

## Title Page

Title: Factors influencing uptake of Measles, Mumps & Rubella (MMR) immunisation in site-dwelling Gypsy, Roma and Traveller (G&T) communities: A qualitative study of G&T parents' beliefs and experiences.

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## **Factors influencing uptake of Measles, Mumps & Rubella (MMR) immunisation in Gypsy, Roma and Traveller (G&T) communities: A qualitative study of G&T parents' beliefs and experiences.**

### **ABSTRACT**

#### **Background:**

Increasing immunisation in the Gypsy, Roma and Traveller (G&T) community is a key priority for improving health outcomes in this community. This study aimed to explore G&T parents': 1) Beliefs about childhood immunisation; 2) Beliefs about the risks of immunisation and non-immunisation; 3) Perceived obstacles to, and facilitators of, immunisation and 4) Views on increasing immunisation levels.

#### **Method:**

A cross-sectional, qualitative study was conducted comprising of five focus groups with 16 site-dwelling Gypsy, Roma and Traveller women with pre-school aged children. Data were transcribed verbatim and analysed thematically.

#### **Results:**

Five main themes were identified:

- 1) Lay understandings of causation and risk;
- 2) Timing of immunisation;
- 3) Children being perceived as vulnerable;
- 4) The fit between lifestyle and healthcare provision;
- 5) The impact of living with a high burden of disease.

#### **Conclusion:**

Understanding of the risks and benefits of MMR immunisation did not differ significantly from the wider population or those promoted by the health service. The majority of barriers stemmed from living with the effects of long-standing health inequalities which posed further barriers to accessing immunisation, and shaped beliefs about immunisation. Factors facilitating uptake occurred where access to immunisation services was made flexible, e.g. immunisation on traveller sites.

# Factors influencing uptake of Measles, Mumps & Rubella (MMR) immunisation in Gypsy, Roma and Traveller (GRT) communities: A qualitative study of GRT parents' beliefs and experiences.

## INTRODUCTION

Immunisation is a cost-effective method for preventing communicable diseases, although coverage is lower among marginalised and lower socio-economic groups (Vandermeulen et al 2008). Increasing uptake amongst under-immunised groups has been identified as a key priority for improving health outcomes and reducing health inequalities (DCLG, 2012; DOH, 2012). Immunisation for the measles, mumps and rubella (MMR) vaccination fell following a discredited 1998 study positing a link between this vaccine, autism and bowel conditions (Wakefield et al., 1998) but has increased in recent years reaching 92% in 2012-13. This is still below the 95% coverage required for a population to achieve 'herd immunity' (HSISC, 2013).

G&T communities comprise of various groups with a history of nomadism such as English Gypsies (Romanichals), Irish and Scottish Travellers, and it is estimated that there are between 58,000 (ONS, 2013) and 300,000 (CRE, 2006) in the UK. In January 2015, 87% of the 20,123 Gypsy caravans in the UK were on authorised (private and public) sites; 9% were on land owned by Gypsies and Travellers (G&T) but with ungranted planning permission and 4% were on unauthorised sites (DCLG, 2012) and a much larger but unquantified number live in conventional housing (Smith and Greenfields, 2013). Gypsies and Travellers have the worst health profile in the UK with a lower life expectancy and higher burden of illness due to low socioeconomic status, environmental conditions, discrimination and poor access to health services (Parry et al., 2004; Smith and Rushton, 2013). G&T populations also have significantly lower levels of immunisation coverage (Cook et al., 2013). Feder, Vaclavik and Streetly (1993) examined the attitudes of Gypsy parents towards childhood immunisation and found two main reasons inhibiting uptake: poor access to services and parental attitudes. Data is sparse, though one study suggested that only 57% of G&T children were fully immunised against MMR (Twiselton and Huntington, 2009). Dar et al (2013) found that of 135 Primary Care Trusts (PCTs) in England, only seven provided immunisation to G&T's onsite with some success (Reynolds, 2007), but Trusts tend to react to outbreaks rather than using site visits to promote and administer immunisation. A disproportionate number of measles outbreaks occur within G&T communities (Cemlyn et al., 2009; Baugh, 2010; HPA, 2007, 2010). The majority of infections in the Thames Valley region between 2006 and 2009 (63%) occurred within G&T communities indicating a 100-fold higher incidence than the general population (Maduma-Butsche and McCarthy, 2012). By June 2012, of 964 reported cases nationally, 49 were in travelling communities with increased transmission of measles occurring during G&T social events starting in the early summer (HPR, 2012).

