



Contents lists available at ScienceDirect

Vaccine

journal homepage: www.elsevier.com/locate/vaccine

COVID-19 vaccination decisions among Gypsy, Roma, and Traveller communities: A qualitative study moving beyond “vaccine hesitancy”

Charlotte Kühlbrandt^a, Catherine R. McGowan^a, Rachel Stuart^{a,b}, Pippa Grenfell^a, Sam Miles^{a,c}, Alicia Renedo^a, Cicely Marston^{a,*}

^a Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT, United Kingdom

^b College of Business, Arts and Social Sciences, Brunel University London, Kingston Lane, Uxbridge, Middlesex UB8 3PH, United Kingdom

^c Barts & The London School of Medicine and Dentistry, Queen Mary University of London E1 2AD, United Kingdom

ARTICLE INFO

Article history:

Received 20 January 2023

Received in revised form 7 April 2023

Accepted 28 April 2023

Available online xxxxx

Keywords:

Vaccination

COVID-19

Gypsy

Roma

Traveller

Discrimination

Qualitative

England

Vaccine Hesitancy

Trust

Trustworthiness

Inequality

Inequity

ABSTRACT

Background: Many people refuse vaccination and it is important to understand why. Here we explore the experiences of individuals from Gypsy, Roma, and Traveller groups in England to understand how and why they decided to take up or to avoid COVID-19 vaccinations.

Methods: We used a participatory, qualitative design, including wide consultations, in-depth interviews with 45 individuals from Gypsy, Roma, and Traveller, communities (32 female, 13 male), dialogue sessions, and observations, in five locations across England between October 2021 and February 2022.

Findings: Vaccination decisions overall were affected by distrust of health services and government, which stemmed from prior discrimination and barriers to healthcare which persisted or worsened during the pandemic. We found the situation was not adequately characterised by the standard concept of “vaccine hesitancy”. Most participants had received at least one COVID-19 vaccine dose, usually motivated by concerns for their own and others’ health. However, many participants felt coerced into vaccination by medical professionals, employers, and government messaging. Some worried about vaccine safety, for example possible impacts on fertility. Their concerns were inadequately addressed or even dismissed by healthcare staff.

Interpretation: A standard “vaccine hesitancy” model is of limited use in understanding vaccine uptake in these populations, where authorities and health services have been experienced as untrustworthy in the past (with little improvement during the pandemic). Providing more information may improve vaccine uptake somewhat; however, improved trustworthiness of health services for GRT communities is essential to increase vaccine coverage.

Funding: This paper reports on independent research commissioned and funded by the National Institute for Health Research (NIHR) Policy Research Programme. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care or its arm’s length bodies, and other Government Departments.

© 2023 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

1. Background

Understanding vaccination decision making is crucial: vaccination can mitigate the impact of epidemics, and slow down infectious disease transmission. The COVID-19 pandemic has demonstrated the numerous complexities and power of achieving mass vaccination in an emergency. The UK National Health Service COVID-19 vaccination campaign was celebrated as an example of an almost unequivocally successful response to the pandemic [1].

Nevertheless, a considerable proportion of the population remains unvaccinated [1]. In this paper we explore the experiences of individuals from Gypsy, Roma, and Traveller (GRT) groups in England to understand how they made decisions about COVID-19 vaccinations. GRT communities are “priority communities” under the Inclusion Health agenda because of existing health inequalities and their unmet health needs [2]. Understanding their experiences and views of COVID-19 vaccinations is vital to reduce disproportionate impacts of the pandemic on these communities, and potentially help to illuminate reasons for other health disparities (e.g. long-term illness and disability[3]) for these and other priority groups. GRT communities are already disadvantaged and have

* Corresponding author.

E-mail address: cicely.marston@lshtm.ac.uk (C. Marston).

<https://doi.org/10.1016/j.vaccine.2023.04.080>

0264-410X/© 2023 The Authors. Published by Elsevier Ltd.

This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

poorer health outcomes than the general population, driven in part by structural factors such as inadequate access to housing, work, and education [3]. Traveller communities in England appear to have lower recorded rates of childhood vaccination [4], although accurate figures on immunisation uptake are not available because Gypsy, Roma, or Traveller identity is often not captured in official records [3].

In the UK, COVID-19 vaccination rates are low in minoritised ethnic groups compared with people from a white ethnic background [5,6]. Differences in uptake of vaccines between ethnic groups were more pronounced for first-dose COVID-19 vaccines than for flu vaccines, with inequalities particularly pronounced in those at greatest risk of severe COVID-19: older adults, those who are clinically vulnerable, and among people living in the poorest neighbourhoods [7]. A rapid systematic review of COVID-19 vaccination uptake in people from minority ethnic groups in the UK found that barriers included pre-existing mistrust of formal services, misinformation, inaccessible communication, lacking information on vaccine safety, and logistical issues [5].

