UNderstanding uptake of Immunisations in TravellIng aNd Gypsy communities (UNITING): a qualitative interview study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

Uptake of immunisation in Traveller and Gypsy communities

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Scientific summary

Background

Gypsies, Travellers and Roma (referred to here as Travellers) experience significantly poorer health, and are less likely to access health services, including immunisation, than the general population. We need to understand what helps, and hinders, individuals in these communities in taking up immunisations.

Aims

1. Investigate barriers to and facilitators of acceptability and uptake of immunisations among six Traveller communities across four UK cities.
2. Identify possible interventions to increase uptake of immunisations in these Traveller communities that could be tested in a subsequent feasibility study.

Objectives

1. Investigate the views of Travellers on the barriers to and facilitators of acceptability and uptake of immunisations and explore their ideas for improving immunisation uptake.
2. Investigate the views of service providers on the barriers to and facilitators of uptake of immunisations within the Traveller communities with whom they work, and explore their ideas for improving immunisation uptake.
3. Examine whether or not and how these responses by Travellers and service providers vary within and across communities and for different vaccines (childhood and adult).
4. Use the data collected from 1–3 to identify possible interventions to increase uptake of immunisations in the six Traveller communities.
5. Conduct workshops in each community to discuss findings and to produce a prioritised list of potentially feasible and acceptable interventions to be considered for testing in a subsequent feasibility study.

Methods

This was a three-phase qualitative study. The social ecological model (SEM) provided the theoretical framework: this identifies five levels of influence (intrapersonal, interpersonal, institutional, community and policy) on behaviour.

Phase 1

Interviews with 174 Travellers from six communities – Romanian/Slovakian Roma, English Gypsy, Irish Traveller and Scottish Showpeople – in four UK cities. Participants reflected a mix of family roles across generations (e.g. grandmother, father, adolescent girl) as well as self-reported immunisation status. Interviews explored views about influences on immunisation behaviours and ideas for improving uptake in their community.

Phase 2

Interviews with 39 service providers explored views on barriers to and facilitators of childhood and adult immunisation for the Traveller communities with whom they work, and ideas to improve uptake. Service providers were a mix of frontline workers (e.g. health visitors) and those in more strategic roles (e.g. commissioners).

Data were analysed using the framework approach and synthesised to explore similarities and differences in perceived barriers, and facilitators, to immunisation across the six communities. We looked for similarities and differences by gender and vaccine (within the UK childhood immunisation schedule, adult flu/whooping cough). Potential interventions for increasing immunisation uptake were identified using a modified intervention mapping approach.

Phase 3

Workshops were held in each city, with a total of 51 Travellers and 25 service providers. They jointly produced a prioritised list of potentially acceptable and feasible interventions to increase immunisation uptake.

Results

Barriers to and facilitators of immunisation uptake

Barriers and facilitators were evident across all five levels of the SEM. There were many common accounts, particularly across the English-speaking communities. Scottish Showpeople were most similar to the general population in their views. Roma communities experienced additional barriers in terms of language and moving to a new country. Generally, men and women described similar barriers to and facilitators of immunisation uptake.

Knowledge

There was widespread understanding among Travellers that immunisation protects against diseases and this appeared sufficient to encourage immunisation. A minority had good understanding and knowledge of specific immunisations was variable, better for childhood than adult vaccines. Among the English-speaking communities the Scottish Showpeople were the most confident in their knowledge; the London Irish Travellers were the least confident. Slovakian Roma people in Glasgow were more knowledgeable than Romanian Roma.

Sources of information and advice

Health professionals were the key source of written and verbal immunisation information, especially for the current generation of parents. Schools were another source of information for mothers and adolescent girls in the English-speaking communities. Media, social media [particularly Facebook (Facebook, Inc., Menlo Park, CA, USA; www.facebook.com)] and the internet were viewed as both positive and negative information sources. Female members of the Scottish Showpeople community focused on negative information about the measles, mumps and rubella (MMR) vaccine.

Acceptance of immunisation

Many Travellers believed that the protective benefits of immunisation outweighed the risks, leading them to take up immunisations for themselves and their children. This was expressed by almost all of the Bristol and Glasgow Roma, three-quarters of the Bristol English Gypsy/Irish Traveller communities and Scottish Showpeople and half of the York English Roma and London Irish Traveller communities. Many followed the advice of health professionals and saw it as a normal thing to do; others weighed up the pros and cons and usually went ahead. Service providers, while cautious in expressing a view, believed that most Travellers now accept vaccinations.

