

UNITING

(UnderstaNding uptake of Immunisations in TravellIng aNd Gypsy communities)

PROTOCOL

Note. We use the term Traveller in its broadest sense to include Gypsy, Traveller and Roma communities, who may be settled, nomadic, and may live on authorised or unauthorised sites, or in houses. However we are aware that these are distinct groups ethnically and/or culturally.

1. ABSTRACT

Travellers experience significantly poorer health and have shorter life expectancy than the general population. They also are less likely to use health services and this includes taking up immunisations.

This is a 3-linked phase qualitative study that will be undertaken in four UK cities (York, Bristol, Glasgow, London) and will focus on six Traveller communities. It has two aims.

1. To explore the reasons for taking up and not taking up immunisations amongst Traveller communities.
2. To identify ideas for programmes to increase uptake of immunisations.

Our main focus will be immunisations that are offered within the UK childhood immunisation programme. However to understand issues relating to adult immunisation, we will also explore views on flu vaccination and on the whooping cough vaccine that is offered to pregnant women.

PHASE 1: Qualitative individual/group interviews with 24 to 45 participants in each Traveller community (total 144-270). Interviews will be held in surroundings familiar to members of the community, and at times and in places convenient to them, whilst ensuring the safety of the researcher. We will explore their views on the intrapersonal, interpersonal, institutional, community and policy influences on their immunisation behaviours and ideas for improving uptake in their community.

PHASE 2: Qualitative individual interviews with 6 to 8 health and community workers in each city who work with the Traveller communities (total 24-32). Interviews will be held in a venue convenient to the health and community worker. We will investigate their perspectives on the barriers and

facilitators (across all five levels of influence) to childhood and adult flu/pertussis immunisations for the Traveller communities with whom they work as well as their ideas for appropriate interventions. Verbatim quotes from the interviews with Travellers in Phase 1 will be used to trigger discussion.

PHASE 3: The findings from Phases 1 and 2 including ideas for interventions will be fed back, discussed and prioritised in Feedback Workshops with a sub sample of participants from Phases 1 and 2 (10 to 12 participants from Phase 1, and 3 to 4 Phase 2 participants for each community; total 78-102). We will refine and produce a prioritised list of potentially feasible and acceptable interventions.

The data collected in Phases 1 and 2 will be analysed using the Framework approach. We will use a method recommended by the National Collaborating Centre for Methods and Tools to achieve consensus in developing evidence-based recommendations) in Phase 3.

2. BACKGROUND AND RATIONALE

The 2011 Census [1] identified 54,895 'White: Gypsy or Irish Traveller' people living in England and the Scottish Traveller population has been estimated at 15,000 [2]. Both of these are likely to be under-estimations and the figure of 360,000 Travellers in the UK is commonly cited [3]. Evidence from literature reviews [4-10] has consistently identified that Travellers experience significantly poorer health and shorter life expectancy compared to the general population. Health inequalities among Traveller communities are greater than in other UK minority ethnic groups and socio-economically disadvantaged white communities [11,12]. Despite greater health need, these reviews identify low uptake of health services, including preventive healthcare. Small local studies using parent self-report [13-16] and NHS records [14] also report low or variable uptake of childhood immunisations in Traveller communities, leading to unimmunised and partially immunised children. This mirrors other disadvantaged groups who are more likely to be unimmunised or not up to date, significantly increasing their risk (and consequent spread) of vaccine preventable disease [17-19].

2.1 Determinants of Immunisation

To identify appropriate interventions to improve immunisation uptake, the determinants need to be understood [24]. A large body of literature [20-23] identifies two broad categories of parental factors influencing uptake of childhood immunisation in the general population and high risk groups [25]. The first relates to socioeconomic disadvantage where, despite being motivated to have their children vaccinated, parents lack access to resources and support to overcome logistical barriers such as no private transport. The second relates to parents' concerns about the safety or beliefs about the necessity of vaccines. Also there are differences in parents who accept immunisation but do not complete the course (partial immunisers) and those who reject immunisation or specific vaccines altogether (non-immunisers) [26]. They are likely to require different interventions. Regardless of parental position on immunisation, trust in health professionals and services is paramount. Studies have also explored factors influencing uptake of immunisations in adults [27,28] including those with 'high risk' conditions [29] and minority ethnic groups [30]. The barriers appear to fall into the same two categories, access and beliefs, including the perception that healthy people do not need immunisations [27].

This literature is informative and many issues identified are likely to be similar for Travellers however to develop interventions that are tailored to the needs of diverse Traveller communities, robust research with these communities is required. To date, a few studies [13-16] have explored the barriers to immunisation uptake specifically in Traveller communities. These identify multiple issues

reflecting the difficulties experienced by marginalised, socially excluded communities [4-10]. Issues specific to immunisation include barriers to accessing primary care services (e.g. the absence of a permanent postal address for recall letters) [15], parental concerns about the safety of vaccines [16] and objection to immunisation arising from strongly held cultural beliefs and traditions [7]. A reluctance to 'self-identify' as Travellers for fear of discrimination [12] and the challenge of maintaining reliable health records for transient communities [8] hinders record keeping of immunisation uptake in Traveller communities. These studies [13-16] highlight some important issues, however they have tended to be small and focus on one community. Whilst Traveller communities may share similar features of lifestyle that distinguish them from the general population they have different beliefs and cultural traditions [12]. We need to understand when, how and in what circumstances one community (e.g. Irish Traveller) compared with another (e.g. English Gypsy) may differ (or not) in the factors that promote or inhibit immunisation. Second, often immunisation is often only one part of a study exploring several health issues. This limits the extent to which the complex nature of barriers and facilitators to immunisation is explored. For example, barriers may be specific to particular vaccines e.g. MMR and differ for adult and childhood vaccines. Finally, most studies were conducted in the 1980/90s so do not consider issues associated with the introduction of new vaccines in the UK childhood immunisation schedule (e.g. Rotavirus in July 2013 [31]) or evolving views about previously controversial vaccines (e.g. pertussis, MMR). We have found no studies on immunisation uptake in adults living in Traveller communities.

