for Gypsy Travellers, the Health Protection Agency conducted a survey and mapping exercise of Primary Care Trusts in England to ascertain what is known about local Gypsy Traveller populations, estimate immunizations rates and describe current services to increase immunization as well as to address wider health issues.

Results Despite improvements in the provision of specialist services for the Gypsy Traveller communities in England, there still remains a considerable number of areas where knowledge of population numbers is poor, service provision is not based on need and the uptake of immunization is low or not known.

Conclusion There is an ongoing need to improve knowledge of population numbers and the provision of and access to services that are culturally sensitive and responsive to the needs of Gypsy Traveller communities. Whilst we have focused on describing immunization uptake, immunization services are only one component of a wider strategy for improving the health of Gypsy Travellers through effective health and social care interventions.

Keywords communicable diseases, ethnicity, immunization

Introduction

A series of reports over the last two decades have concluded that the overall health status of Gypsy Travellers (Box 1) in the United Kingdom is very poor when compared with the general population and relatively poor in comparison with other disadvantaged groups. Despite a government commitment to reducing health inequalities, differences in health outcomes and in healthcare access and service provision have persisted. The most recent Public Health White Paper13 reiterates these findings, specifically drawing attention to the significantly poorer life expectancy of Gypsy Travellers in England when compared with other ethnic groups, even after adjustment for socioeconomic status. The Social Exclusion Task Force also completed an analysis and evidence review into the primary health care and wider health and social care needs of socially excluded groups14 as part of The Inclusion Health workstream. The Gypsy Traveller community was a big focus of this work. Within this overall picture, children within the Gypsy Traveller community remain at risk of not
being fully immunized\textsuperscript{16–18} and in recent years, a number of measles outbreaks have been reported in Gypsy Traveller communities in the United Kingdom and Europe.\textsuperscript{19–23}

\textbf{Box 1 Defining the Gypsy Traveller community}

In the United Kingdom, Gypsies and Irish Travellers have been recognized as distinct ethnic groups in law since 1989 and 2000, respectively.\textsuperscript{41} Despite this recognition in law, they only became part of routine ethnicity monitoring in major surveys such as the Office for National Statistics (ONS) National Census, the General Household Survey and the Health Survey for England in 2011. The notable exception to this is the DFE School Census of children in England where a category for Gypsy and Roma children has been included for some years. In studies of their health and healthcare provision, the term Gypsy Traveller is often used as a generic term to variably include English Gypsies, Welsh Gypsies, Scottish Gypsy Travellers, Irish Travellers and Romany Gypsies from Europe. Each of these groups has a separate ethnic identity, but they share many aspects of a common cultural identity. Health studies often tend to exclude as a subcategory Showmen and New Travellers who also often have a mobile lifestyle but may have a different cultural tradition. UK government definitions for housing and planning purposes for the Gypsy Traveller population have evolved over the years with the latest definition inclusive of people who would otherwise be classified as Showmen and New Travellers. The government now defines ‘gypsies and travellers’ as:

(i) persons with a cultural tradition of nomadism or of living in a caravan and

(ii) all other persons of a nomadic habit of life, whatever their race or origin, including:

(a) such persons who, on grounds only of their own or their family’s or dependant’s educational or health needs or old age, have ceased to travel temporarily or permanently; and

(b) members of an organized group of travelling show people or circus people (whether or not not travelling together as such).\textsuperscript{42}

This definition includes those ethnic Gypsy Travellers that are now permanently housed and have given up the travelling lifestyle. These are estimated to be 50% of the ethnic Gypsy Traveller population.\textsuperscript{1,8} The utility of using a broad definition like this in the design of health services is that it aids planning for all peoples with a mobile lifestyle (such as New Travellers and Showmen), whilst still allowing culturally and ethnically sensitive interventions to be developed for Gypsy Travellers without one.

