

Improving immunization uptake rates among Gypsies, Roma and Travellers: a qualitative study of the views of service providers

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ABSTRACT

Background Gypsies, Roma and Travellers are at risk of low uptake of routine immunizations. Interventions to improve uptake in these communities are seldom evaluated. As part of a qualitative study exploring barriers and facilitators to immunization uptake in Travellers, we report service provider (SP) perspectives.

Methods We interviewed immunization SPs working with six Traveller communities across four UK cities. Participants included frontline staff and those with strategic or commissioning roles. Semi-structured interviews explored perceived attitudes of Travellers to vaccinations, local service delivery, and opportunities and challenges to improving uptake. Audio-recordings were transcribed, analyzed thematically and mapped to a socio-ecological model of health.

Results 39 SPs participated. Four overarching themes were identified: building trusting relationships between SPs and Travellers; facilitating attendance at appointments; improving record keeping and monitoring and responding to local and national policy change. Travellers were perceived as largely supportive of immunizations, though system and organizational processes were recognized barriers to accessing services.

Conclusions Findings were broadly consistent across Traveller groups and settings. The barriers identified could often be addressed within existing infrastructure, though require system or policy change. Development of a culturally competent system appears important to enable equity in access to immunizations for Travellers.

Keywords cultural identity, ethnicity, immunization

Background

The UK vaccination programme provides protection against a range of potentially serious infections^{1, 2} but uptake rates differ markedly between regions,³ by socio-economic status, religion and ethnicity.^{4–7} Outbreaks of infection occur where there are pockets of low immunity.^{8, 9} Gypsies, Roma and Travellers are known to be at risk of low uptake of immunizations^{10–12} with outbreaks of measles reported from these communities.¹³ Similar issues have been noted in migrant, refugee and asylum seeking communities across Europe.¹⁴

Gypsies, Roma and Travellers are a heterogeneous community, made up of people considered for cultural, social and political reasons to be an ethnic group.¹⁵ Unlike in continental

Europe, ‘Gypsy’ remains a non-pejorative term in the UK, used both within and outside the community. In the 2011 census, a new category allowed Gypsies and Irish Travellers to self-identify as ‘Gypsy or Irish Traveller’ for the first time; a Roma category is planned for the next census.¹⁶ Broad definitions of Gypsies and Travellers also include show people, boat dwellers and New Travellers. For the purposes of this article, ‘Travellers’ is used to describe all Gypsy, Roma and Traveller

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people. The size of the UK Traveller community is unknown; one estimate of 200 000 Roma and 200–300 000 Gypsies and Travellers has been reported,¹⁷ though the validity of these estimates is uncertain.

Travellers are generally considered to have poorer health than the general population and when compared to other disadvantaged groups,^{18–20} though health status may vary depending on how Travellers are included in such studies.²¹ Travellers are considered to have lower uptake of preventive health care.^{22–24} Health system contributing factors include discrimination against Travellers^{16, 25} leading to lack of trust in health providers, reluctance to register Travellers by GP practices²⁶ and a failure to routinely collect ethnicity data during NHS care.¹⁶ Within Traveller communities, language and literacy difficulties, insufficient knowledge of health systems, poverty²³ and beliefs about self-reliance²² are perceived by Travellers and service providers (SP) as barriers to accessing services.

Public health decision-makers need to identify effective interventions to improve Traveller immunization rates. Interventions recommended for children from vulnerable groups include special clinics, domiciliary and hospital-based immunization.²⁷ Methods to improve immunization uptake in Traveller communities have included both proactive methods (e.g. specialist health visiting services) and reactive methods (e.g. targeted campaigns during outbreaks).^{28, 29} Such interventions are seldom evaluated, so their acceptability, sustainability and effectiveness are unclear. Most interventions are initiated and implemented by healthcare providers and commissioners, and may have limited involvement of Traveller communities.³⁰ The UNITING study³¹ was commissioned by the NIHR HTA programme in order to understand barriers and facilitators to immunization uptake from the perspective of Travellers themselves, and of those engaged in providing services. This paper reports healthcare providers' and commissioners' perspectives.

Methods

The methods of the UNITING study are described elsewhere.^{31–34} The underpinning theoretical framework was the social ecological model (SEM)³⁵, which recognizes that the determinants of individuals' behaviour are complex and operate at multiple levels (intrapersonal, interpersonal, institutional, community, policy).