2.2 Interventions to increase uptake of Immunisation

The effectiveness of interventions to increase immunisation uptake among children [32] and adults [33,34] has also been reviewed and there are many examples of innovative health and social care provision aimed at improving the health of Travellers [5, 35]. Some target immunisation specifically (e.g. outreach immunisation programmes, tailored health promotion resources) whereas others are generic yet relevant to immunisation (hand-held patient records, specialist health visitors [5], cultural competence training of health professionals [35]). These interventions are rarely rigorously evaluated so it is unclear which are feasible, acceptable and (cost) effective, in which communities they work and how they may (not) work. Moreover, using a theoretical framework to inform the content and delivery of the intervention, and to understand the likely mechanisms of change can increase the likelihood of an intervention being effective [36]. The design and evaluation of existing interventions are typically are not informed by theoretical frameworks.

Our research will advance understanding by addressing the limitations of previous research. We will undertake a multi-site, in-depth qualitative study with six Traveller communities in four UK cities. We

will explore the multi-faceted and complex nature of barriers and facilitators to the uptake of the different vaccines within the UK childhood immunisation schedule [37]. We will also explore views on the flu [38] and pertussis vaccinations [39] in adults either identified 'at risk' of developing serious complications of flu themselves, or in the case of pertussis vaccine, to prevent potentially life threatening infection in their newborn infants. We will collect views of stakeholders who design and deliver immunisation programmes. This development work is the first step in the MRC Framework for developing and evaluating complex interventions [36] and is essential in designing effective immunisation programmes [29]. By framing the study within the Social Ecological Model [SEM, 40] we will identify potentially feasible and acceptable interventions to increase immunisation uptake (for future testing) from the level of the individual Traveller to NHS policy.

This detailed understanding can be used to improve national and local level NHS service delivery to ensure that immunisation programmes are tailored to the needs of local Traveller communities and so reduce inequalities of access to protection against vaccine preventable diseases [17-19]. The potential implications for NHS patients (the Travellers themselves) would be an increase in the uptake of immunisations and associated reduction in vaccine preventable disease (and longer term related health problems e.g. blindness from measles) within their communities. Children and adults in the wider community such as those who are too young to be vaccinated, pregnant women who may be susceptible to rubella or those with medical conditions resulting in suppressed immunity would also benefit if herd immunity was achieved.

3. AIMS AND OBJECTIVES

3.1 Aims

1. Investigate the barriers and facilitators to acceptability and uptake of immunisations amongst six Traveller communities (comprising five distinct ethnic/cultural groups) across four UK cities;
2. Identify possible interventions to increase uptake of immunisations in diverse Traveller communities, to test in a subsequent feasibility study.

3.2 Objectives

1. Investigate the views of Travellers on the barriers and facilitators to acceptability and uptake of immunisations and explore their ideas for improving immunisation uptake ;
2. Examine whether and how these responses vary across and within communities, and for different vaccines (childhood and adult);
3. Investigate the views of Health and Community Workers on the barriers and facilitators to uptake of immunisations within the Traveller communities with whom they work, and explore their ideas for improving immunisation uptake;
4. Examine whether and how these responses vary within and across communities, for different vaccines (childhood and adult) and for different professional roles;
5. Using the data collected from (1 to 4) identify possible interventions to increase uptake of immunisations in different Traveller communities;
6. Conduct Feedback Workshops in each community with Travellers and with Health and Community Workers to discuss findings and to produce a prioritised list of potentially feasible and acceptable interventions to test in a subsequent feasibility study.

4. RESEARCH PLAN

4.1 Design

This is a three-phase qualitative study. Phase 1 comprises qualitative semi-structured, group and individual interviews in six Traveller communities (Objectives 1,2). Phase 2 comprises qualitative semi-structured individual interviews, using vignettes based on Travellers' narratives, with Health and Community Workers (Objectives 3,4). In Phase 3 Feedback Workshops will be held with each Traveller community and associated Health and Community Workers to produce a prioritised list of

potentially feasible and acceptable interventions to enhance immunisation uptake for future development and testing (Objectives 5,6).

We focus primarily on the UK childhood immunisation schedule [37]. In addition, to better understand issues relating to adult immunisation, we will also explore views on flu [38] and pertussis vaccinations [39] in adults either identified 'at risk' of developing serious complications of flu themselves, or in the case of pertussis vaccine, to prevent potentially life threatening infection in their newborn infants

4.2 Theoretical/conceptual framework

The theoretical framework underpinning this proposed research is the SEM [40] which recognises that individuals' behaviour is affected by, and effects, multiple levels of influence (intrapersonal, interpersonal, institutional, community, policy, see Table 1). Levels are 'interactive and reinforcing' [41]. The model also identifies intervention strategies for each level of influence (see Table 1) and it is proposed that to achieve long term health improvements all five levels should be targeted simultaneously. If this is not possible at least two levels should be targeted [41]. In this study we will use the SEM to ensure that all levels of potential influence on immunisation behaviours are considered and we will seek to identify interventions at all five levels. Whilst we do not anticipate designing interventions to change national immunisation policy in a subsequent feasibility study, there may be local policies and/or approaches to communicating national initiatives that fail to meet the needs of these communities and we may identify strategies to tackle this. This multilevel focus is consistent with the WHO conceptualisation of health [41]. Acknowledging the complex multifaceted determinants on behaviour is of particular relevance to understanding health behaviours (to inform future interventions) in socially excluded communities with specific health needs such as Travellers. The SEM has previously been used in the context of flu immunisation [42], child health [43], and with culturally diverse [44] and disadvantaged populations [45].