Concerns about immunisation

A small minority of Travellers were anxious about their children experiencing pain and contamination from needles, but this did not usually deter them. A minority of English-speaking Travellers were concerned about multiple or combined childhood vaccines, particularly MMR, with some paying for single injections. Three participants (Bristol Irish Traveller mother and York English Gypsy mother and daughter) completely rejected immunisation.

Beliefs about specific vaccines

There was general acceptance of immunisation in pregnancy except in the Bristol English Gypsy/Irish Traveller community, in which views varied, particularly about the whooping cough vaccine. MMR vaccine was a particular concern for Scottish Showpeople, whereas in Bristol, York and London previous measles outbreaks meant that most now accepted MMR vaccination. A few women worried about the safety of human papillomavirus (HPV) vaccine. A minority of mothers, fathers and grandfathers (particularly among the Bristol English Gypsy/Irish Travellers) were concerned that their daughters having HPV vaccine would imply that they were promiscuous. Concern that the adult flu immunisation caused flu was expressed by some English-speaking Travellers.

Intergenerational change

Many Travellers and service providers observed that the current generation of parents were more positive about immunisation than previous generations, and this was attributed to greater integration, improved literacy and increased trust in health professionals. This view was not expressed by Scottish Showpeople or their service providers.

Interpersonal influence

Experiential knowledge and advice was still passed down through generations, especially among Irish Travellers in Bristol and London. Very few spoke of friends influencing immunisation decisions.

Decision-making

Mothers tend to see themselves as the main decision-maker about childhood immunisation and believed this to be the community norm; some jointly make decisions with their partners.

Language and literacy

Language and literacy barriers existed for the Bristol and Glasgow Roma communities, leading to a strong reliance on interpreters, who are in short supply. Literacy was also a barrier among the English-speaking communities. There was a widespread preference for simple, written immunisation information with pictures and clear verbal explanations.

Discrimination

A small minority in the English-speaking communities described experiencing discrimination from health services. No Roma participants expressed this. Service providers in each city gave examples of discrimination against Travellers by NHS staff, suggesting that this was mainly a result of poor understanding of Traveller culture and inexperience of working with Travellers.

Housing

Service providers in Bristol, York and Glasgow suggested that isolation and Traveller families being forced to move home were barriers to immunisation uptake. Glasgow service providers spoke of poor, crowded housing conditions for the Romanian Roma families.

Travelling

York English Gypsy and Scottish Showpeople were perceived to be settled, which facilitated uptake of immunisation. Views on the influence of travelling on immunisation were more mixed for the Bristol English Gypsy/Irish Traveller and London Irish Traveller communities. Travelling by the Roma communities was mainly discussed in terms of arrival in the UK.

Attendance at school

School attendance was mainly discussed by female Traveller participants and service providers, with a minority commenting that some adolescent girls do not attend secondary school, which is a barrier to receiving immunisations such as HPV. This was not perceived to be an issue for Scottish Showpeople.

Poverty
Service providers spoke of the impact of poverty on the Bristol Roma, York English Gypsy and Glasgow Roma (particularly Romanian families), and saw it to be linked to language, employment, benefit systems and housing.

Access to health services
A minority of Travellers and service providers described problems accessing health services [e.g. registering with a general practitioner (GP) practice, booking appointments and lack of time with GPs]. This led some to use out-of-hours doctors or the accident and emergency department. Service providers working with Roma communities identified other barriers (e.g. a lack of understanding of how the NHS works when first arriving in the UK).

Relationships with health professionals
Trustful relationships and continuity of care were valued. Many Travellers described positive immunisation encounters with health professionals. A minority of the English Gypsy and Irish Traveller communities in Bristol, York and London described a lack of trust in doctors (usually based on a particular incident). Roma participants did not describe any negative experiences with health professionals and the Scottish Showpeople were rarely negative. Service providers acknowledged the time taken to develop good relationships with Travellers and emphasised having the 'right person' in specialist roles.

Recall and reminders
Most Travellers considered recall letters, reminder texts and telephone calls to be effective. Face-to-face reminders were appreciated, as they provided the opportunity for discussion. Service providers used everyday contact with Travellers to prompt them about immunisation. In Bristol and Glasgow, the recall and reminder systems had been adapted for the Roma communities.

Attending appointments
A minority of Travellers described their frustration in waiting several weeks for appointments. Suggestions for improving attendance were drop-in sessions and walk-in clinics. Service providers described a flexible approach to providing appointments (e.g. opportunistic immunisation, specific clinics for Roma families). Delivering immunisations on Traveller sites was viewed by most Travellers and service providers as only appropriate for those who cannot attend the GP practice.