The latest national census conducted in 2011 estimates that there are 57,680 Gypsy Travellers in England and Wales.\textsuperscript{24} However, estimates from health studies and other government reports suggest that between 90,000 and 120,000 Gypsy Travellers live a mobile lifestyle with a similar number now in permanent housing. The total Gypsy Traveller population of England is thus thought to range from 200,000 to 300,000.\textsuperscript{8,25,26} In England currently, the Health Protection Agency (HPA) is responsible for surveillance of infectious diseases and advises the National Health Service (NHS) on immunization and control of vaccine preventable infections. For this purpose currently, the agency has 26 Health Protection Units (HPU) geographically distributed around the country who liaise closely with Primary Care Trusts (PCT) and Unitary Authorities/Local Authorities (UA/LAs) in their geographical area. From April 2013, HPUs will be incorporated into a new central organization called Public Health England, with their primary surveillance functions remaining largely unchanged. In order to understand immunization services for Gypsy Travellers, the HPA conducted a study of PCTs in England to ascertain what is known about local Gypsy Traveller populations, estimate immunizations rates and describe current services to increase immunization as well as to address wider health issues. In addition, this analysis may inform strategies for improving access to wider community-based health and social care interventions for this marginalized group.

\textbf{Methods}

This study involved two distinct processes: geographical analysis to map population data and a national survey.

\textbf{Geographical mapping of Gypsy Traveller population}

Geographical mapping of Gypsy Traveller communities in England was conducted to make an estimate of their total numbers and to compare this to service provision. This aimed to identify where tailored immunization services and interventions may be required to improve uptake. This was achieved primarily by collecting the latest available figures from the biannual count of gypsy/traveller caravans conducted by the Department for Communities and Local Government (DCLG) in England (Box 2). Estimates derived from the latest annual Department for Education (DFE) count of school children and published estimates of Gypsy Traveller numbers from past studies also informed the results. However, the DFE survey excludes those children who are dually registered (i.e. children registered in multiple schools in different parts of England). As a mobile population like Gypsy Travellers may be disproportionately affected by an exclusion of this type, the study investigators requested the
figures be re-run by the National Statistics team to include dually registered pupils.

**Box 2 Primary data sources in England for estimating numbers of Gypsy Travellers**

(i) The DCLG conducts a biannual count of Gypsy and Traveller caravans during the months of January and July. The count of Gypsy caravans (GS1) return is sent to all English UA/LAs. It requires a count of Gypsy caravans, families, adults and children aged 0–16 on unauthorized sites on Gypsies’ own land (without planning permission) distinguishing between those which are tolerated and not tolerated; unauthorized sites (without planning permission) on land not owned by Gypsies, again distinguishing between those which are tolerated and not tolerated; and authorized sites (with planning permission), distinguishing between council and private sites. However, the data on numbers of adults and children are not analysed and therefore never published.

(ii) The DFE School Census has collected key data on around 8 million pupils and around 25 000 schools annually since 2002. Breakdowns of results are available for each UA/LA in England. It is the only national census at present where ethnicity monitoring includes a separate category for Gypsy/Roma children.

(iii) A national census has been conducted in the UK every 10 years since 1801. It is a count of all people and households. Data are collected on the same day and the same core questions of the whole population are asked. In England and Wales, the national survey is carried out by the ONS. The last census was held on Sunday 27 March 2011 and is the first time that Gypsies and Irish Travellers have been included as a distinct ethnic group.

MAPINFO software was then used to map Gypsy Traveller caravan distribution according to all 320 UA/LA boundaries.

**National survey**

Between September and December 2010, questionnaires were sent electronically to all 26 HPUs in England requesting information on caravan sites, Gypsy Traveller populations, estimated vaccine uptake and specific immunization wider health and social service provision in their respective geographical area of coverage. The questionnaires were completed using information from the HPUs themselves and the 151 PCTs that the HPUs serve. PCTs also gained information from the UA/LAs they are geographically aligned with.

The same MAPINFO process was used to overlay specific Gypsy Traveller immunization service information gained from the national survey onto population estimates to ascertain current service provision.

**Results**

**Geographical mapping of Gypsy Traveller population**

From our mapping exercise, the geographical distribution by UA/LA of Gypsy Traveller caravans in England is presented in Fig. 1. Of 320 UA/LAs, 47 (14.7%) had no caravans; 223 (69.7%) had between 1 and 99 caravans; and 50 (15.6%) had 100 or more caravans within their geographical bounds. The latest DFE School Census in England from January 2010 has counted 10 990 schoolchildren between the ages of 5–17 as being Gypsy or Roma. When the figures were re-run to include dually registered pupils, a smaller-than-anticipated increase occurred in the total number of schoolchildren of Gypsy or Roma origin to 11 294.