Setting and participants

This research involved SP working in four UK cities where six Traveller communities were based (Bristol—English Gypsy

and Irish Traveller, Romanian Roma; Glasgow—Scottish Show people, Romanian and Slovakian Roma; London—Irish Traveller; York—English Gypsy). Within each city we aimed to recruit 6–8 SPs; a mix of 'frontline workers' (e.g. health visitors, community workers) and those working in strategic or commissioning roles (e.g. health protection, public health, Clinical Commissioning Groups).

Access and recruitment

Potential participants were identified from research team networks, local gatekeepers and interviews with Travellers. They were approached by telephone, e-mail or face-to-face, and provided with study information. In Bristol, York and London, SPs were not offered financial reimbursement for their time. In Glasgow, financial reimbursement facilitated recruitment of GPs and practice nurses. Recruitment, consent and data collection occurred between April 2014 and August 2015.

Data collection

Interviews were predominantly one-to-one, except for a few small-group interviews. Interviews were conducted in the participants' workplace or at the local university and recorded digitally. A topic guide ensured consistency of data collection both within and across the four cities, although the format was flexible to allow participants to raise issues they considered important (Box 1). Interviews focused primarily on the UK childhood immunization schedule, though to better understand issues relating to adult immunization, we also discussed adult flu and whooping cough vaccinations.

Box 1 Topics covered during the interviews

- Views on local Travellers' perceptions towards immunization and accessing health services (e.g. changes over time/generations, key decision-makers, impact of housing and employment on Travellers' lives)
- Views of other SP about the local Traveller community (e.g. discrimination)
- Their immunization service provision (e.g. childhood, young people, adult immunization; settled versus roadside, families and in schools)
- Actions or opportunities to increase uptake of immunization in the local Traveller community

Data analysis

The interviews were transcribed verbatim and data subjected to a within-community thematic analysis using the Framework approach³⁶, which is designed to address programme and policy-related questions. The stages of framework analysis (familiarization, constructing a thematic framework, indexing

Table 1 Service provider participants

Role	Examples	Number
Frontline staff	GPs, practice managers, outreach nurses, local authority traveller teams, head teachers, school nurses, voluntary sector workers	22
Strategic or commissioning roles	NHS leads for immunization, primary care, community services, health improvement and children's services, public health leads in local authorities	17
Total		39

and charting, mapping and interpretation) were undertaken independently for each city. QSR NVivo 10 and Microsoft Excel 2010 software packages facilitated data management. The final step was a thematic cross-community and cross-city synthesis that took account of the inferences derived from all SPs' data as a whole.³⁷ The final themes and sub-themes were mapped to the five levels of the SEM.

Results

We interviewed 39 SPs across the four cities (Table 1). Sixteen of the SPs supported immunization uptake for the general population including Traveller communities, whilst the remainder had a specific focus working with one or more Traveller community.

Integrated results from both Travellers and SPs are provided elsewhere.³¹ Here we present four overarching themes arising from the SP interviews that summarize their views on the accessibility of immunization services for Travellers. For each we report potential barriers to immunization uptake for Traveller families and the opportunities and actions suggested by participants to address these issues. Where there were differences in views for SPs working with different Traveller communities, these have been highlighted.

Building trusting relationships

SPs in all cities spoke of the importance of building trusting relationships with Traveller families. A lack of staff understanding of Travellers' cultural norms was viewed as a barrier to establishing relationships. SPs reported the need to understand community concerns regarding specific vaccines (particularly pertussis and MMR) that may underlie historical poor acceptance of vaccines. Fears regarding autism compounded prior concerns about live vaccines. Immunization concerns were reported to spread rapidly within communities by word of mouth and through social media.

"A lot of them would say they know someone who's had a bad reaction; you know, 'oh little Johnny was real bad after that, and my mother said never

to let, she'd never let them have it again', sort of thing. They don't know all the facts... they think they do... they very much react to what they hear on the television... or what someone else on site has told them." (BH301, Health Visitor, Bristol).