Record keeping and monitoring
Service providers commonly observed that NHS systems did not routinely record Traveller ethnicity, with the result that uptake of immunisation was unknown, affecting funding and targeting of services. A different challenge was identified by those working with the Glasgow Roma community, namely a lack of records on individuals' immunisation histories.

Joined-up working
A common view among service providers was that working in partnership within, and across, organisations is important. Examples were offered within health, between health and education, health and social care/housing, health and local authorities and with the police.

Local and national strategies
A small minority of Traveller women spoke of national policy in the context of valuing free immunisations and mandating for childhood immunisation. Service providers working with the Glasgow Roma community spoke extensively of local and national strategies for Roma. Specialist health visitor and community health link roles were unanimously viewed as important.

Funding
Many service providers said a lack of/cuts in funding inhibited their general immunisation work, as well as their targeted work with Travellers, including a loss of specialist health visitor posts. Those working with

the Roma communities suggested that there was little recognition of the complexity of this work, which impacted on funding.

NHS reforms

Service providers described how the 2013 reforms in England challenged the delivery of immunisation and health visiting services, as well as threatening targeted services for Travellers.

Prioritised interventions to improve immunisation uptake

Five 'priority' interventions (1 is the most supported) were agreed across communities and service providers to improve the uptake of immunisation among Travellers who are housed or settled on an authorised site. These interventions were all at the institutional and policy levels of the SEM.

1. cultural competence training for health professionals and frontline staff
2. identification of Travellers in health records to tailor support and monitor uptake
3. provision of a named frontline person in GP practices to provide respectful and supportive service
4. flexible and diverse systems for booking appointments, recall and reminders
5. protected funding for health visitors specialising in Traveller health including immunisation.

Ten 'priority' interventions (in no particular order) were identified by specific Traveller communities and/or their service providers to improve the uptake of immunisation. These fell across all five levels of the SEM.

1. accessible information from trusted health professionals at GP practices (York English Gypsy, Glasgow Scottish Showpeople)
2. accessible information from trusted health professionals via outreach (York English Gypsy)
3. good information in social media and magazines (Glasgow Scottish Showpeople)
4. general information about the NHS in Scotland (Glasgow Roma)
5. training for health professionals to target those most concerned about immunisations (Glasgow Scottish Showpeople)
6. multisectorial working on cultural issues led by health professionals (Bristol Roma)
7. increased access to bilingual support workers or interpreters (Glasgow Roma)
8. recognition that good practice with non-English-speaking Travellers has resource implications (Glasgow Roma)
9. improved joined-up working for commissioning, and provision, of immunisation services (York English Gypsy)
10. representation from Traveller community on Clinical Commissioning Group and/or local immunisation committee (London Irish Traveller).

Two interventions were identified as important to improve the uptake of immunisation among Travellers who live on the roadside and on unauthorised encampments.

1. flexible delivery of immunisation services (York English Gypsy)
2. improve system of temporary registration at GP practices (Bristol English Gypsy/Irish Traveller).

Neither of these ideas, or their prioritisation, came from current roadside Travellers themselves.

Conclusions

Recommendations for research

1. Mixed-methods research to explore the challenges and opportunities of ethnic identification of Travellers in health services, including:
    - exploratory qualitative research with health professionals and Travellers to explore their views on the barriers to and facilitators of recording Traveller ethnicity

- quantitative analysis of immunisation uptake by ethnicity (if recording of Traveller ethnicity improves to a level to enable this) to explore inequality in uptake by ethnic group and aid further targeting of services.

2. Evaluation of the implementation of a national policy plan (and accompanying practice guidance plan) to promote uptake of immunisation among culturally diverse Traveller communities in the UK.
3. Methodological research to identify appropriate methods to capture the views and experiences of immunisation of roadside Travellers and those living on unauthorised encampments.
4. Exploratory qualitative research with roadside Travellers and those living on unauthorised encampments to identify acceptable, and feasible, interventions to improve the uptake of immunisation.
5. Exploratory qualitative research with Travellers to explore their views on the barriers to and facilitators of the uptake of vaccines newly introduced to the routine schedule, such as rotavirus and meningitis B.

Implications for policy and practice

1. Development and implementation of a national policy plan (and accompanying practice guidance plan) to promote the uptake of immunisation among diverse Traveller communities in the UK.
2. Development of national targets to support the effective implementation of a national policy plan (and accompanying practice guidance plan).
3. Integration of a national policy plan (and accompanying practice guidance plan) into key guidance and policy documents.

Trial registration

This trial is registered as Current Controlled Trials ISRCTN20019630 and UK Clinical Research Network Portfolio number 15182.

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