Explanations and analyses of why certain people are less likely to vaccinate against COVID-19 have largely been framed as ‘vaccine hesitancy’ [8–11]. This term is commonly understood in terms of the World Health Organization’s “3C” model, which conceptualises vaccine uptake as determined by a combination of *confidence* in the vaccine, *complacency* about the illness, and *convenience* of access [8].

The concept of vaccine hesitancy emphasises the importance of individual behaviour and individual attitudes, and does not explicitly take into account key factors including social inequalities, discrimination, socio-demographic factors or historical influences [6,8,9]. The United Kingdom’s Scientific Advisory Group for Emergencies’ report on factors influencing COVID-19 vaccine uptake among minority ethnic groups [10] emphasised the need to understand beliefs, needs and barriers to vaccine uptake, and stated that structural and institutional racism and discrimination undermined trust. Several proposals have been made to add another C for “context” to the 3C vaccine hesitancy model [6,11], in order to account for these socio-historic dynamics. However, context is still often overlooked, and little vaccine-related research examines decisions to vaccinate in relation to racism and discrimination [11]. A recent systematic review of global interventions to overcome vaccine hesitancy shows that most interventions still focus on building confidence in vaccines by providing health education [12]. The model assumes that someone who is hesitant to be vaccinated has a deficit of knowledge, which can be addressed by supplying information via authorities and health services. The underlying assumption appears to be that these sources will be trusted to give accurate and helpful information. In this individualistic approach, the information/education interventions are not designed to address wider structural or contextual factors affecting vaccine uptake.

The under-emphasised contextual factors, however, may be crucial. For instance, histories of marginalisation and experiences of discrimination can erode trust in health systems and health providers, and consequently diminish confidence and trust in vaccines in general – regardless of the specifics of the vaccine in question [6,13–16]. Confidence in vaccines comprises trust in the vaccine itself, trust in the provider, and trust in policy-makers [14]. People with lower trust in governments are less willing to vaccinate [17]. The 3C vaccine hesitancy model does not make explicit the need to examine political and historical dimensions of trust; and consequences of historical abuse may instead be conceptualised as located within individuals – for example, categorised as “conspiracy mentality” [13]. Vaccination campaigns based on the 3C vaccine hesitancy model may focus on establishing trust in a vaccine by evidencing its safety, when historical injustices perpetrated by medical institutions and professionals – such as those experienced

by African-American communities as part of the Tuskegee syphilis experiments [18] – have previously led to deep-seated and widespread mistrust in medical institutions unlikely to be rapidly reversed by messaging about the harmlessness of a specific vaccine [19].

Gypsies, Roma, and Travellers (GRT) are frequently written about together for strategic purposes, but this can mask the heterogeneity of cultures and histories that are contained within this umbrella grouping. These groups are diverse, fluid, and overlapping in nature, therefore a clearcut definition is often misleading. A common thread, however, is nomadic lifestyle, nomadic ancestry or culture [20], as well as a shared experience of contemporary and historical marginalisation and discrimination. In parts of Europe, Romani people were enslaved for more than 500 years [21]. Under German National Socialism, family genealogies of Roma and Sinti were created and used to justify the deportation and destruction of the Romani population. Romani children were studied and subsequently deported to extermination camps [22]. In Eastern Europe, in Slovakia, Hungary and Czechia, Romani women were coercively sterilised from the 1970s to the 1990s [23]. Reports of coerced sterilisations of Romani women in Czechia have been reported as recently as 2004 [24].

Gypsy and Traveller communities in the UK share this common history of marginalisation and discrimination. The 1968 Caravan Sites Act mandated that UK councils provide authorised caravan sites to address cycles of evictions caused by enclosure of common land and lack of authorised stopping places. In practice, however, Gypsy and Traveller site provision has remained inadequate, forcing communities either to settle in houses or to keep moving by evicting them from roadside stopping places [25]. The Police, Crime, Sentencing and Courts Bill (2022) criminalises trespass and has been criticised by Gypsy and Traveller advocacy groups for impeding travelling lives and pushing people from these communities into the criminal justice system, thereby compounding existing inequalities [26]. Parliament debated and passed this bill into law during 2021–2022, at the same time as the COVID-19 vaccine roll-out.

We conducted a participatory, qualitative study to understand experiences of the pandemic among GRT communities in England, including reasons for taking up, or not taking up, COVID-19 vaccination in order to inform public health responses and ensure that community voices are taken into account in planning and delivering services.

2. Methods

In this project, “Routes: new ways to talk about COVID-19 for better health. A focus on Gypsy, Roma, and Traveller communities, and migrant workers in precarious jobs”, we used a qualitative, participatory design: the “DEPTH” approach. This is an interdisciplinary approach rooted in co-production, emphasising community involvement, and collaboration with diverse stakeholders to ensure academic rigour and quality (Fig. 1).