SPs widely reported low English literacy amongst communities with predominantly oral traditions. Limited spoken English was a barrier for Roma communities in Bristol and Glasgow, which reduced health workers' confidence that consent was fully informed. As Roma interpreters were rarely available, a third language, usually Romanian or Slovakian was used, risking mis-translation. Concerns were exacerbated if the interpreter belonged to a culturally higher status than the patient; SPs perceiving such interpreters lacked respectful engagement and listened less well to patient's concerns. SPs in all cities reported instances of discriminatory comments or actions; these related to stereotypical views of Travellers as lazy or unclean, or health professionals being resentful of any additional time required. Reassuringly, discrimination was now more likely to be challenged as unacceptable.

"I think there are still pockets where they are very much treated as 'these people'... we do have individuals that challenge within the team and say, 'well that's not appropriate to say that'." (GH304, NHS Service Team Leader, Glasgow).

SPs reported a shift towards higher immunization uptake in younger English Gypsy and Irish Traveller parents which they perceived to be secondary to improved knowledge compared to older generations. Improved knowledge was attributed to better literacy and less dependence on advice from older generations, possibly related to a more settled lifestyle. Roma families were reported to be keen to integrate. SPs reported some communities rejecting the HPV vaccine because acceptance of a vaccine against a sexually transmitted infection could be perceived as endorsing sexual partnerships before marriage. In some areas SPs emphasized its role in protecting against cervical cancer, though this was acknowledged as problematic since cancer was known to be rarely discussed openly within some Traveller communities.

SPs described ways to support the development of trusting relationships. These included continuity of services and individual care providers, and face-to-face engagement. Specialist Health Visitors for Travellers were highly valued in all four cities for their strong relationships with families and knowledge of Traveller culture. At the time of our study, Specialist Health Visitors and community link workers were funded in Bristol and Glasgow, though such posts no longer existed in York or the London study area. Bilingual health workers in primary care settings were also highly valued. Achieving trusting relationships enabled improved attendance.

"[They attend] because they feel safe at that practice, they feel that they are listened to . . ." (BH308, Health Visitor, Bristol).

Facilitating attendance at appointments

SPs reported that many families, not just Traveller families, forget or are too busy to attend appointments. Generic recall and reminder systems work for some, largely settled, Traveller families, but were recognized as not universally effective due to frequent travel or not being registered with a GP. Traveller culture was described by some SPs as being responsive to health need rather than proactive (York, Glasgow). SPs in Bristol and Glasgow reported that Roma families were unfamiliar with the UK primary healthcare system when recently arrived. Having a large family with many children increased difficulties of booking and attending appointments.

"so we try to tailor it to each of their needs really, It would be lovely to have a blanket . . . Traveller . . . everyone comes, but their needs are very different, just like everyday families are very different" (YH005, Children's Centre Support Worker, York).

A shift to less frequent travelling was described by SPs in Bristol, York and Glasgow. This facilitated consistent registration with the same GP and improved immunization uptake. In contrast, Glasgow SPs described travel within the Roma communities that interrupted immunization delivery.

Participants described using opportunistic reminders when families were attending for other face-to-face contacts. These supplemented tailoring the recall and reminder system, e.g. by text or phone calls. First languages could be used where English was known to be limited. Suggested ways of facilitating uptake of immunization appointments included opportunistic immunization in primary care, A&E or drop-in clinics, appointment systems that enable appointments 'today or tomorrow', come-and-wait clinics or specialist Traveller clinics. In Bristol, York and London, SPs recognized that whilst outreach or home vaccination can target those most in

need, this approach does not encourage users to engage with routine services.

" . . . all they want is an appointment to know when they can go" (BH301, Health Visitor, Bristol).

Improving record keeping and monitoring

Of concern for SPs across all sites was the lack of routine data collection on Traveller ethnicity, such as GP practices not recording Traveller ethnicity at registration and the Child Health Information System (CHIS) not including this information. Even when families' ethnic group was recorded by one service (e.g. health visiting or midwifery), systems did not enable these data to be shared with other services.

"If a child's had a vaccination with another health professional, health visiting team, it goes onto a different database and we don't automatically get informed when they have had it" (LH303, Practice Nurse, London).

Currently NHS systems do not offer a Gypsy, Traveller or Roma ethnic category for staff to complete. Some SPs reported that immunizations given in hospital or school took a long time to be recorded on CHIS, often not appearing until after the family had moved. Therefore, SPs meeting a Traveller family newly moved to their area could not reliably access information on the immunizations already offered to, or accepted by, that family.