5. SETTING AND PARTICIPANTS

5.1 Setting

The proposed research will be undertaken in four UK cities and will focus on six Traveller communities (see Table 2). This is a complex, multi-site project working with socially excluded, marginalised communities who are traditionally hard to engage in research [46]. For reasons of feasibility and to enable our approach to be refined in light of experience we will conduct the study in two waves (Wave 1 – York and Bristol; Wave 2 – Glasgow and London). This will enable us to learn

important lessons in Wave 1 to inform Wave 2, for example about gaining the trust of communities. This approach is also consistent with the iterative process of qualitative research. The data we collect on the barriers and facilitators to acceptability and uptake of immunisations, and the ideas for interventions to increase uptake identified in the first Wave Traveller communities will be used to inform the questions in the Wave 2 communities, thus facilitating cross-community comparisons [47].

A brief description of the six Traveller communities is presented in Table 2. Five of the communities (English Roma, English Gypsies, European Roma x 2 communities, Irish Traveller) are recognised in the Race Relations Act 1976 as ethnic minorities [11]). Whilst they have different beliefs, customs and languages, they share common features of lifestyle and culture [11] and are genealogically and linguistically related [14]. In contrast the Occupational Travellers are not recognised in the Race Relations Act or by the aforementioned communities to be part of the 'traditional Travellers' ethnic group. Indeed, they do not want to have recognised ethnic minority status, self-defining as business/cultural communities. It is only their nomadic lifestyle that means that legally they are labelled as 'Travellers' [2]. We are including two Eastern European Roma communities (Bristol and Glasgow) because this is the newest Traveller community in the UK and the one we know least about. The two communities differ in that the Bristol community are mainly Romanian whereas the Glasgow community are mainly Slovakian. In summary, the six Traveller communities reflect five groups that are ethnically and/or culturally distinct, live in different cities and have settled (in housing,(un) authorised sites) versus highly mobile ways of life. These differences may be relevant to uptake of immunisations (and thus the design of appropriate interventions).

Table 1: Overview of the SEM [adapted from 41,42]

Level	Level-specific influences on health behaviour [41]	Examples of level-specific influences on immunisation behaviour [42]	Level-specific intervention strategies [41]
Intrapersonal	Characteristics of the individual e.g. knowledge, attitudes, behaviour, self-concept, skills	Perceptions of risk from disease and effectiveness of vaccine, attitudes towards immunisation, past immunisation behaviour, perceived membership of a vaccine priority group, trust in 'experts'	Education, training, skills enhancement of target population
Interpersonal	Formal and informal social networks and social support systems e.g. family, friendship groups	Beliefs that friends and families (don't) want them to vaccinate, number of people vaccinating in the social network (social norm), social capital	Education, training, skills enhancement of people who interact with target population (e.g. family members, friends, teachers)
Institutional	Social institutions with organisational characteristics and (in) formal rules and regulations for operation	Access to a healthcare provider, reminders and amount of information from healthcare provider, recommendation to vaccinate by healthcare provider	Education, training, skills enhancement of general community beyond target population and immediate contacts including institutional leaders Modifications to institutional environments, policies or services
Community	Relationships amongst organisations, institutions and informal networks within defined boundaries	Presence of disease in community, perceived risk for self and of infecting others	Education, training, skills enhancement of general community beyond target population and immediate contacts including community leaders Modifications to institutional environments or services
Policy	Local, state and national polices	Presence in vaccine priority group, access to immunisation (free of charge, location of services)	Education, training, skills enhancement of general community beyond target population and immediate contacts specific to policy change Creation or modification of public policies

5.2 Participants

PHASE 1: Within each Traveller community we will recruit both men and women living in extended families across generations. We will include young women planning families, parents and grandparents to capture a life span/cross-generational perspective as well as teenage girls eligible for their 3-in-1 teenage booster (diphtheria, tetanus, poliomyelitis, given at 13 to 18 years) and HPV vaccine (given at 12-13 years in school); and adults eligible for the flu vaccine (pregnant – also eligible for pertussis vaccine, over 65 years and with specified long term conditions). Typically decisions on childhood immunisation are made by mothers [20,21] however we are keen to recruit both men and women to explore any potential gender differences in views. Traveller men of a working age may be difficult to recruit [6]. We will, therefore, aim for a quarter of participants to be male. We will purposively seek to recruit a mix of full immunisers/partial immuniser and non-immunisers (based on self-report [14]). We will aim to interview approximately 24 to 45 participants in each of the six Traveller communities (total 144-270 participants). An overview of the proposed sample within each Traveller community is presented in Table 3. This will enable us to look for potential differences and similarities in views *within* a community across gender and age as well as draw out meaningful comparisons *across* Traveller communities, and for different vaccines (childhood and adult) to allow robust conclusions to be made.