We integrated participation processes throughout the research, with each stage informed by a range of academic and community members’ views, allowing an interchange between existing theory and literature, academic interpretation, and lay interpretation. The analysis ultimately combines different expertise, skills, and knowledge, creating synergies using techniques we developed iteratively through previous work [27]. Throughout the project, we used in-depth interviews and dialogue sessions to explore experiences of and responses to COVID-19 in the context of our participants’ whole lives. We explored experiences of testing, contact tracing and other aspects of the public health response [34,35]. Here we report on the vaccine-related findings only.

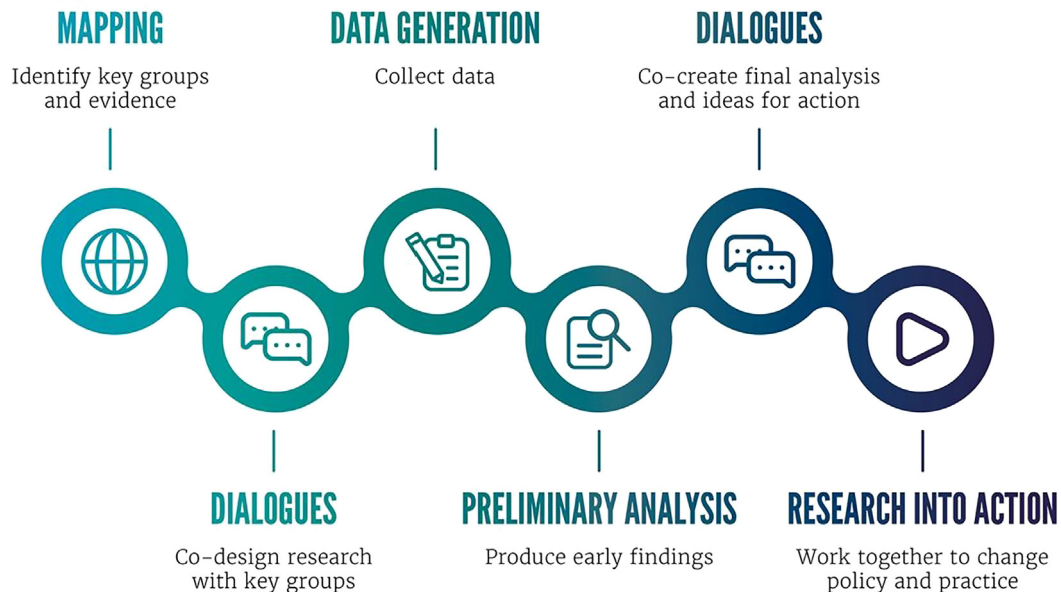


Fig. 1. The Dialogue, Evidence, Participation and Translation for Health (DEPTH) approach.

2.1. Sample and sample size

Members of the research team used their existing contacts within communities to identify participants. Other participants were identified in the mapping phase. Where we were ‘outsiders’, we worked with trusted networks to enter community spaces. We conducted qualitative interviews and dialogue sessions which we carried out in locations convenient to participants. These were conducted in person to address known issues relating to digital exclusion and to observe cultural sensitivities. We aimed for diversity in our sample in terms of age, gender, type of living arrangement, urban/rural, and identity (i.e. Gypsy, Roma, Traveller). We worked in five geographical locations across England (North, South East/East, South West, West Midlands, and London). Participants self-identified their ethnicity – often into more than one category.

We spoke to key informants in formal interviews and informal conversations (contacted via e-mail), including members of advocacy organisations and individuals who work with or represent GRT communities. Most interviews and dialogue sessions were carried out by individuals either from a Traveller background (RS and Serena Farrow), or with experience working with Romani communities (CK). Interviews were conducted in English except for four in Romanian. Interviews in English were transcribed by an agency and spot checked for accuracy by the research team. We engaged a professional translator, Alina Huzui, to transcribe interviews in Romanian and then translate them into English; this work was spot checked by author CK who had conducted the interviews. Dialogue sessions were conducted in English and Romanian language (via an interpreter). Some conversations involved occasional interpreting into and out of other languages ad hoc by participants to assist other participants who spoke less English. We worked with seven co-researchers who were from our focus communities and external to the main research team. They undertook various tasks according to their preference and availability. Tasks included: helping to refine our approach, helping to recruit for interviews and dialogue sessions, interviewing, and discussing and interpreting findings. We also worked with a group of migrant workers as part of the wider study and report findings from this elsewhere [34].

We carried out eight informal dialogue sessions in person (with members of Gypsy, Roma, and Traveller communities), and online (with academic researchers, civil society organisation staff, and Department of Health and Social Care staff) and three formal dialogue sessions each with multiple participants from Gypsy, Roma, and Traveller communities. We also conducted qualitative in-depth interviews with 47 individuals from Gypsy, Roma, and Traveller communities between October 2021 and February 2022. Dialogue sessions were varied in size, from two or three participants, to larger groups; we used these to co-design the work, gain insights, and co-interpret the findings. Table 1 shows characteristics of interview participants. In interviews we asked about people’s living and working environment and circumstances, and how COVID-19 and COVID-19 prevention measures fit into their lives. We also enquired about personal experiences of COVID-19 and of COVID-19 public health responses and services (testing, contact tracing, vaccination), and how these experiences related to previous interactions with healthcare services. This article reports on experiences of COVID-19 vaccinations. Our sample design, number, and location of participants represents a balance between diversity, practical considerations, and the need for

Table 1
Participant characteristics.