To facilitate better understanding of the size and demographics of the local Traveller community SPs described various approaches. In Bristol, SPs reported using postcodes of Traveller sites and 'typical' Roma surnames to estimate the size of Traveller communities. In York, London and Bristol, health visitors welcomed 'hand overs' from colleagues reporting that a Traveller family had moved to their area. In Glasgow and Bristol, GP records had been flagged to facilitate opportunistic and targeted activities. SPs in Bristol, York and Glasgow reported ethnic group being well-recorded on Local Authority Education records. Where it was feasible to link health and education data, this proved helpful.

Responding to local and national policy change

The 2013 NHS reforms in England,³⁸ resulted in changes to the commissioning and delivery of public health services, including immunization. Staff from Public Health teams in Primary Care Trusts who were responsible for the health needs assessment of Travellers and the commissioning of community services moved to Local Authorities, while those involved in health protection and immunization programmes moved to a new organization called Public Health England.

SPs in Bristol, York and London all perceived these to have had a negative impact on their ability to improve uptake of immunizations in Traveller communities. Consequences reported included loss of capacity, contacts, organizational memory and designated authority for action, across both health and partner services. There was a perception from SPs in both Bristol and York that such changes risked widening inequalities in Traveller health, and that teams had shifted from proactive to reactive provision.

“I mean, it was all very coherent, and now it’s not There’s incidents waiting to happen really” (YH003a, Public Health Professional, York).

SPs in all cities described the impact on uptake of reduced funding for immunization. Examples included reduced funding for awareness campaigns or staff training. SPs reported that specialist health visitor posts were sometimes no longer available, and that commissioners and funders failed to recognize the complexity of those roles and their added value. Translation and interpretation services were also affected. One school nurse reported an immunization session in a school being cancelled as there was no budget to pay for the interpreter needed.

“And the frustrations are at times that people just don’t listen. You know last year we pulled [name of school] from immunisations because of, at that point there were more Slovakian families with Slovakian children and yet this year. . . they gave us Roma. . . they gave us Romanian, gave us Polish. . . didn’t give us Slovakian. Slovakian was the one that I needed. So it’s just really hard.” (GH303, School Nurse, Glasgow).

SPs reported that successful initiatives to increase uptake were commonly developed with community members or in partnership with voluntary sector organizations. Examples included a Roma ‘Pathways to health’ resource (Glasgow), a GP registration initiative (London), multi-sectoral advice and signposting ‘drop-in’ services (Bristol and Glasgow) and ‘pop-up’ clinics.

“You know, the problem is if you, if you don’t adapt to the communities you are working with then you end up missing people and people will not get preventative healthcare” (GH302, Social Services Team Leader, Glasgow).

No SP reported the need to adapt services for Scottish Showpeople as their immunization needs were considered similar to the majority population.

SPs across all cities emphasized the value of working collaboratively with agencies outside the health sector. Collaborative working frequently involved sharing information, joint meetings and coordinated strategic planning. Joint visits to

families or working together at Traveller-focused services were common. In Bristol and York, health visitors worked with the Traveller Education Service and Children’s Centre Support Workers. In London, SPs reported that funding for joint working with the Traveller Education Service was no longer available. In Glasgow, education, health, housing and employment services jointly prepared a single strategy to support the Roma community. However, frontline SPs were sometimes not aware of such strategic documents.

Discussion

Main finding of this study

The SPs described a variety of initiatives that influenced the ability of Traveller families to access immunization services. It was recognized how wider determinants of health such as insecure housing tenure, poverty and discrimination impacted on the ability of Travellers to attend appointments. Masseria et al.³⁹ highlight this point in relation to Roma across Europe. Trust is a prerequisite to delivering effective services to children and families,⁴⁰ and thus specialist health visitors for Travellers, through their joined-up working, had the potential to counter the impact of wider determinants of health.