There is little evidence exploring the *reasons* for low uptake of the MMR vaccine in G&T communities. Understanding the barriers and facilitators to immunisation uptake is vital for vaccination initiatives aimed at those G&T communities. Therefore, the current study explored:

- 1) Experiences and beliefs about childhood immunisation;
- 2) Beliefs about the risks of immunisation and non-immunisation;
- 3) Perceptions of obstacles to, and facilitators of, immunisation;
- 4) Views on increasing participation in immunisation programmes.

## METHODS

A cross-sectional, qualitative study was conducted comprising of five focus groups with 16 (N=16=3+3+3+3+4) site-dwelling G&T women with pre-school aged children. Participants were purposively sampled from sites across Kent in South-East England and all focus groups took place in January 2014. The county was selected as it has the highest population of G&T's in the UK and a low level of childhood immunisation amongst this G&T community (KMPHO, 2014). Sites were selected to capture those from English Gypsy and Irish Traveller communities, as well as the Roma community as these groups tend to live together in single sites. Sites were chosen which had recently experienced measles outbreaks. A focus group data collection approach was taken to capture the women's consensual views on

immunisation, and because evidence has shown that focus groups are an effective means of capturing the views of marginalised groups (Parry et al., 2004). The topic guide for the focus group was developed following a pilot survey administered to 31 G&T women by a health outreach worker from within the local G&T community. Focus groups were held at the sites and were conducted by two female members of the G&T community. One of these was the aforementioned health worker and the other a local Gypsy woman who received training prior to conducting the focus groups.

Focus groups lasted seventy minutes on average and following the advice of the two interviewers were not attended by the (male) authors as this would have been considered culturally inappropriate. Data was audio-recorded, transcribed verbatim and analysed for emerging themes afterwards - and before the subsequent focus group. Using this iterative process, the focus groups continued until a saturation point was reached - whereby the data collected becomes repetitive and when adding participants is unlikely to generate new ideas (Silverman, 2006). A systematic review of focus group-based studies has found that this usually occurs at around the fifth focus group (Carlsen and Glenton, 2011).

To ensure rigour, transcripts were read in their entirety by the two authors and a framework of emerging themes were developed, by negotiating and agreeing on the content, as well as the development of new themes (or subthemes) where there was disagreement (Barbour, 2001). Using this approach, quotes were assigned to themes; hence the illustrative quotes given below are examples representing a given theme.

Ethical clearance was gained from the University of Greenwich Research Ethics Committee and procedures regarding signed informed consent, anonymity and confidentiality were adhered to throughout.

## **RESULTS**

Sixteen women with children under 5 took part in five focus groups (FG). Eight (N=8) participants identified as English Gypsies/Travellers, Five (N=5) as Irish Travellers and three (N=3) as European Roma. The majority lived on authorised sites either privately owned or socially rented. Five interrelated themes were identified during analysis and are discussed below (with names changed to protect anonymity).

### **a) Travellers' lay understanding of causation and risk**

Participants generally had a clear understanding of how childhood diseases are transmitted and gave multiple examples of measles, mumps and rubella being spread amongst children. They cited instances where an outbreak followed specific social gatherings such as weddings and funerals, which tend to be attended by large numbers of Gypsies and Travellers. Annual events such as horse fairs were also mentioned.

“That was all around your Iris' funeral, that's where they picked it up - you know, my Johnny picked it up there [...]Everybody you spoke to had them. Everyone you spoke to then, someone had it. It was like wildfire wasn't it going through the travellers. It spread so fast.”

(FG3)

Hence, some participants felt the risks of non-immunisation were situational, and they would take up immunisation as, and when, needed.

“Well, obviously, if they do catch one of those [MMR] uncommon diseases it could endanger their lives – yes, you've got that risk. But they're so uncommon around where we are. If I was to travel into a country where those diseases are common, with my children, I might think differently”

(FG 5)

Participants also noted that children living together in close proximity facilitated outbreaks of MMR. They associated this with living arrangements, for example living in caravans, frequently on overcrowded sites or in housing where a higher number of family members tend to live within the same area and there are frequent visits from extended family members, which they recognised as facilitating the transmission of communicable diseases.

“I think it goes in the air or something like that. Once you've been in contact with a person, so many people had it...”

(FG3)

There was no consensus on the efficacy of the MMR vaccine, with some participants who had taken up immunisation acknowledging that it prevented MMR.