Location	
South East/East	(n = 28, 60 %)
West Midlands	(n = 7, 14 %)
South West	(n = 10, 21 %)
North	(n = 2, 4 %)
Gender	
Female	(n = 33, 70 %)
Male	(n = 14, 30 %)
Age	
18–29	(n = 17, 36 %)
30–39	(n = 14, 30 %)
40–49	(n = 9, 19 %)
50+	(n = 7, 15 %)
TOTAL	N = 47

robust themes to be identifiable that are unlikely to be changed by adding further data collection.

2.2. Ethics

We assured participants that their contributions were confidential and voluntary. Because of low levels of literacy we read information sheets out loud before asking participants in formal interviews and dialogue sessions to provide written informed consent. We provided referral information for Gypsy, Roma, and Traveller organisations to participants as needed. Formal interviews were recorded and transcribed. For discussions that took place as part of community dialogues and other conversations (e.g. during mapping phase), we took fieldnotes (with verbal consent). Participants in formal interviews and dialogue sessions were compensated £40 for their time and travel costs. Co-researchers were paid a set rate based on UK NIHR guidelines and agreed in advance [28]. The study was approved by the London School of Hygiene and Tropical Medicine Research Ethics Committee (No. 26440).

2.3. Analysis

The analysis followed some of the principles of Charmaz's constructionist grounded theory-building using iterative methods of constant comparison that are particularly useful for studying lived experience [29]. Some of the codes were developed *a priori* to explore the thematic areas of interest. We identified other codes inductively from the interview data. The codes were constantly refined in discussions among the team, and by returning to the original data. We drew on interview fieldnotes and discussed emerging themes in analysis meetings with the research team, and co-produced the analysis with co-researchers, and with groups of participants in the second phase of Dialogues (see figure). These dialogical co-production processes helped us to contextualise findings and ensure they were meaningful to our participants and co-researchers.

3. Findings

For Gypsy, Roma, and Traveller groups, the importance of context was clear. Below we present four sub-themes of our first theme, which relates to community members' past experiences with health systems and authorities. These help to contextualise our second major theme, which is about participants' reasons for vaccinating or not vaccinating. We present these deliberations in four sub-themes: reasons for getting vaccinated; feeling coerced; fertility; and unaddressed concerns about the vaccine.

3.1. Past experiences relevant to vaccine uptake

3.1.1. Discrimination, marginalisation, and racism

Speaking about their wider experiences of healthcare, many participants, both vaccinated and unvaccinated, told us about past and present experiences of poor treatment. People spoke of condescension and discrimination from healthcare staff, and of marginalisation and neglect from emergency services.

3.1.2. Reduced care during the pandemic

Many told us they felt abandoned during the pandemic. For instance, some described reduced visits from health and social care workers to children with disabilities, or having to attend the accident and emergency department after failing to obtain appointments with General Practitioners (GPs), or their or their family members' health conditions worsening dangerously because of delays getting appointments. One woman on a council Traveller

site told us no health visitors came to check up on her newborn baby, who was losing weight. She was worried and felt that she was not being taken seriously by the doctors. The health staff told her to weigh the baby herself. She left the site to buy scales, worrying that she would be reprimanded for breaking lockdown rules.

3.1.3. Discrimination

People told us about obstructive GP receptionists who would discriminate against them as soon as they recognised they were from a GRT site: "Well, soon as you give your name over. You give your name over and you give your address, then that's it then." One woman, whose father had a stroke, said that his care was inadequate, that he had been left after a fall in hospital "in a pool of his own blood", with a broken knee. Participants said they would avoid going to hospital for fear of discrimination, even if they had severe COVID-19 symptoms.

"[Even if] they [people from the community] couldn't breathe [...] they were very reluctant to get to go to hospital. [...] They're just, within a lot of hospital settings, obviously, I'm not speaking about doctors because they're [there] to save lives but there's a lot of discrimination, you know what I mean".

3.1.4. Barriers to emergency care

Gypsy and Traveller communities who lived on designated council-owned sites told us they had problems with ambulances being unable to drive onto sites for urgent care. In several of the sites we visited, we found high metal barriers at the entrance. Residents told us the council had installed them to prevent caravans moving onto the site without permission. However, these also obstructed access for emergency services. A woman said one of the reasons she did not want to risk vaccine side effects was because she worried that if anything happened, the ambulance would not be able to attend.

A woman from an English Traveller background told us that years ago a person at the site died waiting for an ambulance, and because of this, she had spent the pandemic worrying about the barrier. A woman on a different council site spoke of trying to obtain emergency care for her husband who had COVID-19. "We had to have a gate codes broke off, because they refused to give us the code". Another resident of the same site told us that because the locks had been broken for ambulances multiple times, the council had taken measures against this as well: "But now what they've done, there's no way could you get that lock off. They've fitted a box round it, so you can't get into it. [...] you'd have a heart attack and you'd be dead".