**National survey**

A total of 26 (100%) HPUs responded to the survey providing information for a total of 135 PCTs out of the 151 (89.4%) PCTs in England. Of the 135 PCTs providing questionnaire responses, only 88 (65.2%) reported having knowledge of caravan sites within the PCT boundaries and sites were identified as authorized, unauthorized, public (council owned) or private; 4 (3%) provided information on housed Gypsy Travellers as well as roadside encampments; 18 (13.3%) reported no caravan sites within the PCT area; and 29 (21.5%) did not know information on caravan sites. The DCLG caravan count from July 2010 identified a total of 18 148 caravans in England, including those on unauthorized (without planning permission) sites.

**Immunization and wider health care service provision**

PCTs were asked whether there are commissioned dedicated health care workers to provide proactive immunization services for local Gypsy Traveller communities. Table 1 shows that 37/135 (27.4%) PCTs stated that there was a dedicated service for Gypsy Traveller communities (this included eight PCTs who were unable to report the number of caravan sites). Of these 37 (27.4%) PCTs with a dedicated service, 7 (18.9%) explicitly stated that this individual provided immunization to Gypsy Travellers’ onsite. In 4/37 (10.8%) PCTs, the healthcare worker reviewed the immunization status as part of a more general health assessment and referred those requiring vaccination onto a General Practitioner (GP) or immunization nurse. In the remaining 26/37 (70.3%) PCTs, the roles commissioned varied and included health
visitor liaison between the PCTs and Gypsy Travellers, specialist health visitors, health advocates and health inclusion workers that provide health promotion and/or health assessments/health checks including immunization advice. One PCT had two healthcare workers from the Gypsy Traveller community itself who undertake all aspects of

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Fig. 1 Distribution of Gypsy Traveller caravans by UA/LA in England and PCT identified healthcare workers providing immunization service.
healthcare work as well provide advice and support for social issues.

A further 26/135 (19.3%) PCTs offer services for Gypsy Travellers that are not dedicated but form part of the health visitor and immunization nurse workloads or generic children services. Six of these PCTs provide onsite vaccinations by the health visitor or immunization nurse, and three PCTs refer those identified in need of vaccination onto the GP or local ‘failsafe’ teams for follow-up.

Of 88 PCTs with knowledge of a local Gypsy Traveller population, 23 (26%) either provided no information or stated no service consideration had been made for Gypsy Traveller communities. PCT locations in England where a HCW service was identified (both dedicated and as part of a broader remit of healthcare staff) are geographically displayed in Fig. 1.

**Immunization uptake in the Gypsy Traveller community**

Figure 2 details 20/88 (25%) of the PCTs with knowledge of local caravan sites who were able to estimate coverage of the third dose of polio, an additional two of these also provided estimates of uptake of first dose MMR. These two vaccinations are good proxy indicators for adherence to the childhood vaccination schedule. Whilst these estimates are collated locally, only 25% of the PCTs with site knowledge provided estimates, and, given the difficulties in assessing this population group, these figures should be read with caution. However, to compare the figures we do have, the national coverage rates in England for Polio and MMR immunization at 2 years of age were 96 and 89%, respectively, in 2010 and 2011.29

**Other sector service provision**

Of the 135 PCTs, 72 (53.3%) were able to identify that one or more of the LAs within their geographical area provided services aiming to improve the health of local Gypsy Traveller populations (Table 1). The majority of services support community development, education and learning in children and capacity building (learning and training) in Gypsy Travellers. Some LAs also provided housing services and employed liaison officers to help Gypsy Travellers get access to mainstream services such as health care. Five LAs also delivered health promotion messages as part of their services to their Gypsy Traveller populations and one LA employed two members of the Gypsy Traveller community as health trainers that are active with the local community.

In 39/135 (28.9%) PCTs, local voluntary services working to improve the health of local Gypsy Traveller populations were identified. Services include advocacy on behalf of Gypsy Travellers, housing and benefit advice, health promotion, social support, refuge for victims of domestic abuse, education and training, signposting to other services and access to amenities such as food and bathing. Some services were ethnicity specific whilst others were targeted at all women and children, also encompassing the Gypsy Traveller community. Only one PCT was identified that recruited volunteers specifically within the Gypsy Traveller community itself to act as health advocates.