PHASE 2: Practitioners and professionals able to influence local policy making, drive health improvement, and/or providing or commission services for Traveller communities in the four cities will be recruited to the study. We will purposively sample these 'Health and Community Workers' in each of the four cities to ensure we interview a mix of 'frontline workers' (e.g. health visitors, practice nurses, community midwives, school nurses, GPs, social workers, range of community workers including third sector) and those working in more strategic/commissioning role (e.g. local decision makers in health protection/public health/Health and Wellbeing Boards/Clinical Commissioning Groups). We will aim to interview 6 to 8 Workers in each city (total 24 to 32 participants). In Bristol and Glasgow where we are working with two Traveller communities some workers may work specifically with one community, others may have a more city wide role. Examples of organisations and workers that we intend to approach in each city are presented in Table 2 although the NHS reforms in April 2013 may have impacted on services and specialist roles with some ceasing to exist. We will identify additional Workers to interview from interview participants from both Phases 1 and 2 (i.e. using interviewee snowballing methods [46]).

PHASE 3: A sub sample of participants from Phase 1 and 2 who agree to be re-approached to take part in the 'Feedback Workshops', specifically between 10 and 12 Traveller participants per community and 3 to 4 Health and Community Workers per city (13 to 17 participants in total per

workshop; 6 workshops comprising 78 to 102 participants). Ideally we will attract a mix of Traveller men and women, across ages (including teenage girls) with different experiences of taking up/not taking up immunisations; and a mix of frontline workers and those with a more strategic role.

Table 2: Overview of participating Traveller communities and examples of Health and Community Workers linked to these communities

Wave	City	Community	Overview
1	York	English Roma	Recognised in British Law as an ethnic group. 350+ families living across three official sites (54 pitches) and some in housing. Examples of organisations/workers: City of York Council-Lead for Traveller and Ethnic Minority Services, Traveller Support Worker; Joseph Rowntree Foundation, Health professionals based at GP practices close to the three official sites, Health visitor who worked at Personal Medical Service (PMS) for Homeless People and Travellers Families project in York. This Service closed in 2011.
	Bristol	Eastern European Roma	Descended from the same people as British Romany Gypsies and have recently moved to the UK from Central and Eastern Europe. Recognised as the same ethnic category as British Gypsies yet distinct from the UK community. 40 families in shared rented accommodation in relative proximity to each other. Examples of organisations/workers: Bristol, North Somerset and South Gloucestershire Strategic Group for Traveller Health, Immunisation leaders in Bristol NHS, local Health Protection Unit, Bristol City Council (BCC) Gypsy and Traveller team, designated Health Visitor, Roma worker funded by the church where the drop-in is located.
		English Gypsy	Recognised in British Law as an ethnic group. 100+ families living on 2 council managed Traveller sites. Examples of organisations/workers: As for Eastern European Roma.
2	Glasgow	Eastern European Roma	See Eastern European Roma in Bristol for overview. Based on GP records there are 1800 residents housed in very small geographical area in Govanhill (8 streets). Examples of organisations/workers: 2 support workers (1 bi-lingual) who are employed to work solely with the Roma Community in Govanhill, health professionals at Govanhill Health Centre, Oxfam, Govanhill Housing Association, Daisy Street Neighbourhood Centre, Govanhill Law Centre, Glasgow Community Health Partnership.
		Occupational Traveller	Scottish showman or traveling show, circus and fairground families. Not recognised in British Law as an ethnic group. Approximately 300 live in fixed sites in the North East of Glasgow. Some sites are owned by the council and some are privately owned. Examples of organisations/workers: Glasgow Community Health Partnership (CHP), health professionals at local Health Centre.

	London	Irish Traveller	<p>Traditionally nomadic people of Celtic descent arriving in Britain in the 1850s. Recognised in British Law as an ethnic group.</p> <p>17000 live in London. Most live in rented accommodation and on local authority sites. London Gypsy and Traveller Unit work with approx. 800 families.</p> <p>Examples of organisations/workers: London Gypsy Traveller Forum, Greater London Authority Public Health Team, Irish Traveller Movement, Southwark Travellers Action Group.</p>
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Table 3: Overview of proposed sample in each Traveller community (up to 32 participants)

Full/Partial immuniser					Non-immuniser				
Male		Female			Male		Female		
< 50 years	50+ years	Teenagers/Young women	30 to 50 years	50+ years	< 50 years	50+ years	Teenagers/Young women	30 to 50 years	50+ years
1-2	1-2	3-4	3-4	3-4	1-2	1-2	3-4	3-4	3-4

6. ACCESS AND RECRUITMENT

PHASE 1: Our research team includes ‘comprehensive gatekeepers’ [46] in all four cities who have long standing trustful relationships with the communities and who can ‘vouch’ for our trustworthiness and thereby enable access and help recruit participants to the study. Our proposed approach in each Traveller community is based on the experience of these gatekeepers as well as drawing on established good practice [48], for example making contact through existing community networks, meeting in surroundings familiar to members of the community, and at times and in places convenient to them, taking time to build trust and to learn from the community.

In each community we will use a multi-pronged approach to access and recruitment. The local PI and/or local researcher and/or local gatekeeper member of the research team will attend existing groups where members of the community routinely meet together. We will also promote the study via local ‘frontline workers’ (e.g. health visitors, community workers) and where, appropriate, the local PI and/or local researcher and/or local gatekeeper member of the research team will accompany them on visits to Traveller sites. The particular approach we take will depend on the local context and details for each community are presented in Table 4. We will work closely with our Community Partners (see Section 12) to ensure that these access and recruitment methods are acceptable; where necessary we will modify our approach. We will also use ‘snowballing’ [46] in circumstances where participants in a particular sampling criterion require boosting to ensure sample diversity within groups.