Site access problems also affected post and deliveries. Another woman who identified as an English Traveller told us she missed several hospital appointments because of the actions of site wardens: "When there was a case of Covid on our site the postmen were told by our own wardens [...] to not deliver letters." On a different site, a woman told us about a courier who refused to bring a package to her caravan: "He said, because the Gypsy site, we're not insured. [...] It's racial discrimination". Community members deliberated about whether to vaccinate against COVID-19 against this context of past and recent experiences of marginalisation and discrimination.

3.2. Reasons for vaccinating or not vaccinating

3.2.1. Reasons for getting vaccinated

Despite these experiences and high levels of distrust, most participants had received one or more doses of a COVID-19 vaccine. Many participants spoke of their reluctance, while some said it was to conform (e.g. "Basically I just done what they said."), or because vaccination was easy or convenient. Other key motiva-

tions cited were concerns for their own health and for the health of others.

One woman who identified as an English Traveller said she had been vaccinated after having COVID-19: “I said I’d have anything that could prevent me getting it again. And I went straight for the first vaccination, and had it done the first chance I got”. Another woman, who identified as a Gypsy Traveller said: “I think it’s a good thing that they’re vaccinating people and because it just gives people that bit of a, erm, security, doesn’t it?”.

Another woman who identified as a Gypsy Traveller said she had received both vaccines because she was a carer and was “definitely going to have the booster” to protect her from more severe symptoms. She knew it would not prevent infection because her neighbour on the site had had COVID-19 after being vaccinated but only had mild symptoms.

3.2.2. Feeling coerced

Given the context against which community members made decisions, it is important to note that many participants said they felt coerced into getting vaccinated. This pressure came from different sources including medical professionals, employers, family, and government.

While some people did get vaccinated after receiving an NHS invitation, others described reminders from health services as persistent and off-putting pressure rather than persuasive. A woman from a council Traveller site said: “They kept trying to push me to get vaccinated while I was pregnant. Um, which is something that I personally completely disagree with. [...] I’ve had like the 20,000 phone calls, the letters [...] I told them once I don’t need it, and now they’re sending me letters and letters and letters all the time, they’re going to come out and come, come see me, like come round. But I said no, and then, then you have to keep, I feel like if someone says no, it’s no. [...] I don’t think it’s fair for anyone to be pushed into having something they don’t want to”.

A Romanian Romani woman told us she did not answer calls from the GP when they were about the vaccination: “I mind my own business and that’s all”. A woman from the Irish Traveller community told us she had gone to the GP for a different reason, but the appointment quickly became dominated by the doctor trying to persuade her to have the vaccine: “I feel like she was forcing me into it. [...] It was like, oh I can book you in now, and I said, no, and she was like, oh, well, call me and I’ll book you in then, I’ll be there, and I said, no. And like I told her why [concerns about fertility] and she was like, no, that’s not true, and everything. But she never said like, oh think about it and come back. It was, you need to have it done and that’s that”.

People also reported feeling pressured by employers. Several people from Romani communities had either already left their jobs or were anticipating losing their jobs because they did not wish to be vaccinated. A Romani man who worked in a care home told us how he finally resigned after trying to defend his position: “When the nurses came into the care home to vaccinate everyone I was the only person that didn’t want it. I actually went and sat in the lounge with everyone else, with the residents and I said, no, I’m not getting it. And then boss was like, oh, come on, you’re a conspiracy, I’m, I’m not a conspiracy theorist, I just don’t want to get it, right, because I don’t think, I don’t think the vaccine has been out for long enough for us to know the long term effects.’ [...] I got really angry. Not long after that, I quit my job. I walked out”.

Outside the workplace, participants felt that although the vaccine was presented as a choice, life for the unvaccinated was restricted: “they’re not saying you’ve got to have it done, but you got to, you’ve got to have it done: if you don’t, you’re not allowed to do this, this, and this. So they’re coercing you into having it”. Increased restrictions on the lives of unvaccinated people were seen as a mechanism to “bully” people into being vaccinated: “they

are bullying people to get it done [...] If you don’t have it, you don’t have no freedom”. A large number of participants said they only agreed to be vaccinated because they wanted to travel abroad to see family members or to go on holiday. Individuals who reported feeling pressured to be vaccinated often also said they felt that the vaccine and COVID-19 legislation were forms of government control. Some participants said they thought that the government used inflated COVID-19 death statistics and exaggerated its severity to scare people into having the vaccination.

3.2.3. Fertility

Some women participants said they worried the vaccine might affect women’s fertility: “I don’t know, I’ve seen some things on the internet where it says that it stops you from having children [...] or something like that. So I’m a bit concerned about that one”.