“But I do believe that MMR do definitely stop them [children] from getting measles. 100%. Because my two young ones got measles and the oldest two that had MMR, they slept in the same bed and everything, and never got it.”

(FG3)

Others were concerned about the risks of immunising children such as children feeling unwell after vaccination – but in most cases it did not outweigh the perceived risks of non-immunisation.

“It took me a deep thought to do it [immunisation], where I decided to go with the flow, but yes there is a lot of risk in it.”

(FG 5)

“My girl got sick with a temperature but I suppose it's better than a full blown sickness if you don't get it done”

(FG 1)

As in the wider population, a few participants also believed there may be an association with autism.

“Sometimes it makes your child backward, and like really stupid – like autistic.”

(FG4)

Participants also gave examples of people who relied on family members and others in the travelling community to inform their decision-making surrounding immunisation.

“We usually ask everybody else around, all the other travelling community, that's how we find out. That's like what's going on now.”

(FG 1)

“When my child gets to a year, I'll definitely give it to him even though most of my family and all that never give them to theirs because they were scared”

(FG 4)

On the whole participants understood the benefits and risks of immunisation, and saw immunisation as a positive health measure suggesting that low immunisation is not a consequence of specific cultural beliefs and practices but is more powerfully shaped by structural factors and the impact of pre-existing health inequalities, as outlined below.

## b) Timing and Immunisation

The theme of timing had three sub-themes – 1) The age of the child, 2) Spacing each immunisation separately rather than receiving the combined MMR and 3) Fitting immunisation in with other, competing, issues.

The first issue concerned the belief that it was more appropriate and safer to administer MMR immunisation when children were older:

“I should have got it [MMR immunisation] when they were about four. They reckon once they’re over 4-5 it can’t cause autistic.”

(FG 3)

“Travellers don’t get it now till their children go over five, they won’t get it.”

(FG 3)

“If you leave it till the baby is over 18 months, it’s OK – because you’re supposed to have MMR in the 12<sup>th</sup> month”

(FG 4)

The second issue related to a preference for spacing immunisations separately rather than the combined MMR in ‘one-shot’:

“I don’t believe in all the combination immunisations, they are so unnecessary. It’s dumping so much chemicals into the body and it’s a really unnecessary overload. This is why so many children get so ill”

(FG 5)

For many, despite preferring the MMR vaccination being administered individually this is only available privately meaning cost was an issue:

“I think what you [other focus group participant] said about having them all in one shot was bad, but I think they put a price on it if you want it individually and I couldn’t do that”

(FG 5)

Finally, there were issues relating to ‘fitting-immunisation-in’ with other competing needs and priorities.

“...[H]ygiene and clean water has got more to do with us being alive ...”

(FG4)

“For traveller girls it’s hard to go and remember when to get it done”

(FG5)

Timing in terms of the children’s age, providing the vaccinations separately over a longer time-period and difficulties accessing information and appropriate services emerged as important issues in shaping *attitudes* towards immunisation.

### **c) The impact of living with a high burden of disease**

As noted, the G&T community experience high levels of illness. The impact of this is evident in the interviews - as the majority of participants discussed how frequent illness in the children shaped their decisions around immunisation.

“I’m definitely going to get him [participant’s son] done with the MMR, because he’s been so sick since he’s born anyway with viruses and ear infections and stuff.”

(FG3)

Here frequent bouts of illness acted as a spur to prevent further illness through immunisation. However, the inverse was also apparent as some participants perceived that even if their child was immunised there was still a risk that they would contract another, more serious, illness – so the ‘risks’ of giving the MMR weren’t worth it.

“... [T]hey can still get meningitis and things like that. So really I think it’s pointless”

(FG 2)

More practically, G&T children are frequently ill and this meant that the child should not receive immunisation (as is medically indicated) as was the case for these participants’ children.

“Even when my Kylie was born. My Kylie was sick and I tried about four doctors and I couldn’t get in.”

(FG1)

“...When he was small – he was really small, he got pneumonia. Because he’d had pneumonia I didn’t want to give him the needle...”

(FG3)

As the participants observe, recurrent and/or serious childhood illnesses can also make parents reluctant to immunise their children due to the resultant perception of the child as being extremely vulnerable to further illness, discussed further below.

### **d) Travellers’ perceptions of children as vulnerable**

Related to the frequency of childhood illness, participants understandably saw children as vulnerable and viewed the immunisation process itself as traumatic and causing unnecessary distress to the child. Even where mothers had immunised their children – they still recalled their children suffering.