Table 4: Approach to access in each Traveller community

City	Community	Examples of existing groups and frontline workers
York	English Roma	Monday Women’s Club, literacy, numeracy, communication and parenting courses at York Travellers Trust. These are mainly attended by women across a broad range age. In September 2013 a literacy group for men is being set up.
Bristol	Eastern European Roma	Roma community a ‘drop in’ situated in a church hall. This ‘drop in’ is facilitated by the Bristol City Council (BCC) Gypsy and Traveller team. Also present are Romanian interpreters and a Roma worker funded by the church. Specialist Health

		Visitor for Gypsies and Travellers.
	English Gypsy	Accompany Gypsy and Traveller team based at Bristol City Council (BCC) on their regular visits to local sites where the English Gypsy community live. Specialist Health Visitor for Gypsies and Travellers.
Glasgow	Eastern European Roma	Roma specific groups which run at the Daisy Street Neighbourhood Centre. These include parent and child groups, employability, youth and music/drama groups. Interpreters are present.
	Occupational Travellers	Liaise with local community workers. There are no specialist services for Occupational Travellers.
London	Irish Traveller	The London Gypsy Traveller Forum, bi-weekly 'advice' sessions and the youth programme at London Gypsy and Traveller Unit (LGTU). Our project advisor (GF) runs a weekly teenage girls group at LGTU.

Irrespective of our approach to access, when the local PI and/or local researcher and/or local gatekeeper member of the research team meet with members of the community they will discuss the study and leave the Flyer and/or Participant Information Sheet (depending on each Traveller's preference) for people to read or have read to them by others, and to discuss with their family members and peers about taking part. For the two European Roma communities information will be in both English and Romanian/Slovakian. They will then return (no sooner than) a week later to talk through the Participant Information Sheet with interested individuals, establish who might wish to take part, and arrange a time and place for the interview. The local PI and/or local researcher will continue to regularly attend during the recruitment phase of the project in each community. In between these visits the frontline workers (see Table 4) and the gatekeeper members of our research team with links to these groups and workers will promote awareness about the study and identify willing participants.

PHASE 2: In each of the four cities we will establish a list of contacts of the relevant Health and Community workers. The local PI and/or local researcher will approach these people by email/post in the first instance with a Participant Information Sheet about the study (which will include our contact details) and then follow this up with a telephone call a week later.

PHASE 3: Participants in Phases 1 and 2 (i.e. Travellers, and Health and Community workers) who agree to be re-contacted about Phase 3 will be re-approached by the local PI and/or local researcher and/or local gatekeeper member of the research team using their preferred method of contact and provided with a Participant Information Sheet about the Feedback Workshop.

7. DATA COLLECTION

7.1 Procedure

PHASE 1: We aim to conduct small group interviews with members of the same family to elicit a cross-generational/lifespan perspective. We also plan to do group interviews with teenage girls, and with young women planning families/pregnant women/those with pre-school children to capture peer influence in immunisation decisions. However we acknowledge that whilst immunisation may not seem a particularly sensitive issue (with the exception of HPV) group interviews may not be appropriate or favoured. Some participants may prefer to be interviewed alone and others may not attend on the date arranged for a group interview. We will, therefore, be flexible about who and how many participants take part in an interview. Individual and group interviews will be conducted face-to-face in participants' choice of setting. This may be in participants' homes or in other locations known to participants, for example at the premises of York Travellers Trust, London Gypsy and Traveller Unit, and the Bristol Roma drop-in. The local PI and/or local researcher will undertake the interviews. With consent of participants, interviews will be recorded digitally and transcribed verbatim. For group interviews the interviewer will also take brief notes to identify who is speaking. Where necessary (e.g. with Eastern European Roma) we will employ interpreters to accompany the local PI and/or local researcher in undertaking the interviews.

PHASE 2: The local PI and/or local researcher will conduct individual interviews with the Health and Community workers, face-to-face in participants' choice of setting. With their consent, interviews will be recorded digitally and transcribed verbatim.

PHASE 3: A Feedback Workshop will be held locally for each Traveller community (six workshops in total). Examples of potential venues are York Travellers Trust, the London Gypsy and Traveller Unit, Samaritan House (owned by Govanhill Housing Association – where many Roma are housed) and the church where the drop-in centre held in Bristol. The local PI and/or local researcher along with the local gatekeeper member of the research team and local 'Community Partners' (see Section 12) will co-facilitate the Workshops.

7.2 Focus of data collection

PHASES 1 AND 2: We will use topic guides for the interviews (individual and group) to ensure consistency both within and across the six communities, although the format will be flexible to allow participants to generate naturalistic data on what they view as important. We will explicitly pursue negative cases ('elements in the data that appear to contradict the emerging view' [49, p51] to enhance validity of our developing propositions. Topics will be revised as necessary on the basis of emerging evidence from preceding interviews both within the same, and other Traveller communities.

Throughout, the SEM [40] will inform the questions that we ask, ensuring that we explore all five levels of influence on immunisation behaviour. Research team members' local knowledge of immunisation and the Traveller community will also feed into the development of the topic guides to prompt dialogue of particular local issues (e.g. outbreaks of measles and whooping cough in the community, introduction/removal of specialist services). Topic guides for Phase 1 will be reviewed and piloted with the Community Partners (see Section 12) by the local PI and/or researcher and/or the local gatekeeper member of the research team.