Unvaccinated participants said they wanted better information to help them make their decision, including dialogue with health professionals about side effects and fertility. One woman said she had been invited to represent the Gypsy and Traveller community at a health forum on COVID-19. She herself was unvaccinated and at the health forum shared concerns that had been brought to her by friends and family but was given short shrift:

“One of the questions that girls here, up here asked me is: can it affect me being able to have kids or anything like that in the future if I have the vaccine? Um, so I asked that, and I got this email back explaining about how women have babies, and I was like: We know! Like: we know how women breed! We know how women fall pregnant! [...] I did send back an email [...] Like, the women in my community have asked me to ask them a question, and I’m glad it was me that you spoke to like that and not them, because sometimes people are scared to ask questions, they’re scared to speak up. [...] And the other person’s question was, can I catch COVID-19 through my eyeballs, so should I be wearing goggles? And yeah, they got answered quite politely, and then I asked about fertility and got spoken to like an idiot.”

There were several similar stories. A woman who identified as an English Traveller told us her adult children had been vaccinated, but that they had been told the booster could cause infertility. Our interviewee felt she could not convince her children without information but did not receive it when she turned to a nurse for advice: “And I asked the other day, when I went in to the nurse, have you got anything that actually says this doesn’t happen? And she said, no”. Consequently she could not persuade her daughter to have the vaccine because she felt she did not have enough information. Note that there is clear information online that the vaccines do not affect fertility [30]. However, it is not clear whether or not our participants had access to this information at the time they were raising their concerns.

3.2.4. Unaddressed concerns about the vaccine

Participants repeated worries circulating in the general population as reasons they had not been vaccinated, despite the mounting pressure: the feeling that the vaccines were developed too quickly, worries about side effects, and worries about vaccine contents. They also mentioned that the vaccine does not prevent COVID-19 infection. Some also expressed a sense that being fit and strong would provide enough protection. Language barriers were also mentioned. For example, a Romani migrant worker said: “We don’t, we don’t get much information. And if we do in letter or text, we can’t understand it”.

Unsatisfactory answers to concerns about the vaccine had wider repercussions for the community. Those asking pro-actively for information were often those advising peers or family on whether

to have the vaccination or not. The health forum representative, for instance, said that she could not, in good conscience, advise other women on the site where she lived to get the COVID-19 vaccine. In one discussion with a group of Romani Slovaks, several women said that they were now so unconvinced by the vaccines that they would no longer let their children have routine immunisations. The information gap left by health professionals and official sources was readily plugged by other, often less reliable sources, e.g. word of mouth, religious texts, or social media.

4. Interpretation

Concerns among GRT communities about COVID-19 vaccines are mirrored in other communities [11,31]. Others have argued that these concerns in other communities are part of a larger picture, in which there is a lack of trust in health care systems and the wider government [32]. We have shown that ignoring broader trustworthiness of institutions by focusing on building trust in communities/individuals for specific purposes means that key components of vaccine “hesitancy” are missed. Health system trustworthiness is linked to the trustworthiness of public authorities more generally and may or may not be affected by individuals’ knowledge and education. Our study highlights how authorities and health services have been experienced as untrustworthy in the past for some of our participants from GRT communities – they were accustomed to experiencing discrimination within health services and this affected both their willingness to trust the motives of people promoting vaccines, and their beliefs about vaccine safety. At the same time, assumptions from public health and vaccine promoters about certain groups not being willing to vaccinate may create what those groups experience as additional pressure, which may be counter-productive. Discourses and presumptions about the ways that certain groups approach vaccination matter because they can affect how marginalised groups engage with vaccination [31] and reproduce structural discrimination.

Community trust in institutions is important – revelations that senior UK government officials including the Prime Minister broke COVID-19 lockdown rules [33] may well have an impact on public trust in government, particularly while the same government is in power. Also, more insidiously, these types of revelations may also create scepticism and potentially make people less willing to take direction from government agencies in future emergencies.

Instead of only considering individual and community “distrust” and aiming to improve “trust in vaccines”, it is also important to examine collective concerns about the health system itself. The array of negative interactions our participants described having experienced before and during the pandemic at the hands of health services and public authorities, give context to their beliefs that the vaccine was being deployed to give authorities more control, for example. Yet such concerns, rather than being treated as a warning sign about overall trust in health services, risk being dismissed as “conspiracy theories” and ignored. For GRT communities in England, there are many ways in which government authorities are increasing powers that disrupt and control lives, including the Police, Crime, Sentencing and Courts Bill (2022). From the perspective of public health authorities, this legislation may not seem relevant to health security. However, in the context of participants’ lived experience there are clear parallels: for instance vaccination status and the Police, Crime, Sentencing and Courts Bill (2022) both restrict or restricted families from engaging in traditional forms of travel. In the context of the Bill, participants were sure that authorities were not acting in their best interests. Our findings highlight how we must attend to these collectively expressed concerns and the wider context – otherwise we will miss important reasons why people are reluctant to be vacci-

nated and in doing so reproduce existing health inequalities and injustices.