“It was horrible – really awful – she cried so much”

(FG 1)

“Nothing could encourage me to have a needle put in my baby’s arm or leg ...and cry and scream his fucking head off.”

(FG5)

For some participants therefore this ‘trauma’ and the distress that being injected caused to their child was sufficient reason to not take up immunisation.

### e) The fit between the nomadic way of life and healthcare provision

Many of the participants were previously nomadic and/or still spent part of the year travelling. Practical issues related to a nomadic lifestyle such as not knowing where local clinics are located or the procedure for having children immunised, were also important factors in reducing uptake of immunisation.

“Also when you’re travelling as well, you don’t know where the clinics are, how are you supposed to?”

(FG 3)

Legislation making unauthorised camping a criminal offence and allowing faster evictions has further impacted on the ability to access immunisation services.

“...you get an appointment and when you get to the appointment you're moved on again. Then if you do get the appointment and you're booked in, then when you book them in for the injections, you'll be moved on because you never get longer than a week.”

“I travel too much and there wasn’t a clinic that would let me immunise him”

(FG 2)

Another obstacle was that without a vehicle, many women were effectively confined to their sites since many are situated in isolated locations, which are often poorly served by public transport and other services.

“[I]f there was a vehicle and the men needed it, well you had no vehicle then because if they don't go to work, we don't eat basically. So if we're left without a vehicle, that's the way it is isn't it?”

(FG3)

Geographic and social isolation, combined in many cases with poor literacy makes conventional health promotion techniques ineffective in reaching G&T communities. To remedy this participants argued, a more proactive and flexible approach by health service providers was required.

“If there was a nurse who would come out and see us, and tell us when and where we could get it done.”

(FG 1)

“To have doctors on sites, or health visitors to come and do the injections ...for the travelling community.”

(FG3)

Hence, in terms of accessing services it was felt greater flexibility in healthcare provision was required and that outreach was an acceptable mode of delivery.

### CONCLUSION

Although access to immunisation services and cultural attitudes did influence uptake of the MMR vaccine, these were preceded by the effects of longstanding, pre-existing health inequalities, which themselves are an outcome of system wide constraints such as the organisation of health care services, poor standards of accommodation and the prevalence of widespread racism and discrimination (Parry et al., 2004; Smith and Rushton, 2013). The effects of these inequalities, e.g. frequent bouts of ill health which informed the perception of children as vulnerable to illness exacerbated existing barriers to immunisation services such as the inability to access services. Previous studies have also focused on accessibility of services and the cultural beliefs of G&T parents’ (Feder, Vaclavik and Streetly, 1993;



Cemlyn et al., 2009). The present findings support earlier findings (ibid.) which indicate that access to health services impacts on uptake of immunisation largely due to the poor fit between healthcare delivery and nomadic lifestyles. This study adds to this by finding that the effects of long-standing inequalities and a related high burden of illness in G&T communities, precedes and informs decisions surrounding vaccination. The effects of these inequalities are often manifested as practical day-to-day obstacles: e.g. frequent childhood illness make it difficult for parents to take their children for vaccination, which is further exacerbated by poor access to health services. The study also found that frequent childhood illness increases G&T parents' sense of their child/children being prone to illness which can either hinder or encourage MMR uptake.

Unlike previous studies suggesting that cultural beliefs shape G&T parents' willingness to immunise their children, our findings demonstrate that G&T parents have a clear understanding of the risks and benefits of immunisation and non-immunisation. Only one participant argued there may be a link between MMR and autism, i.e. suggesting perceptions of immunisation are similar to those held by the wider population (HSCIC, 2013) and that the discredited 'vaccination/autism' scare was not a major factor in non-uptake of immunisation. In fact, G&T immunisation beliefs may not be significantly at odds with those currently promoted by health services and addressing and drawing upon their concerns could be one way to promote immunisation uptake. Participants felt, however, that immunisation services could be made more flexible e.g. separate injections and on-site immunisation outreach.

Limitations of the study relate to this being a self-selecting sample. As participants opted into the research people with positive experiences of immunisation may have been over-represented - although the balance between parents who immunised and those who did not suggests that this is not the case. The study has also focused largely on barriers experienced by the G&T population and not barriers within the health system although participants regarded the way that immunisation is delivered as an important barrier to immunisation. As with all qualitative studies a relatively small sample in one area of England was used and findings may not be generalisable to the wider G&T population.

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