PHASE 1: In the group/individual interviews we will first explore childhood immunisations and then move onto flu immunisation for 'at risk' adults. In the interviews where young women planning families/pregnant women/those with pre-school children are present we will also ask about the pertussis vaccine (which is given during at 28-38 weeks of pregnancy). Interviews with teenage girls will focus on HPV and childhood immunisation. We plan to examine if and how responses vary across different vaccines (objective 3) but acknowledge that it will not be possible to discuss every vaccine in the UK childhood immunisation schedule across all five levels of the SEM. There may be particular vaccines that prompt more discussion than others, for example the pertussis and MMR vaccines are associated with controversies in the 1970s and late 1990s respectively. There are currently high levels of cases of whooping cough in the UK [39]. Exploring views on the rotavirus vaccine after it is introduced in the UK [31] will provide completely novel data. We will be guided by participants and focus on the vaccines that emerge in the conversation, whilst ensuring that we discuss any vaccines that have particular local/community relevance.

PHASE 2: In the interviews with Health and Community Workers the focus will be the vaccines that are relevant to the professional role of the participant, for example an interview with a health visitor will only explore childhood immunisations. As in Phase 1 we will be somewhat guided by participants and focus on the vaccines that emerge in the conversation, ensuring again that we discuss any vaccines that have particular local/community relevance.

Within these Phase 2 interviews we will integrate key emerging issues from Phase 1 within additional interview questions. This will enable us to stimulate discussion of key issues identified by the Traveller communities captured in Phase 1 with a view to developing ideas for interventions to increase immunisation uptake (for Phase 3) that are grounded in the views of both the communities that they are targeting and the Health and Community Workers who have responsibility for designing and delivering immunisation programmes locally.

At the end of Phases 1 and 2, for each of the six Traveller communities, we will (a) understand the potential barriers and facilitators for take up of immunisations (across all five levels of the SEM) and (b)

have ideas for the content and delivery of potentially feasible and acceptable interventions to increase immunisation uptake for all five levels of the model. We also have insight into whether the barriers/facilitators and interventions are similar or different dependent on the gender, age and self-reported immunisation history of Traveller participants, the professional role of worker and across different vaccines (childhood/adult flu and pertussis). These outputs will be presented at the Feedback Workshops in Phase 3.

PHASE 3: The aim of the workshops will disseminate the findings of Phases 1 and 2 and to discuss and 'co-produce' [46] ideas for the content and delivery of potentially feasible and acceptable interventions at all five levels of the SEM; with a view to then identifying one priority intervention at each level (intra-, inter-, institutional, community, policy). Following the presentation of the findings we will use a method recommended by the National Collaborating Centre for Methods and Tools to achieve consensus in developing evidence-based recommendations [65]. We will use a modified approach in recognition that a large proportion of Travellers may not have good reading and writing skills [4-10]. There are three steps [65].

1: REVIEW OF DATA COLLECTED IN PHASES 1 AND 2 – the local PI and/or researcher and the Community Partners will jointly present the aforementioned ideas for interventions (across all five levels of the SEM) to the group. **2: CONSULTATION** – working in small facilitated groups, participants will score and then discuss the impact and feasibility of each of the ideas for interventions (across all five levels of the SEM). **3. SYNTHESIS** – the local PI and/or researcher will synthesise the data from the workshop and make final recommendations for interventions. At this stage we do not know how similar or different the interventions for childhood and adult vaccines will be. If they are very different then we will need to identify a priority intervention at each level for both childhood and adult immunisation (i.e. 10 interventions rather than 5).

8 DATA ANALYSIS

8.1 Within-community analysis

PHASES 1 AND 2: Interviews will be fully transcribed by a research secretary and data subjected to thematic analysis using the Framework approach [51] which is designed to address applied policy-related questions [651]. Importantly for this multi-site project it provides a 'well-defined procedure' [51, p.176] in which the five stages of analysis are clearly documented and therefore accessible and transparent to the entire research team working across the different Traveller communities. This will also help us to manage the large amounts of qualitative data that we will be collecting in this project. Finally, a key feature of this

approach is to facilitate ‘comparisons and associations between and within cases’ [51, p.176]; and so, for the purposes of this study, between and within Traveller communities. The Framework approach has previously been used in a large UK qualitative study exploring health issues with Gypsies and Travellers [52].

The five stages of analysis, specified below, will first be undertaken independently for each of the six Traveller communities and for both Phase 1 and Phase 2 data. This ‘within-community’ analysis will be led by the PI and researcher based in York. Members of the research team and the Community Partners based in Bristol, Glasgow and London will each input into the analysis of their local data. This will enhance rigour and ensure that the local context in which the data are collected is retained. Atlas-ti software will facilitate data management and team working via its ‘team working function’. We will develop a protocol for this across-team analysis.

1: FAMILIARISATION - We will read the interview transcripts to record emerging ideas and recurrent themes. **2: IDENTIFYING A THEMATIC FRAMEWORK** – Using the recorded notes from Stage 1, a thematic framework will be set up which in which the interview data will be organised. This will be informed by the SEM so will initially have 15 themes (views on barriers, facilitators to immunisations; ideas for interventions – for each level of the model). Additional themes representing emerging issues from the data will be added. The framework will be applied to 3 to 4 transcripts to refine. **3: INDEXING** – The thematic framework will be systematically applied to the interview data. **4: CHARTING** – Charts will be drawn up for each theme and summaries of responses from participants (and verbatim quotes) entered. This will enable us to consider the range of views within each theme i.e. on (1) barriers, (2) facilitators to immunisation, (3) ideas for intervention across the five levels of the SEM; and (4) other emerging issues. In each chart participants will be presented in the same order (by the characteristics we believe may impact on their views i.e. gender, age, history of taking up/not taking up immunisations, professional role of Health and Community workers). This will help us systematically look for similarities and differences in views across characteristics within each community (and subsequently across communities in the cross-community synthesis). It is important that participants’ experiences are not defined solely by the community in which they live or work with. We will also ensure that we document which vaccine (within the UK childhood immunisation schedule, and adult flu/pertussis) participants’ views pertain to. **5: MAPPING AND INTEPRETATION** – The charts will be reviewed and interrogated to compare and contrast views, seek patterns, connections and explanations within the data.