How, then, could more trust be built between health systems and marginalised communities? Our study suggests that creating an unpleasant environment for unvaccinated people can have the unintended consequence of creating more concern about the purpose of the vaccine. If public health practitioners engage with communities in ways that respect and address local and culturally specific concerns, they may improve vaccination rates by demonstrating trustworthiness through being collaborative and responsive as much as by addressing specific vaccination queries. However, information and messaging on a single issue may not improve trust or vaccine uptake if broader health services are experienced as racist or uncaring. Community concerns about fertility are a good example: while there was clear information online that the vaccines do not affect fertility [30], such messaging may not have been trusted or may not have been accessible. Experts recommend community engagement as a way to overcome distrust and thereby increase vaccine uptake [10]. Our findings suggest that community engagement that aims to convey information in a top-down fashion to a marginalised group is unlikely to be fruitful. Instead, effective engagement requires a genuine two-way dialogue [27]. By engaging in dialogue, people have the opportunity to express concerns and be heard. They can come up with ideas about how best to present information, design services, and thereby gain ownership over the process, which may make them more likely to engage and to engage others [15,27]. To improve trust in vaccines and healthcare services, it is important to improve trustworthiness of those services, including ensuring there are mechanisms for listening to and addressing concerns in general – including outside the immediate context of the pandemic and vaccinations. Even with a fully responsive healthcare system, it will be increasingly difficult to build good community relations with GRT groups when their ways of life are threatened by old and new legislation.

While we attempted to engage the most diverse range of participants possible, we do not claim to provide information on all GRT community needs and experiences relating to COVID-19. However, it seems likely that similar issues will also apply elsewhere, including outside GRT communities, and in particular for other minoritised groups.

5. Conclusion

This study challenges the received wisdom that the best way to increase uptake of vaccination is via interventions that focus mainly on informing and educating populations about vaccines. Our findings suggest that especially among marginalised minority groups, the socio-historical context in which people make decisions about vaccinations may be crucial, and deserves much greater attention than it is currently given. There is a danger that efforts to increase vaccination uptake may not only be unsuccessful but may even exacerbate existing inequalities by stereotyping certain communities as particularly in need of vaccine promotion efforts, or by putting unacceptable pressure on individuals from those communities to take up the vaccine. In order to improve vaccine uptake, more trustworthiness is needed from healthcare services including provision of adequate services outside of emergencies. This includes working to eliminate discrimination against already marginalised communities, and acknowledging current and past injustices.

Data availability

The data that has been used is confidential.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We thank Serena Farrow, Terezia Rostas, GATE Herts, all of the organisations who spoke to us, and individuals from the Gypsy, Roma and Traveller communities who would prefer not to be named, for their invaluable help and advice on this project. We are grateful to Alina Huzui, who translated interviews in Romanian into English.