The absence of high-quality data describing family ethnic group was a significant barrier to monitoring inequalities in uptake and the impact of targeted activities. Interviews were conducted in the period following the implementation of the Health and Social Care Act 2012 in England.³⁸ Many SPs described how the health system reforms had affected their organizational structure, strategic planning and funding of immunization services in general, often adversely affecting immunization services for harder to reach groups. Such experiences were not reported by SPs in Scotland as the NHS Reforms affected only England.⁴¹

What is already known on this topic

The UK National Institute for Health and Care Excellence (NICE) have produced guidance on reducing inequalities in immunization uptake in the under 19s.²⁷ Recommendations include having a person in every GP practice responsible for leading immunization delivery, but they do not recommend having staff culturally competent to support families. Trust has been found to be essential for engagement.⁴⁰ NICE recommendations to be flexible in the provision of appointments, with targeted invitations, reminder and recall systems are directly supported by the SP participants in this study. McFadden, Smith⁴² and NICE support outreach services for children who have missed immunizations. SPs in England in this study advised that resources and capacity to undertake

home visits are increasingly challenged and that such practices do not encourage engagement with routine services. These findings support evidence reviews indicating that improving access may be both cheaper and more effective than outreach services.⁴³ Other recommendations from NICE include systems for recording and transferring information on vaccination status. However, they do not specify the need to record ethnic group, nor do they recognize the challenges faced by some travelling families who may need to register with a new general practice relatively frequently. The UK Measles and Rubella elimination strategy⁴⁴ highlights how the absence of recording of Traveller status challenges the assessment of uptake of MMR in Traveller families.

What this study adds

Efforts to improve health outcomes in underserved communities may draw on models supporting individual behaviour change⁴⁵ or societal behaviour change.^{46, 47} The UNITING study³¹ found that Traveller communities were largely supportive of immunizations, especially in younger generations. This would suggest that whilst awareness and motivation may be issues for some Travellers, for others it is a failure of a culturally competent system to provide the opportunity to access immunizations. This study found that SP perceived system and organizational barriers were the issues most in need of change, a finding largely supported by the Travellers in this study whose views are reported elsewhere.³¹ This finding is also supported by research in Kent where interviews with Traveller mothers regarding MMR⁴² found that a lack of tailored services and situational constraints, as described in the Tailoring Immunization Programmes approach endorsed by the World Health Organisation,^{48–50} impeded uptake in communities relatively accepting of immunization.

Reviews have highlighted the limited evidence of effective interventions to improve immunization rates in underserved populations.⁵¹ However, the barriers to immunization uptake in Traveller families described by SPs and the jointly prioritized interventions identified through the UNITING study³¹ reflect changes to systems that should be regarded as good practice. It is likely that good practice does exist, variably across the country, but to be fully adopted they will require system change at both institutional and policy level. Trusted outreach workers have the potential to be highly influential to negotiate positive health action in Traveller families,^{52, 53} confirming the value placed on Specialist Health Visitors for Travellers by SPs in this study. We found that SPs, and Traveller participants,³¹ recognized the value of recording of Traveller status in health records to enable targeted support to be made available. Deficits in data recording hinder efforts to address health inequalities and are not acceptable.⁵⁴ Existing

records can be enhanced through data linkage with education or census records.

Limitations of this study

The UNITING study was a large qualitative study following a theoretically based protocol and data analysis framework. We consider that the representational generalisability³⁷ of the data emerging from the SPs involved in this study was good, with 39 participants including both front line and strategic managers and commissioners. There is similarity in the SP professions and disciplines between four sites in this study and other locations across England and Scotland, suggesting that inferential generalisability³⁷ is also robust.

Conclusions

This paper describes the strategies for raising immunization uptake for Traveller families as perceived by frontline immunization practitioners and by strategic decision makers. They describe broadly consistent concerns across four different settings and for six different Traveller groups. The views of Traveller families described elsewhere^{31, 32} agree in part with those expressed by SPs and illustrate the importance of bringing SPs and service users together when exploring health improvement opportunities. The study also illustrates the value of qualitative research to unearth the beliefs and behaviours that underpin health service use. The issues that need addressing could mostly be tackled through system and policy change, should be feasible within existing infrastructure and commissioning arrangements, and may contribute to reducing inequalities in the uptake of immunizations in Traveller communities.

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Authorship

J.M. contributed to study conception and design, co-led data collection in Bristol and prepared the initial draft of this paper. H.B. contributed to the study conception and design, led data collection in London. L.C. contributed to study conception and

design, co-led data collection in Bristol. C.J. was the Principal Investigator of the UNITING study. She conceived, designed and led the study, contributed to data collection in York and data analysis of the main study. All authors read, revised and approved the final manuscript.

Conflicts of interest

None of the authors declare a conflict of interest.

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