### Table 1 Immunization and other services identified by 135 responding PCTs to improve the health of the local Gypsy Traveller population

<table>
<thead>
<tr>
<th>Service identified by responding PCT</th>
<th>PCT health care worker</th>
<th>Local voluntary services</th>
<th>Local authority services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service identified by responding PCT</td>
<td>37 (27.4%) GT dedicated service including immunization</td>
<td>39 (28.9%)</td>
<td>72 (53.3%)</td>
</tr>
<tr>
<td>No service identified by responding PCT</td>
<td>72 (53.3%)</td>
<td>96 (71.1%)</td>
<td>63 (46.7%)</td>
</tr>
<tr>
<td>Total responding PCTs</td>
<td>135 (100%)</td>
<td>135 (100%)</td>
<td>135 (100%)</td>
</tr>
</tbody>
</table>
Discussion

Main findings of this study

Our survey had a response rate of 100% from HPUs and 89.4% from PCTs in England. This compares favourably with the only other national study of health service provision for the Gypsy Traveller community, conducted by the University of Sheffield in 2004.1 The high response rate in the present study may be a function of the focused questions or of using the centralized collation through the HPA to co-ordinating PCT responses. In the University of Sheffield study, 336 PCTs, Strategic Health Authorities and Public Health Observatories were invited to participate and only 98 (29%) organizations (including 90 PCTs) submitted information. From those who did respond, only 43 (43.9%) had information on numbers of Gypsy Travellers and their location within their health district. Only 18 (18.4%) had any information on health services usage for this group and only 19 (19.4%) knew of any specific service provision for the Gypsy Traveller population within their health area. Our results suggest that some progress has been made in terms of the available public health intelligence around population needs and in specific service provision for Gypsy Travellers. We were able to obtain information on the childhood population from DFE, although our numbers may still be an under-estimate as the census, i.e. that it is posted, does not lend itself to accurately capturing a mobile population. However, it is still an important step in the recognition of this group that they were included as a distinct ethnic category for the first time.31 Future Health Equity Audits and measures of inequality should then automatically include measurement of this community.

From our mapping exercise, it is clear that there are very few UA/LAs with no Gypsy Traveller populations at all in England. The results also suggest that a significant number of the 18 PCTs reporting no Gypsy Traveller populations at all within their geographical regions would have been doing so in error. Furthermore, there appears to be no clear correlation between an identified PCT health care provision and the numbers of Gypsy Travellers in the local area. This would indicate that service provision is not being designed on the basis of a needs assessment in many parts of the country. Reasons for this poor local intelligence may include a lack of integration of work between the PCT and the UA/LAs and/or a lack of awareness by PCTs of the significant health inequalities suffered by Gypsy Travellers. It is also important to note that whilst Gypsy Travellers are a large focus for the Government’s Inclusion Health32 project, this work appears to have reached a hiatus and there is no indication that it will continue.33 This could be a great opportunity missed for this population.

Our survey suggests that several urban centres (including London and Manchester) appear to have more PCTs providing a dedicated immunization service for their Gypsy Traveller communities. This may reflect logistical difficulty in designing community-based outreach services over large geographical rural areas in comparison with densely populated urban areas, or the greater experience of urban PCTs in providing for ethnically diverse communities. As large conurbations tend to have lower immunization coverage rates overall, providing improved access to services may be a higher priority in these areas.

Our results show poor knowledge in HPUs and PCTs of immunization uptake by the Gypsy Traveller community countrywide. These findings are in keeping with previously published evidence similarly highlighting a lack of information or systematic data collection on Gypsy Traveller health and use of services.1,2,5,6,34–36 Where rates were estimated, they tend to be lower than those achieved in the general population, consistent with the disease indices (such as measles cases) and in contrast with other ethnic minorities where there is no consistent evidence of low coverage.17 An estimated coverage of 90% was achieved in four PCTs, suggesting that, at least in some areas, this aspect of inequality can be successfully addressed. However, there is still a question around the accuracy of these rates. The most recent census was not able to provide the hoped for accurate denominator for better estimate rates. Going forward, improved Public Health intelligence through the use of equity based tools encompassing health service provision, access and health outcomes could play an important role in reducing both the observed and perceived inequalities affecting this community.