We will start with the same thematic framework to analyse the data for all the six Traveller communities and associated Health and Community Workers although it will be added to where appropriate. Having this ‘common index’ [51] will help us to identify common and divergent themes and views within themes

in the subsequent cross-synthesis. From this above described 'within-community' data analysis carried out on Phases 1 and 2 data, we will understand the potential barriers and facilitators for take up of immunisations (across all five levels of the SEM) and have ideas for the content and delivery of potentially feasible and acceptable interventions to increase immunisation uptake at each level of the model. We will also be familiar with other emerging issues not captured within the model. These findings will be for each Traveller community and have been analysed (thus will be presented) separately for the Traveller participants and the Health and Community Worker participants). These findings will be taken to the Feedback Workshops in Phase 3.

PHASE 3: There is no analysis.

8.2 Cross-community synthesis

The final outputs of the analysis of Phase 1 and 2 data will be a thematic synthesis that takes account of the inferences derived from all the interview data for the sample as a whole [53] Using the charts created in Stage 4 of analysis for each Traveller community (both Traveller participants and Health and Community Workers) we will synthesis the data across all six communities to explore for similarities and difference in views on (1) barriers and (2) facilitators to immunisation, (3) ideas for intervention across the five levels of the SEM; and (4) other emerging issues. At this stage will also look for similarities and difference in views of the two European Roma communities living in different cities. Our earlier analysis exploring 'within-community' patterns of responses by: gender, age and history of taking up/not taking up immunisations of community participants; professional role of Health and Community Workers; vaccine (within the UK childhood immunisation schedule, adult flu/pertussis) will be extended to across communities to enable us to identify transferability of these features across communities. This cross-community synthesis will be led by the PI and researcher based in York however the full research team and the Community Partners based in all four cities will input into the process.

9. ETHICAL CONSIDERATIONS

9.1 Risks and anticipated benefits for study participants

There are two key ethical issues for this research.

1. This is a qualitative study with the primary output being a list of prioritised interventions to increase uptake for testing in a subsequent research study, rather than making actual changes to services as a result of this research. There is, therefore, a risk that we will raise unrealistic expectations of what this research can achieve in the short term with a lack of tangible benefits to the Traveller communities themselves, particularly those members who are transient. We will be very clear from the outset about

the purpose of the research and work with our Community Partners throughout the study to ensure that this stated purpose is widely disseminated within communities. The study findings (the prioritised list of interventions and associated barriers and facilitators to uptake of immunisation) and the plans for the next step in the research will be fed back to all study participants using their preferred methods of contact (working with our Community Partners). All Traveller participants will be offered a £15 voucher of their choice in recognition of their time following the interview (£25 for attending the Feedback Workshop).

2. The HPV (human papillomavirus) vaccine which is now offered to teenage girls (aged 12-13 years) at school prevents infection with the HPV types 16 and 18 that cause 70% of cervical cancer. This virus is typically transmitted through sexual contact. We want to interview teenage girls about their views on the HPV vaccine however its link to sexual health and the possibility that this will be discussed may concern parents. We will provide an information sheet for teenagers and for parents; and seek consent from parents/individuals with parental responsibility (assent from the girls). The interviews will not ask the girls about their own sexual health; and we will reassure them that they can choose to not answer any questions/stop the interview/leave a group interview at any time.

9.2 Obtaining informed consent

PHASE 1: It is likely that there will be high levels of illiteracy within the participating Traveller communities [4-7]. We will develop two versions of all Participant Information Sheets (PIS) for each community. A 'standard' PIS has been submitted with this application. A second version will be developed with our Community Partners and will be in simple language using images where feasible and appropriate. Prior to commencing any interview, the local PI and/or researcher will re-read the PIS and consent form to participants, and consent them by asking them to initial or make a mark on two copies of the form (one for their own keeping) and witnessing /signing this. We have successfully used this approach in our previous research with Traveller communities. According to Gillick competence [54], the teenage girls (under 16 years of age) could consent for themselves to take part in an interview about immunisation if they have sufficient understanding and intelligence to understand fully what is proposed. However we are mindful that Traveller communities commonly remove their children from sex education classes in school [55], and so may be unwilling for their daughters to participate in a discussion about an immunisation to protect against sexually transmitted infections. We will, therefore, seek assent from the girls themselves and consent from a parent/individual with parental responsibility.

PHASE 2: Prior to commencing an interview, the local PI and/or researcher will go through the PIS and answer any questions that the Health and Community Worker may have. The Worker will then be asked to sign two copies of the study consent form (one for their own keeping).

PHASE 3: The same procedures for Phases 1 and 2 will be used.