References

- Timmins N, Baird B. *The Covid-19 vaccination programme: Trials, tribulations and successes*. London: The King's Fund; 2022.
- National Inclusion Health Board. *Commissioning inclusive services: Practical steps towards inclusive JSNAs, JHWSs and commissioning for Gypsies, Travellers and Roma, homeless people, sex workers and vulnerable migrants*; 2013.
- Parry G, Van Cleemput P, Peters J, Walters S, Thomas K, Cooper C. Health status of Gypsies and Travellers in England. *J Epidemiol Community Health* 2007;61(3):198–204.
- Dixon KC, Mullis R, Blumenfeld T. Vaccine uptake in the Irish Travelling community: an audit of general practice records. *J Public Health (Oxf)* 2017;39(4):e235–41.
- Kamal A, Hodson A, Pearce Julia M. *A Rapid Systematic Review of Factors Influencing COVID-19 Vaccination Uptake in Minority Ethnic Groups in the UK*. Vaccines (Basel) 2021;9(10):1121.
- Razai MS, Osama T, McKechnie DGJ, Majeed A. Covid-19 vaccine hesitancy among ethnic minority groups. *BMJ* 2021;372:n513.
- Watkinson RE, Williams R, Gillibrand S, Sanders C, Sutton M, Kretzschmar MEE. Ethnic inequalities in COVID-19 vaccine uptake and comparison to seasonal influenza vaccine uptake in Greater Manchester, UK: A cohort study. *PLoS Med* 2022;19(3):e1003932.
- MacDonald NE, Eskola J, Liang X, Chaudhuri M, Dube E, Gellin B, et al. Vaccine hesitancy: Definition, scope and determinants. *Vaccine* 2015;33(4):4161–4.
- Attwell K, Hannah A, Leask J. COVID-19: talk of 'vaccine hesitancy' lets governments off the hook. *Nature* 2022;602(7898):574–7.
- United Kingdom Scientific Advisory Group for Emergencies. *Factors influencing Covid-19 vaccine-uptake among minority ethnic groups*. London; 2020.
- Willis D.E., Andersen J.A., Montgomery B.E.E., Selig J.P., Shah S.K., Zaller N., Bryant-Moore K., Scott A.J., Williams M. McElfish P.A. COVID-19 Vaccine Hesitancy and Experiences of Discrimination Among Black Adults. *J Racial Ethnic Health Disparities* 2022;1:1–10.
- Singh P, Dhalaria P, Kashyap S, Soni GK, Nandi P, Ghosh S, et al. Strategies to overcome vaccine hesitancy: a systematic review. *Syst Rev* 2022;11(1).
- Betsch C, Schmid P, Heinemeier D, Korn L, Holtmann C, Böhm R, et al. Beyond confidence: Development of a measure assessing the 5C psychological antecedents of vaccination. *PLoS One* 2018;13(12):e0208601.
- Pertwee E, Simas C, Larson HJ. An epidemic of uncertainty: rumors, conspiracy theories and vaccine hesitancy. *Nat Med* 2022;28(3):456–9.
- Razai MS, Chaudhry UAR, Doerholt K, Bauld L, Majeed A. Covid-19 vaccination hesitancy. *BMJ* 2021;373:n1138.
- Wiyosongee CS, Ndwandwe D, Ryan J, Jaca A, Batouré O, Anya B-P M, et al. Vaccine hesitancy in the era of COVID-19: could lessons from the past help in divining the future? *Hum Vaccin Immunother* 2022;18(1):1–3.
- Truong J, Bakshi S, Wasim A, Ahmad M, Majid U. What factors promote vaccine hesitancy or acceptance during pandemics? A systematic review and thematic analysis. *Health Promot Int* 2022;37(1).
- Lin C, Tu P, Terry T. Moving the needle on racial disparity: COVID-19 vaccine trust and hesitancy. *Vaccine* 2022;40(1):5–8.
- Nguyen LH, Joshi AD, Drew DA, Merino J, Ma W, Lo C-H, et al. Self-reported COVID-19 vaccine hesitancy and uptake among participants from different racial and ethnic groups in the United States and United Kingdom. *Nat Commun* 2022;13(1).
- James Z. Hate crimes against Gypsies, Travellers and Roma in Europe. In: Hall N, Corb A, Giannasi P, Grieve JGD, editors. *The Routledge International Handbook on Hate Crime*. Abingdon, Oxon: Routledge; 2015.
- Achim V. *The Roma in Romanian History*. Budapest: Central European University Press; 2004.
- United States Holocaust Museum. *Sinti & Roma: Victims of the Nazi, 1933–1945*. Washington D.C.: U.S. Holocaust Memorial Museum; 2002.
- Stejskalová M, Szilvási M. Coercive and cruel: Sterilisation and its consequences for Romani women in the Czech Republic (1966–2016). Budapest: European Roma Rights Centre; 2016.
- Holt E. Roma women reveal that forced sterilisation remains. *Lancet* 2005;365(9463):927–8.
- Van Cleemput P. Health impact of gypsy sites policy in the UK. *Soc Policy Soc* 2008;7(1):103–17.
- Kirby A. Submission to the Public Bill Committee: on Part 4 PCSCB. Brighton: Friends, Families & Travellers; 2021.
- Marston C, Renedo A, Miles S. Community participation is crucial in a pandemic. *Lancet* 2020;395(10238):1676–8.
- National Institute for Health and Care Research. *Payment guidance for researchers and professionals (Version 1.3)*. London: NIHR; 2022 [Available from: <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>].
- Charmaz K. *Constructing Grounded Theory (Second Edition)*. London: SAGE Publications Ltd; 2014.
- Association of Reproductive and Clinical Scientists, British Fertility Society. *Covid-19 Vaccines and fertility*. 2022; accessed 18.01.2023(accessed 18.01.2023).
- Kasstan B. Vaccines and vitriol: an anthropological commentary on vaccine hesitancy, decision-making and interventionism among religious minorities. *Anthropol Med* 2021;28(4):411–9.
- Abba-Aji M, Stuckler D, Galea S, McKee M. Ethnic/racial minorities' and migrants' access to COVID-19 vaccines: A systematic review of barriers and facilitators. *J Migration Health* 2022;5:100086.
- Davies B, Lalot F, Peitz L, Heering MS, Ozkececi H, Babaian J, et al. Integrated public opinion evidence and implications. *NaturHumanities Soc Sci Commun* 2020;8(1).
- Marston C., McGowan C., Stuart R., Kühlbrandt C., Miles S., Grenfell P., Dix L., Renedo A. Routes: new ways to talk about COVID-19 for better health – a focus on Gypsy, Roma, and Traveller communities and migrant workers in precarious jobs. 2022. Available from <https://researchonline.lshtm.ac.uk/id/eprint/4669580>
- Renedo A, Stuart R, Kühlbrandt C, Grenfell P, McGowan CR, Miles S, et al. Community-led responses to COVID-19 within Gypsy and Traveller communities in England: a participatory qualitative research study. *Social Science and Medicine Qualitative Research in Health* 2023. <https://doi.org/10.1016/j.ssmqr.2023.100280>.