This study suggests that the voluntary sector may be an under-utilized resource in providing a culturally acceptable service. Local voluntary organizations were recognized in survey returns as being particularly good at health promotion, for improving access for Gypsy Travellers to health services, and in improving the cultural understanding and awareness of healthcare workers. Their role in reducing costs (when compared with dedicated services) to the health service was also recognized.

Our study demonstrated that PCT knowledge and services are not well integrated with those in UA/LAs in many parts of the country. Many HPUs and PCTs were unaware or had
minimal knowledge of the services, such as housing and education that UA/LAs provide to Gypsy Travellers, thus limiting their ability to exploit this resource for health promotion. The integration of the NHS Public Health functions into LAs may serve to improve this. However, with public health expertise dispersed into 320 UA/LAs in England, specialist functions addressing the needs of Gypsy Travellers will most likely have to be conducted jointly across a number of LAs to be efficient and cost-effective. The creation of a strategic leadership role within the health service for Gypsy Traveller health that focuses on developing partnerships between the healthcare service, Gypsy Traveller groups, local voluntary services and local authorities may be one viable method for creating such an integrated service.

What is already known on this topic

There are relatively few examples of published research focusing on the health and health needs of the Gypsy Traveller population. Studies have variously supported the use of community health workers, the use of hand-held records for patients, specialist health visitors, mobile outreach units and clinics, having Gypsy Traveller representation and liaison, culturally appropriate health promotion materials and combinations of these to address specific problems. One well-conducted Randomized Controlled Trial was conducted in Ireland, which provided evidence of some benefits from a community mothers’ programme. However, these benefits did not include a demonstrable improvement in immunization uptake and the need for increased qualitative and quantitative research to aid the development of effective community interventions remains.

Specific attitudes to illness and immunization among the Gypsy Traveller population have been described as factors that may lead to fewer and less satisfactory encounters with health professionals more widely and may in part contribute to the poor access to and uptake of services demonstrated by our study. Studies have also identified a number of barriers to healthcare services including widespread difficulties in communication between health workers and Gypsy Travellers, the reluctance of general practitioners to register Gypsy Travellers or to visit sites, and a mismatch of expectations between Gypsy Travellers and healthcare workers. This reinforces the view that targeted service provision accounting for specific Gypsy Traveller cultural needs, and the needs of a mobile community along with the development of culturally appropriate health promotion messages are needed to improve immunization uptake and access in this community.

What this study adds

This study highlights the paucity of accurate estimates on Gypsy Traveller numbers and demonstrates that there is poor knowledge of immunization uptake rates and health services catering to this specific group amongst local health authorities. It also suggests that local health authorities should be encouraged to develop strategies to reduce the inequalities in health service provision seen by exploring interventions that could specifically cater to the needs of this marginalized group.

Limitations of this study

Whilst the response rate for our survey was good, the lack of local knowledge around the Gypsy Traveller Community still makes it very difficult to assess the scale of the population and therefore the level of services that would address their health and immunization needs. The lack of national knowledge also means that immunization rates are difficult to accurately ascertain.

Conclusions

Since the Second World War, Europe has taken great strides in improving the conditions and enshrining in law the rights of ethnic minority groups living within its borders. However, whilst other groups that suffered discrimination in the past have made significant progress in health and socioeconomic terms, Gypsy Traveller communities in many parts of Europe remain a much maligned and marginalized group with the poorest of health outcomes. Our analysis suggests that there is still much unknown about population numbers, and despite improvements in the provision of specialist services for the Gypsy Traveller communities in England, there still remains a considerable number of areas where the uptake of general health services and immunization is low or not known. The recurring measles outbreaks in this community in recent years also attest to these findings. There is thus an ongoing need to improve the provision of and access to services that are culturally sensitive and responsive to their needs. Whilst we have focused on describing immunization uptake, immunization services are only one component of a wider strategy for improving the health of Gypsy Travellers through effective health and social care interventions.

References

www.shef.ac.uk/content/1/cf/02/55/71/GT%20final%20report%20for%20web.pdf (15 May 2012, date last accessed).


9 Beach H. Comparing the use of an Accident and Emergency Department by children from two Local Authority Gypsy sites with that of their neighbours. Pub Health 2006;120:882–4.