10. BENEFITS OF THE STUDY

There will be three key outputs of this research

1. A prioritised list of potentially feasible and acceptable interventions for increasing immunisation uptake across the five levels of the SEM for six Traveller communities (comprising five distinct ethnic/cultural groups). Importantly these ideas for interventions will be grounded in the views of both the communities that they are targeting and also the Health and Community Workers who have responsibility for designing and delivering immunisation programmes locally. We will report what the content and delivery of the immunisation interventions would look like, whether we understand the interventions to be transferable within that community (e.g. for different childhood/adult vaccines, across gender, age, immunisation history) and whether they are potentially transferable between different Traveller communities (e.g. for English Gypsy versus Occupational Traveller communities).
2. Comprehensive, in-depth findings on the barriers and facilitators to uptake and acceptability of childhood / adult flu and pertussis immunisation both within and across six Traveller communities (comprising five distinct ethnic/cultural groups) living in four cities across England and Scotland. Such information does not currently exist in the UK.
3. Methodological development in undertaking research with diverse Traveller communities living in different localities. Historically research has been small scale, localised and with one community. Lessons learnt from this large scale multi-city qualitative study can be used to improve the quality of future research of a similar scale.

The proposed research is highly relevant and timely at national, and potentially trans-national, levels given enhanced mobility across EU member countries' borders. Improving health and well-being for all, and reducing health inequalities, are core objectives of current Government health policies in England [56,57] and Scotland [58]. There is now a 'Ministerial Working Group on tackling inequalities experienced by Gypsies and Travellers' in England [56], a Primary Care Service Framework for Gypsies and Travellers [59] and a Scottish Government Race Equality Statement [60]. These documents state a commitment to improving the health of Traveller communities. Improving uptake of childhood immunisation in Traveller communities is also a priority of health policy in England [57] and Scotland [58].

This research is also relevant and timely on a local level. All four cities in which our research is based have local Traveller Strategies and Action Plans which include a focus on health and immunisation [61-64]. To develop effective immunisation programmes which are responsive to local needs the barriers to immunisation need to be identified and addressed [24].

11. RESOURCES AND COSTS

This is a multi-site project (six Traveller communities in four cities) which mean that we are replicating processes and associated costs. The total cost of the project is £359,178

POSTS AND SALARIES: A major source of expenditure is for staff and for their associated estate/indirect costs at the six collaborating universities (York, UWE, Glasgow Caledonian, UCL, UEA and Anglia Ruskin).

TRAVEL, SUBSISTENCE AND CONFERENCE FEES: In each city (n=4) travel costs are included for the lead researcher and gatekeeper to set up the study and attend the Phase 3 Feedback Workshops (6 communities); for the local researcher/PI to travel to Phase 1 (6 communities) and Phase 2 interviews; and for the gatekeepers to attend bi-monthly 'local' research team meetings. Other costs are for participants to travel to Phase 3 Workshops (6 communities), and travel, subsistence and accommodation for the full research team and project advisors to attend 3 full-day team meetings in York. We include attendance at 2 national conferences: Society for Social Medicine (academic) and Faculty of Public Health Annual Conferences (practitioner).

EQUIPMENT: We have costed a computer for the researcher in York.

CONSUMABLES: We have costed a digital recorder for each of the Traveller communities (6 in total) and an Atlas-ti licence for four universities. Production of all resources e.g. Participant Information Sheets have been costed to York. Consumables in York, Bristol, Glasgow and London are CRB checks, gift vouchers for Traveller participants (Phases 1 and 3), room hire, production of resources, refreshments for the Feedback Workshops.

PPI: Costs are travel for the local researcher/PI, gatekeeper and Community Partners to attend meetings, room hire, refreshments and payment to Community Partners (for 5 meetings in each Traveller community).

OTHER: These costs are sessional researchers (Bristol, Glasgow, London) and interpreters (Bristol and Glasgow only), time of Gatekeeper members of the research team and of Gill Francis (project advisor).

There are no NHS Service Support or NHS Excess Treatment costs.

12. PATIENT AND PUBLIC INVOLVEMENT

We have a PPI advisor to the project. Working with members of the participating Traveller communities in planning and undertaking the research, to ensure a sense of 'ownership', is vital to its success [46]. We intend to adopt a 'collaboration' approach' by working in partnership with five to six 'Community Partners'

in each community for the duration of the project in that city. The local PI and/or researcher and the local gatekeeper member of the research team will undertake this collaborative work. In York and London, the Community Partners will be members of established groups: the Advisory Steering Group at York Travellers Trust, the London Gypsy Traveller Forum at the LGTU. In Bristol and Glasgow, there are no obvious existing groups to work with in this way, so we will identify and work with Community Partners via the well-attended Roma drop in and through key contacts in BCC Gypsy and Traveller team (Bristol); and Community Engagement Development Officers in Glasgow. We hope to gain experience in York and Bristol (Wave 1) to inform our approach in Glasgow and London (Wave 2). Irrespective of how actually 'meet' with our Community Partners, the tasks of the Partners will be the same. We will meet five times over the 12 month period that the study is running in the community. The focus of each meeting is presented in Table 5. 'Community Partners' will be offered a £40 gift voucher of their choice per meeting.

Table 5: Focus of meetings with Community Partners

Meeting	Months (Wave 1,2)	Focus of meeting
1	1, 8	Training on the role of a 'Community Partner'
2	2, 9	Access and recruitment, identify 'imaginative' ways to encourage the community to engage with the study
3	11, 18	Review findings from Phases 1 and 2 in preparation for the Feedback Workshop and discuss approach to disseminating findings across the community
4	12, 19	Jointly run the Feedback Workshop

13. STUDY TIMELINE See over the page.

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